

# **An Evaluation of Different Levels of Structuring Within the Clinical Record**

**Final report for the NHS Connecting for Health Evaluation Programme**



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## Foreword

Maximising the opportunities for health gains and the returns on investment from the substantial eHealth-based programmes now afoot in many parts of the world is crucially dependant on the availability of computable data. Our work has demonstrated that, whilst there is still very considerable scope for further developments in this respect internationally, the UK enjoys a clear leadership role in exploiting the potential of coded electronic data.

We are very grateful to Professor Richard Lilford and his team for their foresight in commissioning this work, which will we hope consolidate this position and to Professor Simon de Lusignan and fellow members of the Independent Project Steering Committee overseeing this work for their thought-provoking suggestions. We also take pleasure in putting on record our sincere thanks to the researchers and administrative staff who worked tirelessly on delivering this project.

Finally, we hope that this work proves useful to policy makers and healthcare systems internationally in supporting professionals to enhance the delivery of care to patients. To this end, we will be delighted to hear from and work with colleagues to build on the foundational work reported in this volume.

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## Executive summary

### Introduction

- There is a drive, manifest globally in multiple and often substantially funded eHealth programmes, to establish national infrastructures to enable clinical data sharing through interoperable electronic health records (EHRs), including the adoption of standardised clinical record structures and terminologies.
- The government and the National Health Service (NHS) in England have invested significantly in a national eHealth infrastructure, in information systems in primary and secondary care, and in informatics tools, such as terminologies, to support improvements in the completeness, quality, availability and utility of EHRs.
- The timely access to human readable clinical information will in many cases meet the immediate need to inform decisions on continuity of care and shared care. However, it is increasingly recognised that computerised systems and tools can augment human (clinician) reviews of historic patient information and helpfully map patient data onto up-to-date medical knowledge. For example, such systems can filter, highlight, alert, advise, guide, communicate and educate in support of direct patient care, as well as enable information to be re-used for clinical audit, quality improvement, public health, prevention and outcomes evaluations, research, and many other purposes.
- The benefits of computer processing of EHR information rely upon *semantic interoperability* – the ability to integrate data originating from multiple systems, care settings, specialties and authors – for systems to be able to interpret clinical information consistently and safely. This in turn requires that EHR information be consistently structured and for the terms used within EHRs to be drawn from standardised terminologies. It is widely accepted that the processing of natural language to derive clinical meaning is not yet accurate enough to support direct care decisions on individual patients.
- Extending across primary and specialist care settings, there is therefore strategic interest in increasing the proportion of the EHR that is captured in structured and coded format. A major challenge is to find the optimal balance, with respect to benefits and risks, between narrative (i.e. sentences and/or informally grouped lines of text), structured (i.e. organised according to a logical model) and coded (i.e. represented using terms taken from a terminology or controlled vocabulary) data.

- The migration towards structured and/or coded representations within EHRs has so far tended to prioritise relatively formalised and easily categorised information structures such as demographic details, numeric laboratory results, diagnoses, prescriptions as well as a limited number of chronic disease monitoring datasets and disease/functional assessment scales. Other parts of the EHR, such as the presenting history, treatment goals, disease management advice given to patients and continuation notes, are however still captured and stored as free-text or narrative entries.
- Current work to agree clinical information standards that specify how clinical entries should be organised, and perhaps coded, is contributing to the expansion of structuring and/or coding into a broader range of clinical information systems. However, this work is hampered by the challenges of agreeing consistent clinical information structures and terms given the diversity of systems used in clinical practice, many of which are not interoperable across clinical communities.
- There are also practical problems associated with the resource implications of data entry effort to populate EHRs with high quality data. This is often done from a particular starting point, leading to a lack of information prior to that date (as data entry tends not to be conducted retrospectively) and a lack of universal coverage (as data are entered at the time of care rather than in anticipation of it).
- Investments in the development of structured EHRs should therefore ideally be targeted on those aspects of documentation that bring maximum and near-term benefits to clinicians and patients, which can be readily appreciated by those investing the additional effort in coding data. However, the evidence base establishing the benefits from structuring and/or coding EHRs and the harms that may arise has hitherto been poorly synthesised making it difficult for eHealth programmes to set appropriate priorities for clinical documentation standards, clinical data structures and relevant term lists.
- This report presents the results of a mixed methods evaluation, drawing upon systematic review and qualitative methods, to investigate the implications of different levels of structuring and/or coding within EHRs. We in particular consider the trade-offs of structuring and/or coding increasing amounts of information (such as symptoms) in real-time that are currently held as free-text within EHR systems (or on paper). In so doing, this investigation seeks to guide the evidence-based setting of national priorities and standards for systematising EHR information.

## Aims and Objectives

- The main aim of this research was to provide evidence to inform deliberations on the extent to which real-time recording of information within medical records during the provision of clinical care should or should not be coded through synthesising evidence on the trade-offs associated with structuring and/or coding increasing amounts of information that is currently held as free-text in EHRs.
- In so doing, we sought to investigate attitudes and strategies perceived as successful for improving the quality and consistency of structuring and/or coding within EHRs. This included:
  - Reviewing the current drivers behind the structuring and/or coding of clinical information within EHRs
  - Understanding the drivers behind attempts at systematically organising clinical information by authors at the time of data entry
  - Assessing the suitability and quality of the semantic resources they have available to do this (such as relevant terms from a terminology)
  - Describing the uses made of structured and/or coded health records.
- This was undertaken by organising our research into four complementary work-packages (WPs), in which we sought to:
  - Identify the published evidence of benefits and risks to structuring and/or coding the presenting patient history, focusing on the benefits to direct patient care (WP1)
  - Explore the perceptions and needs of key stakeholder groups for capturing and using structured and/or coded clinical information (WP2)
  - Examine the drivers, enablers and barriers to capturing and using structured and/or coded records in four purposefully selected case studies, namely: drug allergy, ethnicity, diabetes and depression (WP3)
  - Compare and contrast the approaches, incentives and experiences in promoting the adoption of structured and/or coded records in England with international experiences (WP4).
- It should be noted that investigation of technical approaches for promoting structuring and/or coding, secondary coding undertaken after the primary clinical documentation and the use of language technologies to interpret narrative text computationally were all outwith the scope of this commissioned evaluation.

## Methods

- We employed a mixed-methods approach to pursue our aims and objectives. This involved combining formal reviews of the literature with in-depth qualitative work.
- In WP1, we undertook a systematic review of the academic literature focusing on the search for and critique of empirical evidence published since 1990 on the question of structuring and/or coding the patient history; this involved searching 10 databases, formal quality appraisal of studies and a theoretically-based textural analysis.
- This focused systematic review was complemented by a broader landscape review of publications considering the direct patient care value from structuring and coding EHRs, relating these to the six aims of quality improvement defined in the Institute of Medicine's (IoM) internationally influential *Crossing the Quality Chasm* report. Nine international databases were searched for published and unpublished studies over the period 1990-2011. (WP1).
- In WP2, we carried out a qualitative study using purposeful sampling to gain insights into a broad spectrum of stakeholders, including patients, healthcare professionals, health service commissioners, policy makers, managers, administrators, system developers, researchers and academics. We undertook 23 in-depth interviews (with 26 participants) and hosted six expert discussion groups with a further 43 participants. We also observed relevant professional practices and analysed documentary evidence gathered from participants.
- For WP3, we constructed a collective case study to discover, for each case study, how information is predominantly captured and held in unstructured, structured and coded forms, how and why these patterns arise, and what value (benefit) each format of information provides to different stakeholder groups. The four cases investigated were allergy, ethnicity, diabetes and depression. These four case studies were chosen as exemplar areas to shed light on a spectrum of issues relating to the tensions between use of narrative-based records and more structured/coded data records. Each case study described currently used technologies (i.e. hardware and software) and work practices, with a focus on how and why different forms of data capture – free-text narrative, structured data (e.g. using a template) and coded data (e.g. Read codes) – were being used in EHRs. We then undertook a cross-cutting thematic analysis considering a range of perceptions of the balance between unstructured, structured and coded information, particularly for clinical care, but also for NHS management, service planning, research and audit.
- WP4 involved an examination of strategies that have been adopted to promote structuring and/or coding of clinical information in six other countries (i.e. Australia,

Brazil, Canada, Japan, Sweden and the United States (US)), this being undertaken through interviews with key decision makers involved in these national eHealth programmes and reviews of national policy documents. We were particularly interested in comparing the political and professional drivers, incentives, barriers and any identified success factors in relation to the implementation of structuring and/or coding of EHRs,

- The findings and cross-cutting themes from these four WPs were then integrated through a series of data workshops over the duration of the evaluation. These discussions also highlighted additional areas for investigation and informed subsequent data collection. This iterative and reflexive approach to data generation enabled us to propose key recommendations that the NHS in England may wish to consider adopting in order to successfully promote, and benefit from, a greater degree of systematisation of EHRs.

## **Main Findings**

### **Research dataset**

- A summary of the papers screened and selected for inclusion in WP1 is provided in Table 1. A summary of empirical data generated in WPs 2-4 is shown in Table 2.

**Table 1: Study identification and selection for WP1**

	<b>Systematic review</b>	<b>Landscape review</b>
<b>Number of databases searched</b>	10	9
<b>Papers for consideration</b>	9,207	6,766
<b>Papers screened by title</b>	7,473	5,016
<b>Papers screened by abstract</b>	228	248
<b>Full paper assessment</b>	93	33
<b>Papers included for review</b>	10	13

**Table 2: Dataset summary for WPs2-4**

	WP2	WP3				WP4	
		Allergy	Ethnicity	Depression	Diabetes		Total
<b>Interviews</b>	<b>24</b>	<b>20</b>	<b>14</b>	<b>28</b>	<b>22</b>	<b>13</b>	<b>121</b>
<i>(Participants)</i>	<i>(27)</i>	<i>(20)</i>	<i>(16)</i>	<i>(28)</i>	<i>(22)</i>	<i>(17)</i>	<i>(130)</i>
<b>Discussion groups</b>	<b>6</b>	<b>1</b>		<b>1</b>			<b>8</b>
<i>(Participants)</i>	<i>(43)</i>	<i>(15)</i>		<i>(3)</i>			<i>(61)</i>
<b>Observations</b>	<b>1</b>		<b>1</b>	<b>1</b>	<b>4</b>		<b>7</b>
<b>Field notes</b>	<b>6</b>		<b>2</b>	<b>30</b>	<b>4</b>		<b>42</b>
<b>Documents</b>	<b>20</b>	<b>3</b>	<b>50</b>	<b>7</b>	<b>25</b>	<b>105</b>	<b>210</b>

**WP1: Literature reviews**

- We screened a total of 9,207 reports to identify 10 studies that satisfied our inclusion criteria for the systematic review investigating evidence of the benefits and risks of structuring and/or coding the patient's presenting history.
- Overall, this evidence was found to be of low-to-moderate quality and in the majority of cases provided only indirect evidence in relation to the focus of our enquiry.
- The studies that had been undertaken were mainly concerned with investigating the use of structured templates and these found that, when templates were used, the resulting records tended to be more complete and more detailed; however, only three studies demonstrated that this better information resulted in improvements to patient care, primarily as a result of clinicians being quicker to arrive at a diagnosis. This particular benefit was identified in the following clinical contexts: diagnosis of appendicitis (in hospital), tooth avulsion (in a dental hospital); and acute management of urinary incontinence and falls in the elderly (in primary care).
- Our broader complementary literature review identified 13 controlled studies that had been undertaken to investigate measurable benefits to direct patient care of introducing structure and/or coding clinical documentation. These studies demonstrated that proxy clinical outcomes can be improved and suggested that there may in some instances be an impact on clinical outcomes if a structured EHR is combined with alerting advisory systems in specific targeted areas, namely: the management of a long-term condition (i.e. diabetes), preventive care and appropriate choice of therapy. Prescribing was the principal area in which improvements in patient safety have been studied, these revealed the potential to decrease the risk of hazardous prescribing and prescribing-related adverse events.

- Taken together, these reviews indicate that there has been limited effort made to-date to evaluate empirically the value from structured and coded EHRs for direct patient care, as opposed to secondary use benefits which are better established.

## **WP2: Qualitative enquiry of stakeholder perspectives**

- Our dataset comprised 24 in-depth interviews with 27 participants and six expert discussion groups with an additional 43 participants (n=70 in total). We also observed relevant professional practices and considered related documentary evidence.
- We found evidence of a lack of consistency in written approaches to communicating with patients outside of the consultation, both in relation to how this was done or what was communicated. This lack of structure in communications with patients was found to be a barrier to encouraging and enabling patient understanding of and engagement in their own healthcare. We identified significant potential for more structured feedback to patients (e.g. through charts and diagrams) to improve the accessibility of this information for patients and carers.
- The collection of intimate information for the medical record was found to be a highly interpretative process that drew on personal relationships and professionals decision-making. Participants expressed the views that any increased use of structuring and /or coding should respect patient and clinician individuality, non-standard outcomes and the contingent nature of the clinical process.
- Locally derived systems and processes dependent upon the increased use of structuring and/or coding information were observed in settings where, as a result of systems shortcomings (e.g. lack of functionality or lack of physical access), participants described their use of paper-based systems and locally authored documents (such as Excel spread-sheets). This indicated a mismatch between useful structures to support working practices and information requirements, and available IT systems. These locally derived structures were seen to result in significant duplication of effort and increased potential for human error.
- We further observed significant variations in systems access and utilisation, and differences in documentation practices across different locations, care settings and professional communities. This may be due to the variations in professional guidelines, protocols and education, organisation-specific requirements, government reporting requirements, and medical-legal considerations. This is likely to represent a fundamental challenge in relation to structuring medical records as many assumptions regarding a common approach to the collation, comprehension and

understanding of structured information underpin the potential benefits of shared EHRs.

- With the exception of a few examples (such as prescribing decision support in general practice), stakeholders reported that most of the gains from structured and/or coded records related to population health sciences (e.g. epidemiological research involving interrogation of large healthcare datasets, and use of NHS Health Episodes Statistics (HES) for planning), clinical research and health service management purposes (e.g. commissioning), or used for reimbursement (for example, the Quality and Outcomes Framework (QOF)).
- The association of clinical coding with reimbursement and performance management was found to have a detrimental impact on clinicians' perceptions surrounding the value and importance of structured and/or coded data collection. This was compounded by a lack of perceived practical application of data to support processes of care, for example in the provision of real-time decision-support, prompts, alerts and personalised audit functions (e.g. information relevant to professional appraisal requirements).
- We however also noted some specific examples of more immediate benefits to be gained from the increased use of structuring and/or coding within medical records. These examples evidenced possible productivity gains in terms of the use of clinician time and clinic attendance, the promotion of patient-centred approaches to care, more immediate identification of patterns of disease, and the possibility to support new forms of continuity of care.

### **WP3: Case studies**

#### ***Drug allergy***

- We found widespread acceptance of the value of accurate structuring and/or coding of drug allergies and adverse drug reactions.
- There was evidence of a considerable amount of real-time coding already being undertaken, particularly in primary care. Unfortunately this did not necessarily enable optimal leverage of computerised decision support systems (CDSS); rather, because of both over-reporting and inaccurate coding which in some instances introduced new areas of risk.
- This case study in addition highlighted the importance of wider contextual considerations, these included the difficulties of making a clinical diagnosis, which were compounded by the lack of specialist diagnostic facilities, and inadequacies within current coding terminologies.

- Given the professional buy-in, the substantial coding already being undertaken, and the opportunity to share coded data throughout the NHS (via the NHS Summary Care Record (SCR)), efforts should focus on improving the accuracy of diagnosis and its recording, and the associated wider contextual considerations in order to optimise the use of decision support systems.

### ***Ethnicity***

- There has been a statutory mandate to collect data on ethnicity since April 1994, but despite this, coding of this information has, until very recently been poor in the NHS. This case study therefore investigated why, despite an overarching policy and legal imperative to collect these data, there has until recently been relatively little progress in terms of increasing coding activity.
- Variations in local arrangements for the collection and use of patient ethnicity data may in part be due to issues of perceived clinical irrelevance together with contextual factors, including lack of training for staff, resource constraints, variations in the extent of ethnic diversity in different regions of England and local working practices.
- The lack of central provision of supporting resources for the collection and coding of ethnicity data, such as templates for data collection, staff training and development, incentives and/or sanctions for organisations collecting this information undermined other statutory requirements for the collection of these data.
- Ethnicity has tended to be conceptualised as a fixed category collected within the patient demographic dataset with a single coded entry per patient that remains fixed over time. Such information on ethnic categories is, however, of only limited clinical utility.
- Data on ethnicity-related considerations that had much greater relevance to clinical care (e.g. religion, preferred language of communication, diet-related factors etc.) were in contrast conceptualised as a combination of contingent factors and captured within clinical narratives in free-text format.
- This case study found that ethnicity-related data needed to be conceptualised and captured more broadly (e.g. language needs) if these were to have salience with clinical staff. Also clearly illustrated by this case study were the difficulties of progressing the agenda of wider coding unless the reasons underpinning this are made clear to, and are understood and appreciated by, those involved with undertaking the work associated with coding.

## ***Depression***

- This case study highlighted a number of important differences in approaches to coding for depression between primary and secondary care settings, these included what is coded, by whom and when. In primary care, we found that general practitioners (GPs) enter Read codes directly during consultations; in contrast, in secondary care, notes were frequently made on paper during consultations and coded later by clinical coders, often using the 10<sup>th</sup> version of the International Classification of Diseases (ICD-10). There was no straightforward mapping between these coding systems.
- We found little evidence of clear-cut clinical benefits to inform immediate care decisions in primary care, where data were more extensively coded; it seems likely that this will also be true with respect to secondary care. There were, however, a number of important secondary care uses that were widely appreciated by NHS staff, but the coding of data to serve these ends was often poorly aligned with clinical practice considerations.
- Many interviewees raised the difficulty of fitting complex mental health conditions into coded categories as they felt that context was often lost. Information captured in free-text was therefore valued, whilst coding was perceived to promote labelling, which in some cases was considered inadequate and/or inappropriate. This reluctance was exacerbated by the perceived wider health and societal ramifications of mental health diagnoses – for example, the risk of stigma – and the potential implications for insurance reports and occupational health screening.
- Clinicians tended to find it hard to choose an appropriate coding category, often picking the closest match as opposed to an accurate description of the patient's situation. This had important accuracy implications for secondary users of the data. Most healthcare professionals felt detached from the development of codes, which possibly resulted in reduced clinical utility.
- The large number of codes available often meant that users had to spend extensive amounts of time browsing lists. These codes were felt to be fairly meaningless due to the subtle distinctions between items, which resulted in a potential applicability of any given condition/intervention to more than one category.
- A more meaningful arrangement of codes based on clinically intuitive hierarchies might help address the problem, as might a smaller list of coarser grained codes that avoid the need for an overly precise diagnosis. However, simultaneously, clinicians expressed the need for a richer set of terms to be provided within EHR systems for the faithful documentation of a patient's changing mental health status.

- Clinicians were clear that they valued being able to use structured and coded information to obtain an overview of each patient on a summary screen, to trace developments over time such as evolution of mental health scores and the ability for different healthcare professionals to share patient information better through a well organised EHR.
- It was felt that if coded data entry was made easier and faster for clinical users, this would facilitate better quality (direct clinician) coding.

### ***Diabetes mellitus***

- For a chronic condition for which a clinical review dataset has been established for many years, such as diabetes, the potential for secondary use benefits of highly structured and coded recording and sharing of data seem clear, and are likely to be increased by linkage to other datasets (e.g. cancer and social care datasets).
- At the clinical level, there were marked differences in structuring and/or coding of diabetes information between primary care, where the use of structured templates and Read codes was generally high, and secondary care, where there was much greater variation in current practice.
- The hospital we sampled did not have EHRs. A paper template to structure and standardise the information being collected and recorded for each diabetes patient was used in some clinics, depending on the clinic consultant.
- All coding was done by the hospital's team of professional coders, who worked from the information on patients' discharge summaries.
- The accuracy and completeness of the coded diagnoses and activities therefore depended on the accuracy and completeness of the discharge summaries, which were reported to be highly variable.
- In primary care, staff using existing GP IT systems identified a range of advantages from having structured and coded information in EHRs. These included clinical benefits, such as: having information available for consultations; being easier to share information within the practice; protocol disease management and monitoring of diabetes patients; involving patients in their care through on-screen graphics; and enabling the fast transfer of records between practices when patients moved (i.e. via GP2GP).
- Clinical staff viewed these advantages as compensating more than adequately for minor frustrations with using the IT system.
- Some primary care participants expressed concerns about coding inaccuracies, particularly historical inaccuracies and possible misdiagnoses of the type of diabetes.

- We however found very little evidence that structured and/or coded data in EHRs were currently used to improve diabetes-related information sharing between secondary and primary care providers, despite widespread acknowledgement that this was an important aspect of continuity of care where improvements were desired.
- Both primary and secondary care staff lacked knowledge and understanding of the possible implications of changing to Systematized Nomenclature of Medicine-Clinical Terms (SNOMED-CT), which is planned to be introduced across the NHS in England by 2015.

#### **WP4: International perspectives**

- The challenges of developing better quality EHR systems, and of systematising the clinical data structures within them, are being tackled in many countries in parallel through national eHealth programmes.
- Countries vary in the role and power of the state over regional healthcare services. In some, these national programmes have played a facilitating role enabling national EHRs through common infrastructures and standards (e.g. Australia and Canada), these contrasting with the more centrally directed and mandated approach that has until recently been pursued in England.
- Across the six countries studied there was a broadly comparable list of key political and societal drivers behind eHealth investments. However, countries do differ in which of these are prioritised. Australia, England, Sweden and the USA have, for example, prioritised a shareable patient summary. The USA has focused on a clinical communications summary to support care transfers rather than a longitudinal patient summary. Sweden, in contrast, is concentrating on chronic diseases, using registers (that are potentially linked to their longitudinal electronic patient summary) to support integrated care pathways and the collection of clinical audit data.
- Countries are progressing with a mixed agenda of national and regional initiatives, the latter approach being more sensitive to local needs; they are therefore better able to prioritise and incentivise relevant coding and structuring initiatives, building on the maturity of existing systems and healthcare services; and current areas of innovation and the presence of champions. Some incentive programmes, such as in the US, operate at both national and regional levels.
- Across all programmes there was a recognised need to define priorities, such as the safety of new medication prescriptions, and informing shared care within clinical teams. Supporting the information needs of unscheduled care was noted as being difficult to progress; improving the quality and interoperability of EHR data could, it

was felt, be most rapidly achieved in closely governed remits such as specialist care of people with chronic disorders.

- Despite relatively ambitious timetables for achieving interoperable EHRs, most countries were at a very early stage in developing clinical data structures and terminology subsets to facilitate the consistent and coherent collection of clinical data. Mapping locally used terminologies to newly adopted national ones was consistently found to be proving a significant challenge.
- This WP has highlighted the considerable opportunities for international collaboration on these efforts; in particular, cross-country alignment on specific care scenarios would make the challenges more tractable.

### **Cross-cutting themes across the four WPs**

- Several themes emerged from more than one WP, which are summarised below.
- There is no single answer to the question of the optimal trade-off between the work of coding data and the immediate benefits to clinicians and patients; this varies by, amongst other things, clinical context, setting, speciality and the professionals involved, and is in any case likely to need continual reappraisal, for example, to respond to changing professional priorities and technical capabilities.
- We noted that discussions about the recording and use of medical records were not commonly framed in terms of structuring and/or coding. Our findings indicated that these concepts were discussed in relation to the impact they had on an individual's workload and/or the benefits for their patients, rather than in more abstract terms. This suggests that consensus on which sections of the record to code may be time-consuming and difficult to achieve.
- Discussions with healthcare professionals showed the coding of medical records was frequently associated with the clinical coding of information for performance management, reporting and reimbursement, specifically for the Quality and Outcomes Framework (QOF) and Payment by Results (PbR). The importance of such financially-linked initiatives were understood by managers, but appeared to have diluted the interest and engagement of healthcare professionals, particularly if the link between coding and quality of care was not appreciated.
- The most common tools to support structured and coded records were found to be digital templates and/or pick lists of pre-selected clinical terms. Although clinicians tended to find these irritating, they had the potential to be useful as a reminder (i.e. a prompt) during a consultation, as well as for improving the completeness of data entry.

- Structured data entry using templates was found to be well-established amongst administrative staff and certain groups of healthcare professionals, particularly where guidelines and protocols had been used to develop and standardise professional practice, for example in midwifery, paramedic services and specialist nursing. For other clinicians, particularly doctors, practice was more commonly found to be based on capturing information in free-text formats. Here, the use of templates was less usual and appeared less acceptable. Thus the use of structuring and/or coding in medical records was found to be influenced by professional identity, levels of autonomy in clinical decision-making and mandated standardisation.
- Clinical information standards (i.e. record structures, term lists and rules) that embody good practice guidelines and incorporate decision support have been shown to improve the adoption of those guidelines. Given that a range of stakeholders – policy-makers, managers, professionals, academics and patients – all have a potential interest and role in delivering promoting guideline-based care, it is important that a comprehensive range of stakeholders is therefore considered when designing the clinical data standards.
- We found a need for better harmonised terminologies, consistency in when and how specific terms are used, and alignment of coding practices across care settings.
- Although many participants discussed potential risks associated with incomplete and/or inaccurate coding, it is important to note that we did not find any empirical evidence or reports of *actual* increased harm to patients in our investigations.

## Conclusions and Main Recommendations

- There was clear and consistent evidence of substantial opportunities arising from the secondary uses of coded data for public health, healthcare management, audit and research. However, it is important to bear in mind that these opportunities tend to accrue over time as datasets mature and expand exponentially with the increasing ability to link between datasets. These returns are, however, closely dependent on the quality of the data being generated and so it is crucial that - if there is a policy decision taken to maximise the secondary uses of these data - that hand-in-glove with the drive to increase the proportion of the record that is coded there are concerted efforts to maximise data accuracy and shared understanding.
- Evidence in relation to short-term returns for clinicians entering structured and/or coded data is however far less clear-cut than those associated with secondary uses. There is therefore a need to re-examine policies, professional practices, hardware and software, incentives and reward mechanisms to minimise the inherent tensions

in asking busy clinicians to expend time and effort in coding activities for which they themselves or the patients they care for receive little or no immediate returns and explore how coding can be maximised with minimal effort and disruption to clinical workflows.

- The findings of this research suggest that attempts at increasing the availability and quality of structured and coded data items should focus on well-characterised safety, quality and efficiency challenges that are recognised as important by front-line clinicians, in order to:
  - Promote the development of relevant semantic resources such as clinical data structures and terminology subsets
  - Encourage the enrichment of EHR systems to support workflows and EHR interactions (such as alerts and decision support) that enable clinically important benefits to be realised
  - Target education, incentives, and audit feedback loops, towards improving those aspects of EHR content that are necessary to deliver these benefits
  - Support evaluations that can better establish the evidence for the benefits that are directly attributable to the increased adoption of structures and codes within EHRs.
- There is a need for national clinical leadership to direct future investments and efforts to co-ordinate the compilation of better evidence of value from clinical coding and to promote the national and local opportunities for healthcare improvement from high quality EHRs. These activities might include:
  - Identifying areas of care where clinical practice is already extensively structured on paper, which has the potential to be mirrored using electronic forms and codes
  - Aligning interests and incentivising the coding of data by, for example: considering this issue when developing and implementing national guidelines; greater professional recognition of the importance of good quality health records; and better recognising the impact of financial incentives
  - Greater use of patients entering data on lifestyle and health status into structured templates through online portals, waiting room kiosks, in-hospital touchscreen computers and, in future, through interoperable personal health record systems
  - Show-casing direct care and secondary use value obtained from good quality coding, thereby raising awareness amongst clinicians of the numerous ways in which coded data are now utilised to support quality of care, audit, health planning and research.

- This process can potentially be facilitated and better directed at more local levels by establishing clinical information champions in hospitals and general practices who have, as part of their management responsibilities, the remit to align local coding strategies with wider professional responsibilities and organisational priorities, and also to showcase local benefits arising from good quality data.
- Initiatives to improve data quality could be successful, such as the audit and intervention cycles used in primary care e.g. Primary Care Information Service (PRIMIS). Consideration should be given to extending such approaches into secondary care.
- There is a need to complement financial incentives for collecting data with a reinforcement of professional quality standards, which should be supported by clinical applications (such as data entry templates and decision support) that facilitate the adoption of good practice guidelines and care pathways, and the provision of personalised tools to support evidence-gathering for professional revalidation.
- The development and adoption of guidelines should take into account the codes and structures that will be needed to follow them and to monitor quality of care. This effort might begin with those clinical guidelines that are already well accepted professionally (e.g. those developed by the National Institute of Health and Clinical Evidence (NICE)), but are not well adopted.
- There are also a number of ways in which IT interfaces may facilitate the adoption of structured and/ or coded records, these include:
  - Making greater use of the more portable hardware devices such as tablets and smart-phones
  - Making coded data entry easier (e.g. by using touch sensitive diagrams, voice input mapped to clinical terms, and coding engines that could do much of the term mapping work behind the scenes automatically)
  - Creation of 'favourite' data items that are frequently used in given clinical scenarios, to enable rapid data entry
  - Adopting data entry templates that reflect clinical guidelines and foster good practice
  - Systems applications that enable real-time querying of EHR data for personal audit and professional development, to reinforce the value to clinicians of maintaining good records on their patients.
- Finally, given the considerable progress in coding patient data achieved over recent decades, the favourable emerging policy environment being ushered in by *The Information Revolution* and the substantial technical and academic expertise in the

UK, it is crucial that policymakers appreciate the strategic importance of ensuring the UK retains its leadership in exploiting coded data, which are likely to yield substantial and likely increasing academic, societal and economic returns to the UK.

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## Abbreviations

A&E	Accident and Emergency
APA	American Psychiatric Association
BMA	British Medical Association
BMI	Body Mass Index
BSACI	British Society for Allergy and Clinical Immunology
CaB	Choose and Book
CDA	Clinical Document Architecture
CDC	Clinical Documentation
CDSA	Clinical Documentation Solution Accelerator
CDSS	Computerised Division Support System
CODP	Chronic Obstructive Pulmonary Disease
CPOE	Computerised Physician Order Entry
CUI	Common User Interface
DH	Department of Health
DSM	Diagnostic and Statistical Manual of Mental Disorders
DTD	Document Type Definition
EHR	Electronic Health Record
EML	Ecological Metadata Language
EMR	Electronic Medical Record
FOBT	Faecal Occult Blood Testing
GML	Geography Mark-up Language
GP	General Practitioner/General Practice
GPRD	General Practice Research Database
HCP	Healthcare Professional
HES	Hospital Episode Statistics
HIEI	Health Information Exchange and Interoperability
HIU	Health Information Unit
HL7	Health Level Seven International
HMR	Hospital Medical Record
HRG	Healthcare Resource Group
IBM	International Business Machines
ICD	International Classification of Diseases
IHTSDO	International Health Terminology Standards Development

IPSC	Independent Project Steering Committee
IRAS	Integrated Research Application System
IS	Information Systems
ISO	International Standards Organisation
IT	Information technology
MedRDA	Medical Dictionary for Regulatory Activities
MHRA	Medicines and Health Care Products Regulatory Agency
MML	Medical Mark-up Language
NEHTA	National E-Health Transition Authority
NHS	National Health Service
NHS CFH	NHS Connecting for Health
NHS CFHEP	Connecting for Health Evaluation Programme
NHS CRS	NHS Care Records Service
NICE	National Institute of Health and Clinical Excellence
NLP	Natural Language Processing
NPfIT	National Programme for Information Technology
OPCS	Office of Population Censuses and Surveys
openSDE	Open Structured Data Entry
ORCA	Open Record for Care
OT	Occupational Therapist
P6R	Project 6 Research
PAS	Patient Administration System
PBR	Performance Based Results
PCRN	Primary Care Research Network
PCT	Primary Care Trust
PHQ-9	Patient Health Questionnaire (Version 9)
POMER	Problem Orientated Medical Record
PROM	Patient-Reported Outcome Measures
QOF	Quality and Outcomes Framework
RCGP	Royal College of General Practitioners
RCP	Royal College of Physicians
RCT	Randomised Controlled Trial
SCI-DC	Scottish Care Information-Diabetes Collaboration
SCR	Summary Care Record
SGML	Standard Generalized Mark-up Language
SHA	Strategic Health Authority
SNOP	Systematized Nomenclature of Pathology

SNOMED	Systematized Nomenclature of Medicine
SNOMED –CT	Systematized Nomenclature of Medicine (Clinical Terms)
SNOMED –RT	Systematized Nomenclature of Medicine (Reference Terminology)
SOCC	Standards of Care Committee
SUS	Secondary Uses Service
UKCRN	United Kingdom Clinical Research Network
USA	United States of America
VA	Veterans Association (USA)
W3C	Worldwide Web Consortium
WHO	World Health Organization
WP	Work-package
XML	Extensible Mark-up Language

# Chapter 1

## Background

### 1.1 Introduction

There is considerable strategic interest internationally in the potential that electronic health records (EHRs), and the systems and services that utilise EHR information, have for transforming healthcare into a safer, more effective and more efficient system (1). Towards this end, there has in the United Kingdom (UK) over the past two decades been a progressive move to replace paper-based health records with digital records, this being led from general practice. In an attempt to catalyse this potential of information technology (IT), the National Health Service (NHS) embarked in 2002 on an ambitious programme of modernisation known as the National Programme for IT (NPfIT) (2). At the heart of this Programme was the creation of a cradle-to-grave distributable EHR for every person in England (3-5). Given the historic limited deployment of EHRs in hospitals, the Programme focused on the implementation and adoption of hospital-based EHRs, although it has been argued that inadequate attention was paid to local implementation and adoption issues (4,5).

The key goals of this modernisation agenda were to enhance the quality, safety and efficiency of clinical care, the realisation of which are crucially dependant on the availability of high quality computable clinical information to underpin direct patient care. Structuring and coding both render information computable, which can in turn enable, amongst other things, decision support functionality, the effective and efficient sharing of information between care settings, and a range of secondary uses of these data. Structuring and coding are two related but distinct concepts. These terms are however used inconsistently in the literature and it is therefore important that we make clear our understanding of these terms and explain how they have been used in the context of this report. These concepts are defined in the Glossary, explained below and contrasted with narrative information in Box 1.1.

**Box 1.1: Examples of narrative, structured and coded information****Narrative information:**

- sentences and/or informally grouped lines of text;
- optionally using indentation or bullets;
- in a format that is determined by the author;
- numeric values, dates and times occur within sentences or phrases.

**Structured information:**

- a (possibly nested) set of entries organised according to a logical model, in which the scope of each data item is specified (usually via a label), and where it may be:
  - narrative;
  - coded: representing a term or terms taken from a terminology or controlled vocabulary;
  - a quantity;
  - a date and/or time;
  - Boolean;
  - graphical, multimedia or a reference to such data;
- and where its values may optionally be clustered into lists, tables or trees.

**Coded information:**

- values used to populate one or more parts of a structured record are taken from a terminology system or a controlled vocabulary;
- terms are assigned unique concept identifiers (for example, the concept of myocardial infarction has the unique concept identifier 22298006 in the Systematized Nomenclature of Medicine Clinical Terms or SNOMED-CT terminology).

**1.2 The evolution of structure within medical records**

Until the early 20th century medical record-keeping was erratic and idiosyncratic: most clinicians kept some records about each patient, but these were often held in personal ledgers. Notes were scattered between homes, hospitals and private clinics and were full of private codes and symbols, rendering them useless to everybody except the author; at best they served to jog the clinician's memory.

In 1907, the Mayo Clinic and the New York Presbyterian Hospital pioneered the design of a patient-centred record: the Unit Medical Record (6). Whilst generally popular amongst doctors, problems soon arose regarding the space needed to store and the staff needed to transport these files. Sometimes clinicians took to keeping brief additional notes themselves as a backup. The organisation of clinical information within records was also not addressed by this solution. A 1923 textbook noted that *"from the standpoint of scientific record taking, case histories are most glaringly defective in what they fail to record about a patient"* (7).

Since the 1920's, attempts have been made to address the issue of data omission through the use of standard pro-forma to record essential information. When first introduced these were almost universally unpopular as most physicians demanded that they ought to decide what should be recorded. They insisted that the unique characteristics of each patient and illness required considerable variation and flexibility in the record structure (8). During the mid-20<sup>th</sup> century, as medical technology advanced and specialisation increased, the results of x-rays, laboratory analysis, visiting consultant notes and photographs were often pasted in the margins of records, overlapping each other and sometimes making it difficult to read the original entries. The involvement of different professionals led to records becoming vast repositories of data with little structure to facilitate the processing of these data (9).

In his classic paper, *"Medical records that guide and teach"*, Weed draws attention to the extent of the disorganisation within hospital paper-based medical records (10). He illustrated the way in which a failure to trace the evolution of each problem a patient could result in unnecessary delays in instigating the correct clinical management or result in needless morbidity. The next major advancement was the Problem Oriented Medical Record (POMR) introduced by Weed in 1968 (10). which happened at a time when the patient's story was recorded as a dated and highly abbreviated series of statements. The idea behind POMR was simple, but powerful. Reading and extracting information from such a record was however very difficult. The current active problems were the underlying model for this structuring. The information could be searched using problem headings. By 1996, POMR was a popular conceptual model for designing clinical computer systems in the UK. This was until Bainbridge and others (11) highlighted the limitations of POMR noting that *"although the POMR is a popular medium for data entry viewing, there is certainly room for improvement and development"*. They proposed an extension to POMR adding to the 'Problem', 'Sub-problem', 'Encounter' and 'Episode' elements, arguing that *"These developments must be tempered with knowledge of two conflicting pressures. There is a marked reluctance to reduce the amount of time taken in interaction with the patient in favour of entering data onto a computer. The new items discussed will only be practical if they either require no extra*

*time for data entry or if, by improving the ability of the clinician to gain a 'story' from the record, they reduce time spent elsewhere" (11).*

In 1996, recognising the importance of the clinical narrative, a new model of the medical record which incorporated context, structure, process and use of the medical record within a single narratological framework was proposed (12). This model they argued could be readily understood by those in both lay and technical healthcare professions. By 2004, there were no emerging innovations in clinical record structure and reviewing the research in this field Walsh noted that narratives were essential to the patient's episodes of illness and stated that computers should enable clinicians to capture narrative easily (13). He noted that the structure of the patient's record strongly influences the ease of information retrieval. There is also evidence for changes in physicians' information gathering behaviour and reasoning strategies when they are exposed to computer records (14). Clinical records have over this and the subsequent period become much more complex having been created and used by many stakeholders, both clinical and non-clinical. They are furthermore increasingly being used by patients themselves.

The problems with most paper records are well recognised, including, poor legibility, disorganised layouts with little or no structure, inconsistent content, difficulties in sharing records within or between sites and difficulties in the navigation, comparison or analysis of the information contained in them (10,15,16). Although EHRs have the potential to overcome the above problems, recent reviews of literature showed that EHR use will always require human input to re-contextualize knowledge; that even though secondary work (audit, research, billing) may be made more efficient utilising EHRs, primary clinical work may be made less efficient; that paper may offer a unique degree of ecological flexibility; and that smaller EPR systems may sometimes be more efficient and effective than larger ones (17).

We know that well-structured health records can improve the completeness of the information documented within a clinical encounter (18). In order to support evidence-based management, consistent shared care and to allow clinical audit to take place across a range of clinical settings, standardised templates, proformas and summary sheets have increasingly been adopted across all sectors of healthcare. Well-structured clinical information also importantly underpins service management and planning, public health and clinical research.

The logistic limitations of paper-based records, however well structured, have provided the momentum to computerise clinical information. Since the early seventies, major academic

hospitals have pioneered the application of computers for the management of clinical information. Many of these have their origins in the acquisition and analysis of laboratory data. As they grew in scope and scale some focused on capturing the health problems, investigation reports and medication records of individual patients, others had a greater emphasis on capturing best practice and medical knowledge through on-line access to the medical literature, protocols and alerting systems. These pioneering systems have variously shown that user acceptance, efficiency gains and some outcomes benefits can be demonstrated through their use. This has usually been demonstrated through applications targeting specific clinical care scenarios such as Computerised Physician Order Entry (CPOE),(19) abdominal pain (20) and antenatal care (21). A timeline of the major milestones in the evolution of formalisms and systems for the structuring and coding of health records is given in Table 1.1.

**Table 1.1: The important milestones of structuring and coding**

<b>1660</b> London Bills of Mortality created by John Graunt
<b>1785</b> William Cullen of Edinburgh in 1785 published classification of diseases under the title <i>Synopsis nosologiae methodicae</i> .
<b>1880s</b> Physicians at the Mayo Clinic in Minnesota kept all their patient's records in a personal leather-bound ledger.
<b>1893</b> Bertillon Classification of Causes of Death
<b>1907</b> Patient based records introduced in the Mayo Clinic.
<b>1960</b> Development of first Electronic Medical Record Systems at the Massachusetts General Hospital.
<b>1965</b> (a) The first major attempt to standardise medical records in the UK is with the publication of Tunbridge Report. Standardised hospital medical record (HMR) forms were introduced into the NHS hospitals (b) Systematized Nomenclature of Pathology (SNOP) started
<b>1966</b> Computer based history taking systems (22).

**1968** Lawrence L Weed introduced the Problem Oriented Medical Record (POMR). He proposed that clinical records be structured around the patient's problems

**1968** Professor John Anderson in Kings College London developed a dictionary of medical terms for an electronic medical record. It used 'tree-branching' menus for data entry

**1970** (a) Invention of "mark-up languages" (Charles Goldfarb, along with Ed Mosher and Ray Lorie) invented Geography Mark-up Language (GML), a way of marking up technical documents with structural tags. (b) First real time GP system set up by International Business Machines (IBM) at Whipton , Exeter.

**1970's** VistA system development started in USA. An electronic health record programmed by Federal (USA) employees working for the Veterans Association (VA).

**1972** The Regenstrief Medical Records system was started by Dr Charles Clark in Marion County General Hospital with 35 diabetes patients.

**1974** SNOMED development started.

**1977** SNOMED was released

**1982** Read Code development started

**1986** International Organisation for Standardisation (ISO) adopted Standard Generalised Mark-up Language (SGML) (A specification for defining mark-up languages).

**1989** PEN&PAD programme started at Manchester University for clinical workstations and structured data entry. It was a success but government funding withdrawn.

**1990** International Classification of Diseases (Version 1) (ICD-1).

**1990s** Jon Bosak, Tim Bray, James Clark and others developed Extensible Mark-up Language (XML) (A specification for defining mark up languages).

**1995** The audit commission examined 200 case notes from 8 hospitals and found that many different structures to records and some with no structure. 50% did not have index of contents (23).

**1995** Medical Mark-up Language (MML) was developed in Japan

**1995-1998** NHS initial clinical headings set

**1996** Clinical Document Architecture (CDA) was developed

**1996 NHS** Immediate Discharge Documentation Guidelines (24).

**1996** (a) Narratological framework for medical records proposed (12). (b) Structured data entry. Open Record for Care (ORCA) Data can be extracted from free text using natural language processing techniques, but it can also be collected in a structured fashion at the time of data entry (25).

**1997** Clinical record Architecture (26).

**1998** The Worldwide Web Consortium (W3C) approved Version 1.0 of the XML specification was introduced.

**1998** Clinical headings (27-29)

**1998** Building an XML Document Type Definition (DTD) for a NHS immediate discharge pilot in Scotland.

**1999** (a) The audit commission repeated the audit conducted in 1995, and found improvement in some areas but there was inconsistency (30). (b) ICD-10 was released (c) SNOMED-RT and SNOMED-CT were introduced (d) Standardised records (31).

**2001** Automatic structuring of free-text radiology reports. (Still experimental) (32)

**2001** (a) Clinical Headings (33). (b) The first UK project to send and receive discharge letters using XML (34).

**2002** Kennedy report from the Bristol Inquiry criticised record-keeping practices and standards (35).

**2002** Royal College of Physicians (RCP) Health Informatics Unit (HIU) audited 149 hospital case notes in 5 hospitals in England and Wales and found deficiencies in recording of case notes.

**2003** RCP Health Informatics Unit (HIU) released the draft standards for record keeping was released (36).

**2005** openSDE (Open Structured Data Entry) OpenSDE enables data entry with (customizable) forms based on trees of medical concepts (37).

**2007** International Health Terminology Standards Development (IHSDO) took the control of SNOMED-CT.

**2008** (a) NHS Digital and Health Information Policy Directorate published "*A Clinician's Guide to Record Standards*" reports (38, 39). (b) Structured narrative (40).

**2008** NHS Common User Interface (NHS CUI). Microsoft Common User Interface (MCUI) <http://www.mscai.net/CDSA.htm> Clinical Documentation Solution Accelerator (CDSA) of Microsoft.

**2010** (a) Timeline as an information structuring paradigm useful for decision support (41). (b) Hybrid systems combining coded data and processing of free-text clinical entries. Structured EMR parameters and free-text analyses can be combined into algorithms that can detect ARI cases with new levels of sensitivity or precision. These results highlight potential paths by which repurposed EMR information could facilitate the discovery of epidemics before they cause mass casualties (42).

**2011** The Information Standards Board for Health and Social Care officially approved SNOMED-CT as a "fundamental standard" in the UK

**2015** ICD-11 (expected).

### 1.3 Structuring clinical information

In order to support evidence (guidelines) based management, consistent shared care and to allow clinical audit to take place across a range of clinical settings, standardised templates, proformas and summary sheets have increasingly been adopted across all sectors of health care. The design of forms, for paper or computer use, ideally should facilitate rapid and structured data entry catering for the majority of possible responses. This might include the use of anatomical diagrams, tick-boxes, pick-lists and preferred terms.

It is important to incorporate some flexibility in the design of these templates in order to allow for unique individual findings and for the recording of additional explanatory details. When this flexibility is absent, forms tend not to be completed well and users often revert to using narrative remarks (sometimes using 'white space' on the paper form or repurposing a nearby text field on a screen to capture this). Harris et al. have shown that the exact layout of obstetric booking notes affects the accuracy and completeness of the records made (43). Leiner and Haux argue that clinical documents, whether for paper or electronic implementation, must be rigorously designed for the intended purposes and potential uses that will be made of the data (44). They stress the need to balance the desire for detail with the reality of clinical workflow and workload.

Most clinical settings nowadays use a range of templates and flowcharts that embody published evidence on clinical effectiveness expressed in the form of algorithmic guidelines. Historically, it has proved difficult to integrate guidelines within everyday clinical practice and to ensure that they remain an effective tool when used during patient consultations (45). Grimshaw and Russell demonstrated that the guidelines are most effective if they deliver patient-tailored advice during a consultation (46). This interactive capability is much more easily delivered using a computerised clinical application if the guideline rules are combined with data within each patient's EHR to enable the advice offered to the user to be patient-tailored automatically.

Williams and Morgan describe the need for the structure of information in the EHR to be appropriate to the needs of clinicians (47). They suggest that EHR systems need to offer users a comprehensive thesaurus of terms, with agreed definitions or clinical consensus on their appropriate use. Data can have varying clinical priority and importance that needs to be noted and represented in some way. Observations may be qualified with a degree of certainty or severity. Information may be organised under headings, negative findings may be recorded, and imprecision may be implied by the phrasing of a diagnosis or management

plan. Clinical actions may be intended, planned or carried out, and these must be clearly distinguished. Most clinical applications and EHR systems still lack some of this capability, making it hard for structured computer forms to meet clinical documentation needs without some allowance for free text comments. Moving the balance of clinical documentation further towards structured information and away from narrative probably requires enriching the capability of screen forms to capture these kinds of context, which have recently been formally captured within an international standard on EHR requirements (48).

## **1.4 Coding clinical information**

The concept of coding is, as noted above, related to standardisation and structuring. Information in clinical records may be 'standardised' by mapping concepts committed to the record by the clinician to standard terms from a terminology (known as a controlled terminology). 'Heart attack' and 'infarct' can, for example, both be mapped to the term 'myocardial infarction' in the controlled terminology so that the risk of confusion to a third party or process such as a query or decision support system that is looking for instances of myocardial infarction is minimised. This enables semantic interoperability across different clinical systems. Information is coded when clinical concepts are assigned unique identifiers or codes (Box 1.1). Coded information is therefore very amenable to computational analysis. Terms within a terminology system are related to each other, permitting entries within coded health records to be grouped and compared: for example, diagnoses such as antero-septal myocardial infarction and angina pectoris can be identified as kinds of ischaemic heart disease, or pneumococcus can be identified as a causative organism for pneumonia. Coded information, if taken from a rich terminology, therefore has the potential for sophisticated computer interpretation. The effective and efficient sharing of clinical information is central to modern healthcare systems (49) and in complex healthcare systems in which care is provided by a diverse array of professions operating in disparate settings there is a related need to be able to contribute to and share information between these care providers. This requires syntactic interoperability (i.e. the sending of messages) and semantic interoperability (i.e. sharing of meaning) of data, which in turn both depend upon appropriate structuring and/or coding of information. However, most UK healthcare settings are currently characterised by relatively low levels of health information exchange and interoperability (HIEI) capability, this being particularly true of the hospital sector, where paper-based records are still the main means of recording and communicating clinical information. With increasing investments in EHRs and growing international interest in

increasing coding and structuring of these electronic records, there is considerable potential in overcoming some of these important barriers to facilitating the delivery of joined-up care.

This simple proposition opens another possibility when it is used in a computational environment and that is clinical decision support, for example in medicines management to improve patient safety. However, despite decades of research we are still nowhere near achieving full semantic interoperability or practical clinical decision support systems of the kind which use two or more items of patient data to generate case-specific advice (50). One of the primary reasons for this is that building clinical terminology is hard (51). And even when terminologies are available building user friendly terminology browsers to be embedded in clinical systems is also hard (52).

Controlled terminologies are structured according to a model familiar to clinicians (i.e. a model of medicine). Such a model is called an ontology, which is a specification of terms in the domain and the relations among them. More accurately, the subject of ontology is the study of categories of things that exist and may exist in some domain (53). Therefore, terminological reasoning which can be performed on the basis of the classification or relations among concepts (51) is possible.

## **1.5 The challenges of structuring and/or coding clinical information**

Coding information is a form of structuring. Structuring of information is a prerequisite for information retrieval from any computer system. However, what, how, by whom and when information is optimally structured depends on the domain. In healthcare, structuring and coding is overwhelmingly carried out by humans (e.g. clinicians, administrative staff and coders) with very little if any automatic coding by the computer.

The cognitive burden of mapping a clinical concept to a term in a terminology (using a terminology browser) during normal clinical work has not received much academic attention, although much of general practice data entry occurs this way. The concept to be coded may, for example, be an evolving disease or an uncertain clinical condition. It is believed that diagnostic errors are common and such errors can result in significant harm to patients (54, 55). The role of heuristics, or coherence-based reasoning, has been highlighted as an important factor in clinical reasoning when clinicians are faced with interpreting ambiguous and conflicting information (56). Resulting misdiagnoses will then lead to miscoding. In general, clinicians are reluctant to code unless they can see a clear clinical benefit associated with

this and furthermore coding is both quick and easy to accomplish. The barriers to clinicians coding include: (a) limitations of coding systems and terminologies; (b) skills gap of the users; (c) time and distraction when coding; (d) level of motivation; and (e) the lack of priority of coding within the organisation (57).

It is however known that general practitioners (GPs) achieve high levels of coding when they are appropriately incentivised, if the scope of coding is well-defined and if well-designed tools such as templates are provided to them. This has been a key observation associated with, for example, the introduction of the Quality and Outcome Framework (QOF), which has resulted in a considerable increase in the amount of coded information in GP records.

Structured and/or coded information naturally enable decision making using formal logic (58) and computers can readily use such information. However, a large proportion of clinical records are still captured and stored as free-text narrative. This is partly because narrative remains the most convenient way to write and to read in many clinical contexts, because it permits the most faithful and accurate documentation of a patient's situation, and because the representation and generation of clinical information systems and terminologies are not yet rich enough to cope with the requirements of diverse patients and diverse clinical authors. Although clinical narrative is important as a source of information to support decision making (12, 59), current computer systems are unable to process the free-text narrative and retrieve information easily. Natural language technologies are rapidly extending the capability to interpret narrative, but it may be many years before these have achieved the level of reliability that is needed to support safe clinical decision making.

EHRs with longitudinal clinical records at their core therefore already have information captured and stored in several different formats: clinical narrative, coded information, structured templates, images, scanned documents and even voice. Structuring and coding of this diverse group of information is a challenge.

Entering clinical information within formalised structures such as templates, and using codes, can require greater effort than entering narrative. Improvements to the sophistication of clinical applications and the richness of terminology systems require investment and time to develop and evaluate new solutions. Time and investment are also needed to educate clinicians and to foster changes in workflows and documentation practice if the levels of structuring and coding of health records are to increase. These investments therefore need to be directed towards those aspects of clinical documentation that will achieve the greatest value. There is however also potential risk associated with the move away from free text

towards more codified records. This is because in clinical practice, not all decisions are made on the basis of explicit knowledge; some tacit knowledge and undocumented signals are used in coming to a clinical management strategy. Therefore, there will almost always be clinical judgement applied in decision making. So the current challenges are to find when structuring and/or coding is most appropriate and how clinical judgement can usefully and safely be supported by decision support systems (60) that make use of information in the clinical record. This report presents the results of research investigating this challenge.

## **1.6 The structure of this report and its presentation**

After this introductory chapter we present our aims and overview of our methodology (Chapter 2). This is then followed by detailed presentations of our empirical work (Chapters 3-10) and a final chapter in which we present our overarching conclusions and then tease out the implications for policy, practice and research arising from this complex mixed methods enquiry (Chapter 11). There then follows a series of appendices detailing relevant supplementary information.

In order to assist readers, each of the empirical chapters begins with an abstract providing an overview of its contents. We recognise that not all readers will read every chapter and abbreviations are therefore spelt out with first usage at the beginning of each chapter. We also appreciate that the report contains a number of technical terms and concepts. To assist readers, we have therefore tried in the text to explain these in non-technical language in the text, confining the more technical definitions to the Glossary. Finally, readers should note that this report aims to provide an overview of our work for a general audience interested in this important field of enquiry; more specialist reports aimed at more targeted groups will in due course appear in peer-reviewed publications.

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## Chapter 2

### Aims, objectives and overview of methods

#### 2.1 Introduction

This chapter describes the overall research aims and objectives of this evaluation, and provides an overview of the methods employed in our work. This work was conceptualised as four complementary work-packages (WPs) that were pursued using a combination of quantitative and qualitative approaches. These WPs are outlined below and then discussed in considerably more detail in subsequent chapters (Chapters 3-10).

#### 2.2 Overall aims and objectives

Overall, this study aimed to provide evidence to inform deliberations on the extent to which real-time recording of information within medical records during the provision of clinical care should or should not be coded and to consider the trade-offs associated with structuring and/or coding increasing amounts of information that is currently held as free text in electronic health records (EHRs).

In doing so, we sought to:

- Identify benefits and barriers to structuring within the entire clinical record;
- Critically analyse requirements and match these with current and future forms of structuring and/or coding on paper and/or electronically;
- Liaise with NHS Connecting for Health (NHS CFH) in order to inform current practice of structuring and/or coding of clinical records, design of future technology, and education and training.

#### 2.3 Overview of evaluation design

We sought to achieve these aims through pursuing the following four complementary WPs:

- WP1: Reviews of the relevant theoretical, technical and empirical literature
- WP2: In-depth qualitative interviews with domain experts, users and patients
- WP3: Case studies in four exemplar clinical settings
- WP4: Placing UK experiences in an international context.

In WP1, we undertook a systematic review of the literature investigating the evidence for structuring and/or coding the patient history; this very focused formal systematic review was then complemented by a review of the wider evidence-base in relation to structuring and/or coding other dimensions of the clinical record.

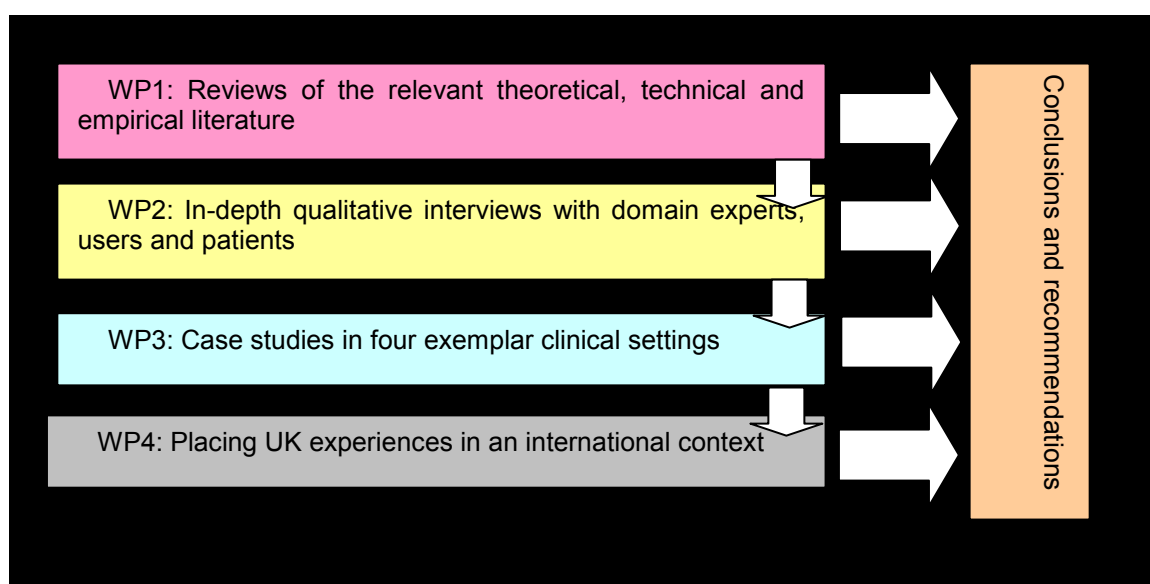
WP2 involved us undertaking in-depth qualitative work with a range of individuals who are potentially involved in coding clinical information and/or utilising these data to understand their perspective, experiences and investigations.

This was then followed by in-depth enquiry in four carefully selected domains (WP3), these being selected to illustrate one or more exemplary challenges/opportunities pertinent to the overall focus of this enquiry. We selected ethnicity as an area in which there is a long-standing legal requirement on the National Health Service (NHS) to collect and code these data, but where data completion rates remain poor. This was juxtaposed with drug allergy where there is no such legal requirement, but where there are typically very high completion rates, particularly in general practice. Our other two case studies undertaken in this WP concerned the management of long-term conditions, namely depression and diabetes. These were selected because it is in relation to depression/mental health that the merits of the clinical narrative being recorded in free text are most often advanced; in contrast, much of routine diabetes care is potentially far easier to code and so studying this clinical area offered the potential for insights of possible opportunities in relation to conditions that are managed within a more biomedical disease model. These case studies were undertaken by individual researchers who undertook sampling and recruitment, data collection and led on analysis; there was then cross-case analysis to draw out key cross-cutting themes.

Our final WP (WP4) was designed to place this work within an international context, in particular seeking to identify any key lessons/insights that could inform NHS deliberations and practice. The six countries chosen aimed to ensure reasonable geographical spread and consideration of a range of healthcare systems.

A diagrammatic overview of these WPs and their inter-relationships is given in Figure 2.1.

**Figure 2.1: Overview of four WPs**



## **2.4 Methodological considerations**

Our work involved a combination of quantitative and qualitative methods, including systematic review-based approaches to searching and synthesising the scientific and grey literature (WP1) (1-3) as well as qualitative explorative (WP2) and case study-based work (WPs 3 and 4) (4-7). Pursuing the work in this way enabled us draw on relevant research (WP1) in order to frame and inform our own field work (WPs 2-4). The case study-based approach in particular allowed us to explore local contingencies and contexts, including different working practices, approaches to coding, available information technology (IT) systems and in-depth considerations of observed practices.

Theoretically, our work was informed by a sociotechnical perspective (8-14). This helped us to explore how the technology was situated within social, organisational, and also wider political environments, which was particularly relevant for our scoping of the international landscape (WP4). This sociotechnical perspective also facilitated investigating how social and technical factors were interrelated and shaped each other as structuring and/or coding systems were designed, implemented and adopted by a range of stakeholders.

## **2.5 Ethics and research governance**

We received ethical approval for this work from the National Research Ethics Service – Brighton West Ethics Committee (MREC Ref: 10/H1111/25). Approval was initially granted for the WP2 qualitative study, followed by approval for the case studies within WP3 as a substantial

amendment to our original protocol. Details of this correspondence are shown at Appendix 1.

Following formal ethics approval, the research team applied for site specific permissions from local Research and Development offices, facilitated by the United Kingdom's Clinical Research Network (UKCRN) and the Primary Care Research Network (PCRN), and administered within the Integrated Research Application System (IRAS) (detailed at Appendix 2).

Where possible, written informed consent was sought from all participants, although in some cases, such as telephone interviews, verbal consent was accepted. All data were anonymised to protect the confidentiality of both participant organisations and individual interviewees.

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## Chapter 3

### Benefits and risks of structuring and coding the presenting patient history in electronic health records: a systematic review

#### Abstract

**Background:** Patient histories in electronic health records (EHRs) currently exist mainly in free-text format thereby limiting the potential for decision support technology to contribute to the accuracy and timeliness of clinical diagnoses when such technology is available. The structuring and/or coding of the patient history renders such information computable, which has the potential to enhance the accuracy and speed of, amongst other things, clinical diagnoses.

**Aims and objectives:** To identify the risks and benefits associated with structuring and/or coding symptoms in the patient's presenting history.

**Methods:** We undertook a systematic review, which involved two reviewers searching nine international databases for published and unpublished studies over the period 1990-2010. Our focus was on the current patient history, which was defined as information reported by a patient or a carer (or caregiver) about the patient's present health situation and health status. Studies were independently quality appraised using the Newcastle-Ottawa Quality Assessment Scale (NOS) and disagreements were resolved through discussion or, where necessary, arbitration by a third reviewer. Findings were synthesised through a theoretically-based textural analysis.

**Results:** Of the 9207 potentially eligible papers identified, 10 studies satisfied our eligibility criteria. These studies were judged to be of weak-to-moderate quality. There was evidence of a modest number of benefits associated with structuring the current patient history, these include the obtaining of more complete clinical histories, improved accuracy of patient self-documented histories, and better associated decision-making by professionals. However, no studies demonstrated any resulting improvements in patient care or outcomes. Where more detailed records were obtained through the use of a structured format no attempt was made to confirm if this additional information was clinically useful. No studies investigated possible risks associated with structuring the patient history. There were no studies that examined coding the patient history.

**Conclusions:** The act of structuring and/or coding the current patient history has the potential to result in clinical benefits. However, the current evidence base does not

demonstrate this and there is insufficient evidence for sound policy making on the optimal representation of current patient history to harness this potential. The risks of structuring the patient history (such as the loss of narrative) have not been evaluated.

### **3.1 Background**

As use of EHR systems becomes more widespread internationally,(1,2,3,4,5) extending across both primary and specialist care settings, there is considerable international policy interest in increasing the proportion of the patient record that is captured in structured and/or coded format as opposed to the more traditional free-text representation of clinical data. However, finding an optimal balance between the more clinically intuitive free-text record and the more computable structured and/or coded record with respect to benefits and risks is far from straightforward (see Chapter 1).

The migration towards structured and/or coded representations within EHRs has so far tended to prioritise relatively formalised and consistent information structures such as (numeric) laboratory results, diagnoses, prescriptions and a limited number of chronic disease monitoring datasets and disease/functional assessment scales. The extension of coding to a broader range of chronic conditions is hampered by challenges in agreeing consistent clinical information structures across clinical communities (6,7), and of populating EHRs with high quality data (8). Other parts of the health record, such as presenting history, treatment goals and disease management advice given to patients are however still usually captured and stored as narrative (free-text) entries. For a patient's presenting history in particular, the potential benefit of structuring and/or coding this information to assist clinical decision-making, and the potential risk of detrimental impact on a patient's personal story and perspective on health and illness, have now been debated in the literature over a long period (9,10,11).

The term "patient history" may encompass a wide range of information about the past history of the patient that is volunteered during a clinical encounter – for example the clerking history taken during inpatient admission (12). Within this broad interpretation there is a clinically important subset of the patient history that focuses on the presenting illness and current health status, which is the subject matter of this paper (see Box 3.1). There are several reasons for selecting this focused interpretation of the patient history. There is at present wide variation in the extent to which this information is structured and/or coded. Furthermore, there appears to be a reasonable body of opinions and arguments both in favour of and against structuring and/or encoding this aspect of the clinical encounter

(9,10,11), but no clear consensus has yet surfaced either to give weight to one direction or the other. The considerable international momentum to establish national EHRs presents an important opportunity to inform policy makers and clinicians of the arguments for and against choosing one course of action over the other (13,14), and on priorities and best approaches to the development of clinical information structures and term lists (15,16).

Structuring is the process of organising the information according to a logical model that is meaningful for humans (i.e. that it is possible to navigate the document and find information easily) and/or computers (i.e. the information is computable). Coding is the translation of clinical terms and concepts into a computer interpretable format to support automated processing and reasoning. A well-written patient history may be a narrative or structured document; patient history captured using a form or template will be structured, but not necessarily coded. Several arguments have been advanced in favour of increasing the structure and/or coding of the patient history. For example, it has been argued that structured records are more complete than unstructured records (17). It has also been argued that there are gains to be made in using automated processing of coded data for research and administration purposes (18), in decision support systems (19), or in quality of care monitoring for example (20). Finally, data structures support the development of standardised interfaces, facilitating the use of medical record data by healthcare professionals and patients alike (21). In response to such arguments, large investments, both financial and organisational, are being made in EHRs in the hope that this will lead to greater structuring and coding of data to enable use of, for example, decision support systems, which are likely to in due course translate into improvements in the quality, safety and efficiency of care (2,22,23,24). The scale of investment, effort and potential benefit indicates the need for a systematic critical review of the evidence.

There are also notable arguments against any increase in structuring and/or coding. These arguments stress the fact that applying codes or working within structures is effortful (25). Furthermore, standards are not uniformly implemented (26); and there are aspects of the clinical encounter that structure and/or code-sets are not rich enough to capture (27). It has also been argued that there are advances in technology that may soon make manual structuring and/or coding obsolete (28-30).

These arguments form the context of the review of structuring and/or coding of EHRs in general, but perhaps there are few other parts of the clinical record in which these arguments are so finely balanced. In order to inform appropriate strategy for the optimal

representation of the presenting patient history, it is essential to determine which of these arguments are supported by empirical evidence.

### **3.1.1 Objectives**

To identify, appraise and summarise empirical evidence for benefits or risks of structuring and/or coding of the presenting patient history.

## **3.2 Methods**

### **3.2.1 Eligibility and search strategy**

The criteria for inclusion during initial title and abstract screening were if the paper referred to any of the following:

- the process of obtaining information on the presenting problem from patients (e.g. interviews, computer-based or self-reporting);
- the quality of patient history information;
- the value of patient-provided history information (e.g. to aid diagnosis, assess status, monitor for deterioration);
- re-use of patient history data (e.g. to aid diagnosis, care planning for clinical audit, population health management, service planning, research, teaching).

The criteria for inclusion during full paper screening were if the paper met all of the following:

- the research included the electronic capture, documentation or use of the presenting patient history or equivalent information;
- the structure of the history was specified (narrative, organised under headings, fully structured, coded);
- a purpose for capturing or using the patient history was stated or could be inferred;
- some assessment was made of benefits or risks of that approach to capturing patient history, or some benefit was derived from the presenting history.

Papers were excluded if:

- the setting for the study was not medical or social care;
- the structuring and/or coding activity pertained to other parts of the health record (i.e. a different interpretation of patient history, such as past medical history or drug history), or if the structuring and/or encoding of patient history was not distinguished from other clinical information.

The protocol for this review (including the detailed search strategies) has previously been published (31). The search strategy was developed by iteratively scoping the literature and through discussion with experts. To maximise sensitivity an extensive set of keywords and subject headings (MeSH) were used. Our search terms were based on four key topic areas: (a) health records; (b) history taking; (c) code and/or structure; and (d) benefits or risks, which were all combined using the 'AND' operator. The final search strategy for MEDLINE, as an example, is given in Appendix 3.

Searches were conducted in MEDLINE, EMBASE, Google Scholar, CINAHL, IndMED, LILACS, NIHR, Paklit, PsycINFO. Hand searches of key specialist journals and the authors' personal libraries were also undertaken in parallel, and this set of relevant papers was supplemented through snowballing and contact with their authors and other experts. All papers meeting the search criteria were included regardless of the language of publication.

Titles and abstracts were screened independently by two authors (BF and DK) and full texts of potentially relevant papers were independently assessed for inclusion by same two authors. Papers were included for full review if either or both screening authors judged that the inclusion criteria had been met.

A preliminary screening of filtered papers published prior to 1990 revealed that these were primarily focused on the technical feasibility of implementing and using computers to capture information from clinicians and patients, and the format of that information was largely dictated by the maturity of the technology at the time rather than clinical benefit. In order to verify this decision, two authors (BF and DK) reviewed 29 pre-1990 publications that had met the initial screening criteria and both agreed that these papers did not yield findings that were not better investigated in more recent publications. A decision was therefore taken (after publication of the original protocol) to exclude pre-1990 papers.

### **3.2.2 Selection of studies and data extraction**

Data extraction forms were designed and piloted using an initial subset of papers. Data for all screened papers were extracted by BF and DK using the customised data extraction form with discrepancies resolved through discussion. Studies were appraised independently for quality by the two authors using the Newcastle-Ottawa Quality Assessment Scale (NOS) for cohort studies. This scale has three categories: 'Selection' (four questions); 'Comparability'

(one question); and 'Outcome' (three questions) to score the quality of the study. A study can be awarded a maximum of one star for each numbered item within the 'Selection' and 'Outcome' categories; and a maximum of two stars can be given for 'Comparability', giving a potential maximum total of nine stars. Studies were not excluded based on methods or methodological quality, but the assessment influenced the importance given to the findings. Outcomes of interest were potential or actual benefits as a result of structuring or coding of patient history information (i.e. completeness, accuracy, time saving etc.) and potential or actual risks (i.e. patient safety issues, structuring or coding errors, errors in decision-making). Because of the nature of the topic and the heterogeneity of the studies and outcomes measures used, quantitative summary estimates of effect were not calculated.

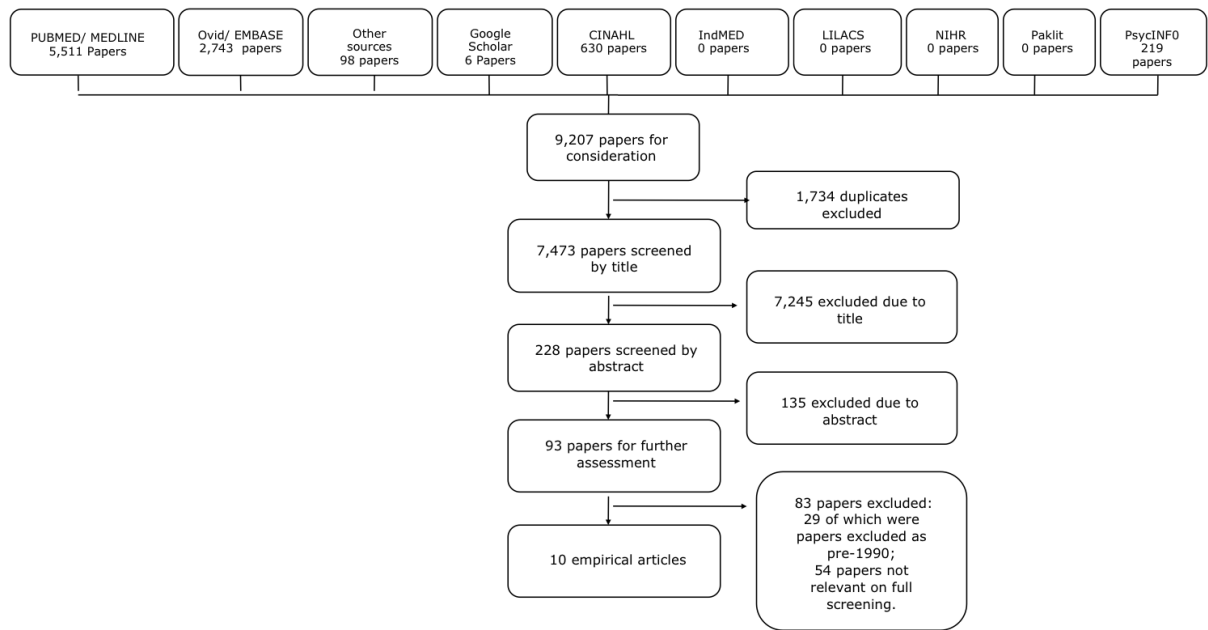
### **3.2.3 Data analysis**

We developed a hypothesis framework to classify the different potential benefits and risks that might be identified from structuring and/or coding patient history (see Table 3. 1), which was used to inform the interpretation of data. This framework was based on our overall familiarity with the arguments in favour of and against formally organising this part of an EHR (32,33), supplemented by re-examining the literature on narratology in particular (10,11,34-37). Data were synthesised descriptively guided by this framework.

## **3.3 Results**

Initial searches resulted in 9,207 papers for consideration, from which 10 papers were finally selected as satisfying our inclusion criteria (see Figure 3.1 for the PRISMA diagram) (38-47). The key characteristics of these 10 studies together with a summary of their findings is summarised in Table 3.2 and our quality assessment of these studies is summarised in (see Table 3.3). The 10 studies that met the inclusion criteria arose from a range of care settings, but were predominantly hospital-based, with half of these emerging from research undertaken in emergency department settings. This does not necessarily reflect the distribution and use of structured history taking, but rather settings in which the value of structured histories has thus far been evaluated.

**Figure 3.1: Flow (PRISMA) diagram, study identification and selection**



**Table 3.1: Hypothesis framework for the benefits and risks from structuring and coding patient history**

	Structuring patient history	Coding patient history
Benefits	<ul style="list-style-type: none"> <li>• Prompts more complete history taking</li> <li>• Allows patients to contribute to more complete histories</li> <li>• Allows patients to contribute to more accurate and specific histories</li> <li>• Make histories easier to use</li> <li>• Improves patient satisfaction</li> </ul>	<ul style="list-style-type: none"> <li>• Leads to consistency which improves re-use</li> <li>• Allows for automated processing, enabling a wider range of uses of the information</li> <li>• Generates unambiguous data which improves accuracy in secondary uses</li> </ul>
Risks	<ul style="list-style-type: none"> <li>• Patient judgements about relevance are lost</li> <li>• Fine details of history are lost due to the limits of the representation</li> <li>• The limits of the representation make it difficult to use the data</li> </ul>	<ul style="list-style-type: none"> <li>• Complete but inaccurate patient history increases clinical risk</li> </ul>

**Table 3.2: Key study characteristics**

Author, (ref)	year	Setting	Population	Intervention	Outcomes
<b>Body R, (20)</b>	<b>2010</b>	UK; Emergency department (ED)	Patients presenting with suspected cardiac pain. 796 patients	A custom-designed case report form (CRF)	Several 'atypical' symptoms usually render the diagnosis of acute myocardial infarction (AMI) more likely, whereas many 'typical' symptoms that are often considered to identify high-risk populations have no diagnostic value.
<b>Das AK, (21)</b>	<b>2005</b>	USA; A faculty and resident group practice of the Division of General Medicine	A systematic sample of 1157 patients between 18 and 70 who were seeking primary care at an urban general medicine clinic serving a low-income population	This study used self-report instrument of Mood Disorder Questionnaire (MDQ) to screen bipolar disorder.	In an urban general medicine clinic, a positive screen for bipolar disorder appears to be common, clinically significant, and under recognised.
<b>Davenport RJ, 1995 (25)</b>		UK; Department of Medicine in a General Hospital	Prospectively identified 244 consecutive stroke patients before and after the introduction of the pro forma.	Introduction of a clerking pro forma	A stroke pro forma improved completeness of history taking
<b>Day PF, (26)</b>	<b>2003</b>	UK; Four dental hospitals	90 records of case histories of dental avulsions	Structured history taking sheet	A structured history should be taken for cases of avulsion as it was significantly better at collecting essential prognostic information
<b>Fung CH, (29)</b>	<b>2006</b>	USA; An academic Veterans Affairs Medical Center	Standardized patients	Computerized condition-specific templates	Templates prompts clinicians to collect appropriate history
<b>Harrop M, (28)</b>	<b>2005</b>	UK;	A retrospective entry in 100 case notes of children attending the paediatric OPD clinic as a re-visit, irrespective of the age of the child or severity of disease, was carried out.	Paper-based paediatric asthma assessment pro forma, designed following a review of published evidence (literature and guidelines)	Pro forma improved completeness of some data items. Potential value for clinical audit is proposed, but clinical benefit not assessed.
<b>Hedges JR, 1998 (31)</b>		USA; Emergency department	126 patients presenting with chest pain	A 2-part "Key" question (Key-Q) - "What are the symptoms that brought you here today" and "When did these symptoms start? Vs. 4 questions	Measurement of out of hospital delay in chest pain patients using a 2-part "Key" question is possible.
<b>Körner H, (27)</b>	<b>1998</b>	Norway; emergency service	1764 consecutive patients	Structured preoperative data collection	Diagnostic accuracy of appendicitis was improved
<b>Porter SC, (24)</b>	<b>2010</b>	USA; An urban children's hospital ED and a general community paediatric ED	1410 parents of children whose primary language is either English or Spanish	ParentLink (parent-centred technology) that captures clinically relevant and parent reported information	ParentLink provided electronic information that met or exceeded the quality of data documented by ED nurses and physicians
<b>Wallace SA, 1994 (30)</b>		UK; Three A&E departments	1260 patients with head injury	Specially designed head injury pro forma	The details of head injury symptoms were completed in over 95% all the patients seen

**Table 3.3: Key findings and quality assessment of studies**

<b>Author, year (ref)</b>	<b>Key findings</b>	<b>Newcastle-Ottawa Quality Assessment (NOS) score for cohort studies (Maximum score of 9)</b>
<b>Body R, 2010 (20)</b>	Discriminating symptoms can be investigated by structured history taking.	5
<b>Das AK, 2005 (21)</b>	Structured symptom scoring instruments can be used for screening	2
<b>Davenport RJ, 1995 (25)</b>	Structured history taking leads to completeness of information	6
<b>Day PF, 2003 (26)</b>	History taking using structured paper instruments improves quality of records in terms of completeness of recording (against a predefined list of prognostic criteria). Structured instruments are significantly better at enabling junior members of staff to record key information	6
<b>Fung CH, 2006 (29)</b>	Templates prompt clinicians to collect appropriate history	-
<b>Harrop M, 2005 (28)</b>	Pro forma improved completeness of some data items.	6
<b>Hedges JR, 1998 (31)</b>	Exact phrasing of a question during history taking can have an important impact on the accuracy of the response	2
<b>Körner H, 1998 (27)</b>	Significant improvement in diagnostic accuracy achieved using a structured registration form	7
<b>Porter SC, 2010 (24)</b>	Structured data collection produces information of superior quality compared to unstructured documentation	6
<b>Wallace SA, 1994 (308)</b>	Pro forma improved degree of completeness of recording of clinical details specific to head injury	6

### **3.3.1 Empirically demonstrated benefits**

The main demonstrated benefit of structuring the patient history was an increase in the completeness of information (Table 3.2) (41,42,44,46). However, it should be noted that completeness was usually judged in relation to the proportion of nominated data items that had values, and only three studies showed that the improvement in this completeness was relevant to clinical decision-making, such as improved diagnostic accuracy (42,43,45,). In other words, a structured format increased the quantity of history data collected, but not necessarily its usefulness. This finding includes patient/parent-provided information, which might be more detailed than equivalent clinically-documented histories, but was not necessarily better used (40).

Although a potential value of patient/parent completed forms is the saving of clinician time there was only very little evidence to support this (46).

One study used a structured history form for clinical research: to investigate the most important (discriminating) presenting symptoms of acute myocardial infarction, i.e. a structured history form was used to obtain the frequency of occurrence of possible presenting symptoms and features, from a predefined set. This frequency distribution was compared with the eventual diagnosis to derive the positive predictive value of each symptom (38).

Structuring tools based on clinical guidelines, especially if they are dynamic and have branching questions, can produce complete and structured information that can be coded. One study demonstrated that clinicians who used this information in contrast to unstructured history could sometimes make more accurate clinical decisions (43).

Overall, the evidence indicated that structuring patient history other than in the context of achieving completeness of information had not been the focus of recent research and as a result other potential benefits of structuring of the patient history (Table 3.1) had not been investigated.

### **3.3.2 Empirically demonstrated risks**

None of the studies proposed, looked for or reported a harm or risk situation through the use of a structured history (Table 3.2). Certain risks such as the non-acceptability to patients of completing a pre-consultation questionnaire, the inability of patients of diverse socio-economic and educational backgrounds and who are too ill to use an on-screen form, the non-acceptability to clinicians of using a structured form and/or of reviewing a patient-completed form, and data entry in

a structured form being more time-consuming, were raised by a few of the authors as a possibility (40,45,46), but were not encountered in practice.

### **3.4 Discussion**

#### **3.4.1 Main findings**

We found very little empirical evidence in support of structuring the history, no evidence of associated risks, and no formal investigations of either benefits or risks from coding it. Evidence for only some of the benefits of structuring shown in Table 1 was found, namely: structured templates can be used by clinicians and patients in care settings; they aid completeness of the record for items that were sought by the form; and the information captured can sometimes help improve diagnostic accuracy. Even this evidence is however not of a particularly high quality (see Table 3.3).

Importantly, we were unable to identify any studies where structuring the patient history was the primary subject of investigation: rather, in the studies reviewed the structured history was a means of validating a new technical intervention such as a patient kiosk, or was a means of obtaining data to substantiate a clinical hypothesis or to validate a modification to a care pathway. The analysis of the record was either for its completeness or for the extent to which it provided the data that was needed for the research hypothesis. No investigation considered the accuracy of information collected, nor did any investigation look at the balance of use between structured and free-text portions of a form (although most offered both). A few studies investigated relevance by considering whether more complete information was simply more information or if the structure had encouraged the capture of important information that might otherwise have been missed. No investigation addressed behavioural dimensions of structure usage. Structured forms can act as a prompt not only to document more completely, but also to actually remind a clinician or patient to address a certain topic (i.e. it can improve contemporaneous care, not just its documentation). This effect has been well-established for reviews of chronic diseases (48), but we were unable to identify similar investigations for patient history. None of the studies examined included a longitudinal dimension, for example using a previously structured history to compare the patient's current status with a past occasion.

#### **3.4.2 Strengths and limitations**

The contribution of this study has been to apply established systematic review methods to a complex socio-technical health informatics question in direct relation to the provision of clinical

care. Further strength of this work is that a theoretical approach was taken to the analysis and interpretation of the results, directed by our conceptual framework of Table 3.1.

The main limitation of this review is that none of the studies examined the implications of structuring and/or coding patient history as the primary objective. There is a possibility that some studies may have been missed due to poor indexing in relation to this study perspective, although this is mitigated to some extent by our hand searching of key informatics journals in which publication of approaches to structuring and/or coding patient history within EHRs would be expected to appear. Another limitation was that all the studies reviewed were conducted in hospital or emergency department contexts while early presentations of illnesses are recorded in primary care where the context may be different. Another challenge in undertaking this systematic review was that although structured pro formas are often used in EHR systems, only a few of these studies were found to have focused on the presenting patient history and to have examined the value of structuring it. A number of studies were therefore excluded from this review because they included a few more general patient history items within a wider clinical encounter form, but had not examined the completeness, relevance, value or disadvantages of those history items *per se*. A large number of studies, that had introduced an EHR system and evaluated its benefits holistically (combining data entry, online historic record access, real time access across an organisation, analysis and reporting features, decision support integration etc.), but not distinguished the particular impact of structuring the patient history were thus also excluded. Structured forms were usually used as a means to obtain specific data for a study rather than as an objective in themselves to be evaluated, even within the 10 selected papers; the focus of the studies was therefore somewhat tangential to this research question, and at times the impact of structured recording format needed to be inferred from the paper.

### **3.4.3 Considering the findings in relation to the wider literature**

Recording patient history is challenging for several reasons. The patient's narrative has its own structure, the order in which information is divulged by the patient may alter the semantics of what is reported and there may be elements of uncertainty that should be recorded in the patient's narrative, which structuring and coding needs carefully to accommodate (49). There may also be an impact on the interaction between the healthcare professional and the patient and structures are usually pre-determined and potentially apply to a large set of patients, whereas patient situations are unique and might require the documentation of information that was not anticipated when the structure was designed (50).

There is considerable interest in the prospect of natural language processing (NLP) technologies being applied to clinical narrative, to obviate the need for structuring and/or coding by clinicians at

the time of documentation. The reliability, accuracy and safety of these techniques for patient level care decisions has not yet been established (see Chapter 5), and it may be some years before the evidence of this alternative way of handling patient history becomes widely adopted. We therefore believe that any near-term intent to gain computable value from patient history will need to utilise structures and/or codes.

Given the varying perspectives on the importance of the patient's history as the key to making an accurate diagnosis, the increasing need for decision support to help clinicians cope with the overload of new medical evidence (51), the importance of personalised healthcare (52) and the need to engage patients more actively in the process of care (53), it is surprising that more research has not been undertaken to provide an evidence base for EHR adoption. We are also seeing a rise in expectations and emphasis on the use of structured and/or coded data for research (54). The lack of empirical investigation into issues of completeness and accuracy surrounding this type of primary data collection should be considered by those planning to base their secondary analysis on these datasets.

#### **3.4.4 Conclusions**

There is a drive to structure and/or code all clinically relevant information in EHRs in order to benefit from computability of information. There are potential benefits and risks to patients of this approach. This review shows that there is no demonstrable evidence either for benefits or risks of structuring and/or coding of patient histories. Whilst the studies reviewed here have shown that the use of structured formats can serve as a prompt for additional history details and result in greater consistency of information, there is a lack of evidence of benefit from either of these changes. However, the absence of evidence does not equate with evidence of no benefit, and research into this area of EHRs needs to be prioritised – investigating both benefits and risks – in order to provide a sound platform on which to consider whether or not to develop future policy in this area.

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## Chapter 4

### A review of the empirical evidence for the value of structuring and coding of clinical information within electronic health records

#### Abstract

**Background:** There is good evidence for the secondary use benefits from structured and coded electronic health records (EHRs). The case has historically been presented that the use of structure and coding within EHRs also provides benefits to direct patient care, but the evidence base for this assertion has hitherto not been well documented.

**Aims and objectives:** Building on a focused review of structuring and/or coding the patient's presenting symptoms, we aimed to identify and appraise the empirical evidence for the value of structuring and coding clinical information within EHRs, where value is defined as an improvement in safety, effectiveness, patient-centeredness, timeliness, efficiency or equitability of healthcare.

**Methods:** We searched for evidence in relation to the direct patient care value from structuring and coding EHRs, interrogating nine international databases for published and unpublished studies over the period 1990-2011. Value was defined using the Institute of Medicine's six key areas for improvement for healthcare systems, namely: improvements in safety, effectiveness, patient-centeredness, timeliness, efficiency and equitability of care. Studies satisfying the Cochrane Effective Practice and Organisation of Care (EPOC) Group criteria were eligible for inclusion.

**Results:** Of the 5,016 potentially eligible papers identified, 13 studies satisfied our eligibility criteria. The majority (n=10) of these studies focused on effectiveness, demonstrating that actual or proxy clinical outcomes (i.e. prevention of thrombo-embolism and improved control of a chronic condition) can be improved if a structured and/or coded EHR is combined with alerting or advisory systems in a specific targeted area: most commonly the management of a long-term condition, immunisation, or appropriate choice of antibiotic therapy. Prescribing was the only example of improvement in safety. No studies were found reporting value in relation to patient centeredness, timeliness, efficiency or equitability.

**Conclusions:** This review indicates that there has been patchy effort made to-date to empirically investigate the value from structured and coded EHRs for direct patient care. Structuring and coding of information is expensive, and a business case for it should be supported by robust evidence indicating the priority clinical areas in which patient care benefits can be obtained.

## 4.1 Background

Many of the intended benefits of EHRs rely upon the ability of computers to process automatically the information contained in them (see Chapter 1). Such benefits are predicted to include: more consistent and complete clinical documentation; more strongly evidence-based and guideline oriented healthcare (1) and thereby better quality healthcare (2); greater use of computerised decision support systems (CDSS); improved workflow management; enhanced interoperability of EHR information between systems; better-informed planning of health services and the healthcare of populations (3,4), and the re-use of information for research (5).

There are limitations to the extent and reliability with which computers can interpret free-text clinical notes, whereas the adoption of structured forms and templates, and the coding of clinical entries, permits computer interpretation and therefore automated analysis for purposes such as providing CDSS (6). We have recently reviewed CDSS and its impact on quality and safety of health care (7). The case has however historically been presented that the use of structure and coding within EHRs provides a wider range of benefits to direct patient care beyond computerised physician order entry (CPOE), as listed above, and that more widespread adoption of structured and coded records should be promoted. Many countries have adopted eHealth programmes that include a structured EHR, usually underpinned by EHR interoperability, clinical modelling and terminology standards. The recent specification of “meaningful use” of EHRs in the United States of America (US) (8), and the USA Certification Commission for Health Information Technology (CCHIT) and European (EuroRec) criteria for the certification of EHR system products are important examples.

However, there are concerns that clinical systems are not yet usable enough for clinicians to structure and code all aspects of their documentation resulting in most record entries on computer still being typed in free-text. The professional education and behaviour change implications of adopting standardised EHRs are significant (see Chapter 5)(9), suggesting that investments in improving the extent to which these are adopted need to be well-targeted on benefits. Historically, clinician behaviours have led to significant volumes of coding errors (10). The process of recording new record information does not adequately include learning from existing EHR data (11), and there are concerns that the move away from narrative recording might depersonalise healthcare (12).

Given these adoption challenges, it is therefore plausible that investments in the development of structured EHRs should prioritise those aspects of clinical documentation that bring maximum and near-term value, rather than proceeding rather opportunistically as they have to date. Some

benefits of structuring and coding that are well-established, and have been prioritised thus far, are for secondary uses of the EHR, such as clinical audit, clinical research, epidemiology, public health, health services research and reimbursements.

However, the evidence base establishing the direct care benefits from structuring and coding EHRs, and any harms that may arise, has hitherto not been well-documented, making it difficult for eHealth programmes to set appropriate priorities for clinical documentation standards.

In this chapter, we seek to build on our more focused systematic review (see Chapter 3) and examine the evidence for value to direct patient care of structuring and coding of clinical information within EHRs, where this information has directly enabled that value. Value was defined as improvement in safety, effectiveness, patient-centeredness, timeliness, efficiency and equitability of the care delivered to individual patients: the six aims of improvement earmarked for 21st century healthcare systems in the Institute of Medicine's (IoM) *Crossing the Quality Chasm* report, listed in Box 4.1 below. (13). We have applied these as the dimensions of quality for which EHR structuring or coding outcomes were sought.

**Box 4.1: The six aims of improvement earmarked for 21st century healthcare systems in the IOM's *Crossing the Quality Chasm* report [13]**

Safety
Effectiveness
Patient centeredness
Timeliness
Efficiency
Equity

## 4.2 Methods

### 4.2.1 Databases searched

Searches were conducted in MEDLINE, EMBASE, Google Scholar, CINHALL, IndMED, LILACS, NIHR, Paklit and PsycINFO. Hand searches of key specialist journals and the authors' personal libraries were also undertaken in parallel, and this set of relevant papers was supplemented through snowballing and contact with their authors and other experts.

#### **4.2.2. Search strategy**

The search strategy was developed by iteratively scoping the literature, through discussion with experts, and from previously published search strategies (see below). To maximise sensitivity an extensive set of keywords and subject headings (MeSH) were used. Our search terms were based on three key topic areas:

- EHRs (7);
- tools and techniques for structuring health records (e.g. templates, terminology browsers and pick lists);
- structuring or coding (14);
- which were all combined using the 'AND' operator.

Keywords relating to the category of evidence, or to the IOM six dimensions of quality, were not included within search strategies as it was found during piloting that these were not reliably used in publications, hence the risk of missing important studies. These criteria were therefore applied manually during title and abstract screening, discussed below. The final search strategy for MEDLINE, as an example, is given at Appendix 3.

#### **4.2.3 Selection criteria**

Title and abstract screening was undertaken on the basis of the criteria defined in Box 4.2.

#### **Box 4.2: Inclusion and exclusion criteria applied during title and abstract screening**

##### **Inclusion criteria:**

a specified introduction of a structured or coded format for capturing and/or analysing EHR data as the primary intervention of the research;

AND deployment in at least one healthcare setting;

AND an empirical evaluation reported of additional benefit obtained from the structured or coded EHR data meeting the Cochrane's EPOC Group criteria, namely: a randomised controlled trial, controlled clinical trial, controlled before-and-after study or interrupted-time-series (15);

AND the evaluation could be related to one or more of the six IOM dimensions of quality of patient care.

##### **Publications were excluded if they met any of the following criteria:**

publications describing relevant new or in-progress projects for which evaluations had not yet been performed;

descriptions (without evaluation) of novel eHealth solutions to deliver EHRs or supporting applications or to automatically encode or analyse EHR data;

feasibility or proof of concept studies demonstrating technical success and/or usability and acceptance of an EHR or clinical application;

feasibility or quality assessments of the potential for EHR data to support a quality improvement or clinical outcome, which did not demonstrate a concrete outcome;

feasibility assessments or actual secondary uses of EHR data for: clinical audit, clinical research, epidemiology, public health, health services research, clinical guideline development, health service evaluations or reimbursements;

the use of an electronic documentation or communication system in which the format of the data was not reported or considered material (i.e. the level of structuring and/or coding was not relevant to the intervention, only that the record is electronic or networked or that a tele-communications channel is used);

benefits from patient diaries in which the format of the data was not material (i.e. the act of keeping a diary is the intervention and the electronic tool simply enhances acceptance over paper diaries, and/or its contents are simply read irrespective of the format);

evidence of increase in data quantity and completeness of data collection or data quality without any evidence of a benefit derived from those additional data;

complex interventions in which any impact from changes to the capture of EHR data was not capable of being isolated from other causes of the impact (e.g. educational programmes and service model changes in parallel to the introduction of a new EHR template or guideline).

Full paper screening involved application of these same criteria. Some publications were excluded if only a conference abstract existed with no follow-up full paper and insufficient detail to assess the intervention, the evidence or the outcome.

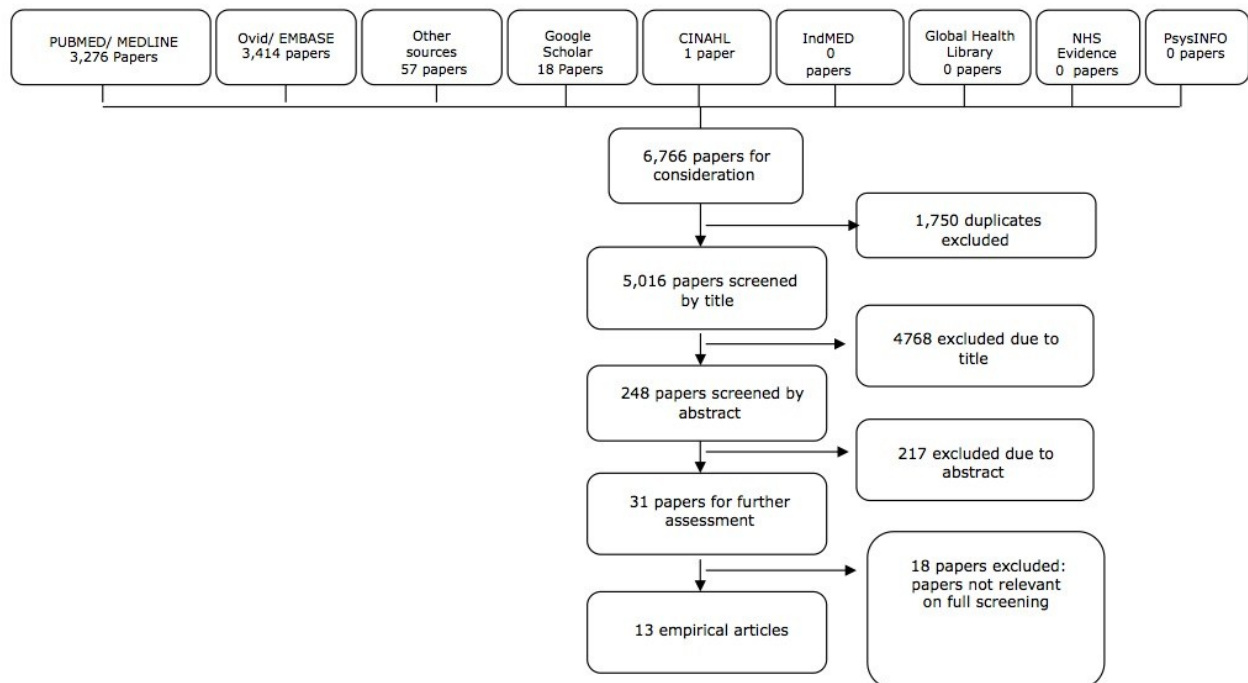
#### 4.2.4 Data abstraction and synthesis

Data from empirical studies were abstracted into evidence table and findings from across studies were thematically synthesised.

### 4.3 Results

Initial searches resulted in 6,766 papers for consideration; this was reduced to 5,016 after removal of duplicates, from which 13 papers were finally selected as satisfying our inclusion criteria (see Figure 4.1 for the PRISMA diagram) (16-28). These papers are summarised in Table 4.1 and below, grouped according to the principal quality dimension for which improvement was evaluated.

**Figure 4.1: Flow (PRISMA) diagram, study identification and selection**



**Table 4.1: Key study characteristics**

<i>Author, year (ref)</i>	<i>Setting</i>	<i>Population</i>	<i>Intervention</i>	<i>Outcomes</i>
Lobach and Hammond, 1997 (15)	Duke Family Medicine Center	Diabetes patients	A patient-tailored encounter form printed before each diabetes review	The tailored printout significantly increased adherence to the guideline, from a mean of 15 to 32%, without extending the consultation length
O'Connor et al, 2005 (16)	2 out of the 18 community clinics run by the HealthPartners Medical Group	Diabetes patients	The EPIC EMR system, with a prompt if a patient had no HbA1c test within 6 months or no urine microalbuminuria test within 1 year	Greater improvement in HbA1C if a prompt is provided that with the EMR alone
Calvert et al, 2009 (17)	147 UK general practices in England	Diabetes patients	Before and after introduction of the Quality and Outcomes Framework	Better glycaemic control in people with type 2 diabetes for the more stringent target (HbA1c level $\leq 7.5\%$ )
Cebul et al, 2011 (18)	46 primary care practices in Ohio	Diabetes patients	Comparison of EHR and paper-based practices	Improvement of care process standards and intermediate outcome standards (e.g. HbA1C) in EHR practices compared with paper-based practices

<i><b>Author, year (ref)</b></i>	<i><b>Setting</b></i>	<i><b>Population</b></i>	<i><b>Intervention</b></i>	<i><b>Outcomes</b></i>
Lecumberri et al, 2011 (19)	University Clinic of Navarra, Spain	All hospitalised patients	Targeted alert within the EHR system for patients at risk of venous thrombo-embolism	Use of VTE prophylaxis in at-risk patients increased from 27% to 60% following introduction of the alert, and VTE incidence during hospitalisation decreased by 50%
Galanter et al, 2010 (20)	University of Illinois Hospital	All inpatients	VTE prophylaxis risk assessment form completion required when making a new CPOE order	Percentage of patients receiving prophylaxis increased from 25.9% to 36.8%, and significant reduction in VTE within the medical unit
Bell et al, 2010 (21)	12 primary care practices across Philadelphia	Asthma patients	Prompts added to a structured EHR	Improved peak flow and increased use of controlling medication such as inhaled steroids
Davis et al, 2010 (22)	Center for Family Medicine, Spartanburg, US	Asthma patients	Introduction of a template to capture routine monitoring visits	Increased appropriate use of inhaled corticosteroids
Körner et al, 1998 (23)	Regional hospital in Stavanger, Norway	All adults presenting with suspected acute appendicitis	A structured pro forma for documenting the clinical encounter and diagnosis	Significantly improved diagnostic accuracy and thereby reduced the number of unnecessary operations

<i><b>Author, year (ref)</b></i>	<i><b>Setting</b></i>	<i><b>Population</b></i>	<i><b>Intervention</b></i>	<i><b>Outcomes</b></i>
Linder et al, 2009 (24)	27 primary care clinics in Massachusetts	Patients presenting with acute respiratory infections	A template for managing acute respiratory infections, pre-populated from the EHR	Marginal but non-significant reductions in antibiotic prescribing, particularly for acute bronchitis
Bourgeois et al, 2010 (25)	Children's Hospital Boston	Children and adolescents presenting with acute respiratory infections	An electronic template to advise on antibiotic use in paediatric acute respiratory illness	No difference in total antibiotic prescriptions between control and intervention clinics
Ledwich et al, 2009 (26)	A hospital-based and a community-based practice in Danville, Pennsylvania	Patients taking immuno-suppressive drugs for rheumatoid conditions	Alert triggered by opening an EHR if that patient should be offered influenza or pneumococcal vaccination, based on underlying EHR data	More than doubling rates of both vaccination rates
Bates et al, 1998 (27)	Brigham and Women's Hospital, Boston	All adults admitted to medical and surgical units involved in the study	Integration of allergy and interaction alerts with a medication ordering system (CPOE), and the co- presentation of salient laboratory values	Reduced serious medication errors by 55%, especially dose errors and known allergy errors

<i><b>Author, year (ref)</b></i>	<i><b>Setting</b></i>	<i><b>Population</b></i>	<i><b>Intervention</b></i>	<i><b>Outcomes</b></i>
Evans et al, 1998 (28)	12-bed intensive care unit at the LDS Hospital, Salt Lake City	All patients admitted to the unit between July 1992 and June 1995	Antibiotic advisory system using structured data within the EHR for diagnosis, medication, microbiology and renal function to provide clinicians with tailored antibiotic recommendations	significantly reduced the frequency of allergies, the duration of the antibiotic course and length of stay
Longhurst et al, 2010 (29)	Lucile Packard Children's Hospital, Stanford University	Patients admitted between January 1, 2001, and April 30, 2009	Implementation of a commercial CPOE system	A significant 20% reduction in hospital-wide mortality

### **4.3.1 Effectiveness**

The majority of relevant publications focused on improved clinical effectiveness (normally through improved adherence to a clinical guideline) (16-25). These have been sub-grouped below by disease area. Only two studies introduced a structured format as the only intervention: almost all made use of the structured data to present prompts that were the main influential intervention, or evaluated the use of an EHR system as a whole. However, these studies did demonstrate improvements to actual or proxy outcomes when a structured EHR is combined with alerting functions. Although some studies referred to the use of coded information, these offered users a non-hierarchical list of terms (e.g. as a pick list) that served to standardise data entry. (No studies employed a hierarchical terminology, in which terms of varying granularity are organised to permit aggregated analysis).

#### ***Diabetes***

Lobach and Hammond demonstrated that a diabetes clinical guideline could be successfully tailored for specific patients, based on prior information in each patient's EHR (16). The EHR system at Duke Family Medical Centre was modified to generate a patient-tailored encounter form for each diabetes review. Thirty clinical staff were randomised to receive this tailored form or a generic form reflecting the whole guideline. Median compliance for the group receiving the tailored recommendations was 32.0% versus 15.6% for the control group ( $P = 0.01$ ). There was no significant difference in the duration of the clinical consultation. Despite this improvement, guideline compliance was lower than the authors had expected. This was attributed to the increased workload that would be required for full compliance and to various patient-specific factors that the system had not taken into account.

O'Connor et al undertook a controlled study investigating the impact of introducing an EHR system on diabetes care, which involved comparing two community clinics of the HealthPartners Medical Group (17). One practice adopted an EHR system that collected structured diabetes reviews, and prompted clinicians if a patient with diabetes had had no HbA1c test within six months or if HbA1c levels were  $\geq 8\%$ . The other practice continued to use paper charts. Frequency of HbA1c tests increased at the EHR clinic compared with the frequency at the non-EMR clinic ( $P < 0.001$ ). However, HbA1c levels improved in both clinics ( $P < 0.05$ ) with no significant differences between clinics at two years ( $P = 0.10$ ) or four years ( $P = 0.27$ ) after EHR implementation. Similar results were observed for Low Density Lipoprotein levels. (Both practices had achieved

similar standards of care, including HbA1C control, before the introduction of the EHR system.)

Cebul et al have more recently demonstrated that intermediate outcome measures for diabetes care are significantly better in practices using an EHR than those using paper records (18). Their study included 46 primary care practices in Ohio, of which 33 were computerised and 13 were paper-based; this study involved the follow-up of 27,000 patients over one year (2009-10). Outcomes were defined as meeting composite quality of care standards derived from outcome measures defined by the American Diabetic Association. Achievement of composite standards for process of diabetes care (e.g. measurement of HbA1C) was 35.1% higher at EHR sites than at paper-based sites ( $P<0.001$ ), and achievement of composite standards for outcomes (e.g. HbA1C  $<8\%$ ) was 15.2% higher ( $P=0.005$ ). However, the authors pointed out that: *“inferring that EHRs fully account for the observed differences in quality is not warranted, in part because of the participation of exceptional EHR-based organizations, a non-representative sample of paper-based organizations, and inadequate adjustment for patient characteristics”*. The authors did not specify the extent of coding within the diabetes records.

### ***Venous thromboembolism (VTE)***

Lecumberri et al have demonstrated that significant costs in the management of deep vein thrombosis (DVT) in hospital can be avoided if alerting software is used to prompt clinicians to use VTE prophylactic measures in high-risk patients (19). The study, conducted at the Clinic of Navarra in Spain between 2006 and 2009, covered over 25,000 patients before and after the introduction of the alert. At-risk patients were identified on the basis of American College of Chest Physicians' guidelines. The risk assessment for each patient was performed computationally, and automatically, by using data within the EHR that had been routinely collected from medical orders, daily nursing reports, surgery registries and laboratory results. The software was able to offer targeted alerts because of the existence of this relevant, routinely-collected, coded data. Use of VTE prophylaxis in at-risk patients increased significantly from 27% to 60% following introduction of the alert, and VTE incidence during hospitalization decreased by 50% (95% confidence interval 0.29–0.84). The development and maintenance of the alerting system averaged €0.35 (\$0.48) per patient, and the increased use of prophylaxis between €9 and €12 (between \$12.3 and \$16.4) per patient. After accounting for the costs avoided of managing each prevented episode of

VTE, and authors conclude that the introduction of the alert has resulted in an average saving of €6.54 (\$8.92) for every hospitalised patient.

At the University of Illinois Hospital, Galanter et al have shown that the introduction of a structured risk assessment form for VTE prophylaxis can significantly increase the extent to which prophylaxis is used, and reduce the incidence of VTE in patients who received prophylaxis during their admission from 25.9% to 36.8% ( $P < 0.001$ ). (20). A structured form, primarily completed using tick-boxes, linked to a decision support component that could generate alerts, was introduced via the physician order entry system as a mandatory prerequisite to ordering on behalf of a new inpatient. A strength of this approach was that it did not require the pre-existence of relevant data items within the hospital's EHR system. The new data items that were captured via this form were then re-used whenever fresh orders were made for that patient.

### ***Asthma***

Bell et al have demonstrated that the introduction of an asthma decision tool within an EHR system can improve the peak expiratory flow rate of asthma patients, and increase the use of controlling medication such as inhaled steroids (21). This cluster randomised trial involved 12 primary care practices across Philadelphia and included almost 20,000 patients. Because the control group of practices had access to the same EHR system, clinical guidelines and educational sessions, the intervention effect could be attributed to the active alerts provided by the decision support tool. As this study did not introduce a change to the way in which clinical data were captured within the EHR system, it is an example of the way in which structured information can be exploited by decision support to improve adherence to guidelines and in turn improve proxy clinical outcomes (assessed through improved peak flow rates).

Davis et al have shown that the introduction of a template to capture routine monitoring visits for patients with asthma in primary care can increase the appropriate use of inhaled corticosteroids (22). Their template included checkboxes for documenting the number of days per week that the patient had symptoms, nights per month with symptoms, FEV1, a history of exacerbation since the last visit, and use made of rescue  $\beta_2$  agonists. This study involved 180 records of patients attending the Center for Family Medicine, Spartanburg, USA over two six-month periods before and after introduction of the template. Use of inhaled steroids increased significantly from 39.4% to 51.1%. ( $P = 0.017$ ). Unfortunately the study did not track other outcomes such as emergency attendance and hospital admissions.

### ***Antibiotic prescribing***

Linder et al describe the implementation and evaluation of a “Smart Form” for managing acute respiratory infections in primary care, in Massachusetts. The Smart Form was integrated within the main EHR system, pre-populated relevant fields from a patient’s record when opened, supported the clinical encounter with structured fields such as tick boxes and drop-down lists, and simplified the generation of commonly required prescriptions and letters (23). The system advised on whether and which antibiotics were indicated (using published professional guidelines), advised on streptococcal testing, and checked prescribed medication for interactions and allergies. The system therefore combined features of a structured EHR (supporting data entry) with decision support (supporting appropriate prescribing). The evaluation, involving 27 primary care clinics randomly assigned to use Smart Forms or the unmodified EHR system for six months, showed marginal but non-significant reductions in antibiotic prescribing, particularly for acute bronchitis. Antibiotics were prescribed to 43% of patients with acute respiratory infections in control clinics and to 39% of patients with acute respiratory infections in intervention clinics (95%CI 0.6–1.2). The authors of this study proposed that the reasons for this limited effect is the low frequency of use of the form, since it had to be deliberately invoked by the physician rather than being automatically triggered from a symptom or diagnosis.

A study by Bourgeois et al in Boston illustrated how the adoption of a new tool to support better quality prescribing, in their case an electronic template to advise on antibiotic use in acute respiratory illness in children, can prove challenging and limit the potential benefits to patients (24).

### ***Immunisations***

Ledwich et al have shown that an algorithm that is triggered by opening a patient’s EHR and then queries that record to raise the alert if that patient ought to be offered influenza or pneumococcal vaccination, can more than double vaccination rates (25). The study, involving over 750 patients, was performed over two consecutive years both at a hospital- and a community-based practice in Danville, Pennsylvania.

### 4.3.2 Safety

As no studies were found that specifically demonstrated improved safety from the use of structures or codes within EHRs it may be said that neither the act of entering data via a structured pro forma or the review of previously entered structured data have been evaluated from a safety perspective. Three papers are summarised below that have demonstrated improvements in safety or mortality from CPOE systems, which take advantage of structured clinical information within the EHR to present advice or alerts and thereby improve prescribing safety. Apart from support for prescribing, no other safety benefits were found from the literature.

In 1998, Bates et al demonstrated at the Brigham and Women's Hospital in Boston that the integration of allergy and interaction alerts with a medication ordering system (CPOE), and the co-presentation of salient laboratory values, reduced serious medication errors by 55% (26). The impact was primarily on dose errors and known allergy errors, both of which required structured and computable data entry and the retrieval of relevant data within each patient's EHR. The primary success factor behind this kind of system is the decision support alerts which combine EHR data (such as a medication list) with a knowledge base (such as drug-drug interactions), and algorithms that trigger user alerts.

In the same year Evans et al demonstrated at the LDS Hospital in Salt Lake City that an antibiotic advisory system can use structured data within the EHR for diagnosis, medication, microbiology and renal function tests to provide clinicians with tailored antibiotic recommendations (27). A before and after evaluation revealed that the system significantly reduced the frequency of allergies, the duration of the antibiotic course and length of stay, thereby also reducing costs.

Implementation of a commercial (locally modified) CPOE system in an academic children's hospital was associated with a significant 20% reduction (95%CI 0.8-40%) in hospital-wide mortality (28). The authors of this observational study of 17,432 hospital inpatient episodes, compared with 80,063 historical pre-implementation controls, have sought to account for trends or other factors that might have influenced this rate. They conclude that the success factors behind this include the standardisation of the information used to create orders, shared EHRs including vital signs and medication records, and the consequent better support of team-based care. The authors do not define the characteristics of the health information that might have contributed to this improvement, and it is therefore difficult to infer the value gained specifically from structuring or coding parts of the record.

### **4.3.3 Patient centeredness, timeliness, efficiency and equitability**

No studies were found that investigated these quality dimensions. Two of the studies summarised above (19, 27) included an estimate of cost savings from the quality improvement, but no formal economic evaluations of the impact of introducing structured or coded EHRs were identified.

## **4.4 Discussion**

### **4.4.1. Main findings**

It is intuitive and often declared that EHRs are of direct benefit to patients and that investments that increase the levels of structuring and coding of EHRs will increase these benefits. This assumption is largely extrapolated from pilot studies often undertaken from highly specialist research centres (7, 29), and from theoretical models.

The majority of empirical studies identified here focused on effectiveness as a quality dimension, demonstrating that actual or proxy clinical outcomes can be improved if a structured EHR is combined with prompting or advisory systems in a specific targeted area: most commonly the management of a long-term condition, a preventive intervention, or appropriate choice of therapy. Prescribing was the only example found of improvement to safety. No studies were found reporting value for patient centeredness, timeliness, efficiency or equitability.

This review focused on studies reporting the structuring or coding of EHRs as the primary intervention, although many of the EHR systems included an alert-generating component. Other published reviews have focused on studies primarily implementing CDSS and their impact on patient outcomes (6,7). CDSS systems inevitably rely upon computable EHR data, which must therefore be structured and/or coded. Our reading of the CPOE/CDSS systematic review literature indicates that where carefully designed and implemented and then used, these can certainly translate into improvements in practitioner performance, but that these signals are relatively weak and quite high up in the causal chain such that there are limited opportunities to have any substantial impact on patient-level outcomes. This is of course compounded by the fact that many of the outcomes of interest (e.g. anaphylaxis to a drug) are relatively uncommon such

that the sample size/length of follow-up needed to demonstrate an improvement in clinical outcomes is often prohibitive.

#### **4.4.2. Strengths and limitations**

This review has used components of previously validated search strategies, a well-accepted definition of quality and a standard definition of evidence to investigate a research area that has not hitherto been well-documented. Although only a small number of studies met our criteria these did demonstrate benefits to patient care. However, it is easier to show presence of evidence with evidence than to show absence of evidence with evidence. We have searched specifically but found little good quality evidence to demonstrate that increased structuring and/or coding of clinical information adds value to healthcare systems. Some possible reasons for this are: (a) it is difficult to locate the relevant studies due to the way literature is indexed; (b) the papers, if any, which describe any added value describe the intervention at EHR system level rather than at the EHR information level.

#### **4.4.3. Implications for policy, practice and research**

Our findings suggest that the underlying assumption that structuring and coding can be isolated as an intervention is probably a fallacy: this intervention will usually form part of a broader re-organisation and systematisation of a particular aspect of clinical practice, for which the intervention is necessarily more holistic, and the health record information effect is difficult to isolate. The findings suggest that the progressive adoption of EHRs needs to be better studied, in particular with regard to improving the evidence base of benefits to direct patient care from the progressive adoption of structure and the use of coded terms.

#### **4.4.4. Conclusions**

This review indicates that there has been patchy effort made, to date, to empirically evidence the value from structured and coded electronic health records for direct patient care, as opposed to secondary use benefits. Structuring and coding of information is expensive and effortful, and a business case for its promotion should not be made without more robust evidence indicating the priority areas in which patient care benefits can be obtained.

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## Chapter 5

### **“Swings and roundabouts”: qualitative evaluation of the benefits and risks of increasing structuring and coding within the electronic health record**

#### **Abstract**

**Background:** A key aim of structuring and coding electronic health records (EHRs) is to aid the timely retrieval of information for clinical decision making by enabling, for example, use of computerised decision support systems (CDSS), inter-operability and data exchange. Coded clinical data are also potentially amenable to a variety of secondary uses, these including health planning and commissioning, surveillance, audit and research. The format, content, accuracy, completeness and reliability of information required for decision making may vary between different groups, users and contexts.

**Aims and objectives:** We aimed to explore the views, attitudes, needs and expectations of a range of stakeholders in relation to the structure, coding and use of EHRs. We in particular sought to understand likely benefits and risks surrounding the structuring and coding of records, and to obtain insights of how these concerns might be addressed.

**Methods:** We carried out a qualitative study which involved the undertaking of in-depth interviews and discussion groups in order to understand the views of patients, healthcare professionals, health service commissioners, policy makers, managers, administrators, system developers, researchers and academics. We observed working practices within a GP practice and collected documents suggested by participants during our fieldwork. Thematic analysis of the data was conducted by two members of the research team and emerging themes were then discussed by the wider research team in a data workshop.

**Results:** We undertook 24 in-depth interviews with 27 participants and hosted six expert discussion groups with 43 participants. We also observed relevant professional practices and analysed 20 related documents. Five main themes emerged in relation to structuring and coding of data: patient perspectives; uses in relation to the provision of clinical care; secondary uses; and examples of the where increased use of structuring and/or coding was seen to have added value (benefit). A novel unanticipated finding related to the lack of consistency in approaches to written communications with

patients outside of the clinical encounter, both in relation to how this was undertaken and what was communicated. This lack of structure in patient communication was found to be a barrier to encouraging and enabling patient understanding of, and engagement in, their healthcare. Participants emphasised that any increased use of structuring and/or coding should respect patient and clinician individuality and non-standard outcomes. We observed significant variations in documentation practices across different locations, care settings and professional communities. A lack of access to, and utilisation of, computerised systems was seen to contribute to the use of locally derived systems (such as structures within notebooks and Excel spreadsheets). These in turn led to duplication of effort and increased potential for error. With some notable exceptions (such as prescribing decision support in general practice), stakeholders reported that most of the gains from structured and/or coded records related to population health sciences (e.g. epidemiological research), clinical research and health service management purposes, or for reimbursement. The association of clinical coding with reimbursement and performance management was found to have a detrimental impact on clinicians' perceptions as to the value and importance of structured and/or coded data collection. This adverse effect was compounded by a lack of practical application of data to support processes of care, for example in the provision of real-time decision-support, prompts, alerts and personalised audit functions (e.g. information relevant to professional appraisal requirements). We noted specific and relevant examples of immediate value to be gained from the increased use of structuring and/or coding within medical records, including more effective use of clinician time, the ability to identify trends in disease, and improved integration services across health and social care.

**Conclusions:** The increased use of structuring and/or coding in medical records has the potential for immediate gain in relation to the reduction of errors within clinical processes, productivity gains in terms of the use of clinician time and clinic attendance, the promotion of patient-centred approaches to care, more immediate identification of patterns of disease, and the possibility for new forms of continuity of care. However, the unintended consequences of more structured information should also be considered, these including the possible de-personalisation of care and unintended impacts upon clinician/patient interactions.

## 5.1 Background

The National Health Service (NHS) is committed to an ambitious programme of modernisation including the richer and more strategic use of information technology (IT). Key goals of this modernisation agenda include the desire to strengthen the quality and safety of clinical care. Important anticipated outcomes include the

availability of better quality detailed clinical information to underpin health service quality assurance, planning, public health and to support clinical and biomedical research.

At present, clinical information (that is, personal health, healthcare and wellness information about an individual citizen or patient) is scattered across multiple repositories, in both paper and electronic forms. The design and implementation of EHRs for improved data capture, retrieval and usage depend heavily upon the increased use of structuring and/or coding of information. Work is currently being undertaken within the United Kingdom (UK) to develop standards and guidelines for the structuring and/or coding of medical records. This represents an important milestone in evolution of EHRs and is internationally significant (see Chapter 10). The work involved in achieving such changes in the documentation of healthcare should not be underestimated, given that the modification of medical records has proved central to major reforms of medical care during the 20<sup>th</sup> century (1). However, the impact on clinical practice of the standardisation of medical records through the application of increased coding and/or structuring has been subject to very little direct empirical study, as discussed in the previous chapters (see Chapters 3 and 4).

Structured and/or coded information can enable decision making by formal logic (2), and computers can readily use such information to support decision-making and analysis. In clinical practice, however, not all decisions are made on the basis of explicit, computable knowledge such as biomedical data; individual and contextual dimensions such as tacit knowledge and intuitive understanding are frequently used in deciding on a clinical management strategy (3). Therefore, there will almost always be clinical judgement applied in decision making, which cannot be recorded using structured information and codes alone. We also know little of the additional demands for healthcare professionals associated with increased structuring and coding of information. For example, the cognitive burden of mapping a clinical concept to a term in a terminology (using a terminology browser) during normal clinical work has not received much academic attention, although much of current general practice data entry occurs in this way. Classification systems provide a method of ordering information within a domain and should allow for the comprehensive labelling of all relevant concepts (4). However, in medicine, the application of a classification may imply false certainty when the concept to be coded may, for example, be an evolving disease or an uncertain clinical condition (see Goldstein-Jutel (5) for further consideration of this area). Clinicians are further sometimes reluctant to code during their clinical work and there are many barriers to clinical coding. These include:

limitations of coding systems and terminologies; skill gap of the users; time and distraction when coding; level of motivation; and the priority of coding within the organisation (6). On the other hand, when the coding of clinical records is undertaken retrospectively by clinical coders, as is the case in many hospitals, this may be prone to inaccuracies (7).

The Department of Health's (DH) recent consultation document *An Information Revolution* (8) seeks to promote a culture of open information to overcome these risks within the National Health Service (NHS). It is proposed that healthcare providers will be under clear contractual obligations, with sanctions, in relation to the accuracy and timeliness of their data collection. They will also be required to use agreed technical and data standards to promote compatibility between different systems. An important new paradigm driving these proposals is the focus on the inclusion of information generated by patients themselves and the use of Patient-Reported Outcome Measures (PROMs). The provision of medical information by patients is not a new idea (see for example Greist, Gustafson et al. (9), Porter, Silvia et al. (10), Porter and Kohane, (11), Hershey and Grant (12), O'Connell, Poljak et al. (13), Porter, Forbes et al. (14). However, shared access to the medical record by the patient, potentially at an alternate location independent of support and clarification by healthcare professionals, signals a significant change in the application of clinical documentation. Medical records are currently based on "a shared, practical understanding of common tasks, experiences and expectations" (15: 298). Patients have not previously been a part of this shared understanding. Patient access to their health records is only just beginning to be investigated and research is currently limited by a lack of universal coverage of EHRs (16).

Most current medical records are intended to serve the needs of professionals. These shared understandings draw on medical terminologies and classifications, known as nosological systems, developed by pioneers such as Thomas Sydenham and John Locke in the 18<sup>th</sup> century to enable communication and education between doctors and their students, and to further medicine as a science (17). In modern practice, a medical record is a biomedically orientated, de-personalised document that provides a distillation of information, which is determined by the author's professional point of view (18).

The need to include patients within the user group for medical records therefore presents a potential challenge to the dominance of biomedical models of recording and documentation. This dominance has been debated within considerations of patient-

centred medical care including, for example, Weed's Problem Orientated Medical Record (POMR) (19) (as discussed in Chapter 1), Engel's "biopsychosocial model" (20), and work suggesting the inclusion of patient stories of their illness in the medical record (21-23). The impact of these debates has not been empirically studied in relation to alternate structures of EHRs that are to be shared with patients. Some IT systems deploy the POMR, which uses some the subjective information, objective information, assessments and plan (SOAP) format. Other systems structures may be orientated towards time, source, or episode of care models, or a combination of approaches (24). If a policy objective is that the content of medical records is to shape a patient's understanding of their own health, choice of healthcare providers and inform their self-management, particularly of long-term conditions, questions about the structure of information to facilitate computation need to address more than biomedical analysis and decision support.

To understand the potential benefits and risks of the increased use of structuring and/or coding of information we therefore sought to consider events, processes and practices that may impact upon their implementation and adoption from a range of perspectives within the stakeholder community of individuals affected by the use of medical records. We aimed to consider the potential of coding more of the record than is currently the case, particularly in relation to symptoms and signs of the clinical history, from the perspectives of a range of participants. We sought to explore the views, attitudes, needs and expectations of key stakeholders; the perceived effects of structuring and coding of clinical records on everyday working practices and care; the perceived benefits and concerns surrounding the coding and structuring of records together with ways in which concerns can be addressed and different needs can be met; and how these standards may transform the user interface designs of future NHS IT systems.

## **5.2 Methods**

We carried out a qualitative case study (25 -28) that involved purposefully sampling of patients, a broad array of NHS staff from primary and secondary care and academics with an interest in the structuring and/or coding of medical records. This work was informed by a sociotechnical perspective (29–35). This theoretical lens allowed us to examine how the technology was situated within social, organisational, and wider political environments. Further, it facilitated in-depth investigation into the interplays between social and technical factors to shape each other over time.

### **5.2.1 Sampling**

We used purposeful sampling (36) to identify patients, a range of healthcare professionals, health service commissioners, policy makers, managers and administrators, system developers, researchers and academics based in England in a variety of care settings including primary and secondary care, and within a community context outwith designated NHS buildings, such as hospitals or GP surgeries.

In addition to interviews, we hosted six expert discussion groups as part of an eHealth Masterclass in March 2011, the Programme for which is shown in Appendix 4. This event was free to attend and accredited for Continuing Professional Development (CPD) for medical staff by the Royal College of Surgeons. Details were circulated widely amongst professional networks and existing contacts to encourage maximum participation. Each delegate was able to take part in one of six expert discussion groups as relevant to their interests and experience. Participants included a range of healthcare professionals, health service commissioners, policy makers and terminology specialists, information professionals, researchers and academics.

### **5.2.2. Recruitment, data generation and analysis**

Interviewee recruitment was facilitated by liaison with our own professional networks and also by UK Clinical Research Network (UKCRN) and the Primary Care Research Network (PCRN) who publicised our study and encouraged participation. Semi-structured interviews following topic guides developed by the research team and tailored to capture varying perspectives of different stakeholder groups (37) were conducted on a predominantly face-to-face basis in a setting of the participant's choice or by telephone. Sample information sheets, participant consent forms and interview topic guides are available in Appendices 6 - 14. The focus of the interviews was on gaining insights regarding perceived benefits and concerns surrounding the coding and/or structuring of records and how potential concerns could be addressed and different needs could be best met. Questions were open-ended and participants were actively encouraged to raise issues important to them relating to the broad topics of structuring, coding, information capture, retrieving information, and decision making. During patient interviews we utilised anonymised replica excerpts of information drawn from the research teams' clinical practice that might typically be found within medical records to stimulate discussion. Examples of these are shown in Appendices 15 and 16.

Our data collection was conducted between October 2010 and September 2011, by which time we had reached theoretical saturation – the point at which no new themes were emerging from the data (38). We also observed relevant professional practices and analysed related documentary evidence. A list of the documents collected for this WP is included at Appendix 17. All discussion groups and interviews were recorded subject to participant consent. Recording facilities failed during the telephone interview and field-notes were taken by the researcher. We also collected documentary evidence, observed working practices and photographed unusual technology, captured computer screen images ('screenshots') raised for discussion and/or demonstration by participants, and took reflexive field-notes during the course of our data collection.

Recorded data were transcribed verbatim and analysed with accompanying field notes, photographs, screenshots, presentations and documentary evidence. A deductive approach to analysis was developed to allow the key themes within the findings to emerge. Thematic analysis of the data was initially conducted by two members of the research team using NVivo8 (subsequently upgraded to NVivo9) who worked independently to increase validity (39). This analysis was then discussed by the whole team within a focused workshop to identify areas of interest, consider disconfirming evidence and reflect on the role of the research team within data generation (40) and themes for further investigation. We then reviewed our analysis and met as a research team within a further two informal workshops to validate our findings and gain deeper insights into the emergent themes. Finally, we discussed our findings with the Independent Project Steering Committee (IPSC), to draw upon their experience and knowledge as expert practitioners. These findings are considered in detail in the following section.

### **5.3 Results**

We undertook 24 in-depth interviews with 27 participants and hosted six expert discussion groups with 43 participants, thus involving a total of 70 participants. We also observed relevant professional practices and considered related documentary evidence. Table 5.1 provides a summary of the data collected. Table 5.2 details interviewee participant characteristics and Table 5.3 summarises the expert discussion group topics and numbers of participants.

**Table 5.1: Summary of data collected**

Data source	Number
<b>Interviews</b>	24
<i>(Participants)</i>	<i>(27)</i>
<b>Discussion groups</b>	6
<i>(Participants)</i>	<i>(43)</i>
<b>Observations</b>	1
<b>Field notes</b>	6
<b>Documents</b>	20

**Table 5.2: Interviewee participant characteristics**

Identifier	Role	Gender	Setting	Interview method
1	Researcher	Male	Primary care	Face-to-face interview
2	Researcher	Male	Primary care	Face-to-face interview
3	Systems Developer	Male	Secondary care	Face-to-face interview
4	Clinical Lead	Male	Secondary care	Face-to-face interview
5	Systems Developer	Female	Secondary care	Face-to-face interview
6	Researcher	Male	Research institution	Face-to-face interview
7	Researcher	Male	Research institution	Face-to-face interview
8	GP Practice Manager	Female	Primary care	Face-to-face interview
9	Clinical Lead	Male	Primary care	Face-to-face interview
10	GP Practice Administrator	Female	Primary care	Face-to-face interview
11	PCT Data Quality Manager	Female	Commissioning	Face-to-face interview
12	GP Practice Information Manager	Male	Primary care	Face-to-face interview
13	Diabetes Dietician	Female	Secondary care	Face-to-face interview
14	Diabetes Specialist Nurse	Female	Secondary care	Face-to-face interview
15	Head of Midwifery	Female	Secondary care	Face-to-face interview
16	Clinical Coding Manager	Female	Secondary care	Face-to-face interview
17	Hospital Pharmacist	Female	Secondary care	Face-to-face interview
18	Clinical Coding Manager	Female	Secondary care	Face-to-face interview
19	Research and Audit Assistant	Female	Unscheduled care	Face-to-face interview
20	Clinical Improvement Officer/Paramedic)	Male	Unscheduled care	Face-to-face interview
21	Patient 1	Female	Primary care	Face-to-face interview
22	Patient 2	Male	Primary care	Face-to-face

				interview
23	Patient 3	Male	Primary care	Face-to-face interview
24	Clinical Information and Records Assistant	Female	Unscheduled care	Face-to-face interview
25	Clinical Information and Records Assistant	Female	Unscheduled care	Face-to-face interview
26	Clinical Coding Manager	Female	Unscheduled care	Telephone interview
27	Senior Academic	Female	Research institution	Face-to-face interview

**Table 5.3: Expert discussion group topics and number of participants**

Group	Discussion topic	Number of participants
1	Are there areas of clinical practice where structuring and coding could make an immediate and positive impact?	7
2	How close are we to realising the potential of Natural Language Processing to supersede formal templates and terminologies?	9
3	Is it appropriate and useful to code a patient's clinical history?	7
4	Should patients be offered the facility to review and populate their own health records using structure templates and terminologies?	7
5	What do secondary use services (SUS) need from clinical coding? How does this complement and conflict with the needs of clinical care?	6
6	What should we do about data quality? This group will consider the problems of poorly coded data, the types of data that may be coded and for what purpose, educational needs to ensure accurate coding for both practice and research.	7

Our analysis identified five main themes within the data in relation to the use of structuring and/or coding; patient perspectives; uses in relation to the provision of clinical care; secondary uses, and examples of where increased use of structuring and/or coding has added value (benefit). More details of these themes are given in Box 5.1.

### Box 5.1: Summary of themes and sub-themes

#### Patient perspectives

- Patient expectations and concerns;
- Understanding information;
- Providing information.

#### Use in relation to the provision of clinical care

- Medical records as a co-constructed story;
- The impact of EHRs;
- Variations in the practice of documentation.

#### Secondary uses

- The impact of incentives and reimbursement on structuring and coding;
- Secondary uses of structured and/or coded information;

#### Examples of added value (benefit) from structuring and/or coding;

- Increased productivity;
- Promoting patient-centred approaches to care;
- Identifying patterns of disease;
- Redefining continuity of care.

### 5.3.1 Patient perspectives

This section considers our findings in relation to patient use and understanding of information. Patient access to their medical records formed the topic for discussion for an expert discussion during the eHealth Masterclass. Key points from this discussion are summarised at Appendix 18.

#### ***Patient expectations and concerns***

In talking to patients about structured and coded information it became clear that patient expectations were based on certain assumptions about the availability and use of computers by healthcare professionals.

*“Obviously all that is on the computer, like all my, like I’d like to think all my medical problems are on the computer.”* (Interview 23, Patient 3, Primary Care)

*“If I come up here for a check up for cholesterol I mean the doctor he doesn’t know, he knows me but I mean he sees thousands of patients, he doesn’t know all my personal*

*details, probably of anybody, you know, he can remember certain things but what they do now obviously is switch on their computer and they just go through that or you might say I'm not feeling too good and he might take, say I can see something's wrong with you here's, go and have, you know, we'll give you some treatment for that, that should then go on the computer shouldn't it, you know, so he can refer back to it. Whereas before that computer system he wouldn't have even, he would just have done a prescription and that would have been it sort of thing."* (Interview 23, Patient 3, Primary Care)

These patient expectations seemed to be enveloped in a kind of folklore created by the British press and popular misconceptions as to what could and could not happen to this information:

*"You read in the paper that they're spending all this money on computerisation and then it doesn't work. They spend millions setting up these systems and they don't always work."* (Interview 21, Patient 1, Primary care)

*"If you, you know, there was an issue that you didn't particularly want revealed to say insurance people could they tap into your medical records?"* (Interview 21, Patient 1, Primary care)

*"I mean I'm retired now but if you were going for a job could they tap into your records, that is a worry that other people who you wouldn't really know."* (Interview 22, Patient 2, Primary care)

### ***Understanding information***

Whilst unsure about how information might be used by others, patients were able to describe their experiences of receiving medical information in relation to their own conditions, detailing problems with processing the information received. They noted how this impacted upon healthcare professionals time, describing how they contacted surgeries and attended clinics to gain information or have things explained in a way they could understand.

*"Well you've got to read the whole thing and then you would probably have to note down the different problems where as if it was listed it would be easier to understand and act upon".* (Interview 21, Patient 1, Primary care)

*"I mean probably medical people would understand it but I certainly can't understand it but I suppose in a way I'm not meant to but then when you would like to know what our records are he would have to describe that to me personally wouldn't he?" (Interview 23, Patient 3, Primary Care)*

*"I had a copy of it and I couldn't understand two-thirds of it, the words he was using, I was going good God but the other fella up at [the hospital] picked it up straight away, knew what it was all about." (Interview 22, Patient 2, Primary Care)*

*"What I find is that if I need some information as to what, you know, effects, certain things I'll ring up like what is my cholesterol reading and they say oh it's gone down to 4.5 or whatever it is, you know, and so, but I don't always, I would not get a letter probably about that only by ringing up the surgery and anybody in the surgery even the receptionist can look on the computer." (Interview 23, Patient 3, Primary Care)*

*"And I mean some of the technical terms are not known to Joe Bloggs, I mean, you know, you've got to have ology's to understand them, some of the phrases. What I tend to do is I see Dr. [name] more often than I do Dr. [name] and I just say am I alright to take these even if it's only aspirin or Anadin or something, am I alright to take this with that." (Interview 23, Patient 3, Primary care)*

*"I think when you get a referral from your doctor to a hospital then you get a copy of that, then the surgeon that sees you, the consultant he responds and sends you a copy .... But from there on in you get very limited information." (Interview 22, Patient 2, Primary care)*

These issues regarding patient understanding were also recognised by other participants. Our findings emphasised the different contexts within which patients may be receiving information.

*"There's a lot of nationally recognised abbreviations within maternity but we also need to decode that for a woman cause she'll read it and go well what does that mean, so there's a mixture of full text and a mixture of abbreviations." (Interview 15, Head of Midwifery, Secondary care)*

*"It's not just that they are in a physically vulnerable state but they are in a different kind of a vulnerable state about access to information and knowing what they have a right to do and to say. But there's also a pragmatic point to this, if you are really, really sick and*

*frail, all of your energy goes into getting through everyday much less spending a lot of time researching your particular illness or whatever so a lot of people don't think about that"* (Interview 3, Systems Developer, Secondary care)

A patient representative noted that complications and co-morbidities impacted on the level of support needed for patients to understand information and suggested that this should be considered in relation to the way in which such information was presented to them. The example of allowing the patient to see coded information was felt to be particularly inappropriate and disempowering for the patient by allowing medical terms to dominate descriptions of the patient experience of being unwell. This description was consistent with that of a specialist nurse:

*"When the doctors see them they'll get the full eh data sheet you know when I said with all their medications and their diagnoses and all the biometrics on, so they'll get that sheet plus a letter which the GP, which the [inaudible] writes to the GP, so that's what they receive, a copy of that, the patient does a few weeks later. Em that's very medical though, the data sheet is very medical, it's not something that you would go through particularly as a patient and understand I don't think. Em and also the letters are much too, the language is much too medical I think. You know some, some specialities now I understand write, write to the patient and copy to the GP. So the language has to be in patient friendly language."* (Interview 14, Diabetes specialist nurse, Secondary care)

The lack of consistency regarding communication with patients evidenced a lack of structure or predictability in terms of what information was provided where and when as part of the medical record. This was also evident in the interface between hospitals, General Practitioner (GP) practices and patients. Our research indicated that GP practices did not know whether a patient had received a copy of a letter from another healthcare professional and had no routine procedure of recording this information.

*"You just assume that perhaps the hospital have given them a copy [letter]. I don't know it just comes through in the post, sometimes the patients actually come and hand them to us, they've got their envelope, it's got the doctors name on it and they hand it to us."* (Interview 10, GP practice administrator, Primary care).

The issues with communication described above were inhibitors to patients' understanding of their own healthcare, created extra demands on healthcare professionals when patients booked consultations to ask their healthcare professionals to explain and translate information provided, and caused ambiguity and uncertainty for

patients who were already vulnerable. There was significant potential for effective and evidenced forms of structure to improve the accessibility of information for patients. As one patient noted:

*“I think it comes down to one word, it’s clarity isn’t it?”* (Interview 21, Patient 1, Primary care)

### ***Providing information***

When considering the information provided by patients during their care, patients noted the degree of trust inherent in the consultation. The information collected was felt to be highly personal.

*“You probably say a lot more to your GP than you would say to a lot of your family, you know, you feel that what you say to them is between you and he or her.”* (Interview 23, Patient 3, Primary care)

Given the intimacy of the information provided, a non-judgemental and honest environment was considered essential, and potentially inhibited by the presence of knowledgeable healthcare professionals, even though patients were providing information in relation to their own healthcare needs:

*“One of the things dieticians do you take diet histories and I don’t think I ever met anybody who’s completely honest when you take a diet history of what they ate. I, I wouldn’t be honest, if you asked me I wouldn’t be honest so why should I expect that somebody else would be honest, never, never.”* (Interview 13, Diabetes dietician, Secondary care)

*“Where people have diabetes they need to be doing most of the time some kind of blood glucose, sometimes food recording, so when I mean that, that’s one of the things that I would print things off the computer, I will print them off forms so they can go and do some, some hard work in recording and measure. But you know it’s not so much for us to keep the, the records it’s for them to, to look at and learn from). So it’s, they’re doing it for themselves rather than doing it for me.”* (Interview 13, Diabetes dietician, Secondary care)

Structured forms and templates were noted as a possible counter to interpersonal

difficulties in the provision of intimate information, for example where a patient was less embarrassed to provide sensitive information they felt they may be judged upon in writing, such as alcohol consumption or substance misuse. However, participants stressed that levels of literacy and language were not to be automatically assumed. One nurse specialist described her use of a pro forma:

*“I use it it’s usually with people who don’t really, I know that they’re gonna struggle to find something to talk about themselves and I’m trying to engage them with their health care. So I might sit with them and help them fill it in or I’ll say would you like me to tick and I’ll just read it to you and you, cause some of them don’t read, they don’t speak English very well.”* (Interview 14, Diabetes specialist nurse, Secondary care)

It was felt that the use of structured information may be unfamiliar to patients and insensitive in some contexts, for example where information is felt to stereotype or carry inherent social judgements. These issues are explored in further detail in relation to ethnicity and depression in Chapters 7 and 8. Alternatively, presented within a familiar context, participants felt that the collection of structured information from patients may have led to greater patient involvement in care and facilitate more accurate recording and self-management. We observed this in areas such as obstetric and diabetic care.

In obstetric care, we heard how groups representing women’s interests have worked with healthcare professionals to develop records shared between patients and professionals, using structure to facilitate patient understanding. This was described as a development over time and was attributed by one participant to the desire of women to have more control and involvement in their antenatal care, and to organisational and professional needs and requirements for accurate documentation for medical-legal considerations.

*“I’ve been a midwife for over 20 years and when I first started midwifery, the first booking appointment a women ended up with something called a Kerb Card which was an A4 piece of paper which sort of folded in on itself and that was just boxes and you filled in tiny writing that which basically said how she was at that current appointment, over time women have asked for more information plus we have to record more information from a litigation perspective and we want people, we don’t want to have hospital and had held notes, they’re the same thing really so the current booking appointment now, the notes are there for women, give them a lot of information and they’re also there for staff so staff can see what was said before plus in those notes*

*they've got everything they need to know i.e. all the results of their past blood tests and their past history so you're not having to keep asking the same question. So notes in a maternity perspective if used properly, are very informative for both the woman and healthcare professional." (Interview 15, Head of midwifery, Secondary care).*

In diabetes care, information was described as essential for patients to manage their condition, and one participant described how many of her patients were seeking to use technology in this regard:

*"People who have diabetes use blood glucose meters and most blood glucose meters you can download the data from the blood glucose meter onto your pc. And you can do that and then they have wonderful programmes that will draw graphs and will colour things and will do all kinds of wonderful stuff with the data but the diabetes nurses who are the ones who do most of the practical kind of moving the insulin about and playing with things hate it, they can't use it at all. And then we will say well when you're going to come and see us write it down on paper [laughs] for two weeks before you come That's quite an interesting paradox you know isn't it because you've got people with these whizzy i-phone four applications and then they come into hospital and you've got a little, a little piece of paper." (Interview 13, Diabetes dietician, Secondary care)*

The technology available to patients was felt to be increasing patient desire for information and encouraging them to be proactive in their own healthcare. Examples of this were given in relation to patients managing their own long-term conditions, for example diabetes, and those on anti-coagulant medication:

*"Certainly we get in patients who are self-testing, self-managing and our intent is to make them able to access their own data directly without going through any of the bureaucracy. But only their own data...they sort of won't get access to other people's data...but to download and do whatever they want with it, it's theirs." (Interview 4, Clinical lead, Secondary care)*

Participants further stated that medications management was an area that could greatly benefit from the provision of structured information to and from patients, allowing patients a greater understanding of what they should be doing, and more accurate reporting of what they were doing.

*"Very often compliance is a big issue, people never take their medications as you would expect them or want them to take 'em. And yeah they'll come to hospital and,*

*and people aren't going to say oh I take it once it a month [laughter] or I never take it at all. So you know you have to investigate a little bit and sometimes it goes down to actually going to GPs and saying could you look at their prescriptions [laughs] how often do they fill these prescriptions?"* (Interview 13, Diabetes dietitian, Secondary care)

*"What I have found is sometimes we wait because the hospital could have already given them a prescription, especially if they've actually had a stay in hospital they could have already given them, they could have come out with a month's worth of tablets. The doctor will put them, especially if it's new medication, the new medication into the system for the prescriptions, you know, for their prescription request but I think normally what happens is we wait for the patient to ask us when they need medication so they say I've been in hospital, I haven't had these from you before, sometimes they might even bring the box in or we query it and say right have you had it from us before, not the hospital gave us, so then we can say to the doctor, you know, could the patient have this prescription as per hospital letter of whatever date."* (Interview 10, GP practice administrator)

In addition to issues of compliance and medicines management, there was also the potential for informed patients to be more involved in medicines administration.

*"The next stage is that we've suggested to some patients an interest that might want to go the whole hog and do self management and this is where they do the lot, within parameters and they will test their blood as they are doing at the moment but they will then dose themselves."* (Interview 17, Hospital pharmacist)

One area where patients were contributing to authorship of their own records was in the use of self-service kiosks in out-patients. We observed this technology being used as an independent interface with patients in a way that was familiar due to patient experiences with similar kiosks in supermarkets and during airline and train travel. These kiosks allowed patients to review and amend the data held about them within EHRs. A photograph story board of the sequence of screens presented to patients is shown in Figure 5.1. Two managers interviewed described how these had allowed a significant reduction in patient queuing times when booking in to clinics, which in turn reduced queuing for follow-up appointments and other administration post-consultation. They were described as having increased confidentiality as patient information was unable to be overheard, in addition to improving access to minority groups by offering five languages, options for those with visual impairments, reducing the impact of

hearing impairment and catering for wheelchair users. One manager also noted that by presenting structured information to patients they allow for amendment, update and correction by the patient, ensuring that self-defined data such as ethnicity were accurate. By involving patients in this manner processes had been automated to release manpower whilst at the same time improving the accuracy of the medical record. The kiosks were working with demographic information at the time of our interviews and observations and were being developed to utilise bar coding technology to identify patients via bar codes on their hospital correspondence. It was planned to use the kiosks to automate services provided by staff and volunteers, for example patient management between several appointments on the same day where the order of appointments may be dependent upon certain sequences of events, such as patients attending for cancer clinics who are reliant upon test results for their next consultation.

These patient-centred models of care required shared record keeping intended to change the medical record from an artefact shared between healthcare professionals to something that is authored to a greater or lesser degree by healthcare professionals, the patient and, where appropriate, their carer. As one healthcare professional noted:

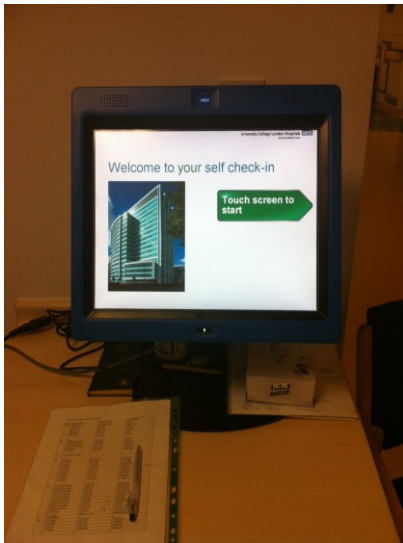
*“It’s their information, it’s not information from us, it’s information from them, but if they’re looking at it and they can’t decide what to do next, they might say you know what do you think and we’ll give them a second opinion.”* (Interview 13, Diabetes dietician, Secondary care)

It was felt that this will demand new forms of structure that move beyond medical models and conventions of practice to more generic structures. Our findings indicate that such movement may overcome some of the tensions inherent in current patient documentation. These tensions are now considered in relation to the use of structuring and coding within medical records by healthcare professionals.

Figure 5.1: Self-service check-in an out-patient clinic: the story so far



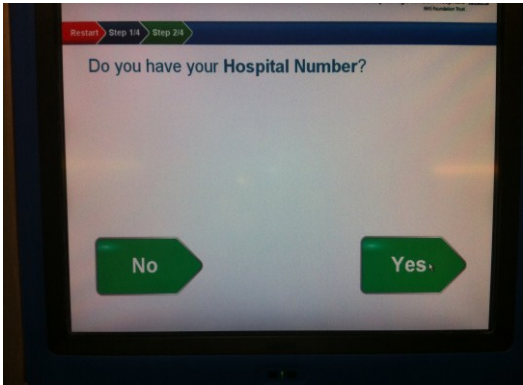
Check in Kiosk



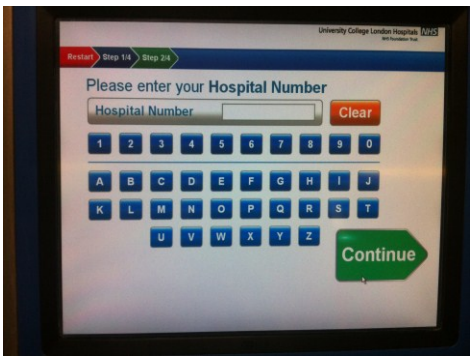
Welcome screen



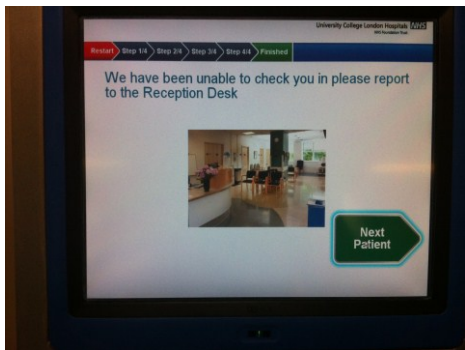
Language selection screen



Hospital Number request (1)



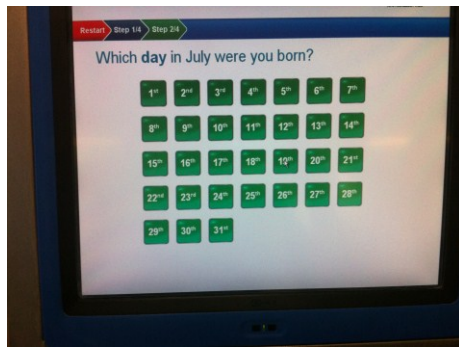
Hospital Number entry



Error message and directions



Further information request if hospital number unavailable



Date of birth request if hospital number unavailable



Date of birth request if hospital number unavailable

Bar code scanner

### 5.3.2 Use in relation to the provision of clinical care

#### *Medical records as a co-constructed story*

The collection of information within a medical record was found to be a highly interpretative process that drew on an individual's decision-making not only about the information received, but what took priority within that information and how it was to be accounted for.

*"There is a big division as to whether a symptom is coded or a diagnosis is coded. And I'm sure there are huge patient factors that influence that decision."* (Interview 6, Researcher)

*"They assumed that GPs consistently recorded, Read coded symptoms and they don't. They only code a symptom you know on the whole...and I've talked to many GPs about this and I think they will usually just code the main symptom and free text the others."* (Interview 7, Researcher)

The use of structure and/or coding within the medical record was aimed at the collection and storage of information. The areas of clinical practice where structuring and/or coding could make an immediate and positive impact and the coding of a patient's medical history formed the topic for discussion for expert discussion during the eHealth Masterclass, the key points of which are detailed at Appendices 19 and 20.

Much of the patient information collected during the provision of care was felt to be highly intimate and gathered as a function of the healthcare professional's relationship with the patient.

*"It's real people and they're real lives but we have to be sensitive about the information we're collecting and staff need to be able to ask those questions in a sensitive way cause you can rattle through a list but could be very impersonal and women will just sit and say "no, no, no" whereas if you say it in a different way they will reveal a lot more."* (Interview 15, Head of midwifery, Secondary care)

*"For us it's about the clinicians making decisions and demonstrating why they've made those decisions. You can't do that by ticking boxes."* (Interview 20, Clinical improvement officer/paramedic, Unscheduled care)

This process took place under pressure within very short time-frames, which sometimes resulted in incomplete record keeping.

*"Basically they'll give information in the letters diagnosis and things like that, doctors decide whether they want to put the information on the system or not and there's a lot of information they don't put into the system they don't think is necessary cause it's not that important but they could do, but it's a question of time that's the thing."* (Interview 7, Researcher)

*"The time pressure is just immense in terms of completing the notes."* (Interview 6, Researcher)

The impacts of processes of interpretation and abstraction were magnified further during the retrospective coding of information by administrative staff.

*"We have to process something. We can't...we can't leave that blank. We haven't got a code that we can put in for a blank code. So obviously we're not clinically trained so we kind of have to make a bit of a guess, read through the form. Sometimes it will be obvious and if you know it was an asthma patient then we'll put the code in for asthma and just think the clinician has just forgotten to do it. But some of them can be quite complicated which is probably why they haven't put the code down in the first place because none of them fit to that condition."* (Interview 10, GP Practice Administrator)

A number of participants noted the nature of coding systems, which also impacted on the accuracy of recording, particularly through the use of generic codes that were either broad enough to approximately capture information or to exclude the codes available by choosing the 'other' option:

*"We need something that we can do instantly as a one-off that's not wildly inaccurate, it points towards the kind of problem but at the same time without committing to a definite definitive diagnosis."* (Interview 9, Clinical Lead, Primary Care)

*"It's very limited, sometimes too limited and very often you end up putting other, other reason for encounter because none of the codes that are there are quite enough."* (Interview 9, Clinical Lead, Primary Care)

The restrictions of the coding system were felt to provide ready answers to recording information, allowing healthcare professionals to develop short-cuts to get the job done, a practice which in turn offered the potential for habits influencing data entry, for example over-reliance on favourite or familiar codes, words and phrases.

*"The work that I am going to do is to find out which of the codes are being used frequently because that could be...is it because the GPs are quite familiarised with it or is it really a frequent occurrence in patients."* (Interview 6, Researcher, Research Institute)

*"They seem to have a quite...I don't know, kind of a....a homogenous way of sort of setting certain things out. So you think there is certain phrases and language that are almost like kind of codes. But obviously written in the free text box."* (Interview 26, Clinical Coding Manager, Unscheduled Care)

*"I always code through free text....It's just the way I find it easier. A lot of people seem to memorise the code, the numbers and will put the code in. I just type in a keyword in and if it's not...you know then I can, I can choose from a list of you know what code would be the best one."* (Interview 8, GP Practice Manager, Primary Care)

The ambiguity of information was a significant influence on coding practices. This ambiguity was felt to be unavoidable given the nature of the diagnostic process and implications of clinical decisions. Coding information was felt to imply a certainty regarding diagnosis that may not reflect the clinical process.

*“The data item of what you said then can be captured, but doesn’t actually mean a great deal in terms of the journey you’re on. So data items are a moment in time and often in clinical care you have a journey.”* (Interview 4, Clinical Lead, Secondary Care)

*“Sometimes there’s more than one code for...that means exactly the same thing. That’s what I find hard to understand.”* (Interview 8, GP Practice Manager, Primary Care)

*“How GPs might code symptoms which is different to how they might code diagnose.”* (Interview 7, Researcher, Research Institute)

*“Our feeling is that people are likely to enter a symptom Read Code when there’s diagnostic uncertainty and when the condition is serious enough that they are not prepared to make an assumption about the diagnosis.”* (Interview 6, Researcher, Research Institute)

In addition to concerns about falsely implied certainty, issues of labelling and use of language, particularly in relation to conditions with implications for a person’s status as an competent individual (such as dementia) or associated social stigma (such as obesity), were felt to influence documentation and coding as a reflection of the contingent nature of clinical processes:

*“Putting a diagnostic code in is akin to labelling in some way and there may be clinical reasons for it...maybe they don’t want to commit themselves early to a diagnosis and particularly for something like rheumatoid arthritis.”* (Interview 6, Researcher, Research Institute)

*“They tend to err on being less specific on the whole you know so similarly when we were working with old age psychiatrists who wanted to do work on dementia they thought, they assumed they would be able to differentiate between Alzheimer’s dementia and Multi-Infarct dementia whereas in fact the vast majority of people with dementia in the THIN dataset are either senile dementia or dementia not otherwise specified and you’ve got no way of knowing which sub-type of dementia they have because on the whole GPs are not going to commit themselves to sub-typing especially when there’s uncertainty like there is in dementia.”* (Interview 7, Researcher, Research Institute)

*"We never get the term obesity ever written down; we get a BMI [body mass index] written down so we've had to take advice from our bariatric surgeon here to give us advice, what is obese? So he's given us all the national definitions so that we can actually code accurately people who have only ever got written in their notes BMI 40, BMI 40 is obviously high, in fact I think it's verging on, well it is morbid obesity. See that's another change we don't write big, fat, we can't do any of that but years ago people did actually write that when I first came to the health service but you don't even, very rarely get the term obesity written down so you get this BMI and then my coders were sitting there saying well how do we know what's fat which is fair."* (Interview 16, Clinical Coding Manager, Secondary Care)

The possibility for human error was also noted within coding processes as staff retrospectively classified information. Staff were aware of error rates and described local strategies to reduce inaccuracies:

*"I mean we have a sort of...about 8% of forms that are actually wrong, incorrect."* (Interview 24, Clinical Information and Records Assistant, Unscheduled Care)

*"A person who has had a hysterectomy you can have one uterus you can't have 10 but in their records you would have hysterectomies done 10 times that's because when they come for review they don't say review they say hysterectomy again."* (Interview 18, Clinical Coding Manager, Secondary Care)

*"Sometime clinicians will put in by accident the wrong code or they won't code it properly whatever, if I just did it that way, just pulling off this system, I might not get all of the...you know all of the cardiac arrests or whatever and so I kind of rely on them to also when they're going through on initial sift to pull out all the ones that say cardiac arrest or they can sort of see from other areas of the form would...that should be included. Even if they're coded wrong."* (Interview 26, Clinical Coding Manager, Unscheduled Care)

One participant noted the interpersonal issues involved in correcting errors by healthcare professionals.

*"You sit there and think that's just not right, that just cannot be right and sometimes it does take a lot to actually go up to see a consultant and say excuse me but this doesn't really look as I think it should and then it's well what do you think gone on and you tell them and you sit there and think, you're only hoping you're going to be right and you*

*can see their crestfallen face yes you are.”* (Interview 16, Clinical Coding Manager, Secondary Care)

These errors were felt to be completely excusable given the level of expert knowledge and skill required for effective coding.

*“The national clinical coders classification service decided to bring in an exam, a professional coding exam and what they’ve actually found is although people can pass an exam it doesn’t necessarily make them a good coder.”* (Interview 18, Clinical Coding Manager, Secondary Care).

This highlights the intimate and intuitive nature of information gathering and collation that supports authorship of the medical record and the difficulties associated with classifying this information within imposed structure or coding terminologies.

### ***The impact of EHRs***

Structures and coding frameworks were embedded within the IT systems available to healthcare professionals to support clinical care. However, systems were not seen as a substitute for the skills underpinning documentation within medical records.

*“We did have one student, young doctor who got up at one of these sessions and said well why can’t we do this all on a computer, this is ridiculous and another consultant just got up and said look you don’t even know how to write properly how do you think you’re going to type in and do all of this if you don’t actually know what a discharge summary is, you don’t actually know how to summarise the care you’ve given, that’s not going to change that is it? And he was spot on, if you can’t use a pen and a piece of paper why are you going to suddenly have, you know, a vision when you turn on a computer it’s not going to happen.”* (Interview 16, Clinical Coding Manager, Secondary Care)

Much of the use of structure within IT systems was determined by the purpose of data collection and storage. The potential for use of free text data entry and Natural Language Processing within medical records formed the topic for discussion for an expert discussion during the eHealth Masterclass. Key points from this discussion are summarised in Appendix 21. Some interviewees noted that there may be some instances where it is not worth spending time authoring data structures.

*“Structured data enables you to be more computational so you can’t search very easily in unstructured data. You can’t do decision support very easily with unstructured data, you can’t return unstructured data as an audit result quite so well. But structured data has disadvantages as well, like it is quite time consuming to enter and very often information comes to clinicians in an unstructured way.”* (Interview 3, Systems Developer, Secondary Care)

*“If you don’t expect to do any decision support or any computation, any audit report on the basis of this letter the effort involved in extracting the data will usually be too much.”* (Interview 5, Systems Developer, Secondary Care)

Appropriate structuring of system interfaces for clinical systems was felt to be critical for usability:

*“If it’s not designed correctly then it’s not very user friendly for me when I’m you know trying to sort of input the information into that.”* (Interview 8, GP Practice Manager, Primary Care)

*“It was drummed into me at medical school just the very basic taking history, doing an examination to do it in a structured way and I have a very set way and I’m sure all doctors do. An order that I examine the chest in for instance and that means I’m less likely to forget a bit and the same comes when you’re writing it up, you’re less likely to omit it. So both in your brain, if you were writing on a blank piece of paper it’s useful to have a structure and obviously when you’ve got that on an IT system, if you’ve got that as a structure so long as it’s a structure that’s roughly similar to your own structure otherwise it can jar and wind you up and annoy you.”* (Interview 9, Clinical Lead, Primary Care)

In discussing IT systems, it was interesting that not all healthcare professionals could fully contribute to the EHR even if they were a frequent user as they did not have data entry permissions:

*“It’s a good database you know and, and it, because they have a, a proforma you know it makes sure that they check all the bits they need to check when they review patients. It’s useful, and it’s like you know when, where it’s in the paper notes of the patient you can be sure that you’ll find all the information once you’ve found any database sheets that are there, so it’s very helpful. But I’m not able to put in (access), yeah, well I mean I, I can look up things on it but I can’t put anything into it.”* (Interview 13, Diabetes

Dietician, Secondary Care)

In some cases the structures built into IT systems was seen as a direct hindrance to practice as it did not support perceived logical workflows and standard practices:

*“One reason it puts me off the template, when you put a blood pressure in Adastra, it doesn’t come out as 80 over 120. It comes out as two different lines with a gap in between, you know and it doesn’t read like we’re used to reading it sort of thing. So it...yeah I guess it does undermine the clinical narrative.”* (Interview 9, Clinical Lead, Primary Care)

*“When I’m doing the examination bit especially which is when the templates are meant to be, you’ve done a bit of free text generally, not systemically unwell, maybe some of the drop down boxes. Then you go into templates and the templates automatically jump to the top so it switches round the order and again, it changes how it reads, you know.”* (Interview 9, Clinical Lead, Primary Care)

For many practitioners, this hindrance seemed to offer little payback due to the inability of reporting functions to offer information at an individual level:

*“At the moment we can produce information for when we do clinical audits and use information we can say you know this particular sector has done this. What we can’t do is because it’s too laborious is to go down to individual clinician level. At the moment our clinicians get information because time has always been the key target.”* (Interview 26, Clinical Coding Manager, Unscheduled Care)

The lack of intelligent decision support within clinical systems was also noted by participants, even for the most basic functions such as automated checking.

*“It doesn’t do any checks I can put any rubbish I wanted into that, into the system even with the postcode there’s no checks until that record goes down to the health authority and they will do it the, checks are done there.”* (Interview 8, GP Practice Manager, Primary Care)

As a result of systems shortcomings, participants often described their use of paper-based systems and locally derived systems such as Excel spreadsheets, indicating a mis-match between useful structures to support working practices and information requirements, and supplied systems structures resulting in significant duplication of

effort and potential for human error whilst retrospectively entering data:

*“I keep a list offline on a spread-sheet of what each person on that register’s got so obviously one person may have – may be on lots of registers so I’ve got a spread-sheet of all the patients on any register and I keep that up to date as well during that time I keep that up to date so if patient have come off a register I take them off my list, if they go on I add them on so I keep that up to date so because there is times when you might want to know you know what different registers patients are on and that’s an easy way of looking at information, if you go to the audits you’d have to look at each individual register to see are they on this register, are they on this register there’s no one register.”* (Interview 8, GP Practice Manager, Primary Care)

Interestingly, whilst EHR systems were often discussed as a significant change when introduced, EHRs themselves needed to continue to evolve post implementation to keep pace with service developments. Participants described the difficulties in achieving consensus about systems developments and adaptations.

*“Any changes need to be made on it you know to make more eh possibility of entering information there’s always a big to do about it.”* (Interview 14, Diabetes Specialist Nurse, Secondary Care)

*“So from my point of view whatever the domain is it always works the same way, they tell me what the structure is and then I make a database. There’s a long period of arguing the toss about what the structure ought to be but that’s clinical.”* (Interview 3, Systems Developer, Secondary Care)

This was felt to present a significant issue given the evolving nature of healthcare provision, for example the lack of structure within medical records to accommodate patients consulting healthcare professionals by email. In discussing IT systems, we encountered a number of healthcare professionals who were storing information in structured formats on paper and even in personal jotters as they were unable to gain access to technology that would help them fully utilise this information in a timely and useful way.

*“The majority of the forms that we can actually process electronically are the emergency ones. We do sometimes get the paperwork for the patient transport services and the out of hours but at the moment, we can really only file those, we can’t*

*actually process them.” (Interview 25, Clinical Information and Records Assistant, Unscheduled Care)*

*“Whenever we supply data, one of the frustrations from my point of view is never being able to do it immediately. So I couldn’t tell you today how many hyperglycaemic incidents we attended yesterday. I couldn’t even tell you with any reliability how many incidents we attended last week or last month. I would have to go back a couple of months before so that I knew how many records we’d processed otherwise it’s a matter of flicking through boxes to find information. So it’s...it isn’t particularly high-tech at the moment.” (Interview 19, Research and Audit Assistant, Unscheduled Care)*

*“That’s the downside because our current system can not flag patient, it can only flag an address. So if you’ve got a block of flats, we can flag the block of flats.” (Interview 20, Clinical Improvement Officer/Paramedic, Unscheduled Care)*

In evaluating the use of structuring and coding in medical records we found that the many medical records were paper-based and there were significant variations in of systems access and utilisation by healthcare professionals.

### ***Variations in the practice of documentation***

In addition to variations in systems access and utilisation, we observed significant variation in documentation practices across different professional communities. This was a fundamental challenge in relation to structuring medical records as many assumptions regarding collation, comprehension and understanding of structured information were seen to underpin common assumptions about the potential benefits of shared EHRs.

*“It is true that we are seeing more awareness of the value of shared records. It’s not couched in terms of structured and unstructured. It’s couched in terms of mutual understanding of a record so we might go to a hospital and say yes we can build you an application that does such and such and actually that’s not really what you want. What you really want is a set of enabling technologies that enable you to have good quality recording that enable you to share care with other professionals particularly the general practitioner but also the patient and which are going to be understandable in a wider context, both international and cross-professional etc.” (Interview 3, Systems Developer, Secondary Care)*

*“Health informatics itself goes back a lot of decades. I don’t think it’s necessarily the case that the storage and information on a computer is particularly new. What might be new is how it appears to people so the fact that we can readily get access to it through new technologies as opposed to having to be at a physical particular, particular physical work station to get access to it, that’s new. Having a larger quantity of it accessible is arguably new, being able to merge it from multiple sources is arguably new.”* (Interview 3, Systems Developer, Secondary Care)

Variations in documentation within medical records happened locally, between professions and within professions. Local and national variations in practice depended on individual behaviours, for example individual GP practices, or where there was a lack of specificity within guidelines, or ambiguity due to organisational arrangements, as was the case within the ambulance service.

*“There’s always outliers, we sometimes end up excluding [GP] practices because there’s such extreme outliers we are doubtful of the reliability of their data. Either they’re just never entering anything at all or they’re way off the scale.”* (Interview 7, Researcher, Research Institute)

*“A lot of sort of Department of Health guidelines and NICE guidelines tend to be more general or based at acute trusts or primary care and we have to kind of pick out the bits that actually apply to us.”* (Interview 26, Clinical Coding Manager, Unscheduled Care)

*“We look at the guidelines which are set out...the guidelines we follow are by a body called JRCALC which is the Joint Royal Colleges...JRC...of Ambulances Liaison Committee I think it stands for. JRCALC.”* (Interview 26, Clinical Coding Manager, Unscheduled Care)

*“All ambulance services have different codes. Ours works for us, it’s not perfect and we’re looking at changing it.”* (Interview 26, Clinical Coding Manager, Unscheduled Care)

The number of healthcare professionals involved in individual clinical care itself presented the problem of achieving consensus amongst users as to how best to structure information within computer applications:

*“The difficulty I think from the clinical standpoint is probably that different people want to get different things out of an application and a difficulty from my point of view is only*

*that we need one set of data that we are going to record and there are so many points of view, potential points of view.”* (Interview 5, Systems Developer, Secondary Care)

These challenges were described in the differing practices of doctors and nurses for example:

*“The nurses are very good at using the templates and lots of the nurses every time they do a blood pressure or temperature will put it on a template. And myself and I think most of the doctors, we just do it as free text which is fine and it gets enough information to their own GP.”* (Interview 9, Clinical Lead, Primary Care)

*“In my experience most doctors do the same thing but I was teaching the nurses recently on abdominal examination and they do it in a totally different order. I was always told inspect and then palpate you know and then percuss and then listen. Whereas they would inspect and then listen and to me it was totally the wrong order but it was the one they were taught. So if they had it as a template presumably they would want it in their order rather than the order that we had.”* (Interview 9, Clinical Lead, Primary Care)

Some healthcare professionals were also forced to keep alternate sets of documentation due to the unavailability of notes when care was provided by more than one healthcare professional at one time, for example in different treatment rooms within an out patient department.

*“We dieticians keep two sets of records really, one in the patient’s medical notes and we have our own patient cards. We do that really only because we never reliably get the patients notes every time they come to see us.”* (Interview 13, Diabetes Dietician, Secondary Care)

An overview of how this might work for one patient was provided by a pharmacist who described working with many different sources of information, each of which was structured and stored differently.

*“The good old drug chart is you know our primary source of information, what we work with most commonly both on the ward, at ward level and down in pharmacy and that’s another paper record of course it will be replaced/partly replaced I don’t know what the plans are at the moment with e-prescribing but yeah the drug chart is our main record and I guess on an out-patient basis you can add to that you have the out-patient*

*prescription form which is another formal record and you know but when you think about it in terms of medication orders shall we say to use that broad term, there are all sorts of bits of paper floating around cause its not only the drug chart, there could be authorised prescription sheets which are stapled to the back of drug charts which are also used for something like, for example slide scale insulin prescription will be stapled to the back of it so supplementary information that may go along with that drug chart, the other records I've thought of as well that we use, again at ward level would be the patients end of bed notes so you've got the, at our trust there's the multidisciplinary health record which sits at the end of the bed which is completed when the patient has been clerked and then its mostly the nurses that use that to record their nursing notes."* (Interview 17, Pharmacist, Secondary Care)

Differences in practice were also observed between healthcare professionals in the same profession. Some of this was due to organisational structures which allowed for local variation in the absence of national guidelines.

*"Every ambulance service in the UK has a different patient record.....our patient record is very different to just about everybody else's because just about everybody else's is just a tick box, there's not much free text."* (Interview 26, Clinical Coding Manager, Unscheduled Care)

DH reporting requirements could be seen as key influencers in the structuring of information, i.e. if information was required for reporting it would be collected in a structured and/or coded format. The structure of medical records was also seen to be driven by the professional training provided. Structure was described as a tool to shape practice during consultations, for example in the provision of patient-centred diabetes and midwifery services:

*"We structure the consultation around eh eliciting the patient's agenda up front, adding our own agenda and then having a discussion and eh eliciting patient's goals for their treatment and then working out an action plan with them and deciding what follow up to do. And we've had discussion about whether you could template that onto the free text box or, or, or have some other you know template on there to prompt us to structure the consultation in that way. But in the event we've been using em well we all sort of, we've all had special training in this you see so it's becoming em natural to structure the consultation in that way."* (Interview 14, Diabetes Specialist Nurse, Secondary Care)

*"I've been a midwife for over 20 years and when I first started midwifery, the first booking appointment a women ended up with something called a Kerb Card which was an A4 piece of paper which sort of folded in on itself and that was just boxes and you filled in tiny writing that which basically said how she was at that current appointment, over time women have asked for more information plus we have to record more information from a litigation perspective and we want people, we don't want to have hospital and had held notes, they're the same thing really so the current booking appointment now, the notes are there for women, give them a lot of information and they're also there for staff so staff can see what was said before plus in those notes they've got everything they need to know i.e. all the results of their past blood tests and their past history so you're not having to keep asking the same question. So notes in a maternity perspective if used properly, are very informative for both the woman and healthcare professional." (Interview 15, Head of Midwifery, Secondary Care)*

*"We do use a lot of nationally accepted abbreviations although you, some people still slip in things that are like local and if you go between hospitals you still sometimes say "what does that mean" but we're trying to stop people using that because actually that's not good practice at all." (Interview 15, Head of Midwifery, Secondary Care)*

Within recently introduced professions such as nurse specialists and paramedics, participants recounted how professional training was linked to highly structured information gathering informed by protocols and guidelines for practice. As practice evolves these structures were also developing to reflect changes relating to issues around professional autonomy and control.

*"We now teach them a kind of...we call it sort of a modified medical model of recording information. So it's slightly more along the lines that you would get in hospital in terms of the structure of the record but kind of amended to our purposes if you like. And it's done to a greater and lesser degree. We don't kind of haul people over the coals if they don't record stuff in the medical model and we still have people who write very, very little which is never terribly useful. But we moved that way because, partly to reflect the fact that in recognising that practitioners are more autonomous." (Interview 26, Clinical Coding Manager, Unscheduled Care)*

*"We changed over from the records that we used to have which were like I say just very much tick boxes. Part of that's been driven by the fact that we have moved from...years ago in the ambulance service you had a set of protocols that you had to you know...you turn up at this particular patient, you have to do this, this and this and*

*on the record there is a set of tick boxes and aid memoirs to say to you you've got to do this, this and this. And now we moved to sort of guidelines and giving clinicians the opportunity for some clinical decision making of there own. And with that has become sort of more freedom to record information in a slightly different way."* (Interview 26, Clinical Coding Manager, Unscheduled Care)

In addition to the control inherent within documentation structures and IT system interfaces, we noted the overt control of medical records as a legal record of the clinical care provided. The structure of medical records was described in relation to the role of recording in the handling of complaints and investigations into practice. This was felt to be imperative for both individual practice and healthcare providers as employing organisations.

*"The standards we require in today's world because its litigation, it comes back down to litigation and we need to remind people of the levels of what they should be putting in there to protect them because there is nothing worse than going to court, the lawyers can pull, pick holes in everything and its cruel cause nobody comes to work to harm someone."* (Interview 15, Head of Midwifery, Secondary Care)

*"We see all these litigations coming in. The Trust asks us to copy case notes of all the litigation cases and some of the things that we're, you know, the litigation is about you can just see it, you know, you know what ones are going to go, you're training people to actually say this looks odd and immediately you say it looks odd you take legal advice and then they might be saying right we know that's going to go we need copies start the ball rolling and you can see a lot of it is to do with lack of communication, people not writing in case notes properly, people having no interest in their case notes so when a patient makes complaints, I mean the other side of it is complaints where people come in and say my mother hasn't been for three days which she probably was but nobody maybe has written in the case notes."* (Interview 16, Clinical Coding Manager, Secondary Care)

Given the importance of medical records within management information, secondary uses and medico-legal considerations, the structure within these records was designed to meet requirements for use beyond individual clinical care.

*"But because of the detail that's required at the moment its still paper and cause you've got to get the solicitor to accept electronic version."* (Interview 15, Head of Midwifery, Secondary Care)

Use beyond clinical care was a significant consideration when planning the information journey for medical records. It is to the use of medical records beyond clinical care, in relation to incentives and re-imbursement and secondary uses of data, that we now turn our attention.

### **5.3.3 Secondary uses**

The needs of those conducting secondary analysis, in contrast to the needs of those providing individual patient care, formed the topic for discussion for an expert discussion during the eHealth Masterclass. Key points from this discussion are summarised at Appendix 22.

#### ***The impact of incentives and reimbursement on structuring and coding***

One of the driving forces behind the structuring and/or coding of medical records related to the organisation of healthcare and the need to report on and account for activity to secure re-imbursement. We found this was achieved through two key mechanisms. The first was the Payment by Results (PbR) scheme, a rule-based system for paying secondary care providers from NHS funds. In the NHS, codes were chosen predominantly from International Classification of Disease, Version 10 (ICD-10) diagnostic coding terminology. In primary care coding was predominantly, but not exclusively determined by the requirements of the Quality and Outcomes Framework (QOF). This was the national primary care pay-for-performance scheme introduced in April 2004 as part of the new General Medical Services (GMS) contract. It was based upon Read coding within GP IT systems. This formed the topic for discussion for an expert discussion during the eHealth Masterclass. Key points from this discussion are summarised in Appendix 23.

Our study indicated that the structures and coding requirements of these payment schemes impacted upon coding practices and the collection of information within medical records in the UK over recent years. One participant described how this had evolved through her years of service:

*“It was there to provide, you know, a basis for audit, it was there for the statistical, for HES [hospital episode statistics] data, all of that type of thing and then originally when I came into the health service those were the sorts of things we were coding for. Payment by results means that we need to have much more richer information as well*

*because if we're picking up co morbidities it could well mean that it would push us into a higher HRG [Health Resource Group]."* (Interview 16, Clinical Coding Manager, Secondary Care)

*"We are also having to code a lot more things now than we have ever done... we have been given a whole ranch from the national coding people that we must code on every episode now, so things like living alone, things like diabetes, past histories of strokes, all sorts of things there that actually add to the severity of that particular person are now coded and that list is going to get bigger."* (Interview 16, Clinical Coding Manager, Secondary Care)

The clinical coding managers we interviewed described how their small teams of low-graded administrative staff were retrospectively coding inpatient episodes with significant financial consequences for their employing organisation.

*"I think I was told I'm responsible for something like 70+ million pounds, that's the horrible side of my job because it never used to be that, we never used to code for money purposes."* (Interview 16, Clinical Coding Manager, Secondary Care)

Although these staff were professionally qualified there seemed to be limited opportunities for career progression to build upon their specialist knowledge and poor local recognition of their skills. Clinical coding managers interviewed described limited contact with medical staff and each expressed similar experiences of hospital consultants being highly dismissive of clinical coding and coders, whom the consultants described as *'bean counters'*. Those clinicians who were engaged with issues around coding seemed to coding managers to be driven by their research interests or were seeking to influence their departmental incomes.

*"No the only codes we use is financial codes which is, so episodes of care are coded from a financial perspective and again that's the national agreed list and I can't remember what the initials are but a normal vaginal birth is a 3 letter code, a normal vaginal birth of a teenager is a different 3 letters and so there's a long list and that's how we get paid so that's the only coding we do."* (Interview 15, Head of Midwifery, Secondary Care)

In primary care, the impact of QOF as a method for re-imbursement was described to us by a senior employee within the NHS in England as a method of *'driving behaviours, but not sustaining them'*. This was a reason for year-on-year changes in the incentives

offered, which were not intended to indicate that previously incentivised practices were no longer required, but more to represent a cumulative drive towards quality of care. Our findings indicated the very significant role of coded data within processes to implement QOF and the profound effect this linkage between the drive to improve quality and re-imbursement had been felt to have upon the use of coding.

*“In some sense it’s great because you know you know who’s in the QOF and who’s out with the QOF. You know how you’re going to get paid. And you have to think very carefully about labelling people as well.”* (Interview 6, Researcher, Research Institute)

*“Don’t forget that GPs are small business people on the whole partners. I mean you might find that there’s a difference between salaried GPs actually and GP partners. You know I’m a salaried GP in a practice so it makes no difference...how I code something makes no difference to my income and I purposely have chosen to do that because I don’t like the idea of having how I work affecting what I earn and being influenced in that way. But you know certainly for partners anyway they you know they despite themselves people that I consider wouldn’t work that way within the practice that I work for example I do see them influenced, I do see them playing the QOF game in the way that they ask us all to code in order to meet their targets for QOF.”* (Interview 7, Researcher, Research Institute)

*“We’re trying to obviously the maximise the number of points we get on QOF cause anything that can help does, so [name] is very busy obviously looking why patients haven’t been reviewed or whatever I mean she does it throughout the year but it gets a bit more intense this time of the year because obviously well the state of play at the end of March that’s what we get paid on so doesn’t matter what happens throughout the year it’s the end of March so that’s that.”* (Interview 8, GP Practice Manager, Primary Care)

In primary care, clinical staff, particularly GP partners, tended to undertake coding in line with the perceived importance of the task, for example when coding was believed to have a direct impact upon income. We found that coding medical information was perceived as a function of resource allocation and this has in turn impacted upon perceptions of its use and application.

*“The bigger emphasis from a Trust point of view is obviously money and that’s not just this Trust it’s every Trust in the country. I’d still like to think that when I read a newspaper and it’s broken down about how many hernias are done and, you know, all*

*this, you know, wonderful medical information and how we do what that we've had an input into that. I like to think that what I do does affect patient care somewhere down the line that we can look at maybe changing services, changing our service delivery for specific groups of people who live in our community but that's me being me, but logically I know really that the biggest emphasis for people is about making sure we get funding and if we don't, you know, everybody looks to the coding team to make up a deficit."* (Interview 18, Clinical Coding Manager, Secondary Care)

These perceptions and attitudes towards coding seemed to be embedded within organisations and were perceived to impact upon clinical staff's willingness to engage with coding, and upon their perceptions of the functions and utility of coding. It seemed that clinical staff often did not see clinical coding as part of their job. Moreover, clinical codes were not seen as relevant to clinical practice, but rather as a retrospective process done for reimbursement purposes.

### ***Secondary uses of structured and/or coded information***

One area in which coding may be seen to support clinical practice is that of clinical audit.

*"There's quite a lot of work that goes on in terms of audit work and partly some research type work as well which involves data that we collect from patient records. So I'm in charge of the research programme and in charge of the clinical audit programme. And in terms of the clinical audit stuff, we have an annual work plan that encompasses the Trust priorities, anything that comes out of complaints and making experiences count and any kind of serious untoward incidents, that sort of thing."* (Interview 26, Clinical Coding Manager, Unscheduled Care)

Perceptions of the usefulness and availability of data seemed to vary greatly across clinical specialties and care settings. We found many examples of effective, locally developed IT systems that were providing useful information at a local level. Descriptions of these systems indicated pockets of knowledge and expertise where structured information was being used to improve clinical care. However, these systems were not always widely known and the benefits they offered were limited within small teams of enthusiasts. There appeared to be no national co-ordination of these initiatives nor natural forum for sharing best practice, resulting in an undue emphasise on word of mouth and professional networks to promote best practice and innovation.

Some data that was collected within healthcare systems was used at regional and national level by local and national bodies, for example primary care trusts (PCTs) and the English NHS HES service. Data were used to assist with service planning, audit, commissioning and research. This process appeared to be poorly understood by healthcare professionals working directly with patients other than in relation to reimbursement and related incentives.

*"I can't think of a single GP, even myself working as a GP wouldn't think about how it might be useful for research. No, it's entirely for clinical use, entirely for your own clinical use, for you and your other colleagues in your practice and for medic-legal purposes for recording what you've done and what you haven't done so recording important negatives. That's another thing that people didn't realise as well. Another key mistake that I've found that non-GP researchers have made is they don't appreciate that GPs record a lot of important negatives so they put. If they do look at free text for example, which some researchers do, they don't realise that people will often write no cough or no abdominal pain and they've got to make sure that they've counted for that."* (Interview 7, Researcher, Research Institute)

One practitioner described how they had challenged external requests for information:

*"One of the things we said right at the beginning of the clinical governance process was now guys commissioners, practitioners, academics we are not going to collect any data unless you can show us how it is going to be used and show us that it is useful not just for the time but in time in the future. And it's quite extraordinary, everybody said 'couldn't agree more' and so we then had the commissioners saying 'well I want this data collected' they said. Well tell us how you're going to use it and there was silence so we said we're not going to collect it and they said ok."* (Interview 4, Clinical Lead, Secondary Care)

A lack of awareness as to how data was used beyond immediate clinical care, together with a belief that commissioning bodies could *"pick up information any information they like basically on patients"* (Interview 8, GP Practice Manager, Primary Care) undermined the importance of structured data collection.

### 5.3.4 Examples of added value (benefit) from structuring and/or coding

In this final section of our findings we briefly consider specific examples of how the use of structuring and coding within medical records added value. As noted above, there were many examples of innovative practice in this area, but these were often domain-specific and not widely known beyond particular communities of practice. We did not seek to offer an exhaustive list of best practice, but rather considered practical examples of where increased levels of structuring and coding are making a positive impact on healthcare.

#### ***Increased productivity***

Drop-down boxes and prompts were in common use to prompt and offer reminders to support clinical decision making, for example in prescribing medications. These were very simple techniques that proved particularly useful for busy staff.

*“I was showing one doctor the other day, they typed virtually word for word what was there and I said ‘oh two clicks and the whole sentence would be there’ and they just weren’t aware of it. I think when people get in the habit because it’s a time saver and it also prompts you some of the more important questions to ask as well.”* (Interview 9, Clinical Lead, Primary Care)

*“I can think of a lady recently about 35 and I’d just forgotten, I’d given her antibiotics for a urinary infection and I’d just forgotten and she didn’t ask about it. But then I saw it on the pick list and I went outside and caught her in the car park and said ‘oh can I just check, are you on the pill?’ You know and it enabled me to...and it would have been very easy just to tick it and not do it but obviously it would have been unprofessional to do so.”* (Interview 9, Clinical Lead, Primary Care)

*“What we’d like ideally is some of the things that we do for Clinical Performance Indicators, we expect patients who have had a stroke to have a fast test taken and we say we don’t just want one, we want two. So what we’d expect is that if...in an electronic record if you type in the code for a stroke, that a little box pops up and says ‘bing have you thought about doing a fast test, have you thought about taking the patient’s blood pressure?’”* (Interview 26, Clinical Coding Manager, Unscheduled Care)

The use of structure was also seen to facilitate the reducing of employee time in data entry by allowing patients to input and validate data, for example in use of self-service kiosks as described above, or by automating data entry between devices.

*“What we also want is we want the...we have a variety of medical devices, ECG [electrocardiography] monitors, blood pressure monitors, things like that. Obviously from our point of view, if you’ve got an electronic blood pressure monitor or an ECG machine, you don’t want the paramedic to have to write down what you also want is that the tablet has the capacity to suck information in from those local devices. And so we’re also you know specking that that is part of what we want really. Is that it should be able to take information in from this device, that device so that we don’t then have to write it down. And actually so that it will be more contemporaneous and more accurate.”* (Interview 20, Clinical Improvement Officer/Paramedic, Unscheduled Care)

### ***Promoting patient-centred approaches to care***

We learned of information structures that had been used to promote patient-centred approaches to care and enable patient self-management, for example in the use of patient diaries and forms to collect information prior to consultation with a healthcare professional. This had particular importance in the management of long-term conditions such as diabetes.

*“I know that some local GP’s have changed their EMIS template to prompt them to put in patient’s agenda and self-management goal..... I mean we describe the patients eh moving from not self-management, managing to self-managing effectively as the patient journey and at the beginning they haven’t taken on board the concept at all, it’s very much you’re the doctor you tell me what to do, or the nurse tell me what to do. Em it’s, it’s nothing really to do with me, I’ll take the medication or I might not but you know. Em and the, it’s the same for clinicians so they may not be on board with the whole concept of supporting self-management and you can hook in some quite easily but some are thinking no, you know, the medical model suits me thanks you know and anyway patients they you know they, they need to be told what to do you know because what, what, well what are we here for if we’re not telling people what to do.”* (Interview 13, Diabetes Nurse Specialist, Secondary Care)

### ***Identifying patterns of disease***

Structured data was also shown to facilitate the identification of particular patterns and trends within patient populations, accelerating research into new conditions, drawing on and informing clinical practice. We noted a particular example of this in relation to the recent avian flu outbreak.

*"We were one of the first people to realise that the flu epidemic for instance last year, avian flu. The avian flu vaccine created havoc with people's anticoagulation. So we were able to actually say 'hey what have you done?' 'No I'm perfectly alright, I did have the flu vaccine'. And suddenly we twigged and we reported it."* (Interview 4, Clinical Lead, Secondary Care)

### **Redefining continuity of care**

It was noted by several participants that structured data was necessary to store information within EHRs to enable the sharing of medical records. A less discussed dimension and under-investigated consideration was the potential of EHRs to achieve improved quality of recording through structured data capture. In achieving consistent documentation and allowing holistic review of patient care, EHRs were suggested as a new form of continuity of care, allowing longitudinal review across treatment plans to make sure elements of clinical care were not missed as a result of multi-disciplinary treatment plans.

*"One of the things I used to feel passionately about was continuity of care and I assumed that seeing the same clinician was of vital importance to the patient, I thought they wanted that. But there's very interesting research shows that they actually don't require it as long as the practitioner they're seeing has the information about them, either in paper form or electronically so that they know about them and as long as the person is nice etc. they don't mind not seeing the same person."* (Interview 4, Clinical Lead, Secondary Care)

*"We try to make this user friendly so every consultation that takes place in the anticoagulant domain is captured. Now we have to keep that quite simple so that there's not reams of pages. So the structuring of collecting the INR, the blood tests today means that we've got that data, we've got that consultation that takes place. So that structure is actually very helpful for the practitioner and for the commissioner for the governance so everybody benefits from that. From the practitioner's perspective, when they go in in a month's time they can actually see the outcome of that consultation and the one before in terms of a chart and one can do it in other ways but just there's a chart. So that they can see how the person has been performing for the past three consultations but they can look further back if they want. So that's sort of structure. The other place where structure really is important, we're working on this now to kind of see how we can do it. One of the nightmares of running an anticoagulant clinic is that nobody takes responsibility, everybody assumes it's the other person. The*

*hospital assumes it's the GP, the GP assumes it's the hospital. Within the hospital, the practitioner, the cardiologist who referred the patient for anticoagulation presumes the haematology department will look after the on-going care including should the patient still be on the drug and it's a dangerous drug and the haematology say that's not part of our role, that's your role. So patients don't get reviewed."* (Interview 4, Clinical Lead, Secondary Care)

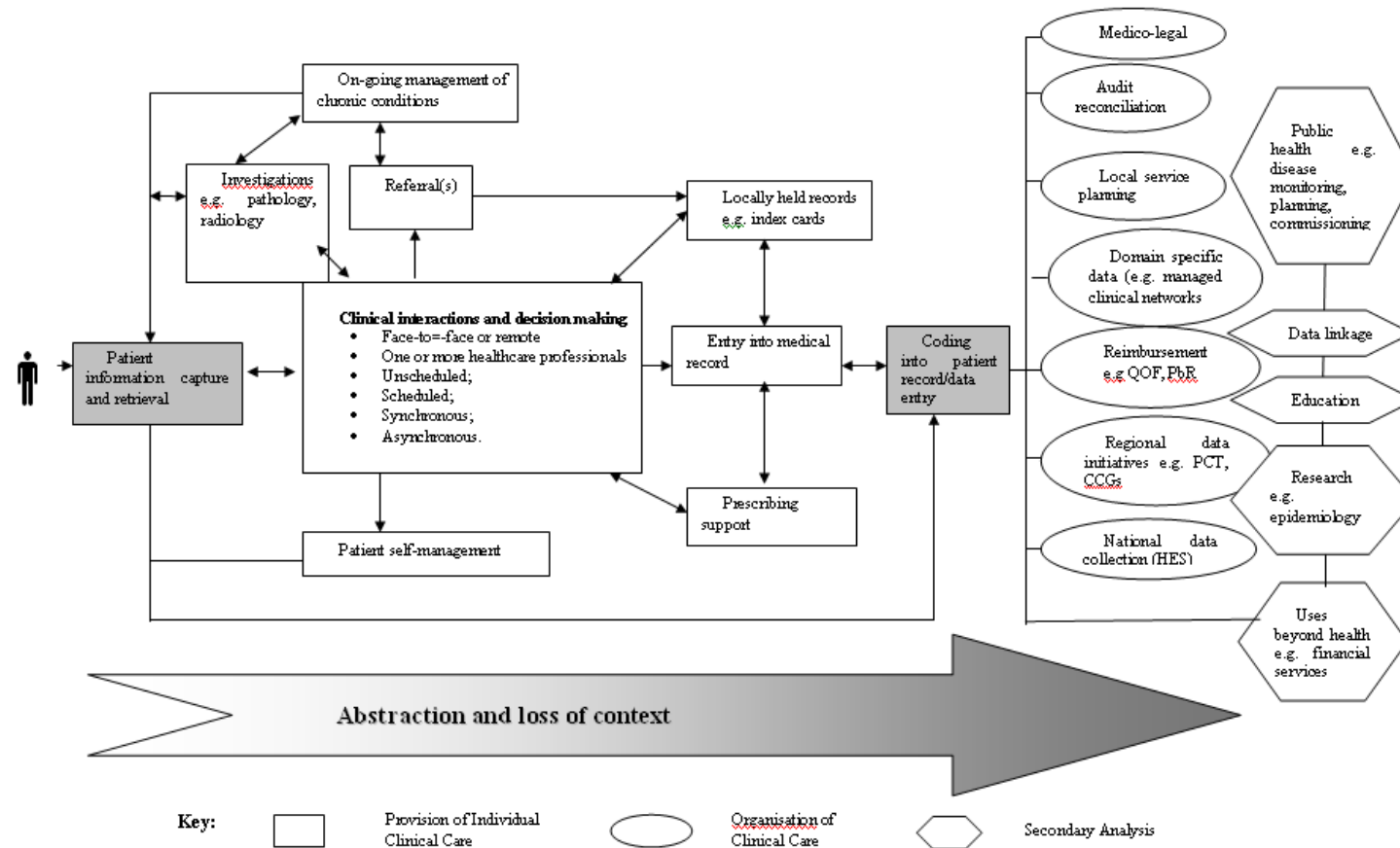
These were noted as particularly important capabilities given the formation of integrated care organisations. Boundaries were felt to be blurring between patients and practitioners, health and social care, research and practice. Structured information was noted as a possible new foundation to support these new landscapes of care.

## **5.4 Discussion**

### **5.4.1 Summary of main findings**

We observed information within medical records that had been collected within different context and interpreted for recording by healthcare professionals and/or those involved in retrospective coding. Participants described the interpretative processes undertaken when distilling complex information about patients into medical records; the impact of IT systems upon these processes; variations in documentation practices, including documentation as an imperative for medico-legal considerations; and concerns regarding the importance of contextual information and how structure may create a false impression of certainty. In considering these findings, we found it useful graphically to depict the collection, retrieval and use of information provided by patients for purposes related to healthcare and held within medical records. We used process mapping techniques (41) to identify the exchange of information between social and technological actors prior to, during and subsequent to the delivery of direct care. We conceptualised this as an information journey, as depicted in Figure 5.2.

Figure 5.2: Medical records and the information journey



#### **5.4.2 Strengths and limitations**

A key strength of this study is in the breadth of stakeholders perspectives considered. This has allowed us to explore the medical record as a co-constructed narrative influenced by both social and technical actors. A further strength of this study is its isolation of structuring and/or coding within medical records as a subject of qualitative enquiry. We noted that discussions about the recording and use of medical records were not commonly framed in terms of structuring and/or coding. Our findings indicated that, whilst structure was a major factor in the practice of collection and interpretation of information, it was not routinely discussed. Indeed, we spent time during data generation to reflect upon how we might frame our investigation using language and ideas familiar to participants. We suggest that our study may stimulate research attention and theoretically informed consideration of the increased use of structuring and/or coding within medical records, as implied within the development of EHRs systems worldwide.

A limitation of this study was our relatively small sample of patient participants. It was not possible to expand upon this within the time and resources available yet this is clearly a potentially rich line for further investigation. This investigation may take the form of further qualitative work, and also the development and trial of structure and/or coding based interventions to facilitate consistency in approaches to and content of patient communications.

#### **5.4.3 Exploring our findings in the light of the existing literature**

In considering a variety of stakeholder perspectives we have highlighted the extent of usage of the information collected during the provision of individual clinical care, including in the organisation of healthcare and for secondary uses relating both to healthcare and to domains beyond healthcare, such as population tracking and financial services. (as illustrated in Figure 5.2). With the exception of a few examples (such as prescribing decision support in general practice, and progress made as a result of increased coding within primary care), stakeholders reported that most of the gains thus far from structured and/or coded records had been for population health sciences (e.g. epidemiological research involving interrogation of large healthcare datasets, and use of NHS Health Episodes Statistics (HES) for planning), clinical

research and health service management purposes, or used for reimbursement (for example, the QOF).

Altmann and Michael (42) recently highlighted the challenges of providing information to a diverse range of healthcare providers, secondary use services, commissioners and patients. These challenges place an additional burden upon those working to provide direct care who may argue that healthcare professionals are populating treasure troves of information for the benefit of others. This is a potential barrier to change, particularly as only limited work has been done to consider the impact of this additional workload (for example de Lusignan (6), O'Dowd (7), Patel et al, (43), Karsh et al, (44)).

The association of clinical coding with reimbursement and performance management was found to have a detrimental impact on clinicians' perceptions as to the value and importance of structured and/or coded data collection. This indicates tensions between professional jurisdictions as considered by Waring and Currie (45). These tensions manifested in clinical coding managers' perception that medical staff were dismissive of information professionals working to code and use data within medical records. This was further exacerbated by the low grade allocated to qualified coding staff and particularly to the lack of a designated path for their professional development and career progression. Our findings indicated that perceptions around this were exacerbated by a lack of immediate benefits in support of clinical care, such as decision-support to reduce diagnostic error, and a failure to provide audit information to support individual clinicians, such as record keeping for CPD and appraisal. The introduction of computerised systems requesting clinical staff to choose from codes and lists as part of structured data entry may well contribute to the blurring of boundaries between quality driven re-imbursement and the provision of clinical care, to achieve both direct patient benefit and effective resource allocation. However, the implementation of systems such as this will need to overcome these common perceptions regarding the function of coded data if they are to be successful. Thus relevance of coded data must be established in direct and meaningful relation to an individuals' professional practice rather than simple '*bean counting*'. This suggests that the benefits of structured data information must be communicated to healthcare professionals in a compelling way that demonstrates relevant, tangible benefit which healthcare professionals can use to inform and develop their own practice.

We found that the collection of highly personal information for the medical record is an intimate process for both the healthcare professional and the patient. Whilst structured and/or coded information can support decision-making by use of formal logic to order information (2, 4), our findings indicated that the exchange of information during clinical care is a highly interpretative process that draws on personal relationships, supporting previous work to consider the importance of tacit knowledge and intuitive understanding within clinical decision-making (3). Indeed, our findings support work done to consider the impact of contextual factors and ambiguity upon an individual professional's decision-making not only about the information received, but what takes priority within that information and how it is to be accounted for (5). This highlights the importance of the clinical narrative as a source of information to support decision-making (53, 54). Some clinical participants expressed the concern that, given the contingent nature of clinical processes, any increased use of structuring and /or coding should respect patient and clinician individuality and non-standard outcomes. This indicates that any increase in the use of structure and/or coding and consequent standardisation of data collection and storage should, in so far as is possible, take into account both anticipated and unanticipated benefits and risks. We suggest that, wherever possible, increases should therefore be subject to empirical assessment.

Many of the healthcare professionals and administrative staff interviewed shared with us insights into their locally derived systems and processes which were dependent upon the increased use of structuring and/or coding information. Many of these had been derived as a result of systems shortcomings (e.g. lack of functionality or lack of physical access) and were considered necessary tools for getting the job done. They included basic paper-based systems (such as the use of index cards for repeatedly accessed patient information) and locally authored documents (such as Excel spreadsheets). The proliferation of local systems would seem to support work considering the flexibility of paper-based systems and the advantages of small scale EHRs (46-49). This is also consistent with the bodies of literature considered for review in Chapters 3 and 4 of this report, much of which described the small scale use of tools and techniques to structure information within specific clinics or specialties. Given that many of these studies do not isolate structuring and/or coding for investigation much of this learning is difficult to capture in relation to the subjects investigated here.

The proliferation of locally derived systems also indicated a mismatch between useful structures to support working practices and information requirements, and available IT systems or any form of EHR. These locally derived structures seemed highly personalised and subject to inconsistencies of practice due to their informal nature. This was particularly true where locum staff or those under going rotational training were being asked to adapt to local nuances of practice. Consequently these informal local practices present the potential for significant duplication of effort (for example entering information in more than one system, and in training new staff adopt practices peculiar to a particular department or location) and increased potential for human error (for example when retrospectively transferring patient information from paper to computer, losing index cards and so forth).

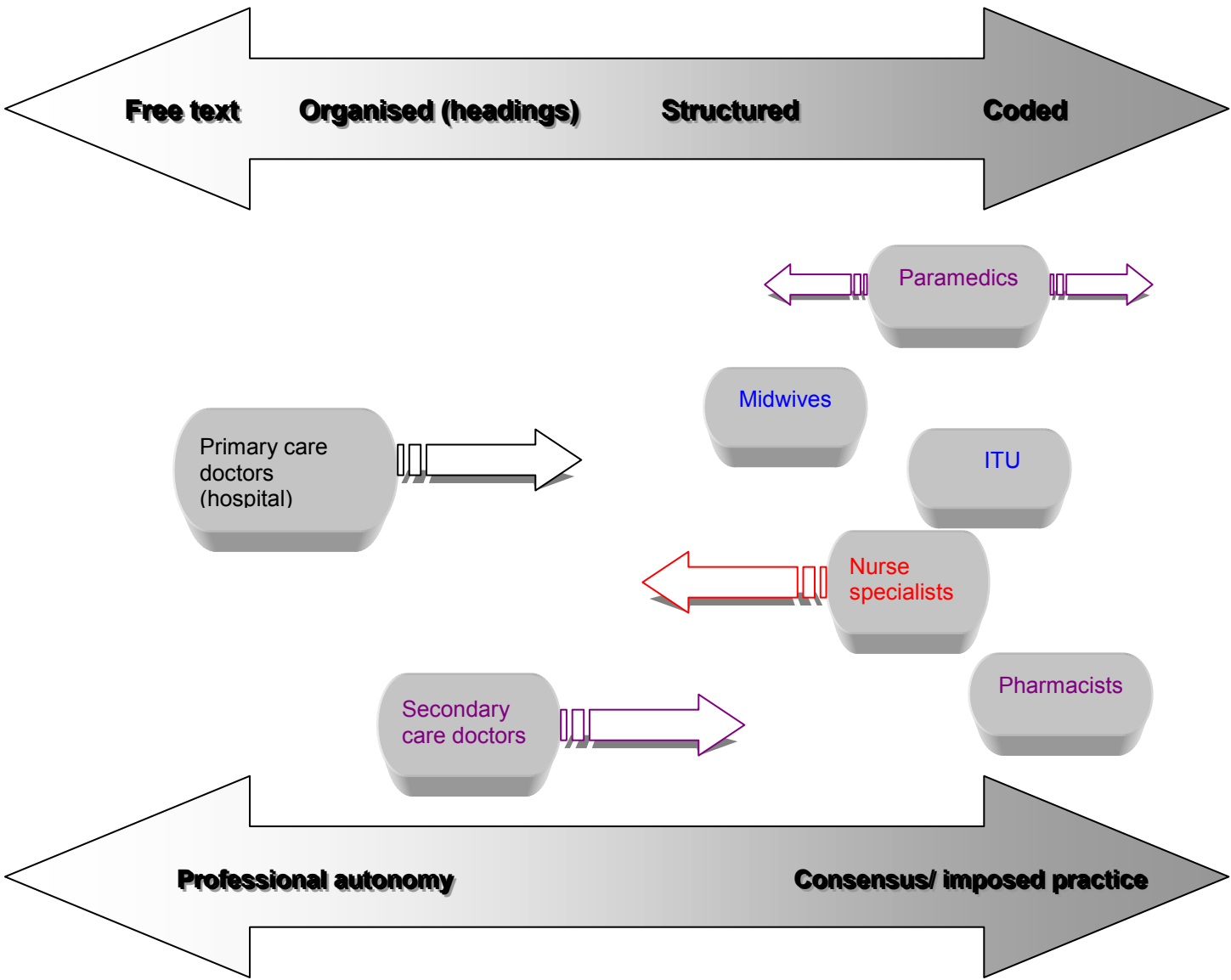
Further variations in practice were found between professional communities, for example between physical locations and care settings. This presents a challenge to ideas of homogenous bodies of uniform professional practice. It also indicates that some of the issues attributed to the use of paper based records, such as inconsistent content and difficulties in sharing and comparing records (50-52), may not be fully addressed by the introduction of EHRs. These variations may be due for example to an absence of professional guidelines, locally determined protocols, organisation-specific requirements, commissioning and audit requirements, and medical-legal considerations.

Structured data entry using templates was found to be well established amongst administrative staff and certain groups of healthcare professionals, particularly where guidelines and protocols had been used to develop and standardise professional practice, for example in midwifery, paramedic services and specialist nursing. For other clinicians, particularly doctors, practice was more commonly found to be based on capturing information in free text formats. Here, the use of templates was less usual and appeared less acceptable. Thus the use of structuring and/or coding in medical records was found to be influenced by professional identity, levels of autonomy in clinical decision-making and mandated standardisation of care. These variations across professional stakeholder groups are illustrated in Figure 5.3. They illustrate that, whilst increased use of structuring and/or coding may standardise how information is stored and exchanged there are still important nuances of interpretation and understanding within and between different stakeholder groups, which are of

themselves important and valuable. These nuances of interpretation and understanding warrant further consideration as many assumptions regarding a common approach to the collation, comprehension and understanding of structured information underpin the anticipated benefits of shared EHRs (55, 56).

We noted specific and relevant examples of immediate value to be gained from the increased use of structuring and/or coding within medical records. These examples evidenced possible productivity gains in terms of the use of clinician time and clinic attendance, the promotion of patient-centred approaches to care, more immediate identification of patterns of disease, and the possibility for new forms of continuity of care. The most common tools to support structured and coded records were found to be digital templates and/or pick lists of pre-selected clinical terms. Although clinicians tended to find these irritating, they had the potential to be useful as a reminder (i.e. a prompt) during a consultation, as well as for improving the completeness of data entry. This is an area where it would seem secondary care could learn from other care settings, in the documentation of remote consultations by telephone and email, for example NHS 24.

Figure 5.3: Healthcare professionals’ use of structuring and coding in the medical record



A novel, unanticipated finding related to the lack of consistency in approaches in communicating with patients, both in relation to how this was done and what was communicated. This is an important consideration given the policy recommendations within the recent NHS information revolution consultation (8). This lack of structure in communications with patients was found to be a barrier to encouraging and enabling patient understanding of and engagement in their own healthcare. It was also found to be an additional burden upon clinician time as patients described their booking of clinic appointments for the purpose of having medical correspondence explained. We identified significant potential for the trial and introduction of more structured feedback to patients (e.g. through charts and diagrams) to improve the accessibility of this information for patients and carers.

In our introduction we noted the significance of the inclusion of patients within the designated group sharing both authorship and readership of medical records intended for professional audiences (15). The preliminary discussions with patients undertaken within this study highlight both the importance of medical records and the difficulties they currently present for patients. This may well present a new challenge to the dominance of biomedical models of recording and a resurgence of interest in alternate models, for example POMR (19), the inclusion of patient stories (23 -23) and combined approaches (24), and new approaches. Given what we know of the impact of the reform of medical records as a major catalyst for reform of medical care the consequences of patient-focused approaches to documentation may only be evident in the long-term.

#### **5.4.4 Conclusions**

Our study has identified a number of notable benefits from the increased use of structuring and/or coding within medical records. An area for immediate gains is the reduction of duplication and potential for error within clinical processes (for example the reduction of diagnostic errors). We also learned of actual and potential productivity gains in terms of the use of clinician time (for example in increased patient understanding leading to a reduction in the number of consultations and increased self-management of long-term conditions). The increased use of structuring and/or coding lends itself to the promotion of patient-centred approaches to care (for example in the use of templates and pro-formas, prompts and alerts) and the possibility of new forms of continuity of care across clinical and social care settings. An immediate and

important benefit of the increased use of structure relates to the more immediate identification of patterns of disease, including the prompt identification of factors influencing epidemic. In addition to these identified benefits, we note the possibility of unintended consequences of more structured information within healthcare, such as the possible de-personalisation of care and unintended impacts upon clinician/patient interactions. Given the potential benefits and risks, recommendations relating to different levels of structuring and coding medical records should be isolated for empirical investigation to allow evidence-based implementation focusing on outcomes and benefits.

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## Chapter 6

### **“The trouble is that allergy, you know, is a very...widely used and misused word”: exploring structuring and coding considerations in relation to reducing the risk of repeat allergic reactions to drugs**

#### **Abstract**

**Background:** Adverse drug reactions are responsible for significant morbidity and, in some cases, may also result in mortality. The risk of recurrence of preventable adverse drug reactions – which include the majority of allergic drug reactions – may be reduced by use of computerised decision support systems, also sometimes known as ePrescribing systems. These decision support tools are dependent on the availability of computable data.

**Aims and objectives:** We sought to understand approaches taken to structure and/or code adverse drug reactions and drug allergy and to explore the views and opinions of a range of healthcare staff on how current practices could be improved with a view to enhancing patient safety.

**Methods:** Qualitative case study involving interviews with a purposefully selected group of stakeholders with an interest in adverse drug reactions and general practitioners (GPs), on-site observations of computerised recording of adverse drug reactions and a group discussion with the Allergy and Respiratory Expert Resource Group of the Royal College of General Practitioners (RCGP). Supporting documents were identified and reviewed. Data were thematically analysed.

**Results:** We undertook 21 interviews, had a discussion group involving 15 participants, undertook four observations and reviewed 19 documents. The main themes related to: approaches to recording information on drug allergies; the extent of coding; the usefulness of coding (benefits); the risks of coding; and the influence of contextual considerations. Most adverse drug reactions were likely to be unrecognised and even then not all recognised reactions were recorded. This was in part due to difficulties associated with diagnosing drug allergies. Information recorded may not have been

accurate and, if so, may potentially have compromised patient safety. Furthermore, the process of documenting adverse drug reactions was found not to be standardised. More information was generally collected in primary care than in secondary care, but this varied by context. There was some training offered on how to record adverse drug reactions in electronic systems in secondary care, but not in primary care. The use of templates in electronic health records (EHRs) was the main approach to structuring and coding this information. There were important differences in how this information was recorded in primary and secondary care, these having knock-on implications for sharing this information. There were important perceived benefits of structuring and coding of this information, particularly the opportunity to make use of computerised prescribing decision support, but also for pharmaco-vigilance and research. We found evidence that electronic Yellow Cards were being integrated into prescribing modules in GP clinical systems.

**Conclusions:** There is widespread acceptance among healthcare professionals of the need for accurate coding of adverse drug reactions, such that financial incentives are largely irrelevant. There is a considerable amount of coding carried out at present in the National Health Service (NHS) (at least in primary care), but the fact that it is undertaken does not necessarily enable optimal leverage of decision support systems; rather, the difficulties in accurate coding in some instances introduced new problems. This case study has highlighted the importance of wider contextual considerations such as ambiguity of clinical diagnosis, the extent of diagnostic certainty/uncertainty and the inability to resolve this due to a lack of diagnostic facilities and the inadequacy of current coding terms. Healthcare professionals recognise the importance of coding information in relation to adverse drug reactions, but find accurate diagnosis is difficult due largely to the lack of capacity for testing. There is as yet no formally agreed dataset for recording adverse drug reactions. An attempt should be made in the first instance to develop a maximum dataset (also sometimes known as an archetype) from which subsets of data appropriate for different situations could be compiled for designing structured data entry templates in each situation. We propose effort be made to improve professional standards in diagnosis, documentation and reporting of adverse drug reactions and further research on developing maximal data sets and situation specific data subsets and capacity for testing. Given this professional buy-in, the already substantial coding and the opportunity to share coded data throughout the NHS (via the Summary Care Record (SCR)), this represents an area that is ripe for further work.

## 6.1 Background

Adverse drug reactions now account for an estimated 6.5% of hospital admissions in the United Kingdom (UK) (1). The risk of one or more adverse drug reactions as a result of drugs initiated at the time of admission to the hospital or continued in hospital has been estimated at 14.7%, of which just over half are judged to be possibly or definitely avoidable (2). An estimated 0.7-2.3% of deaths following adult emergency admissions with adverse events are attributed to treatment in primary care (3). Adverse drug reactions – including drug allergy – need to be documented for direct patient care: that is to inform future prescribing decisions. Clinical decision support systems (CDSS) have the potential to reduce future adverse drug and drug allergic reactions when this information is structured and/or coded, thereby rendering these data computable (see Chapter 1). (4) Adverse drug reactions are reported spontaneously by healthcare professionals and now also by patients to the Medicines and Healthcare Products Regulatory Authorities (MHRA) using Yellow Cards (5). In this case, the data need to be shared with the same meaning (i.e. semantic interoperability; see Chapter 1). Drug allergy and adverse drug reaction information, irrespective of the purpose for which it was recorded is likely in the future to have a range of important secondary uses (6, 7). Although a strong case can thus be made for structuring and/or coding of drug allergy and adverse drug reaction information, the amount of computable and sharable information currently available is thought to be less than desired.

An adverse drug reaction is defined as any harmful or unpleasant reaction resulting from an intervention related to the use of a medical product, which predicts hazard from the future administration and warrants prevention or specific treatment, or alteration of the dosage regimen, or withholding the product (8). The terms “adverse reaction” and “adverse effect” are closely inter-related: an adverse effect is seen from the point of view of the drug, whereas an adverse reaction is seen from the point of view of the patient. The term adverse effect (which is the preferred term) encompasses all unwanted effects (e.g. “side-effect”, “toxic effect”); it makes no assumptions about mechanism, evokes no ambiguity, and avoids the risk of misclassification. The pharmacological classification of adverse drug reactions for which causality has been established currently rests on the perceived dose dependence and predictability of the adverse reaction (9). A Type A reaction is dose dependent and predictable from

pharmacology of the drug (available in the drug knowledge-base in a computer system) whereas a Type B reaction is not dose dependent and is therefore unpredictable. Although logical and at face value simple, use of this classification system is often problematic in practice. For instance, dose dependent nausea and vomiting (Type A) associated with erythromycin use is liable to recur with repeat use, but this can also be classified as a Type B reaction because it is not pharmacologically predictable. This Type A / Type B classification is based on the properties of the drug – its pharmacology and the dose dependence of its effects. However, Aronson and Farmer proposed that other criteria should be taken into account in the classification, including properties of the reaction (i.e. time course and severity) and properties of the individual (i.e. genetic, pathological and other biological differences that confer susceptibility). They proposed a three-dimensional classification based on dose relatedness, timing and patient susceptibility (DoTS) (9). This is how most pharmacologists characterise adverse drug reactions, which provides insights into how adverse drug reactions may be more meaningfully documented.

Recognition of drug allergy or adverse drug reaction (diagnosis) is the first stage of the documentation process. Often this diagnosis is not easy. Instruments to help diagnose drug hypersensitivity have been developed (10). Similarly, Cantrill and Cottrell have used an eight item questionnaire to identify drug allergy (Table 6.1) (11). Two simple questions: “Have any medicines or tablets ever disagreed with you or caused an allergy?” and “Are you able to take aspirin or penicillin?” have been shown to be reasonably specific for detecting adverse drug reactions (12).

**Table 6.1: Questionnaire to identify drug allergy (11)**

- |  |
|--|
| <ol style="list-style-type: none"><li>1. a. Have you ever taken any drugs or tablets that have disagreed with you or caused an allergy?<br/>b. If yes, can you remember the name(s) of these drugs?</li><li>2. Can you describe the reaction that you had?</li><li>3. Did you take the drug by mouth (as a tablet or medicine), or was it an injection?</li><li>4. How soon after starting the drug did the reaction happen?</li><li>5. How long ago did this happen?</li><li>6. Did anyone tell you it was an <i>allergic</i> reaction, or did you decide for yourself?</li><li>7. a. Have you ever taken this drug, or similar one, again?<br/>b. If yes, did you experience the same problems?</li><li>8. Have you told the doctors or nurses about your reaction or allergy?</li></ol> |
|--|

A single record of drug allergy or adverse drug reaction can consist of many facets of information that have the potential to be documented: for example, the name of the drug, a description of the reaction, its severity, the certainty of the diagnosis, and co-factors such as other drugs taken and the health situation at the time. There are information models for recording drug allergy and adverse drug reactions that are under development such as the Australian Adverse Reaction: Detailed Clinical Model Specification by National E-Health Transition Authority (NEHTA) (13) and the Compound Healthcare Headings Packets being developed by the NHS Scotland Data Recording Advisory Service. This issue of documenting drug allergy and adverse drug reactions has also been studied in relation to EHRs in the NHS (14-16). There is design guidance for recording adverse drug reaction risks in EHRs (17), and recommendations for recording drug allergy in GP computer systems are available (18). Documentation of suspected adverse drug reactions for reporting to regulatory authorities is a different scenario to that of direct patient care. In the former, a detailed documentation of adverse drug reaction as an event is required while in the latter scenario, recording of the same as a risk (or propensity) is required.

Notwithstanding the above developmental work, there is a need for further detailed enquiry into this issue for the following reasons:

- The current low levels of documentation of drug allergy and adverse drug reactions by healthcare professionals in some clinical settings;
- This information needs to be recorded in system specific way in order to enable;

- Decision support features;
- Multiple coding systems are used to code drug allergy and adverse drug reactions making data aggregation challenging;
- The impact of recording this information electronically has not been fully explored;
- In order to understand how functionality in electronic systems determines how information is recorded (19);
- Drug allergy and adverse drug reaction information is now a core component of shared record summaries, in particular the SCR in England (and its equivalent in other countries), hence the additional importance of comprehensive, accurate and interpretable information being shared across the NHS;
- Drug allergy and adverse drug reaction information in different clinical systems is not interoperable because of different coding systems used; coded information is degraded to free-text during messaging (18).

This case study sought to explore how drug allergy and adverse drug reactions are recorded in EHRs or spontaneously reported electronically and why particular approaches have been adopted.

## **6.2 Methods**

### **6.2.1 Design**

The sociotechnical dimensions of eHealth interventions are poorly understood and inadequately investigated, even though it is known that such factors play a crucial role in the successful adoption of IT innovation (20, 21). Structuring and/or coding of drug allergy and adverse drug reactions is no exception and a case study-based approach was therefore used to explore the current practice of documentation of drug allergy and adverse drug reactions (see Chapter 2). The process of documenting drug allergy and adverse drug reactions electronically, and the value derived from the documentation, was conceptualised as the case and this was studied using a combination of in-depth interviews, documentary analysis and observations.

### **6.2.2 Sampling and recruitment**

Initially interviewees were selected from a group of people whom the team was aware had an interest or expertise in drug allergy and/or adverse drug reactions. We then snowballed from this initial sample on the basis of suggestions made by interviewees. Potential interviewees were sent an email invitation that included information about the evaluation in general and this case study in particular and a consent form. A single email reminder was sent to those who did not respond to the initial invitation after three weeks.

Qualitative data were collected from a cross-section of stakeholder roles that represented multiple scenarios of drug allergy and adverse drug reaction documentation or reporting, such as general practitioners (GPs), pharmacists, pharmacologists, nurses and hospital consultants. Five GP practices were recruited with the support of the South East Primary Care Research Network for site visits. GP practices with different clinical systems were selected for the site visits as the most developed recording systems were available in primary care. Telephone interviews with this purposefully selected sample of stakeholders were carried out by a single researcher. Verbal consent for recording was always asked for and recorded, and additionally the signed consents received were filed with the digital interview file and transcript.

### **6.2.3 Data generation and handling**

Interviews were the principal data source. We developed and used a topic guide (Table 6.2) to support the interview discussions. Interviews and observations were undertaken during site visits to the GP practices. Semi-structured interviews were employed to elicit views and practices of documentation of drug allergy and adverse drug reactions. In addition, observations of drug allergy and adverse drug reaction recording in EHRs were made during site visits. A group discussion was held on approaches to accurate code for allergy with members of the RCGP's Allergy and Respiratory Expert Resource Group in November 2010. The literature on documentation (18), messaging of drug allergy and adverse drug reactions (14) and design of computer systems to facilitate safe and efficient recording was reviewed (13,16,17).

**Table 6.2: Topic guide for interviews**

<b>Main structure</b>	<b>Specific topics and issues</b>
Introductions, permissions, confidentiality, thanks	Background to the work. Documentation, structuring, coding, drug allergy, adverse drug reactions, electronic records. Consent to record interviews was obtained
<b><i>Any questions?</i></b>	
About yourself	Role description, experience, systems used
In what ways does the interviewee presently capture and store drug allergy and adverse drug reaction information, for what purposes and for whose benefit/use?	Modified according to the role. If the interviewee was a primarily a user of structured or coded information, then the opinion on how information is/should be recorded was asked.
What are the main drivers for structuring this category of clinical information?	This was often indirectly discussed.
If structures (templates, forms, tables, checklists etc.) are used, are they standardised/shared, or ad hoc?	This was specifically asked whenever it was relevant to the role
How completely do the structures (templates/forms) cover what users feel needs to be recorded, in terms of completeness and accuracy and in terms of enabling good use of the information?	Accuracy and completeness of recorded information
Are there areas where the available structures (templates/forms) need to be improved?	A discussion on how drug allergy and adverse drug reactions are recorded in practice. The challenges faced. Positive features and facilitators
Are there examples of drug allergy and adverse drug reactions which are difficult to record well in any structured format?	Issues relating to identification of drug allergy and adverse drug reactions
Which uses of the structured drug allergy and adverse drug reaction information are successful?	How structured information is currently used

Main structure	Specific topics and issues
What impact does the use of structures (templates/forms/codes) have on clinical care and outcomes, or on patient experience and engagement?	This question was asked if and when relevant to the role
Are there potential uses of the information that are under-exploited, and if so, why?	
Which drug allergy or adverse drug reactions are useful and important to encode, and why?	Discussion on commonly structured/coded adverse drug reactions or drug allergy
Do the available terminology systems adequately cater for what needs to be recorded, in terms of completeness and accuracy and in terms of enabling good use of the information?	Coding systems used were discussed
Are there example situations in which it is difficult to record the relevant drug allergy and adverse drug reactions using terminology/codes?	Challenging scenarios of documentation
Which uses of the coded drug allergy and adverse drug reaction information are successful?	How drug allergy and adverse drug reaction information is currently used
What impact does the use of terminology have on clinical care and outcomes, or on patient experience and engagement?	
How well do the available clinical systems support structuring and/or encoding this information?	Usability of systems
Are there any other barriers to collecting good quality drug allergy and adverse drug reaction information?	
Are there any drivers or incentives that would improve the quality or uses made of this category of information?	The place of incentives was discussed
How accurate/complete is recording of	Accuracy of recorded information

<b>Main structure</b>	<b>Specific topics and issues</b>
drug allergy/adverse drug reactions?	discussed
What factors determine/contribute to completeness and accuracy of drug allergy/adverse drug reaction recording	The barriers to recording
<b><i>Concluding remarks</i></b>	
Anything else?	
Thanks and any questions?	
Anyone else can be recommended for interview?	
Any relevant literature?	

Interviews were professionally transcribed and checked by the researcher for any errors, which were corrected.

#### **6.2.4 Analysis**

Data collection and analysis took place concurrently allowing us to modify the topic guide for the future interviews. Transcribed data from interviews, the observations and field-notes from the discussion group were read repeatedly by one researcher, and emerging themes were identified and categorised manually for analysis. The main themes emerging were judged to be converging towards saturation. Results were discussed with the wider team where alternative explanations for the findings and emerging themes were explored in detail.

### **6.3 Results**

The final dataset consisted of 21 interviews, four site visits, one discussion group involving 15 people and 19 documents. The full data set is summarised in Table 6.3 and details about the interviewees are given in Table 6.4.

**Table 6.3: A summary of the full dataset**

<b>Data source</b>	<b>Number</b>
Face to face interviews	4
Telephone interviews	17
Discussion group participants	15
Documents reviewed	19

The secondary care interviews consisted of a consultant anaesthetist, three consultant pharmacologists, one hospital doctor, one consultant paediatrician and two senior pharmacists. The primary care interviews included eight GPs and a practice nurse. In addition, one industry/international expert, one manager from the MHRA, a manager from the General Practice Research Database (GPRD) and a pharmacist/informatics PhD student.

**Table 6.4: Descriptors of interview participants**

	<b>Role</b>	<b>Description</b>
1	GP	Interest in allergy and immunology
2	Pharmacist	Director of pharmacy, secondary care, ePrescribing
3	Hospital consultant	Pharmacologist. ePprescribing
4	GP	Expert in prescribing safety, academic
5	Practice nurse	Allergy testing and policy
6	Anaesthetist	Anaphylaxis,
7	Pharmacist	Hospital, head of department, e-prescribing system deployment
8	Pharmacologist	Expert on adverse drug reactions, academic
9	Pharmacologist	Expert on adverse drug reactions, academic
10	Hospital doctor	Allergy and immunology
11	GP	Salaried and part-time, academic, no special interest on adverse drug reaction recording
12	Pharmacist	Informatics, standards, drug database development, PhD student
13	Industry expert	Legal and international context

	Role	Description
14	Paediatrician	Secondary care, interest on adverse drug events
15	Manager	Pharmacovigilance, MHRA
16	Manager	GPRD
17	GP	Modelling adverse drug reactions information for computer storage

### 6.3.1 Approaches to recording information on drug allergies

Documentation of drug allergy and adverse drug reactions before coding was the norm except when templates or pick list of terms were used for coding. In primary care, all GPs interviewed (n=8) preferred to document drug allergy and adverse drug reactions in the electronic record themselves rather than delegate this responsibility to other members of the team. This was because GPs recognised the importance of accurately documenting this information.

*“...it would be the doctors themselves who would record it and would probably record the vast majority of the drug allergies simply because I’m the only full time doctor here.”*  
(Interview 11, GP on a site visit)

*“...I feel it is very important issue to record patient’s allergy and it has to be 100% accurate therefore I thought that it is my role as a clinician to enter all the allergy, and take sole responsibility for entering, and to date nobody else enters allergy but me.”*  
(Interview 11, GP on a site visit)

In hospitals, doctors’ nurses and pharmacists documented drug allergy and adverse drug reactions in electronic prescribing systems when available.

*“...at [hospital X] it’s [recording] [by] medics and pharmacists.”* (Interview 7, Senior pharmacist)

*“Absolutely the current situation is a combination of different healthcare professionals. Basically nursing staff, medical staff, and pharmacy staff can record allergies and adverse reactions on our system. Probably the nursing record the highest percentage*

*followed by pharmacists and then by medical staff.”* (Interview 2, Director of Pharmacy, Secondary care)

*“Elsewhere I have worked with electronic prescribing; nursing staff have also recorded information. And that led to particular problems when you think about things like diarrhoea and so on with penicillin. That’s not an allergy, clearly.”* (Interview 2, Director of Pharmacy, Secondary care)

The recording of drug allergy and adverse drug reactions was reported as often being inadequate and incomplete:

*“Well I think the biggest challenge is first of all whether it is recorded.”* (Interview 8, Senior Academic Pharmacologist)

*“I think it’s actually the documentation is actually quite poor, allergies and adverse reactions. And one reason for that is that there’s not a single record....most patients’ have multiple records and the information isn’t consistent across the records”.* (Interview 6, Consultant Anaesthetist, Secondary care)

Recognition of drug allergy and adverse drug reactions was considered difficult. None of the interviewees reported that they used scoring tools (10) to help identify drug allergy or adverse drug reactions. Taking a detailed history was, however, considered to be very important and this was therefore the preferred approach to diagnosis.

*“...I always tell my...students when I teach them on adverse drug reactions is that if a patient develops any new symptoms following start of a drug, make sure that you have adverse reaction of the drug in your list of differential diagnosis.”* (Interview 9, Senior Academic Pharmacologist)

Healthcare professionals often had difficulties in distinguishing between allergies, adverse drug reactions, intolerances and side-effects.

*“A lot of clinical staff struggles to make a difference between allergy adverse drug reactions.”* (Interview 7, Head of Pharmacy, Secondary care)

What was documented was almost always a suspected drug allergy/adverse drug reaction, this reflecting the lack of capacity for diagnostic testing in the NHS. Therefore, in the coded record, it was often not possible to distinguish between confirmed diagnoses and the majority of suspected reactions. “Drug allergy” was thus in some respects a widely used and misused term. Hence adverse drug reactions were often incorrectly recorded as drug allergy with unintended consequences.

*“The trouble is that allergy you know is a very you know widely used and misused word. You know a lot of people who have an adverse drug reaction you know believe that it’s an allergy but of course it isn’t in true terms, true immunological terms an allergy.”* (Interview 8, Senior Academic Pharmacologist)

*“The trouble is if the...there can be a downside to that in that if people are recorded as having adverse reactions to drugs which they haven’t in fact had an adverse drug reaction to then you know that can prevent a potentially important treatment being given to patients. You know you think of patients who are wrongly recorded as being allergic to penicillin not then being given penicillin when it’s clearly the best treatment on a future occasion.”* (Interview 8, Senior Academic Pharmacologist)

GPs were divided in their views on editing or removing incorrect records. Some GPs deleted incorrect drug allergy records to prevent false alerts, while others argued against it.

*“I do remove because otherwise we get a warning every time which isn’t necessary because it’s no longer valid.”* (Interview 11, GP on a site visit)

*“I do have a dilemma of removing it because at the time it was a valid problem so I’m not removing an historic problem even though it’s not valid now but it was important at the time of but there’s no other way around that.”*  
(Interview 4, GP)

Templates were commonly used for structured data entry, and data entry fields were bound to pre-assigned clinical codes. Therefore, when templates were used, clinical coding was a background and invisible activity. Templates served two functions: they helped ensuring completeness; and they structured the information displayed.

However, there were advantages and disadvantages in using templates. The advantages were the quick and easy entry and the automatic coding of data. One of the main disadvantages, however, was the limited opportunity for faithful representation:

*“...I think sometimes it forces you to adapt your history to fit the boxes. But at the same time in lots of ways I think it is better to have structure because otherwise everyone will be putting very different things down and some people may record information than others so that at least it gives a sort of minimum level of information.”* (Interview 11, GP on a site visit)

Severity of reaction can be documented in some templates, but one interviewee felt that it was not necessary. However, the dose at which the reaction occurred could be particularly relevant. In some hospital systems, the presence of drug allergy was not coded and this information could only be displayed back to the user as it was typed in, but it could not be used computationally.

*“And if they have no known drug allergies then that’s the one entry that’s codified. So basically when they go on to the allergy recording screen, if they’ve no known drug allergies they can select that automatically. But if they have an allergy or an adverse reaction then they then they’ve got to type the information that associated with it.”* (Interview 12, Pharmacist, Secondary Care)

GP systems for recording drug allergy and adverse drug reactions were in general more sophisticated than those found in hospitals. In some GP systems, drug allergy and adverse drug reactions could be recorded as a class (penicillins or tetracyclines) while in other systems they could only be recorded as individual drugs (penicillin V or oxytetracycline). GPs were often unsure how the system worked depending on how information was recorded, but they all felt the systems seemed to work satisfactorily for them.

In hospitals, specially trained coders read and interpreted clinical notes for coding important concepts. When the main diagnosis recorded for a hospital spell was a drug allergy or adverse drug reaction, this was coded using a classification system the International Classification of Diseases Version 10 (ICD-10) (22).

Adverse drug reaction information when coded could be used for pharmacovigilance. The World Health Organization's Adverse Reactions Terminology (WHO-ART) and the Medical Dictionary for Regulatory Activities (MedRDA) are medical terminologies used for coding adverse drug reactions in pharmacovigilance databases. Both of these terminologies lacked formal definitions for terms and the capability to perform the terminological reasoning which was possible in Systematized Nomenclature of Medicine - Clinical Terms (SNOMED-CT). Data from multiple databases were used in pharmacovigilance investigations and code mapping tables used to aggregate data.

*“...SNOMED is for medical information and DM&D [the NHS Dictionary of Medicines and Devices] for product information, two terminologies that are not used in medicines regulation, there are approaches to develop a mapping where when we receive the electronic file from the general practice that we identify the SNOMED code and have it translated electronically into the MedDRA code and that we identify the DM&D code and translate that into the appropriate drug within our pharmacovigilance drug dictionary. We need to do this to avoid manual resource being used re-coding thousands of messages.”* (Interview 15, Manager, MHRA)

### **6.3.2 Extent of coding**

The extent of coding of drug allergy and adverse drug reactions at the point-of-care was greatest in primary care where structured data entry using templates was common, whereas in secondary care hospitals templates were not often used and this information was not coded.

*“...templates, [it is] no. Basically we have a pathway through which you record allergies and adverse drug reactions but most of it consists of free text.....it is the kind of the biggest failing with our system that it's not codified data that we capture, it is free text data we capture.”* (Interview 12, Pharmacist, Secondary Care)

There were some important patterns to how this information was recorded, which impacted on how the information was used. For instance, prescribed drugs were sometimes discontinued by the prescriber or patient, and in certain situations this was because of a drug allergy or an adverse drug reaction. It may, however, have

represented a completed course of treatment. The reason for discontinuation was not usually recorded; electronic prescribing systems were not designed to capture this.

*“Reason for discontinuation is quite interesting because, you know...lots of drugs are discontinued and it can be for a whole variety of reasons, it can be lack of efficacy which can just be because, you know, the drug doesn’t seem to be working, it can be lack of efficacy because the disease is getting worse and it’s no longer strong enough. It can be the patient is not happy with the number of pills they’ve got to swallow a day, it can be that it is associated with some drug interaction with another drug that the doctor wants to give for something else and it can be associated with an adverse event which might be minor or, you know, up to major.”* (Interview 16, GPRD Manager)

Likewise, some adverse drug reactions went unnoticed and were only detected by retrospective analysis of coded (and unstructured) information (23).

*“I assume if a patient was put on penicillin and then there are symptoms which occur in the right time period after that first dose of penicillin the GP is likely to make a reasonably correct decision that that was allergy to penicillin and will record it as such. But if a person takes a Cox-2 inhibitor and has a myocardial infarction 10 days later I wouldn’t expect that to be recorded as an adverse drug reaction. That is a myocardial infarction which may be associated with the Cox-2, but equally it might not be and that’s exactly the type of research that is done in GPRD to demonstrate in cases and in controls or by cohort analysis that there is an association between the Cox and, the use of the Cox and the myocardial infarction or there isn’t an association”* (Interview 16, GPRD Manager)

One interviewee reported that external and internal validity of adverse drug reaction codes in research databases such as the UK’s The General Practice Research Database (GPRD), was high as evidenced by the number of peer-reviewed publications using these data. The interviewee further reported that this database was often used as a hypothesis testing dataset for pharmacovigilance.

Decision support functionality in EHRs was limited to the display of information back to the prescriber. Only when adverse drug reactions could be recorded at drug class level were more appropriate alerts produced. SNOMED-CT was assumed to have a

comprehensive set of terms for coding drug allergy and adverse drug reactions and their relationships organised as a knowledge base. There were no prescribing systems in use that made use of relationships in terminologies (and not drug databases) such as SNOMED-CT for decision support.

### **6.3.3 Potential benefits associated with coding**

The ability to use drug allergy and adverse drug reaction information for decision support was the main potential benefit of coding. The following quote also illustrates the common usage of the phrase “structured data” when referring to coded data:

*“...one thing I would say that this is an area that is absolutely known to be worth putting structured data and clinical decision support in, it is absolutely known to be worth... There are lot of other areas in clinical communication where structured data doesn't have as much value at the moment, it may well do in the future but allergies and adverse reactions it does so it seems to me we might well invest in it”* (Interview 12, Pharmacist, Research)

Re-exposure of patients to preventable adverse drug reactions could be minimised by well designed CDSSs for which accurate and complete coded information was needed. Some innovative decision support tools had been piloted.(15)

*“So you know rather than...necessarily showing all the details it's sort of only as if were systems where permissive and straight took you away from drugs where there may have been drug reactions or allergies in the past and put them into the bottom of the [pick] list. So turned the decision support on its head.”* (Interview 3, Consultant Physician, Secondary Care)

### **6.3.4 Possible risks of coding**

We found concerns were expressed that some drug allergy codes in EHRs could be incorrect leading to false positive alerts. Also, recorded drug allergy and adverse drug reactions were incomplete and/or not up-to-date, thus minimising the benefit of shared information, for instance in the NHS SCR. One of the reasons for inaccurate coding

was that “allergy” was seen to be an over-used and on some occasions even an abused term.

*“The trouble is that allergy you know is a very...widely used and misused word.”*  
(Interview 8, Senior Academic Pharmacologist)

Sharing of coded drug allergy and adverse drug reactions had particular risks relating to difficulties in identifying drug related events correctly.

*“...where do medication errors end and adverse reactions begin? And you know that’s sometimes difficult to work out.”* (Interview 8, Senior Academic Pharmacologist)

In GP systems, information needed to be documented in a system specific way in order to generate alerts. GPs reported that they had not received training on how to use the system properly but learned this information through clinical practice over time. There was a risk that some documented drug allergy and adverse drug reactions may therefore not produce alerts.

*“So, I interestingly finding that’s not necessarily a life threatening adverse reaction I might actually code it as a adverse reaction just so that it’s that information’s easily available to me”* (Interview 17, GP, Senior Academic)

In primary care, GPs did not record “no known drug allergy” (NKDA), but in hospitals this was often the case. When information was shared between primary and secondary care there was a potential risk of confusion.

*“Whereas within primary care you wouldn’t tend to record the negatives as it were. You would probably leave the record blank and there is the potential inconsistency in the way the two care settings will record the information which can lead to problems”*  
(Interview 2, Director of Pharmacy, Secondary care)

### 6.3.5 Influence of the context

Documenting adverse drug reactions in clinical systems for direct patient care and recording them for the purpose of reporting to regulatory authorities such as MHRA for pharmacovigilance were two different scenarios.

*“....you are trying to do very different use cases. In clinical care, you are trying to run decision support...In pharmacovigilance you are trying to collect to find adverse reactions not just allergies, most particularly in medicines surveillance”* (Interview 12, Pharmacist, Research)

Electronic Yellow Cards (e-Yellow Cards) have recently been integrated within the SystemOne GP system, developed by The Phoenix Partnership (24). Other systems suppliers were being encouraged by the MHRA to follow suit.

*“...not adding new fields [to the GP system]...identifying the fields when there is an ADR [Adverse Drug Reaction] to structure the message in a consistent way so that it comes through to [MHRA] in a way that translates directly into [MHRA] database. So the GP will not have any new screens for patient care but ...”* (Interview 16, GPRD Manager)

This was a new situation where drug allergy and adverse drug reactions were recorded explicitly for two scenarios and its influence on direct patient care would need evaluation in the future.

Both scenarios reflected unscheduled (or spontaneous) recording of information and there was no mandated scheduled (or routine) documentation of drug allergy and adverse drug reactions. Neither activity was incentivised in the UK.

Primary care-based professionals did not have formal training on how to record drug allergy and adverse drug reactions in EHRs.

*“As in most things with GPs we just try things don’t we, we just teach ourselves quite often, no one taught me”* (Interview 11, GP on a site visit)

It was reported that healthcare professionals in some hospitals were, where relevant, offered training on how to use electronic systems to record drug allergy and adverse drug reactions.

*“Everybody that uses the system has a training programme and they are shown what to do. Coupled with junior doctors actually get feedback on their performance based on alerts that fire off”* (Interview 2, Director of Pharmacy, Secondary care)

Some interviewees felt that incentives for recording this information were not a good idea. Patient safety and professional standards should be the drivers for recording or reporting adverse drug reactions.

*“No. I mean I think incentivising would not necessarily be you know would be...I don’t think would be a good thing. I do actually think that they should be some professional responsibility”* (Interview 8, Senior Academic Pharmacologist)

## **6.4 Discussion**

### **6.4.1 Main findings**

We found widespread acceptance among healthcare professionals of the need for accurate structuring and coding of drug allergies and adverse drug reactions. This was because such support was considered clinically important such that incentives were considered almost irrelevant. There was a considerable amount of coding carried out at present in the NHS (at least in primary care), but the fact it was being undertaken did not necessarily enable optimal leverage of CDSS; rather because of difficulties in accurate coding, this in some instances introduced new problems. This case study has highlighted the importance of wider contextual considerations, these including the ambiguity of clinical diagnosis, the extent of the lack of diagnostic facilities and inadequacy of current coding terms. Given the professional buy-in, the already substantial coding and the opportunity to share coded data throughout the NHS (via the NHS SCR), this represents a ripe area for further work.

#### **6.4.2 Strengths and limitations**

We purposively sampled those with an established interest in this area, but also those who were more front-line clinicians; hence we have been able to understand this issue from a broad range of perspectives. These interview-based data were supplemented by observations made during site visits to GP practices, data collected during a group discussion with an Allergy and Respiratory Expert Resource Group and by reviewing relevant publications (1,2,8,9,15-18), all of which helped us to contextualise findings. Interpretation of findings was aided by discussions amongst members of our multi-disciplinary group.

The relatively small sample and the consequent challenges of confirming that we achieved saturation were the main potential limitations of this case study.

#### **6.4.3 Comparing findings with the wider literature**

The Standards of Care Committee (SOCC) of the British Society for Allergy and Clinical Immunology (BSACI) has published guidelines for the management of drug allergy intended for allergists and others with a special interest in allergy (25). These guidelines highlighted the fact that routine or validated tests are not available for majority of drug allergies. A thorough history is essential for the management of drug allergy. Laboratory testing has very limited role in the management of drug allergy (26). Therefore, considerable experience is required for investigation of drug allergic reactions and to undertake specific drug challenges. Drug allergy documentation is, therefore, usually inaccurate and incomplete. Better strategies are needed to improve this essential aspect of history taking (27). Standardised forms are recommended for improving recording of drug allergies (28). Although there is a large amount of coded adverse drug reaction information in primary care extraction of this data is a challenge (29).

#### **6.4.4 Implications for policy, practice and research**

Diagnosis of drug allergy and adverse drug reactions is challenging to healthcare professionals. Drug allergy and adverse drug reactions should always be part of any differential diagnosis in practice. Professional bodies should recognise this issue and

appropriate guidelines and support for education should be initiated in clinical training and should also be available to staff in practice. Facilities for drug allergy testing are not routinely available to NHS staff and represent a major barrier to accurate diagnoses. This needs addressing by the NHS commissioners of healthcare services. There is furthermore no standardised dataset for recording drug allergy and adverse drug reactions. Development of a data model to record this information should be given priority in policy making. Terminologies such as SNOMED-CT need to be evaluated to determine if relevant codes are available. There also need to provide the opportunity and flexibility to record suspected reactions.

#### **6.4.5 Conclusions**

At minimum, the drug suspected of causing a reaction and a narrative description of the observed adverse reaction are the two pieces of information that always need to be documented. Depending on the intended use of this information (e.g. for direct patient care or pharmacovigilance) additional facets of information may also need to be recorded. Although it appears that there is no formal agreement on drug allergy and adverse drug reaction information that needs to be documented electronically, in reality there is an informal consistency amongst practitioners to document what they believe is needed to inform future patient care. Each situation in which this information arises and is used determines the template that is adopted. It is possible, and an attempt should be made, to develop a maximum data set (also called an archetype) from which subsets of data appropriate for each situation could be compiled for designing structured data entry templates in each situation. Data linkage technology with appropriate data anonymisation can provide the data needed for secondary uses such as epidemiological research.

The primary approach to coding was the use of structured data entry templates. This has the advantage that coding becomes an invisible background process. It was likely for this reason that the majority of interviewees related their experiences in recording drug allergy and adverse drug reactions with hardly any reference made to the structuring and/or coding of that information. All those interviewed appreciated the importance of structuring and/or coding this information, but individually the discussion focused on the particular uses of the information that were most relevant to them. This case study did not provide direct evidence for any relationship between the approach to

coding, the amount of information coded, and the benefits or risks of coding. We did however identify several perceived benefits and risks associated with coding data on drug allergies and adverse drug reactions. Structuring and/or coding of drug allergy and adverse drug reactions were not incentivised, but this did not matter because the main drivers related to patient safety and professional integrity. Other drivers were the fact that pharmacovigilance and research e-Yellow Cards are now integrated in some GP systems (24). Such developments have the potential to increase the coding of information on drug allergies and adverse drug reactions.

This case study has highlighted the importance of recognising the direct care and pharmacovigilance reasons for documenting and using drug allergy and drug adverse reaction events. The present approach to structuring and/or coding this information is inconsistent between primary and secondary care, even though this information must be sharable between care providers for individual patients, and be capable of aggregation for monitoring purposes. A single standard terminology used throughout the NHS for this documentation needs to be complemented by templates and user interface tools that encourage consistent and high quality allergy and adverse event information. SNOMED-CT needs enhancing to record suspected and confirmed drug allergy and adverse drug reactions, probably by post-coordination of terms. Connectivity between systems needs to enable information known about each patient to be combined so that each care provider is well informed and so that reporting of adverse events can be automated and thereby less dependent on clinician effort.

A more challenging problem is the diagnosis of drug allergy and adverse drug reactions, which is not easy, and is an educational and resource issue. The situation is complicated by the general lack of diagnostic facilities. Even when reactions are correctly diagnosed as adverse drug reactions, not all are recorded. This too might be an education issue and point to a need for better professional guidance. We propose effort be made to improve professional standards in diagnosis, documentation and reporting of adverse drug reactions, and further research on developing maximal data sets and situation specific data subsets. Resources should be allocated to develop diagnostic facilities for adverse drug reactions.

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## Chapter 7

### “Relevant data, meaningful use”: rethinking patient ethnicity data

#### Abstract

**Background:** The systematic collection of ethnicity data is potentially important for a range of uses, these including assessing compliance with anti-discrimination legislation, monitoring health inequalities, supporting clinical decisions and informing the provision of culturally sensitive care. However, the codification of ‘ethnicity’ is problematic in that there is no agreed scientific definition of the term, rendering any normalised data coding system highly subjective. The purpose for the collection of this type of data must be transparent, legal and ethical. In the United Kingdom (UK), the collection of patient ethnicity data is a national requirement for all publically funded healthcare providers and recommended as best practice by the British Medical Association (BMA). Despite this long-standing legal requirement, the completeness of recording of patient demographic data regarding ethnicity remains poor. The study of ethnicity coding therefore offers an important opportunity to understand factors that hinder the coding of data.

**Aims and objectives:** We aimed to consider the capture, storage and usage of data relating to patient ethnicity within electronic health records (EHRs), explore how these practices have developed, understand the barriers inhibiting ethnicity coding and reflect on what value (benefit) these data potentially offer to different stakeholder groups.

**Methods:** An in-depth qualitative case study drawing on documentary analysis, stakeholder interviews, postings within an on-line discussion group, and observations within primary and secondary care settings in the UK.

**Results:** We consulted extensively with academic and practitioner experts; conducted 14 interviews with 16 participants working in primary and secondary care, observed an on-line discussion group between the 10 months from February–November 2011, and analysed 50 documents including seven example forms for self-reported patient data. Our findings indicate that there is a great deal of variation in the definition, approaches to collecting and completeness of demographic and clinical data relating to patient

ethnicity within medical records in the UK. There was no request for demographic ethnicity data within the standard National Health Service (NHS) form for new patient registrations, which is used for new patients with no medical card. Forms used to gather patient ethnicity information are devised locally and in many cases differ significantly from the computerised coding options available for data entry, which are derived from categories used within the 2001 census of the four nations comprising the UK. There is currently no place to record patient ethnicity data within nationally implemented EHRs (such as the Summary Care Record (SCR) and the referral system Choose and Book (CaB)). Levels of completeness of clinical information relating to patient ethnicity within narrative structures are currently unknown in both primary and secondary care. We identified significant benefits for the increased use of structured data relating to patient ethnicity in the planning and provision of personalised clinical care and preventive health strategies, secondary analyses in relation to health (for example, disease monitoring and research) and in relation to domains beyond health such as population sciences and human geography. There are also considerable risks associated with the failure to collect these data, including: the risk of, harm during clinical care; inequalities in service and consequent legislative challenge; lack of participation in preventative healthcare; and an inability to identify ethnic specific trends in disease incidence and prevalence.

**Conclusions:** The ethnicity related data that are currently required to be collected were found to have little or no relevance to clinicians, healthcare provider organisations or indeed in many cases to patients, hence it is unsurprising that there has been considerable inertia on the part of healthcare professionals and organisations. Variations in local arrangements for the collection and use of these data may also be due to contextual factors, including lack of support, education and awareness, resource constraints, variations in community diversity and local working practices. These data are however useful for important secondary uses, these above all including assessing compliance with the Race Relations Amendment Act, which charges public bodies with delivering equitable services to all sectors of the population. It is important that the collection of data on ethnic codes continues, but by administrative staff and/or patient self-completion wherever possible. There is however also the need to code wider ethnicity related data on, for example, diet, language, and religious needs, which have the potential to be more clinically useful and support the delivery of personalised care.

## 7.1 Background

This case study considers the collection of patient ethnicity data to support clinical care. Ethnicity is a contested term, but for the purposes of this study we used the definition formulated by Bhopal in which ethnicity is defined as: *“The social group a person belongs to, and either identifies with or is identified with by others, as a result of a mix of cultural and other factors including one or more of language, diet, religion, ancestry, and physical features traditionally associated with race.”* (1) This term is distinct from ‘race’, which has been defined as: *“the group (subspecies in traditional scientific usage) a person belongs to as a result of a mix of physical features such as skin colour and hair texture, which reflect ancestry and geographical origins.”* (1) Race is now largely a discredited term in scientific circles as it fails to recognise the common genetic stock of people of different skin colours, emphasises above all physical characteristics, has been used to advance arguments in favour of biological determinism, and undermines the socially constructed nature of many people’s ‘ethnic’ identity.

The systematic collection of ethnicity data is important for several purposes. Ethnicity data are required for monitoring compliance with anti-discrimination legislation, monitoring health inequalities, and research (2). An appreciation of a patient’s beliefs, values and culture – all of which may or may not be impacted on by their ethnic grouping – also have the potential to inform the provision of personalised, culturally sensitive care (3). We consider in brief the case for these requirements before moving on to consider the literature regarding issues of classification, collection and codification, together with the benefits and associated risks of approaches to the collection and use of patient ethnicity within the UK context.

The importance of this type of information can extend beyond healthcare as it reflects how we describe our society and the extent to which we appreciate the rich diversity of the population. The purpose for its collection must be transparent, compliant with anti-discrimination legislation and for ethical use only. Healthcare and health research are no different from other areas of society in demonstrating both indirect and direct racism during recent history, including for example the Tuskegee Syphilis Study, which for many people continues to highlight the potential dangers associated with focusing on ‘race’ in medical research (4). In many countries, legislation exists to combat

discrimination against “racial” and ethnic minority groups and health services are required to demonstrate that they are meeting the needs of ethnic minorities (5). In the UK, both healthcare and health research are subject to the legislative requirements of The Race Relations (Amendment) Act 2000, the Equality Act 2010, and Directives by the Council of the European Union, including Council Directive 2000/43/EC (2000). (6-8) This legislative framework goes beyond the statutory obligation for service providers to protect against the infringement of patient rights in establishing a duty to prevent discrimination and inequalities by promoting equitable practices. This represents a move in policy away from retrospective, punitive measures for discriminatory practice to prospective incentives aimed at encouraging equitable practices and aiming to reduce ethnic inequalities (2). The collection and monitoring of patient ethnicity data is central to the delivery of this policy direction and to the countering of any legal claims brought against a particular service on the grounds of discrimination relating to a patient or group of patients’ ethnicity.

Ethnicity data are also required for public health monitoring of health inequalities and disease prevalence. Inclusion of minority groups in healthcare research is furthermore increasingly acknowledged as an important component of strategies to reduce health inequalities (9-14). Indeed, failure to include a representative spectrum of subjects in research may have scientific ramifications in terms of limiting the generalisability of study findings (15-17). Health inequalities linked to patient ethnicity relate to health outcomes, access to services and certain conditions which have significant impact upon particular communities. These include, for example, people of South Asian origin who are at least five times more likely than White European-origin adults to develop Type 2 diabetes and, once established, they are at particularly high risk of poor outcomes (18). Similarly, a high prevalence of coronary heart disease in South Asians (19) and ethnic variations in asthma frequency and morbidity rates have also been identified (20, 21). Inadequate data on patient ethnicity undermines, for example, the potential for further research into these areas of inequity (5).

As the incidence of some diseases (e.g. sarcoidosis in people of African-origin) and response to treatments can vary with ethnic grouping, the availability of clinical data relating to patient ethnicity should directly impact on clinical care decisions, yet the use of ethnicity data in treatment decisions is an under-researched area (22). Practical examples of the types of information that may prove clinically relevant include the

requirement for interpreter services to aid communication with healthcare professionals (23), and the possibility of cultural norms and community influences which may impact upon healthcare delivery (20, 21, 24); cultural preferences in what and how care is provided, such as a preference or requirement for a same sex clinician, preventive health and lifestyle choices, and the acceptability of certain kinds of clinical intervention (25). Whilst assumptions should not be made about individual patient needs, these factors illustrate how information relating to ethnicity should inform clinical decisions and the provision of personalised care. Failure to provide such services limits access and inclusion of some of the most vulnerable patient communities, for example recent migrants and those with little or no English language (26).

Despite the acknowledged importance of patient ethnicity data, concern has been expressed that the recording of ethnicity remains poor, for example, the majority of UK health datasets do not collect any data on ethnicity (27). Data collection in this area presents a number of challenges, particularly potential difficulties with normalised coding systems that hide the underlying politics of classification (28). Ethnicity is a highly subjective classification that an individual is required to articulate within a simple data item structure and as such it has been argued that the only true meaningful categorisation is self-definition (1). The use of pre-determined data structures presents problems if those structures are not felt to be meaningful or, worse still, seen to be offensive by those asked to complete them; for example if they do not reflect sufficient diversity and as such are perceived to exclude certain population groups. Conversely, the availability of very many categories may also prove difficult to accommodate practically within data collection templates and information technology (IT) systems. One answer to this may be to provide detailed data definitions within multi-axial terminologies to maximise the options available, for example those within the Systemised Nomenclature of Medicine – Clinical Terms (SNOMED-CT). However, over complicated coding hierarchies may also make it more difficult to identify data trends, for example, individuals who may be in high risk groups, owing to variations in use and use of non-specific codes (29).

In some healthcare contexts patient ethnicity data may not be routinely collected as is the case, for example, in the United States (US) (30). In other nations, such as France and Germany, the collection of data on ethnic origin continues to meet with official resistance and is subject to restrictions (31). In contrast, the UK officially recognises

the importance of patient ethnicity data and has pioneered work in this area. In primary care, this data collection for new patients has been incentivised in recent years by inclusion within the Quality and Outcomes Framework (QOF) (32), although this is now no longer the case. This national framework comprises the pay for performance scheme introduced in April 2004 as part of the new General Medical Services (GMS) contract and determines up to 25% of the income of every NHS general practice (GP). In secondary care, the collection of data relating to patient ethnicity has been a mandatory reporting requirement since April 1994 (33) although there is currently no explicitly stated sanction for a failure to comply and no direct incentive offered within the Payment by Results (PbR) scheme, which is the UK-wide, government determined system for paying NHS secondary care providers from public funds.

Both the QOF and PbR schemes focus on the universal inclusion of patient ethnicity data within individual patient records. In both primary and secondary care, patient ethnicity data is usually collected by administrative staff asking patients to complete information forms upon practice registration, first hospital appointment or when attending for unscheduled care. These demographic data are then entered into the patient administrative systems (PAS) within primary and secondary care. Despite the national requirement, the completeness of recording of patient demographic data regarding ethnicity remains poor (27). Within clinical systems (i.e. medical records), clinically relevant data relating to patient ethnicity may be captured as part of the clinical narrative and recorded within free text, for example within the patient history. Collecting and recording this information can lead to practical issues including additional workload, provision of staff training and access to appropriate technology (34, 35). These difficulties may be compounded by the use of multiple coding hierarchies which complicate data entry processes (29). Other methods of attributing ethnicity to patient records include, for example, attribution to whole practice populations through indirect methods using alternate indices, such as geographical postcode linkage to national census data, and the matching of the ethnicity profile of hospital admissions data to whole practice patient profiles (36). Researchers using these alternate methods of composition must acknowledge the resulting levels of accuracy that may reasonably be claimed.

This brief overview summarises some of the main reasons that have been advanced for the collection and usage of patient ethnicity data in the UK context. This synopsis

also highlights potential concerns and conflicts between the various purposes for which information might be collected: for statutory returns, equity monitoring, to identify cultural preferences, specific health or advocacy needs, languages to be catered for, genetic or environmental health risks and treatment effectiveness. Despite a substantial body of work in this area, issues in relation to definitions, (in)completeness, (in)accuracy and meaning persist, indicating a need for further empirical investigation. We therefore aimed to consider enablers and barriers to the capture, storage and usage of data relating to patient ethnicity within EHRs, how these practices have developed, and what value (benefit) this information provides to different stakeholder groups.

## **7.2 Methods**

This case study was included in the Research Ethics Committee (REC) approval and secured local site permissions as outlined in Chapter 2 of this report.

### **7.2.1 Design**

We conceptualised this research as a case study (37, 38) of data relating to patient ethnicity, where ethnicity is defined as the social group a person belongs to because of a mix of cultural and other factors including language, diet, religion, ancestry, and physical features traditionally associated with race (1). This case study is one of four comprising a collective case study (38) relating to information within the clinical record, namely: drug allergies, patient ethnicity, depression and diabetes mellitus. These studies are detailed in Chapters 6-9 of this report. In view of the significant body of work in this area, we consulted extensively with relevant academic colleagues and reviewed relevant professional on-line discussions, prior to commencing qualitative interviewing within primary and secondary care settings. We also reviewed data collected during stakeholders interviews for work-package (WP2) to enrich our insights into practice in this area.

### **7.2.2 Sampling and recruitment**

There are in the UK a number of leading academics and senior NHS personnel working to evaluate and improve practice in relation to patient ethnicity data. We purposefully

sampled individuals from this group (39), and in addition monitored the on-line discussion group MINORITY-ETHNIC-HEALTH run by Johnston as part of the UK National Academic Mailing List Service (<https://www.jiscmail.ac.uk/cgi-bin/webadmin?A0=minority-ethnic-health>). We in addition worked with the UK Clinical Research Network (UKCRN) and the Primary Care Research Network (PCRN) to invite primary and secondary care organisations with an interest in ethnicity-related data to participate in this case study. Those expressing an interest were forwarded the information sheet shown at Appendix 6 to allow them to further consider participation. Informed consent using the form shown at Appendix 9 was gained in writing prior to participant interviews.

### **7.2.3 Data generation and handling**

Our data were derived from a combination of consultation, interviews and observation of a range of individuals and groups, these including senior academic colleagues, senior managers, clinical coding managers, research and information professionals, GP practice managers and administrators, and academics. We conducted semi-structured interviews, observed a multi-disciplinary meeting of senior clinical and managerial staff, gathered and analysed documents from participants in relation to the subjects discussed, and observed postings within an on-line discussion-group aimed at professional with an interest in healthcare for minorities. This approach allowed us to consider a range of perspectives and approaches encompassing variations in profession, geographical location and care setting.

A sample interview topic guide is shown at Table 7.1. This guide was augmented and adapted during data generation to consider and clarify themes emerging within the data. Interviews were digitally recorded subject to participant consent. On a number of occasions, participants chose to withhold consent to record the interview. This choice was respected without further question and researcher field-notes were used as an alternative method of data capture. Recorded interviews were transcribed in full, anonymised and checked against the original recording. Key issues explored included tools and techniques for the collection of patient ethnicity data, approaches to coding the information during data entry processes, external requirements and guidelines as barriers and enablers for data entry, perceptions regarding the relevance of patient ethnicity data and areas for possible improvement. Data generation continued until

saturation could reasonably be assumed (40). A reflexive approach was adopted in considering and adapting the researcher's own role as a participant within the data generation process.

**Table 7.1: Sample interview guide**

<b>Main structure</b>	<b>Specific topics and issues</b>
Confidentiality, aims, thanks	Theorised and actual benefits and risks, drivers, incentives, barriers and how to address these
Any questions?	
<b>About yourself</b>	Can you tell me a bit about your role and what you do here?(setting, profession, coding system, electronic system)
Understand local processes relating to the collection of patient ethnicity data.	Ask participants to describe how they collect and store patient ethnicity data, related documents, forms and local processes.
Do the <b>structures and/or codes cover what you feel needs to be recorded – any areas for improvement?</b>	In terms of <b>completeness and accuracy</b> and in terms of <b>enabling good use of the information</b> Any potential <b>uses of the information that are under-exploited?</b> If yes, why?
<b>Overall</b>	
How well do the available clinical systems support structuring and/or encoding the information?	
Any <b>other barriers</b> to collecting good quality information?	
Any <b>drivers or incentives</b> that would improve the quality or uses made of this information?	
Any <b>developments</b> in relation to structuring and/or coding patient ethnicity data they are aware of?	Any examples of innovation/centres of excellence? Aware of particular practical issues or areas of concern?
<b>Concluding remarks</b>	
Anything else?	Anyone they can recommend for interview? Any relevant literature?
Thanks, any questions or further things you should like to discuss?	

#### 7.2.4 Analysis

Analysis was conducted iteratively throughout and subsequent to the data generation process. Analysis of the initial academic consultations highlighted areas for

investigation during interview which were then considered and discussed by the research team within an analytic framework deduced from a review of relevant literature. Upon completion of interviews and observations further inductive analysis identified emergent themes and areas for clarification (41). We actively sought disconfirming evidence, including the secondary analysis of data generated as part of WP2, and adopted a reflexive approach to mitigate the influence of researcher prior knowledge and assumptions upon data analysis (42). Finally, results were discussed with the whole research team and considered together with a small group of supportive academic experts.

### **7.3 Results**

We conducted 14 semi-structured face-to-face (n=13) and telephone interviews (n=1). Two of the face to face interviews were conducted with two interviewees, yielding a total of 16 participants. We also observed a two-hour multi-disciplinary meeting of senior clinical and managerial staff with designated responsibility for the collection of patient ethnicity data within a single Health Board in Scotland. We gathered and analysed 50 documents from participants in relation to the subjects discussed, including seven example forms for self-reported patient data. We observed posting by members of an on-line discussion-group over 10 months (from February–November 2011 inclusive). A summary of this data generation is provided in Table 7.2 Table 7.3 details interviewee participant characteristics.

**Table 7.2: Summary of data collected**

<b>Data source</b>	<b>Number</b>
<b>Interviews</b>	14
<i>(Participants)</i>	<i>(16)</i>
<b>Observations</b>	1
<b>Field notes</b>	2
<b>Documents</b>	50

**Table 7.3: Interviewee participant characteristics**

<b>Identifier</b>	<b>Role</b>	<b>Gender</b>	<b>Setting</b>	<b>Interview method</b>
1	Senior Academic	Male	Research Institute	Face-to-face interview
2	Senior Academic	Male	Research Institute	Face-to-face interview
3	Senior Academic	Male	Research Institute	Face-to-face interview
4	Senior Manager	Female	NHS Scotland;	Face-to-face interview
5	Clinical Coding Manager	Male	Secondary care	Face-to-face interview
6	Research Nurse	Female	Secondary care	Face-to-face interview
7	Information Manager	Male	Secondary care	Face-to-face interview
8	Senior Manager	Male	NHS England;	Face-to-face interview
9	GP Practice Manager	Female	Primary care	Face-to-face interview
10	Administrator	Female	Primary care	Face-to-face interview
11	GP Practice Manager	Female	Primary care	Face-to-face interview
12	Administrator	Female	Primary care	Face-to-face interview
13	GP Practice Manager	Female	Primary care	Face-to-face interview
14	Information Manager	Female	Secondary care	Face-to-face interview
15	Senior Manager	Female	Secondary care	Face-to-face interview
16	Clinical Coding Manager	Female	Secondary care	Telephone interview

Four main themes emerged from the analysis (see also Box 7.1 for a more detailed description of sub-themes):

- Amounts and type of information coded regarding patient ethnicity
- Approaches to coding patient ethnicity
- The benefits and usefulness of coded patient ethnicity data
- Associated risks of coding patient ethnicity information

These themes are examined in more detail in the paragraphs below. Where relevant, direct quotes from participants are given as transcribed from digital recordings. Where interviews were not transcribed findings are presented based upon researcher field-notes.

**Box 7.1: Summary of themes and sub-themes**

Amounts and type of information coded regarding patient ethnicity

- Defining patient ethnicity data for demographics;
- Defining patient ethnicity data for clinical care;
- Completeness of data.

Approaches to coding patient ethnicity

- Completeness of data in primary care patient administration;
- Completeness of data in secondary care patient administration;
- Differences in approaches to coding between care settings.

The benefits and usefulness of coded patient ethnicity data

- Clinical relevance and personalised care;
- Access and participation;
- Uses of secondary analysis.

Associated risks of coding patient ethnicity information

- Failure to provide appropriate care;
- Inequalities in service and consequent legislative challenge;
- Failure in appropriate service commissioning and reimbursement;
- Lack of access and participation in preventative healthcare;
- Failure to identify accurately trends in disease prevalence.

### **7.3.1 Amounts and type of information coded regarding patient ethnicity**

#### ***Defining patient ethnicity data for demographics***

The collection of patient ethnicity data related to two types of information: demographic data collected and entered by administrative staff and that collected within the clinical encounter. Demographic data were usually collected by administrative staff at the time of new patient registration in both primary and secondary care, including by paramedic staff, in accident and emergency (A&E) services, and in both inpatient and outpatient settings.

Demographic data comprised one single data item, namely ethnic origin. This information was collected from patients by use of lists of values for patients to choose from. The chosen category was then encoded within the EHR, typically by receptions staff as part of patient administration. In primary care, this data was stored within the administrative element of the individual patient record as opposed to the clinical element of the system. In secondary care, this data was stored within the PAS, which was often separate to clinical systems and not always accessed by clinicians. During data collection and entry ethnicity was where relevant often linked to language considerations and the identification and recording of any need for interpreter services. Patients were given the option to choose not to state their ethnicity and codes existed to accommodate this choice.

This type of demographic ethnicity data is based on the classifications derived from the UK's national decennial censuses. The categories currently in use are drawn from the 2001 classifications. These were reviewed and amended for the 2011 census. Whilst broadly similar, there are some important differences across the four home nations comprising the UK. The codes used to collect patient ethnicity data in primary and secondary care had not been changed to reflect new thinking from the 2011 census at the time of our fieldwork; this meant that the ethnic categories available had remained unchanged for at least a decade. Change is however imminent and new categories will, for example, be introduced into Scotland from 1<sup>st</sup> April 2012 in Scotland, where the census ethnicity classifications recommended by the Scottish Government will be used. This has the advantage of ensuring that population denominators are available for ethnicity data from the health service. In contrast, we learned from the English

Department of Health (DH) that a decision had been taken that there was “*No business case*” (Interview 8, Senior Manager, NHS England) for moving from 2001 to 2011 census classifications. This was felt to be due to the extent of infrastructure change that would be needed with relatively little additional return. This planned change in Scotland will thus further widen the geographic disparity between data collection in Scotland and other home nations.

Another disparity in data collection was evident between primary and secondary care. In primary care, EHRs were populated using Read codes, whereas completion of the secondary care PAS was undertaken using International Classification of Disease Version 10 (ICD-10) codes. Although both sets of codes are based upon the 2001 census categories there are significant differences. When using the Read codes on the Vision system, for example, we observed some 83 codes available for data entry in addition to the code accommodating patients who chose not to state their ethnicity. These codes are reproduced in Table 7.4. In secondary care, we observed the ‘16+1’ ICD-10 codes in use, with the ‘one’ representing the patient’s prerogative to choose not to answer this question. Given these differences in granularity between the two coding systems, there are challenges in mapping categories between codes if data are to be exchanged. This mapping would constitute a process of abstraction of the information from the patient self-defined classification.

**Table 7.4: VISION computer entry ethnicity options in England**

<b>Ethnicity not given - patient refused</b>	<b>Other mixed background</b>	<b>Other ethnic category</b>
<b>British or Mixed British</b>	Other Mixed background	Chinese and White
British or mixed British	Black and Asian	Vietnamese
Irish	Black and Chinese	Japanese
<b>White or Mixed White</b>	Black and White	Filipino
Other White background	Chinese and White	Malaysian
English	Asian and Chinese	Buddhist
Scottish	Other Mixed or Mixed unspecified	Hindu
Welsh	White and Black Caribbean	Jewish
Cornish	White and Black African	Muslim
Northern Irish	White and Asian	Sikh
Ulster Scots	<b>Asian or Mixed Asian</b>	Arab
Cypriot 9part not stated)	Indian or British Indian	North African
Greek	Pakistani or British Pakistani	Mid East (excl Israeli, Iranian & Arab)
Greek Cypriot	Bangladeshi or British Bangladeshi	Israeli
Turkish	Other Asian Background	Iranian
Turkish Cypriot	Punjabi	Kurdish
Italian	Kashmiri	Moroccan
Irish Traveller	East African Asian	Latin American
Traveller	Sri Lankan	South and Central American
Gypsy/Romany	Tamil	Mauritian/ Seychellois/ Maldivian/ St. Helena
Polish	Sinhalese	
Baltic Estonian/ Latvian/ Lithuanian	Caribbean Asian	<b>Language</b>
Commonwealth (Russian) Independent States	British Asian	Additional main spoken language
Kosovar	Mixed Asian	English as a second language
Albanian	Other Asian or Asian unspecified	[click for list of languages]
Bosnian	<b>Black or Mixed Black</b>	<b>Interpreter required?</b>
Croatian	Caribbean	[click for list of languages]
Serbian	African	
Other Republics former Yugoslavia	Other Black background	
Mixed Irish and other White	Somali	
Other White European/ European unspecified/ Mixed European	Nigerian	
Other mixed White	Black British	
Other White or White unspecified	Mixed Black	
	Other Black or Black Unspecified	

### ***Defining patient ethnicity data for clinical care***

In clinical contexts, our data suggested potential for wider, socially patterned ethnicity-related data, this including information on country of birth (which may, for example, have a bearing on travel patterns), languages spoken, religious affiliation, diet, nationality, citizenship and migration status. However, we were unable to locate a recommended structure for the collection and retrieval of such information. These items were described as being collected at the clinician's discretion within the clinical narrative and recorded in free text formats in EHRs. This information was considered potentially important to the provision of personalised clinical care and, if overlooked, could result in sub-optimal care. Despite this risk, there was no recommended format for the consistent, structured recording of this data by clinicians.

### **7.3.2 Approaches to coding patient ethnicity**

#### ***Completeness of data in primary care patient administration***

The collection of demographic data relating to patient ethnicity was the focus of much discussion, predominantly around levels of completeness i.e. the number of patient records with a valid ethnicity code. We found the amount of information to vary widely due to a number of contextual factors. One exemplar borough in London had worked hard to capture this information which they saw as fundamental to their work:

*“Equity has been a particular concern because we work in a very diverse, ethnically and socially, community we’re rich in diversity and so we thought we would capitalise on our riches and look at trying to document them. So for the last almost 10 years now we have been promoting the recording of self-reported ethnicity by patients in GP records and we’ve set up coding structures, templates that allow that for all new patient registrations, six week baby checks, chronic disease management have all got these templates built in, staff have been trained in practices and it’s been supported by...you know financially by the enhanced service, by the three PCTs [Primary Care Trusts] such that we’ve now got over 80% of self-reported ethnicity recording in the total population and over 90% in people with long term conditions so we have complete ethnicity recording across 800,000 people in the most disadvantaged, socially diverse population in the UK.” (Interview 1, Senior Academic)*

Nationally, completeness of patient ethnicity data in primary care was recently incentivised for all patients. Participant recollections of these initiatives were clear and they were able to discuss the work undertaken and the resultant revenue.

*“Two years, there was a Local Enhanced Service, sorry a Direct Enhanced Service came out to encourage practices to record the ethnic origin of patients and yes I mean we started from there. We were able to do a bulk change of patients.”* (Interview 9, GP Practice Manager)

*“Scotland had delivering enhanced services schemes that practices could choose to do for extra income. Ethnicity was one of them for total patient population. They were aiming for certain percentages, between 80 and 90%. Not all practices chose to do this and difficult to know how many did. Estimated 69% of practices took this up (c.1,030 practices in Scotland).”* (Interview 4, Senior Manager, NHS Scotland).

In addition to national level (Direct Enhanced Service (DES)) requests to complete this information, some local Primary Care Trust (PCT) initiatives (e.g. Local Enhanced Services (LES)) had been introduced to drive improvements in completeness of data collection:

*“Actually a lot of the improvements in the ascribed quality outcomes framework have not simply been due to the quality outcomes framework, they’ve been due to the PCTs further paying practices for quality improvement.”* (Interview 2, Senior Academic)

These national and regional incentive schemes operated at practice level and offered financial incentives for levels of completeness as a percentage of patients registered. Other initiatives were similarly aimed at whole practice patient populations, but were not necessarily high cost schemes – for example the Race for Health programme, an incentive scheme based on peer comparisons. This scheme was founded on the principle that collecting patient ethnicity data is simply *“The right thing to do”*. (Interview 2, Senior Academic).

A further financial incentive was offered by QOF, which promoted the completion of patient ethnicity data for all new patients. Although the amount offered was relatively

small (i.e. one QOF point, worth £127 in the financial year 2010-2011), a number of participants described how their practices undertook significant amounts of work to earn this quality payment. Other GP practices however felt that the incentive was not sufficiently attractive to make it worth their while to collect these data. In the financial year 2011-2012, this incentive was omitted from the QOF framework. The reasons for this were not clear to staff we interviewed, some of whom expressed frustration at this change.

*"It's almost as if they've dangled this carrot in front of you with this Direct Enhanced Service and they've said we'll pay you this, so you've got the process going of asking the ethnic origin on registration, something that, you know, you get into the habit of doing over the next couple of years and you're carrying it on but they've taken the money away from you and they've taken everything else but you're still expected to, because it's part of our, it's ingrained into our processes now we just do it but we're just not getting paid for it. I mean it was a miniscule amount anyway."* (Interview 12, GP Practice Manager, Primary Care)

A possible reason for this change was that the collection of ethnicity data was felt to have become embedded in normal working practice and therefore the incentive was no longer necessary. We explored this amendment to the QOF framework with the DH, who explained the purpose of the quality drivers:

*"QOF is to drive behaviour not sustain it"* (Interview, Senior Manager, NHS England)

In the GP practice systems we observed, the removal of the completeness of new patient ethnicity data requirement from QOF was accompanied by its removal as an option within the standard reporting menu. This resulted in the practical problem that practices could not run a standard query to audit their data completion:

*"But it's a bit annoying that I can't, I can't see, they've taken the audit off."* (Interview 13, GP Practice Manager, Primary Care)

One participant practice followed this up with their system supplier and was able to run the report again, but only by special request. This presented a potential barrier to

sustained efforts at ensuring the collection of ethnicity data as it proved difficult to run relevant audits.

### ***Completeness of data in secondary care patient administration systems***

In secondary care settings, All hospitals were expected to report using the same set of categories. This information was uploaded on a monthly basis as part of the main contractual data flows from individual PAS systems to the DH Information Centre and made available to the Second Uses Service (SUS). There was less focus here on completeness than we had observed within primary care and QOF:

*“80% is enough to get the statistics needed – you don’t need 100% coverage.”*  
(Interview 8, Senior Manager, NHS England)

There was furthermore no sanction for failing to collect these data. The amount of information coded varied within secondary care depending on the speciality, for example:

*“The reason it’s higher on disease registers is: A) because the people are coming more frequently; and B) because that’s something that you know as it were a counsel of quality in the practices you’d check to see whether the people that you’re seeing you know have that box checked, that they have ethnicity in their record.”* (Interview 1, Senior Academic)

Thus, an individual Trusts’ overall recording levels may have been misleading as they were based on an average figure for the organisation, which may reflect a huge variety in levels of recording across different services within a single NHS Trust.

### ***Differences in approaches to coding between care settings***

When speaking to staff, the coding of patient ethnicity data was viewed as a straightforward administrative task

.

*“When the patient signs on or fills in all the forms to come here we’ve got a questionnaire and it says your nationality, ethnic and first language and everything so when I put them on for the health authority on the computer I go in and code them*

*English, Scottish or whatever and their first language and that's it really.*" (Interview 10, GP Practice Administrator)

In both primary and secondary care we found no set format for the collection of patient ethnicity information from patients and templates used for self-definition of ethnicity were devised locally. Although templates in use of secondary care offered similar choices, albeit in different formats, templates in primary care varied widely. We collected four example GP patient registration forms designed locally to capture the relevant information ready for data entry. The options available for patients to complete within these forms are shown in Table 7.2, which clearly illustrates the degree of variation between practices. In secondary care settings, this practice was more standardised due to the mandating of data collection and the restricted number of codes used.

How these data were entered into the computer was determined by the structures available within individual computer systems. Somewhat surprisingly, we observed no clear relationship between locally written templates for data collection and how this information was electronically stored, thus data storage was a process of interpretation by the administrator entering the data from the patient-defined information. What information categories were present on the computer determined how this information was defined. Suppliers were therefore hugely influential:

*'Between them, Vision and EMIS cover 46 million people. Both of them have about half each. So I think EMIS is, I think EMIS has got slightly more, I think 30 million.'* (Interview 1, Senior Academic)

When the options detailed in Table 7.5 are compared to the data entry codes listed in Table 7.4 we see the extent of interpretation necessary to map these categories to those available for coding.

**Table 7.5: Examples of GP practice patient ethnicity data collection forms**

GP Practice 1	GP Practice 2	GP Practice 3
New Patient Questionnaire	Patient Ethnic Origin Questionnaire	New Patient Questionnaire
<b>WHITE</b>	<b>White</b>	Ethnicity
British	British	
Any other white background - please specify	Irish	Main 1st spoken language
<b>ASIAN OR BRITISH ASIAN</b>	Any other white background please write in below	
Indian/ British Indian	<b>Mixed</b>	
Pakistani/ British Pakistani	White and Black Caribbean	
Bangladeshi/ British Bangladeshi	White and Black African	
Any other Asian background - please specify	White and Asian	
<b>MIXED</b>	Any other mixed background please write in below	
White and Black Caribbean	<b>Asian or British Asian</b>	
White and Black African	Indian	
White and Asian	Pakistani	
Any other Mixed background - please specify	Bangladeshi	
<b>BLACK OR BLACK BRITISH</b>	Any other Asian background please write in below	
Black Caribbean/ British Caribbean	<b>Black or Black British</b>	
Black African/ British African	Caribbean	
Any other black background - please specify	African	
<b>OTHER ETHNIC GROUP</b>	White and Asian	
Chinese	Any other black background please write below	
Other - please specify	<b>Chinese or other ethnic group</b>	
	Chinese or other ethnic group	
I DO NOT WISH TO ANSWER	Any other please write below	
Do you need an interpreter?	First Language	
Please state your first language		

GP Practice 4		
Patient Profiling Form		
White British	Arab	24 language options listed
White Irish	Kosovar	
Traveller	Albanian	If your service is provided in English do you need an interpreter/advocate? (Yes or No)
Greek	Bosnian	
Turkish	Croatian	If you have a visual impairment do you require?
Kurdish	Serbian	Braille (Yes/ No)
Estonian/ Latvian/ Lithuanian	Other Yugoslav	Large Print (Yes/ No)
Russian	Other White	
		What is your faith or religion, if any?
Jewish	British Asian	14 options including Agnostic, None and Religion declined
Bengali/ British Bengali	Mixed Asian	
Pakistani/ British Pakistani	Chinese	
Indian/ British Indian	Vietnamese	
Sri Lankan	Japanese	
Tamil	Filipino	
Sinhalese	Other Asian	
Black African	Mixed Black	
Black Caribbean	Mixed White/ Black Caribbean	
Somali	Mixed White/ Black African	
Black British	Mixed White/ Asian	
East African Asian	Any Other Mixed	
Caribbean Asian	Other Non-mixed	
Middle Eastern		
Other Black	I do not wish to state my ethnicity	

A challenge in coding these data was felt to lie in obtaining the information from patients. This was felt to be problematic due to staff embarrassment, fear of causing offense and in some cases perceived irrelevance (particularly in the context of emergency care provision by, for example, paramedical staff). The exemplar borough we visited in London had developed patient support mechanisms and staff training to gather this information from patients.

*“Somebody talks the sheet through with them, they’ll fill it in and give it in and that will be then coded by administrative staff onto the patient’s record.”* (Interview, Senior Academic 3)

*“We have a facilitator who will go out to practices, they’re our spinal cord. They go out to the practices and they say you know let me just go through this with you in a meeting and we’ll take you and your staff, your administrative staff through and we’ll have a meeting to tell them how to fill this out, what they should be doing. So that’s all been set up over time, over the last 10 years, you know training up staff and now they’re kind of self-trained really.”* (Interview 1, Senior Academic)

One suggestion for obtaining the information from patients was to change the time at which information is collected:

*“In hospital it may be easier to ask in hospital discharge – because you’re ticking sheets anyway.”* (Interview 4, Senior Manager, NHS Scotland)

In investigating differences in approaches to coding we considered Scotland’s work in this area as an exemplar of good practice. Previous analyses of recording levels across Health Boards in Scotland showed extreme variations and shortcomings in levels of completeness of patient ethnicity information recording. These issues in data collection were addressed within a national programme comprising a six strand national initiative to increase levels of coding:

*“We had 6 work streams:*

- Originally about getting IT in place*
- Classifications needed to be right*
- Training resources*

- *PFPI(Patient Focus and Public Involvement) engagement – BME (Black and Minority Ethnic) communities, learning disabilities, citizens panel (see publications)*
- *Research group*
- *Human resource.”*

(Interview 4, Senior Manager, NHS Scotland)

The programme, developed and implemented over a 10 year period, included the development of an Ethnic Monitoring Toolkit, training resources including and handbooks for staff. The historical account of the progress of this programme was consistent with other descriptions of the “*years of work*” (Interview 4, Senior Manager, NHS Scotland) invested in improving the completeness of data.

*“We’ve got you know data on year on year improvement in ethnicity recording. We’ve got better at it, we got you know as I say we’re now at 85%. We’ll be at 90% next year, I can guarantee it...If you’d come to me five years ago, I would have had 60% recording.”*  
(Interview 1, Senior Academic)

We observed the meeting of one a multi-disciplinary working group convened by a Health Board to increase the levels of completeness of patient ethnicity data collection. Their objective was to increase ethnicity coding in primary and secondary care to 90% completeness within three years experience. This represented a shift from a starting point of 5% completeness in secondary care and 35% completeness in primary care. Whilst the group was making a significant difference in secondary care due to local policy directives, systems changes and clinical leadership, they were less able to influence the more autonomous primary care practitioners (see Chapter 5).

Our findings indicate that the level of completeness of patient data and approaches to coding were subject to local, regional and national views on its relevance and usefulness, individual practice responses to financial incentive schemes, patient turnover rates and local collection mechanisms, staff training and support. We also noted that, whilst the collection of these data was considered mandatory in secondary care, it was perceived to be optional within primary care. Participants based within primary care were often unclear as to what use was made of this coded information and felt they were only collecting it because of some top-down directive. We consider the perceived usefulness of coded patient ethnicity data in more detail below.

### **7.3.3 The benefits and usefulness of coded patient ethnicity data**

We noted a number of significant omissions in processes and practices that adversely impacted upon realisable benefits and perceptions of usefulness of these coded data. We found no widely available support and/or resources to assist GP practices in collecting patient ethnicity data in a manner that facilitates accurate, efficient data entry. We also observed that collection of patient ethnicity data is not supported by the General Medical Service One (GMS1) form used in new patient registration when the patient does not have a medical card, as is often the case for vulnerable members of minority groups, such as asylum seekers and immigrants. Patient ethnicity data were not available within national EHRs such as the SCR or CaB. Despite governmental guidelines and legislation, such as *The Essential Guide to the Public Sector Equality Duty* (43) and the Equality Act 2010, we could not identify any national agreements, recommendations or resources to support processes for GPs to share this information in referrals. We noted the absence of a national data set in primary care on ethnicity.

#### ***Clinical relevance and personalised care***

Many of the staff interviewed did not know how patient ethnicity information was used or indeed why it might be relevant or necessary:

*“The demographics is just a surname, forename, gender, date of birth and that’s how we would find a patient but again there’s no, nothing on there for ethnic origin. I don’t know whether they ask that at the hospital when they attend.”* (Interview 13, GP Practice Manager)

*“The only other thing is for diabetics who are, I suppose that’s more religion I suppose, obviously being diabetic and fasting.”* (Interview 12, GP Practice Administrator)

*“Most PCT’s get demographic info from the ethnicity question in the census.”* (Interview 3, Senior Academic)

*“I can’t think that we do anything to the hospital, I think they do they’re own monitoring but we certainly don’t provide it or we’re not asked to provide it to the hospital ... All they know is*

*how many people we've recorded but they've never asked me for a break down of the actual groups."* (Interview 7, Information Manager)

### ***Access and participation***

One area where the data was seen as useful was in making services more accessible to patients, particularly for patients with language considerations:

*"It's just a data exercise really and as I say we're just noticing ethnic minorities coming into the practice so I'm having to think ahead, I'm thinking right what changes am I going to have to make, i.e. material that we have in our waiting room, making sure that I know how to get hold of an interpreter for, it's just things like that that I'm having to be aware of now whereas perhaps years ago you just didn't need to."* (Interview 11, GP Practice Manager)

*"Over the period of five years even I've really seen a difference in the demographics of the surgery. You'd say that probably [Place Name], [Place Name] [Place Name] had all the minorities but yeah they're creeping into [Place Name] and of course you've got to adjust the way of working, you know, things like leaflets in the waiting room I've now got to think about it's not just, you know, Braille for the blind or big, you know, for elderly I'm having to think of other languages to put out in the waiting room."* (Interview 11, GP Practice Manager)

One administrator detailed her frustrations with the practice cervical screening programme due to non-attendance by women who could not read the letters inviting them to attend for testing. This was attributed to a lack of resources for translating patient correspondence, which was de facto creating inequalities in the practice population. A similar example was given of children not attending for immunisation. In these examples, staff were concerned regarding lack of access and inclusion of minority groups within the community, but there was no attempt to generate data to verify these concerns nor to refer to the data available within the practice.

Some secondary care participants we spoke to knew that the data were collected, but did not know what happened to the information and had never engaged with it for the purposes of their work. Conversely, we visited two sites in London, one in primary and one in secondary care, who were both able to give direct examples of the relevance of this information in service provision, particularly if linked to other patient data:

*“I mean having got ethnicity recorded we’re then able to record equity of provision by ethnic group so we’ve just been running a project funded by [name] to report the data for chronic diseases by ethnic group and by social deprivation, both those things because we also have Townsend score for deprivation on all our patients and there’s an interaction between ethnicity and deprivation, as we all know.” (Interview 1, Senior Academic)*

*“It will depend upon what the programme is, so around diabetes we they set up a diabetes care pathway which takes some of this information into account and you know has been setting up a care closer to home programmes that are more accessible and more appropriate for the diverse communities that we serve.” (Interview 1, Senior Academic)*

*“We’ve got principal language not English is about 30% so that’s about right. But this doesn’t make sense total interpreter need recorded ever well you know it’s just whether it’s in there doesn’t help us but whether there’s been an interpreter present so. Then we’ve got stuff on using the phone interpreting service which is different again so kind of part of the service. Anyway so that’s you know so we’re all doing it, we’re feeding it back...chronic airways disease, depression and anxiety, cardiovascular disease you know... but what we did as part of the broader health equity project and what we’ve persuaded the PCT to do now is to establish an equity dashboard” (Interview 1, Senior Academic)*

### ***Uses for secondary analysis***

We noted many examples of current and potential benefits of studies using secondary analysis to learn from patient ethnicity data. Many of these studies were drawing on census information and were looking at considerations of equality and diversity beyond healthcare. These included for example: population tracking; considering the use of IT by BME and migrant groups in Europe; and comparing NHS employment data with population data from census and the Labour Force Survey. These uses were described by researchers as highly cost-effective contributions to the development of policy and practice in the UK. Ironically those providing this valuable information seemed largely unaware of their contribution to this work.

Our findings indicate that the benefits of collecting patient ethnicity data are currently limited by a lack of national support, staff training and resources, a lack of data sharing across care

settings, a perceived lack of organisational and clinical relevance, and pronounced variations in emphasis on equality and diversity and knowledge of data usage. The benefits and usefulness of this data for secondary analysis were detailed as potentially extremely significant, although a lack of completeness of data was felt to impact upon progress in this area.

#### **7.3.4 Associated risks of coding patient ethnicity information**

We identified four principle risks surrounding current practices in the collection and use of patient ethnicity data: failure to provide appropriate care; inequality in service provision and consequent legal challenge; lack of access and participation in preventative healthcare; and failure to identify accurately trends in disease prevalence.

##### ***Failure to provide appropriate care***

The need to provide culturally sensitive care has been outlined in professional and educational guidelines from professional organisations such as *Tomorrow's Doctors*, published by the General Medical Council (GMC) (44). Academic participants expressed concern that this might become increasingly difficult in the absence of meaningful ethnicity data. They highlighted the relevance of various contingent elements of ethnicity as key decision-making tools within the diagnostic process and the provision of personalised care, including culturally sensitive care. Examples of these contingent elements of ethnicity included deprivation, language, migration status and citizenship status (e.g. for asylum seekers and refugees). We also noted examples of ethnicity informed early interventions for conditions with increased prevalence in certain communities, for example diabetes mellitus within South Asian communities and gestational diabetes within pregnant women originating from Somalia, the failure to anticipate which could result in preventable harm.

##### ***Inequality in service provision and the consequent potential for legal challenges***

Failure to collect patient ethnicity data was felt by participants to be increasingly important given the diverse nature of the UK population and the potential cessation of the decennial census. Expert academics and clinical participants with a particular interest in health

inequalities were concerned by the potential risks arising from a lack of data or data that were increasingly out of date and unavailable to service commissioners.

*“Monitoring gives you live data that allows you to track changes. If you can’t track changes you can’t redirect resources and allocate effectively.”* (Interview 2, Senior Academic)

One participant noted the importance of GP access to up-to-date ethnicity information given their planned role in service commissioning. A more general risk noted by more senior participants was the potential for legal challenge to service providers based on alleged contravention of equalities legislation. The need to refute any such legal action was cited by several participants as a key driver for the collection of ethnicity information.

### ***Lack of access and participation in preventative healthcare***

Participants described their concerns regarding non-participation in preventive healthcare initiatives and programmes due principally to language and/ or cultural considerations. Examples of these included very poor attendance for routine cervical screening by Eastern European women which was attributed to patients being unable to read the letters of invitation which were written in English. Although this was a known concern in one participating GP practice, this had not been addressed because of the lack of resources to support interpreting services for patient correspondence in anticipation of care. Other examples given were the failure of children to attend for immunisation due to similar problems with communication; the non-participation in breast screening programmes by BME women due to the involvement of male staff, and similar barriers to participation in Faecal Occult Blood Testing (FOBT) for bowel cancer screening.

### ***Failure to identify accurately trends in disease incidence and prevalence***

Senior academic researchers described in detail important secondary uses for data relating to patient ethnicity that were allowing the UK to pioneer the identification of trends within subsets of the population. The capacity to do this was felt to be testimony to the work carried out within the NHS to collect patient ethnicity data. This work was felt to be critical to the global reduction of health inequalities and to offer significant potential for cost effective advances in knowledge utilising data linkage techniques to further investigate phenomenon

of interest, such as patterns in disease incidence and prevalence; access to, and the efficacy of, healthcare services and interventions. Any failure to maintain and improve on patient ethnicity data collection within the NHS in the UK was felt to be a major risk to progress achieved in this area to date and future scientific endeavour.

## **7.4 Discussion**

### **7.4.1 Summary of main findings**

There has been a statutory mandate to collect data on ethnicity since April 1994, but coding has until very recently been extremely poor in the National Health Service (NHS). This case study therefore offered the opportunity to investigate why, despite an overarching policy and legal imperative to collect these data, there was for so long so little progress in the NHS. We observed significant variations in local arrangements for the collection of patient ethnicity data in primary care and, to a lesser degree, secondary care. This may be due in part to contextual factors, including lack of training for staff, resource constraints, variations in the extent of ethnic diversity in different regions of England and local working practices. At a national level, we noted the omission of ethnicity data within nationally procured EHRs, together with the lack of central provision of supporting resources such as templates for data collection, training and development, incentives and/or sanctions for organisations collecting this information. This was at odds with other guidance recommending the collection of this data as best practice, for example that of professional bodies such as the British Medical Association (BMA).

### **7.4.2 Strengths and limitations**

This case study sought to consult an established groups of experts in ethnicity and health in the UK. Colleagues were supportive and interested in this important area and we gained insights from a broad spectrum of contributors. A strength of this case study is the combination of perspectives from a variety of academic disciplines, senior managers from NHS Scotland and NHS England, and managerial and administrative staff working in both primary and secondary care. This enabled us to consider both the strategic importance of the collection of patient ethnicity and the practical challenges of doing so.

The main limitation of this study was our focus on demographic data relating to patient ethnicity. Due to the resources available we were unable to conduct in-depth investigation into issues relating to the capture of data relating ethnicity within clinical narratives. We did not examine medical records to consider this information, nor interview non-expert (i.e. without a special interest in health inequalities) clinical staff regarding their accommodation of ethnicity related factors within the provision of personalised care. This work is, so far as we can establish, yet to be done and we recommend it as an important area for further investigation.

#### **7.4.3 Exploring our findings in the light of the existing literature**

Ethnicity is one of the seven strands of diversity established within the 2010 Equality Act (7). Demographic data relating to patient ethnicity are required for monitoring compliance with anti-discrimination legislation, monitoring health inequalities, and informing research (2). Data relating to a more broadly conceptualised patient ethnicity, including information relating to language, culture, religion, nationality, citizenship or migrant status, support clinical decisions and inform the provision of personalised, culturally sensitive care (3). Our findings confirm existing work in relation to the collection and completeness of this data within patient records in the UK, indicating that there has been considerable time and effort invested in the implementation and improvement of processes relating to the collection of patient ethnicity data (27, 31, 33), but we note that this has predominantly focused upon demographic data only. We have sought to extend this work by considering in detail examples of local arrangements for the collection and use of patient ethnicity data in the context of relevant national requirements and guidelines. We have also considered perceptions as to the clinical relevance and meaningful use of the current data collected and coded, and the potential for more meaningful construction of patient ethnicity related data as a contingent factor enabling personalised clinical care.

We found significant variations in the methods of collecting and coding ethnicity data, confirming known practical difficulties associated with the collection of this data (34, 35). These variations included differences between the census categories applied in Scotland and elsewhere in the UK, differences due to the local specification of forms used to collect information from patients, the use of Read codes in primary care and ICD-10 codes in secondary care. These variations appeared to have been masked in some ways by discussions regarding completeness of patient ethnicity data as opposed to consistency.

That said, we noted potential value to be gained from variations in data collection regarding patient ethnicity as different clinical domains and locations may need different approaches that reflect the needs of their local communities. Approaches to the collection of this information need to be constructed to increase perceived clinical relevance and to accommodate contextual sensitivities, for example the requirements for palliative care (26) may be very different from the information needed by paramedics. Our findings indicate that currently these data are determined according to similar DH reporting requirements.

We identified exemplars of practice in promoting the collection of ethnicity data that offered a significant body of learning over many years. Staff training and the availability of resources to support the collection of patient ethnicity data were found to have significant and positive impact upon the completeness of data in Scotland. Similarly, in London much developmental and research work had been conducted to ensure services responded to the needs of a community rich in diversity. These examples of best practice could be drawn in the provision of national support and guidance to further improve this use of coded information within EHRs.

We noted the previous offering of financial incentives in primary care and the mandating of data collection in secondary care as key factors in the successful nationwide implementation of the collection of demographic data relating to patient ethnicity in the UK (31, 33-35). The sustainability of data collection in primary care was felt to be less assured given recent withdrawal of financial incentives within QOF. Meantime, the importance of these data may well increase due to the potential cessation of the UK's decennial census. We suggest that a new impetus be given to the collection and coding of demographic data relating to patient ethnicity to capitalise on the accomplishments achieved in the NHS and build capacity for the planning and commissioning of services responsive to the individual care needs and health promotion priorities of the UK population as it changes over time.

Somewhat surprisingly, despite arguments for the relevance of data relating to patient ethnicity in the provision of personalised care (19-21, 23, 32) (e.g. religion, preferred language of communication, diet-related factors etc.), how and when this information is captured within clinical narratives has not been studied for completeness and effectiveness in supporting clinical decision-making. We recommend this as a priority area for further

investigation to inform the development of patient-centred approaches to care and the reduction of health inequalities.

#### **7.4.4 Conclusions**

A key insight offered by this case study is the distinction between demographic and more clinically relevant data relating to ethnic identity and the ways in which this may or may not impact on care provision. Our findings indicate that although the collection of self-assigned ethnic category is important for legal, public health and academic purposes, it has no clear clinical value. Arguments for the collection of such data should therefore not be conflated with clinical considerations – these data need to be collected wherever possible by non-clinical staff or perhaps even by self-completion by patients, whether online, through kiosks (see Chapter 5) or any other route. It is furthermore important that a common set of categories is used across the NHS in order to facilitate both consistency of data and efficient data sharing.

This work has however also made clear that there is a range of wider ethnicity-related information on, for example, the ability to speak or write in English and dietary requirements which may impact more directly on care provision. The codification of such data could potentially be of clinical value, but these tend to be collected in free text format. Consideration should therefore be given to supporting the collection, recording and use of such data to enhance delivery of care to all sectors of the population.

This case study was deliberately juxtaposed with the case study on the recording of data on drug allergy (see Chapter 6), where although not mandated or incentivised, data collection and coding is, particularly in primary care, much more complete than it is for ethnicity. Taken together, these case studies clearly highlight that even though coding increases workload for staff, clinicians are willing to undertake this if they feel it is of benefit to them or their patients. This point will be explored further in the following case studies relating to the management of people with long-term conditions.

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## Chapter 8

### “There are too many, but never enough”: exploring structuring and coding of information in depression

#### Abstract

**Background:** Information technology (IT) systems are increasingly being implemented in an attempt to improve the quality, safety and efficiency of healthcare. Realising the potential benefits of, for example, order entry and decision support tools is currently dependant on the processing of structured and/or coded data. Mental healthcare offers an interesting perspective on the optimal balance between free text and structured/coded data because it is a long-term condition in which the need for retaining the patient and clinical narrative is perhaps most acutely felt by clinicians. There is furthermore the need to obtain a rounded appreciation of the needs of different stakeholders perspectives on this issue as work hitherto has tended to focus on either clinical or managerial viewpoints, with little or no reference to the perspectives of, for example, clinical coders.

**Aims and objectives:** We sought to explore: 1) how clinical information relating to depression is structured and coded in different clinical settings and; 2) the perspectives of and implications for different stakeholders with a view to understanding how these may, where appropriate, be aligned.

**Methods:** We conducted a qualitative case study-based investigation conceptualising depression as a case study. We collected qualitative data relating to depression from a range of stakeholders and geographical locations spanning United Kingdom (UK) primary and secondary care settings in which depression is managed.

**Results:** Our dataset consisted of 28 semi-structured interviews, one focus group, 30 field notes, seven documents relating to information on codes and/or structuring standards, and two hours' observation of coding activities. Participants consisted of a range of healthcare professionals (i.e. nurses, doctors and allied health professions), managers, and clinical coders. We identified a range of approaches to structuring and/or coding information in depression including templates and use of drop-down lists of diagnoses and interventions, but these varied between systems and settings. The complex nature of mental disorders, co-morbidity and associated issues with diagnoses were particularly prominent in primary care settings, resulting in a tension between the number of categories and clinical utility. Although

a range of managerial and research benefits were identified, there remained a lack of perceived direct clinical benefits of coding and classification systems, despite the fact that it was at the clinical interface that much of the coding related work took place, particularly in primary care contexts. As a result, we observed tensions between the tailoring of systems to increase clinical utility and the need for standardisation to obtain meaningful data for secondary uses. Participants in secondary care settings emphasised the role of clinical coders in ensuring data quality and consistency of coding, which was at odds with the current drive to increase healthcare professional coding at the point of care.

**Conclusions:** This case study has highlighted a number of important differences in approaches to coding for depression between primary and secondary care settings, these including what is coded, by whom and when. There is overall little evidence of clear-cut clinical benefits to inform immediate care decisions in primary care, where data are more extensively coded. It is likely that this will also be true with respect to secondary care. There were however a number of important secondary care uses that were appreciated by NHS staff, but the coding of data to serve these ends was often poorly aligned with clinical practice considerations. On the basis of our findings, we devise recommendations that may be applicable beyond depression and also beyond the mental health area. Strategically, these include the need to devise common standards to promote data exchange between settings, whilst still allowing for some local tailoring to make systems clinically useful. This may involve reducing the number of diagnostic categories in primary care settings as cut-off points are often difficult to determine. From a system development perspective, efforts should focus on making systems more clinically meaningful by facilitating the capturing of relationships between clinical terms within terminologies and coding of evolving symptoms. Organisations may wish to identify and draw on coding champions to promote good practice, increased training in coding activities, and to promote the relationship between healthcare professionals and clinical coders. At all levels, efforts should begin with reaching agreement on what coding systems are trying to achieve and what data will be used for as the effort to collect data at the point of care requires significant additional effort. In this context, the central drive to promote healthcare professional coding at the point of care may need to be critically reflected upon.

## 8.1 Background

IT systems are increasingly used to facilitate the safety and efficiency of healthcare (1). For these systems to operate most effectively, information needs to be processed in a structured

and/or coded format (see Chapter 1) (2). IT-based coding and classification systems can be used to generate data on performance measures, resource allocation, medical research, and billing (3,4). Similarly, structured and/or coded data entry can facilitate information exchange between different settings involved in a patient's care (4-8).

Mental health offers a unique perspective on electronic clinical information capture due to its distinctive attributes. Here often highly sensitive information is predominantly recorded as an extensive free-text narrative and diagnoses tend to be formulated over lengthy periods of times. As a result, clinical coding of diagnoses can be extremely challenging.

With the move from paper-based towards more structured and/or coded data entry accompanying IT-based systems, there is thus the need for a significant shift in recording practices in order to maximise potential benefits. In order to achieve this, systems need to satisfy not only managerial requirements, but also clinical needs of users, often referred to as *"clinical utility"* (7-10). The concept is defined as the applicability and relevance of structuring and/or coding systems to clinical practices. However, in relation to mental health in particular, the clinical utility of existing classification systems has repeatedly been questioned (7,8). As the focus is often on achieving managerial benefits, many systems fail to address communication needs between care settings, have problems fitting in with existing clinical practices, and do not aid the management of disorders (7,8). In short, they seem to lack immediate clinical benefit. This shortcoming is also recognised by the World Health Organization (WHO) which advocates that *"a mental health information system is a system for action: it should exist not simply for the purpose of gathering data, but also for enabling well-informed decision-making"*(4).

So why do mental health structuring and/or coding systems frequently fall short of clinical utility? Although there is a dearth of empirical work in this area, many have argued that existing coding and classification systems do not appropriately reflect the reality and specific characteristics of mental healthcare (8,11,12). These coding systems are often based on physical diagnoses and are not well suited to accounting for changing pathways and the multitude of professions, as well as the number of agencies involved in mental healthcare (9,11). In relation to depression, concerns have also been expressed that diagnostic systems may mask the complexity of such disorders and may lead clinicians to focus on symptoms present in a classification system, whilst potentially neglecting other significant factors such as contextual dynamics (e.g. social circumstances of patients) (12,13,14).

The particular challenges associated with structured and/or coded data capture in mental health illustrate the need for work exploring these issues further. Whilst clinical utility is clearly important, it is also vital that managerial needs are met. In the light of these developments, we sought to explore: 1) how clinical information relating to depression is structured and/or coded in various settings and; 2) the viewpoints of and implications for different stakeholders with a view to devise recommendations on how these can be aligned.

## **8.2 Methods**

As mental health is an extremely large area, we focused on the area of depression. Within depression, diagnostic categories blur and are often difficult to categorise, this illustrating potential tensions with structured and/or coded recording of information. Patient information also tends to be recorded by a variety of healthcare and other professionals (e.g. psychology, social services and the community mental health team).

Depression, the majority of which is diagnosed and treated in primary care (15), is one of the most common mental disorders with numbers steadily increasing worldwide (14,16). Codes across care settings are most commonly mapped onto the International Classification of Diseases 10th Revision (ICD-10, developed by the WHO) and the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) published by the American Psychiatric Association (APA) (17-19).

### **8.2.1 Design**

For the purposes of this work, we conceptualised the disorder depression as a case study (20-22). In doing so, we collected qualitative data relating to depression from a range of stakeholders and geographical locations spanning primary and secondary depression care settings. We also collected information from other stakeholders with an interest in the area of depression and structuring and/or coding in order to obtain a more holistic picture than would be possible by focusing on immediate care settings alone. These included clinical coders and academics.

### **8.2.2 Sampling**

We initially purposefully sampled a range of academic General Practitioners (GPs) with an interest in coding and/or depression through personal contacts (23). These interviews

helped to provide an insight into secondary uses of data and a preliminary overview of structuring and/or coding practice as well as tensions in this setting. Participants were asked to recommend other potential informants, which helped us to snowball sample additional primary care stakeholders with a variety of perspectives including those with no particular interest in coding, as well as clinical coders. This allowed us to explore the dynamics of everyday depression structuring and/or coding in primary care from a variety of angles.

This primary care perspective was complemented by a study of secondary care staff, this being facilitated by the recruitment of a mental health trust with the support of the UK Clinical Research Network (UKCRN) (24). Here, we purposefully sampled a range of stakeholders with an insight into depression and/or coding practices from a variety of backgrounds, including healthcare professionals (i.e. nurses, doctors, allied health professionals), managers and clinical coders (23).

### **8.2.3 Data generation and handling**

This case study involved a combination of semi-structured face-to-face (and telephone) interviews, a focus group, an observation of selected coding activities, and collection of documents to aid understanding of context (e.g. information on codes and/or structuring standards). Data were collected from academic GPs initially in order to gain an overview of the area and the most pertinent issues. We then conducted interviews with GP practice staff, before collecting data in secondary care. This facilitated making detailed comparisons between different settings.

Interviews represented the main data source. Key issues explored included attitudes towards structuring and/or coding in relation to depression, perceived barriers and facilitators, perceived benefits, and recommendations for improvement (see Table 8.1 for a sample interview guide).

**Table 8.1: Sample interview guide**

<b>Main structure</b>	<b>Specific topics and issues</b>
Confidentiality, aims, thanks	Theorised and actual benefits and risks, drivers, incentives, barriers and how to address these
Any questions?	
<b>About yourself</b>	Role, do you capture and store health information yourself and, if yes, what and how? (setting, profession, coding system, electronic system)
Main drivers for structuring and/or coding clinical information in depression	In what <b>instances is structured and/or coded clinical information really helpful?</b> What <b>impact</b> does the use of structures and/or codes have <b>on clinical care and outcomes, or on patient experience and engagement?</b>
Do the <b>structures and/or codes cover what you feel needs to be recorded – any areas for improvement?</b>	In terms of <b>completeness and accuracy</b> and in terms of <b>enabling good use of the information</b> Any potential <b>uses of the information that are under-exploited?</b> If yes, why?
<b>Overall</b>	
How well do the available clinical systems support structuring and/or encoding the information?	
Any <b>other barriers</b> to collecting good quality information?	
Any <b>drivers or incentives</b> that would improve the quality or uses made of this information?	
Any <b>international developments</b> in relation to structuring and/or coding in depression they are aware of?	Any examples of innovation/centres of excellence?
Aware of any other areas e.g. prisons, learning disability, homeless shelters and coding there?	
<b>Concluding remarks</b>	
Anything else?	
Thanks, any questions?	
Anyone they can recommend for interview?	
Any relevant literature?	

Topic guides were tailored to the roles of individual participants and modified in line with emerging issues. They were constantly refined throughout the research and emerging

issues were fed back into subsequent rounds of data collection. Interviews centred on issues that interviewees perceived to be important, rather than strictly following the interview schedule. These interviews therefore often took the shape of informal conversations.

A telephone focus group with clinical coders in the secondary care setting and an observation of coding activity in a primary care setting were conducted to complement interviews and to aid understanding of context (25). The observation involved the researcher practising coding on dummy patients whilst discussing activities with the relevant healthcare professional. To aid understanding, we also reviewed the existing literature, searching specifically for issues relevant to structuring and/or coding of information relating to depression in various settings.

In order to make the research process as transparent as possible, the researcher kept a field journal outlining emerging ideas and impressions. Data collection continued until no new themes emerged. All information obtained was anonymised and assigned codes so that no individual or location was identifiable.

#### **8.2.4 Analysis**

Data collection and analysis took place concurrently to allow emerging issues to be fed back into future data collection. Transcribed data from interviews, the observation, field notes and the focus group were uploaded into NVivo8 software (26). A coding framework was developed on the basis of the topic guide, and on the basis of the literature review specifically relating to coding of information relating to depression. Although this coding framework was refined constantly, the overall categories included: background and context (relating to systems, interviewees and settings); existing practices; definitions and diagnoses; facilitators and barriers to structuring and/or coding in depression; perceived benefits; and recommendations for improvement. In addition to this deductive approach to analysis and based on the coding framework, inductive approaches were employed to allow new themes to emerge from the data (27).

Initial results were discussed with the wider team and any inconsistencies and unexpected findings were explored in most detail, continuously seeking for novel and potentially unexplored evidence (28).

The necessary ethical permissions were obtained (Appendices 1 and 2).

### 8.3 Results

Our overall dataset consisted of 28 interviews, one observation in the primary care setting, one telephone focus group with clinical coders, field notes, and a range of documents (Appendix 17). Box 8.1 provides a summary of data collected and Table 8.2 provides an overview of participant characteristics.

#### Box 8.1: Summary of data collected

Primary care interviews: seven academic GPs, three non-academic GPs, a Quality and Outcomes Framework (QOF) manager and a primary care data entry clerk.

Secondary care interviews: four consultant psychiatrists, two centre managers with nursing backgrounds, a research nurse, a ward manager with nursing background, a nurse practitioner, an information service manager, a consultant geriatrician, a cognitive behavioural therapist, a physiotherapist, an occupational therapist.

Additional interviews spanning both primary and secondary care: a representative from the mental health welfare commission, a clinical coding tutor from a national information services division.

Field notes from one observation in the primary care setting lasting two hours.

One focus group with three clinical coders from a secondary care setting.

30 field notes.

7 documents relating to information on codes and/or structuring standards.

**Table 8.2: Participant characteristics**

Identifier	Profession	Gender	Setting	Method
1	Academic GP	Male	Primary care	Face-to-face interview
2	Academic GP	Male	Primary care	Telephone interview
3	Academic GP	Female	Primary care	Telephone interview
4	Clinical Coding Tutor	Female	Primary/secondary care	Telephone interview
5	Academic GP	Female	Primary care	Telephone interview
6	Academic GP	Male	Primary care	Telephone interview

7	Academic GP	Male	Primary care	Telephone interview
8	Welfare commission employee	Female	Mental health	Face-to-face interview
9	Academic GP	Male	Primary care	Telephone interview
10	Consultant psychiatrist	Male	Secondary care	Face-to-face interview
11	GP	Female	Primary care	Face-to-face interview
12	Data entry clerk	Female	Primary care	Face-to-face interview
13	GP	Female	Primary care	Face-to-face interview
14	GP	Female	Primary care	Face-to-face interview
15	GP	Female	Primary care	Observation
16	QOF manager	Female	Primary care	Face-to-face interview
17	Consultant psychiatrist	Male	Secondary care	Telephone interview
18	Centre manager	Male	Secondary care	Telephone interview
19	Research nurse	Female	Secondary care	Telephone interview
20	Ward manager	Female	Secondary care	Telephone interview
21	Information services manager	Female	Primary and secondary care	Telephone interview
22	Three clinical coders	Female	Secondary care	Telephone focus group
23	Consultant	Male	Secondary care	Telephone interview
24	Cognitive behavioural therapist	Female	Secondary care	Telephone interview
25	Physiotherapist	Female	Secondary care	Telephone interview
26	Occupational therapist	Female	Secondary care	Telephone interview
27	Centre manager	Male	Secondary care	Telephone interview
28	Consultant psychiatrist	Male	Secondary care	Telephone interview
29	Nurse practitioner	Female	Secondary care	Telephone interview
30	Consultant psychiatrist	Male	Secondary care	Telephone interview

Based on our results we have identified four themes (see also Box 8.2 for a more detailed description of sub-themes):

- Amounts and type of information coded in depression;
- Approaches to coding in depression;
- The benefits and usefulness of coded data in depression;
- Associated risks of coding information in depression.

**Box 8.2: Summary of themes and sub-themes**

Amounts and type of information coded in depression

- The particularities of depression;
- Coding needs and practices in different care settings;
- Differences in IT systems and implications for associated coding practices.

Approaches to coding in depression

- Differences in approaches to coding between care settings;
- The role of clinical coders – consistency of interpretation;
- Professional differences in coding practices;
- Tailoring of systems versus standardisation;
- Incentives;
- Innovative approaches to coding.

The benefits and usefulness of coded data in depression

- Direct benefits to clinicians and patients.

Associated risks of coding information in depression

- Coding as labelling;
- Definition of depression and diagnostic rigour;
- The number and meaningful arrangement of codes;
- Updating structures and/or codes in pace with professional practices;
- Lack of involvement of healthcare professionals;
- Impact on time spent with patients.

These themes will be examined in more detail in the paragraphs below and illustrated with illustrative quotes from the data.

### 8.3.1 Amounts and type of information coded in depression

#### *The particularities of depression care*

Most participants stated that contexts and conditions in depression care were distinct from other “*more biomedical*” areas of care, in that conditions here were felt to be characterised by a difficulty defining them, care occurred over periods of time with often changing pathways, and responsiveness to treatment tended to vary significantly between individual patients. Consequently, there were often no prescribed care pathways once a diagnosis of a mental disorder had been made.

*“It’s [referring to the depression care] fuzzy, very, very woolly and there’s lots of, no limits around things, it’s not straight-forward, a broken leg will heal in six weeks, but, you know, it’s very difficult to predict and different people benefit from different interventions because of personality traits being different so there’s no prescribed care pathway you’ve still got to use your own judgment really.”* (Interview 26, Occupational Therapist, Secondary Care)

The use of free text was therefore viewed as extremely important and although certain information would be coded, this was almost always accompanied by free text entries to reflect the subtleties of the particular situation at hand and the thoughts and feelings of individual practitioners to capture the individual patient’s journey over time.

*“And actually, you know, if you look even within, within a consultation, you know, there will be these sub headings and you have to tab through the boxes or whatever but actually often a mental health consultation will just exist in history, you know, and in that history chunk will be, you know, reports, you know, feeling more depressed this time, what’s been going on and also my, and any, you know, whether I asked them specific questions and even my thoughts and formulation may all just sit in that box because actually it comes out of my head in one chunk that is, you know, three or four lines of text.”* (Interview 1, Academic GP)

Although most stakeholders agreed that the care of people with depression was distinct from other areas of care, some GPs stated that coding in depression was in essence no different to coding in other more biomedical conditions. These individuals also tended to believe that there were clear diagnostic criteria for the disorder and their common approach was to code symptoms initially (e.g. low mood) and then add diagnostic codes once they were convinced that symptoms were persisting over time.

*“It’s not a problem, it’s like relapsing back pain or you know people with bad backs often have bad backs that flare up from time to time just like depression flares up. It’s not to me any different. And it’s not particularly difficult to code.” (Interview 13, GP)*

### ***Coding needs and practices in different care settings***

In relation to depression, GPs coded information relating to symptoms (e.g. depressive mood), diagnoses, history, and investigations. Investigation findings and treatment plans, on the other hand, tended to be inputted in free text format.

Coded information in our secondary care data collection site included recording of:

- Interventions/activities (e.g. assessment of mental state, cognitive testing, care management, advice on medication) – this was done by nurses and allied health professions for both inpatients and outpatients;
- Admission diagnoses/review and discharge diagnoses - this was done by doctors and for inpatients only;
- Clustering adult mental health users to one of 21 HONOS-based diagnostic pathways<sup>1</sup> – this was done by nurses and allied health professions for both inpatients and outpatients.

The use of computer systems and associated coding practices in UK primary care is relatively well established (see Chapter 1). In secondary care, on the other hand, computerised data entry and associated coding practices tended to be perceived as a recent development.

Despite a general agreement that the depression area somewhat differed from other areas, diverse care settings tended to draw on different structuring and/or coding systems tailored to their needs. Secondary care depression services used the ICD-10 classification system for coding diagnoses, whilst GPs used Read codes.<sup>2</sup>

Different needs in these settings may reflect the result of different patient populations. For example, although the majority of depression is diagnosed and treated in primary care,

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<sup>1</sup> This allows clustering of depression for psychosis with varying need e.g. including substance misuse, severity. It also allows clustering an individual patient’s care into potentially chosen pathways in the service.

<sup>2</sup> Please note: Read codes map reasonably well onto the ICD-10 classification, but are far greater in number.

secondary care tends to manage the more severe spectrum of depressive disorders. Primary care professionals, in contrast, tended to manage more mild-to-moderate cases of depression.

Some participants stated that, as a result of these differences patient populations, diagnostic coding in secondary care settings may need to be more granular than in primary care contexts.

*“I mean psychiatrists have always had lots of codes. I mean the fine...the fine grained detail in my opinion of diagnosis at that level is more relevant than it is in primary care.”* (Interview 1, Academic GP)

### ***Differences in IT systems and associated coding practices***

Differences in IT systems and associated coding practices were apparent in both primary and secondary care settings. For example, some systems were felt to facilitate coding of information more than others. The following extract from an interview with a GP, describing the balance between free text and coded entries in different systems, illustrates this:

*“...some systems that facilitate Read coding much more. So for example SystmOne. When you add things in you add them into a template and it tends to Read code a lot more there because you’ll add in a history Read code and then you’ll add in an examination Read Code. Whereas on Vision what you tend to do...what I tend to do at least, is you add in a history Read code and then all of the stuff that goes with it in the free text so the examination findings, the plan.”* (Interview 11, GP)

As a result of varying systems, those that used data from GP practices for research purposes often found it hard to obtain comparable data as outputs of these systems would vary significantly.

*“So that’s another problem that we’re encountering at the moment with our research cos we’re getting information from the GP...sort of twenty odd GP surgeries in south London and there’s striking differences between EMIS [Egton Medical Information Systems] which is by far and away the best and these other systems which are chaotic. In terms of how they organise. Yeah well it’s not so much in...it’s in terms of how they organise the information. So for example active problems and current problems and some of the systems you can’t tell*

*whether a problem how ever it's been coded is active or current or past. That sort of thing. So you can't work it out just by looking at it. Then you've got codings that are completely useless like we're looking at depression and heart disease so there's lots, lots, there's some systems where everybody seems to use just the term ischemic heart disease. Now that doesn't actually mean anything really. It means they've got coronary artery problems probably but it doesn't tell you any detail whatsoever and so you see that in somebody's notes and you've got no idea whether they've got angina, chest pain, whether they've had a heart attack, whether they've had heart surgery, you can't tell anything from that."* (Interview 7, Academic GP)

There were also differences in the degree to which different systems mandated coding. In some, coding was compulsory in that the system would not allow the user to move on to a different screen unless a code had been picked; whilst in other systems, users could ignore requests to code and focus on free text entry only. The latter was most commonly the case in primary care practices, possibly due to the greater autonomy of GPs as opposed to nurses and allied health professions, who tended to perform the majority of healthcare professional coding activity in our main secondary care research site that had implemented a "home-grown" computer system. It was generally stated that those systems that did mandate coding resulted in "some grumbling" from users, but over time this feature was accepted as part of their daily work.

*"Yea, it's become a mandatory part of some of the electronic screens so at certain points along the patient's care you can't complete a screen unless you've done that and it's also monitored as well so that we get, you have to complete it, it throws you into those screens automatically when you're doing your data work so you've got to do it at that point and you can't move on usually until you've done it...even if people grumble about it and don't like doing it they get used to it so the grumbles are less, you know, a year, two years on."* (Interview 18, Centre Manager with nursing background, Secondary Care)

The "home-grown" nature of the locally used IT system was in many ways perceived to be an advantage, as it meant that it was relatively easy to tailor in relation to associated codes. This was characterised by the close relationship with system developers.

*"We've found is because we've got our own system we can develop the system to capture what we need very quickly, it's quite responsive and that's kind of put us streets ahead of the other Trusts in that respect. So I think what we've decided is we won't ditch the system it's*

*actually quite valuable to us, if we bought a ready made system it would be costing us a fortune to have all these amendments made to it.”* (Interview 19, Research Nurse, Secondary Care)

*“Anything is technically possible... for example, like I said we’ve put in care clusters...and that actually you answer a load of questions and it says this patient is one of these, do you agree yes or no and most Trusts haven’t been able to do that because they haven’t got an in-house system so it is very flexible and you can do pretty much whatever you want with it.”* (Interview 21, Information Services Manager, Secondary Care)

We also encountered RiO in secondary care, this being procured as part of the National Programme for IT (NPfIT) and therefore, in relation to tailoring, quite the opposite to the “home-grown” system mentioned above. The approach here was different, in that the system was mostly based on free text; real-time coding of clinical data was therefore something of an exception. This was, according to interviewees, a deliberate strategy to engage clinical users to input data themselves as it was judged that they would be more amenable to inputting free text rather than more structured data.

*“RiO which is in London. And what they deliberately did of course as you’ll know is they didn’t put clinical codes on...they actually back-filled all the patients who’d been through their care. So they typed out all the paper records basically. And didn’t code it because it was often the subtleties in the text that was much more important than the label you slapped on somebody... there’s always a story and I think that’s why the London folk did what they did. Rather than trying to code everything, just say let’s do the free text and if we think coding will be useful, we’ll do it in the future.”* (Interview 6, Academic GP)

### **8.3.2 Approaches to coding in depression**

#### ***Differences in approaches to coding between care settings***

At the time of data collection, there was no unified coding system operating across primary and secondary care. Participants felt that this resulted in difficulties of sharing data between these settings as each coded their own information internally and there was no software that could translate between ICD-10 and Read codes. When a patient was transferred between

primary and secondary care, this information had to be re-coded, which was viewed as a duplication of effort.

*“They [referring to GPs] all use different ones and then their computer system doesn’t link up with ours so none of the codes match across primary and secondary anyway, you know, the codes don’t follow the person...they get recoded and do you know what I mean? And it’s the same from, you know, if you’re looking from Trust to Trust, if you’re looking from GP to GP, PCT [Primary Care Trust] to PCT, you know, and I know we were sort of hanging on and things about things being centralised and that’s not happening and costs and things.”*

(Interview 24, Cognitive Behavioural Therapist, Secondary Care)

Participants anticipated more direct clinical benefits from being able to share coded information between different care settings. A unified coding system was viewed as desirable in order to achieve this.

*“I think as far as I’m concerned coding needs to be...accessible to everybody because there’s no point if, I can find out at the moment if an OT [Occupational Therapist] has seen a patient but I can’t find out what the OT has done. It would be quite useful if you actually had cross disciplines so we couldn’t change what they’d put in, I can find out who’s treated the patient but I then still have to phone the OT up to find out. If you actually had this cross discipline it would make life a lot easier really.”* (Interview 25, Physiotherapist, Secondary Care)

In addition to differences in patient populations and resulting needs mentioned above, there were also differences between settings in relation to how information was coded. In primary care, GPs did some coding during the clinical encounter, whilst in our secondary care site doctors did not code themselves. Instead, their diagnosis was translated into codes and inputted into the IT system by a designated central clinical coding team. In addition, some intervention and cluster coding was done by other healthcare professionals (e.g. nurses, allied health professions).

*“They [doctors] don’t do [coding]... the clinical coding team are the ones who translate the words into the diagnosis. Now the intervention codes though the clinicians do themselves, they say what they’ve done and obviously the cluster allocations...it prompts you and says we think this client is a three do you agree, and three being a non-psychotic, moderate/severe which involves depressed mood, anxiety and other disorders, they say yes*

*that sounds like my client and they will actually accept that, mark it onto the clinical system ...*" (Interview 21, Information Services Manager, Secondary Care)

Coding by healthcare professionals was however not, as in primary care, done during the consultation. Instead, notes were taken on paper and then information was coded after the clinical encounter. This was felt to be necessary in depressed patients as there was often a significant amount of counselling involved in encounters and coding information was viewed as disrupting communication flows.

*"We just remember it and then at the end of the day put it in the computer who you saw and what you did, perhaps do a scribbly note to yourself of who you saw."* (Interview 26, Occupational Therapist, Secondary Care)

*"Because we do write quite a lot and second when we are seeing patients we have to talk the patient we can't be actually sitting in front of the computer and typing because that is practically, I guess if, from the patients point of view you can't, you need to communicate with the patient you can't just do the typing while you are talking to patients. We generally used to and trained to write while talking to patients and if there, if you don't write at the same time, you won't remember everything after so you have to write at the same time otherwise you are not going to remember everything that you discussed, our appointments are generally for 1 hour, we take all the background information and psychiatry history, personal history so it can sometime take 1½ hours so while you are talking a new assessment can be 3-4 pages so you need to have writing along as you go along."*

(Interview 30, Consultant Psychiatrist, Secondary Care)

Some clinical coders were also present in primary care. In relation to depression, they would for example translate scanned Patient Health Questionnaire (PHQ-9) scores into numeric codes and input these on the system.

*"All the post, all the clinical letters come into us, they get scanned next door and then it's then distributed to the GPs. They look at it, read it and tell us what they want to do with it."*

(Interview 12, Clinical Coder, Primary Care)

### ***The role of clinical coders – consistency of interpretation***

The role of clinical coders was frequently discussed in interviews, particularly in secondary care settings, this perhaps reflecting their concerns about the increasing drive to achieve coding by healthcare professionals at the point of care. Most clinicians stated that they would prefer clinical coders to input information for them as they were busy with providing patient care. Clinical coders were viewed as a reasonable compromise on quality (as their coding may not be as precise as that of clinicians) and on utility (as the benefit from real-time coding may be lost).

*“I actually think that, this is a compromise, it is an issue that clinicians are not coding themselves yes, the difficulty is that at the moment we don’t have within our Trust a quick way of doing the coding which means that the clinicians who are under pressure to see patients actually find that they lack the time to do it.”* (Interview 17, Consultant Psychiatrist, Secondary Care)

Some stated that coding by clinicians at the point-of-care provided a more timely and up-to-date patient record than if coding was done retrospectively by coders. In addition, increasing the amount of coding done by clinicians themselves was felt to have the potential of addressing inaccurate coding by clinical coders who may not have the clinical expertise that is in some cases necessary for accurate coding activity.

*“I suppose the problem that you get is that if it’s a non-clinical person so a data entry person having to put it in and they then have to decide what the diagnosis is if they’ve got a letter or something like that then they have to decide. Then they’re actually making sort of what they would consider to be a clinical decision...”* (Interview 14, GP)

The potential of “getting it wrong” was also reflected in accounts of clinical coders, who stated that they could only be as good as the information they were getting from doctors. They saw their job as “translating” information they were given into codes as opposed to making clinical decisions. As a result, it was felt that they could only be as good as the information they were given.

*“So a coder, and this is very, very important I think, a coder is only as good as the information that a consultant or a health professional gives them on a patient. They can’t*

*read case records and make up their mind that this patient's depressed or they've got schizophrenia or whatever, alcoholism or whatever else might be wrong with them."*

(Interview 4, Clinical Coder, Primary Care)

However, some participants, notably those that worked with coded data outputs, argued that clinical coders were particularly valuable in ensuring consistency.

*"So yeah you could, you could allow clinicians to do that [coding], certainly the inpatient ICD coding could be done at source on the ward as opposed to being done centrally by the team but it's, like I said it's a question of well is that going to make it better, worse, more or less consistent? Because to me certainly when it comes to data and analysis of data which is what we do day in day out it's about consistency and that is the biggest problem that you've got with any data because actually if everybody used the system the same way you'd know that what you got off was consistent but they don't."* (Interview 21, Information Services Manager, Secondary Care)

Coders were viewed as experts in the field of allocating codes, which was not the field of expertise of healthcare professionals. In line with this, some doctors acknowledged themselves that they had struggled to input the correct codes in the past and were therefore highly appreciative of the coders' work.

*"I'm sure there's a whole host of problems, you know, without us directly inputting the information but I do know when we were inputting things into the [name] system we were getting it wrong which meant that it was causing more problems hence it being taken back off us for the clinical information team to do."*

(Interview 20, Ward Manager with nursing background, Secondary Care)

Consistency was viewed as being difficult to achieve through healthcare professional coding, and interviews with doctors themselves supported this, as individual differences in coding practices were often identified as a threat to data quality.

*"Well people code depression in multiple different ways. So people can be you know repeatedly coded. You know they might have the same person with the same presentation but different doctors code it all in different ways, some of which are frankly bizarre."* (Interview 2, Academic GP)

*“...its probably just a quality measure that the data is completed so there are one or two people who are checking rather than relying on hundreds of people where there can be more errors...”* (Interview 30, Consultant Psychiatrist, Secondary Care)

Similarly, clinical coders were often highly appreciated in educational terms by clinicians as they would frequently phone to double-check diagnoses.

*“We kind of yeah we double check everything really just to make sure that it’s right. We then yeah. Through here we can reroute it and we’ll send it back to the GP and we’ll get them to look at it and advise us and then they will send it back and then we’ll action it again.”*  
(Interview 12, Clinical Coder, Primary Care)

*“...generally it [referring to clinical coders checking diagnoses with clinicians] also acts for the clinicians to avoid that mistake happening again so it becomes educational and then reduces further errors. So in one way this is not a common occurrence but sometimes it happens it becomes a part of education and if you didn’t write it properly maybe next time you need to write it differently so I suppose it has its positive aspects as well.”*  
(Interview 30, Consultant Psychiatrist, Secondary Care)

### ***Professional differences in coding practices***

We also observed some professional differences in coding practices, notably between doctors and other healthcare professionals. Doctors we interviewed in secondary care settings did not code at all, whilst GPs did some coding, but often felt it was an extra step and of no particular value to them or to patient care (further discussed below).

Nurses, on the other hand, were often viewed as being more used to working with structured data entry and therefore more amenable to coding. They were also viewed as being more specialised, which some felt, may also facilitate structured and/or coded data entry.

*“It’s [referring to consultants not coding themselves] just convenient for them [referring to consultants], one is it’s traditional for them but also it’s very convenient because we’ve got the facility to be able to code certain activity routinely. And also the sort of work they do is codable in a predictable sort of way, they have clinics to do certain things if you’re with me so it’s less varied in that sense. It’s very easy to manage like that where for other clinicians*

*the spread of codes might be greater.” (Interview 18, Centre Manager with nursing background, Secondary Care)*

### ***Tailoring of systems versus standardisation***

We further observed a tension between tailoring of systems to suit individual practices of users and the need for some degree of standardisation to ensure the usefulness of coded data for management and research purposes. On one hand, participants felt that tailoring of IT systems and codes was desirable in order to engage users whilst, on the other hand, some standardisation of data items was viewed as necessary in order to make meaningful comparisons with the data extracted from the system.

*“...we’ve had some teams who’ve actually developed their own codes that they’re happy with, that reflect the way that they work...I’ve spent a lot of time trying to get people to put the data into an IT system and the way to do that is by showing them that they can make use of the data afterwards, but they can only really do that if that data is meaningful to them so I think there are real advantages in letting teams develop their own codes and their own systems of work because then they can make use of that data, they’re happy with it, they’re familiar with it. Obviously the big drawback of that is it’s very specific to that team and you can’t make comparisons across the board.” (Interview 19, Research Nurse, Secondary Care)*

Approaches employed to try to address this tension included the use of templates in both primary and secondary care settings, and formularies in primary care settings. These allowed tailoring of items to reflect individual ways of working and needs, whilst at the same time ensuring some degree of standardisation. For example, one GP described how formularies of code items offered in a drop-down list could be set up as defaults at practice level:

*“...you can develop a formulary so that when I put in DEP for depression, I don’t get every possible depression code. Or indeed every possible thing that comes up starting up DEP...It will actually just give me the ones that the practice prefers. I can move beyond that if I don’t like any of the ones I’m offered...it makes it quicker. So that I can for example, and I can tell it, I don’t know that everybody in the practice knows this. But I can tell it what I want to come up. I can dictate what comes up when I put up DEP so if I want a specific Read Code to always come up, I can tell the computer that when I put DEP in, that’s what I want it to...all*

*my partners have the same choice as I do. Which means that there is power in certain hands and that of course is very useful if you're trying to get some sort of consistency."*

(Interview 5, Academic GP)

Templates were also used to ensure more consistent and accurate coding. These were devised by individual organisations relating to various conditions and/or for different practitioners. They consisted of screening questions, assessments, reviewing treatments, reviews, care plans and treatment plans. Templates guided the clinical user through a series of items that were automatically translated into codes. This was assumed to make data input more user-friendly by translating abstract codes into text-based workflows.

*"And they [referring to templates] will have all the correct Read Codes within this template. So in other words when the doctors...can choose a diagnosis and it's already coded. So it's a click button exercise rather than...they hate entering and hopefully that's what they told you? Because I...my understanding is they hate putting in codes and they like to do it this way or type in wording rather than actually physically putting hash, G3064. "*

(Interview 16, Clinical Coder, Primary Care)

However, these templates, although commonly used by nurses and allied health professionals, were less frequently used by doctors, as they were still viewed as too restrictive and time-consuming.

*"Nurses tend to fill out templates whilst doctors don't, nurses are trained to fill in templates, templates are "huge" and too much work to fill in, she feels that it is a bureaucratic exercise."*

(Observation notes, Primary Care)

### ***Incentives***

The main incentives for coding information in relation to depression across care settings were identified to be financial. In primary care settings, participants referred to the QOF in this respect. Depression was one of the conditions included in this payment incentive scheme in April 2006 (29). QOF encouraged GP practices to submit activity levels in relation to certain conditions to commissioners in order to get paid. GPs themselves were acutely aware of this and many stated that QOF was the main incentive to code information relating to depression.

*“I don’t see any value in encoding any specific bits of that other than a particular depression score which I get paid for recording and why else would I do it?” (Interview 1, Academic GP)*

*“It’s [referring to QOF] been one of the major ways that GPs get paid. And in order to conform to the Quality and Outcomes Framework, you code various diseases and then you provide an auditable standard of care. For example in depression you would code the depression and then you would have to have shown that you’d assessed it using a pencil and paper questionnaire such as the PHQ-9 and that you’d re-examined the patient after five to twelve weeks using the same questionnaire. And if you do all of that, if you conform to all of that, you will get paid. And your payment is based on the proportion of those patients diagnosed with depression according to your coding that you’ve...to whom you’ve administered these questionnaires.” (Interview 2, Academic GP)*

However, in some ways QOF was also found to discourage coding of major depressive episodes. GPs were often reluctant to code this as it meant that they had to administer the PHQ-9 and follow up after a certain amount of time. Consequently, many coded under less specific symptom codes such as ‘low mood’ to avoid these lengthy protocols, particularly if they were not absolutely clear if a particular patient was actually depressed.

*“Because until you are going to do the whole thing you know do the scoring, put them on for follow-up because some of the quality indicators of the care of depression that follows the diagnosis, there is quite a clear piece of advice that you don’t put the diagnosis until you’re prepared to do all that stuff.” (Interview 3, Academic GP)*

Many implied that there may therefore be a higher prevalence of diagnoses of depression than data from GP coded diagnoses reflected.

*“I think it’s from five to twelve weeks after you diagnose somebody and started treating them you get paid for seeing them again and reviewing them. What...and then what’s happened is...that the GPs have thought well actually if this is the patient that is unlikely to come back at five weeks or six weeks or whenever it is, I’m going to call them something else altogether and so. So they’ve been coding them as adjustment disorder or something...rather than major depression. So the you know the rates for major depression have probably gone down.” (Interview 7, Academic GP)*

Some participants also stated that the quality of coding in conditions that are not covered by QOF may suffer. These may include other mental health conditions.

*“So QOF and non-QOF would be quite different. When it’s non-QOF I would have thought the...there’s less incentive to code well...conditions which aren’t in QOF get a bad deal, they don’t get the same attention because they’re not...because there isn’t a reward or an incentive.”* (Interview 7, Academic GP)

In secondary care, the financial incentives to code were dominated by Payment by Results (PbR). This scheme, which is currently being rolled-out across mental health Trusts England, requires Trusts to submit activity levels to commissioners and, similarly to primary care, was to determine how Trusts were paid. Many participants stated that accurate coding was crucial to get adequate financial reimbursement reflecting diagnoses and treatments given to patients. This was felt to be exacerbated by the current tight financial climate.

*“...as we move into Payment by Results...will really be dependent on the coding and, because the coding will give some indication of severity and the sort of treatment that the individual needs so coding and accuracy there will actually potentially penalise us financially because if a person is given the wrong code, you know, if they’re given a generic code for depression rather than the sub-categorisation we may not be paid according to the severity of the condition...I mean this is not blackmail it’s the truth there are no pots of money in the NHS that we can turn to and the only thing that we’ve got left is staff reduction if we lose budget.”* (Interview 17, Consultant Psychiatrist, Secondary Care)

*“I think people will probably be more likely to code better. If people realise that they’re not going to get paid unless they’ve actually done things for the patient they’re more likely to put correct stuff in...”* (Interview 25, Physiotherapist, Secondary Care)

In addition to financial incentives, some users also stated that tailoring of coding systems in line with individual preferences or frequency of use would motivate clinical users. It was also felt that, as the effort of inputting coded information was significant for clinical staff, they desired some kind of feedback as to what the data they were inputting was used for.

*“The problem with that is you’re given a list to choose from...you could spend half your life putting it on the computer so I suppose that...sort of begs the question to people like me of what do I want to put this on for, you know, where’s it being used and if, because I’ve been*

*working for 30 years now and so about 20 years ago we started recording data like this...very, very detailed but it was pre computer so we did it all on paper and we discovered that all this paper we were generating was being stored and not used so, you know, that sort of thing would de-motivate staff. So I think built into the system there does need to be some sort of feedback to the person who's inputting that's useful to them."* (Interview 26, Occupational Therapist, Secondary Care)

*"...the reason people don't see benefit is because there is no feedback mechanism to feedback from, so that may be the reason but if you do get a feedback on sort of the quality aspects of your case load or diagnosis and other thing then I guess it becomes more relevant to the clinician."* (Interview 30, Consultant Psychiatrist, Secondary Care)

### ***Innovative approaches to coding***

Some innovative approaches to inputting coded information were also discussed in interviews, although these took place in other settings that participants had heard of or experienced in previous employment. For example, one participant described a surgeon who, when operating, spoke out loud and a nurse coded the information simultaneously and in real time using the Systematized Nomenclature of Medicine – Clinical Terms (SNOMED-CT).

In addition, many participants mentioned the importance of exploring alternative interfaces for data entry to facilitate coding by clinicians as close to the clinical encounter as possible. Here, it was felt that if coded data entry was made easier and faster for clinical users, this would promote coding.

*"You need to bring coding into the point of the encounter otherwise it's always rubbish...interface design is absolutely crucial. People aren't averse to coding. If you ask ordinary clinicians why don't you code very well? They say haven't got the time, don't type very well and it's too clunky and things like that. If the coding was faster than putting in loads of text, people would do it at the drop of a hat and that's what we need to do. We need to get the interfaces which are slick enough and flexible enough that people can code on the fly."* (Interview 9, Academic GP)

The potential of voice recognition, natural language processing (NLP) with systems offering codes whilst users are typing in free text, and portable hardware devices such as iPads was

felt to be of particular importance in order for systems to integrate more effectively within individual workflows.

### **8.3.3 The benefits and usefulness of coded data in depression**

For some clinicians coding was seen as *“just more work”* and *“an extra step”*, but it was generally accepted amongst those that did code as part of their work. Although participants' views in relation to benefits and usefulness of coded data varied to some extent, depending on the background of the interviewee (e.g. clinical user, management, research) and the IT system they were using, some central themes emerged from our analysis. Perceived benefits of coding information were mainly stated to include drawing on information for management and research purposes.

In relation to the former, many participants across care settings mentioned the potential of using coded information for local audits. This was seen as immediately useful not only for organisations, but also for individual teams as it allowed an insight into activity levels and helped to monitor patient populations. In many instances, the information obtained would be used for allocating resources for services where they were needed most.

*“It’s about teams understanding their own activities, their own ward, you know, what’s going on in the ward, you know, admission rates, discharge rates, average patient stay, average age of patients and it does break down into diagnosis as well which from a team point of view is very helpful for us to understand what’s going on in any given month really and appreciating, you know, the throughput and, you know, what conditions people are experiencing, whether we’re catering for the majority and so, you know, it’s a regular review.”* (Interview 20, Ward Manager with nursing background, Secondary Care)

Similarly, and perhaps because coding was so intimately related to payment, drawing on coded data was often viewed as a way to get paid and monitor spending as it would indicate what interventions and treatment each patient had received.

*“So from where I’m sitting when I’m looking at an audit package that sits behind this which is here, those codes then don’t go into the audit and say yes that’s been done correctly, suck the data out to QMAS [Quality Management and Analysis System] who then pay the doctors. They’re then paying them on less than they’ve actually done.”* (Interview 16, Clinical Coder, Primary Care)

Information on activities further tended to be used for feedback of clinical performance to teams and individuals as well as a means to manage effective working.

*“And also feeding back to the team so at some point, you know, you’ll be able to say to individual practitioners look what we’ve learned when we look at the work you do is that actually you spend most of your time doing this, and some time doing that and it’s got to help us in terms of managing cases and the efficiency of the team.”* (Interview 18, Centre Manager with nursing background, Secondary Care)

Data on patient populations were often used to facilitate care planning by tailoring the service provided to the conditions that patients presented and planning care pathways specifically targeting specific conditions.

*“...we’re already beginning to see, you know, especially as we’re a secondary service we actually see currently where most of our kind of clients are coming from which currently are the mild to moderate conditions, anxiety and depression or the on-going and recurring psychosis with then this sort of off layers around that within the other clusters so it’s giving us an idea of the kind of client...we can actually have care pathways so specific care pathways for people who are referred so if you come through on this particular cluster, say with anxiety and depression and we’ve got an anxiety and depression program and we can offer specific interventions that are identified as being therapeutic evidence based to actually help people to address their condition.”* (Interview 27, Centre Manager with nursing background, Secondary Care)

The potential of coded information for research purposes was also frequently mentioned. Participants expressed this mainly in relation to disease registers and epidemiology.

*“There are people who do quite a lot of research on depressive illnesses and allied things like alcohol abuse and all that sort of stuff ...”* (Interview 6, Academic GP)

Some also felt that coding systems promoted faster diagnoses as opposed to being entered earlier in the diagnostic pathway, which they stated, had the potential to help in relation to medico-legal considerations such as defence against lawsuits.

*“Well put it this way, here’s a real benefit for you. GPs have seen their defence premiums rocket over the past 10 years. I mean they’ve gone up four-fold I think in 10 years. Because*

*more and more GPs are getting sued, failure to diagnose promptly is the commonest cause of GPs being sued.” (Interview 9, Academic GP)*

### ***Direct benefits to clinicians and patients***

Despite these indirect benefits to patients, some interviewees stated that coding had very little value for direct patient care. It was felt that in terms of the clinical encounter itself, the process of coding was *“just more work”*, designed to achieve organisational, as opposed to direct patient or clinical, benefits.

*“Clinically it feels like you’re doing it really for the organisation rather than for any benefits for the patients... it’s just time out that’s not helpful, it feels like you’re feeding information back to the Trust for commissioning purposes so that you get paid basically rather than it being a clinically useful tool.” (Interview 24, Cognitive Behavioural Therapist, Secondary Care)*

*“I don’t believe myself; myself a clinician or especially the patients can get any benefit out of it. The only ones who get kind of benefits out of it is of course it informs the Payment by Result system, it’s of no benefit to anyone really especially the patients.” (Interview 28, Consultant Psychiatrist, Secondary Care)*

Many clinical users therefore felt that coded data input was a time-consuming administrative activity, which often detracted from the focus of delivering patient care.

However, when prompted, some participants did outline direct benefits of structuring and/or coding to clinicians and patients. In both primary and secondary care settings these included, for example, the ability to obtain an overview of information on the summary screen, and the ability for different healthcare professionals to share patient information.

*“... if you are interested in it and the patient’s coming in and feeling low again, you would see that at the front page of their notes, ah they’ve had it before and you do that and you can get the details. So you open the book and get the details. So that’s a very useful thing and it’s very good for other doctors to have some important information.” (Interview 13, GP)*

*“And also for a clinician who perhaps is new to an area and takes over someone’s care to have a brief history in front of you...we tend to get a lot of people in the system, secondary care mental health who, you know, it’s their life, they’re in and out and in and out...so you*

*don't know what sorts of interactions they've had or not had, they're not sure whether it was cognitive therapy or psychotherapy or just counselling, they can't tell you so to see something that gives an overview of a history is useful.*" (Interview 26, Occupational Therapist, Secondary Care)

Some participants also mentioned that coding of information allowed tracing of developments over time, which was particularly valued in relation to depression as conditions were often changing subtly over extended periods. In relation to depression, for instance, the PHQ-9 was frequently mentioned in primary care settings as it was administered over different intervals. The scores were then inputted into the system, which allowed GPs to obtain an overview as to how the patient responded to treatment.

*"Historically it's been tell me how you are today and I will kind of construct the timeline or we will construct the timeline but the idea that part of that function can be done by repeated completion of the same questionnaire about a month or two apart probably is a transformative technology which we may start to see more of."* (Interview 1, Academic GP)

The potential of structuring and/or coding to facilitate adherence to quality indicators was also mentioned. This was particularly valued in the context of using templates, which were perceived to be able to guide clinical decision making by ensuring that appropriate aspects were considered.

*"Are they boozing? That is on that one [pointing at template]. This is our system for monitoring lithium because that's a very dangerous drug to be prescribed without monitoring. This mental health quality indicator form... is more patient relevant. And it actually covers all the things you would cover as a clinician."* (Interview 13, GP)

Other direct clinical benefits included the use of coded information for clinical decision support systems, and the potential of facilitating medication reviews (e.g. allowing to link problems to medications)

#### **8.3.4 Associated risks of coding information in depression**

##### ***Coding as labelling***

Many interviewees raised the difficulty of fitting complex mental health conditions into coded categories as they felt that context was often lost. Information reflected in free text was

therefore valued, whilst coding was perceived to facilitate labelling and force-fitting patients into boxes.

*“...the clinicians are always saying, you know, you’re putting people into boxes...the clinicians are saying people don’t fit in these boxes, you know, they’re more complex than that.”* (Interview 19, Research Nurse, Secondary Care)

*“I think one of the biggest issues of coding is the fact that you try and, the coding you see on screen is a summary, a variety of other codes if you like, you know, they’re simplified on screen for you to be able to code within an area and sometimes it can be hard to translate what you’ve done into a code and I think that’s always going to be the case...I think in mental health generally. I suppose in my naive way I always imagine that in the world of physical health that coding is a much simpler activity, I could be wrong there.”* (Interview 18, Centre Manager with nursing background, Secondary Care)

*“Sometimes people just don’t fit the coding within the ICD-10, especially people who come in, it’s probably more social related problems and you’re actually trying to fit them into the ICD-10 rather than the ICD-10 being created to match the general public really...but sometimes you are putting a square peg in a round hole.”* (Interview 29, Nurse Practitioner, Secondary Care)

As a result, clinicians tended to find it hard to choose an appropriate coding category, often picking the closest match as opposed to an accurate description of activity.

*“You do have a drop-down list, somebody somewhere has decided what’s on the drop down list and it doesn’t actually cover, myself and my colleagues frequently say well that doesn’t cover what, there’s nothing on there that covers what I’ve actually done and so you sort of, you’re almost guessing well shall I put that or shall I put that.”* (Interview 24, Cognitive Behavioural Therapist, Secondary Care)

As a result of the perceived issues surrounding the rigidity of applying labels to complex mental health conditions like depression, clinicians particularly in the primary care setting (that dealt with the less severe spectrum of the disorder), were often hesitant to apply diagnostic codes due to the uncertainty surrounding the persistence of symptoms and the potentially contestable nature of diagnoses.

*“There are big issues around coding, you know, the rigidity of which you apply labels and the permanence that you apply to codes so, you know, there are certain things that are non-negotiable, diagnosis of bowel cancer it’s pretty non-negotiable, it’s there it’s concrete. Diagnosis of depression is contestable, diagnosis of paranoid psychosis is contestable between a doctor and a patient but as the doctor keeps the records the doctor wins”* (Interview 1, Academic GP)

This reluctance was further exacerbated by the potential ramifications of depressive disorder diagnoses beyond the clinical care setting. For example, the associated stigma as well as the potential of an individual being included in the mental health register as a result of coding activity, was felt to have potential implications for insurance reports and occupational health screening.

*“...because it’s depression and because of the stigma attached to it potentially Read Codes with that are more powerful for the patient. Just thinking with regards you know specifically to insurance and occupational health things and jobs. And you know it shouldn’t make a difference if a patient’s had a previous diagnosis of depression when they go for a job but you never know whether it does and whether that’s really the reason why they didn’t get a job.”* (Interview 11, GP)

*“So that would possibly be something that would go on a mental health register so OK yes a doctor puts on depression and if they just do it without thinking of what they’re putting on, they’ve actually diagnosed that patient with a mental health illness. And it will go on to a mental health register.”* (Interview 16, Clinical Coder, Primary Care)

Although these issues surrounding labelling through diagnoses were not apparent in secondary care settings, potentially due to this setting managing the more severe spectrum of depressive disorders, in some instances clinicians in secondary care were reluctant to code potentially sensitive issues as these may be seen by patients yielding a negative reaction (e.g. personality disorders or suicide risk).

*“So somebody might come and somebody saw a doctor or somebody has assessed them and they’ve got depression but in secondary care a lot of people have got a co-morbid personality disorder as well but nine times out of ten it’s only the axis 1 problem that’s coded anyway because the patient hasn’t been told that they’ve got a personality disorder.”* (Interview 24, Cognitive Behavioural Therapist, Secondary Care)

### ***Definition of depression and diagnostic rigour***

There were also perceived issues surrounding the definition of depression, which further complicated diagnostic coding. This is related to the multi-dimensional nature of depressive disorders, and the fact that there were no biomarkers to help determine diagnoses. In primary care settings where clinicians tended to deal mainly with the less severe spectrum of the disorder, GPs stated that they needed to be cautious in applying diagnostic labels as some individuals presenting with depressive symptoms may not necessarily be depressed, but merely experiencing a bad day or a normal reaction to adverse life events.

*“But yeah I think there’s still, you have to be careful with labelling people. And yes it might be you know is it a depressive episode because their serotonin levels are low? Is it that actually they’ve just got too much on their plate at the moment and they’re juggling you know a couple of jobs and a family and you know various other bits and pieces. You know is it because actually their partner’s just lost their job and finances are tight and actually it’s stress and worry about that which isn’t entirely appropriate and not depression.”* (Interview 11, GP)

Similarly, GPs noted that diagnostic coding of depression was complicated by the difficulty in determining a cut-off point between severity levels as the disorder tended to occur on a continuum.

*“I mean that...so if I’m not, at what point am I maybe have a bad day, late night, not working very well, oh can’t be bothered I’m going home. I’m not depressed. Am I depressed? And at what point do you say now you’ve got clinical depression?”* (Interview 6, Academic GP)

The difficulty of applying diagnostic codes was further felt to be complicated by the fact that depression often co-occurred with other conditions such as anxiety.

There were also some concerns that screening tools such as the PHQ-9 were not appropriate for determining diagnostic codes. Most GPs saw the questionnaire as a bureaucratic exercise as it was required for QOF, rather than a tool to assist them with the diagnostic process.

*“They require you to use it, I think within a month of diagnosis and then again within five to twelve weeks for a repeat one as well. I’ve started to make it work for me and for the*

*patients. But I think it is a bit of a jumping through hoops exercise if I'm honest."* (Interview 11, GP)

In secondary care, issues surrounding cut-off points were less pronounced as this setting often tackled more severe cases, but a few participants raised concerns about the diagnostic rigour associated with different types of depression and the resulting representativeness of coded data.

*"My concern about coding is that it's associated with accuracy in diagnosis and I feel that we are diagnostically sloppy and using depression as an example there are several codes associated with depression depending on the symptomatology and the severity and it makes a big difference because as we move, first of all it makes a big difference in terms of passing information on, in terms of epidemiological data and treatment as to which subsection of depression we code at."* (Interview 17, Consultant Psychiatrist, Secondary Care)

### ***The number and meaningful arrangement of codes***

Participants across care settings further expressed a tension relating to the number of codes IT systems offered. On one hand, existing code lists were felt to be too detailed resulting in a large number of items which users had to browse, whilst, on the other hand, items included in lists often did not accurately reflect diagnoses or interventions. This led some to conclude that *"there are too many but never enough"* items at the same time.

*"You know there's anxiety with depression, there's recurrent depression, there's depressed mood, there's loads of them, ok? So you have to select a suitable Read code and Read codes have two...they are...they're never exactly right. They are...there's either too many of them so you don't know which one to chose or there's not enough because the one circumstance that you've got sitting in front of you isn't the one that's got a code."* (Interview 5, Academic GP)

This tension was felt to be particularly pertinent to the mental health setting as patients would often present with a range of complex conditions that were difficult to categorise.

*"...most of our patients don't have just one problem, they have, many of them also have kind of personality disorders or substance misuse problems. I mean it does make it horrendous for that also, that would have been a better system to use really but we don't, we use the ICD-10 which actually, you know, to find the diagnosis really but sometimes you scratch your*

*head and you say where do I fit him? ” (Interview 28, Consultant Psychiatrist, Secondary Care)*

The large number of codes often meant that users had to spend extensive amounts of time browsing lists. These were felt to become increasingly meaningless due to the subtle distinctions between items which resulted in a potential applicability of any given condition/intervention to more than one category.

*“...if you’ve got too many codes then it’s problematic for people to find, it’s time consuming because they can’t find the right one. You have to be very specific so you have to sort of narrow that down to something that people can work with but in doing that I think that... it loses the meaning and it’s really difficult to get that right. So what you find is you get a list of words that kind of become meaningless.” (Interview 19, Research Nurse, Secondary Care)*

Participants therefore recommended that, to increase clinical utility of code lists, the number of codes relating to depression should be reduced to more overarching categories as then individual diagnoses and interventions would be easier to fit into these.

*“Yea, part of the problem is that there are, because of the way Read is structured there are a very large number of codes and there are a very large number of codes, there’s about 20 sub-codes for depression most of which are, you know, depression, moderate severity first episode or, you know, moderate severity second episode so there are branches that just multiply number of codes and so if you put it in depressed you get a whole bunch of codes and really what you want is one useful code. So yeah there are, so there’s a problem, you know, you end up being spoilt for choice with codes most of which aren’t good, you spend so long trying to work out which classification does this belong to and actually all you want is one code that just says depressive episode, that’s fine, that’s really all I need” (Interview 1, Academic GP)*

Some participants also stated that they would like to see a more meaningful arrangement of codes based on hierarchies to address the problem.

*“...the Read coding system is...has far too many useless alternatives, it’s highly illogical and I think at some point some good person is going to take this one on, get rid of Read and you know give us a better simpler coding system that we can use. It would be simpler and it would have a clear algorithm with branches. You know it would just be a simple branching coding system. And someone would take Read out and beat him. To punishment and take*

*all this money away. He must have made...who is he anyway? I'm going to look him up while we're... on the internet...Dr John Read. I've got...I really got a bee in my bonnet about this."* (Interview 2, Academic GP)

### ***Updating structures and/or codes in pace with professional practices***

Participants, particularly those in primary care settings, expressed concerns that Read Codes were not being de-commissioned without any efforts being directed at updating and (re-)organising the codes in line with evolving professional practice.

*"I mean James Read wrote the Read codes 25 years ago as a clinician and early informatics guy 30 years ago, well, you know, a long, and just sat down with a kind of classification system and they are relatively dead codes, they're relatively stagnant in that people will add to them as the need arises but there is no, to my knowledge there's no kind of systematic tidying up and, you know, housekeeping going on that would say right well we're going to get rid of this bunch of codes and we will run, you know, you could legitimately probably do some kind of housekeeping script where you just say right well we'll change, you know, we'll map that to that, that to that, that to that and we'll just clear these out."* (Interview 1, Academic GP)

### ***Lack of involvement of healthcare professionals***

Most healthcare professionals felt detached from the development of codes, which possibly arose from and contributed to the lack of clinical utility described above. They often felt that the use of coding systems was externally imposed and stated that clinical users lacked choice in relation to which items were included.

*"It seems nobody ever asks the clinicians, and I'm not talking about centre managers even because some of them don't see patients on a one-to-one basis, nobody ever comes to the people that actually see the client and says what would be helpful it's all imposed on you...I'm not aware of any ground for people that have been asked what do you want on here? What would be helpful? Why would it be helpful and this is what we're going to do with it, do you know what I mean? "* (Interview 24, Cognitive Behavioural Therapist, Secondary Care)

This was exacerbated by the fact that many clinical users were unsure as to why they were recording coded information and what exactly the data were used for. This was particularly prominent in secondary care settings.

*“Well the big issue for me is that I have no idea what the purpose of it is. I literally have no idea because nobody, I’ve only been doing it for about three months and what has happened is I’ve been told how to actually use the programme but not the purpose of the program. I mean what I understand is it’s to do with Payment by Results but whether it means the Trust get more if I code somebody as a 17 or if I code them as a 16 I don’t know. Whether the way in which I treat a patient ideally is altered by what the number is of the care cluster I don’t know because nobody has explained that to me.”* (Interview 23, Consultant, Secondary Care)

### ***Impact on the time spent with patients***

Overall, clinical users found it hard to juggle the demands of data input with delivering adequate patient care and cater for the complex demands of depressive patients. This was particularly pronounced in primary care settings, where consultations were typically shorter than in secondary care settings.

*“And so what you do is you try and talk to your patient and then quickly enter everything on to the template. But you have ten minutes. Before somebody comes in and interrupts you, will you just sign this prescription, then the phone rings and somebody says oh doctor there’s somebody in treatment room, I think they’ve got cellulitis, will you just run across and see if they need antibiotics. So you do that, so you’ve then got six minutes. For a psychiatric patient, to assess them and make all the notes. It’s not actually possible.”* (Interview 13, GP)

Clinical users therefore in some instances felt that coding activity took away valuable time from patient care.

*“... it means that in the mean time you’re spending more time on the computer and it’s, you know, all these things add up, you know, and meanwhile there’s a patient out there that actually wants some good care.”* (Interview 24, Cognitive Behavioural Therapist, Secondary Care)

Coding was often viewed as a bureaucratic exercise with no particular purpose in itself and a lack of meaningful reflection on what clinical activity had actually taken place.

*“Now I had a few debates about that, how can I give a diagnosis to a patient that I don’t believe he has just because I have to give a diagnosis. I mean coding becomes really the, you know, it, coding becomes the main target, not really to treat the patient, it becomes the main aim. We have to code and who cares about what the patient really has, I mean it’s all about coding and it has become kind of too much.”* (Interview 28, Consultant Psychiatrist, Secondary Care)

Again, this was felt to be particularly pronounced in the mental health area, where the quality of contacts with individual patients was often viewed as more important in relation to outcomes than the quantity of consultations.

*“...it is a worry to me that quantity takes over from quality and...we’ve seen this many patients, this many episodes and this many contracts with this staff and it’s actually quite meaningless because, you know, 20 contacts sounds great but you could be doing nothing with them whereas one decent thorough contact that does something, the real clinical outcome could be, you know, very worthwhile and it sort of, it’s going hand in hand with being attached to the measuring effectiveness and researching what’s effective.”* (Interview 26, Occupational Therapist, Secondary Care)

In primary care settings, where information was coded during the patient encounter, some GPs also felt that coding activity interrupted the flow of the consultation.

*“Well it’s just...it’s just not how you think. I mean does it take much longer I mean, typing and writing and code selection and things? I’m not sure which takes the longest, I just know that it’s not how you think. It’s contrary to the flow of a consultation because I am trying to put down a story the patient’s given me, my impressions of it, along with a few brackets to explain why perhaps I didn’t do something or I thought about the other or reminding me what I’m going to do next time or whatever it is. It’s a story I’m putting down.”* (Interview 5, Academic GP)

## **8.4 Discussion**

### **8.4.1 Summary of main findings**

We have described approaches to structuring and/or coding data in primary and secondary care settings using depression as an exemplar condition. By drawing on a range of

stakeholders, we have outlined how differences in settings and IT systems have shaped approaches to coding in complex mental health conditions. In exploring tensions across care settings, we have discussed the role of clinical coders in ensuring consistency, professional differences in coding practices, and the tension between standardisation and tailoring of systems. Incentives to coding information were mainly financially driven, with a lack of benefits for clinical users and direct patient care. However, the potential of drawing on coded data for management and research purposes was noted as being substantial. We also identified a range of potential risks of coding information in depression, these including, in primary care, reluctance to diagnose patients with major depressive episodes due to a lack of agreement on definitions, and the potential ramifications of diagnoses for patients' personal lives. In secondary care, such concerns were less pronounced as this setting treated the more severe spectrum of depressive disorder. Nevertheless, there were some concerns relating to diagnostic rigour, the appropriateness of clinicians spending time on such activities, impact of coding activity on time spent with patients, and the lack of involvement of healthcare professionals in system development.

#### **8.4.2 Strengths and limitations**

We have collected data from a range of stakeholders in a variety of settings. As far as we are aware, this work is the first empirical attempt to explore the approaches and needs to structuring and/or coding information in depression. We have used depression as an exemplar condition to focus our data collection, but our findings may be transferable to other mental health conditions. Mental health clearly varies from the more biomedical areas which have traditionally been the subject of empirical work on coding benefits and practices. Based on our work we have devised a range of recommendations to align different stakeholder perspectives and thereby derive maximum benefits from structuring and/or coding practices.

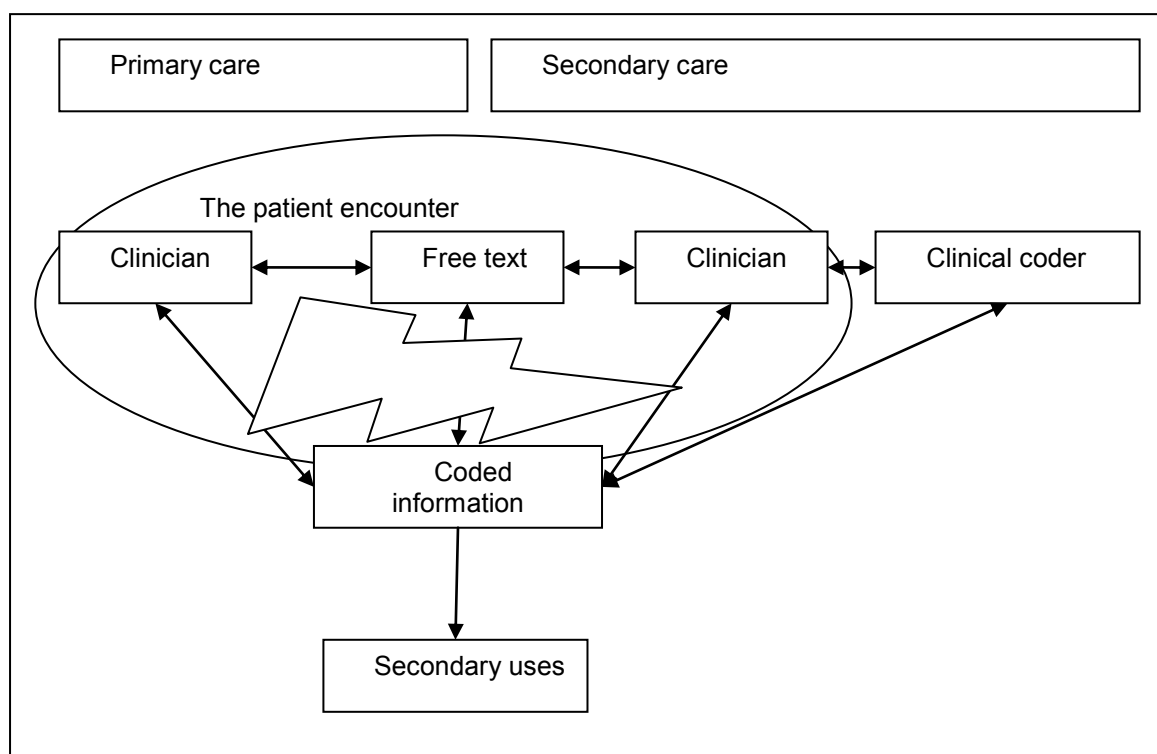
Nevertheless, there are also some limitations, which need to be acknowledged. For instance, our efforts lacked an insight into system developers' perspectives. We have attempted to speak to these stakeholders, but commercial sensitivities associated with system designs complicated access to willing participants. There is clearly a need to obtain this perspective, which may be achieved by incentivising commercial players for participating in research, whilst ensuring protection of their commercial interests. This may best be achieved through legal arrangements directly between universities and industry.

Moreover, our data would have been enriched by more in-depth observations of structuring and/or coding activities across care settings. Our exploratory focus in an area that lacked empirical insights meant that interviews were appropriate in the context of our study. However, exploring how best to integrate different systems within complex individual user workflows and derive maximum benefits for all concerned, warrants the need for some more targeted in-depth observational work in individual settings. This should also include drawing on multi-disciplinary focus groups to explore potential ways to achieve this through consensus building.

### 8.4.3 Exploring our findings in the light of the existing literature

We have summarised our findings graphically in Figure 8.1 below. Individual components of this model will be discussed in turn and integrated with the existing literature.

**Figure 8.1: The relationship between approaches to coding, efforts and associated benefits in depression**



Overall, we have identified aspects surrounding coding and classification of mental health systems that have to date received little attention.

Firstly, we have shed light on the often neglected perspectives of clinical coders and compared and contrasted some of the trade-offs between coding by healthcare professionals during the clinical encounter and retrospectively by clinical coders. Although there is generally a drive to increase coding at the point-of-care to improve data quality, our results suggest that this may in fact lead to decreases in data quality by increasing inconsistency of coding. The implicit assumption that coding at the point of care is desirable should therefore be questioned in the mental health setting and perhaps beyond.

Secondly, there are often implicit assumptions about the benefits of coding and classification systems. Our results have confirmed that the potential of drawing on coded data for managerial and research purposes is indeed significant, but direct clinical benefits are currently lacking. This is despite most efforts being invested and most risks occurring at the micro-level. These included a perceived reduction in the quality of patient contact due to increased administrative activity and potential implications of coding patient diagnoses of often stigmatising mental health conditions.

### ***Structuring and/or coding complex mental health disorders***

Existing coding and classification systems are based on groupings of symptoms and presumed causes. As opposed to many physical conditions, however, the definition of mental disorders is extremely complex, which was reflected in our participants' accounts. Diagnoses of depression were perceived to be subjective and often changing over time with causes being contested. Participants also raised the many potential interpretations of symptoms, particularly in the primary care setting where less severe depression tended to be diagnosed. These findings are in line with ongoing discussions in the literature (3,8,9,11,14,30). Different mental disorders may have diverse and overlapping causes to differing degrees – some of these may be biological, but some may be experiential (9,14). Despite an increasing recognition that classification and coding systems need to take this complexity into account, existing systems are often viewed as inadequate resulting in inaccurate coding or codes that may not necessarily reflect reality (3). These tensions illustrate the need to balance classification systems without masking the unique complexity of mood disorders. This was reflected in our findings with participants stating that, on the one hand, the number of codes was too large whilst, on the other hand, it was still often difficult to find appropriate categories.

One of the most pertinent discussions relating to the classification of depression in our work, and closely related to the difficulty surrounding definitions, is the temporal and continuous nature of both diagnosis and occurrence. The resulting challenges for any classification and/or coding system are clear: such systems work on the basis of definitions of categories based on symptoms but in relation to depression there is no commonly-agreed clear-cut point as to when depression should be placed into another category. For example, the DSM-IV diagnosis of a major depressive episode assumes that there is a threshold at which point the episode becomes major i.e. when five or more symptoms are observed (31). However, a patient below the threshold may still have a mood disorder that needs to be treated despite not fulfilling the criteria for a diagnosis of depression (13). It has therefore been argued that this dimensionality is not adequately taken into account in existing systems as the threshold between different behaviours and mood disorders is set somewhat arbitrarily (7,9,13,30,31). In addition, the literature indicates that, to complicate matters further, existing classification systems assume that all symptoms contribute to depression to an equal extent, which may not necessarily be the case. Some have therefore advocated that classifications should allow for weighing of different symptoms (31). Our work shows that these discussions are particularly relevant in the primary care setting as diagnostic decisions more contestable at the less severe end of the depressive spectrum.

Moreover, and relevant to both care settings and also mirrored in the literature (9,13,14,16,32), depression tends to co-occur with other disorders (e.g. anxiety) which further complicates diagnosis. The two are therefore often grouped together in existing classification systems such as the ICD-10 (9). However, many have argued that the co-occurrence of anxiety and depression means that there may be some higher order categories that are not reflected in existing classification systems (12,13,30). As a potential solution, some authors have advocated an arrangement of codes surrounding meaningful clusters grouping depression and anxiety under the general heading “internalising disorders” (12).

### ***Tailoring of systems versus standardisation***

Tailoring systems to individual needs, be it countries, care settings, organisations, or individual users, has frequently been proposed in the literature as a way to facilitate adoption (8,9,33). This may entail giving users and/or organisations the authority to sort categories individually according to what is most meaningful to them and increased involvement in the

development of structures and/or codes (4). For example, Modai and Valevski report on the implementation of an information system in psychiatric care (33). Here, structuring of forms in the IT system was a key implementation activity being informed by user requirements. The process included an assessment of each individual department's needs and then designing electronic forms according to these.

However, our work has sharply brought into focus the need to achieve a balance between tailoring of systems to promote clinical utility and the need for a degree of standardisation to allow meaningful analysis of data on a larger scale. A potential solution could be the combination of structured and/or coded entry with free text, which has been found to improve categorisation rates amongst users (34).

### ***Incentives***

We have further illustrated the importance of financial incentives in promoting coding activity across care settings. This is consistent with the literature (35,36). In relation to QOF, there is also some evidence that linking healthcare professional performance to payment can improve the quality of care (37-39). However, there remains a need to explore alternative incentives, such as for example feedback on user performance, as conditions that are not included in payment schemes may suffer (37-39).

### ***The number of categories***

Tensions between the need to standardise whilst maintaining some clinical utility were also illustrated by debates surrounding the number of categories in existing mental health coding and classification systems. Participants felt that subcategories were becoming increasingly specific as this was desirable for research and management purposes. However, this meant that clinical users were faced with rising numbers of terms, which they often found time-consuming to browse and difficult to remember. Consequently, and in line with our work, existing studies have found that many diagnostic categories in psychiatric settings are not used at all and there is a high incidence of unspecified diagnoses (8,12,40).

A potential way to address this, frequently mentioned in the literature and also by our participants, could be to reduce the number of diagnostic categories (7,30,34,41,42). The

literature suggests that a way to achieve this may involve grouping these together around meaningful clusters (7,12,30). This has been found to be particularly true for depression as many existing criteria could be excluded whilst retaining validity in making accurate diagnoses (8,12,42). Hence, the detail reflected in coding systems may not be needed. For example, Andrews and colleagues found that when reducing the DSM-IV symptom set for major depression from nine to the five, around 97% of patients that met the nine criteria also met the five criteria. The authors argue that there is therefore no clinical utility in keeping the full nine symptom set if the five symptom set is sufficient (7,12). In relation to the future versions of the DSM-IV and ICD-11, reducing the number of categories in mental health has frequently been discussed. However, the ultimate decision will not only depend on clinical utility, but will also be decided on the basis of, amongst other issues, public health utility, which generally requires more granularity (9,30).

Our findings further indicate that different settings have different needs that should be reflected in coding and classification systems. This is increasingly also recognised in the literature. For example, to make existing classification systems more applicable to primary care, the WHO published a primary care version of the ICD-10 (ICD-10-PHC) with a reduced number of categories in 1996. Similarly, the APA produced a primary care version of the DSM-IV (DSM-IV-PC) in 1995. There is now an ongoing discussion whether to have different versions of DSM-IV and ICD-11 for primary care as GPs may require a smaller number of categories than other psychiatric settings (9,13). This is likely to help address some of the issues discussed by our interviewees (e.g. in relation to the smaller number of categories perceived to be needed in primary care settings). Our work has contributed to these discussions in important ways. Although the number of categories was discussed across settings, it was generally felt to be more pressing for primary care as higher order categories were perceived to blur more than in secondary care where diagnoses are often more straightforward. In addition, clinical utility of coding systems may be more important in primary care as data entry is often done by the GP, whilst secondary care doctors often rely on clinical coders.

#### **8.4.4 Potential ways forward**

Based on our work, we have a range of recommendations, which policy makers may wish to consider when deliberating strategic directions in relation to structuring and/or coding of

information in the mental health setting and beyond. These are summarised in Box 8.3 and we elaborate on the most important aspects in the paragraphs below.

**Box 8.3: Summary of recommendations emerging from this case study**

Strategic

- Definitions relating to both clinical terms and related content to be based on an agreed set of criteria to ensure consistency in coding practices;
- Agreed coding standards between care settings to facilitate information exchange;
- Aligning different existing coding and classification systems;
- Updating structures and/or codes in pace with professional practices.

Development of systems

- Arranging categories in more meaningful clusters (ideally based on hierarchies);
- Reducing the number of categories – particularly in primary care;
- Balancing structured and/or coded entry and free text based on severity of symptoms and settings;
- Devising systems that facilitate meaningful coding of interpreted syndrome components;
- Devising coding systems that capture relationships as well as codes to derive most value out of systems (e.g. changes in diagnoses over time).

Organisational

- Coding champions to ensure consistent approaches to coding amongst teams;
- Promote the relationship between clinicians and coders by placing them as close to clinical work as possible;
- Pay attention to professional differences in coding practices;
- Training of healthcare professionals in coding practices and increased involvement in development of codes;
- Agreement on coding practices within individual settings and/or health communities to ensure consistency;
- Explore and encourage innovative approaches to coding e.g. voice recognition, portable hardware.

In terms of overall strategy, there is a need to agree coding standards between care settings to facilitate information exchange, as opposed to within settings as is currently the case. Updating structures and/or codes in pace with professional practices is likely to be essential for achieving this. Such developments would help to make coding systems immediately

clinically useful and contribute to more accurate coding by healthcare professionals. In order to achieve this, a central setting of standards promoting information exchange between systems is necessary but this should not be too restrictive for individual organisations and users, as allowing some degree of tailoring of systems to local need is necessary to allow effective integration within work practices. These efforts should also be characterised by attempting to align different existing coding and classification systems, ensuring consistency in relation to both clinical terms and related content based on an agreed set of criteria in order to ensure consistency in coding practices. This may be led by, for example, quality improvement initiatives such as the National Institute for Health and Clinical Excellence (NICE) guidelines to ensure coding in line with evidence-based practice.

Development of systems will require a closer working relationship between system designers and healthcare professionals to ensure clinical utility of tailored elements. This may need to involve efforts of arranging categories into more meaningful clusters based on hierarchies and capturing relationships between codes. This can then help clinical users to devise a more problem-oriented medical record (see Chapter 1), capturing for example, reasons for encounters linked to coded observations linked to coded diagnoses. The option of free text in mental health settings is likely to be of continuing importance, but there may be value in deliberating a balance of structured and/or coded entry and free text based on severity and type of diagnoses. For instance, whilst mild depression may need an increased amount of free text as life circumstances are often important, severe depression may be more amenable to coding as patients are most likely to benefit from standardised treatments. Systems should further facilitate coding of symptoms initially, followed by coding of diagnoses. This would help to address the evolving nature mental health conditions.

Finally, organisations themselves may wish to consider investing in coding champions, who can show colleagues to code accurately and consistently illustrating how most clinical value can be derived from systems. This should be accompanied by appropriate training programmes and consistent contact with clinical coders, who are ideally based close to clinical users of systems. Throughout, recognition of professional differences in coding practices is necessary as some professions and their associated nature of work may be more amenable to coding than others.

#### **8.4.5 Conclusions**

Our work has shed light on important aspects relating to structuring and/or coding information in the mental health setting. In line with the existing literature, we found that coding in this area differs in important ways from the more biomedical conditions with issues surrounding definitions, cut-off points and the evolving nature of mental disorders. Our work has, however, also raised some questions, in the main relating to the implicitly assumed benefits of coding and classification systems. We found these to be lacking in the immediate clinical context and in relation to the drive to encourage coding by healthcare professionals during the clinical encounter. An important feature of our work was the inclusion of a variety of perspectives from primary and secondary care settings, including the views of clinical coders which are often neglected in empirical work. Based on our findings, we have made a number of suggestions that may be considered to address existing issues and explored these from a range of strategic, technical, and organisational angles.

Overall, we feel that it is important to now take a step back and re-consider our own implicit assumptions about effectiveness and benefits, recognising that these may be associated with significant trade-offs. This should involve deliberating why and for what purpose information is gathered on different levels including large-scale (e.g. epidemiological), organisational (e.g. management), and micro-environmental (e.g. the clinical encounter). The first step to achieving this, will involve formulating a challenge and then develop technical solutions to address this. Otherwise there is a danger that clinicians are asked to spend valuable clinical time on coding information, which may never be used even in relation to secondary uses.

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## Chapter 9

### “SNOMED? What’s that?” Exploring structuring and/or coding of information in diabetes records

#### Abstract

**Background:** Globally, diabetes mellitus presents a substantial and increasing burden to healthcare systems and society. The World Health Organization (WHO) estimates a prevalence of 346 million, which is predicted to continue rising in both in low- and higher-income countries. In England there are nearly three million people diagnosed with diabetes, and the increasing prevalence of Type 2 is largely due to obesity and the changing age and ethnicity profiles of the population. Structuring and/or coding of information in the electronic health record (EHR) underpins attempts at promoting continuity of care by making it possible to share and search for information. Having such records for those diagnosed with long-term, essentially biomedical conditions such as diabetes is expected to bring direct as well as secondary use benefits, and to allow greater priority to be given to individual patients’ self care. Nonetheless, an incorrectly coded and/or incomplete record could adversely effect clinical management decisions. Coding errors and omissions are likely also to reduce the potential benefits of secondary uses of diabetes data, for example, by undermining research findings based on (inaccurate) routinely collected data. Further, there might be a clinical need to record information about the patient and the disease that is not amenable to structuring and/or coding, hence valuable information may potentially be lost where there is an emphasis on structured and/or coded data capture. This case study sought to investigate if, how and why records for adults with diabetes were structured and/or coded in the National Health Service (NHS) in England; and to explore a range of UK stakeholders’ perceptions of approaches to record keeping for patients with diabetes.

**Methods:** We carried out a qualitative, theoretically informed case study of documenting healthcare information for diabetes in primary and secondary care in England, using semi-structured interviews, observations, systems demonstrations and documentary data.

**Results:** We conducted 22 interviews, four on-site observations and reviewed 25 documents. With respect to secondary uses – research, audit, public health and service planning – the benefits of highly structured and coded diabetes data were clearly articulated

and it was believed that these could increase through linkage to other datasets (e.g., cancer and social care datasets). Healthcare professionals were most likely to be persuaded to use the systems that led to fulfilling the potential of secondary uses data if they perceived immediate benefits to themselves and their patients in addition to secondary uses and existing financial incentives to code.

In the clinical setting in England, we observed marked differences in levels of diabetes data structuring and/or coding between primary care, where the use of structured templates (data entry forms) and coding seemed generally high, and secondary care, where practices relating to recording diabetes data varied widely and could still be based on paper records. In an English NHS hospital without a specialist IT system for diabetes care, we found strong support among clinical, managerial and coding staff for increased structuring and coding to improve information availability and quality. Hospital staff perceived that the principal barrier to doing so was financial. In primary care, interviewees were positive about using their existing general practice (GP) information technology (IT) systems for highly structured and coded capture of information on patients with diabetes. The immediate benefits identified by interviewees included: having relevant, up-to-date information available for consultations; making it easier to share information between practice staff, and to organise patients' care; protocol disease management and monitoring; helping to involve patients in their care by illustrating points graphically on the screen; and enabling GP2GP fast transfer of records when patients moved practice. Clinical staff viewed these advantages as compensating more than adequately for any "niggles" with using the IT system, or some concerns about coding inaccuracies, particularly historical inaccuracies and possible misdiagnoses of which type of diabetes. We found very little evidence that structured and/or coded data in EHRs were being exploited to improve information sharing between primary and secondary care. Further, we found evidence that NHS staff were uninformed about the planned, NHS-wide change to the Systematized Nomenclature of Medicine - Clinical Terms (SNOMED-CT) terminology for coding.

**Conclusions:** Using high levels of data structuring and coding in EHRs for diabetes patients can lead to significant benefits in terms of secondary uses. It can also bring immediate, if marginal, clinical benefits in terms of managing and monitoring the condition and perhaps encouraging patient self-management. Each of these has the potential to be exploited more fully in the future. A first step would be for all English hospitals to attain levels of health IT infrastructure and systems use commensurate with those in primary care. We recommend future steps include learning lessons from developments and innovations elsewhere in the UK.

## 9.1 Background

The number of people worldwide with the long-term, complex endocrine condition of diabetes is predicted to rise above 470 million by 2030, reflecting global population growth, ageing populations and lifestyle-related factors leading to increasing levels of obesity (1).

There are now nearly three million people diagnosed with diabetes in England (2,3) and, as elsewhere, the prevalence of Type 2 diabetes is increasing rapidly, linked to rising levels of obesity, an ageing population and ethnicity factors (2,3,4). Diabetes is a serious disease and is very costly in terms of NHS resources and in terms of patient morbidity and mortality. The more effective and efficient management of chronic illnesses is a key priority for the Department of Health (DH) in England because of the very high burden now posed by long-term conditions (5).

Diabetes has individual and ethnic differences in its presentation and prognosis that are not yet fully understood. However, the disease and its complications are largely preventable, or controllable, with active management by patients and their healthcare professionals (4). The NHS focus for managing diabetes, therefore, is on: supporting self-care; improving early diagnosis and disease monitoring; timely interventions (which often involve a range of healthcare specialists in addition to GPs); and planned, structured service provision.<sup>3</sup> All of these activities rely on good quality, accurate patient information being documented, available and sharable. Because of the nature of diabetes and its complications, patients may be receiving care from specialist nurses, dieticians, hospital ward staff, podiatrists, renal and cardiology teams and retinal screening staff, for example, as well as from a GP surgery. Hence, for integrated care for people with diabetes, information needs to be available – and comprehensible – to disparate healthcare providers as well as, perhaps, to social care staff (6). Patients' information also needs to be accessible over geographical distances and over time.

Natural Language Processing (NLP) is being developed with the promise of making free text readily searchable by computers. However, despite advances, NLP is thought unlikely to be appropriate for handling critical information for caring for patients in the near future (2). Hence the main focus remains on coding NHS records to enable data searching and sharing for supporting integrated care and patient self-management.

Drivers for structuring and coding diabetes-related data in the UK have changed over time. In primary care, where information about long-term conditions has been electronically recorded for many years, there is an incentive of payment-related Quality Outcomes Framework (QOF) points for coded, diabetes management activity (7). QOF datasets aim to improve standards of clinical care, but are arguably more income-related rather than clinical tools. A retrospective cohort study in the United Kingdom (UK) reported that while diabetes care had improved since the 1990s, it was not possible to relate those improvements clearly to the introduction of a QOF diabetes dataset (see Chapter 4) (8).

There are several genetic and other medical subtypes of diabetes in addition to the more commonly diagnosed Types 1 and 2 variants, although as yet there is no internationally agreed, clinical guideline for classifying the disease (2). A further problem with the current QOF system is that, despite an array of QOF codes for diabetes, only those coding for Type 1 and Type 2 diabetes attract practice payments. Thus the financial incentives for GPs to code diabetes might distort how the diabetes classification is recorded, and lead to a less accurate diabetes disease register (9). Nonetheless, an important clinically-related component of QOF is establishing disease registers; patients with a currently coded diagnosis of diabetes Type 1 or Type 2 are included in the register, so that recall and review prompts are in place. Again, a corresponding improvement in clinical outcomes has proved more elusive (4). The most widely used clinical coding system in EHRs in general practice has been Read codes. These clinical codes are due to be replaced throughout the NHS in England by 2015 by the more comprehensive SNOMED-CT coding system (10).

Since the advent of Payment by Results (PbR) in 2004 (an activity-based system of payments to hospitals), hospitals also have a financial incentive to report diabetes management data. This information is mainly in the form of statistics. Hospitals use a combination of coding systems to enable reporting, including International Classification of Disease (ICD) codes and Office of Population, Censuses and Surveys Classification of Surgical Operations and Procedures (OPCS) codes. Usually, ICD-10 codes will be used for diagnoses and OPCS-4 codes for hospital procedures. In some UK hospitals, SNOMED-CT codes may also be used. Secondary care organisations have specialist computer systems (e.g. Diamond) for recording structured and coded diabetes-related data.

Secondary uses of such structured and coded data are for NHS diabetes service planning, (3) audit (11) and research. For instance, QRESEARCH (12) specialises in research using primary care electronic health data. Such data have allowed the development of risk prediction tools, such as the QDScore (13) diabetes risk calculator and the cardiovascular risk tool, QRISK; (14) 80% of people with diabetes die of heart disease (4). Similarly, routinely collected diabetes-related data from secondary care in England are also used by researchers and analysts, for example, by the Dr Foster organisation (15).

Clinical coding of diabetes-related information, as it is the case in other clinical areas, is not without recognised problems. An incorrect and incomplete EHR may adversely affect an individual's clinical management. Coding errors and omissions also reduce the potential benefits of the diabetes disease register, undermine efforts to plan diabetes services and bias research findings based on (inaccurate) routinely collected data (16,17,18,19,20).

A recent report<sup>2</sup> by the Royal College of General Practitioners (RCGP) and the NHS reviewed the coding, classification and diagnosis of diabetes in England with a view to making recommendations for improvements. The authors noted that the classification and diagnostic criteria for diabetes were not static. A pilot of an audit tool they developed for GP IT systems identified individuals who had been miscoded (the wrong code(s) entered), misclassified (coded for the wrong type of diabetes) and misdiagnosed (wrongly coded as having diabetes). They also noted that the two main reasons for discontinuities in the data held on individuals' primary care records were changing GP or receiving diabetes care in hospital.

Other authors who have highlighted problems with correctly classifying diabetes advocate that researchers who use routinely collected electronic datasets should always assess likely error levels and adjust for bias (19).

While some literature suggests that, overall, EHRs are likely to be associated with better patient care, (21,22) in such complex, long-term conditions as diabetes there might be a clinical need to record information about the patient and the disease that is not amenable to templates (data entry forms) or coding. Hence, the ideal capture of information in the EHR might be some mixture of free-text, narrative and structured and/or coded record keeping. Regardless of how the information is documented, given the multiple complications of diabetes and the range of healthcare professionals involved in providing diabetes care, the

goal is to document data that translate into meaningful information that can be shared between care providers and between different NHS settings (see Chapter 1) (3).

The aim of this case study was to inform NHS practice in relation to using structured and coded data in the EHRs of adults living with diabetes. More specifically, we sought: to investigate if, how and why records for adults with diabetes are currently structured and/or coded in the NHS in England; and to explore a range of UK stakeholders' perceptions of approaches to record keeping for patients with diabetes.

## **9.2 Methods**

The study was a qualitative case study (23). The “case” was the documenting of diabetes healthcare provision in patients' records, that is, if and how information on these patients was being digitally captured and transmitted. An in-depth case study allowed the description of currently used technologies (hardware and software) and work practices, with a focus on how and why different forms of data capture – free-text, narrative, structured data (e.g., using a template) and coded data (e.g., Read codes) – were being used in these health records. The case study design also allowed detailed exploration of a range of views on the optimal balance between unstructured, structured-uncoded and structured-coded data recording, particularly for clinical care, but also for NHS management, diabetic service planning, research and audit. We sought to illuminate how the ways in which data were being documented facilitated – or could in future facilitate – management of this long-term condition, for instance, through call and recall prompts, health status monitoring, supporting self-care and enhancing communication between the different healthcare professionals who are typically involved in caring for diabetes patients.

### **9.2.1 Sampling and recruitment**

Two primary care sites and a NHS hospital Trust in the same region in England were identified through the UK Clinical Research Network (UKCRN) (24) and recruited. We chose to sample associated primary and secondary sites to gain a coherent picture of a geographical health community. The majority of patients diagnosed with diabetes receive their healthcare in such NHS communities. The sampling approach was also designed to generate context-specific findings from each site as well as allowing us to identify any

common findings that were likely to be generalisable from considering these sites together as a holistic “case”.

We used purposive sampling (25) within the sites and beyond them to identify and recruit a wider range of individuals who affect or are affected by the processes and outcomes of documenting diabetes patients’ healthcare. Interviewees outside the sites were selected to provide contextual information for the case study and to provide additional, informed perspectives. Throughout, we actively sought to sample a range of experiences and views, including outlier views. Interviewees included clinical staff (i.e. doctors, nurses, and a dietician); patients; NHS managers; clinical coders; clinical systems developers/suppliers; and academics.

Initially, we purposively recruited and interviewed seven individuals with a particular interest in diabetes and structuring and/or coding of health records in order to gain their perspectives as academics (including academic clinicians) and healthcare informatics experts (including developers of systems). This was achieved through research team contacts and snowballing, whereby one informant suggests another informant. Snowballing led us to recruiting participants from Scotland as well as from England because of the innovative developments in Scotland that were reported to us in early interviews. These initial interviews allowed us to conduct the subsequent interviews in the case study sites in the context of having more detailed information about the situation more widely in the UK and beyond.

### **9.2.2 Data collection and handling**

Interviews were guided by initial topic guide schedules, derived from the research protocol (Box 9.1), which were adapted by the case study’s lead researcher as the investigation progressed. Audio files of recorded interviews were transcribed professionally. The resulting transcripts were then checked for accuracy and cleansed of personal details that would identify the interviewee. One researcher conducted all the case study site interviews.

Additional data were collected in field-notes taken during two non-participant observations in a primary care diabetes review clinic and two non-participant observations in hospitals.

Although this study did not aim to assess the technologies, demonstrations of some IT systems commonly used for diabetes management in primary and secondary care provided further background information. This study's lead researcher arranged to have demonstrations of two, commonly used GP IT systems (i.e. EMIS and Vision); of a commercial, specialist system that has been implemented in several English hospitals; and of a national, single diabetes record system that combines information from multiple sources, the Scottish Care Information-Diabetes Collaboration (SCI-DC) (26).

**Box 9.1: Initial topic guide (for healthcare professionals)**

In this interview, we would like to:

1. Discuss how you currently produce structured data in patient records with particular reference to a) advantages you perceive and b) challenges you perceive
  - What sort of forms are you asked to fill in?
  - What sorts of templates are used?
  - When in a consultation would you use a form?
  - When would you use unstructured entry?
2. Discuss how you currently produce coded data in patient records with particular reference a) advantages you perceive and b) challenges you perceive
  - What sort of medical terminologies are familiar?
  - Which do you use?
  - When, in a consultation, would you code information?
  - When would you use descriptions or natural language?
3. Discuss your perception of how structured data is used, both by yourself and others with particular reference to a) advantages you perceive and b) challenges you perceive
  - When is structured information preferable to free text in your work?
  - When might others appreciate structured information?
  - When would free text be preferable in your work?
  - When would free text be preferred by others
4. Discuss your perception of coded data (as above)
5. Explore your perceptions of the future use of structured and coded data from your own experience in your role
  - Where you might see a need for more structured and coded data, and why
  - Where you might feel data should be captured in free text, and why

Throughout the data collection period, we reviewed relevant documentary data, including diabetes-related websites, for example, the website of the national diabetes charity, Diabetes UK (<http://www.diabetes.org.uk/>) and the National Diabetes Audit website (<http://www.ic.nhs.uk/diabetesaudits>). We also collected documentation on different coding systems, and current local and national guidelines and protocols.

Data were collected between May 2011 and November 2011.

### **9.2.3 Data analysis**

Thematic data analysis and data collection were iterative, allowing us to further explore emerging themes and to investigate any discrepancies between individuals' accounts or between data sources. Interview transcripts and notes, field-notes from systems demonstrations and on-site observations and the collected documents were uploaded into the qualitative software package NVivo 8 (27).

For the thematic analysis, coding was guided by an initial framework of categories derived from the research protocol, a literature search and research team discussions. The initial categories were: amounts and types of structured and/or coded information for diabetes care; approaches to coding for diabetes; and perceived consequences of more coding. These categories were refined with additional sub-themes as the case study data collection and analysis progressed. Coding combined top down coding, based on the coding framework, and bottom up coding in which new or more fine-grained themes emerged out of the data (28). Interpretation of the findings was influenced by a socio-technical theoretical understanding i.e., that technologies and those who work with them function inter-dependently (29).

Approaches to validating data quality and credibility in this qualitative study included checking data for face validity, looking for disconfirming evidence, data triangulation by data source, and discussing data collection, coding and emerging themes collectively in the research team during regular, frequent team meetings throughout the study (28-30).

Please see Appendix 17 for the study's ethical and local site permissions.

## **9.3 Results**

The case study dataset comprised 22 semi-structured interviews; observations in primary and secondary care; documentary data; systems demonstrations; and field notes. The data sources, including the occupations of the interviewees, are given in Table 9.1. The main themes derived from this dataset related to the different contexts of the primary and secondary care settings we sampled (Working in different worlds); the limited electronic

exchange of information between the two sectors (Communicating across the divide?); and to the different approaches to diabetes data structuring and coding we observed (Drivers; Who codes and how?; Involving the patients; Coding enablers and barriers). The final theme reported here related to study participants' views of the consequences of coding (Clinical and research benefits). The initial coding categories by which the data were organised and the main themes derived from each of these are given in Table 9.2.

**Table 9.1: The dataset for this case study**

<b>Interviews n=22</b>
Contextual – 7 (6 academics/clinicians; 1 systems supplier)
Primary care staff – 5 (1 GP; 2 diabetes nurses; 1 practice manager; 1 coder)
Diabetes patients - 2
Secondary care staff – 8 (1 diabetes consultant; 1 registrar; 1 ward nurse; 1 diabetes research nurse; 1 dietician; 2 coders; 1 data manager)
<b>On-site observations n=4</b> (GP surgery x 2; hospital x 2) (field notes)
<b>Diabetes IT systems demos n=4</b> (primary care systems x 2; hospital systems x 2) (field notes)
<b>Websites and documents review</b> (25 documents)

**Table 9.2: Initial coding categories and additional themes**

Category: Amounts and types of structured and/or coded information for diabetes care. Themes: Working in different worlds; Communicating across the divide?
Category: Approaches to coding for diabetes. Themes: Drivers for structuring and/or coding; Who codes and how?; Involving the patients; Coding enablers and barriers.
Category: Perceived consequences of more coding. Themes: Clinical and research benefits.

### 9.3.1 Amounts and types of structured and/or coded information for diabetes care

#### *Working in different worlds*

Our case study sites illustrated a marked contrast between the settings sampled in secondary and primary care. In a busy NHS teaching hospital, diabetes patients admitted into hospital wards were typically very unwell, for example, with kidney or heart failure, or were maternity patients. The hospital consultants and their teams looked after hospital inpatients. In a relatively recent initiative, hospital consultants also saw diabetes patients in community clinics. These clinics were organised by the Primary Care Trust (PCT) in a PCT-run building. Here they worked in collaboration with community nurses, although not with GPs. Hospital doctors relied on paper to record information about diabetes patients. The hospital had implemented a number of different IT systems, such as a pathology system, but had no comprehensive EHR system.

*“There are plans to introduce electronic health records, in the future. The hospital x-ray system is different from the system for blood results, which is different from the patient management system. At the moment, I have to log into about at least five different systems to get information on a patient. So I created my own diabetes template. Yes, it’s a paper template and I use it for my patients, and a couple of other consultants have been using it for their clinics too.”* (Interview 21, Doctor, Secondary Care)

In contrast, the context in which GP practice staff worked was a self-contained, computerised surgery, where the use of GP IT systems and coding were well established.

*“We’ve got a good system in place. We’ve been doing it a long time here. We code everything. Whoever is entering it does a Read code.”* (Interview 13, Doctor, Primary Care)

There were four types of data capture using the GP IT system’s diabetes template: numerical values (e.g. weight and height); yes/no options (e.g. smoking); drop-down menus (e.g. diagnosis); and free text boxes (e.g. for comments on dietary advice that had been given). In addition, information about diabetes patients and their care was recorded in free text in a separate part of the EHR, which was also coded. There was minimal free text that was unrelated to an entered code. For example, a GP described coding all her entries in the patient’s record with the exception of, for example, a free text comment on her reasons for

altering a patient's management plan. Unlike in the hospital setting, where the paper template meant handwritten entries were structured but there was no coding in the record, the primary care record entries were predominantly coded.

### ***Communicating across the divide?***

The GP surgery was the main healthcare setting in which the majority of diabetes patients received most of their care. Nonetheless, some patients would be referred to community clinics, to be seen by hospital consultants, and there were patients who had episodes of inpatient hospital care. NHS staff interviewees from each sector described largely working in isolation from the other. Letters were the most common method of communicating information between the sampled hospital and GPs. Phone and fax messages might be used instead of paper if the message were more urgent. Digital data sharing across the primary care-secondary care boundary was restricted to some lab results, which would then be coded in the GP IT system.

*“So, say, blood results are shared with the local hospital, and urine analysis, that is shared locally. It comes through automatically from the hospital, and it is automatically coded. Everyone has boxes, the clinicians, so the clinician who referred, say, it would go into their box, and it needs to be accepted, then it's entered automatically. It's quite good.”* (Interview 11, Coder, Primary Care)

*“Everyone functions sort of independently. We get each other's letters. Most letters are probably accurate, but it's not in real time.”* (Interview 25, Doctor, Secondary Care)

From a system supplier's perspective, the difficulties of modernising communications between GPs and hospitals with IT systems were less technical than political and economic.

*“We can put what you like in the can. But there are very few good examples of good integration between primary and secondary care in England. The reason is partly from a lack of will – there is demand, lots – but no-one is picking up that ball. How to fund it? Also, there are some issues around information governance and so on. GPs are cautious about who sees their data and so on. The majority of processes are not integrated across primary and secondary care at all.”* (Interview 7, System Supplier, Commercial)

A hospital doctor described dictating his letters to the GP in front of the patient, and a copy of the letter being returned to him for review and signing after it had been transcribed by a secretary, then the letter being posted – a process which took several days, with hospital test results often following later. Electronic document transfer would be a relatively straightforward step that would reduce some delays in passing patient information from one sector to the other and allow patients' records to be updated in a timely manner:

*“For communications, it’s normally in the form of a letter, and there are tools for configuring and producing letters, and it’s possible to convert to electronic document sharing at some sites - but integration – that’s the next leap.”* (Interview 7, System Supplier, Commercial)

Elsewhere in the UK, the integration gap for diabetes patients was being addressed through IT. In Scotland, a national, computerised system, called SCI-DC,<sup>27</sup> combined information from a number of sources, including from podiatrists, dieticians, hospitals and the GP, to give diabetes patients a single, quickly updated record. However, a hospital consultant using the SCI-DC system in his diabetes clinics said there were still not as many GPs using the system as he would wish:

*“GPs don’t really use it enough. Maybe it’s hard to open a new page, to remember another password. I’d like them to use it more.”* (Interview 3, Doctor/Academic, Secondary Care)

This clinical system had taken some 10 years of investment to collect the data and set up the systems, building out from a smaller, regional system. Interviewees in Scotland said the development of SCI-DC had benefitted from the drive and enthusiasm of particular individuals who had been its ‘champions’ but they were unanimous in reporting that the long effort had been sustained by the interest and support of the clinical community more widely.

*“The approach was always to work with those who wanted to sign up to the system and let the uninterested or refusers see the benefits over time and join in later. Now nearly all GPs and all hospitals are signed up. ... It’s about integrating the whole thing into work patterns, and also about the rewards for clinicians, such as having blood results available for the consultation, not having to dictate results any more and having an organised letter. Scotland has gone a wee bit independent, and is doing very well.”* (Interview 3, Doctor/Academic, Secondary Care)

### 9.3.2 Approaches to coding diabetes information

#### *Drivers for structuring/coding diabetes information*

The secondary and primary care case study sites shared a financial incentive to code diabetes data. For the hospital, it was Trust income related to reporting activity under the PbR scheme. PbR payments accounted for a significant proportion of the Trust's overall income. All participants at the site were acutely conscious of the financial state of the NHS during a period in which employees' posts were being reviewed and the clinical workforce was being pared back, although not all made the link between coding, PbR payments and the Trust's finances.

*"I don't think I ever thought about it until I started research work. I mean, you never hear about it. You go all through your training and so on, and coding and its importance is never mentioned, or if it is, nobody takes it in. It's just something that goes on behind the scenes. You don't even know where the hospital coders are!"* (Interview 22, Nurse, Secondary Care)

Similarly, primary care interviewees mentioned payment-related QOF points as being one driver for coding.

*"Have you heard of QOF, yes? There is a diabetes register. If it is all put in correctly and coded correctly, then it fires QOF. It makes sense if everything is coded correctly because it is income for the Practice."* (Interview 13, Doctor, Primary Care)

In addition to the financial driver, primary care staff referred to a 'culture' of using computers and coding in GP surgeries, where computer systems had been in use for years. Clinical and non-clinical GP surgery staff recognised the need for coding in order to be able to carry out searches and audits as part of their everyday work. They were also motivated to code because having coded information was perceived to improve patient care.

*"I call for people to come [to clinics]. It's based on readings really, so I can go and do a search and generate a list and call them. It's not just with diabetes, for all sorts of things, codes mean you can search and identify patients, say, who need six monthly BP checks or*

*who have not turned up for a B12 injection. It does improve patient care.”* (Interview 11, Coder, Primary Care)

Improved patient care was also given as the reason for structuring patient information using the hospital consultant’s paper templates. Paper templates were a pragmatic solution to encourage standardised, clinical practice and to aid the completeness of recording patient information in the absence of EHRs and digital templates.

*“In an ideal world, yes, I would like a diabetes IT system but in real life, if I aim for it, it won’t happen because of finance, so I just got on with this. It’s working very well in my clinic. Otherwise, people tend to miss things, like height and weight. It can be very variable between individuals and it’s just ensuring that it is continued through, irrespective of who’s working in my clinic. From the first day someone hits my ward, they get a yellow sheet and all the co-morbidities, medications, interventions are there, and we update the yellow sheet on a regular basis. It forms the basis of the discharge letter. Simple things, like pre-conception counselling – it is very easy to miss it otherwise.”* (Interview 21, Doctor, Secondary Care)

### ***Who codes and how?***

We observed marked difference between primary and secondary care with respect to who did the coding and how this was done.

Read codes were used in primary care. These are an extensive list of terms, each attached to a unique code, which covers information ranging from the patient’s occupation to signs and symptoms, tests, diagnoses, interventions to medications, and more. In the GP surgeries, it was predominantly diabetes specialist nurses who completed diabetes templates during, or sometimes shortly after, diabetes review appointments. Read coding was embedded in the template. The GPs were more likely to use another part of the EHR for their consultations with patients with diabetes, and to code those entries themselves. Another staff member also had a specific coding role, whether the job title was ‘coder’, ‘clerk’ or ‘secretary’. This individual would complete data entry and coding in the EHR when, for example, a letter about a patient arrived from the local hospital.

*“Filling in the template automatically fires codes behind the scenes. It is embedded in the system. We always code for Type 1 or Type 2 diabetes. I would say nine out of 10 templates are fully completed. Obviously, some of it can’t be done during the review appointment, for example, when someone has an eye check at the opticians, obviously we don’t do that here, but when the paperwork comes through from the optician, or the hospital letters with, say, blood pressure results, I put it on the patient’s template. All letters normally get sorted within a couple of weeks. If there was anything urgent, they would fax, but normally it’s routine results by letter and they get updated and coded in the patient’s record within a couple of weeks.”* (Interview 11, Coder, Primary Care)

In the hospital, coders used ICD and OPCS codes. Coding was based on the content of patients’ discharge summaries, which were sent to a team of professionally trained, full-time coders. The coding team was accommodated in one large room in the hospital, where the coders worked from their own copies of thick, heavy books that were extensively annotated and individualised with comments, reminders and coding updates. They dealt with coding queries arising from information that was unclear, inconsistent or missing from the discharge sheet by telephoning the doctor who had written it. An interviewee described how they were tightly constrained by the content and completeness of the discharge summaries that doctors produced. There were variations between hospital departments and between individual doctors, which coders came to recognise:

*“We have one doctor who doesn’t like calling people ‘geriatrics’ so she won’t put down a geriatric fall, she will put down a mechanical fall, but there is no code for mechanical fall – so we have to phone her up. And it could be that the person fell and broke their leg because they were hypo and really it was diabetes that caused the fall but that won’t be what’s on the discharge summary, it’ll be surgery for a broken leg, so that’s what’s coded.”* (Interview 23, Coder, Secondary Care)

Coding based on discharge summaries, rather than the whole record, had implications beyond missing diagnoses codes. Interviewees discussed how some activities also became ‘invisible’. For example, a dietician would spend time on a non-diabetes ward giving dietary advice to a patient with diabetes, but it would be the activities relating to the primary reason for patient’s admission – not diabetes - that would feature on the discharge summary and hence get coded.

In some instances, a coder might work in a clinical department and code directly from the patient record. This depended in part on the availability of accommodation for the coder in the department and on the coding interest of key individuals in that speciality. A coding manager reported this was time consuming but resulted in more complete and accurate coding. The hospital's coding department was being relocated and losing a number of desks, which meant that in future coders would be more likely to do at least some of their work from home.

*“Coding from the patient’s record has real advantages over coding from discharge summaries. That would be the ideal. A big part of what we are trying to do now is to get out there, for coders to meet clinicians, so at least they remember a face, and they understand what we are doing and why it is important. But we are juggling with other considerations too, like fewer desks for us in the new hospital.”* (Interview 26, Coder, Secondary Care)

Another participant described noticing misclassification of diabetes type in the course of research work she had conducted at the hospital, based on her own specialist knowledge of the disease.

*“I could see Type 1 and knew it was not but it got put on because of insulin and once it was coded that way....”* (Interview 22, Nurse, Secondary Care)

Similarly, a GP also remarked on the problem of miscoding of Type 1 and Type 2 diabetes in the GP system, particularly from coding in the past:

*“The only problem is where someone is coded as insulin dependent, and is it truly Type 1 or Type 2? Some of the old codes in the system need a bit of tidying up.”* (Interview 13, Doctor, Primary Care)

In Scotland, the coding approach for the national research register derived from the SCI-DC system included inferring diagnoses of diabetes. Recognising that statistics from any one source were unreliable, such as a diagnosis of diabetes being missed from a hospital discharge summary, SCI-DC was designed to reconcile diabetes data from multiple sources, including laboratory data, the retinopathy screening programme, podiatry and data from both secondary and primary care, in order to improve the quality of the aggregated dataset.

*“We would like all diabetes diagnoses and check ups to be properly coded but this is not done. We are conservative in making any inferences, we err on the side of caution. For example, a blood sugar check, no, but if a GP had coded for a diabetes clinic check up, although they have not coded a diagnosis of diabetes, yes, we could infer a diagnosis of diabetes.”* (Interview 2, Doctor, NHS National Services Scotland).

### ***Involving the patients***

Practice nurses were observed using the IT system to generate graphs on screen to illustrate trends for that individual in such measures as weight and glucose control. The graphic illustration was accompanied by the nurse’s reassurance and praise for good control or was used to initiate a discussion with the patient about management where the trend showed some deterioration. Both nurses and patients reported finding this helpful. Echoing the hospital consultant who used a paper template to ensure the completeness of recorded information, nurses said the digital template was useful for making sure nothing was missed during the appointment. Having items on the screen prevented them “skipping bits” or forgetting to go back to them before the close of the consultation.

Participants perceived that accessing the IT system during diabetes review appointments facilitated the nurse-patient interaction, or was neutral. It allowed quick comparisons of new test results with previous results during the consultation, and was potentially useful for encouraging patients’ involvement in their own care. Using the IT system well was part of the health professional’s consulting skills.

*“If it’s there, it reminds me. You can’t fly through. Part of the skill of using it is it isn’t a problem. I suppose there could be exceptions, patients who didn’t like having a computer in the room - but I honestly can’t think of an occasion, I can’t think of anyone ever picking me up on it!”* (Interview 12, Nurse, Primary Care)

### ***Coding enablers and barriers***

Hospital coders sampled in this case study were comfortable that they had the necessary training, support and competence to code. They were supported to undertake additional professional qualifications and appeared to take pride in their medical knowledge and coding skills. There was evidence of job satisfaction, partly derived from a belief in the importance

of what they were doing. The principle barrier they perceived to better coding was the limitations of working from discharge summaries.

*“Honestly, I never thought I would love coding, but I do! It’s fascinating, I love my job, I could talk about this for hours.”* (Interview 23, Coder, Secondary Care)

Similarly, coders in primary care described good access to support and training, and in their case also having a GP IT system that was by and large easy to use because much of the coding was automated.

*“I’ve had Read code training from the PCT, and done IT courses at college, and audit courses. The Practice paid for them and they have given me time to go over the years. The PCT is very good, they’ve normally got a course, or they will send a trainer if you get a group together. And if I’m not sure, there’s always someone you can ring in the PCT.”* (Interview 11, Coder, Primary Care)

Being part of a small team in a GP surgery was also seen as helpful:

*“We work pretty well together here. We all know each other and get on. We sit in the same room as each other so if there’s a query or a problem, or you notice something is missing that needs coding, you just ask the person.”* (Interview 11, Nurse, Primary Care)

Interviewees were asked their views on Government plans for all NHS organisations in England to change to using a new clinical terminology in the near future. The supplier participant was well aware of the advent of SNOMED-CT, however, no other interviewee knew about SNOMED-CT codes or that they were due to change over to using these codes.

*“SNOMED. March 2015. Yes. I suppose it will happen. But it’s too early for us to jump yet. We haven’t got anybody in the NHS asking us for it, not yet, but we are fully aware and know what to do.”* (Interview 7, Supplier, Commercial)

*“SNOMED? What’s that? I haven’t heard of that. No, we haven’t heard about that, I don’t know. It’s not on our radar yet!”* (Interview 11, Coder, Primary Care)

None of the primary care interviewees indicated that difficulties with using the GP IT system posed a barrier to coding for them. One nurse paused to think before saying she supposed there were some “niggles”, such as having to click to change screens, but she said these were really not a problem.

*“No, I’m positive about it.”* (Interview 8, Nurse, Primary Care).

### **9.3.3 Perceived consequences of more coding**

#### ***Clinical and research benefits***

Both primary care and hospital clinicians in our study identified marginal, clinical benefits from structuring and coding diabetes data. These related to the availability of information for consultations, disease management by protocol and speed of information sharing in the case of GP2GP electronic transfers of EHRs for patients moving to a new practice. A greater benefit, according to some interviewees, lay in secondary uses of coded data. Clinical interviewees and academic clinicians believed that coding would lead to significant improvements in public health and epidemiology, service planning and audit and, particularly, in research. These participants were based in the case study sites and in academic institutions outside those sites.

*“At the moment, I can’t answer even basic questions about our diabetes patients, unless I go through all the records one by one and can you imagine how long that would take? Coding is fundamental for researchers.”* (Interview 22, Nurse, Secondary Care)

There was particular enthusiasm for the SCI-DC system in Scotland. This supported regional diabetes registers, prompting screening calls, and research participation through a national patient research register (Figure 9.1).

*“SCI-DC is the way ahead. Everybody is going to find their way on to it somehow because it uses multiple sources. We can extract more value from SCI-DC by linking. In effect, we have potentially huge cohort studies. There is enormous potential value through linkage for public health.”* (Interview 3, Doctor/Academic, Secondary Care)

In addition to cohort studies, interviewees suggested that the availability of a comprehensive dataset of the population with diabetes would lead to wider public participation in medical research and held the promise of easier, faster and cheaper, large-scale randomised controlled trials (RCTs).

*“The diabetes dataset we have in Scotland is among the best in the world, and researchers from other countries are coming to us now wanting to use it too. It links to other datasets, such as the cancer register and maternal data, which makes it hugely valuable for future research.”* (Interview 1, Academic Researcher, University)

**Figure 9.1: Screen-shot of the SCI-DC system. Researchers, with a password from SCI-DC, can access the Scottish Diabetes Research Network/SCI-DC research register of people with diabetes to search for participants for diabetes studies. (Patients can choose not to be contacted this way)**

**SCI-DC Clinical Information System - Microsoft Internet Explorer provided by NHS Tayside**

Address: <https://diabetes.mhs.scot.nhs.uk/rothian/scidc/>

**SCI-DC**  
SCOTTISH CARE INFORMATION  
DIABETES COLLABORATION

**Permission to contact: Data Entry Form**

**SDRN**  
SCOTTISH DIABETES RESEARCH NETWORK

**Logout**

Name: \_\_\_\_\_ CH: \_\_\_\_\_ Age: \_\_\_\_\_ Type of Diabetes: \_\_\_\_\_

**Patient Details:**

Date: \_\_\_\_\_ Address: \_\_\_\_\_

Contact No: \_\_\_\_\_

E-Mail: \_\_\_\_\_

Mobile: \_\_\_\_\_

Consent Recorded By: Paul McIntosh Postcode: \_\_\_\_\_

**GP Details:**

GP Name: \_\_\_\_\_ GP Practice: \_\_\_\_\_

GP Practice Contact: \_\_\_\_\_

GP Practice Phone number: \_\_\_\_\_

GP Practice E-Mail Address: \_\_\_\_\_

**Recording Consent:**

☐ Patient has been informed that they are required to provide consent for their details to be held on the SDRN Research Register. (This tick box needs to be selected before any confirmation of consent can be recorded)

☐ Patient has been issued a:

☐ Permission to Contact Form

☐ Patient Information Sheet

☐ Contact Card with details of how to leave the register

☐ Patient has completed, signed and returned the "Permission to contact form" (This tick box needs to be selected before any confirmation of consent can be recorded)

**Patients Preferences:**

Please complete the following: **0800**

☐ Patient has given consent to be contacted regarding any research study they are eligible to participate in.

☐ Patient has denied consent as they are not interested in being contacted regarding any research study.

Reason:

☐ Patient is undecided about giving consent to be contacted regarding any research study.

**Patients Preferred method of Contact: 0800**

☐ Letter/Post ☐ E-Mail ☐ Telephone ☐ Mobile

**Submit Form** **Reset**

**Submit Permission To Contact Form**

**Start** **SCI-DC Clinical Inform...**

Internet 11:03

## **9.4 Discussion**

### **9.4.1 Summary of main findings**

Our case study showed currently high levels of diabetes-related data coding in GP practices in England. However, the levels of data structuring and/or coding in diabetes records were found to vary considerably between primary care and secondary care, and between secondary care Trusts. We found that the advantages of highly coded diabetes data for secondary uses, such as research, public health and service planning – especially if diabetes data could be combined with other disease registers, as now happened in Scotland – were potentially immense. For example, they held the promise of revolutionising medical research by making randomised controlled trials quicker and cheaper to run and by encouraging large cohort studies through supporting assessment of eligibility criteria and enabling more targeted recruitment decisions.

However, we also found more marginal, clinical benefits within an NHS organisation. Direct benefits identified by interviewees included: having relevant, up-to-date information available for consultations; making it easier to share information between members of staff, improving disease management and monitoring; helping to involve patients in their care by illustrating points graphically on the screen; and enabling GP2GP fast transfer of records when patients moved practice. This study found no evidence in the sampled sites of other hoped for benefits, such as improving communications between different NHS organisations and supporting better integrated care, or of enhancing patients' self-management. Nonetheless, there was the SCI-DC (26) model being developed north of the border, where a single, diabetes patient record was created from multiple information sources, which included the GP and the hospital.

Case study interviewees using GP IT systems were in the main satisfied with their systems and felt data coding was relatively straightforward and worthwhile. Our sampled hospital site used paper records. Clinicians spoke in favour of having a specialist diabetes IT system to support more structured data capture, but these interviewees saw no prospect of getting such a system in the foreseeable future because of financial cutbacks in the NHS. There was widespread awareness of problems arising from inaccurate and incomplete coding, among clinicians, managers and coders. There was virtually no awareness among NHS staff

in the case study sites of the Government's plan to make SNOMED-CT codes the universal standard in the NHS in England.

#### **9.4.2 Strengths and limitations**

The strengths of this case study are the range of interviewees who described their experiences and views on data structuring and/or coding for diabetes and the sampling of three sites from one area (two GP surgeries and one hospital), which gave a picture of diabetes information recording across a local health community. We selected diabetes as an exemplar of long-term, biomedical conditions. As such, our diabetes-related findings may to at least some extent be transferrable to other long-term conditions, for instance, to asthma, Chronic Obstructive Pulmonary Disease (COPD) and stroke, in which on-going monitoring and disease management by health professionals and by patients are also important factors in care. The work was enriched by observations of both professional clinical coders at work and of clinical consultations between specialist nurses and patients. It was also strengthened by eliciting the perspective of a major supplier of specialist diabetes IT systems.

The main limitation of the work also relates to the highly variable approaches to diabetes data capture in English hospitals. Our detailed, on-site findings are restricted to one health community in which the sampled hospital used paper-based diabetes records; had resources permitted, it would have been valuable also to sample a hospital in which EHRs were established. While this chapter provides an accurate reflection of the data we collected, we acknowledge that data saturation was not necessarily achieved. There may be quite different experiences and perspectives that we failed to capture here, despite interviewing a diverse range of clinical and non-clinical participants.

#### **9.4.3 Relating these findings to the existing literature**

A diagram of the observed relationships between amounts and types of structuring and coding of diabetes records in primary care, the drivers for coding and the clinical benefits perceived by NHS staff is given in Figure 9.2.

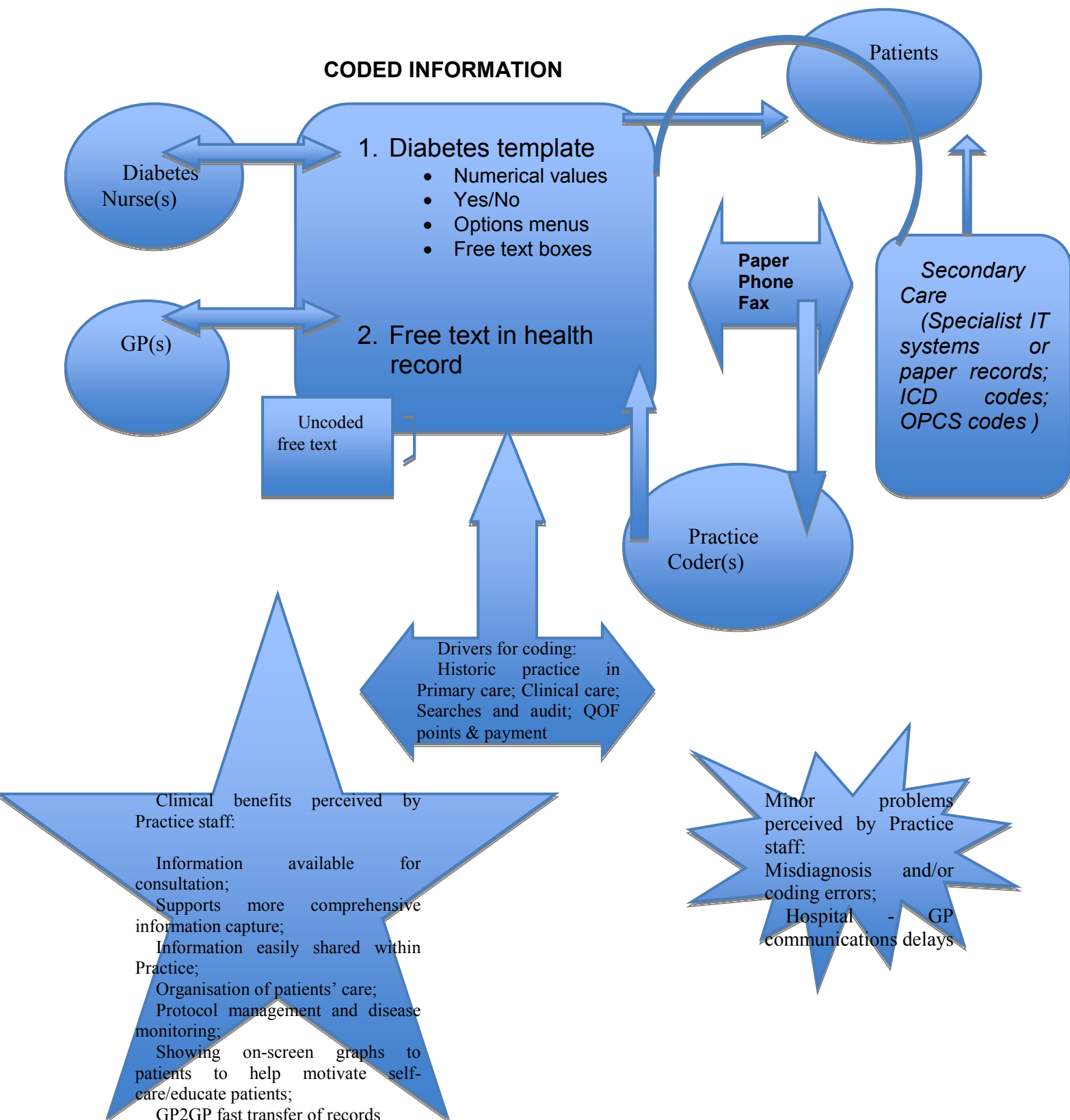
Our data supported previously reports of the misclassification of diabetes Type 1 and Type 2, and wider concerns about inaccurate and incomplete coding of diabetes data, leading to

the distortion of diabetes-related statistics (16,17,18,19,20,,31,32). In addition, our detailed case study of a sample health community illustrated the wide discrepancies in the amounts, types and approaches to coding that can currently be found in primary care and secondary care in England. A common factor found for both sectors was that financial incentives were a driver for coding, but it was one amongst other drivers for coding for our interviewees, who also highlighted the importance of perceived, direct benefits. Further, in our sampled secondary care site, the importance of coding for financial reasons varied by role, with coders and managers more aware of the implications of coding for the Trust's finances than clinical staff. Rather, in our work, secondary care clinicians viewed the Trust's finances to be the main barrier to implementing specialist diabetes IT systems and hence more structured and/or coded data. While previous research has investigated the influence of EHRs on the quality of the management of diabetes patients (21,22), our study suggested a widespread perception in primary care, and in secondary care settings where clinical work was supported by diabetes IT systems, that structured and coded information had direct benefits for clinical care. The observed emphasis on highly structured and coded data capture in primary care did not seem to discourage recording of any aspects of the clinical consultation, as has sometimes been speculated.

**Figure 9.2: Diabetes records in primary care: relationships between structuring and/or coding, coding drivers and perceived clinical benefits**

*Primary Care*

*(Primary care systems; Read codes)*



#### **9.4.4. Conclusions and recommendations**

Examples from places in the UK where high levels of diabetes data structuring and coding are in common use – such as many GP practices in England, and in the smaller UK nation of Scotland – indicate the value of striving to have this approach adopted more widely. There is potential for substantial secondary uses benefits, notably for research, and for more marginal, clinical benefits within individual organisations. Where clinical staff are already working well with existing codes, they will have to be persuaded of any benefits of replacing familiar codes with a new clinical terminology in accordance with Government plans to roll out SNOMED-CT.

Scotland has a significantly smaller population than England. Differences in scale and in the national political environment mean developments in Scotland are unlikely to be able to be directly transplanted to England. Nonetheless, England's neighbour offers examples of successful progress and innovation; the model there of slowly rolling out a largely standardised approach to digital diabetes data collection, which was always clinically led, and of combining multiple data sources to improve the quality of secondary uses data, rather than focusing on improving individuals' coding, is one which other countries in the UK and further afield could usefully study, and perhaps follow.

Initially, efforts in England might be best directed towards reducing the discrepancies between primary care and secondary care with respect to healthcare IT, and particularly the variability in secondary care in how diabetes data are currently captured, stored and shared. If diabetes IT systems became universally established in NHS organisations in England, the next steps could then focus on using digital data for improving real-time information sharing between primary and secondary care, and between those sectors and community health and social care providers; and on supporting patients' access to information about themselves and how to manage living with diabetes.

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## Chapter 10

### International approaches to systematising clinical information

#### Abstract

**Background:** The adoption of electronic health records (EHRs) is essential to the benefits realisation strategies of many national programmes, in particular to help improve healthcare quality whilst improving efficiency. These benefits largely depend upon the computability of EHR information, which in turn requires relevant information in them to be structured and/or coded. The challenge of appropriately directing efforts towards increasing the extent to which records are structured and coded is therefore being tackled in many countries in parallel.

**Aims and objectives:** We sought to investigate the approaches being adopted outside of the United Kingdom (UK) in order to identify lessons that might prove useful to the National Health Service (NHS).

**Methods:** After conducting a scoping survey exercise, we selected six exemplar countries – Australia, Brazil, Canada, Japan, Sweden and the United States (US) – which were conceptualised as case studies. We developed a data extraction form, which was used to summarise relevant high-level insights obtained for each country from reviewing national policy documents and undertaking semi-structured in-depth interviews with key experts. Data were thematically analysed to identify common and distinguishing approaches, and emerging issues at both national and international levels.

**Results:** Our dataset comprised 105 documents and 18 interviews. Across the six countries studied, we found a broadly comparable list of key political and societal drivers behind eHealth investments. These included the need to help counter the effects of ageing populations and the associated increase in prevalence and complexity of treatment of chronic diseases, and recognition of the pressing need to improve the efficiency of healthcare services and reduce costs,. The most widely promoted benefit of EHRs was better adoption of clinical guidelines, which it was expected translate into improvements in the quality of healthcare. The technical approaches being adopted for national EHRs varied between predominantly Health Level Seven International (HL7) or International Organization for Standardization (ISO) 13606 standard architectures. Some countries were found to be developing clinical models using openEHR / ISO 13606 archetypes and many countries had

nominated Systematized Nomenclature of Medicine – Clinical Terms (SNOMED-CT) as the intended national terminology for the future. Apart from Sweden, which has sought alignment with professional quality drivers, and the USA which has implemented financial incentives, there was little evidence of specific incentives or encouragement for clinicians to adopt structured and/or coded EHRs.

**Conclusions:** It is too early to determine from these countries what balance between narrative, structured and coded information is likely to prove beneficial to direct patient care, or will successfully enhance the quantity and quality of the data available for secondary uses. However, this high-level review of the international landscape has highlighted the considerable opportunities for international collaboration on these efforts; in particular, mapping locally used terminologies to newly adopted national ones was consistently found to be proving a significant challenge.

## 10.1 Background

It is increasingly recognised, globally, that computerised systems and tools are vital to augment human (clinician) reviews of historic patient information and to map patient data to up-to-date medical knowledge. Computers may helpfully filter, highlight, alert, guide, advise, communicate, escalate and educate in support of direct patient care, as well as enable information to be re-used for clinical audit, quality improvement, public health, prevention and outcomes evaluations, research, and many other purposes (see Chapters 1, 4 and 5).

These benefits are essential to enable healthcare services to improve quality and safety whilst containing costs. There is thus now an international drive, manifest in multiple and substantially funded eHealth programmes across the globe, to establish national infrastructures to enable clinical data sharing and formalisations of the EHR including its structural organisation and clinical meaning. Much of the published empirical literature on the uses and benefits of EHRs is however based on pilot projects and short-term empirical studies of “home-grown” small-scale EHRs (1).

The tools, specifications and standards needed to gain major benefit from structured/coded records are relatively new, and these tend to have the maximum chance of delivering the benefits listed above when implemented on a large-scale (2).

The International Health Technology Standards Development Organisation (IHTSDO) is, for example, now strongly promoting SNOMED-CT as a resource targeted to enhance global health by facilitating better health information management. Clinical archetypes are a

formalism for defining the clinical data structures to be used in interoperable EHRs: originally pioneered by the openEHR Foundation (3), an information model for archetypes has now been published as an international standard (4) and work is ongoing to develop quality criteria (5) and professionally-driven processes whereby good quality archetype libraries can be established for different clinical domains. The National Health Service Connecting for Health (NHS CFH) Logical Record Architecture (6) uses the latest generation of EHR interoperability standards (7), archetypes and SNOMED-CT. Other countries such as Sweden and Brazil have recently made similar decisions (8-10). These and other developments suggest that an international overview of national approaches to systematising clinical information is not only important and opportune, but it could also inform and enrich the findings of our UK focussed enquiries (see Chapters 5-9).

### **10.1.1 Objectives**

Building on our earlier more UK-focused qualitative work and case studies, we sought to:

- Understand why and how different countries are seeking to balance efforts in support of narrative and/or structured and/or coded EHRs, and their approaches to the development and adoption of clinical data standards for the organisation of records and the choices being made for terminology standards;
- Identify any incentives being used to increase the structuring and coding of EHRs being pursued in other countries;
- Identify novel strategies being employed to overcome any barriers encountered when attempting to increase the extent of coding within EHRs.

## **10.2 Methods**

The business justifications behind current major national investments, the approaches to implementation of EHRs, and the structuring and/or coding of information in EHRs within these programmes (since these might point to potentially successful strategies) were examined internationally to obtain insights into the global landscape. A case study approach was adopted as this offered the opportunity to generate an in-depth, bounded and contextualised investigation of these national plans (11). We purposefully identified and reviewed six national/large-scale eHealth programmes to identify the key anticipated benefits and risks associated with improved structuring and coding in EHRs, and to discover the approaches being used to maximise the chances of realising these benefits whilst at the same time mitigating potential risks.

### **10.2.1 Design**

We chose to focus on the following six countries: Australia, Brazil, Canada, Japan, Sweden and the US. These were chosen as they were known to be at differing levels of maturity in their programmes, to have started with different levels of legacy EHR system infrastructure and were known to be following contrasting approaches. We began by outlining the methods to approach the issue, followed by an overview of each of six exemplar countries conceptualised as case studies. In each exemplar country, we conducted a semi-structured, in-depth qualitative enquiry involving both interviews with a targeted group of experts/policy makers and documentary analysis of key policy documents. The selection of those countries aimed to provide an overview of international practices and possible future directions of structuring and coding clinical information in EHRs. Findings were first analysed for each case study (i.e. country) by integrating different data sources and then in order to identify more trans-national themes. Based on our work, we developed an explanatory model which interprets national approaches to structuring and/or coding in case study sites.

### **10.2.2 Sampling and recruitment**

We sampled from our existing list of contacts and those identified from our reviews of the literature (Chapters 3 and 4). We selected the six exemplar countries (i.e. Australia, Brazil, Canada, Japan, Sweden and the US) because they offered insights into contrasting healthcare systems and demonstrated different approaches to implementing EHRs and structures/codes for clinical information: predominantly commercial vs. state-funded healthcare systems; top-down vs. bottom-up eHealth programmes; national vs. devolved approaches for the use of standards of codes; high level of EHRs take-up vs. low level; different levels of incentives; and countries with different political systems and economic development. They also reflected a diversity of levels of programme maturity in EHR adoption and were known to have differing starting points in terms of legacy systems and legacy infrastructure.

In order to identify and reach the most appropriate interviewees we created contact lists for targeted countries based primarily on personal contacts of national experts, and advice from key personnel connected with the programmes in each selected country. Individuals were sought who had an understanding of the drivers and approaches of their nation's programme and had an understanding of clinical information and the approaches being promoted to structure and/or code it.

Once the contact lists were completed, listed individuals were approached by email or personal contact at meetings, in order to request relevant policy/strategy resources and to set up interviews. This sometimes required several steps to reach the appropriate person as the nature of the topic is very specialised.

When the country had a centralised unit for interoperability, we aimed to obtain at least two peoples' views, but in countries with more federated or fragmented approaches, we sought to interview four to five people per country to capture a more multidimensional view about the country's situation.

### **10.2.3 Data generation and handling**

Data generation was facilitated by the use of a structured survey template, which was designed by the project team members and used as our key data collection instrument. The template was informed by a previously undertaken (but unpublished) survey undertaken by ISO Technical Committee 215 (Health Informatics) in 2007, and repeated in 2009, led by one of the authors (DK). After going through several iterations of sub-headings and questions by testing them with international experts attending ISO meetings, the template was finalised (see Appendix 23). The template was used to extract relevant information from policy documents for each country. Unidentified areas from the policy documents were explored through the interviews with senior/top-level experts on this topic. The template was accompanied with a one page of summary of our project and the aims of this international study on systematising clinical information and it was circulated as an information documents to potential interviewees prior to the interviews.

Key issues explored during the interviews included general background information about healthcare systems and EHR adoption in each country, national standards for EHR interoperability, innovative approaches to improve the quality of structuring and/or coding clinical data, perceived barriers and strategies for overcoming them (see Table 10.1 for a sample interview guide).

**Table 10.1: Sample interview guide**

<b>Main structure</b>	<b>Specific topics and issues</b>
Confidentiality, aims, thanks	Theorised and actual benefits and risks, drivers, incentives, barriers and how to address these
Any questions?	
<b>About yourself</b>	Role, do you capture and store health information yourself and, if yes, what and how? (setting, profession, coding system, electronic system)
Background information about <b>healthcare systems</b> and <b>national eHealth programmes</b>	How has the healthcare system been governed? Are/were there any national eHealth programmes? If so, what are/were they? What is the strongest business driver for large scale EHR adoption? At political level? At professional level? At public level?
<b>Overall</b>	
<b>Priority areas for structuring and/or coding clinical information</b> behind the policy	What are the top priority areas for collecting coded data?
What kinds of <b>approaches</b> are taken for <b>EHR interoperability standards</b> ?	Data structure standards Clinical record standards Terminology standards Clinical content modelling standards
What kinds of <b>incentives</b> do you have?	Reimbursement Grant/funding Any other forms of incentives?
Any <b>other barriers</b> that your country is facing at the moment?	
<b>Innovative approaches towards the improvement of the quality</b> of coded data	Any examples of innovative approaches or tools developed?
<b>Lessons learned</b>	What kinds of lessons have you learned

	so far?
<b>Concluding remarks</b>	
Anything else?	
Thanks, any questions?	
Anyone they can recommend for interview?	
Any latest/unpublished policy documents and relevant literature?	

Rather than conducting standardised interviews, we used the topic guides more flexibly by modifying and adjusting the contents to reflect the specialist areas of the interviewees, the information filled in the survey templates and the stage of the country's national EHR programme and the extent of EHR adoption. This led us to conduct exploratory, semi-structured interviews to identify the key issues for each country. The topic guides were continuously reviewed throughout the research and emerging issues were fed-back into subsequent rounds of data collection. All the interview data were anonymised for analysis to protect the privacy of the informants.

#### **10.2.4 Data analysis and interpretation**

The survey template provided the framework for the analysis and extracted information from the relevant policy documents was used for comparative analysis based on each sub-heading. Over 100 documents, slide presentations and national programme Web sites were reviewed (see Appendix 23: Data Collection Template for WP4 for the details of the resources we inquired for this study). After identifying any distinctive characteristics to each country, they were used as supporting information for the qualitative analysis of the interview data.

All the interviews were recorded and then transcribed for data analysis. The analysis approach involved initial integration and analysis of the data from the documents with that from the interviews for each case country, which was followed by a more cross-cutting analysis of the themes and sub-themes across countries. Where necessary, we made further contacts with national experts and programme leads in order to clarify issues and obtain further information.

The data obtained from the semi-structured interviews provided us with greater ease of comparative analysis of the data across the countries (11). The transcribed data were read

by researchers for interpretive (12) and the qualitative software NVivo version 8 was used to search for key phrases and to explore data (13). A coding framework was developed from our survey templates and the topic guide. The overall categories were: background (e.g. healthcare structure, EHR adoption across the country, priority areas for EHR adoption); policy (national EHR programmes, past national/large-scale eHealth initiatives, business drivers at political, professional and public level); anticipated benefits of coding clinical information; adopted approaches (incentives and any particular initiatives); planned and/or adopted EHR interoperability standards; validation processes of proposed standards/relevant resources for roll-out; approaches to improve data quality beyond incentive schemes; narratives/free-text; challenges/barriers; overcoming strategies; lessons learned. Using these categories, the analysis was conducted by adopting an 'abductive research strategy' as a deductive approach and a 'retroductive research strategy' for inductive analysis (14,15).

### **10.3 Results**

Our overall dataset comprised the policy documents and grey literature for the six countries and qualitative data obtained from semi-structured in-depth interviews. Box 10.1 summarises our dataset with the salient features of our interview participants.

**Box 10.1: Summary of data collected****Australia:**

Interviewee 1: Interoperability specialist working for the national EHR programmes

Interviewee 2: Clinical Leaders working on the national EHR programmes and the development of national terminology standards

**Brazil:**

Interviewee 3: Independent interoperability specialist

**Canada:**

Interviewee 4: Strategic investor and interoperability specialist working for the national EHR programmes.

Interviewee 5: Terminology specialist working for the national EHR programmes  
(Interview 4 and 5 for one interview)

**Japan:**

Interviewee 6: Technical consultant to the government, independent interoperability specialist

Interviewee 7: Medical informatics specialist, academic

Interviewee 8: Standards body, technical specialists

Interviewee 9: Standards body, technical specialists

Interviewee 10: Standards body, technical specialists

(Interviewee 8 – 10 for one interview)

Interview 11: Terminology specialist, academic

Interviewee 12: Clinical leader for one of the regional EHR programmes

**Sweden:**

Interviewee 13: Terminology specialist working for the national EHR programmes

Interviewee 14: Medical informatics specialist working for the national EHR programmes

**The US:**

Interviewee 15: Medical informatics specialist (interoperability), academic

Interviewee 16: Medical informatics specialist (interoperability), academic

Interviewee 17: Medical informatics specialist (policy)

Interviewee 18: Medical informatics specialist (terminology), clinician

**10.3.1 National pictures**

Boxes 10.2-10.7 below provide high-level summaries of the salient findings for each of the six sampled countries that influenced the approach to the clinical content of the EHR. Emphasis has been given in each case to the most strongly promoted priorities and approaches identified from responses from interviewees and from strategy documents.

### Box 10.2: Australia

Political and professional drivers declared as the justification for the national EHR programme

- Ageing population
- Control of healthcare costs
- Data to improve commissioning

Key benefits of a national EHR being promoted to the public and professions

- Improved information sharing, better care coordination
- More effective and safer medications management
- Increased patient participation, especially Aboriginal peoples and Torres Strait islanders
- Better measures of health care quality
- Research

Priority use cases for early adoption

- Personally controlled EHR – accessible by patients and with access to it controlled by them
- Shared health summaries
- Event summaries, discharge summaries
- Consumer entered information
- National quality registers

Technical standards and infrastructure components being used to implement the national EHR

- National communications infrastructure
- National patient identifiers
- Identifiers for health care provider organisations and staff
- National development of clinical data structures and templates, similar to openEHR archetypes
- HL7 clinical document architecture
- SNOMED CT (several other terminologies are currently in use)

Initiatives used to promote the increased adoption of structures and/or codes by clinicians

- Financial incentives to purchase a standards-based EHR system
- No specific standards or targets clinical data quality or coding adoption
- The role of clinical leaders is increasing its importance, e.g. in the development of clinical dataset templates and terminology standards

Lessons learned, in relation to structuring and coding, from experience to date

The emphasis of the programme was previously too focused on technology solutions, which failed to engage the clinical professions or the public. This has recently shifted to promoting the vision of an EHR directly to consumers as an enabler of healthcare reform.

### Box 10.3: Brazil

Political and professional drivers declared as the justification for the national EHR programme

- Increasing demand for healthcare
- Ageing population
- Emerging new diseases

Key benefits of a national EHR being promoted to the public and professions

- Improved care coordination
- Improved health promotion and disease prevention
- Better support for clinical decision-making

Priority use cases for early adoption

- Improved records within primary care
- Communicating laboratory results
- Chronic disease management
- Child health
- Tele-health (connecting patients in rural areas to clinicians)

Technical standards and infrastructure components being used to implement the national EHR

- Standards for the electronic health record (ISO 13606 and HL7 CDA)
- SNOMED-CT and LOINC
- Pilot projects in the largest state (Minas Gerais) to develop collections of archetypes
- Promotion of open source software

Initiatives used to promote the increased adoption of structures and/or codes by clinicians

- None as yet; efforts are being made to encourage the use of good quality EHR systems by Brazilian states:
  - National funding to subsidise state driven eHealth programmes
  - Active promotion of EHR interoperability standards (published during 2011)

Lessons learned, in relation to structuring and coding, from experience to date

- None as yet: the programme is still in its early stages

#### Box 10.4: Canada

Political and professional drivers declared as the justification for the national EHR programme

- Improved and secure access to healthcare services
- Improved quality of care and health outcomes
- Improved productivity

Key benefits of a national EHR being promoted to the public and professions

- Reduce medication adverse events
- Reduce unnecessary tests
- Reduce waiting times
- Improve immunisation rates

Priority use cases for early adoption

- EHR systems in primary care
- Provider order entry systems in hospitals
- Improved waiting time management systems
- Consumer self-care systems
- Chronic disease management, starting with diabetes
- Telehealthcare

Technical standards and infrastructure components being used to implement the national EHR

- Strong, centrally directed, standards development program
- HL7 version 3 messages for most communications, including medication, laboratory, diagnostic imaging, clinical correspondence, public health, claims
- Standardised Clinical Terminology Services
- SNOMED-CT and LOINC as the main terminologies being promoted across Canada

Initiatives used to promote the increased adoption of structures and/or codes by clinicians

- None at a national level, and no specific measures at province level

Lessons learned, in relation to structuring and coding, from experience to date

- Previous priority investments have now become widely adopted, and are building support amongst professionals and the public for continued investments in eHealth:
  - Patient and provider registries
  - Radiology Information Systems
  - Laboratory test result communication
  - Medication and immunisation profiles

### Box 10.5: Japan

Political and professional drivers declared as the justification for the national EHR programme

- Use eHealth to help cope with a shortage of clinicians in rural areas
- Be in a better position to handle healthcare delivery in disaster situations

Key benefits of a national EHR being promoted to the public and professions

- Standardised high quality care, especially in non-urban areas
- Secondary uses such as service planning, disaster planning and research

Priority use cases for early adoption

- Standardised care pathways for major diseases (priorities are cancer, stroke, diabetes and acute myocardial infarction)
- Deliver EHR systems in five priority care settings (emergency hospitals including paramedics, paediatric hospitals, perinatal hospitals, disaster medical centres and regional medical liaison hospitals)
- Five anonymised clinical data warehouses are being established across Japan, primarily to study medication safety

Technical standards and infrastructure components being used to implement the national EHR

- National development of health information and communication standards
- Standardised drug codes
- Use of Digital Imaging and Communication in Medicine (DICOM) for digital images
- Standardised Japanese clinical laboratory message standards
- Recent interest in using HL7 for other healthcare messages
- Early interest in using openEHR and ISO 13606 for EHR communications
- No formal decision on using an international terminology such as SNOMED-CT (significant translation and cross-cultural challenges with this)

Initiatives used to promote the increased adoption of structures and/or codes by clinicians

- It is recognised that there are yet no incentives, and this will be an important priority for the future
- Limited clinical coding is used only for reimbursement from the government, and health insurance claims

Lessons learned, in relation to structuring and coding, from experience to date

- None as yet: the programme is still in its early stages

### Box 10.6: Sweden

Political and professional drivers declared as the justification for the national EHR programme

- Improve the quality of healthcare
- Improve patient empowerment (personal e-services for all citizens, interactive services for patient participation, web-based support for free choice of care provider)
- Provide better information on clinical outcomes

Key benefits of a national EHR being promoted to the public and professions

- Use aggregated clinical information to improve the knowledge underpinning care pathways and clinical guidelines
- Improve quality of care through better adoption of clinical guidelines
- Enable comparison of quality and outcomes between care providers
- Engage citizens in self-care

Priority use cases for early adoption

- National patient summary
- Electronic capture and communication of chronic disease data to quality registers (which cover more than 50% of inpatient-managed conditions)

Technical standards and infrastructure components being used to implement the national EHR

- ISO 13606 EHR architecture
- openEHR archetypes
- Swedish national clinical process model
- Multi-professional nationally adopted terminologies, now progressively been mapped to SNOMED-CT
- All of the above integrated within a national EHR architecture

Initiatives used to promote the increased adoption of structures and/or codes by clinicians

- Working with national professional bodies and disease speciality groups to promote quality registers and relevant EHR archetypes
- It is widely recognised amongst professionals that these registers will only deliver value if the information in them is fully structured and coded

Lessons learned, in relation to structuring and coding, from experience to date

- Early experience with the heart failure quality register has confirmed that EHR data can populate the register electronically
- However quality register data structures have not proved rich enough for routine clinical documentation, and additional archetypes are now having to be developed

### Box 10.7: US

Political and professional drivers declared as the justification for the national EHR programme

- Greater value from healthcare expenditure
- Improvement in quality

Key benefits of a national EHR being promoted to the public and professions

- Patient focused health care services
- Reduction of medical errors
- Better quality data for public health, research and for support in national emergencies

Priority use cases for early adoption

- Key national priorities have been bundled within a concept of "Meaningful use" (16, 17)
- The priority information content for EHRs comes from the headings of a continuity of care clinical document standard (these headings are actually underpinning the shared medical summary in many countries)
- The collection of data to monitor for inequalities, for example ethnicity data, are also seen as advantages from meaningfully used EHRs

Technical standards and infrastructure components being used to implement the national EHR

- Specifically for the EHR, the principal information exchange standard is the continuity of care document standard, a specialisation of the HL7 Clinical Document Architecture
- SNOMED-CT, LOINC for laboratory and RxNorm for medication are proposed for interoperability
- HL7 version 2 messages are used widely for other healthcare system communications and for billing

Initiatives used to promote the increased adoption of structures and/or codes by clinicians

- Medicare and Medicaid, and insurers, dictate the coding situations and the codes clinicians should use for reimbursement purposes; coding for clinical value is far less frequent
- The Meaningful use incentive programme includes substantial funding for healthcare providers who adopt specified levels of data collection and functional use of clinical information systems
- (This will inevitably increase the quantity of structured and coded information that is directly entered by clinicians)

Lessons learned, in relation to structuring and coding, from experience to date

None as yet: the programme is still in its early stages

## 10.4 Discussion

### 10.4.1 Main findings

Countries vary in the role and power of the state over regional healthcare services. In some, these national programme have played a facilitating role enabling national EHRs through

common infrastructures and standards (e.g. Australia (16-18) and Canada (19, 20)), these contrasting with the more centrally directed and mandated approach that has until recently been pursued in England.

In all of the countries surveyed, strategic decisions and investments are directed at a regional level (which may be termed state, province, or county). National roles are therefore focused on the setting of priorities, development of standards, and formulating and offering financial incentives for alignment with these priorities and standards.

Across the six countries studied there was a broadly comparable list of key political and societal drivers behind eHealth investments. The predominant drivers were to improve the efficiency of healthcare services and to reduce costs, to help counter the effect of an ageing population and the increase in prevalence and complexity of treatment of chronic diseases. Increasing the extent of patient empowerment and patient self-care was frequently mentioned. Secondary uses, particularly the use of data to monitor outcomes and for research, were other drivers behind national level investments. The most widely promoted benefit of EHRs was better adoption of clinical guidelines and consequent expected improvements in the quality of healthcare.

However, countries differed in which parts of an EHR they prioritised. Australia, England, Sweden and the US, for example, placed a shareable patient summary amongst their top priorities. The USA focused on a clinical communications summary to support care transfers rather than a longitudinal patient summary. Sweden, in contrast, is concentrating on chronic diseases, using registers (that are potentially linked to their longitudinal electronic patient summary) to support integrated care pathways and the collection of clinical audit data.

Whilst a medical summary is a common priority for adoption, the intended benefits of this were not usually well articulated. For example, it was not usually clear whether this was primarily intended to support unscheduled emergency care, or to better enable continuity of chronic disease care between care providers. Since the clinical summaries required for these used cases might be different, the lack of clarity about purpose may eventually limit the utility of these summaries.

The technical approaches being adopted for national EHRs varied between predominantly HL7 or ISO 13606 standard architectures. Most countries are developing clinical models using openEHR / ISO 13606 archetypes or an equivalent approach, such as (Sweden (21, 22), Australia (18, 23) and to some extent Brazil (10). Although many countries have

nominated SNOMED-CT as the intended national terminology for the future, most appear to be at an early stage of transition from other national terminology systems. Some interviewees reported that this process of mapping between terminologies is proving to be a major effort. This challenge has also been identified as significant in other national programmes with which the authors are familiar (e.g. Singapore).

Countries are progressing a mixed agenda of national and regional initiatives to adopt EHR systems, the latter approach being more sensitive to local needs. Some incentive programmes, such as in the US, operate at both national and regional levels (24-26). Apart from Sweden, which has sought alignment with professional quality drivers, and the USA which has implemented financial incentives, there was little evidence of specific incentives or encouragement for clinicians to adopt structured and/or coded EHRs. This is a surprising finding given the importance of clinical engagement in collecting high-quality data to realise the benefits behind these national investments.

Despite relatively ambitious timetables for achieving interoperable EHRs, most countries were at a very early stage in developing clinical data structures and terminology subsets to facilitate the consistent and coherent collection of clinical data. Very little of the intended clinical EHR functionality has yet been deployed and put into operational use through these programmes. It is therefore too early to determine the success of the technical approaches being adopted. It is also too early to determine from these countries what balance between narrative, structured and coded information is likely to prove beneficial to direct patient care, or will successfully enhance the quantity and quality of the data available for secondary uses.

#### **10.4.2 Strengths and limitations**

In each country included in this review, at least one expert was interviewed who has been working on architectural standards and/or clinical terminology standards and directly involved in the development of interoperable clinical data exchange within national EHR initiatives, except Brazil where no clear vision of national EHR has been fully developed yet. Therefore, the findings reported here should reflect the latest insider perspectives and experiences to advance knowledge in this field. All the qualitative data obtained through interviews were originated from decision makers or senior-level informatics experts. This allowed us to gain insights into the subject beyond the content of publicly available policy

documents and filled the gap between those documents and what is happening in the real world.

Policy documents were collected through a search of the Internet, identification of references in other policy documents, reading of academic articles and grey literature, and consultation with experts. However, there is possibility that we may have missed some important key policy documents available in English. Also, in some countries where the national language is not English, we had to rely on the limited English-based information to supplement the input from the experts. Some of the non-English language websites were examined with the help of Google Translate, but there is a risk that significant information was missed.

The national case studies are inevitable snapshots from available information initiated from some key direct contacts with experts in this field from the selected countries. Due to this, there is a possibility that countries providing significant insights have not been included in the study. Also, due to the limited time-frame, some important developments within the studied countries might have been overlooked.

As the focus has been placed on the policy perspective, clinicians' views as coders have not been covered in the study. For future studies, detailed investigation including a range of users/stakeholders from a wide range of countries would give richer data which would be beneficial to international communities working on this topic. Also, for future studies, investigations into the role of vendors in the development of standard codes would be beneficial as the importance of such studies is often overlooked.

#### **10.4.3 Implications for policy, practice and research**

The case studies of the six countries show that most of the countries are still making an effort to increase the diffusion level of EHRs in primary care and/or secondary care (e.g. the US, Canada, Japan and Brazil). Due to the past huge investment and financial incentives for coding, especially in primary care, the UK is now in a leading position to provide insights into the success factors that encourage coding clinical information by healthcare professionals. However, due to the nature of being an early adopter of EHRs at a national level and requiring healthcare professionals to code clinical information using standards, the UK may have to make some adjustment while they are continuing the current practices. Latecomers to national EHR programmes like Australia and Canada have studied the UK's experiences and reflected their learning in their own policy developments.

#### **10.4.4. Conclusions**

This work has demonstrated that others healthcare systems in the world are also in a state of flux in relation to EHR-centred redesign. The investments and associated policy developments are motivated by broadly similar concerns/aspirations in relation to quality, safety and efficiency. The interest in structuring/coding dimensions is motivated by a similar desire to improve clinical outcomes and in the longer-term through facilitating secondary uses.

This work has highlighted how other countries are also grappling with how best to achieve better quality and more computable EHR. It has furthermore revealed considerable opportunities for international collaboration on these efforts; in particular, mapping locally used terminologies to newly adopted national ones was consistently found to be proving a significant challenge. Cross-country alignment on specific care scenarios might make the challenge more tractable.

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## Chapter 11

### Conclusions

This chapter provides an overview of our findings, discusses the strengths and limitations of our work, and implications for policy, practice and further research. Rather than replicate information discussed in earlier chapters, high-level findings from the individual work-packages (WPs) have been integrated to present common themes and lessons that are potentially transferable to other contexts (1).

#### 11.1 Overview of findings

We began our work by conducting a systematic literature review on the direct benefits of structuring and/or coding the presenting patient history to patient care and then followed this up with a wider landscape review reviewing the evidence in relation to the quality and safety of patient care (Chapters 3 and 4). These reviews indicate that there has been limited effort made to-date to empirically evaluate the value from structured and coded electronic health records (EHRs) for direct patient care, as opposed to secondary use benefits which are far better established. We found no strong evidence to justify efforts to extend coding across the breadth of clinical care – for example coding of symptoms to enable diagnostic decision support. Rather, this work suggests that the adoption of structures and/or codes that underpin clinical guidelines/pathways and incorporate decision support can in carefully selected areas improve effectiveness in care processes.

In-depth interviews with a purposefully selected sample of key stakeholders aided contextualisation of the literature and helped to understand issues from a variety of perspectives (Chapter 5). Here, we found a significant variation in documentation practices across locations, care settings and professional communities. Collection of information within a medical record is a highly interpretative process, influencing documentation priorities and the level of detail recorded. There is often a mismatch between structures and/or codes that would be useful to support working practices and what is provided by the available information technology (IT) systems, resulting in duplicate paper or electronic systems (e.g. spreadsheets). The immediate value gained from the use of structuring and/or coding was most apparent in relation to prescribing decision support in general practice and the monitoring of some long-term conditions, as well as practice management and secondary

uses purposes. While linking clinical coding to reimbursement and performance management were reported to have increased the quantity of coding, we heard evidence that this had a parallel detrimental impact on the perceived value and importance of structures/codes. A lack of structure in communications with patients was found to be a barrier to encouraging and enabling patient understanding of and engagement in their own healthcare.

We then built on these first two strands of work using case studies of clinical records from four different settings to explore these issues further and found further evidence of significant differences in relation to perceived value of structuring and/or coding practices between these distinct areas (Chapters 6-9). For example, whilst in relation to drug allergies and diabetes care, structuring and/or coding of clinical information was perceived to result in direct value to patients and clinicians, in the areas of ethnicity and depression structuring and/or coding were more contested with clinically important information being primarily recorded in free text.

We then sought to place our work within a wider global context (Chapter 10). Our international comparisons of similar efforts to promote structured and coded EHRs in six other exemplar countries indicated that similar challenges were being faced by national eHealth programmes, independently of their actual implementation approach. Whilst the potential benefits of structuring and/or coding of clinical information are recognised internationally, most countries are still at an early stage of developing clinical data structures and terminology subsets to facilitate the consistent and coherent collection of clinical data. In this context, mapping locally used terminologies to newly adopted national terminologies is proving particularly challenging and this therefore presents an important opportunity for international collaboration to share experiences and lessons.

## **11.2 Strengths and limitations of our work**

Our work has, as far as we are aware, provided the first detailed inquiry into the benefits and risks associated with the structuring and/or coding of clinical information. This was facilitated by drawing on a mixed-methods approach (2), using systematic reviews to scope the literature and in-depth qualitative work to examine issues in context and from a variety of perspectives.

The skill-mix of our research team; consisting of methodologists, clinicians, psychologists, social scientists, informaticians and health managers proved extremely valuable throughout

the conduct of this work as it facilitated exploring issues from a variety of angles and helped to contextualise our findings. In addition, our ongoing involvement with other work commissioned by the NHS Connecting for Health Evaluation Programme (NHS CFHEP 001, NHS CFHEP 005, NHS CFHEP 010), enabled us to integrate emerging issues within current thinking and develop policy recommendations that are we hope both credible and useful.

However, we also faced a number of challenges. For example, the sparse existing literature in the field meant that we found it difficult to construct a rich evidence base. Where relevant empirical material existed, structuring and/or coding was often not the focus of inquiry, but the way electronic information was organised was often treated as a by-product of other more pressing concerns such as patient outcomes (3). These complex contextual circumstances surrounding our work meant that we may have missed some potentially relevant literature in our reviews as existing efforts may not be adequately indexed. In relation to our case studies, we had clear reasons for choosing particular exemplar areas (outlined in Chapter 2), but we could have focused on other areas such as the impact of structuring and/or coding on the interfaces between health and social care. Moreover, our scoping of other international approaches and experience was of necessity relatively limited, being influenced by time and resource constraints. As a result, we obtained a limited degree of depth of data in each of the countries and had limited scope for cross-country comparisons.

On a more practical level, we faced issues with access as the process of applying for ethical approval and local research and development permissions was often hampered by bureaucratic processes, which were not well understood by those on the ground (4). This, in turn, limited the amount of time we could spend in the field.

### **11.3 Implications for policy, practice and research**

Looking forward, our work indicates that the issue of structuring and/or coding now needs to be more firmly embedded within existing policy and research as an issue in its own right, as opposed to being part of the more general IT and modernisation agenda as is currently the case (5;6). In this context, it is essential that in the long-term the quality of clinical documentation, including the structuring and/or coding of records, becomes more embedded in professional value structures as opposed to being driven largely by financial incentives, which tend to deliver quick, but possibly short term coding take-up (7). This may be best achieved through closer alignment with national initiatives such as major guidelines that already have currency and professional buy-in. In the short-term, there is a need to work

towards developing a single nomenclature, better-harmonised terminologies, consistency in when and how specific terms are used, and alignment of coding practices across care settings. This is likely to be best achieved through consistent local/regional and national political, informatics, and clinical leadership. The forthcoming *Information Revolution* strategy will, it is hoped, further these ends (8).

When considering implications for practice, it is important that clinicians learn to appreciate that structuring and/or coding activity is important and worthwhile, as data can usefully be drawn on for secondary uses as well as for linkage work. Here, it is vital to recognise that benefits may accrue not only for the situation at hand (i.e. the clinical encounter), but also for the population at large. As primary care has made significant headway in relation to structuring and/or coding of clinical information, there is now an opportunity for hospitals to learn from primary care settings where barriers to structuring and/or coding activity have been overcome to some degree. This may usefully be promoted through tools and structures that are designed to support clinicians and facilitate the integration of systems within workflows.

In hindsight it might have been helpful to examine more specifically the value of structured scales such as activities of daily living, disease activity and so forth. We also note the exclusion of secondary uses from the scope of this study. Overall, we have shown that there is clearly a need for more empirical and applied work in the area. For example, there may in particular be merit in exploring the potential of structuring and/or coding of clinical information the management of (the more biomedical) chronic diseases, which have been translated into clinical pathways, in more detail. This may include diabetes, where a large amount of numerical structured data already exists and could easily be coded, which may then be usefully built upon to explore how much structuring and/or coding is actually useful and beneficial for various stakeholders including patients and clinicians. Similarly, certain paramedical areas (e.g. ambulance records), where the majority of information is structured, but presently written and stored on paper, may lend itself as an area of potentially innovative electronic coding practice.

In relation to patient-level benefits, our work suggests that there is considerable scope to empower patients to more actively engage with their care, this including the process of creating the clinical record (9). This may involve patients coding information, such as their own symptoms, themselves. As we have found, self check-in kiosks to facilitate such practices already exist and are perceived as valuable by patients, but there is now a need to build on these early successes. In this context, there is also a need to increasingly learn

from industry, where patient recording of symptoms is for example already routinely employed onto for example smart-phones and tablets/pads in clinical trials.

The move towards using the Systematized Nomenclature of Medicine – Clinical Terms (SNOMED-CT) as a single standard terminology across primary and secondary care is, we believe, likely to be a positive development as this should enable the sharing of coded data between and across care settings. However, it is important to recognise that it is not a panacea for record quality and consistency; there is furthermore the need to remain alert to the risk of unanticipated consequences. Investing in adequate training and better clinical applications, and maximising the opportunities for deriving value from already coded information and communicating this widely amongst NHS staff, is therefore essential to any future efforts to maximising the quantity, quality and usefulness of coded data.

In summary, our work suggests that the UK is in many respects a world leader in coding clinical data and exploiting its usefulness and this position is likely to be further enhanced if the ideas for unlocking and encouraging innovative uses of data central to the *Information Revolution* and recent policy developments encouraging the growth of life sciences in the UK are followed through (8, 10). There is also room for useful policy direction to harness the benefits of structured and/ or coded data, including for example national standards for clinical incident reporting, opportunities to conduct national audits using routinely recorded data captured at the point of care,(11) and both observational and prospective research using patient records. These coded data are already yielding substantial management, academic and intellectual returns to the UK and these are likely to accrue rapidly as datasets mature and the opportunities for data linkage increase exponentially. Whilst the benefits associated with more near-term benefits to patients and the professionals undertaking the work of coding are at present less well-established, our research has identified a number of areas in which there is the potential to reduce the additional burden for professionals associated with coding, to align this better with professional priorities, and also for enlisting the active involvement of patients in this integral aspect of care. This work suggests that if the wider encoding of the clinical record is pursued in carefully selected areas of care in which there are known and acknowledged quality, safety and efficiency challenges, this offers the best opportunity to see whether more near-term benefits – for example, in relation to improving the accuracy and speed of diagnosis, improved disease stratification, enhancing evidence-based practice and improving prognostication – can be realised.

Finally, given the considerable head-start we have, the favourable emerging policy environment and the considerable expertise in the UK, it is crucial that policymakers appreciate the strategic importance of ensuring the UK retains its leadership in this respect, which is likely to yield very substantial returns to patients, the NHS and society more generally.

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## Glossary

Term	Synonyms	Description
Body Mass Index (BMI)		A number calculated from a person's weight and height.
Classification system		Arrangements of all elements of a domain, into groups according to established criteria [1]. e.g. International Classification of Diseases (ICD).
Code		A representation applied to a term so that it can be more readily processed [1] e.g. The Read code for asthma is H33..
Coded entry		An entry that has a coded value from a terminology (either by the author selecting a term from a list of possible values, or by the user entering a phrase or sentence and the software matching the words to a closest fit term).  In the latter case the coded entry might include the original text entered by the author as well as the code corresponding to the matching term.  In either case the code meaning might be stored along with the code, or might be stored separately and retrieved for display whenever the code is accessed by a user of the information system.
Code meaning	rubric	The word or phrase that describes the concept represented by a term. The meaning is usually a short and succinct phrase that is as unambiguous and precise as possible, to help ensure that the term is used consistently by different people e.g. by different authors when entering data into electronic health records.

Term	Synonyms	Description
Concept		Unit of knowledge created by a unique combination of characteristics [2], which might have sub-components or relate to other concepts.
Entry		Documentation of a discrete item of health information. An entry might represent the documentation of a clinical observation, an inference, an intention, a plan or an action [3]. The data value of an entry might for example be narrative, coded, a date, a quantity, Boolean, a unique identifier or an image.
Ethnicity		The social group a person belongs to, and either identifies with or is identified with by others, as a result of a mix of cultural and other factors including one or more of language, diet, religion, ancestry, and physical features traditionally associated with race.[4]
Free text entry		Property of a computer screen field or database field that permits the entry of textual information without constraint (except perhaps for its length).
General Medical Services contract (GMS)		Contract covering the pay arrangements for General Practice (GPs) funded within the UK NHS.

Term	Synonyms	Description
Healthcare Resource Groups (HRGs)		Standard groupings of clinically similar treatments which use common levels of healthcare resource. HRGs are currently used as a means of determining fair and equitable reimbursement for care services delivered by providers. Their use as consistent 'units of currency' supports standardised healthcare commissioning across the service. They enable the comparison of activity within and between different organisations and provide an opportunity to benchmark treatments and services to support trend analysis over time. [5]
Hospital Episode Statistics (HES)		These statistics are returned by NHS Trusts to the national statistical data warehouse for England to report the care provided by NHS hospitals and for NHS hospital patients treated elsewhere. HES is the data source for a wide range of healthcare analysis for the NHS, Government and many other organisations and individuals. [6]
Information		One or more data values that includes sufficient contextual data for their interpretation and use (optionally, by a given kind of user and/or for a given purpose).
Information model		Structured specification, expressed graphically and/or in narrative, of the information requirements of a domain, from a given perspective, for a given purpose. □e.g. the information model of an EHR.
Knowledge		Facts that are accepted to be true for a given domain.

Term	Synonyms	Description
Metadata		<p>Metadata refers to a formalised set of data associated with a primary data value that specify the context needed for the interpretation and use of that value. The distinction between primary data and metadata is relative to the perspective of the information user, since what distinguishes a primary value and what kind of context is relevant to its use are strongly related to the intended use.</p> <p>For example, metadata about an entry in an electronic health record might include the identity of the author, the data and time and location at which the data value was recorded. For device captured data the metadata might include the type and model of the device, and when it was last calibrated. Some kinds of context information, such as the fasting state of a patient, are often considered to be additional primary data values to a blood glucose reading rather than metadata, but this is convention.</p>
Narrative		Textual information expressed as phrases, sentences and paragraphs.
Ontology		Represents knowledge as a set of concepts within a domain, and the relationships between those concepts
Patient history (narrow interpretation)	History of presenting illness, History of presenting complaint, Chief complaint	The information regarding the patient's present health situation and health status, both volunteered by the patient /carer and elicited by direct questioning of the patient/carers, whether these are undertaken synchronously in a clinical encounter or asynchronously either before or after a clinical encounter.

Term	Synonyms	Description
Patient history (wide interpretation)		The information provided by the patient to describe his or her present health situation, past health and healthcare events, family history, medication, allergies, lifestyle, social and occupational situation etc.
Payment by Results (PbR)		A rules based system for paying NHS secondary care providers from government funds within the UK NHS.
Quality and Outcomes Framework (QOF)		The national primary care pay for performance scheme introduced in April 2004 as part of the new General Medical Services contract (GMS)
Race		The group (subspecies in traditional scientific usage) a person belongs to as a result of a mix of physical features such as skin colour and hair texture, which reflect ancestry and geographical origins. [4]
Semantic interoperability		Capability of two or more systems to communicate and exchange information, and for each system to be able to interpret the meaning of received information and to use it seamlessly with other data held by that system.
Structure		Arrangements of and relations between the parts or elements of something complex. [7]
Structuring		Structuring is the process of organising information according to a logical model. This model is either meaningful for human or computable or both.
Syntactic interoperability		Capability of two or more systems to communicate and exchange data through specified data formats and communication protocols. [8]
Template		Preset format for a document or file. [7]

Term	Synonyms	Description
Term	coded concept	One member of a terminology, describing one concept. A term typically comprises a code and its corresponding code meaning. e.g. asthma.
Terminology	terminology system, coding system, coding scheme	The set of concepts within a domain (e.g. healthcare), structured according to the relations among them (such as a hierarchy of fine grained concepts contained by coarser grained concepts). e.g. SNOMED CT.

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## Appendices and supporting material

### Appendix 1: Ethical approval for this evaluation

Document description	Author
Letter stating that Ethics application will be reviewed at meeting on 17 <sup>th</sup> May 2010 (letter dated 30 <sup>th</sup> March 2010)	National Research Ethics Service – Brighton West Ethics Committee
Letter requesting further information for Ethics committee (letter dated 20 <sup>th</sup> May 2010)	National Research Ethics Service – Brighton West Ethics Committee
Letter giving ethical approval (letter dated 14 <sup>th</sup> June 2010)	National Research Ethics Service – Brighton West Ethics Committee
Substantial amendment (letter dated 21 <sup>st</sup> March 2011)	Professor Aziz Sheikh
Letter stating that substantial amendment will be reviewed by committee (letter dated 25 <sup>th</sup> March 2011)	National Research Ethics Service – Brighton West Ethics Committee
Letter stating that no objections raised to substantial amendment on ethical grounds (letter dated 18 <sup>th</sup> April 2011)	National Research Ethics Service – Brighton West Ethics Committee

## Appendix 2: Research and development approval details by site

Site	Date of Approval
A	Accepted 7 <sup>th</sup> December 2010
B	Accepted 22 <sup>nd</sup> February 2011
C	Accepted 11 <sup>th</sup> May 2011
A	Continuing approval after ethics amendment of 22 <sup>nd</sup> March 2011 (letter dated 1 <sup>st</sup> June 2011)
D	Accepted 8 <sup>th</sup> June 2011
E	Accepted 18 <sup>th</sup> July 2011
F	Accepted 19 <sup>th</sup> July 2011
G	Accepted 20 <sup>th</sup> July 2011
H	Accepted 25 <sup>th</sup> July 2011
I	Accepted 29 <sup>th</sup> July 2011
J	Accepted 3 <sup>rd</sup> October 2011
K	Accepted 19 <sup>th</sup> October 2011

### **Appendix 3: Example search strategy for the systematic review (Chapter 3)**

#### 1) Benefits or Risks: (4,591,987):

benefit\* OR advantage\* OR gain\* OR assist\* OR help\* OR improve\* OR ease OR easy OR desire\* OR intend\* OR risk OR cost OR barrier\* OR upheaval\* OR obstacle\* OR obstruction\* OR difficult\* OR confus\* OR disrupt\* OR hazard\* OR threat\* OR problem\* OR \*danger\* OR disadvantage\* OR avoid\* OR undesir\* OR unwanted

#### 2) Code or Structure (2,138,602)

code\* OR encode\* OR read code\* OR diagnosis related group\* OR international classification of diseases OR medical subject headings OR icd OR snomed OR hrg OR drg OR mesh OR language\* OR ontolog\* OR systematized nomenclature OR controlled vocab\* OR structur\* OR metadata OR template\* OR form\*

#### 3) Health records: (95,075)

electronic record\* OR health record\* OR patient record\* OR care record\* OR medical record\* OR ehr OR scr OR ecr

#### 4) History taking (4,451,621)

history taking OR clerking OR note capture OR note taking OR patient interview\* OR reason for encounter OR clinical documentation OR structured documentation OR clinical noting OR Kardex OR interface terminology OR symptom\* OR presenting complaint\* OR concern\* OR presentation\* OR patient histor\*\*

#### Final Search:

1 AND 2 AND 3 AND 4 (5,511 results)

(benefit\* OR advantage\* OR gain\* OR assist\* OR help\* OR improve\* OR ease OR easy OR desire\* OR intend\* OR risk OR cost OR barrier\* OR upheaval\* OR obstacle\* OR obstruction\* OR difficult\* OR confus\* OR disrupt\* OR hazard\* OR threat\* OR problem\* OR \*danger\* OR disadvantage\* OR avoid\* OR undesir\* OR unwanted) AND (code\* OR encode\* OR read cod\* OR diagnosis related group\* OR international classification of diseases OR medical subject headings OR icd OR snomed OR hrg OR drg OR mesh OR language\* OR ontolog\* OR systematized nomenclature OR controlled vocab\* OR structur\* OR metadata OR template\* OR form\*) AND (electronic record\* OR health record\* OR patient record\* OR care record\* OR medical record\* OR ehr OR scr OR ecr) AND (history taking OR clerking OR note capture OR note taking OR patient interview\* OR reason for encounter OR clinical documentation OR structured documentation OR clinical noting OR Kardex OR interface terminology OR symptom\* OR presenting complaint\* OR concern\* OR presentation\* OR patient histor\*\*)

## **Appendix 4: Example search strategy for the landscape review (Chapter 4)**

### 1. Tools and techniques search records returned = 12,558

(tool OR tools OR technique OR techniques OR questionnaire\* OR computer based questionnaire\* OR patient-completed history questionnaire\* OR computer-administered patient interview\* OR form OR forms OR structured form\* OR problem –specific report form\* OR self-report form\* OR structured registration form\* OR \*template\* OR template-generated medical documentation OR documentation template\* OR documentation system\* OR case histor\* OR standardized interview question\* OR structured data collection OR medical history-taking device\* OR history-taking system OR computer history taking system\* OR patient-driven health information OR data entry kiosk\* OR pro forma\* OR proforma\* coded chief complaints OR structured encounter forms OR encounter note OR diary OR diaries OR “automated speech recognition” OR automated health assessment)

### 2. Structuring and coding records returned = 1,820,787

(clinical coding [MeSH] OR code\* OR encode\* OR read code\* OR diagnosis related group\* OR international classification of diseases OR medical subject headings OR icd OR snomed OR hrg OR drg OR mesh OR language\* OR ontolog\* OR systematized nomenclature OR controlled vocab\* OR structur\* OR metadata OR template\* OR form)

### 3. Electronic health records returned = 15,227

(computerised decision support OR medication decision support OR ePrescribing OR electronic prescribing) OR (electronic health records [MeSH] OR electronic patient record) OR (ehealth OR telehealth OR telecare OR telehealthcare or mhealth)

(1 OR 2) AND 3 published after 1990                      3,276

## Appendix 5: Masterclass programme



Imperial College  
London

NHS Connecting for Health Evaluation  
Programme (NHS CFHEP)

### eHealth Masterclass

**The Coding and Structuring Of Clinical Information  
In Electronic Health Records.**

**The Informatics Forum, The University of Edinburgh,  
8<sup>th</sup> March 2011**

We are delighted to invite you to a Masterclass on eHealth, supported by the NHS Connecting for Health Evaluation Programme. This workshop aims to inform and improve practices relating to clinical coding at point of care. Objectives will be to consider areas for targeted improvements in the coding and structuring of information, including possible improvements for immediate consideration, the involvement of patients in coding, educational opportunities to improve coding practices amongst healthcare professionals, and the role of emerging technologies in this area. This event will be of interest to clinicians, researchers, technicians, managers, policymakers and members of the public with an interest in the use of health information technology.

**This event is free and places will be allocated upon receipt of application. Please register early to avoid disappointment. This event is CPD accredited.**

**To register for this event, please visit: [www.ehealthmasterclass.eventbrite.com](http://www.ehealthmasterclass.eventbrite.com)**  
**Programme**

**10:00 – 10:30 am**      *Registration and coffee*

**10:30 – 10:40 am**      **Introduction to eHealth Masterclass series:**

Professor Aziz Sheikh, University of Edinburgh

**10:40 – 11:10 am**      **Opening address:**

Professor Dipak Kalra, University College London

**11:10 – 11:30 am**      **Questions and Planning for Group Discussions**

**11:30 – 12:00 pm**      *Tea and coffee*

**12:00 – 12:45 pm**      **Group discussions:**

**Group 1:** Are there areas of clinical practice where structuring & coding could make an immediate and positive impact?

**Group 2:** Can and should the use of free text data entry and Natural Language Processing (NLP) now displace the role of templates and clinical terminologies?

**Group 3:** Is it appropriate and useful to code a patient's clinical history?

**Group 4:** Should patients be offered the facility to review and populate their own health records using structured templates and terminologies?

**Group 5:** What do secondary use services (SUS) need from clinical coding? How does this complement and conflict with the needs of clinical care?

**Group 6:** What should we do about data quality?

<b>12:45 – 1:30 pm</b>	Feedback from Groups and Discussion
<b>1:30 – 2:30 pm</b>	<i>Lunch and networking</i>
<b>(2.15-2.30 pm</b> Architect, Autonomy)	<b>Talk:</b> 'Meaning Based Healthcare' by Fernando Lucini, Chief
<b>2:30 – 3:00 pm</b>	Keynote address by Dr Nick Booth
<b>3:00 – 3:30 pm</b> <b>3:30 pm</b>	Plenary session <b>Review and close</b>

## Appendix 6: Non-Patient Interview Information Sheet



Centre for Population Health Sciences  
GP Section,  
The University of Edinburgh  
Doorway 1, Medical School,  
Teviot Place,  
Edinburgh EH8 9AG  
Email: ebyrne@ed.ac.uk  
Telephone: 0131 650 2678

### INFORMATION ABOUT THE RESEARCH

#### Appropriate levels of structuring and coding in the medical record

##### Introduction

We would like to seek your views, as part of a research study we are undertaking, about the way information is organised within medical records. Before you decide if you wish to take part, we want to let you know a bit about the study and what it involves. This leaflet tells you all about the study. Please read it, and ask us any further questions that you wish, before deciding. You can discuss this study with someone else first, if you wish.

##### What do we mean by structuring and coding?

Information is organised in medical records in a number of different ways. Information that you tell a health professional, facts they find when they examine you, or treatment plans which they propose might be written in your medical record as sentences (on paper or on a computer). It might be written in a structured form like a template, with boxes to enter words or phrases or numbers in particular places on the page or computer screen. A further option is for the words they enter into the forms to be provided by the computer as a list of choices from which the clinician selects the words that best fit what he or she wishes to describe.

##### What is the purpose of the study?

We want to find out how information in the medical record is most appropriately stored. There are advantages with sentences, and advantages with forms, and advantages with lists of words and phrases. There are also disadvantages with all three ways of organising the information. We wish to learn more about the best balance between these.

##### Why have I been chosen?

Because you are either:

- a health care professional who produces or uses structured data
- a systems designer who develops electronic record systems
- a clinical coder responsible for entering coded data
- an information manager responsible for using or maintaining structured or coded data.
- an expert in the field of health informatics or research based on health records

##### Do I have to take part?

*No. It is up to you to decide. It's OK if you say no. And if you decide to take part, you are still free to change your mind at any time without giving a reason.*

**What will happen to me if I take part?**

Our researcher, Emma Byrne, will contact you to arrange a time to talk to you. She will then come to interview you for about 30 minutes (it can be shorter if you want). Emma will want to ask you about your use of structuring and coding in your day to day work. It is entirely up to you how much information you provide.

Emma would like to record the interview, because it is hard to note down everything you might say and a recording enables her and her colleagues to check that we have noted all of your answers correctly. But she will make sure that you're happy with this first, and you can say no. At the end, you will have a chance to listen back to the recording to make sure you're happy with it.

After the interview, the research team will write down what was said in the recording.

**What do I have to do?**

If you want to take part, please fill in the reply form and return it to Emma by email or in the envelope provided. Emma will contact you and arrange to meet you at a time and place you choose. She will explain the study and answer any questions you have. If you do not want to go ahead, we will not contact you again. If you do decide to take part, Emma will ask you to sign a consent form and will then interview you.

**What are the possible benefits of taking part?**

This study will be used to determine the future development of standards and tools and your input will help to shape this. This interview will also give you a chance to reflect on your use of structured and coded data, and to hear what our research has found so far.

**Will my information be kept confidential?**

Your name and contact details won't be shared with anyone outside the research team. Any information you give us will be kept confidential. No-one will be able to recognise you from any report about the study – your name and other personal details will be removed. In our reports, we may quote you but we will not use any information which could identify you. We may use your job title as long as there is no chance that this would identify you. We will keep the recordings and written records we make in a secure location, with all names removed, for 5 years. We will then destroy them.

**What will happen to the results of the study?**

The research team will write a full report for the NHS. We will also send you a short summary of the findings. You will not be able to be identified in any report.

**Who is organising and paying for the research?**

The study is being paid for by the NHS. They want to know how best to use structured and coded data. The research team is part of a group of people at The University of Edinburgh and University College London who are interested in health informatics.

**Who has reviewed the study?**

Before any research goes ahead, it has to be checked by a Research Ethics Committee to make sure it is fair. This was done before we made contact with you.

**Contact for further information**

If you would like to talk to Emma Byrne you can contact her by emailing [ebyrne@ed.ac.uk](mailto:ebyrne@ed.ac.uk) or on 0131 650 2678. If you would like advice from someone not involved in the study, you can contact Fionagh Thomson ([Fionagh.Thomson@ed.ac.uk](mailto:Fionagh.Thomson@ed.ac.uk)). Fionagh can offer independent advice as she is a very experienced researcher who is not part of the project.

**Complaints process**

If you have any concerns about any aspect of this study, please telephone the project manager, Emma Byrne and she will do her best to answer any questions. If you remain unhappy and wish to complain formally, please contact Fionagh Thomson (Fionagh.Thomson@ed.ac.uk or 0131 650 9458) or write to her at

Centre for Population Health Sciences,  
GP Section,  
The University of Edinburgh  
Doorway 1, Medical School,  
Teviot Place,  
Edinburgh EH8 9AG

Thank you for taking the time to read this information.

**Appropriate levels of structuring and coding in the medical record**

**REPLY FORM**

**Yes, I am willing for Emma Byrne to contact me about taking part in the study.**

**Name** \_\_\_\_\_

**Address** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Phone number** \_\_\_\_\_

**Email address** \_\_\_\_\_

**Please return this form to the person who told you about the study, or direct to Emma Byrne in the envelope provided, or email [ebyrne@ed.ac.uk](mailto:ebyrne@ed.ac.uk)**

**Emma will contact you soon. How would you like her to get in touch?**

**Text** ☐

**Telephone** ☐

**Email** ☐

**If by phone, what are the best days/times to contact you?**

\_\_\_\_\_

**Thank you for agreeing to participate in this research.**

## Appendix 7: Patient Interview Information Sheet



Centre for Population Health Sciences  
GP Section,  
The University of Edinburgh  
Doorway 1, Medical School,  
Teviot Place,  
Edinburgh EH8 9AG  
Email: ebyrne@ed.ac.uk  
Telephone: 0131 650 2678

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Information is organised in medical records in a number of different ways. Information that you tell a health professional, facts they find when they examine you, or treatment plans which they propose might be written in your medical record as sentences (on paper or on a computer). It might be written in a structured form like a template, with boxes to enter words or phrases or numbers in particular places on the page or computer screen. A further option is for the words they enter into the forms to be provided by the computer as a list of choices from which the clinician selects the words that best fit what he or she wishes to describe. You might also see this information as part of your NHS Healthspace record (<https://www.healthspace.nhs.uk>) or stored in an external service such as Google Health Records.

##### What is the purpose of the study?

We want to find out how information in the medical record is most appropriately stored. There are advantages with sentences, and advantages with forms, and advantages with lists of words and phrases. There are also disadvantages with all three ways of organising the information. We wish to learn more about the best balance between these.

##### Why have I been chosen?

Because you are an NHS patient with a medical record, although we do not wish to see your actual medical record as part of this research and we will not be influencing how your own medical record is organised. We only wish to know your opinions.

##### Do I have to take part?

*No. It is up to you to decide. It's OK if you say no. And if you decide to take part, you are still free to change your mind at any time without giving a reason.*

##### Will my decision whether to participate affect my health care in any way.

No. You will receive exactly the same health care, whether you participate in the study or not.

**What will happen to me if I take part?**

Our researcher, Emma Byrne, will contact you to arrange a time to talk to you. She will then come to interview you for about half an hour (it can be shorter if you want). Emma will want to ask you about ways in which you might provide or read information (not necessarily health information) as part of your daily life, at work or at home. It is entirely up to you how much information you provide.

Emma would like to record the interview, because it is hard to note down everything you might say and a recording enables her and her colleagues to check that we have noted all of your answers correctly. But she will make sure that you're happy with this first, and you can say no. At the end, you will have a chance to listen back to the recording to make sure you're happy with it.

After the interview, the research team will write down what was said in the recording.

**What do I have to do?**

If you want to take part, please fill in the reply form and return it to Emma by email or in the envelope provided. Emma will contact you and arrange to meet you at a time and place you choose. She will explain the study and answer any questions you have. If you do not want to go ahead, please also let us know so that we do not contact you again. If you do decide to take part, Emma will ask you to sign a consent form and will then interview you.

**What are the possible benefits of taking part?**

This study will be used to help advise the NHS on how best to organise medical records in the future. We are approaching many different kinds of people as part of this study, including some doctors, nurses, other health professionals, other parts of the NHS and even people working in other countries. Your input will help to shape this advice.

**Will my information be kept confidential?**

Your name and contact details won't be shared with anyone outside the research team. Any information you give us will be kept confidential. No-one will be able to recognise you from any report about the study – your name and other personal details will be removed. In our reports, we may quote sentences you say but we will not use any information which could identify you. We may describe your occupation as long as there is no chance that this would identify you. We will keep the recordings and written records we make in a secure location, with all names removed, for 5 years. We will then destroy them.

**What will happen to the results of the study?**

The research team will write a full report for the NHS. We will also send you a short summary of the findings. You will not be able to be identified in any report.

**Who is organising and paying for the research?**

The study is being paid for by the NHS. They want to know how to improve the use of medical information to improve patient care, the quality of the NHS and our knowledge of health and illness. The team is part of a group of people at The University of Edinburgh and University College London who conduct research on health information.

**Who has reviewed the study?**

Before any research goes ahead, it has to be checked by a Research Ethics Committee to make sure it is fair. This was done before we made contact with you.

**Contact for further information**

If you would like to talk to Emma Byrne you can contact her by emailing [ebyrne@ed.ac.uk](mailto:ebyrne@ed.ac.uk) or telephoning 0131 650 2678. If you would like advice from someone not involved in the study, you can contact Fionagh Thomson ([Fionagh.Thomson@ed.ac.uk](mailto:Fionagh.Thomson@ed.ac.uk) or 0131 650 9458). Fionagh can offer independent advice as she is a very experienced researcher who is not part of the project.

**Complaints process**

If you have any concerns about any aspect of this study, please telephone the project manager, Emma Byrne and she will do her best to answer any questions. If you remain unhappy and wish to complain formally, please contact senior researcher, Fionagh Thomson. She can be reached at [Fionagh.Thomson@ed.ac.uk](mailto:Fionagh.Thomson@ed.ac.uk), telephoned on 0131 650 9458 or you can write to her at:

Centre for Population Health Sciences,  
GP Section,  
The University of Edinburgh  
Doorway 1, Medical School,  
Teviot Place,  
Edinburgh EH8 9AG

Thank you for taking the time to read this information.

**Appropriate levels of structuring and coding in the medical record**

**REPLY FORM**

**Yes, I am willing for Emma Byrne to contact me about taking part in the study.**

**Name** \_\_\_\_\_

**Address** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Phone number** \_\_\_\_\_

**Email address** \_\_\_\_\_

**Please return this form to the person who told you about the study, or direct to Emma Byrne in the envelope provided, or email [ebyrne@ed.ac.uk](mailto:ebyrne@ed.ac.uk).**

**Emma will contact you soon. How would you like her to get in touch?**

**Text** ☐

**Telephone** ☐

**Email** ☐

**If by phone, what are the best days/times to contact you?**

\_\_\_\_\_

**Thank you for agreeing to participate in this research.**

## Appendix 8: Non-Patient Consent Form



Centre for Population Health Sciences:  
GP Section, University of Edinburgh.  
Doorway 3, Medical School,  
Teviot Place,  
Edinburgh EH8 9AG

Participant Identification Number:

### CONSENT FORM

#### Appropriate levels of structuring and coding in the medical record

Name of Researcher:

Please initial box

1. I have read and understand the information sheet dated 03/06/2010 (version 2) for the above study and have had the opportunity to ask questions. ☐
2. I understand that I do not have to take part. It is my choice and I can change my mind at any time if I want. ☐
3. I agree to the audio recording of the interview. I understand that recordings will be made available exclusively to the research team. ☐
4. I agree that you can write down what I tell you, and use my exact words in your reports if you want to. ☐
5. I understand that you won't put anything in your reports that could be used to identify me (e.g. my name or where I work). ☐
6. I agree to take part in this study. ☐

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

1 for participant; 1 for researcher

## Appendix 9: Patient Consent Form



Centre for Population Health Sciences:  
GP Section, University of Edinburgh.  
Doorway 3, Medical School,  
Teviot Place,  
Edinburgh EH8 9AG

Participant Identification Number:

### CONSENT FORM

#### Appropriate levels of structuring and coding in the medical record

Name of Researcher: Emma Byrne

Please initial box

1. I have read and understand the information sheet dated 29/03/2010 (version 1) for the above study and have had the opportunity to ask questions. ☐
2. I understand that I do not have to take part. It is my choice and I can change my mind at any time if I want. ☐
3. I understand that my choice whether or not to take part in the research will not affect my medical care in any way. ☐
3. I agree to the audio recording of the interview. I understand that recordings will be made available exclusively to the research team. ☐
4. I agree that you can write down what I tell you, and use my exact words in your reports if you want to. ☐
5. I understand that you won't put anything in your reports that could be used to identify me (e.g. my name or where I live). ☐
6. I agree to take part in this study. ☐

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

1 for participant; 1 for researcher

## Appendix 10: Work-Package 2 Healthcare Professional Interview Topic Guide



### NHS Structuring and coding of the medical record

#### Qualitative Interview Topic Guide: Health Care Professionals

Note that this guide:

- Will be developed further once interviewee's specialisms have been identified.
- Will be updated after each interview to include new questions/issues raised by each participant.
- Will not be used verbatim as each interviewee will respond to different styles of interviewing.

#### **Opening notes:**

- Greetings and introduction
- Summarise information sheet: Focus on:
  - We're interested in your views on the role of structured and coded data in the way you use patient records.
  - Assurance of privacy/confidentiality regarding names and information
- Remind them we are interested in their experiences and their views will inform the future development of policies and tools
- Request permission to record and obtain signatures for 2 copies of consent form (1 for the participant and 1 for the research team).

**Part one:** discuss how you currently produce structured data in patient records with particular reference to.

- 1) the advantages you perceive
- 2) the challenges you have experienced

Prompts:

- What sort of forms are you asked to fill in?
- What sort of templates are used in your IT systems?
- When, in a consultation, would you use a form?
- When would you use unstructured entry instead?

**Part two:** discuss how you currently produce coded data in patient records with particular reference to:

- a) the advantages you perceive
- b) the challenges you have experienced

Prompts:

- What sort of medical terminologies are you familiar with?
- Which medical terminologies do you use?
- When, in a consultation, would you code information?
- When would you use descriptions or other natural language instead?

**Part three:** discuss your perception of how structured data is used, both by yourself, and by other HCPs, planners, policy makers, researchers etc. with particular reference to:

- a) the advantages you perceive, or that others perceive
- b) the challenges you have experienced, or that others have experienced.

Prompts:

- When is structured information preferable to free text in your day-to-day work?
- When might others appreciate structured information?
- When would free text information be preferable, in your work?
- When would free text be preferred by others?

**Part four:** discuss your perception of how coded data is used, both by yourself, and by other HCPs, planners, researchers etc. with particular reference to:

- a) the advantages you perceive, or that others perceive
- b) the challenges you have experienced, or that others have experienced.

Prompts:

- When is coded information preferable to free text in your day-to-day work?
- When might others appreciate coded information?
- When would free text information be preferable, in your work?
- When would free text be preferred by others?

**Part five:** explore your own perceptions of the (*future*) use of structured and coded data from your own experience as a (health professional/systems designer/information processing staff member/patient).

Prompts

- Where do you see a need for more structured and coded data? (And why?)
- Where do you feel data should be captured in free text? (And why?)

**Part six:** we would like to ask other issues raised by other health professionals in earlier interviews (if we haven't discussed these issues during this interview).

**Thank you very much for your time**

## Appendix 11: Work-Package 2 Information Professional Interview Topic Guide



### Structuring and coding of the medical record

#### Qualitative Interview Topic Guide: Information Professionals

Note that this guide:

- Will be developed further once interviewee's specialisms have been identified.
- Will be updated after each interview to include new questions/issues raised by each participant.
- Will not be used verbatim as each interviewee will respond to different styles of interviewing.

#### Opening notes:

- Greetings and introduction
- Summarise information sheet: Focus on:
  - We're interested in your views on the role of structured and coded data in the way you use patient records.
  - Assurance of privacy/confidentiality regarding names and information
- Remind them we are interested in their experiences and their views will inform the future development of policies and tools
- Request permission to record and obtain signatures for 2 copies of consent form (1 for the participant and 1 for the research team).

**Part one:** discuss how you currently produce structured data in patient records with particular reference to:

- a)\_ the advantages you perceive
- b) the challenges you have experienced

Prompts:

- What sort of forms are you asked to fill in?
- What sort of templates are used in your IT systems?
- When, in your day to day work, would you use a form?
- When would you use unstructured entry instead?

**Part two:** discuss how you currently produce coded data in patient records with particular reference to:

- a)\_ the advantages you perceive

b)\_ the challenges you have experienced

Prompts:

- What sort of code sets are you familiar with?
- Which code sets do you use?
- When, in your day to day work, would you code information?
- When would you use descriptions or other natural language instead?

**Part three:** discuss your perception of how structured data is used, both by yourself, and by other HCPs, planners, researchers etc. with particular reference to:

a)\_ the advantages you perceive, or that others perceive

b)\_ the challenges you have experienced, or that others have experienced.

Prompts:

- When is structured information preferable to free text in your day to day work?
- When might others appreciate structured information?
- When would free text information be preferable, in your work?
- When would free text be preferred by others?

**Part four:** discuss your perception of how coded data is used, both by yourself, and by other HCPs, planners, researchers etc. with particular reference to:

a)\_ the advantages you perceive, or that others perceive

b)\_ the challenges you have experienced, or that others have experienced.

Prompts:

- When is coded information preferable to free text in your day-to-day work?
- When might others appreciate coded information?
- When would free text information be preferable, in your work?
- When would free text be preferred by others?

**Part five:** explore your own perceptions of the (*future*) use of structured and coded data from your own experience as an information processing professional.

Prompts:

- Where do you see a need for more structured and coded data? (And why?)
- Where do you feel data should be captured in free text? (And why?)

**Part six:** we would like to ask other issues raised in earlier interviews (if we haven't discussed these issues during this interview.)

**Thank you very much for your time**

## Appendix 12: Work-Package 2 Researcher Interview Topic Guide



### NHS Structuring and coding of the medical record

#### Qualitative Interview Topic Guide: Researchers

Note that this guide:

- Will not be used verbatim as each interviewee will respond to different styles of interviewing.
- Will use a tailored topic list suitable to each respondent.
- Will be developed further once the interviewee's interests/capabilities/affiliations are known.
- Part Six will be updated after each interview to include new questions/issues raised by each patient/patient group.

#### **Opening notes:**

- Greetings and introduction(s)
- Summarise information sheet: Focus on:
  - We are interested in your views on the role of free text and of structured and coded information in patient records as a source of research data.
  - Assurance of privacy/confidentiality regarding names and information collected
- Remind them that we are interested in their experiences and their views which will inform the future development of policies and tools
- Request permission to record and obtain signatures for 2 copies of consent form (1 for the participant and 1 for the research team).

**Part one:** How much variation is observed in structuring and coding?

Prompts: When using large datasets of patient information from many different practices,

- how homogeneously are codes applied?
- how much variation is there in completeness?

**Part two:** Data quality – how is it measured? How are problems with data quality addressed?

Prompts:

- Do you have any indicators as to the degree of accuracy/completeness of the data set?
- How do you place confidence intervals on the data used?

**Part three:** Clinical pressures – what determines the balance between free text and coding?

Prompts

- Are there patterns that you have observed in the types of GPs/Practices/Conditions that are more or less likely to lead to coding/structuring?
- Is there a longitudinal dimension –is there a trend to more coding/structuring over time? Or has it reached a plateau?

**Part four:** patient privacy: large, automated datasets, and pseudo- and anonymisation

Prompts:

- What are the privacy and security issues that arise from having such large collections of automatically processed information?
- What are the arguments for pseudonymisation (rather than anonymisation)?
- How are patients currently consulted about their data security? How is consent given?

**Part five:** we would like to ask about other issues raised by other patients in earlier interviews (if we haven't discussed these issues during this interview.)

**Thank you and Close**

## Appendix 13: Work-Package 2 System Designer Interview Topic Guide



### Structuring and coding of the medical record

#### Qualitative Interview Topic Guide: Systems Designers

Note that this guide:

- Will be developed further once interviewee's specialism and their specialisms have been identified.
- Will be updated after each interview to include new questions/issues raised by each participant.
- Will not be used verbatim as each interviewee will respond to different styles of interviewing.

This topic guide has 3 stages as outlined below.

#### **Opening notes:**

- Greetings and introduction
- Summarise information sheet: Focus on:
  - We're interested in your views on the role of structured and coded data in the way you use patient records.
  - Assurance of privacy/confidentiality regarding names and information
- Remind them we are interested in their experiences and their views will inform the future development of policies and tools
- Request permission to record and obtain signatures for 2 copies of consent form (1 for the participant and 1 for the research team).

**Part one:** discuss how you currently produce templates for health care professionals with particular reference to

- a) understanding how data is produced
- b) understanding how data is used

Prompts:

- What sort of forms are you designing? Or do you design?
- How do you go about designing templates and forms?
- How is structured information stored

**Part two:** discuss how you currently use implement coding support systems, with particular reference to

- a) understanding how data is produced
- b) understanding how data is used

Prompts:

- What sort of medical terminologies are you familiar with?
- Which medical terminologies do you use?
- Wherein the system are codes encouraged? Required?
- When would you use descriptions or other natural language instead?

**Part three:** discuss your perception of how structured data is used, by HCPs, planners, researchers etc. with particular reference to.

- a) the advantages you perceive, or that others perceive
- b) the challenges you have experienced, or that others have experienced.

Prompts:

- When is structured information preferable to free text?
- When might others appreciate structured information?
- When would free text information be preferable, in your work?
- When would free text be preferred by others?

**Part four:** discuss your perception of how coded data is used, by HCPs, planners, researchers etc. with particular reference to:

- a) the advantages you perceive, or that others perceive
- b) the challenges you have experienced, or that others have experienced.

**Part five:** explore your own perceptions of the (*future*) use of structured and coded data from your own experience as a systems designer. Prompts:

- When is coded information preferable to free text?
- When might others appreciate coded information?
- When would free text information be preferable, in your work?
- When would free text be preferred by others?

**Part six:** we would like to ask other issues raised by others in earlier interviews (if we haven't discussed these issues during this interview.)

**Thank you very much for your time**

## Appendix 14: Work-Package 2 Patient Interview Topic Guide



### NHS Structuring and coding of the medical record

#### Qualitative Interview Topic Guide: Patients

Note that this guide:

- Will not be used verbatim as each interviewee will respond to different styles of interviewing.
- Will use a tailored topic list suitable to each patient
- Will be developed further once patient's/patient groups' interests/capabilities/affiliations are known.
- Part Four will be updated after each interview to include new questions/issues raised by each patient/patient group.

#### Opening notes:

- Greetings and introduction(s)
- Summarise information sheet: Focus on:
  - We are interested in your views on the role of free text and of structured and coded information in patient records.
  - Assurance of privacy/confidentiality regarding names and information collected
- Remind them that we are interested in their experiences and their views which will inform the future development of policies and tools
- Request permission to record and obtain signatures for 2 copies of consent form (1 for the participant and 1 for the research team).

**Part one:** explain what we mean by structured patient records and why the topic is important. We will use a fictionalised clinical record (physical examples to be shown to the patient) to show examples of

- a) information that is written in free text (*unstructured information*)
- b) information that is tagged or laid out in a particular way so that the part can be identified by the computer for a given purpose then (*structured information*). If whole paragraph or parts of it is arranged in a particular way on the screen so that a healthcare professional can scan through and find the information needed quickly and accurately then that information is also structured.

Information that is stored as Read or other codes. We will help to make this notion more familiar to the patient by using the example of the UK postcode system.

**Part two:** discuss how patients view the different ways of recording information in their record. Using the fictionalised examples, we will prompt patients to articulate their preferences regarding:

- a)\_ Where they would prefer to see each of the different types used
- b)\_ Why they prefer one type of recording over another in different scenarios

Prompts:

- Which, if any, parts of a medical record do you think should be left as free text and why?
- Which parts do you think should be structured? Why? What difference do you think this would make?
- Which parts do you think should be coded? Why? What difference do you think this would make?

**Part three:** explain some of the ways structured and coded information are changing healthcare and ask the patient how they feel about these changes:

Prompts

- Structured information can be used to help computers to provide reminders, warnings to the doctor or nurse. Are you aware that your information is used this way? What do you see the advantages and disadvantages of this might be?
- With the permission of your GP, coded information may be used for research purposes. What's your view on your information being used this way?
- Your doctor may ask you questions based on prompts on their computer screen. Have you noticed them being prompted in this way? If yes, probe for more information about the experience.

**Part four:** we would like to ask about other issues raised by other patients in earlier interviews (if we haven't discussed these issues during this interview.)

### **Thank you and close**

Patients will be thanked for their time and asked if there is anything they would like to add. All patients will be given the project website address as an opportunity to find out more about the study and to contact us again should they wish to do so.

## Appendix 15: Work Package 2 Patient Interview Narrative Letter

**Diagnosis: Palpitation  
Hypercholesterolaemia**

Thank you for asking me to see this pleasant man from... I think his symptom complex is related to a "mini panic attack". I think he has already been much reassured by seeing you.

Physical examination is entirely satisfactory. He has known about his high cholesterol for a while. In the context of a normal family history, I am not inclined to take much action other than to encourage him to return to regular physical activities and to eat healthily with a lot of fish, fruit and vegetables and the avoidance of saturated fat.

Today I found his BP to be very satisfactory indeed. He has a minimal tremor and quite cool peripheries. I think this merely reflects his anxiety levels. I think they are brought to a head by some financial difficulties, his girlfriend leaving to go home and his inability to find work. He has come to terms with all of these and is now in satisfactory employment.

Please let me know if you want me to see him again.

Yours sincerely

## Appendix 16: Work Package 2 Patient Interview Integrated Care Pathway Example

The Whittington Hospital Trust - Integrated Care Pathway  
Fractured Neck of Femur - **ACCIDENT & EMERGENCY**

Day: ..... Date: ...../...../.....

## Assessments - Nursing

a) Record Baseline Observations:

Temp:..... Pulse:..... BP:..... Resp:.....

b) Observe - Shortened Leg: Yes ☐ No ☐ Observe - External Rotation : Yes ☐ No ☐

**Red Flags** - Tick any of the following if appropriate.

On Floor > 12 Hrs.	<input type="checkbox"/>	SOB	<input type="checkbox"/>	Hypertension > 120	<input type="checkbox"/>
Stroke	<input type="checkbox"/>	Chest Pain	<input type="checkbox"/>	Hypotension	<input type="checkbox"/>
Confusion	<input type="checkbox"/>	Pyrexia	<input type="checkbox"/>	Hypothermia	<input type="checkbox"/>
Heart Attack	<input type="checkbox"/>	Resus. Needed	<input type="checkbox"/>	Abnormal Vital Signs	<input type="checkbox"/>

If any of the *Red Flags* above apply you should refer to the CAS Doctor to continue care

Referred to Doctor ☐ Not Applicable ☐ ..... initials

### Assess Mental State using 10 Point Scale : - Nursing

Name	.....	Time	.....
Address for Recall	.....	Year	.....
Hospital	.....	Two People	.....
Date of Birth	.....	WW1(ie 1914-18).....	
Monarch	.....	20-1 =	.....
		Total	.....
			..... initials

### Medical History - Nursing

- Record Medication on Admission:
- Doses: \_\_\_\_\_ Frequency: \_\_\_\_\_
- Allergies \_\_\_\_\_
- Record Time \_\_\_\_\_ Record Time \_\_\_\_\_
- Of Last Meal: \_\_\_\_\_ Of Last Drink: \_\_\_\_\_
- Record History / Circumstances of Admission/ Event \_\_\_\_\_

• Known MRSA YES ☐ NO ☐ ..... initials

## Appendix 17: Sample List of documents collected by Work Package

This list provides samples of the types and nature of the documents collected and analysed during this evaluation.

### Work Package 2

Royal College of General Practitioners Medical Abbreviations
Census 2001 classifications (data classifications)
SWAST guidelines for completing patient clinical record (CR1)
SWAST Guidance notes
SWAST Re-investing in care
SWAST Twentyfourseven
Helping Us to Help You
Public Health Past Present and Future
An Ethnic Monitoring Toolkit for the NHS
Scottish Public Health Network and Observatory
Equality & Diversity Information Development Programme
Compliance, Risk, Legal and Regulatory Technologies
Meaning Based Computing
Autonomy Overview
Auminence
Population Health Briefing-Obesity
Health and Wellbeing Profiles 2008 Scotland Overview Report
Good information for a better service? A consultation with people with learning disabilities about disclosing personal information
PFPI Report-Patient Focus Public Involvement Providing More Personal Information to the NHS
PIAG The use of patient information in the long term conditions programme

### Work Package 3 – Allergy

Advice from the GPC - Allergy recording in GP clinical systems
Representation in EPRs of Allergic Reactions, Adverse Reactions, and Intolerance of Pharmaceutical Products
Representation of drug allergies, intolerances and adverse reactions in GP EPRs

### Work Package 3 – Ethnicity

List to reflect populations in East London (Template for Ethnic category - 2011 census)
EMIS national template (Template for Template GMS - Ethnicity V12)
Version 4 - Jan 2008 GP Contract & Enhanced Service Ethnicity - Patient Profiling Template Guide
Patient Profiling Form
Tower Hamlets Chrisp Street HC Audit Results Enhanced Services 2009-2010
Health Equality in primary care: Cardiovascular disease, diabetes and COPD in inner east London
City and Hackney Newham Tower Hamlets General practice chronic disease management 2004-2009
Clinical Coding Clinicians Nov 2010
ECTF Communications Plan Aug 11 update ADJG
Final EDIP Update July 2011
Lothian ECTF primary care examples of clinical relevance
ECTF Checklist primary care jun11
Agenda 27 Sep2011
Action Notes ECTF 290611 final
Boroughlough practice report sep10
SMR Ethnicity codes and date ranges
Ethnicity Lothian Hospital Figures 190911 to 250911
EEHRG Meeting 060911
The essential guide to the public sector equality duty
Culturally responsive JSNAs: a review of race equality and Joint Strategic Needs Assessment (JSNA) practice
Collecting Ethnic Category Data
Fairness and Freedom: The Final Report of the Equalities Review
Department of Health Data Standards: Ethnic Category
Ethnic Category Standard (v3.0.1) Change to an Information Standard
Ethnic Category Standard (v3.0.1) Change to an Information Standard Human Behavioural Guidance
Relevant Info from Information Standards Board for Health and Social Care
Practical Guide to ethnic monitoring in the NHS and social care
Summary of Responses to consultations
Improving data collection for equality and diversity monitoring all Scotland
Collecting Equality Information Guidance on asking questions on: Ethnic Groups
Equality and diversity
Scotland's New Official Ethnicity Classification

Meeting with Golden Jubilee 270111
Problems and Barriers to the collection of ethnicity and migration related data: the UK experience
HES Data Dictionary
Recording of Ethnic Group: Information for Patients (South Tyneside)
Date about ethnicity: Information for patients and carers (London Hospitals)
GP Contract & Enhanced Service Ethnicity - Patient Profiling Template Guide
Data Entry Codes available on EMIS/Vision
New Patient Registration Form (Chatham Medical Centre)
New Patient Registration Form (Yellow Suite)
Medway DES - Ethnicity (& First Language)
Data Quality Audit Ethnicity April 2011 (Yellow Suite)
Ethnicity Protocol (Yellow Suite)
New Patient Registration Form (King's Family Practice)
Data Quality Audit Ethnicity 2011 (King's Family Practice)
Patient Participation Questionnaire (King's Family Practice)
Medway LES - English not 1st Language Service Level Agreement
Taskforce Summary 270911
Ethnicity recorded ECTF report Sept 2011

### Work Package 3 – Diabetes

NCASP National Diabetes Audit
Strategic Health Authority guide: diabetes
2008_Partners in Care
ADA guidelines full
ADA standards 2010
DH Six years on framework annual report 2010
DH Your health your way self care
Diabetes UK 2010 integrated care group report June 2010
Diabetes in the NHS commissioning providing specialist services
HotTopics 2009 Annual Report
Map of Medicine diabetes suspected in adults England & Wales
National Diabetes Audit Executive Summary 2008-2009
QOF Guidance 2009 final
QRISK2 2010 Annual Update Information
RPS NPA 2010 integrating community pharmacy into the care of people with diabetes
Scotland 2010 action plan 0103402
Understanding the data gaps NHS Final Data Report

### Work Package 3 – Depression

New GMS Contract QOF implementation dataset and business rules depression indicator set
Coding and Mental Health Information Systems: A Review of Current Approaches
NHS Information Centre. Mental Health Minimum Dataset (MHMDS)
The Royal College of Psychiatrists. Health of the Nation Outcome Scales
Mental Health Policy and Service Guidance Package: Mental Health Information Systems
QOF Mental Health and Depression Toolkit
The Burden of Disease and Injury in Australia 2003

## Work Package 4

audit commission improving data quality in the NHS
Information Revolution A consultation on Proposals
Information Revolution Executive Summary
A Revolution for Patients Consultations on an information revolution and greater choice and control
Liberating the NHS An information revolution fact sheet
Meaningful Measurement of Quality Health Care using Electronic Health Records
Observations on Meaningful Use of Health Information Technology
Report of Hearing on Meaningful Use of Health Information Technology
Report to Secretary of the USA Dept of Health and Human Services on Enhanced Protections for uses of Health Data
Personal Health Records and Personal Health Records Systems
Eliminating Health Disparities Strengthening Data on Race, Ethnicity, Language in the US
Letter report to Secretary Leavitt on Personal Health Record (PHR) systems
Letter to Secretary Thompson on Population based data collection
Letter to Secretary Thompson - ICD 10 Recommendations
Letter to Secretary Thompson on Targeted Data Collection
Letter to Secretary Thompson on Racial and Ethnic Disparities in Health Care
Letter to Secretary Thompson on Populations-based data for racial and ethnic minorities
NCVHS Patient Medical Record Information Terminology Analysis Reports
NCVHS PMRI terminology standards
The relationship between Electronic Health Records and Patient Safety Future Directions for Canada A Summary
Improving health care for remote communities with electronic medical records
Electronic Health Information and Privacy Survey What Canadians Think - 2007

## **Appendix 18: Discussion Group Key Points Summary, eHealth Masterclass, March 2011.**

### **Should patients be offered the facility to review and populate their own health records using structured templates and terminologies?**

1. Some patients want to get into their own records, be able to use Google, NHS Direct and other sources to look up and say 'what on earth was my doctor saying to me today?' Many of these patients want to do this to avoid wasting their GP's time. An example of where this works well is Renal View where people with renal failure can actually logon and see what their results are.
2. This is a 'terrifying idea' for GPs.
3. There are a number of counter issues which should be considered in this debate, for example coercive relationships at home which may lead to patients being bullied into giving away their health information to a partner. Another example of the potential lack of understanding of the use of modern communication tools such as Twitter, which highlights the risk of patients unwittingly sharing their health information.
4. There is a danger that the records held are not accurate or complete or may contain out of date information.
5. There is a balance to be struck as to how much information patients can access, and how much is filtered, and what can be changed by whom.
6. A large proportion of patients want to see their information and more information is being shared with patients in general, but it may not be worthwhile to share all information. Legal considerations as to what a patient is entitled to see may impact here with potential variation between UK home nations.
7. Patient characteristics such as age may impact on the sharing of information, for example when elderly people attend for care accompanied by family members.
8. Patient access to information may result in more demands on clinician time, for example in further discussion and explanation. Discussions regarding shared information would need to be recorded effectively from a medical legal perspective.
9. There has been very little research in this area and more evidence is needed.
10. Relevant websites should be recommended to patients as reliable sources of information.
11. The use of patient diaries and pre-consultation questionnaires has been claimed to improve communication with the doctor because they're structuring the information. They're providing the information in response to a pre-determined structure that's a sort of common format that they can then debate with their doctor. This may be easiest to do as part of disease management subject to testing acceptability and usefulness.

## **Appendix 19: Discussion Group Key Points Summary, eHealth Masterclass, March 2011.**

### **Are there areas of clinical practice where structuring & coding could make an immediate and positive impact?**

1. A key challenge is how to elicit a huge variety of information from a patient and at the same time record it as a comprehensive record.
2. Information systems suppliers are trying to support this process of collection of information, accuracy and completeness.
3. A further challenge is to convince people who are not fans of the computer, for whom documentation is a pain in the neck, to actually take an interest in the quality of what they document and produce an overall culture that cares about quality documentation.
4. Benefits may be realised more quickly if suppliers start with current practice modification, modelling processes on current work practices to encourage clinicians to work with suppliers to develop the solution, moving on towards full electronic collection. Suppliers should work with healthcare professionals to combine technologies together to best suit various clinical contexts.
5. We should be focusing on information knowledge utilisation for which IT then becomes a very handy way of achieving the end. The end is not to be able to be computer literate and use IT. The purpose is better harnessing information and knowledge.
6. It may be claimed that clinicians argue that entering data on electronic records takes more time, that they do not type fast enough, and that they need to keep eye contact with patients. However, this is based on the idea that everyone is the same, which is not the case. It isn't one size fits all. Clinicians are highly innovative and enjoy change where they see value in the change.
7. It is about the leadership as well about how change is brought in. The frontline staff are there trying to deliver at the point of care in a quite a chaotic environment with lots of pressures upon them and there's a disengagement as they are being asked to do too much within a busy environment. Engagement of junior staff is extremely important as they are the ones using the systems.
8. Dealing with patients in a protocol driven, standardised way should respect patient individuality and non-standard outcomes.
9. We need to record diagnosis, treatment and outcomes. Changes must be determined by clinical need not the available technology, although there must be a dialogue between the two. There needs to be a shared aim to provide a system that's fit for purpose in the clinical environment. Systems need to be developed in phases as not every requirement can be specified up front because it's hard to visualise the end gain.
10. Healthcare professionals can be incentivised to code data by offering accessible patient information. Structure may also offer a means of patients providing information in a useable format.

## **Appendix 20: Discussion Group Key Points Summary, eHealth Masterclass, March 2011.**

### **Is it appropriate and useful to code a patient's clinical history?**

1. There are probably cross-disciplinary differences in documentation. Doctors particularly prefer to use free text rather than having to code. They're not very good at it, they're not very consistent at it and therefore they prefer to not use it. Nurses are compelled to do it by having protocol driven templates.
2. It is possible to separate clinical contact with patients into that which is easily structured and that which is easily coded. It is the very richness of many disciplines that is extremely difficult to code and not always easy to structure particularly in the time frame allowed. The majority of clinical practice is quite unstructured, gaining rich data is not easily coded or structured within a ten minute consultation.
3. The patient has already translated their experience into something they can bring into a doctor, then the doctor translates it into a conventional medical history and then has to translate it into something that a computer can understand. This information then needs to be translated into a usable format for the next stage of the workflow.
4. The assessment of patients is a very highly structured process: a social history, family history, systemic enquiry and then examination, presumptive diagnosis, differential diagnosis and investigations. So the actual process that a doctor will follow is highly structured. A challenge is translating the information that we are able to see instinctively into a form that's then easily put into a computer.
5. Narrative descriptions are a very potent way of describing and summarising situations which have evolved over a long time. Hospitals use their early warning system which has five or six clinical variables which determine actions to be taken.
6. A large amount of the data in any person's record is never going to be used again. It is recorded for medical-legal or historical reasons but there is no need to code or structure it as it is not going to be extracted.
7. Clinicians may be reluctant to type while the patient is present because they can't do it without taking their eyes off the patient. This is particularly the case with regard to selecting from drop-down lists.
8. Using a checklist as an aide memoir may lead to decreasing skills within healthcare professionals.

## **Appendix 21: Discussion Group Key Points Summary, eHealth Masterclass, March 2011.**

### **Can and should the use of free text data entry and Natural Language Processing (NLP) now displace the role of templates and clinical terminologies?**

1. We do need some structure and we should be starting where it's important and reasonably concise as a problem. A way forward may be to focus on a few highly structured points to begin with, for example what's the discharge diagnosis of a patient, what's the procedure a surgeon has just done?
2. A balance between structure and narrative is to be achieved. What's in free text and narrative often may not be coded in a meaningful or useful way. Medical narratives are rich with terminology, which itself is evolving, and agreeing a common way to describe things is very difficult.
3. Whilst we are getting to the point where, instead of us formatting data for the computers, there's the ability for the computers to understand information the way that we do, but NLP does not weight the importance of information.
4. Data can be used for health risk predictions and to support decision-making. This requires a combination of different structures compared and combined together with free text.
5. A narrative is structure, it's structured language, and that language is being created to give some structure to meaning. Free text is a dense structure. If the information is very dense, if everything is linked with everything else, then there is not useful structure. The more complex the use of the language, the harder it is to report back in any sensible structured way, for example dealing with synonyms and abbreviations.
6. Meaning is very much about how people understand and experience their own illness. Coding presents the huge danger of losing contextual information about people's actual experiences. From a predictive point of view how individuals are likely to behave comes more from the context of what they're saying than from something that can be coded out of that narrative.
7. Precision rates of NLP are affected by types of manual involvement. The consequences of precision rates depend on the application of the data, for example in individual patient care precision is essential whereas in a large data driven study lower precision rates are tolerated.
8. The words that people use in the text in their natural language might not always map well to the sort of terms that people use in coding schemes. To map between coding schemes such as Read and SNOMED is easier than to actually go from SNOMED beyond to natural language and map all possible ways of saying those terms in natural language.
9. Whilst Natural Language Processing cannot yet displace the role of templates and clinical terminologies there is a place for using techniques like these to help support epidemiology and to provide aggregated data.
10. If people are trained in good narrative writing skills and to be precise in their language that will actually will make the processing of that text easier in the long run.

## **Appendix 22: Discussion Group Key Points Summary, eHealth Masterclass, March 2011.**

### **What do secondary use services (SUS) need from clinical coding? How does this complement and conflict with the needs of clinical care?**

1. In Scotland, since about 1980 onwards, the Information Services Division of the NHS has coded secondary care data within data sets called Scottish Morbidity Records which are broadly equivalent to the Health Episode Statistics in England. Work is currently underway to improve data quality, clinical richness and timeliness.
2. It's important that we collect the right sort of information so that it is not an additional burden on clinicians. Stakeholder interviews tell us that they want to be able to look at the whole patient client journey from wellness through to managing chronic conditions and potentially multiple chronic conditions.
3. At the moment it's difficult to get the kind of information that you require. There is quite a lot of information but it's not held in the one place. A challenge for the future will be to have different organisational relationships which will let us link data appropriately for appropriate purposes.
4. Information governance must allow appropriate data capture and sharing.
5. The last ten or fifteen years have seen more interest in coding the process of care and now outcomes of care, neither of which are well catered for by the existing clinical coding systems. The coding of disease and symptoms has been constant over the last decade but we now have three times as many codes per person per year due to the increased coding of the process of care. This should help us learn to make it more efficient and timely.
6. We need to have evidence on the outcomes for which there's no coding support and limited consensus regarding the definition and measurement of outcomes.
7. A lot of data can't be naturally measured and are instead translated into numerics by various assessment scales..
8. There's a wealth of information to be had from the health insurance industry in relation to classification.
9. Qualitative information is needed to provide context for data.
10. The Quality Outcomes Framework has standardised the codes that are used in general practice.
11. It is difficult to know how Read codes will be mapped to SNOMED-CT.
12. When using off the shelf Hospital Episode Statistics you've no idea what the quality of the coding is like.
13. Systems suppliers are difficult to engage with despite the potential for research in this space.

## **Appendix 23: Discussion Group Key Points Summary, eHealth Masterclass, March 2011.**

### **What should we do about data quality?**

1. Data quality issues are different for primary use of data for the management of that patient and secondary use. In secondary care people generally don't see something that they actually know is coding in the way that they do in primary care.
2. Primary care is much more heavily computerised than secondary care and data entry is closer to the patient and the clinician as the GPs often do it themselves. In secondary you are reliant on people picking it up thereafter. We do not know if either of these methods of coding is better.
3. Training is an issue for clinicians: coders only code what they are given and they code it in that order. Many people have said they didn't get any training on clinical coding in medical school and it was only passed on from whoever they met through their training.
4. Many clinicians want to be there to treat patients, interact with patients and see the paperwork as a downright nuisance because it's perhaps not immediately beneficial to him or her or necessarily to the patients. The benefits come further down the line on the next appointment for that patient or the public health benefit or so on.
5. Systems design should provide incentives for clinicians to code information. Systems could also do more to automate and facilitate coding and data quality.
6. Data audit as a routine procedure may improve data quality
7. Data quality has a huge impact on PbR because if you miss out certain codes it could cost the trust thousands of pounds lost.
8. Clinical leaders should work to influence data quality by stressing its importance to their staff.
9. Increasing the knowledge that coding performance will be measured and reported upon will improve accountability.
10. Due to resource limitations and practical considerations, improving data quality is a question of getting the balance right between what is absolutely imperative, what is desirable and may be considered optional.

## **Appendix 24: Data Collection Template for WP4**

### **An international survey of national approaches to systematising clinical information Template for summarising country specific strategy , approaches and experience**

Thank you for assisting us with information about your country's approach to capturing, organising, sharing and analysing information within national electronic health records.

The aim of this study is to identify the main business and clinical drivers, and strategies, behind national level investments in EHRs – with particular reference to the structuring and coding of records – and from these to identify the kinds of benefit that are national priorities in different countries.

We seek to:

- Understand how and why different countries are seeking to balance efforts in support of narrative or ad hoc structured records versus the development and adoption of clinical data standards for the structural organisation of records and the use of standard terminologies.
- Explore approaches to increasing the structuring and coding of EHRs being pursued in other countries and to integrate the findings of this review with our current UK-based project.
- Identify novel strategies being employed to overcome the known barriers to increasing the coding of EHRs.

The attached template covers the areas of policy and strategy, approach and experience about which we hope to obtain insight through extractions of detail from policy documents, published evaluations, and obtaining personal insights from interviews with key stakeholders and opinion leaders in each country.

We would be grateful if you could review the headings within this three page template, and provide copies or links to any documents or web sites that might help us to obtain relevant information for your country, or insert a few sentences or bullet points that summarise your own knowledge in certain areas.

If possible we would like to conduct a telephone interview with you, to better understand your perspectives on your national EHR adoption programme, and will contact you shortly to ask if you can be available for this.

An international survey of national approaches to systematising clinical information	
Date:	Researcher:
Resource type: (Person/document):	
Resource description: (Address/URL):	
Country:	
DRIVERS, STRATEGY, BENEFITS	
<b>Strongest business drivers for large scale EHR adoption</b>	
<b>Political level:</b> <i>What benefits have politicians and health ministries publicly declared to be the main drivers for investing in a national EHR?</i>	
<b>Professional level:</b> <i>What benefits have health professional bodies declared to be the reasons why they wish for a national EHR?</i>	
<b>Public:</b> <i>What improvements in health care services do public bodies, the press, health charities and NGOs cite as the reasons why they are behind investments in a national EHR?</i>	
<b>EHR systems adoption strategy (any particular initiatives, incentives):</b> <i>What are the key features of the approach taken to drive forward a national EHR e.g. central procurement of infrastructure, or of new EHR systems, ring-fenced budgets or subsidy to healthcare organisations who invest in EHR systems, usage incentives such as meaningful use, data quality and interoperability performance targets etc.?</i>	
<b>EHR priority use cases for adoption:</b> <i>Is EHR adoption being promoted and driven across the whole of healthcare at once, or have early adopting (priority) groups been identified e.g. particular care settings such as primary care, particular health professional groups, particular age groups such as children or the elderly, particular conditions such as diabetes or cancer?</i>	
<b>Anticipated benefits for health care:</b> <i>Irrespective of the publicly stated benefits, what are the widely accepted quality improvements to health care that are expected from a national EHR?</i>	

<p><b>EHR data re-use priorities (e.g. commissioning, research, public health):</b>  <i>Have any particular uses of EHR data been prioritised apart from benefits to direct care e.g. public health, commissioning, health service planning, research?</i></p>
<p><b>Anticipated benefits from re-use purposes:</b>  <i>What are the widely accepted benefits <u>excluding direct patient care</u> that are expected from a national EHR?</i></p>

APPROACHES
<p><b><i>EHR interoperability standards being used, and state of progress with adoption</i></b>  <b>Data structure standards for EHR interoperability:</b>  <i>e.g. HL7 Clinical Document Architecture, ISO EN 13606, openEHR</i></p>
<p><b>Clinical record standards:</b>  <i>Methods for capturing business requirements for clinical content (what kinds of professional organisations and publications (e.g. guidelines) are used to help ensure suitable clinical models will be developed?</i></p>
<p><b>Terminology standards:</b>  <i>e.g. SNOMED CT, LOINC, national coding schemes (more than one might apply for different purposes)</i></p>
<p><b>Clinical content modelling standards:</b>  <i>e.g. archetypes (openEHR or ISO EN 13606), HL7 Templates, nationally developed clinical models, ad hoc</i></p>
<p><b>Rules for decision support or alerts:</b>  <i>e.g. Arden Syntax for representing rules, but possible other local initiatives will exist and have been used to inform decision support for key areas such as prescribing safety</i></p>
<p><b>Clinical workflow support:</b>  <i>What approach is being pursued to enable patient journeys or care pathways to be interoperable between different clinical applications and systems e.g. Map of Medicine</i></p>
<p><b>Published semantic interoperability resources</b>  <i>Apart from the above answers to the formalisms and design approach, does the national EHR programme yet have a substantial body of actual resources (e.g. archetypes, templates, clinical models, term lists etc.)?</i></p>

<p><b>What is available for industry, for professions (what kind, in which clinical areas, on what scale):</b></p> <p><i>What resources are now published and available for EHR system vendors and health professionals to use i.e. what areas of clinical activity have been covered.</i></p>
<p><b>How resources are being developed (e.g. which stakeholder are engaged, what evidence is being used):</b></p> <p><i>How have semantic resources been developed? Which key stakeholders have been involved, what documentary evidence used, and approximately what design processes have been followed?</i></p>
<p><b>How are they being validated before used:</b></p> <p><i>Is there a process of testing and validating the semantic structures used for a national EHR before adoption and roll-out? If so, what processes and how effective are they proving to be?</i></p>
<p><b>Approaches and incentives to encourage structured records:</b></p> <p><i>What incentives or penalties are being used to encourage the structuring of selected areas of clinical documentation?</i></p>
<p><b>Approaches and incentives to encourage clinical coding (direct entry by clinicians, indirect approaches):</b></p> <p><i>What incentives or penalties are being used to encourage the coding of selected areas of clinical documentation?</i></p>
<p><b>Approaches and incentives to improve data quality:</b></p> <p><i>What incentives or penalties are being used to encourage good quality data collection, and how are quality and quality improvement being assessed?</i></p>
<p><b>Credence given to narratives and documents:</b></p> <p><i>Is there any formal and explicit recognition that some aspects of care might be better documented as narrative?</i></p>

EXPERIENCE
<b>Benefits already observed (and how assessed):</b> <i>Have any benefits already become apparent as the national EHR is being implemented and rolled out?</i>
<b>Challenges identified:</b> <i>Have and particular challenges surfaced to slow down or radically change the strategic direction or its progress?</i>
<b>Barriers encountered:</b> <i>Have and specific barriers to adoption or acceptance been identified?</i>
<b>Strategies proposed to overcome the barriers and challenges:</b> <i>What strategies have been used to overcome these problems, if any were encountered ?</i>
<b>Lessons learned:</b> <i>Are there particular changes to the EHR strategy that you or your colleagues would make in the light of your experience, key lessons you have learned ?</i>

NOTES
<b>ADDITIONAL NOTES:</b> <i>Please use this area to record details of any unique situations or experiences that would be interesting to highlight in the report.</i>

Completed by:

Date:

Any outstanding follow up actions: