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Independence, Engagement, Relationship and Partnering:

Essential dimensions in models of web-based feedback mechanisms for quality improvement

Final Report

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We normally use the term service user when writing reports, because of the implicit passivity in the term patient. However, because the main audience is health service staff and the public, this term is not always understood. As the evaluation is also of *Patient Opinion* the term 'patient' is used throughout for consistency.

1. Introduction and context

The Health Foundation has a major ongoing programme of work which aims to build knowledge, practice and policy around the question of how the quality of healthcare can be improved by transforming the current dynamic between patients and healthcare professionals. This work programme incorporates various forms of activity including complex national improvement initiatives, commissioned research and policy-related roundtable and seminar meetings. The topics covered within this work programme reflect the diverse ways in which the dynamic between patient and professional could be improved, including:

- shared decision-making in relation to treatment choices
- better management of the patient's emotional experience of care
- self-management support for people with long-term conditions
- care planning
- patient involvement in patient safety, including open disclosure following adverse events, and improving the relationship between communities and their local health services.
- This emphasis on quality mirrors the policy direction for the NHS. Lord Darzi's Next Stage Review (*High Quality Care for all* (DH 2008a) examined what high care quality should look like for patients and the public. Identifying three core dimensions of quality - *patient safety*, *patient experience* and the *effectiveness of care* – it set out a framework for embedding quality improvement, that would become integral to NHS service provision including:
- requiring providers to systematically measure and publish information about the quality of care from the frontline up. Measures will include patients' own views on the success of their treatment and the quality of their experiences. There will also be measures of safety and clinical outcomes.
- Making funding for hospitals that treat NHS patients reflect the quality of care that patients receive (Commissioning for Quality and Innovation Scheme (CQUIN). For the first time, patients' own assessments of the success of their treatment and the quality of their experiences will have a direct impact on the way hospitals are funded.
- a legal requirement on healthcare providers working for or on behalf of the NHS to publish '*Quality Accounts';* reports on the quality of services they provide, focusing on safety, experience and outcomes.

At a time when there is an increasing policy emphasis on patient experience, there is also increasing evidence that much of the NHS lacks effective systems for either gathering or acting upon patient feedback. This is due to a number of reasons including public cynicism about the impact of involvement (Smith, 2005); certain groups being significantly under-represented and the need for encouragement of Black and Ethnic Minority communities (Sheldon and Rasul, 2006); the need to use a range of methods as not all people have the same preferences (Ipsos MORI 2008, Entwistle et al 2003); and information developed for patients and the public is written at an above average reading ability, making it difficult for many people to understand (Coulter and Ellins, 2006).

In addition, research suggests that the existing channels do not produce a satisfactory experience for those who wish to offer feedback or make a complaint. Since 1996, numerous reviews of the NHS complaints procedure have taken place, each highlighting problems and identifying improvements, for example (*Being Heard*, 1994; *NHS Complaints Procedure National Evaluation,* 2001; *Spotlight on Complaints,* 2007; *Is anyone listening? A report on complaints handling in the NHS,* 2007; *Feeding back? Learning from complaints handling in health and social care*, 2008; *Making Experiences Count*, 2008; and more recently government policy has shifted its focus to a customer relations approach (*Listening, Improving, Responding: A guide to better customer care*, 2009*)*.

All of these reviews highlight the NHS complaints procedure as flawed, serving neither patients nor providers. Furthermore, they provide compelling evidence to show that in the NHS, *complaints* often become escalated, and positions entrenched as a result of poor initial handling of complaints by front-line staff or managers. This leads to a protracted process and a dynamic of contestation and defensiveness, instead of learning and resolution, and has led to rising litigation costs for the NHS (*Making amends. A consultation paper setting out proposals for reforming the clinical negligence system*, 2005).

Lastly, it seems to be clear that the proactive use of feedback to inform and drive quality improvement is far from being achieved in the NHS not just because of ineffective feedback mechanisms (Vingerhoets, 2001; Wensing, 2003; Davies and Cleary, 2005; Rogut and Hudson, 1995; and Tasa et al, 1996).

Other sectors and industries, however, have developed vastly more sophisticated approaches to capturing and actively using feedback. A far more diverse set of platforms are used in these contexts to achieve this than has classically been on offer through the NHS; in particular there is a far greater use of real-time and near-real-time methods and proactive seeking of views via, for example, prize-draw incentivised surveys, telephone surveys etc., and far less of a focus on passive receipt of complaints than has traditionally been the case in the NHS.

In this context, the emergence of web-based platforms for patient feedback, such as the independent *Patient Opinion* and *I Want Great Care* sites and the "official" *NHS Choices* feedback facility, appears significant, since the evidence from other sectors would suggest that such platforms may have the potential to overcome some of the key limitations of traditional feedback and complaints mechanisms outlined above and to lead more directly to tangible improvements in the quality of care.

However, little evidence is was available as to whether this potential benefit is being realised in the NHS. In this context, the Health Foundation sought to extend their work to explore how far innovative web-based mechanisms have the potential to overcome some of the key limitations of traditional feedback and complaints mechanisms and contribute to tangible improvements in the quality of care and organisational learning. They partnered with Patient Opinion, an independent social enterprise, as a case study, to develop a commissioning brief in a shared desire to make a valuable contribution to evidence and knowledge in this field.

1.1 Patient Opinion

Below, we provide a brief description of Patient Opinion extracted from their website (www.patientopinion.org.uk) and the Health Foundation tender specification:

Patient Opinion was founded by Paul Hodgkin a GP in Sheffield who wanted to make the wisdom and insights of patients, available to the NHS, so he devised Patient Opinion, which uses the power of the web ("Web 2.0") to enable citizens to engage with, and perhaps improve, their health services, by providing feedback. The aim of the website is to establish a transparent, open and public feedback loop between patients, providers, commissioners and other stakeholders.

As a not-for-profit social enterprise Patient Opinion creates revenue to sustain its services and its ability to innovate by charging health service organisations a fee to "subscribe" to the web service.

A subscription enables the organisation to engage with patient feedback through automated email alerts, responding, reporting and analysis of the feedback information. In addition Patient Opinion provides training and support to staff using the system. Feedback is used by subscribers in three ways:

- To monitor how patients are rating services provided;
- To give doctors, nurses and managers a feel for what patients are saying about the service they manage;
- To plan how to develop and improve services;

In addition the Care Quality Commission (the independent regulator of health and social care in England) receives all published stories and uses them to work with healthcare providers to improve services.

Launched as a pilot across South Yorkshire in September 2005, the service was rolled out to cover all hospitals in England by January 2006. To date Patient Opinion cover all major NHS providers of healthcare in the UK, including acute hospitals, community services, mental health trusts, ambulance services and hospices.

Patient Opinion is delivered by a team of 7, headed by Paul Hodgkin and has its own independent board. It is entirely separate from the NHS and is structured as a company limited by shares.

1.2 The commission

A partnership of the Health Services Management Centre at the University of Birmingham and the Tavistock Institute were commissioned to build the evidence around the capacity of patient feedback and complaints to lead to improvements in the quality of care. The aim is to produce a research report which produces an objective, independent assessment of the relative value and potential of web-based platforms as a vehicle for improving the way in which NHS organisations capture and actively use patient feedback as an aspect of their approach to constant quality improvement.

1.3 Research questions

Five research questions were posed:

a) On the basis of existing research, in what ways do current NHS complaints and feedback mechanisms fall short in meeting the needs of users, and in realising the potential of user feedback to drive quality improvement in the NHS?

b) In principle, how might web-based approaches offer an opportunity to overcome the limitations of existing systems for feedback? In particular, what might be the capacity of web-based feedback mechanisms to lead directly to improvements in the quality of care?

c) In practice, how far are web-based systems actually overcoming existing limitations and helping users to give feedback when, how and if they choose to do so and to secure any action by the NHS organisation where that was their motivation for providing feedback, and being used by NHS as a contributing or indeed a driving factor in their work to improve the quality of care? If this is happening, what is the mechanism by which it is happening within those organisations? (process evaluation)

d) What factors need to be present in a healthcare organisation for platforms like Patient Opinion to allow both user objectives and quality improvement objectives to be met? How far is the impact of such a platform within any particular healthcare organisation dependent on potentially vulnerable factors, such as key individuals or a favourable organisational context? How far is the causal chain between receipt of feedback and steps taken to improve the quality of care sustainable, strong and replicable across the constituent parts of each NHS organisation and between NHS organisations?

e) Is there any evidence that there are particular advantages or disadvantages to an independent as compared with an NHS-run feedback platform? How significant are the underlying values and positioning of the platforms in determining the value of different feedback sites to patients and NHS stakeholders? Is there any evidence of a differential impact on feedback as a driver of quality improvement?

2. Research approach and design

2.1 Approach

The background to this evaluation was one of wide-ranging cultural change, taking place in a fast-moving and evolving environment where theories and practice are sometimes contested. Against this background, the evaluation approach incorporated the following characteristics:

- it reflected a range of different evaluation ‘purposes’, balancing the need to demonstrate outcomes and impacts with the need to capture and apply learning in order to support the future development of service user feedback initiatives;
- it incorporated a ‘theory of change’ model, aimed at identifying the explicit and implicit ‘visions’ of change that underpin these initiatives and reflecting these in evaluation methods and instruments;
- It used a context-sensitive approach. An important challenge for the evaluation was to explore the importance of context – for example how different service user environments, involving different types of user – shape the use of such systems and their value;
- it used a stakeholder approach, reflecting the perspectives and positions of different stakeholders, including policy-makers, professional staff, patients and public. This allowed for *polyvocality* (different voices to be heard) in the evaluation and, more importantly, allowed different perspectives of the value of patient feedback to be mapped and analysed;
- it used triangulation. This allowed for the synthesis of evidence of different types and from different sources, and represented different stakeholder positions, in order to arrive at research conclusions. In practice, this meant: multiple sources of data, including secondary data (drawn from existing studies and databases, and primary data (acquired through an on-line survey, service user interviews, case study site visits and a system audit); a multi-methodological approach - the research included an element of quantitative analysis, together with qualitative data;
- It had an evolutionary focus in that the evaluation was sensitive to the changes that occurred and as initiatives developed; and
- It had a learning focus, aimed at applying the learning from the evaluation to supporting operational improvements in the ongoing programme, and applying learning to future strategic developments.

Good evaluation design always starts with a statement of purposes. In this case, four main sets of evaluation purposes were identified:

- An ‘Effects’ purpose, covering the ‘summative’ evaluation objectives and was intended to establish what works, for whom and under what conditions;
- A ‘Developmental’ purpose, aimed at supporting the evolution of the initiative by valorising and disseminating the learning that takes place;
- An ‘Operational’ purpose, aimed at reviewing and supporting the implementation of the Patient Opinion initiative by focusing on its processes, for example the management of the initiative; and

- An ‘Accountability’ purpose, aimed at assessing the value added of the initiative.

These purposes shaped the main objectives of the evaluation: how the evaluation questions were addressed, the methods and techniques used to gather and analyse data, the timing of the activities and its key milestones and deliverables, and the nature of involvement of the different stakeholders. The various stakeholders were expected to have differing, and potentially conflicting, priorities for the evaluation. The evaluation sought to be sensitive to these different perspectives and needs, and drew on different tools to enable the different stakeholder ‘voices’ to be heard. This links to the use of triangulation in the evaluation framework.

Essentially, triangulation allows for the synthesis of evidence of different types and from different sources, drawn from evaluation activities, using multiple sources of data – combining both quantitative and qualitative data- and a multi-methodological approach in order to arrive at evaluation outcomes. However, it also entailed a recognition that stakeholders hold positions and ‘world views’ –different ‘constructions of reality’ - and different ideas about what is appropriate evidence. Thus, the evaluation also considered:

- how the delivery context influenced take-up of Patient Opinion services and their outcomes (in different institutional contexts e.g. acute, mental health trusts, PCTs)
- the role of different actors and agencies (e.g. PCT commissioners; PCT providers; voluntary organisations)
- the type of feedback provided and received (e.g. stories; concerns; questions; endorsements)
- the value attributed to feedback by different actors (e.g. patients; carers; health professionals)
- the delivery mechanisms involved (on-line; paper-based; hybrid)

In turn, stakeholders have different – explicit and implicit – underlying ‘visions’ of what change is and how it should be promoted. The overall evaluation methodology therefore incorporated a ‘theory of change’ model. Theory of change evaluation approaches seek to identify both the explicit and implicit paradigm of change that lie at the heart of programmes and initiatives – in other words the ‘transformative models’ that underpin the ‘vision’ of the intervention, and its ‘intervention logic’ (Weiss, 1995 [1]; Sullivan and Stewart, 2006 [2]). Thus, the evaluation sought to identify and clarify the explicit and implicit theories, models and expected outcomes of change embedded in the operational and technical models used by Patient Opinion to support patient feedback; assess the coherence and goodness of fit between these and the initiative’s objectives, set against the wider policy background of quality and culture change; compare the expected changes in stakeholder behaviour associated with the vision of the initiative with actual changes; on the basis of what has been learned in the evaluation, make appropriate recommendations for adjustments and refinements to the ‘theories of change’ that currently underpin the initiative in order to support future policy and programme development.

The main objectives of the ‘learning’ element of the evaluation approach were: to promote dialogue between the various stakeholders involved in the initiative; support shared understanding and ‘sensemaking’ between stakeholders (Wieicke, 1995; Mase, Sumi & Nishimoto, 1998; Coomey & Stephenson, 2001); promote dissemination of the evaluation results; and more broadly, ensure the learning from the evaluation is applied to the future development of the initiative and similar

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[1] Weiss, C 1995. "Nothing as Practical as Good Theory: Exploring Theory-Based Evaluation for Comprehensive Community Initiatives for Children and Families." In *New Approaches to Evaluating Community Initiatives: Concepts, Methods, and Contexts*, ed. James P. Connell et al. Washington, DC: Aspen Institute.

[2] Sullivan H and M Stewart (2006), Who Owns the Theory of Change? Evaluation, Vol. 12, No. 2, 179-199

initiatives.

Early on into the scoping phase of the project, it became clear that the independent status of Patient Opinion and the organisation's service model had significant implications for our approach to this evaluation and the analytical framework. As an independent organisation, Patient Opinion had two customer bases and therefore a dual focus in their activities:

- **Individual facing:** access and utilization (use by patients and public)
- **System facing:** impact on quality (use by organisation subscribers)

The potential complexity involved in cross boundary interventions would need to be captured in the different evaluation methods and in the analytical framework.

2.2 Design

Full details of the research design is shown in the evaluation toolkit attached as Appendix 1. Below is a summary of the key elements of the design employed to undertake this work.

2.2.1 Establishing a reference group

In our experience engaging stakeholders in an inquiry about desired content and effective delivery strategies is an important first step to generate ownership and interest in development programmes. Such a group also provides useful input into the design and sense making of the research and findings. Patient Opinion established a Reference Group comprising representatives from the Health Foundation, Patient Opinion staff, subscribers and service users of Patient Opinion. This group met three times to jointly review the work and the research team reported progress and sought advice on the focus and direction for aspects of the study.

2.2.2 Research activities

The evaluation was implemented through a work programme comprising of five integrated sets of activities (work packages), as follows:

- ***Work package 1: Scoping***. This enabled the evaluation team to gain an understanding of the policy and practice environment; carry out an 'audit' of relevant data sources and contacts; carry out a review of the policy and practice 'landscape'; 'fine tune' the evaluation approach and methodology; and develop a data collection and analysis 'toolkit.
- ***Work package 2: Benchmarking***. This focused on an outline of evidence of best practice and evidence from other sectors about the optimum ways of securing, analysing and using customer feedback as a factor in continuous quality improvement. It also includes developing and applying an analytical framework to define and describe the characteristics of web-based systems such as Patient Opinion and an analysis of how far they have the capacity to match up to best practice.
- ***Work package 3: Field work.*** This element of the evaluation focused on gathering quantitative and qualitative evidence from the key stakeholders in a range of delivery settings, through: collation and analysis of data automatically generated through the Patient Opinion website (e.g. utilisation patterns; analysis of postings); an on-line survey; interviews with service users; a web-site functionality audit; impact assessment (visits to case study sites and interviews with key stakeholders) and process evaluation (content analysis).
- ***Work package 4: Data synthesis and Reporting.*** This drew together the results of the preceding work packages in order to: (i) analyse and synthesise results; (ii) draw conclusions on the basis of these results; iii) put forward recommendations. The main objective was to co-ordinate production of the key evaluation deliverables.

- ***Work package 5: Developmental evaluation.*** The main objective here was to apply the results of the evaluation to the strategic and operational development of Patient Opinion, and future initiatives. This work package comprised feeding back the evaluation findings to Patient Opinion and stakeholders, and working with them to identify appropriate developments and change.

Underpinning each of these elements, the overall implementation of the evaluation was coordinated through developing and applying a quality plan in order to ensure the work plan ran to agreed timescales and met key milestones, and that the evaluation outputs were relevant, appropriate and of a high quality.

3. Research findings

3.1 Research question 1:

On the basis of existing research, in what ways do current NHS complaints and feedback mechanisms fall short in meeting the needs of users, and in realising the potential of user feedback to drive quality improvement in the NHS?

The grey and research literatures were reviewed in relation to complaints mechanisms in health and social care; and feedback mechanisms in the NHS. In addition, we examined healthcare policy development dating from 1994, when the first major review of the NHS complaints procedure was undertaken (*Being Heard*, 1994). We chose to start from this review as it followed the introduction of the Citizen's Charter[3] and Patient's Charter in 1991; the Citizen's Charter Complaints Task Force set out a new service philosophy and culture in the NHS in 1993.

We commence the review by first defining *complaint* and examining the *reasons* why people complain and what they *expect* to happen. We then address the two elements of the research question posed (emphasis ours):

- The way in which current NHS complaints and feedback mechanisms fall short in *meeting the needs of users,* and
- the potential of user feedback *to drive quality improvement* in the NHS?

3.1.1 Defining a complaint

Given the plethora of reviews and policy developments in relation to NHS complaints handling, it seemed appropriate to draw on the National Audit Office's definition in their report *Feeding Back: Learning from complaints handling in health and social care, 2008*:

"an expression of dissatisfaction, disquiet or discontent about the actions, decisions or apparent failings of service provision which requires a response" (NAO, 2008:13).

Cowan and Anthony (2008) suggest that there are two integral elements that lead to a decision to complain; the *reason* (what gave rise to the complaint) and the *motivation* (the emotional response and expectations about what will be achieved).

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[3] Introduced by John Major in 1991, it was designed to improve standards in public services.

3.1.2 Reasons for complaining

Longley suggests that for the public, complaint mechanisms are used to ensure professional accountability, uphold a sense of justice, and safeguard standards of service quality (Longley, 1993a; 1993b).

McCrindle and Jones (1998:41) identify the main reasons why people complain as:

- information – a request to find out what happened;
- acknowledgement and apology – a request for public display of malfunction;
- prevention of recurrence – "will not happen again";
- apportioning blame and disciplinary action – "who did it and what is going to happen";
- compensation – desire for litigation.

In the ICAS report (*Independent Complaints Advocacy Service (ICAS): The First Year of ICAS, DH 2004*), information and communication is similarly raised as are:

- aspects of clinical treatment; and
- the attitude of staff.

In a review of a report by the Healthcare Commission (HCC) *Spotlight on Complaints, 2009,* 8,949 complaints were reviewed over a four year period. In each case, the complainant felt that their concerns were not addressed to their satisfaction when first raised with their local organisation, so these were picked up the HCC. The report suggested that issues have remained broadly consistent over the four year period, with the main concerns[4] being about the "fundamentals of healthcare, such as safe care and clinical treatment, and the essential elements of a considerate, customer-focused approach to complaints – such as communication and the way that the complaint was handled overall" (HCC, 2009:45).

When examining HCC managed complaints in both 2007 and 2008, the most frequently raised issue in the cases reviewed in 2008 was how the complaint was handled by the healthcare provider - 19% of cases compared to 16% in 2007. This was partly due to a change in categorisation for safe clinical practices.[5] Poor communication and insufficient information remained consistently high at 16%; poor attitude of staff increased by half (6%) and a lack of access to and disputes about personal clinical records also increased by half (5.8%).

However, the report also seemed to confirm Cowan and Anthony's (2008) idea that both *reason* and *motivation* are integral to the complaint; people were: "... not only concerned about the issue that gave rise to their complaint (for example, the care provided), but also about the way that their complaint was investigated and responded to" (HCC, 2008:18).

The Royal College of General Practitioners (RCGP, 2006) suggest that in general practice written complaints mostly fall into one of two basic categories: 'private grievances' against the doctor or the practice and clinical problems e.g. delays in diagnosis, prescribing errors, delayed referrals.

In local authorities, Simons and Preston-Shoot both argue that most complaints about community care are about 'allocation of resources' (Simons 1995; Preston- Shoot 2001). This contrasts with health complaints research literature which suggests that health complaints are often made

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[4] The top five reasons for making a complaint were: safety; communication/information to patients; complaints handling; clinical treatment; and patient experience

[5] Safe and effective practice is allocated across a number of different categories in 2008 which makes it difficult to compare across the two years.

retrospectively and are less likely to be about reallocation of resources than about ‘calling the authority to account’ (Mulcahy 2003).

3.1.3 Motivations

The literature suggests that in the main, patients don’t want to complain, because this takes them into a quasi-judicial process that brings with it contention. Instead, people prefer to give feedback to the service about their experience, and, as discussed above, this is to ensure that their bad experience doesn’t happen to others in the future ((Bark, et al, 1994; Vincent et al, 1994; Friele and Sluijs, 2006).

The policy reviews suggest that a *formal complaint* is usually something that people do when they have exhausted other possibilities for redress - it is not a default option but a last resort (HCC, 2009).

This suggests that complaints are not being adequately well dealt with when initially raised, and this is leading them to escalate into a formal and more protracted process (NAO, 2008, HCC, 2009).

3.1.4 Expectations

Cowan and Anthony (2008:165) suggest that while there is both ample guidance and support on how complaints handling can be managed, there is less guidance to assist those investigating complaints in “identifying and meeting complainants expectations.”

This is reflected in the National Audit Office’s report (*Feeding back*,2008:) “Whilst direct early contact with the complainant is one of the most important factors in resolving complaints satisfactorily, one third of trusts deal with complaints without assessing the expectations of the complainants. In some cases, a simple acknowledgement, apology or promise to improve the service may be all that is required. Of 10,950 reviews completed by the Healthcare Commission in its first two years, a fifth simply wanted an apology or recognition of the event” (*Feeding back*, 2008:8)

Friele and Sluijs (2006), state that there has been little research into what complainants *expect* from a complaints process, and suggest that complainants are not going to be satisfied with complaints handling that does not meet their expectations. They found that “complainants appeared to be rather unanimous in their opinions about a fair complaint handling process”. They identified three dimensions of the process that complainants expect to be fair:

- The procedure needed to be both fair and impartial procedure (87% of respondents).
- People wanted to be treated with respect and with understanding (82% of respondents), with 71% wanting to be given a chance to tell their own story of what had happened.
- A change in the hospital’s practices (79%). A high percentage (84%) also wanted the professional concerned to admit if he/she had made a mistake and 65% wanted an explanation of how the incident occurred. An apology or expression of sympathy, while still considered important, rated lower than wanting an admission that a mistake had been made.

Friele and Sluijs (ibid) concluded that the dimensions of *communication*[6] and *outcome* (change) are equally, if not more, important than the complaint itself.

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[6] We would contend this category; too often ‘communication’ is used as a ‘catch-all’ for interactions between professional and patient, where information is involved. A more detailed analysis of the examples – respect and understanding – might alternatively be categorised as *attitude* as power is implicated in the relationship.

3.1.5 Meeting users needs and driving quality improvement

Moving on to specifically address the two dimensions of the research question. First, we looked further at how existing mechanisms fall short of meeting service users' needs. A content analysis of the policy literature identified four elements: access, responsiveness, redress and independence.

The second dimension of the research question was to examine the potential of user feedback to drive quality improvement. Here we first identified potential drivers e.g. new public management, public service reform, choice and contestability, consumerism, social marketing, reputation or empowerment. While these themes threw up a considerable amount of literature within which this research project is situated, all but the last two could be subsumed within *policy implementation*, and the evidence from the various literatures show that there is variable and short term change, often different to the policy intentions set out (Peck and 6, 2006).

In addition, because the focus is on quality improvement, almost all of the literature on feedback and improvement processes identified *implementation* and *embedding* of change as the key barriers. As a result, we decided to search for *indicators of embedded practices*.

A second content analysis of the same literature was undertaken, as was a review of the involvement, engagement and quality improvement literatures. Six elements were identified: strategic accountability and creating a learning culture; establishing standards of behaviour; having formal planned processes for coordination and change; monitoring and reporting of performance; feedback to directorates and staff teams; and training and development of staff competences. These are now discussed in detail.

3.1.6 Meeting the needs of users

3.1.6.1 *Access*

In 2001, The *NHS Complaints Procedure National Evaluation* identified high levels of dissatisfaction with how the system operated, both at the local resolution and independent review stages (p3)

In January 2002, The Department of Health's response to the Report of the Public Inquiry into children's heart surgery at the Bristol Royal Infirmary stated their intention to implement a new NHS complaints procedure by December 2002. A new proposal was finally proposed in April 2003: *NHS complaints reform, making things right (DH, 2003)*. The changes – although not radically different, also identified the need for open and easy access to complaints processes.

In September 2004, the Neale and Ayling Public Inquiries called for accessible and easily-used systems and the Commission for Social Care Inspection (CSCI) consulted on proposals for the independent review stage of the social services complaints procedures. The Health Service and Local Government Ombudsmen response expressed concern about the complexity of the complaints process.

In October 2007, the Healthcare Commission published *Is anyone listening? A report on complaints handling in the NHS*, which reported on an in-depth audit of the local handling of complaints in the NHS. Amongst a number of key findings, the report said that complaints handling differs markedly across the country, with fragmented processes applied inconsistently across the NHS; basic elements of a complaints handling system were evident, but the emphasis was on procedures rather than on outcomes; and more needed to be done to open the system and make it more accessible to people with special needs, and people from culturally and linguistically diverse backgrounds (p7-8).

In October 2008, the National Audit Office published a report *Feeding back? Learning from complaints handling in health and social care* (NAO, 208), which specifically looked at the cost of services and complaints, and reported a number of findings in relation to individual users including access.

3.1.6.2 *Responsiveness*

In 2001, the *NHS Complaints Procedure National Evaluation* reported that “dissatisfaction was mainly caused by unhelpful, aggressive or arrogant attitudes of staff, poor communication and a lack of information and support” (p3).

In April 2003, the *NHS complaints reform, making things right (DH, 2003),* which emerged following the Bristol Royal Infirmary Inquiry, identified the need for a responsive process.

In February 2004, *Standards for Better Health* (2004) – the performance framework for the NHS - included seven *outcome* domains – Safety; Clinical and cost effectiveness; Governance; Patient focus; Accessible and responsive care; Care environment and amenities; and Public health.

Each outcome domain also included a series of related developmental standards. The fourth domain – *patient focus*– includes developmental standard D8 which states ‘Health care organisations continuously improve the patient experience, based on the feedback of patients, carers and relatives’ (more applicable to providers of services). The fifth domain – *accessible and responsive care* - (more applicable to commissioners) includes core standard C17 which states: ‘The views of patients, their carers, and others are sought and taken into account in designing, planning, delivering and improving health care services’ while developmental standard D11 states: ‘Health care organisations plan and deliver health care which reflects the views and health needs of the population serviced.’ As with *access* above, the Neale and Ayling Inquiries in September 2004 called for better communication.

In March 2005, the Health Service Ombudsman published a report *Making things better A Report on Reform of the NHS Complaints procedure in England, 2005* making a number of recommendations for change. She found five key weaknesses in the system and approach, which the interim changes introduced in 2004 including that the complaints system was not centred on patients’ needs - inflexible processes; slow speed of response and lack of targets and timescales – and that this was deterring primary care complaints.

In April 2008, the government set up an Early Adopter Programme. Ninety-four health and social care organisations helped develop and test the new complaints process, in order to assist in the development of good practice guidance and a national toolkit. The expected outcome would be to raise the overall standard of *complaints handling* and *organisational responsiveness*.

On 26th February 2009, *Listening, Improving, Responding: A guide to better customer care* was published. This document outlined best practice in terms of resolving and learning from complaints, and provided a detailed guide on complaints handling.

3.1.6.3 *Redress*

In June 2003, the Chief Medical Officer reported on clinical negligence claims; Making amends. A consultation paper setting out proposals for reforming the clinical negligence system. The report revealed that the system was complex, unfair, slow, costly in legal fees, and that it encouraged defensiveness. It also found that patients were dissatisfied with the lack of explanations and apologies or reassurance that action has been taken to prevent repetition (TSO, 2005). The report proposed a new NHS-based system of redress for patients who have been harmed as a result of NHS hospital care, which would be administered by a body 'building on the work' of the NHS Litigation Authority (NHSLA). Payment would only be made if there were serious shortcomings in the standards of care, the harm could have been avoided or if the adverse outcome was not the result of the natural progression of the illness. The new arrangements would have four main elements:

- investigating the incident;
- providing an explanation to the patient and action to prevent repetition;
- developing and delivering a package of care;
- providing payment for pain and suffering, out of pocket expenses and care or treatment which the NHS could not provide.

Access to the scheme would only follow local investigation; investigation by the HCC; delivery of a recommendation by the Health Service Ombudsman; or following the investigation of a claim made directly by a patient or relatives to the NHS Litigation Authority. The Department of Health also set out proposals for reforming the procedures for second stage review of NHS complaints, including making the Healthcare Commission responsible for independent review.

In March 2005, the Health Service Ombudsman’s report *Making things better A Report on Reform of the NHS Complaints procedure in England, 2005* found key weaknesses in the system and approach, which the interim changes introduced in 2004 did not resolve including ‘just remedies’. There remained long standing concerns; limited scope of the proposed NHS redress scheme; and a lack of clarity in the current system.

In June 2008, the Department of Health consulted on proposals for an NHS Constitution. The draft constitution comprised commitments and pledges on rights for patients, the public and staff. It included reference to the need for a *system of redress* that is both proportionate and has the trust of patients and the public.

In 2009, in their final report, the Healthcare Commission suggested that people need both an apology from the organisation (for the events that triggered the complaint) and also reassurance from the organisation that they will tackle the problem and prevent it affecting/happening to others (HCC, 2009)

3.1.6.4 *Independence*

In 2000, *Listening to People: A consultation on improving social services complaints procedures* was published. This was a national consultation on proposals to amend the arrangements for handling social care complaints. The outcome of this included concerns about the membership, independence and decision-making of social services complaints review panels.

The September 2001, the national evaluation (*NHS Complaints Procedure National Evaluation,* 2001) was published, revealing that a key structural failure was the 'perceived lack of independence in the convening decision and in the review process generally' (p3).

Also that same month, the Department of Health, responding to the findings in the evaluation, proposed providing locally based *Independent Complaints Advocacy Services* (ICAS)[7] in England, operating to core standards; introducing *Patients' Forums* in every Trust, to bring the patient's perspective to Trust management decision-making.

In November 2001, a national Commission for Patient and Public Involvement in Health (CPPIH) was to be established with local networks and community outreach workers. It was envisaged that CPPIH and Patients Forums would be established at the beginning of 2003. Provision for these changes was subsequently made in the National Health Service and Health Care Professionals Act (2002).

There were also a number of public inquiries that identified independence as a key issues: in April 2003, the *NHS complaints reform, making things right (DH, 2003),* which emerged following the Bristol Royal Infirmary Inquiry, identified the need a fair and independent process; the Neale and Ayling Inquiries in September 2004 called for an independent element to the system; and the fifth report of the Shipman Inquiry (December 2004) was published, recommending a role for Primary Care Trusts in receiving direct from individuals, and investigating complaints in particular about GPs.

In June 2007, the Healthcare Commission published a report *Spotlight on Complaints* which indicated that despite changes to the NHS complaints system, the independent evaluations and the Health Service Ombudsman’s report (*Making things better?* 2005), many problems remained.

3.1.6.5 *Feedback without fear*

According to a Scottish survey of people’s preferences for different methods (Entwistle et al 2003), there was a general preference for anonymous systems as people expressed reluctance to voice concerns openly for fear of compromising their care.

MORI also found reponses from a ‘real-time’ survey were significantly more positive i.e. resulted in higher quality or satisfaction scores than those from the paper-based survey. They suggested that there might be various reasons for this including patients fear a negative response could affect their care (Ipsos MORI 2008).

3.1.6.6 *To be able to find out about the experiences of others*

For patients and service users, the availability of information from other patients is seen to be authentic, genuine and practical. According to MORI’s research, most patients said they would welcome the opportunity to provide feedback on their own experiences, in order to benefit others. ‘Patients indicate that a key component of their enthusiasm for patient feedback is the power they are given to improve things for future patients’ (Ipsos MORI 2008, p53)

This has also been the experience of Thinkpublic Design Company - an organisation that has worked with a number of NHS organisations (largely through NHS Institute commissions) to capture patient experience and use this to co-design changes to service delivery, known as Experience Based Design (EBD).

According to the company’s Director, Deborah Szbeko, the organisation’s interventions ‘create a culture whereby patients are given permission to contribute and suggest changes and that this can prove extremely motivational -giving people a sense of purpose to make a difference for others.’

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[7] The Health and Social Care Act 2001 included provisions (Section 12) to place a duty on the Secretary of State for Health to make arrangements to provide Independent Advocacy Services to assist individuals making complaints against the NHS.

3.1.7 Driving quality improvement

3.1.7.1 *Strategic accountability and creating a learning culture*

In September 2001, the national evaluation (*NHS Complaints Procedure National Evaluation,* 2001) was published. Recommendations included "accountability for complaints should be held at the highest level – with the Board ... The board should take active responsibility for all aspects of complaints-handling... and should accept responsibility for ensuring that an action plan is produced and that agreed actions are implemented" (p3).

In March 2005, the Health Service Ombudsman's report *Making things better: A Report on Reform of the NHS Complaints Procedure in England, 2005* found five key weaknesses with the system and approach, one of which related to leadership, culture and governance. She recommended the need for strong leadership and a learning culture and governance and accountability.

In October 2008, the National Audit Office published a report *Feeding back? Learning from complaints handling in health and social care* (NAO, 208), which specifically looked at the cost of services and complaints, and reported a number of findings in relation to individual users emphasised the need to address organisational culture and attitude.

The West Midlands Report on the *Real Time Patient Feedback Project* (Brown, Davidson and Ellins , 2009) identified that Boards and Chief Executive Officers needed to be accountable and create a culture of openness and learning for quality to be embedded into everyday practice.

3.1.7.2 *Establishing standards of behaviour*

The national evaluation (*NHS Complaints Procedure National Evaluation,* 2001:3) recommended that training in handling complaints should be a compulsory part of induction and continuing education.

There were a number of issues identified in the October 2007 Healthcare Commission report *Is anyone listening? A report on complaints handling in the NHS* relevant to establishing standards:

- no single trust addressed standard C14b, pertaining to discrimination, comprehensively;
- little evidence of using complaints data to inform decision making when commissioning services;
- complaints handling was more effective where staff had access to support from complaints handling professionals, who are trained in related and complementary skills such as customer care, investigation, mediation and resolution;
- no nationally-available standardised tools and resources. At trusts where these were available, staff felt supported and better able to manage complaints;

In February 2009, *Listening, Improving, Responding: A guide to better customer care* was published. This document outlined best practice in terms of resolving and learning from complaints, and provided a detailed guide on complaints handling. A significant part of the guide was dedicated to setting out appropriate customer focussed behaviours.

In April 2009, the Care Quality Commission (CQC) – came into being and would be responsible for examining the standard of complaints handling and the implementation of learning from complaints, as part of its statutory inspection duties. The new procedure sought to focuses on the complainant and promoted a process that enabled organisations to tailor a flexible response that seeks to resolve the complainant's specific concerns. This process was based on the principles of good complaints handling, published by the Parliamentary and Health Service Ombudsman and endorsed by the Local Government Ombudsman:

- Getting it right

- Being customer focused
- Being open and accountable
- Acting fairly and proportionately
- Putting things right
- Seeking continuous improvement

3.1.7.3 *Formal planned processes for coordination and change*

Huberman (1987, cited in Tasa, 1996), notes that an organisation's dissemination strategy is one of the most important aspects in effective use of feedback.

The national evaluation (*NHS Complaints Procedure National Evaluation,* 2001:3) recommended that staff managing complaints have adequate administrative resource and access to senior managerial supervision and support and complaints procedures should be integrated into the clinical governance/quality framework of the organisation.

There were a number of issues identified in the Healthcare Commission's report *Is anyone listening? A report on complaints handling in the NHS, 2007* relevant to coordination and systemisation:

- little evidence of using complaints data to inform decision making when commissioning services;
- improving links between data on complaints with other safety and quality data, can lead to complaints being taken more seriously as a source of information and feedback on the standard of service or care being provided;
- Few trusts appeared to capture and report on complaints data in a systematic way and link this to long term planning as part of a trust-wide strategy to help focus on patients;
- Most complaints lead to one-off changes to service delivery, rather than embedded change.
- Also, Brown, Davidson and Ellins (2009) identified that:
- an infrastructure needs to be in place that straddles strategic, operational and front-line staff for implementation purposes;
- The organisation should develop a communications and engagement strategy and know where feedback fits within this;
- formal organisational processes for coordinating data collection, collation, analysis and dissemination need to be developed; staff need to know who is responsible; and
- Data should be gathered using *robust methods*, from a cross-section of different groups, in ways that are acceptable to patients and are appropriate to their particular circumstances

3.1.7.4 *Monitoring and reporting of performance*

The Healthcare Commission report *Is anyone listening? A report on complaints handling in the NHS, 2007* identified a serious absence of systems to monitor if care has changed or been altered as a result of a patient or carer making a complaint.

Brown, Davidson and Ellins (2009) identified that actions should be monitored and performance regularly reported.

3.1.7.5 *Feedback to directorates and staff teams*

Brown, Davidson and Ellins (2009) identified that data should be fed back to directorate staff and used by them to improve the patient experience and that turning feedback into action requires 'interpretive competency and effort'.

3.1.7.6 *Training and development of staff competences*

The national evaluation (*NHS Complaints Procedure National Evaluation,* 2001:3) also recommended that training in handling complaints should be a compulsory part of induction and continuing education and that organisations should ensure that all staff are supported in the event of a complaint being made against them.

The Healthcare Commission report *Is anyone listening? A report on complaints handling in the NHS, 2007* identified complaints handling was more effective where staff had access to support from complaints handling professionals, who are trained in related and complementary skills such as customer care, investigation, mediation and resolution and using complaints data and real life case studies can promote positive attitudes to complaints among clinicians.

The National Audit Office's report *Feeding back? Learning from complaints handling in health and social care* (NAO, 2008), which reported a number of findings in relation to individual users focussed significantly on the need to learn lessons from complaints to improve complaints handling and improve services.

In February 2009, *Listening, Improving, Responding: A guide to better customer care* was published. This document outlined best practice in terms of resolving and learning from complaints, and provided a detailed guide on complaints handling. Part of this guide addressed the need for focussed training and development in customer focussed behaviours.

3.1.8 Identifying good practice

A framework of good practice was developed from this first stage of the work which provided the basis for the analytical framework (see Appendix 1 The Evaluation Toolkit,) and for research question 2. This framework is shown below in box 1.

Box 1: Complaints handling and quality improvement: dimensions of good practice

Meeting users needs	Dimensions of Good Practice
Access	Complaints procedure to be accessible and simple to navigate[8]
Responsiveness	To have the complaint handled well with early resolution[9] To receive a response with an explanation, apology To have action taken in a timely manner To have staff value your feedback and respect you
Redress	To be provided with 'Just' remedies, redress or compensation
Independence	To have impartial and independent people analysing and judging the outcome To be provided with information and supported to make a complaint without fear To be able to find out about the experiences of others

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[8] To be able to voice good and bad experiences and be able to navigate the procedures easily

[9] Listening to complainants and offering support and advocacy

Quality improvement	**Dimension required for embedded practice**
Governance, culture and organisational learning	Boards/CEOs need to be accountable and create a culture of openness and learning Standards of behaviour are established
Systematised information and processes for capturing and routing feedback and taking action	There are planned process of coordination and change Performance is monitored and reported There is feedback to directorates and staff teams
Education and learning in customer focussed behaviours[10]	There is training and development in core competences

3.2 Research question 2:

In principle, how might web-based approaches offer an opportunity to overcome the limitations of existing systems for feedback?[11]

As discussed above in section 1 and demonstrated in section 2 above, *complaints* are initiated by users in response to an event. They are passively received, often become escalated, positions entrenched, and the process leads to a dynamic of contestation and defensiveness between the user and service/organisation. This differs markedly from practices by organisations to capture *feedback* through proactively seeking the views and experiences of users, and using this feedback to make changes to their organisational practices, services and products.

In this section we present out findings from a literature and two web based searches on best practice in the commercial and third sectors, and a systems audit and a technical audit of Patient Opinion in comparison to best practice. Our approach was limited to published or otherwise available material, with no opportunity to ask follow-up questions due to time available. However, a number of the case studies include information on impact.

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[10] What is missing from the public service and academic literature is the focus on maintaining customer relations; this emerged from the comparisons analysis with commercial sector organisations

[11] We felt that the second part of this research question - *In particular, what might be the capacity of web-based feedback mechanisms to lead directly to improvements in the quality of care?* – duplicated what was being asked in question 3, so have addressed it in the next section at 3.3.

3.2.1 Using the internet to gather customer feedback

Here we look further at evidence of best practice, focussing on other sectors to examine optimum ways of securing, analysing and using customer feedback as a factor in continuous quality improvement. Drawing on the criteria identified in box 1, data from the initial scoping interviews with Patient Opinion and prior knowledge of web based customer feedback mechanisms, the following criteria were developed for selecting types of feedback:

- Does the business model look innovative?
- What is the underlying theory of change?
- What are drivers for change?
- What is the service model, and the configuration of technology that supports the business model?
- What are its approaches to awareness raising and engagement of users?
- Is the provider independent from the organisations/users to be influenced?
- Does it have high traffic levels?

Using these criteria, a literature and web based search was undertaken. Six distinct approaches for gathering web-based feedback were identified, plus two more that are less well defined (but which could be used in conjunction with the others): Customer discussion forums; Market research communities; Democracy and transparency websites; Review and purchasing/booking websites; Content submission and rating; Multichannel contact centres; Social tools and services; and Joining other forums.

A second search was then undertaken to identify specific websites. From this, 16 comparator service websites were identified comprising initiatives from both the commercial and third sectors. Within each of the comparator services we examined eight key factors drawn from the analytical framework (see Appendix 1): business model; theory of change; drivers for change; service model; awareness raising and engagement approach: independence; traffic levels; and key success factors.

For a full review of the 16 comparator services see Appendix 2. Below, we summarise the key factors that have direct relevance to the future development of web-based patient feedback systems.

3.2.1.1 *Transparent information and communication to influence change*

In many ways democracy and transparency websites are the closest comparator services to Patient Opinion, in that their driver for change, theory of change and business model are very similar, and they act independently from the services or organisations to which feedback is provided.

These websites provide easy-to-use tools that help members of the public to obtain information from public bodies and communicate with their elected representatives and use Internet forms which provide a very easy-to-use interface for feeding back specific kinds of information. Information does not need to be too constrained: passages of text can be included along with more specific information, for example relating to the sender’s name or address. Forms can also enable other media to be uploaded, for example photos.

One example is *MySociety.org* which is a not-for-profit web development company owned by a charity, UK Citizens Online Democracy. It is committed to citizens empowering themselves through the Internet. It builds democracy and transparency websites for public use, and also builds websites “of a democratic bent” on commission for other organisations. Websites it operates include www.FixMyStreet.com; www.WriteToThem.com; www.WhatDoTheyKnow.com; www.TheyWorkForYou.com; www.PlanningAlerts.com; http://petitions.number10.gov.uk.

MySociety forwards posts on its websites automatically to their intended recipients. Unlike Patient Opinion, it does not appear to moderate them actively. Instead, it asks site users to report unsuitable and offensive posts to site management.

Use of these websites is very high, for example FixMyStreet had 692 reports in one week, and over 1,000 reported problems were fixed in a recent month. WriteToThem sent over 183,000 messages to elected representatives in 2008. Over 10.5 million signatures have been left on the No.10 Downing Street Petitions website. Much of this is down to multiple awareness raising and engagement strategies:

- Sponsored links on search engines;
- PR and press relations;
- Email newsletter;
- Public outreach, evangelising services to public officials, citizens and representatives throughout the UK;
- Online blog;
- Developing widgets that service users can incorporate in their own websites.

In addition, the non-executive Board members of MySociety, and Trustees of its parent charity UK Citizens Online Democracy, are very well-connected. For example, one of them was a civil servant in the Prime Minister's Strategy Unit, and a previous Board member was Head of Technology at Guardian News and Media.

One important success factor is that the technology underpinning the websites is cheaply scalable, enabling the websites to cope with considerable increases in traffic.

In many ways these websites are the closest comparator services to Patient Opinion, in that their driver for change, theory of change and business model is very similar, and they act independently from the services or organisations to which feedback is provided.

3.2.1.2 *Reviewing and rating services*

Given the drive for patient choice in the UK and the ability to rate services on the Patient Opinion web site, it seemed appropriate to look at websites featuring customer and/or expert reviews and ratings. A number of websites cover domestic and business products e.g. www.kelkoo.co.uk, www.dooyoo.co.uk, typically permitting price comparisons between suppliers of a specific product as well as comparisons between products. Reviews may cover suppliers as well as products. Revenues come from advertising on the website and from the suppliers for click-throughs to their sites and/or purchases completed. A similar model has been applied with restaurant and hotel reviews e.g. www.toptable.com, www.hostelbookers.com. In all cases shorter or longer customer reviews are coupled with ratings on one or more scales; if several scales are used, a single overall rating is often derived.

Toptable (www.toptable.com) is a restaurant review and booking website operating in a number of countries worldwide. The site presents all the information about a restaurant that might be needed to make a booking (a profile, photos, address and sample menus), together with diner reviews and ratings on six scales combined to give an overall rating. A booking can be made directly from the website. Traffic levels are very high; the website displays the total number of reviews posted, over 800,000, and the number of reviews posted on the current day (over 1,200 when last viewed). It claims over 3 million site visits each month, and expects to generate over £130m for the restaurant industry from bookings this year.

There are a number of transferable elements of these kinds of websites as they are independent from service providers. Firstly, reputation and service rating underpins its theory of change and the service and business models. These are core features of many forms of feedback and service based websites e.g. Ebay and Amazon. Secondly, the synergy between reviews and booking capability creates a virtuous circle with high volumes of traffic ensuring volume and recency of reviews. Thirdly, by finding synergistic ways of working with customers, restaurants and the media , a website like Toptable manages to promote the interests of all parties.

The business model may well be transferable in a more competitive market where the new multi-disciplinary (currently GP) clinical consortia across primary and secondary care may wish to bring choose and book, together with rating and advertising their services.

3.2.1.3 *Content submission and rating*

Internet technologies now allow users to upload content in a range of media, including graphic images, pictures, video and audio. On sites such as Flickr (www.flickr.com), YouTube (www.youtube.com) and Facebook (www.facebook.com), photos and videos are uploaded and viewed for social and entertainment purposes. However organisations are starting to harness these technologies more systematically to generate inputs and associated feedback from customers.

Threadless (www.threadless.com) sells T-shirts with designs on them. They have solved the problem of sourcing designs by asking visitors to their website to submit their own designs, by inputting them in the form of graphic images. They have solved the further problem of researching which images will sell well by asking website visitors to score recently submitted images. They receive about 800 submissions per week, and pick the most popular four for production. The opportunity to submit and vote on designs has created a community of current and potential customers who return to the website regularly. More specifically, there are a number of niche communities, e.g. designs by young children for young children, and professional and limited edition artist designs. The case is described in Tidd and Bessant, 2009, and at http://www.managing-innovation.com/case_studies/Threadless.pdf.

The powerful dynamic of this approach as well as discussion forums is that they involve users in the production of knowledge (and in this case products), rather than this remaining the sole domain or demand of the service provider. Giving users the power to offer ideas or exchange experiences also actively increases the power and control users have over what happens; a factor too often missing in the design and delivery of public services.

In contrast to Toptable, the Threadless business model is underpinned by creating an online community with which the service provider has shared values. Critical elements in sustaining this community have been the absence of advertising, and lack of emphasis on ‘monetising’ the community, i.e. obviously exploiting the community for financial gain. Like Toptable, Threadless has generated synergistic ways of working with and promoting the interests of community members as service providers, designers and niche customers.

This means that not only is traffic high, the total website user base is claimed to be over 700,000, but the business model also removes major sources of cost and business uncertainty.

3.2.1.4 *Incentivizing data feedback*

Many organisations convene market research communities to provide feedback in response to specific questions, or contribute new ideas. These communities differ from discussion forums in that the convening organisation sets the agenda, not the participants themselves. Participants may be motivated by a wish to be helpful or have their say, or by rewards such as vouchers, payments or participation in a prize draw. In some cases the communities are convened by specialist market research companies, typically to a specific sampling profile. The *Institute of Directors (IoD)* has recruited a research panel, called ‘Policy Voice’, from its membership of company directors to provide inputs on public policy. Panel members are invited by email to complete a 15 minute web-based survey each month on policy issues that affect business, for example transport, pensions and employment law. The survey data are used to inform the Institute's policy and its activities in lobbying Government and publicising its views in the media.

The IoD feedback mechanism appears to have been very successful in recruiting panel members, and may have as many as 2,000 – 3,000. It runs a prize draw for participants in each survey, and also circulates by email a quarterly newsletter providing feedback on survey results and how the Institute is using them in developing policy and lobbying government. An important motivation for participants is likely to be having their voice heard and influencing the Institute's policy and Government policy. The two key success factors that are transferable here are identifying and targeting a community that is motivated to respond and providing feedback to ensure panel members stay engaged and motivated.

3.2.1.5 *Effective access, responsiveness and impact management*

A number of web-based and other information technologies are now coming together to allow companies to offer improvements in customer service, for example integrated multi-channel contact centres; interactive communications in real time; customer databases; knowledge bases of answers to customers' questions; analytic tools that track customers' behaviour on a website; and business rules systems. These types of systems are relevant to services such as NHS Direct, the swine flu helpline and interactions with NHS administrative systems. In patient records the NHS also has the repository of customer data required to exploit these technologies fully, although they would need to be held in digital form. There are a number of ways in which these technologies can be used to collect customer feedback, for example being invited to complete a brief customer satisfaction survey after each contact; creating surveys and distributing them to very specifically targeted recipients, and collating the results; spotting trends in issues raised by customers and ensuring that specific categories of incidents are forwarded to the appropriate managers. Three case study examples are of relevance:

Rotherham Metropolitan Borough Council has brought its environmental services together under the brandname *Streetpride*. It has set up a fully computerised, state of the art contact centre to act as a single point of contact for citizens; re-engineered back office processes and systems to interface with the contact centre; and invested in image, branding and publicity to ensure that the new service was immediately recognisable and accessible to all. The service is operated by RBT Customer Service, a joint venture between Rotherham Council and BT.

Citizens can contact Streetpride by phone, email, web chat with a live advisor, text, face-to-face or by post. Phone is the most popular means of contact, via a 'single golden number', followed by email. Web chat and text are targeted at a specific end user group. Calls coming in are routed automatically to agents using Automatic Call Distribution (ACD), a call handling and call monitoring system that records all customers' telephone calls. The system allows calls to be queued to the relevant section of advisors whose skill sets allow them to deal with the query. The system also allows supervisors to monitor call quality and review previous recordings. Advisors' call handling is supported by Siebel Customer Relations Management (CRM) software to ensure that all environmental reports are properly logged, tracked and followed through to completion.

Another example is *iRobot* (www.irobot.com) which makes Roomba Vacuuming Robots. Customer support is very important for a product and customer base of this kind. In addition, as a pioneer in a new market, iRobot needs to find out very quickly what customers want. iRobot has set up a contact centre providing phone, email, web and online chat support. Because a single system handles phone and email interactions with customers, staff have a complete view of all past service interactions with a customer, so that they can resolve the customer's issue as efficiently as possible. Analytic tools give iRobot an overview of customer issues. iRobot also uses the system to manage monthly customer satisfaction surveys, sending a questionnaire to 4,000 different customers every month. This enables iRobot to track the impact of improvements in customer service procedures, and get early notice of any problems.

Black & Decker is the world's largest producer of power tools and accessories, with a turnover of $6.4 billion. It has set up a customer contact centre and incident management system to handle customer questions, complaints and feedback by phone, email and web channels. The system enables contact centre staff to address customer issues quickly and effectively, and creates a single repository for all customer inputs. Business rules have been implemented to distribute data about specific incidents automatically to whoever needs them. For example, incidents associated with specific products are forwarded to the appropriate product manager. Patterns in customer complaints can be detected very quickly, and appropriate corrective action taken immediately.

A key feature of all three services – public and commercial – is that they provide an integrated contact centre and database giving a complete view of all service interactions with the customer. This maximises the effectiveness of the service, and enables the organisations to offer a high level of service. Analysis of customer data and regular feedback channels (S*treetpride* and *iRobot*) give early notice of product or service problems, and provide rapid feedback on changes required, again helping the organisations to optimise customer service and maintain quality. Business rules route incident data to the managers responsible for acting on them, enabling corrective action to be taken as quickly as possible.

As running an effective and efficient contact centre is one of the more difficult management challenges, it is essential to have motivated and properly trained contact centre staff. HR policies, training plans and contact centre staff management that ensure effective performance and high levels of staff retention are integral to this service model.

However, this service model – although generating high levels of traffic - might be more suited to healthcare organisations taking on this function themselves as it does not apply as readily to an independent feedback mechanism.

3.2.1.6 *Promoting services and gathering feedback via social networking communities*

Organisations do not have to limit themselves to their own website to gather customer feedback. They can join communities where customers congregate, in particular social networking sites, and collect feedback there by building a profile and offering content and services that attract links, contacts and friends.

Like many other commercial and public sector organisations, the *Topeka and Shawnee County Public Library* has set up profiles on Facebook and MySpace, its own pages with images on Flickr and videos on YouTube, and its own location in Second Life. It uses Twitter feeds to provide updates on forthcoming events. It has attracted substantial numbers of 'Fans' on Facebook and 'Friends' on MySpace. It is hosting some discussions on Facebook, and is using the 'Post Comment' facility on MySpace to try to collect feedback. Flickr has the facility for users to post comments on individual pictures. On its YouTube page the Library states "We are experimenting with different ways to connect people to stuff, as well as to advertise the library and our events."

YouTube has a variety of interactive features which the Library is exploiting: users can post comments on the Library page and on individual videos, and also rate the videos.

Success in using these social networking communities depends on respecting the norms and conventions for communicating; a 'corporate' approach and flagrant advertising are not well received on many social networking sites. In addition, content has to be sufficiently interesting for users to engage with it.

3.2.1.7 *Promoting two way communication*

There is a variety of social tools and services that can be incorporated in a website to enable customers and third parties to provide feedback and other inputs of various kinds, and stimulate two-way communication on the site: they include blogs, wikis, tagging, and user ratings or polls (also known as 'Seals of Approval', or SOAPS).

A website can give space to one or more blogs. These are web pages with regular entries of commentary on a particular topic, descriptions of events or other material such as graphics or video, and often include links to other blogs, web pages and other media related to their topic. There are also video blogs, made entirely in video. The more successful blogs are usually authored by an individual with a distinctive personal voice. Typically the author is an employee of the organisation owning the site, although there is no reason why this should always be the case. Many blogs allow viewers to post comments, and blogs are often written in such a way as to stimulate comment.

A wiki is a simple online database, consisting of interlinked pages of information. They are often collaboratively written, allowing users to edit any page or create new pages. The best known example is Wikipedia, but small wikis can be incorporated in other sites. Tagging is assigning keywords or terms to individual pieces of information. Tags describe the item and allow it to be found again by browsing or searching. For example Flickr encourages users to tag photos. Tags can be shared through internet communities such as StumbleUpon. Users can be asked to rate particular posts, or vote in snap online polls. The average ratings or running poll totals are then displayed. The case studies above include examples of the use of ratings and polls.

The BBC (www.bbc.co.uk) uses a variety of approaches to encourage users to make contributions and provide feedback, for example the site runs a number of blogs written by named senior correspondents; a section, 'Have your say', invites users to comment on topical subjects and provide feedback on the 'Have your say' section itself; for breaking stories, users are sometimes invited to submit their own images and videos; there is a facility for users to email a story to a friend (the most frequently read and emailed stories are listed prominently on the website); in the 'Magazine' section there is a letters page, a caption competition, and an opportunity to submit unusual photos on a specified topic; and there is an Editors' blog, and readers are invited to post comments. Like Patient Opinion, comments are moderated in all cases.

The *Topeka and Shawnee County Public Library* (www.tscpl.org) uses a range of social tools and services on its website to promote user interaction. For example users are invited to make comments on and rate most of the website postings; on the home page there is a prominent feature providing instant messaging contact with a librarian; there is a Teen page on the website which also includes a facility to add an RSS feed of the teen page to the user's favourite blog or newsreader program; a real-time online conference on the subject of emerging web media; and video and web pages describing the library's strategic planning process for the next decade and inviting users to post comments on a blog or ask questions by email. The website also has a catalogue search facility, and a facility for the user to set up and manage their own library account.

The key factor about both these websites is that they offer a range of two-way communication features including internet forms, easy-to-use facilities for uploading media, user rating scales and voting, tagging and email forwarding facilities, listings of most frequently viewed and emailed items, instant messaging, online conferencing, and profiles on social networking sites.

3.2.1.8 *User to user interaction and support*

Many organisations have found that setting up mechanisms for customers or service users to interact with each other provides an excellent source of customer feedback. In the comments they make to each other, customers reveal much about their needs and requirements, and how they think about the products or services in question. For example *Cisco Systems*, who supply telecommunications network equipment, pioneered customer support forums. Customers post technical queries, and other customers offer solutions. Cisco discovered that customers are happy to help each other resolve technical problems and share expertise. The exchanges provide a wealth of feedback for Cisco. This is primary market research data, and very helpful to the hosting organisation in improving current products and services and planning new ones. (See http://forums.cisco.com/eforum/servlet/NetProf?page=main.)

Creating a sense of community is important to the success of discussion forums. Often this comes naturally where participants see themselves as sharing a professional or social connection or an interest. Where this is not the case, it is more difficult to attract and retain participants. The *Alzheimer's Association* (www.alz.org) is a voluntary health organisation in the United States dedicated to the care and support of people with Alzheimer's and research into the condition. It operates a comprehensive website with information, online message boards and interactive chat forums for people with Alzheimer's and care givers looking after them. The message boards enable people affected by Alzheimer's to share experiences, and obtain support and advice. Neither case study organisation operates independently from the service provided so all feedback is about their own services. In this way they are not necessarily comparable to Patient Opinion. However, they both have high traffic levels; Cisco in particular actively raises awareness of the customer support forums to new or existing customers and customers seeking support are directed to the support forums.

3.2.2 Technical and Systems Audits

In this section, we summarise our findings from two audits which provide an analysis of the key technical and operational characteristics of Patient Opinion. As with the previous chapter, our focus for the analysis, is on the key factors that have direct relevance to the future development of web-based patient feedback systems.

3.2.2.1 *Technical audit*

The technical audit involved collating data from content analysis of relevant documentation and any interview data to document the technical infrastructure, software and procedures used to deliver the service.

This covered as far as possible, all aspects of the access infrastructure (telephone; web; e-mail etc). The audit involved collating data on 15 items shown in box 2 below:

Box 2: Technical Audit Items

Accessibility standards (compliance with WC3 initiative; in particular, WAI http://www.w3.org/WAI/
Content Database
Content management system
CRM system – how it handles customer data
Security measures
Profiling of users
Language capacities
Reliability of the system

Speed of network/internet
Traffic (volume of postings on the website)
Interoperability
Support for software/hardware
Performance indicators
Maintenance of systems
Production of documentation

The audit was supplemented by a hands-on user trialing of the infrastructure, systems and tools website to test operating systems and main functionalities, including an overview and aesthetic 'look and feel'; the home page; site wide navigation structure and menuing; and functionality and capability (speed of access of Web 2.0 and other tools; technical effectiveness – frequency of crashes; technical problems; comprehensiveness of functionalities; degree and nature of collaboration tools).

3.2.2.2 *Systems audit*

The aim of the system audit was to collect and make transferable learning from comparator services available to Patient Opinion. Carrying out the system audit required collating and analysing data drawn from the literature review on key features of patient complaint and feedback approaches (box 1): interviews with key informants; case study site comparisons analysis of 16 health and non-health sectors which represent good practices in user feedback (see 3.2.1) , identifying the key success factors in the cases analysed.

This was undertaken in a way that was coherent with our approach and the analytical framework, and which enabled comparison between PO and the comparator services. To do this, both *common organisational processes* and *operational elements* needed to be identified.

Together, these provided the benchmarking evidence sources for comparing the services. Twelve common organisational processes were identified as shown in box 2:

Box 3: Organisational processes

How does the service meet user's needs?	How is quality improvement actioned and embedded?
Mission and values	Management and governance
Service model	Establishing systematised information and processes
Business Model	Customer focused behaviours
Marketing strategy	Capturing and routing feedback
Organisational structure	Acting on feedback
Technical platform	Maintaining customer relations

In addition, three benchmarking operational elements were identified. They were the 'evidence sources' on which the audits drew to compare the services. These are shown in box 3 below.

Box 4: Operational elements

Operational elements	What this comprises
Structure	the organizational infrastructure in place to support service delivery (e.g. institutional and human competences; technology platforms and tools; governance and management structure)
Practices	the ways the organization uses its resources to deliver services (e.g. the business strategy

	of the organisation; its targeting and access policies; its customer service approach; its promotional activities)
Performance	the interaction between work practices and structure, focusing on outcomes and impacts, such as: service outcomes; cost-effectiveness; technical effectiveness.

Full details of the technical audit is shown in Appendix 4 and the systems analytical framework and evidence sources is shown in Appendices 5a and 5b.

3.2.2.3 *System audit: key findings*

Detailed data from the findings is not presented in this section as this is discussed fully in section 3.3, 3.4 and 3.5; instead, we have summarized the key issues for consideration.

The analysis seeks to look at how Patient Opinion might optimize their system and technical offering to enhance the service further. However, it is recognised that the organisation is small, and funding base limited. However, the focus of this evaluation is about both the *progress* and *potential* of web-based feedback mechanisms. On this basis therefore, findings from both the system and technical audits are offered in the spirit of optimization within the available resources.

Mission and values

Present in Patient Opinion's service model is a strong value base, an enthusiastic and committed staff and charismatic leadership. The combination of these three factors works very effectively as the findings below show.

In addition, the principles of learning in Patient Opinion are embedded in the organisation's approach. This is based on positive psychology rather than 'name and shame' but it takes a lot of effort to maintain this stance, as it cuts across 'normal' NHS culture. Usual NHS feedback procedures are about accountability, blame and redress (Complaints) or enquiries (PALS); Patient Opinion is therefore unusual and challenges the way things are usually done through communicating in a different way. This is core to their theory of change which discussed further in section 3.3 below.

Offline relationships with subscribers are usually restricted to a small number of highly engaged 'champions'; not NHS service staff as a whole, nor senior management who are responsible for quality assurance and can authorize use of such services.

Governance and accountability

At the moment Patient Opinion doesn't have active external shareholders, or a board/governance structure within which the interests of a broader spectrum of stakeholders is represented (particularly the interests of potential subscribers). While this has strengths in terms of maintaining its independence, this might limit the potential for constructive involvement and development.

Given the strong values and philosophy underpinning the organisation, extending the stakeholder interest in the governance of the organisation might support further understanding the interests of the *local* NHS, and might lead to better communication, greater trust and more closely honed activities the causal chain of activities.

Learning about the needs of customers

Patient Opinion has two customer bases: individual patients (non-paying) and healthcare organisations (paid subscriptions). Current activity to actively solicit feedback in order to understand patients' needs mostly comes from evaluations or generic feedback[12] via the website; which are then put on a development list and acted upon within allowable resources. To optimise customer needs, it might be useful to consider further ways of finding out about customers' needs.

Currently, there is a strong alignment with the ideological needs[13] of subscribers and this works very effectively in engaging them to work with patient feedback. However, there are no formal mechanisms yet to embed feedback from subscribers on use of Patient Opinion's service; those organisations that have stopped subscribing are particularly useful sources of information. This might suggest that Patient Opinion is not currently fully 'meeting the needs' of its subscribers, and there is some data from subscriber feedback in this evaluation to suggest they would like additional activities, e.g. in-depth reports on feedback and quantitative service ratings data like those provided by NHS Choices[14].

It might therefore, be important to develop monitoring structures which enable the organisation to systematically understand subscribers' needs, which can also be purposive i.e. collating data which can be used to create a case for change to staff, or provide commissioners and the DH data on quality involvement and use of feedback.

Marketing and publicity

Patient Opinion is effective in marketing itself on a national stage e.g. in the newspapers and with government bodies, and is keen on fostering ties with the digital community, often organizing and attending conferences on use of new media. Although the organisation receives a lot of attention from national media in terms of their values and innovative use of Web 2.0, it is not clear that this is reported in media that might be read by patients or staff interested in using the website.

Although much time and energy is given to working with subscribers, marketing and promotion at a local level is less well developed and given the feedback by both service users and health service staff that they often don't know about Patient Opinion or what it does, how the organisation becomes more known seems vital to the generation of both patient feedback and staff engagement, which is core to the success of the service model.

In section 3.5.3 below, we discuss the dependence of the service model on volume of feedback and on *active agency* by subscribers; it might be that Patient Opinion needs to use its stakeholders to assist in jointly developing alternative routes to promotion, for example, a joint editorial in the Health Service Journal (HSJ) with subscribers; links with the Royal College of Nursing (given the bulk of the workforce to be engaged with are nurses) on use of feedback for learning, use of local patients groups to use local media.

3.2.2.4 *Technical audit: key findings*

Multi-channel access

Patient Opinion's technical system rates highly in terms of accessibility and usability. This is important in terms of the likely audience i.e. 55% of users are over 60. However, survey results showed that older people are the least frequent users of the internet and prefer not to use it when offered other choices. While Patient Opinion does also offer telephone and post options for providing feedback, they nevertheless are primarily an online platform. Findings from the commercial sector comparator sites, suggests multi-channel access is more effective in providing

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[12] Patient Opinion also meet with some patients through its work with subscribers and links with user organisations

[13] These values include not naming and shaming, and not mobilizing citizens in a punitive manner.

[14] Patient Opinion said that they were not necessarily interested in developing this side of the service *internally* but there was the possibility to link with another organisation for this aspect of the work.

for a range of needs. There are obvious resource implications involved in increasing the multi-channel access so that it is more balanced, however, it might be worth examining what activities are incrementally possible within resources available.

Capacity to respond to increased volume of postings
Although Patient Opinion can technically handle major peaks and ebbs in flow of contacts, the heavy dependence on staff to monitor and obtain feedback on postings means that there are limitations to how many of these can be promptly responded to; where there is a sudden rush, all staff with editorial capabilities have to be redeployed to address this. Since the number of posts is reliant on traffic – they usually receive a post for every 100 hits – any significant increase in the traffic may lead Patient Opinion to struggle for capacity to deal with editing the feedback. Online feedback in general needs to account for this ratio of feedback to traffic and large marketing pushes will therefore also need capacity building. This has major implications given the expressed desire for the team and organisation to remain small. Again, findings from the commercial sector, suggests drawing on constituents for support e.g. drawing on patients as a community to partake in some service processes. This is something that Patient Opinion has been discussing.

Software and hardware support
Maintaining and evolving the technical system is highly dependent on individual input, and it is not clear that there is an adequate legacy or capacity building the internal skills base. It would be good to be building in more capacity as a back-up to the main technical expertise.

Automated learning
There may be potential for a more sophisticated technical system to 'learn' more about different needs of users and adapt itself to these. However, how far this is relevant to a system which is primarily about feedback for impact, rather than providing a service, is open to question

3.3 Research question 3:

In practice, how far are web-based systems actually overcoming existing limitations and what is their capacity to lead directly to improvements in the quality of care?[15]

In this section, we begin by mapping Patient Opinion's *Theory of Change* before moving on to examine the actual experiences of service users and staff using the Patient Opinion service compared with Patient Opinion's theory of change to see if feedback leads to quality improvement.

Then we explore whether feedback is being used by the NHS as a contributing or a driving factor in their work to improve the quality of care? If this is happening, what are the mechanisms by which it is happening within those organisations?

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[15] a) helping users to give feedback when, how and if they choose to do so and to secure any action by the NHS organisation where that was their motivation for providing feedback, and
b) being used by NHS as a contributing or indeed a driving factor in their work to improve the quality of care? If this is happening, what is the mechanism by which it is happening within those organisations? (process evaluation)

Sources for the analysis included data drawn from the literature review, interviews with key informants from Patient Opinion and the Health Foundation, the comparisons analysis identifying the key success factors in the commercial and third sector cases analysed, the on-line and postal surveys together with the four case study site visits and patient and staff interviews.

3.3.1 Theory of change

The Health Foundation suggested that *"the most complex aspect of the evaluation is likely to be the work with staff within NHS organisations to identify the causal chain (if any) between receipt of patient feedback and steps which improve the quality of care as a direct result of that feedback*".

As a result, the underpinning methodology for the impact assessments was the *Theory of Change* (Weiss, 1995; Sullivan and Stewart, 2006). This approach looks to identify the explicit and implicit theories that govern the way change programmes and initiatives work – that is the *transformative models* that underpin the vision of the intervention, and the *intervention logic* (ibid).

The process can defined as a systematic and cumulative study of the links between the activities, outcomes and context of an initiative. It involves the specification of an explicit theory of how and why a programme or project might cause or have caused an effect and the use of this theory to develop a set of hypotheses regarding these links, to guide the evaluation.[16]

Theory of change acknowledges that the body of existing evidence does not provide us with enough knowledge and experience to be confident about the nature or extent of causality between the intervention and its intended effects. It is therefore necessary to rely on the theory to make some of the links between the intervention and its outcomes, focusing not on the activities per se but on the response that the activities generate (mechanism of change)[17], and upgrade and refine our knowledge as the intervention and its evaluation unfold by continuously updating and refining the initial theory of change map.

Another useful element in this approach is that it recognises that there may be multiple theories of change held by different stakeholders in the intervention: ideally, the approach would involve representatives of different stakeholder groups in contributing to theory-building process. Indeed, the programme theory is ideally agreed upon by these stakeholders in a process of consensus-building as it is they who best understand an intervention and will have to be convinced that the outcomes can be attributed to the intervention theory they approved.

By making assumptions about causal pathways explicit and then testing these, theory of change further addresses some of the associated challenges that complex and multi-faceted interventions pose to experimental research. The process of ongoing revision and amendment of the initial theory of change also addresses the issue of alternative explanations to the identified causal pathway because in the process of theory building these are highly likely to be integrated if relevant for the impact of an intervention.

Here we begin by mapping out the 'theory of change' underlying the Patient Opinion service model, to generate a series of hypotheses concerning the way in which this will impact on both service users and subscribers. This guides the subsequent assessment as to whether the process and impact were broadly consistent with those anticipated by the theories underlying the Patient Opinion service model from three perspectives – patients, subscribers and Patient Opinion.

The mapping looks to clarify five elements: service rationale; the issues it seeks to address; the

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[16] DTI (2006) Evaluating the impact of England's Regional Development Agencies: Developing a Methodology and Evaluation Framework, DTI Occasional Paper NO 2

[17] Stame, N. 2004, "Theory-based Evaluation and Types of Complexity", *Evaluation*, vol. 10, no. 1, pp. 58-76.

desired impacts; the outcomes and outputs, and finally the activities that are designed to bring achieve the impacts, outcomes and outputs.

3.3.2 Service rationale

Patient Opinion has a ‘social mission’ which they articulate as:

“ to use the internet to bring patient’s opinions to the forefront and dynamically change the way feedback has been done ... [we] want patients to be heard by the NHS and for their comments to make a difference.”

Delivery of Patient Opinion’s social mission seems to be influenced by their excitement at the idea of “*finding technological solutions to social problems.”* This is done by taking advantage of innovations emerging as a result of the networked information economy (Benkler, 2007), in particular, disruptive innovation (Christensen et al, 2000) and the development of social movements (Smelser, 1963), both which offer the possibility of reversing control mechanisms and democratising patients’ voices.

Patient Opinion’s Chief Executive Paul Hodgkin, citing Ebay[18] as an example (2006:121), sets out an argument for the way in which the internet has transformed the way people relate to public and commercial services and politics when they are dissatisfied, moving beyond traditional systems such as ‘exit’[19] and ‘voice’[20]. Instead, he argues, “The new kid on the block is a “resurgent, automated and highly visible *system of reputations*” (2006:121). He goes on to suggest that this transparent system could be applied to the NHS: “anyone can use the web to describe their experience of care publicly ... anyone can use their mobile to take a photo of the filthy toilet on Ward 19 and post it to www.flickr.com....” (2006:123).

Hodgkin holds that both spectacular transparency (McGivern and Fisher, 2010) and micro-conversations in the public domain, become “*automatic quality drivers”* (ibid:124) because they challenge reputations. This process strengthens traditional systems like ‘exit’ and ‘voice ‘to bring about change.

Summarising this, we propose two hypothesis:

- The internet enables individuals to exercise choice and control by publicly telling others about their experiences of services;
- Stories about the quality of services appearing in the public domain that affect an organisation’s reputation will automatically become a *driver for quality*.

3.3.3 What the service seeks to address

Interviews with Patient Opinion staff elicited a range of issues that their service sought to address, including: making a difference to the quality of services; empowering patients; mediating greater engagement between the NHS and patients; increasing openness; acknowledgement; contact and involvement; providing positive feedback to engage front-line staff; and breaking down barriers through innovative ways of working.

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[18] In 2003 10 million trades were made on ebay.uk. At that time fewer than 100 were fraudulent

[19] where people choose to leave a provider and this in turn creates pressure for improvement; and

[20] where people suggest, complain or campaign for improvements directly with the service provider”(2006:121)

Some of these issues are also supported by findings from the literature review, as well patient and subscriber perspectives:

3.3.3.1 *Complaints systems are ineffective and disliked*

As discussed in 3.1 above, since 1996, numerous reviews of the NHS complaints procedure have taken place.[21] All highlight the NHS complaints procedure as flawed, serving neither patients nor providers. Furthermore, they provide compelling evidence that complaints often become escalated, and positions entrenched as a result of initial poor handling of complaints. This often leads to a protracted process and a dynamic of contestation and defensiveness, instead of learning and resolution.

Patient Opinion's Chief Executive reiterated this: *"...everyone hates complaints...I am sure the literature review will show the procedure is loathed by everybody and has been repeatedly, despite multiple reconfigurations every 3 years..."*

3.3.3.2 *Current systems are not independent, impartial or fair*

In September 2001, the national evaluation (DH,2001) revealed that a key structural failure was the 'perceived lack of independence in the convening decision and in the review process generally' (p3). There were also a number of public inquiries that identified independence as a key issue: in April 2003, following the Bristol Royal Infirmary Inquiry, the *NHS complaints reform, making things right (DH, 2003),* identified the need a fair and independent process. Friele and Sluijs also (2006) highlighted the importance of an impartial and fair procedure.

For Patient Opinion independence from funders was a principle they felt strongly about because:
" ... the state isn't the right person to do this; the citizen won't trust the state..."

" We felt that we weren't going to go down that route so ... we walked away and I think ... you only know what the values are when you look back and see how you acted and not what you have asserted."

even when it meant walking away from available funding:
"We walked away at that point because being independent was really important for these tools... they were throwing millions, hundreds of thousands pounds a week to get this thing built."

Patient Opinion also seem to recognise the importance of independence being reflected in what they do: *"Our business model aims to create trust and ensure independence. [It is] Free to patients, carries no advertising, all postings are previewed prior to posting and edited if appropriate, we are a not-for-profit social enterprise, and our financial independence is secured through subscriptions from many organisations rather than a few large grants."*

3.3.3.3 *Reasons and motivations go beyond blame and redress*

The literature suggests that in the main, patients don't want to complain, because this takes them into a quasi-judicial process that brings with it contention and fear. Instead, people prefer to give feedback to the service about their experience, to ensure that their bad experience doesn't happen to in the future (Bark, et al, 1994; Vincent et al, 1994; Friele and Sluijs, 2006). Patient Opinion are aware of different motivations for feedback:

" People want to share experiences and have varied motivations."

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[21] For example (*Being Heard*, 1994; *NHS Complaints Procedure National Evaluation,* 2001; *Spotlight on Complaints,* 2007; *Is anyone listening? A report on complaints handling in the NHS,* 2007; *Feeding back? Learning from complaints handling in health and social care*, 2008; *Making Experiences Count*, 2008;

" Sometimes people want to work through issues. We ask questions well in advance, and ask their views. We try to facilitate the process for them."

From this, we can hypothesise that Patient Opinion is seeking to address:

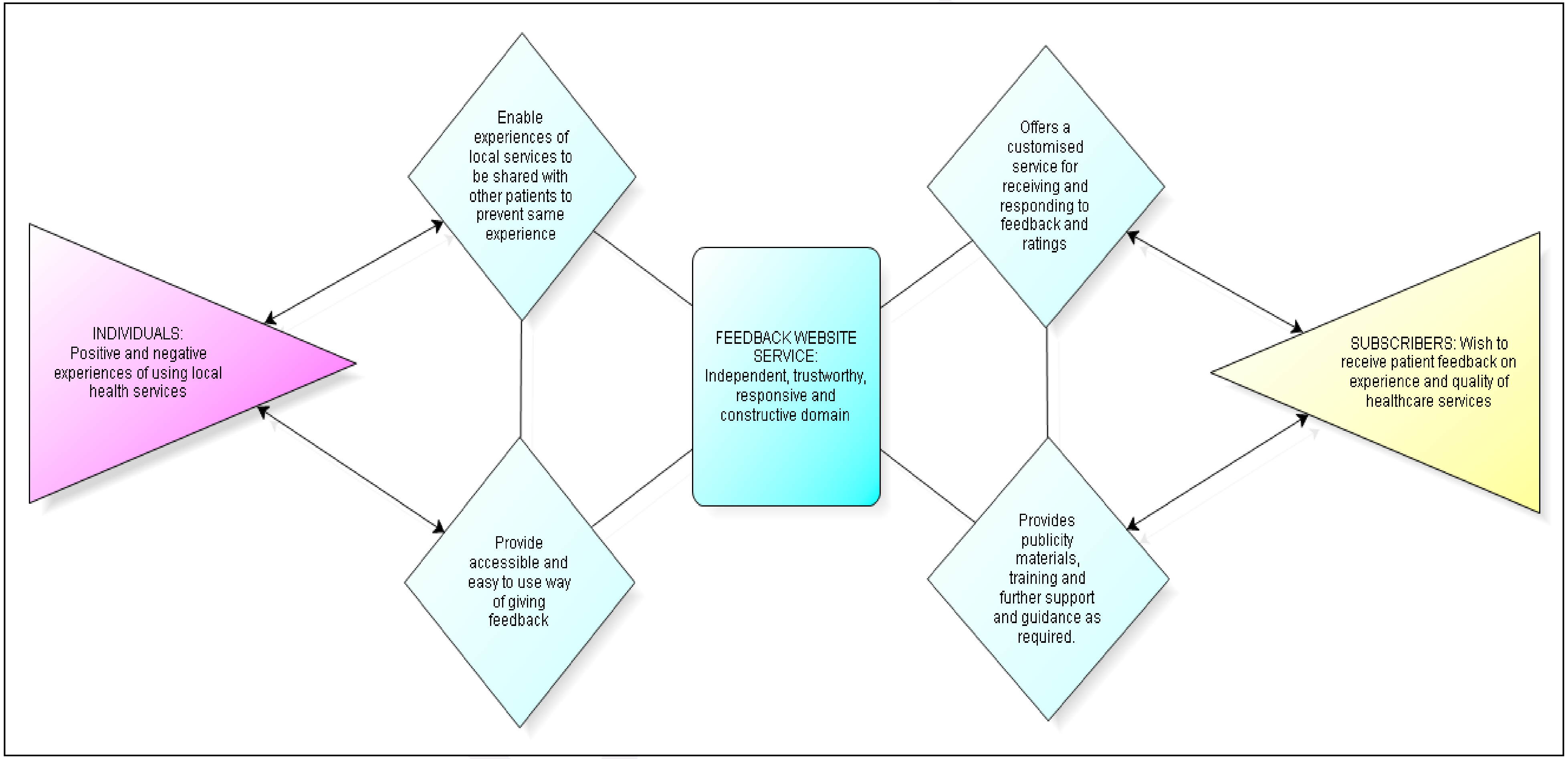
- Patients need an accessible and easy to use processes for feeding back experiences of services;
- Patients need an independent and trustworthy feedback process
- Patients want to share experiences with others and prevent their bad experience from happening again in the future.

3.3.4 Business model

When pulling together the various rationales for the service, Patient Opinion can be seen as a mission-centric social enterprise. Their business model is akin to a *market-linkage model*, facilitating transactions between the target population or "clients," (NHS subscribers) and the external market (NHS users). In this model, the social mission is the business, and income generated from enterprise activities (subscriptions) is used as a self-financing mechanism for its social mission. Patient Opinion is therefore more concerned with fulfilling its social mission than creating a profit.

Data for mapping the business model was obtained from the system analysis, Patient Opinion publicity materials and interviews with Patient Opinion and subscribers. This is depicted in Figure 1 below.

Figure 1: Patient Opinion's mission centric market-linkage model



3.3.5 Impact

"The overall aim is to make the NHS better... at the end of the day we want services' to improve."

Patient Opinion wants the patients to be heard by the NHS and for their comments to make a difference, by "*dynamically changing the way feedback is done."* When exploring this further, two important elements emerged from interviews with staff:

3.3.5.1 *Using a positive approach to enable hearing and learning*

One of Patient Opinion's Directors explained the importance of positive feedback as an incentive for change: *"we have a strong view about the need for staff to feel positive about their job and to feel that there is space and interest in them in improving the service, and for them to get the headroom to do that, they would need to have some sense about their own positivity and their roles. So in that sense I feel starting with the positive feedback and making sure that that gets through to staff ... most staff don't get any of that, they just know when they get hounded by the sister to help with responding to the complaint."*

The importance of being constructive was a strongly held value by other team members: *"We don't believe that any staff try to do a bad job. We validate good work and for bad work it provides an opportunity to improve the service."*

"We send out hard copies of positive feedback... we need to do this to persuade staff that that they are there to make good change."

"*We're in a beautiful position between the NHS and patients who give the gift of their opinion. We can think constructively about how to use the data.....we have to be a happy service for the NHS."*

They also felt their approach was important to counteract (a perception of) the prevailing culture in the NHS: *"...We're breaking down the blame culture. We struggle initially to show Patient Opinion isn't here to blame..."*

And that engagement and relationship was core to building trust between themselves and NHS staff: *"We are passionate about changing services but we have to swim through toffee to do it. Change happens when you engage staff. Usually the NHS tries to protect staff. Patient Opinion wants to engage staff through the use of the web... Relationship building is hugely important especially when bad news comes...."* and between NHS staff and patients: *"We want to see greater engagement between the NHS and patients, with increased openness, acknowledgement and contact."*

What is clear from this data, is while there are opportunities for *spectacular transparency* (McGivern and Fisher, 2010) as with www.iwantgreatcare.com Patient Opinion's values and beliefs means that they are not willing to exploit this as a mechanism for change.

We would conclude that the desired impacts Patient Opinion is looking to achieve is:

- To create conditions for learning[22] by recognising staff does a good job; and
- Patient feedback is heard and leads to improvements in the quality of care; and

and that there is an interdependent relationship between the two. This depicted in figure 2 below:

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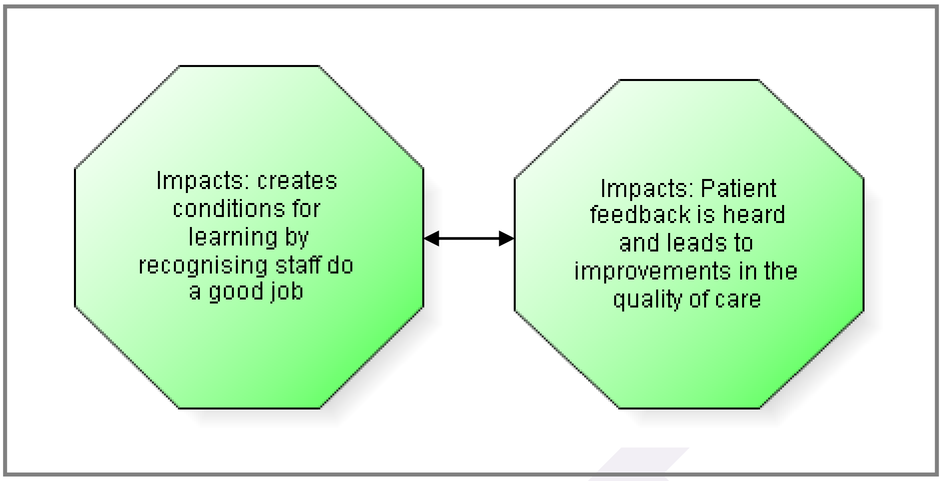
[22] Through engagement, relationship and positive feedback

Figure 2: Desired impacts



3.3.6 Outputs and outcomes

Data from the web site, the system analysis and staff focus group enabled us to map the outputs and outcomes that make up the component parts of the theory of change. This is shown in box 5 below:

Box 5: Outputs and outcomes

Outputs	Outcomes
Patient's story or feedback / rating of service is posted on the Patient Opinion (PO) web site.	Feedback can be categorized as: concern, review, story, suggestion, thank you or a tip.
Automatic acknowledgement of the posting is generated which also lets patient know that this is being looked at.	Patient's know their message has been received.
PO give post a criticality score[23], tag[24] , anonymise, and edit in line with their policy[25], sometimes adding grammar and punctuation to make postings more readable.	Moderated feedback that is 'acceptable' to PO, user and subscriber is produced.
PO publish individual's feedback on their web site.	Patient's experience/story appears in the public domain for anyone to see.
Subscribers receive email alerts when feedback has been given.	Patient's experience/story has been delivered to the health care service.
Subscriber responds (acknowledges feedback) in a timely and considered manner, sometimes asking for more detail.	Patients see that their message has been received and that the service is responsive.
Subscriber passes feedback to staff in relevant services, for a response.	Staff discuss the feedback and provide a response to be communicated to the patient.
Staff make changes in response to issues raised Staff are praised for their good work.	The quality of the service is improved Staff feel positive about their contribution.
Subscribers feedback changes made / appreciation, to the patient.	Patient can see that their feedback leads to change or appreciation from staff for praise.

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[23] 95% of posts are published but there are certain circumstances when PO won't publish a post e.g. highly sensitive cases, like a death.

[24] 'Tags' are available to subscribers so that they automatically cascade down to selected local services.

[25] editorial policy: http://www.patientopinion.org.uk/info/editorial_policy2

3.3.7 Activities

Patient Opinion's website is insufficient in itself, to achieve the intended impact. The key services it offers subscribers are essential to its success. These include:

- **A customised service:** to enable services to receive and respond to feedback about, and ratings of, services; and
- **Marketing, publicity materials, training and support:** To enable organisations to establish the service and make best use of the technology opportunities available to them

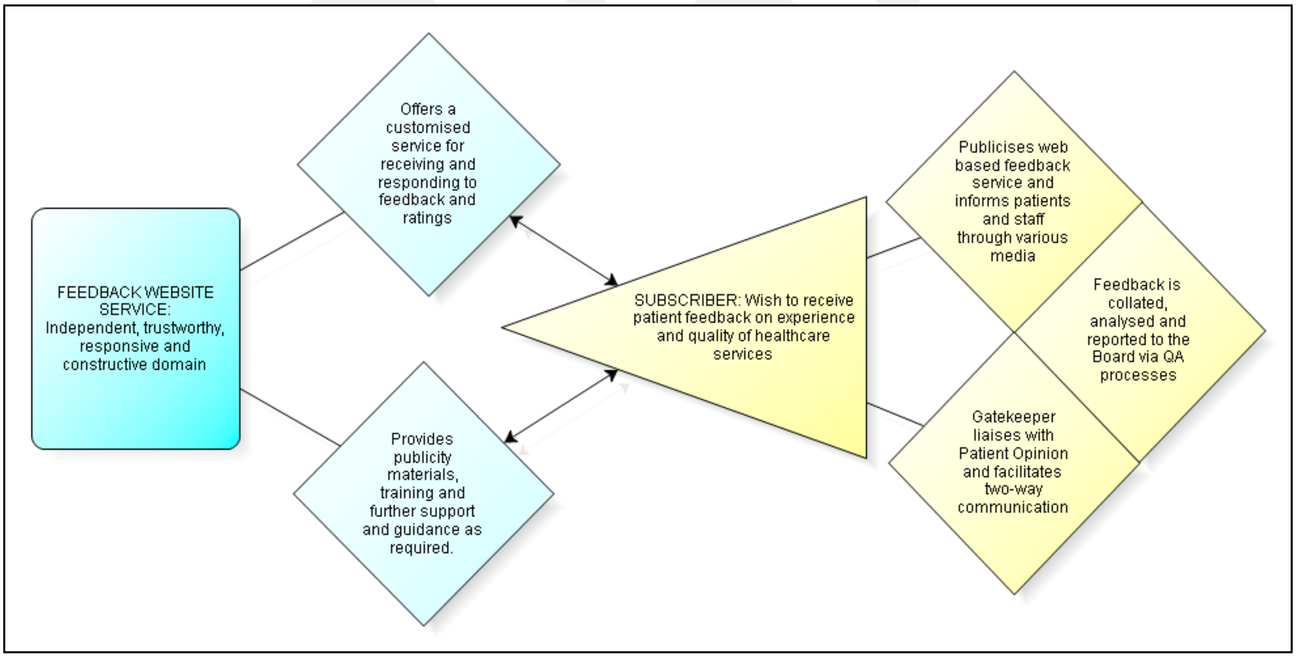
As Patient Opinion is independent of, and external to, the healthcare services provided, it doesn't have any authority to make changes *within* the NHS. This means that Patient Opinion is reliant on subscriber organisations to initiate a series of activities to engage services, the staff delivering the services and patients, to use and work with the feedback service, in order to achieve the intended outcomes.

The subscriber associated activities that are required to make the theory of change work include:

- **Publicity and promotion:** to let services, staff and users know about the facility;
- **Active agents:** at the boundaries of the different systems to champion and manage the process of using the feedback internally and externally;
- **Embedding feedback data:** gathering, collating, analysing and reporting feedback data alongside other quality improvement data to staff, directorates and the Board.

These activities are depicted in Figure 3 below:

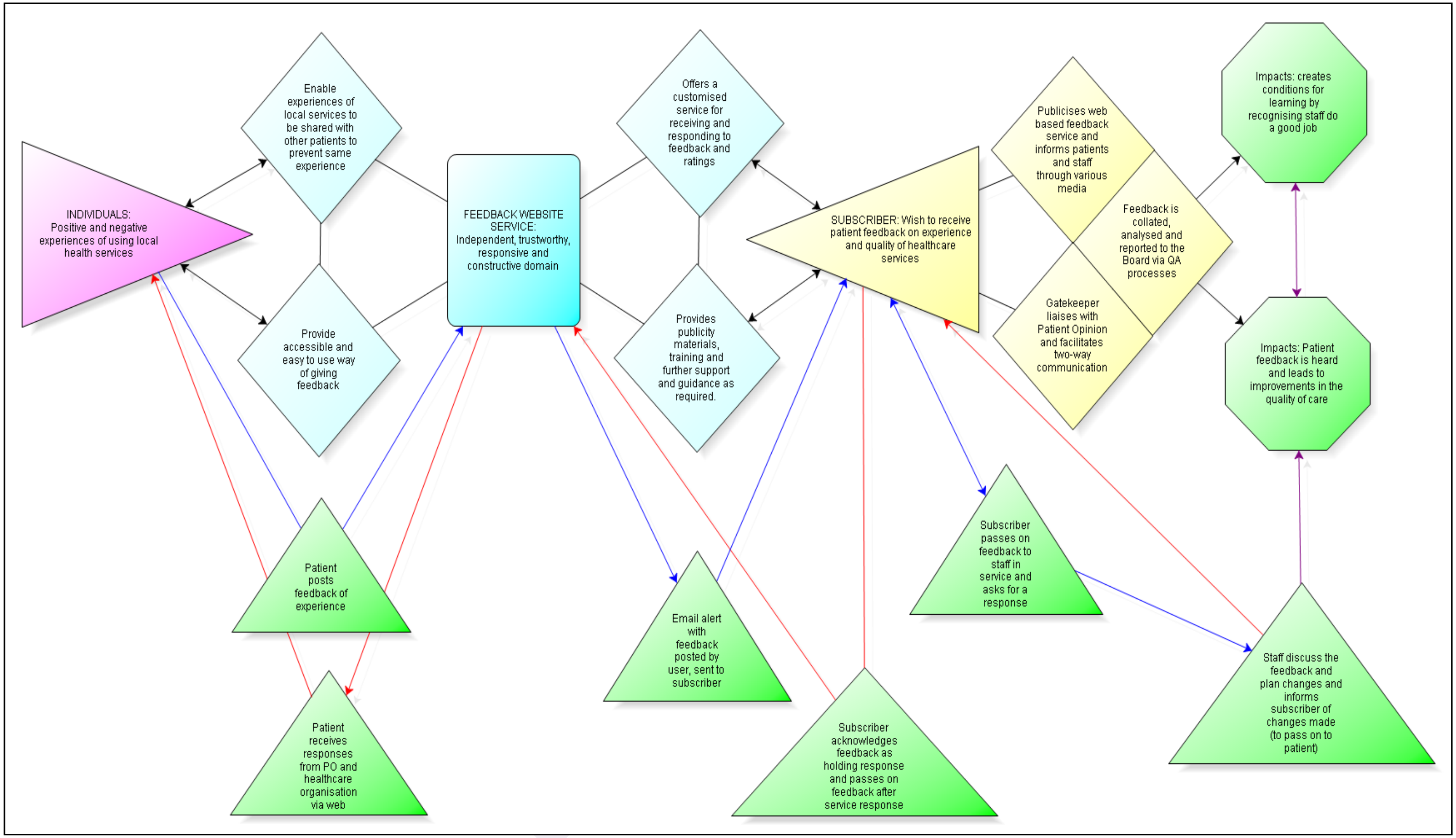
Figure 3: Patient Opinion and subscriber generated activities to achieve impact



When each of the component parts so far mapped out, are put together, the casual pathways can be seen. This then provides a guide to the subsequent assessment as to whether the process and impact were broadly consistent with those anticipated by the theories underlying the Patient Opinion service model from three perspectives – patients, subscribers and Patient Opinion

The theory of change map is shown below in figure 4:

Figure 4: The Theory of Change of Patient Opinion's Service Model



3.4 Actual experience of using Patient Opinion's service model

3.4.1 Case study site sampling

For the overall impact evaluation, we needed to track feedback from the point of posting by a patient through to its reception in the subscriber organisation and any subsequent actions taken.

Following the on-line and telephone survey[26], 17 patients consented to follow up interviews. 'Type of posting' was used as a sampling criteria. We needed to include both *concerns* to test whether patient feedback is heard and leads to improvements in the quality of care, and *thank yous* to test whether patient feedback creates the conditions for learning, by recognising staff do a good job.

A *purposive sampling* (Bryman, 2004) approach was taken for selection of the case study sites. Resources and time allowed for five sites to be selected from the totality of subscriber organisations available (10 patient's feedback to follow-up); criteria for selection included:

- Organisations to whom feedback had been given, by patients who consented to take part in the study;
- A range of types of subscriber organisation e.g. mental health, acute, commissioning;
- Subscribers who had established the feedback service and had been operating for some time; and
- Subscribers who were known by Patient Opinion to be responsive and actively used the service.

Of the five sites selected, one site declined participation as they felt that the feedback service had not been used sufficiently, and one site although initially consenting to participation, was not able to take part due to a demanding Foundation Trust application process that took up all their time. Of the three remaining, one was an acute trust and two were commissioning PCTs. As there had been a protracted process before the second Trust pulled out, time was running out so we revisited the list of subscriber organisations and selected a mental health trust.

As patients in the newly selected fourth site had not participated in the on-line and postal survey, we worked with the Trust to seek volunteers through the user forum. Three came forward. In total we tracked the feedback of 8 patients across all four sites.

Four case study sites were initially visited and core staff interviewed including:

- Patient Opinion lead role/gatekeeper
- PALs Manager
- Complaints Manager
- Director responsible for Quality Improvement
- Clinical Director (not all sites)

Once patients had been interviewed, we then conducted a series of follow-up telephone interviews. staff interviewed depended on the feedback issue being tracked, so was not consistent across all sites, but did include the Patient Opinion lead role/gatekeeper; manager and staff of the service concerned and in some cases the Head of Communications.

Below we first explore findings in relation to the issues the service seeks to address, before discussing the impact assessment which compares the actual outcomes and outputs and the activities that were designed to achieve the impacts against the theory of change. Then the desired

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[26] An on-line and postal survey was sent out to 1236 people. Group A - people using web between 1/1/2009 and 30/9/2009 who gave an email and consented to contact = *1136 people;* and Group B - people posting in the same period who gave a phone no but no email = 100 *people* . Number of responses N=500 (40.45%)

impacts, the service rationale and business model are discussed in light of these findings.

3.4.2 What the service seeks to address

Here we examine the three areas that were identified in 3.3.3.3 above:

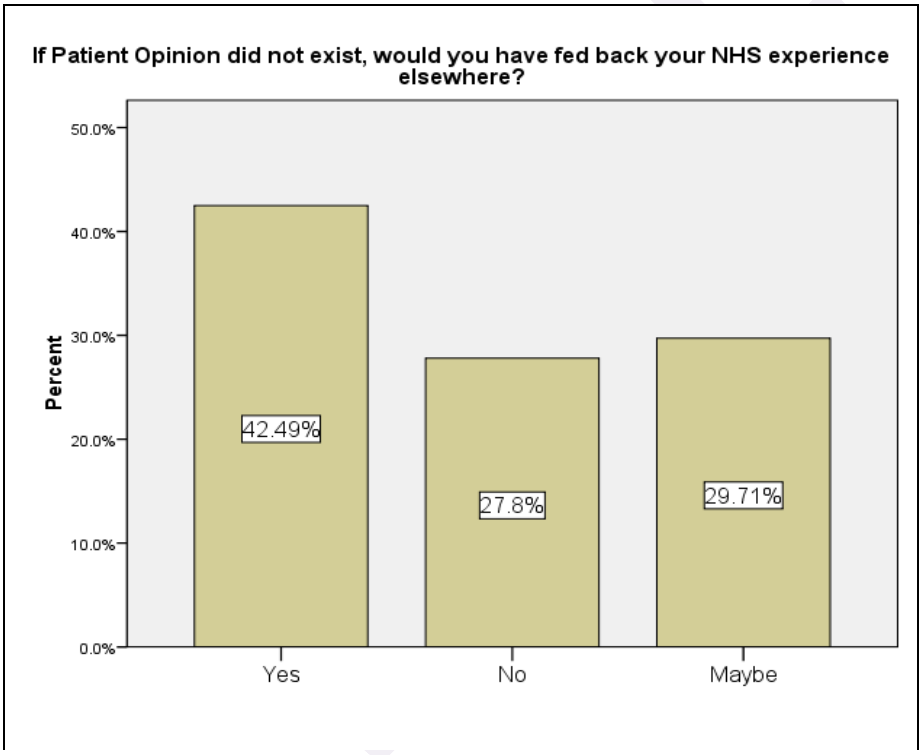
- Patients need an accessible and easy to use processes for feeding back experiences of services;
- Patients need an independent and trustworthy feedback process;
- Patients want to share experiences with others and prevent their bad experience from happening again in the future.

3.4.2.1 *Accessible and easy to use process*

Despite the average age of patients using Patient Opinion being 55, survey findings showed that Patient Opinion's web-site is easy to access, use and navigate.

The survey also showed that for 27.8% of participants, Patient Opinion is meeting a need that other services are not providing.

Figure 5: Using Patient Opinion for feedback



3.4.2.2 *Responsiveness*

Nearly 53% of those who posted feedback received a response[27]. Of these, survey findings showed that responses were usually quicker than expected with just under one third quicker or much quicker than patients expected.

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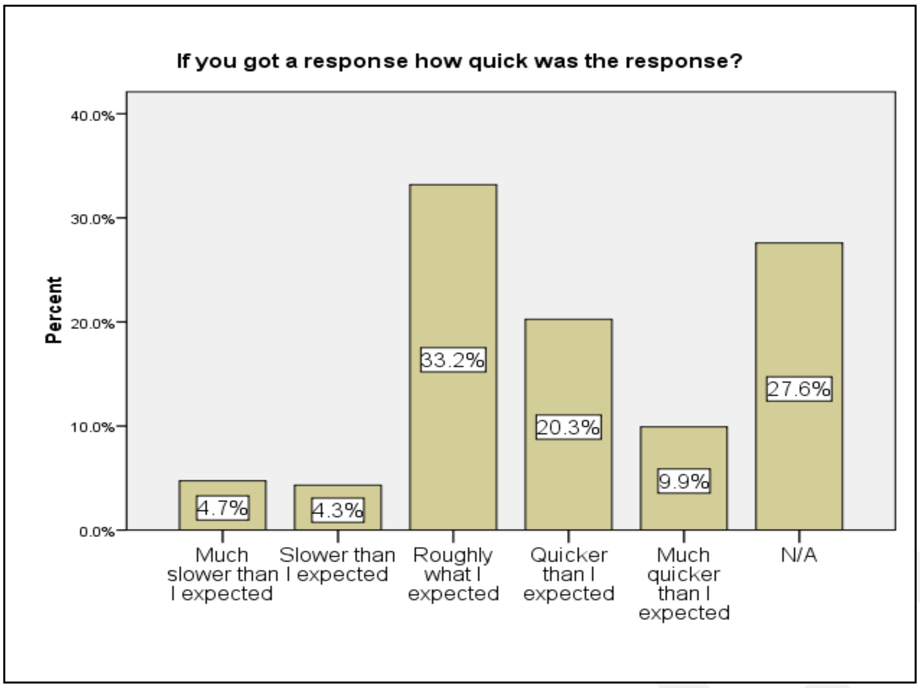
[27] A number of postings were made to healthcare services who were not subscribers to Patient Opinion and who did not respond, despite being given the opportunity free of costs.

Figure 6: Speed of response



Subscribers when comparing Patient Opinion to other providers were clear about the speed of the service:
“ Patient Opinion captures experiences in real time. NHS Choices often has no responses after a year!”

A sorry indictment of NHS services was that both the survey and some of those interviewed showed that patients generally did not expect a response. Survey results show that only 37% of participants who were 55-65 years of age did not expect to get a response and 21% of those didn’t know a response was possible. This experience was reflected in interview:

“I didn’t expect a response so was happy when I received one...”

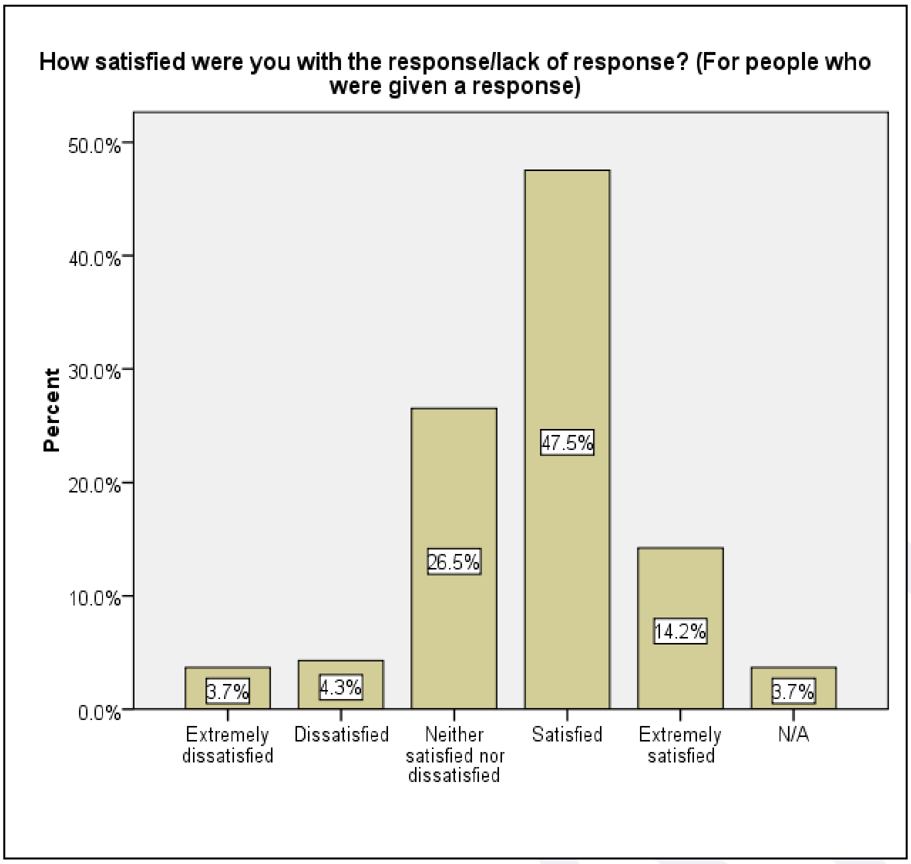
Having said this, it was pleasing to find that there was a good level of satisfaction with the responses received, with 61.7% satisfied or extremely satisfied.

“ I was very satisfied by the response. I hadn’t expected a response.”

“ Thought they’d have gone ‘we’ll do the best we can’ but I was surprised that they’d gone to the people involved, I was shocked really. Normally you get a stock response.”

“I got a response the same day or the next day. I wasn’t expecting it. It was a surprise. I was glad that my feedback had been passed on. It made me happy”.

Figure 7: Satisfaction with responses



3.4.2.3 *Independent and trustworthy*

The independence of Patient Opinion was strongly supported by patients:
" I read up on Patient Opinion first. Independence had a something to do with why I used it."

" It is good that it is independent. Even the Advocacy Group has an office outside of the hospital."

"Long may it continue! Seriously, the independence is critical, it's vital. If the NHS started funding it, it would very quickly lose its independence."

One subscriber also felt that independence gave more credibility to the feedback process: "*...we always held that Patient Opinion had more credibility than NHS Choices as it was independent..."*

Patients alluded to issues of power, truth and honesty when discussing Patient Opinion's independence:

" I am not keen on PALS as it is controlled by the NHS. "Patient Opinion is good as it is independent unlike PALS. Patient Opinion gets true facts, studies facts and can act on them."

" It is good that it is independent...this is how it should be. I want it to be honest. It will be more honest if it is independent."

Three patients talked about the relationship between complaining and the fear of possible retaliation, or that it would affect the care provided:

“...users are often nervous about complaining. They don’t want to make things difficult for themselves and be victimised.”

“I think it is good that it is independent- you can say what you think without worrying about the service telling you off.“

“I thought, if you complain about your treatment it might prejudice your care and that was quite disempowering.”

If you do made a complaint you are discriminated against. You’re treated much less kindly by nurses as a result of past complaints.”

Central to the findings around independence and linked to the theme of retaliation, was the importance of anonymity:

“... I like that you can make up a name on PO and that it is anonymous. I am <u>not</u> *worried about who sees my PO post as it has no names on it. “No names and it is alright. I would be worried if they asked you for your name and address...”*

“ I would not ring the Centre up to give feedback but I’m not sure why. I think that it maybe because that is not anonymous, whilst Patient Opinion is.”

Some were similarly concerned about anonymity for clinical staff: “...i*t is good no names are mentioned on it, as that wouldn’t be fair to your doctor...”*

The Mental Health subscriber understood this because of patients often had strong feelings about mental health services and therefore staff:

“ Staff can reply anonymously- so they don’t have to feel worried about come back, as many people have very strong feelings about mental health services. I don’t think that it is a problem that Patient Opinion is anonymous.”

They also valued the moderation offered:
“ PO is a great way to capture patient’s stories. NHS choices is not set up well for mental health patients as we have to moderate it ourselves and we don’t have the time. We trust PO team to moderate the posts.”

“Staff can sometimes have a fear of unedited forums, as they see them as having biased opinions, lobbying information and no context. But Patient Opinion invest time and energy into stopping this from happening (editorial policy and team). P sees it as important to inform his staff of this to destroy the “fear”. The Patient Opinion editorial policy is seen as <u>*so vital*</u>*”.*

The importance of anonymity is supported by findings from the comparisons analysis[28], which suggests that it is important that people don’t have to authenticate who they are; just being able to give feedback is central to what makes it work. Patient Opinion staff recognised this:

“People divulge more when it’s anonymous”

Key to Patient Opinion’s values is not to publicly identify either patients or staff. However, findings suggest that subscribers find it difficult to progress a complaint through Patient Opinion when patients remain anonymous.

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[28] Appendix C

" Since the postings are confidential, we can't follow them up directly with the person making the posting."

"Staff could see the anonymity of Patient opinion as a barrier if something happened in their service and they do not know who was involved."

Patient Opinion say that they have a difficult interface with subscribers at times, because of anonymity:

"We ask them not to put their real name and we don't publish their email or postcode... but [subscribers] get very cross about it. They quite often would like to identify the patient though can't, so a lot of the responses on patient opinion are along the lines of we are so sorry this happened, without further details we can't help you and do anything about it, please would you rings PALS and let them know which ward it was and who was on duty"."

3.4.2.4 *Share experiences and prevent bad experiences from happening again*

There was some evidence that patients wanted to raise concerns about their treatment and prevent that from happening again:

" I Wanted other patients to be aware of the fact that the care I received was well below what I was expecting ... felt a great deal better for getting it off my chest. Hospital may ignore it but other people will see it at least."

" I used Patient Opinion coz I was concerned about my treatment and what others may receive...mistakes have been made and they need to be rectified ... I don't want others to face what I faced."

"I am bothered about others. Others matter to me." Providing feedback also seemed to have a positive psychological impact on the individual: *"I feel more positive about the NHS. I just wanted to help others, it does not matter who they are. I was brought up like that."*

A number of patients used other people's feedback and rating to check on hospitals to inform their choice:

"Before the surgery I did some research, I did a Google search on 'x' hospital and Patient Opinion came up. So I looked at other people's stories on the hospital."
"If I need further surgery the Patient Opinion website will help me see if I will use a particular surgery. I can see which one is the best."

" I know several people who've used it. Three people actually posted comments as they chose where to go as a result of Patient Opinion."

We also found that people liked to share their positive experiences:

" I wanted to give feedback so that others would realise how good my experience was.. I told my friends and family via emails but wanted more people to hear my story.....I chose the web as more people would see my experience."

Two patients were pleased to have been able to publicise their good experiences and give praise:
"It was good as I had done what I wanted to do. It got to people involved and they were grateful".
"I like how Patient Opinion shows good and bad stories…it is important to say thank you to staff. Overall, they do a good job and are improving".

This is congruent with encouraging positive feedback as a way of engaging and enabling staff to learn; findings from the comparisons analysis suggest that building a strong community of website users motivated to help other users, and with the expertise to do so is central to this approach.

Another talked about the importance of story-telling:
"*PALS is not out there and is about statistics unlike Patient Opinion, which is about your story and experiences. I like how Patient Opinion has free entry text so you can tell your story.*"

From this analysis we might conclude that the issues the service seeks to address are:

- The need for an accessible, easy to use and responsive process for feeding back and telling stories of experiences of services;
- The need for an independent, safe and trustworthy process for feeding back experiences of services;
- The need for a constructive and non-confrontational process.

3.4.3 Impact assessment

In these last two sections of chapter 3, we examine in detail the actual experiences of service users and staff to see if feedback leads to quality improvement.

3.4.3.1 *Outputs and outcomes*

Using a RAGs[29] system, we are able to show those areas where theory and practice differed.

Box 6: Actual outputs and outcomes

Outputs	Outcomes
Patient's story or feedback / rating of service is posted on the Patient Opinion (PO) web site.	Feedback can be categorized as: concern, review, story, suggestion, thank you or a tip.
Automatic acknowledgement of the posting is generated which also lets patient know that this is being looked at.	Patient's know their message has been received.
PO give post a criticality score, tag, anonymise, and edit in line with their policy, sometimes adding grammar and punctuation to make postings more readable.	Moderated feedback that is 'acceptable' to PO, user and subscriber is produced.
PO publish individual's feedback on their web site.	Patient's experience/story appears in the public domain for anyone to see.
Subscribers receive email alerts when feedback has been given.	Patient's experience/story has been delivered to the health care service.
Subscriber responds (acknowledges feedback) in a timely and considered manner, sometimes asking for more detail.	Patients see that their message has been received and that the service is responsive.
Subscriber passes feedback to staff in relevant services, for a response.	Staff discuss the feedback and provide a response to be communicated to the patient.
Staff make changes in response to issues raised Staff are praised for their good work.	The quality of the service is improved Staff feel positive about their contribution.
Subscribers feedback changes made / appreciation, to the patient.	Patient can see that their feedback leads to change or appreciation from staff for praise.

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[29] **Red** where there is little evidence to show that the desired outcomes and outputs are being achieved; **Amber** where practice is inconsistent; and **Green** where the theory of change and findings are the same or broadly similar.

Overall, the table allows us to see that when Patient Opinion were responsible for outputs – the first five steps in the process – they were found to be working effectively and the outcomes positive. However, when the responsibility for outputs shifted to the subscriber organisations, we found that in the main, practice was inconsistent or that there was little evidence to show that the desired outcomes were being achieved. These are discussed below in more detail.

Subscriber responds (acknowledges feedback) in a timely and considered manner – patients see that their message has been received and that the service is responsive

The practices of responding to feedback varied. There were some that were broadly consistent with practice in the commercial sector:

"I like to always send a holding post as soon as possible."

"We try to respond in two days and follow up. It's important that the patient feels listened to."

Some try to immediately but recognise there are times when this is not the case, but still ensure that it is done within the week received:

"Pretty much instantaneous. Never more than one week, whatever it is."

But not all the case study sites automatically responded to feedback:

"*There are no set deadlines for responding to posts."*

or thought it was necessary despite training from Patient Opinion. They suggested that:

"*feedback did not always require a response"* and *sometimes we wait until the service gives us a response before we get back to them..."*

When we asked the staff member how the service user would know their feedback had been received by the organisation, they realised that no immediate response could lead to a number of assumptions including that the service wasn't doing anything about the feedback.

It was encouraging to see that they changed their practices immediately after the interview to include a holding response.

Responding to posts was also complex, took more time and needed to be sensitively handled where the subscriber was the commissioner but the service being discussed was run by a provider that was not a subscriber:

"For providers who aren't subscribers we respond to all. They do sometimes take quite a while."

"On some things it can be quite contentious between commissioners and their providers so we try to keep the working relationship between ourselves and the comms. people good."

There were a few examples of services asking for more details in their initial responses:

" Thank you for taking the time to share your story. I am very sorry to hear that you had problems with .... and that you had to wait to see the nurse who had done your test. If you would like to discuss your story in anymore detail please do not hesitate to contact the Patient Advice and Liaison Service (PALS) on freephone..."

and that patients did not necessarily like this:

" I did a response from my second post. The public representative person replied and asked me to call PALS to give more information on my post, but I don't like PALS so didn't."

Subscribers pass feedback to staff in services for a response - Staff discuss the feedback and provide a response to be communicated to the patient

There was some publicly posted responses from subscribers to state that concerns and thank yous were passed on to service staff to respond to and take action:

" I want to assure you that the .... process has been reiterated to all staff in the relevant areas to prevent this situation occurring again."

"Thank you for taking the time to share your experience at .... I shall pass your comments onto the staff who provided your care / treatment. Thank you once again..."

" Thank you very much for your comments. We are pleased to hear that you have been listened to as a carer and that new ways of working have enabled the referral to the ... service. We will pass your comments on to this service and hope this proves to be a positive experience for your son and your family."

"At the Band 7 meeting we encourage the matrons to discuss the feedback."

Although the survey showed that more positive feedback received responses than negative feedback[30], visits to the case study sites differed to this. Where feedback was negative (complaint or concern), it was acted upon more often than positive feedback:

"I replied straight away and then I passed the post onto the General Manager and the Modern Matron. They acknowledged the post but did not react to it. Compliments often get less of a response and a slower response. I had to push for responses from staff but this is improving. Now more staff are subscribers and responders."

One of our researchers recalled another example:

" She did however observe that one limitation – in all their patient feedback systems – is that they respond to complaints and shortfalls, but don't really make as much as they could of complements and patient observations about good practice – which they could seek to generalise to elsewhere. This is something she thought they could do more of in the future."

It may be the discrepancy between the survey results from users' experiences and staff experiences in interviews, is that those responding to posts said that they would pass the feedback on but may not have acted upon that.

We also found that responses were possibly provided by managers before feedback was passed on to teams:

"As it's positive [feedback] he might have just said thanks."

Other accounts also pointed to responses coming from managers:

" I wish to apologise that this was your first experience of ... services. The ... (service) which has been in operation for the last few months, is designed to provide a swift and efficient service as possible ... what should have happened when you telephoned is that your details were passed onto your team of ... (clinicians) who would then have contacted you to arrange a consultation.

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[30] Postings data showed that a number of complaints were made about services that did not subscribe to Patient Opinion which might be one explanation for this finding.

I want to assure you that the process has been reiterated to all staff in the relevant areas to prevent this situation occurring again. I hope that you feel you are given every opportunity to communicate effectively with everyone involved in providing your care. If I can be of any assistance then I would be happy to help. Please contact me ...”

In some cases, cascaded email alerts were deleted or ignored:

“ The staff respond most of the time, but sometimes they do not read my email or delete it because they do not understand what Patient Opinion is (especially if they are very busy and in a powerful position). I have to be careful how I write my emails to get them to open them. Sometimes I put the subject as “don’t delete this”!

and in other cases, getting an organisation to take responsibility was complex:

“There was one that D sent which confused me as it was about the ... (service) which is run by the hospital though it was labelled as us (commissioners). So I sent it to the Communications Lead. They sent it back saying it’s nothing to do with them but then the Communications Lead for the whole of the area programme actually emailed her and our comms lead after noticing it was on Patient Opinion and said what are we doing about this? Anyway they’ve since posted a response.”

Sometimes, commissioners don’t keep track or follow-up as part of their commissioning role:

The Acute Trust don’t have a Patient Opinion subscription so we sign post feedback to them. That response was from the Acute Trust. Maybe we sent a holding response too, I can’t remember. I don’t know what was done as a result of the feedback, we don’t generally call them and ask what happened.

Data showed that there was a good deal of liaising between the centre and services about responding to feedback. In the main there tended to be more activity of this nature related to concerns or complaints, because the response would be seen publicly and potentially reputationally damaging:

“There is a danger that Patient Opinion could become about a single issue i.e. about closing a service. People may use PO for media reasons and petitions. We do not want this. There is a danger that it could be a campaign tool. This may sew the public’s opinion of the Trust ... [there is a] danger of Patient Opinion being used for tit for tat and people responding again and again; air our/their dirty laundry. This could escalate. There needs to be a dialogue and ask the person to come and meet staff if they keep on replying. But then they will not be anonymous.”

“ It’s so high profile as people’s comments will sit there for years to come ...from a communication’s point of view as there could be a dialogue with a person just continually slagging off the NHS!...”

“ If the post is clearly a complaint then we would post a reply with our telephone number and the Complaint team’s. We would encourage them to call us. We cannot play it out on the internet- it is a balancing act- Patient opinion wants to be open but not a chat room. Patient Opinion is not a complaint service. It is really clear that there is a distinction between complaint and feedback. It does help that they moderate the posts and they can get in touch with us. They give us advice on how to deal with posts.”

In almost all circumstances, the final wording of responses was checked by the Head of Communications or from designated senior people:

"The Communications Manager tries to make a corporate response with everyone. She's a moderation process."

"At the moment the three official responders are myself, Head of Involvement and x (Patient Opinion link person). We know how to respond as we have corporate awareness and Patient Opinion training. We need to protect our reputation. The responses are from service managers but we look over them and send them to Patient Opinion."

Staff make changes in response to issues raised / Staff are praised for their good work The quality of the service is improved / Staff feel positive about their contribution

Subscribers feed back changes made /appreciation, to the patient - Patients can see that their feedback leads to change or appreciation from staff for praise.

Senior management were clear that positive feedback was motivating and reduced fear in staff:

"Compliments are easier to handle than complaints. It is good that Patient opinion also shows compliments as it can help decrease staff's fear of Patient Opinion. If they receive compliments then they will stop worrying about Patient Opinion and see that it can help them. It does help that Patient Opinion is anonymous, as many staff and patients would be nervous about their details being on the internet."

"Staff definitely like to get positive feedback. If you get positive feedback from an independent site it gives it more cache."

There were a number of examples of responses from teams about changes or appreciation:

"Yes, a draft leaflet on the Mental Health Act has been drafted and circulated to the Advocates for comments. "This is a good step to take..."

"I received a holding response from the Involvement Team. It said that they had received my post and would pass it on to someone. A few days later a reply came from the Acute Care Team, who said my suggestion was a good idea".

But positive feedback was not always formally communicated:

" For a positive one I just say can you make sure this gets to the right person....when sending it I will say this person is being very complementary can you let them [staff] know."

There were a few examples where the initial responses included information about the changes made, but actual changes to the processes were not able to be substantiated. At times, assumptions were made by patients that action had been taken:
"I think that changes were made due to my feedback but I don't know ... they have taken notice, they have listened and this will help the doctors".

"There is no other mechanism. No change, if I was to be cynical. But I will say yes, as it is the only mechanism I know. I don't believe PALS can achieve anything".
And some where patients perceived changes would not be made or needed to be made:
"No, not really."

"I don't think there would be any changes as my feedback was saying thank you. I did not want them to make any changes. I just wanted to let them know that I found the service good."

What had not been anticipated, but is obvious when looking at the literature, is that giving both positive and critical feedback had a positive impact on patients:

"It was good as I had done what I wanted to do. It got to people involved and they were grateful".

"Glad I posted. I just hope that they get on with my suggestion".
" I just feel better for doing it".

"I feel more positive about the NHS."[as a result of posting feedback]

From these quotes, we can see that praise does have a positive effect on and responsiveness from, staff and that is evident to patients in some of the examples. However, this was not a consistent finding across all sites.

For evidence of change, it is important to differentiate between the *intention* to make changes and actual *actions*. The literature shows that one of the biggest gaps in relation to service user feedback is use of that feedback to make a difference (impact). There was some evidence of actual changes and a responsiveness from services, however, much of the evidence seemed to fall within the *intent* category, as it was hard to substantiate whether changes had actually happened. This was mainly down to difficulties in data collection; speaking with the staff involved or seeing hard evidence of change.

3.4.3.2 *Activities*

As discussed in 3.3.6 above and depicted in figure 3 (p42), the associated activities that are required to make the theory of change work include:

- Patient Opinion provide:
- A customised service: to enable services to receive and respond to feedback about, and ratings of, services; and
- Marketing, publicity materials, training and support: To enable organisations to establish the service and make best use of the technology opportunities available to them
- Subscribers provide:
- Publicity and promotion: to let services, staff and users know about the facility;
- Active agents: at the boundaries of the different systems to champion and manage the process of using the feedback internally and externally;
- Embedding feedback data: gathering, collating, analysing and reporting feedback data alongside other quality improvement data to staff, directorates and the Board.

Findings in relation to these areas are explored below.

A customised service with training and support

Interviewees and participants at a regional conference spoke very positively of their experience of the bespoke and responsive approach, and capacity for support, provided by the Patient Opinion team:

"Anything, they're so supportive. The mental health trust asked for help and Patient Opinion said they'll help in any way that you want. Patient Opinion were really reassuring, said they'll answer any queries – it's a very bespoke support, they go over and above."

"For the subscription you get unlimited support, the packs and reports..."

" I was impressed with PO. They are very responsive and very willing to help. They are willing to go the extra mile...they are a small organisation who are willing to go the extra mile."

Interviewees also commented on the team’s ability to engage service users:

“ PO held a workshop..for service users. Some people made a post at the event. The users were extremely responsive to PO ... PO are very responsive and very good ... their training is excellent.

“ [The] Patient Opinion workshop was brilliant. Absolutely brilliant. People wrote posts there and then. One man posted and got a response. He wrote a response as he was still not happy. The Modern Matron then took his ideas to the Acute Care forum...”.

But there was a question both with subscribers and the team themselves about capacity if the feedback mechanism grew:

“How will they evolve if they do get more posts?”

“If we got a lot more posts- how would we evolve? [perhaps] we would be more confident in using Patient Opinion by then.”

Training and support on practical issues to do with setting up the service and how to use it was also reported very positively, with advice received on marketing; how to respond to feedback; and responsiveness:

“We had an initial meeting ... and a training session in how to use and respond to feedback. L felt she had had a lot of support from the team – by phone mainly or e-mail – on how to market the service and how to respond to difficult postings.”

“ Patient Opinion came to do a workshop here, they were brilliant, they were really good. Initially they came to us on how to access the site – everyone, including practice managers. We’ve got access to Patient Opinion and then they did training on how to articulate a response as the response is less formal than a complaint. They told us how best to get use out of Patient Opinion. The comments are a mix of compliments and concerns. The immediacy is important too. The patients don’t want to give a complaint. Patient Opinion helped us to focus on practical usage. We even found out that as a patient you could do a pdf report on the local services.”

A couple of interviewees were less engaged or enthusiastic, either because two-way contact had been sparse or because their needs were perceived as not being addressed:

“ I’ve not really had many dealings with Patient Opinion – only when you mislabel things. K just passed on the user name and password.”

“ I actually went to a presentation a few months ago in Manchester ...it was an interesting event. There wasn’t much from a commissioner’s point of view, but it was good that they want to get people together and good from a networking point of view.
There’s more to be said from the commissioner’s perspective, looking at how other commissioners use Patient Opinion.“

Marketing and promotion (Patient Opinion)
Promotion of Patient Opinion to the public involves two sets of activities:

- General profile raising activity led by Patient Opinion
- Supporting local or service-specific activity led by the subscriber

General profile raising activity led by PO happens in two ways:

Online: using the internet to link in with the public in other web-based locations for example Google AdWords, Twitter, Facebook and blogging. The organisation also creates links from subscribers and others'websites through use of their widget. This is their logo that is placed on a subscriber's website which when clicked, will take you straight to the Patient Opinion web site:

In addition, they focus on *search engine optimisation* – making sure that when the public are looking for somewhere to feedback their experiences of services, the Patient Opinion website will be offered by the search engine used.

Offline: promotion through other media for example, Patient Opinion issue press releases which aim for press and online coverage. The Team speak at events and recently have started relating to broadcasters and are building a relationship with Embarrassing Bodies. Example of Patient Opinion's press coverage can be found at: http://www.delicious.com/patientopinion

Supporting local or service-specific activity led by the subscriber is available through postal, phone and web-based feedback routes. Patient Opinion provide advice, guidance and help in using promotional resources and linking to their widget builder. They provide a starter pack of such materials to organisations at the start of their subscription. They also have a range of materials that are available via their web, which can be printed off by subscribers on an on-going basis, for example:

- print materials: http://www.patientopinion.org.uk/info/print-materials
- postal leaflets: http://www.patientopinion.org.uk/info/print-our-feedback-leaflets
- widget builder:http://www.patientopinion.org.uk/widget

In terms of take up and use of this publicity:
"we find it can take quite a while for subscribers to engage practically with this - but when they do (and when they follow our advice) they do usually get predictable steady streams of feedback. Often they have their own views on how this should be done - sometimes these are effective, sometimes not.."

As discussed in the systems audit in section 3.2.2.3, Patient Opinion is effective in marketing itself on a national stage and with the with the digital community However, it is less clear what publicity and promotional activity takes place in media that might be seen by patients or staff interested in using the website, for example local newspapers and radio, hospital radio, library news, Trust newsletters, via health professional networks, and patients groups.

Patient Opinion do not have a large budget for publicity, so provide support to help subscribers think through their marketing of the feedback service, how to engage service users and staff, and sometimes attend subscriber events to help promote patient opinion in subscribers services. Patient Opinion are clear that they see subscribers as having *contractual* responsibility to promote the feedback service in their organisation:

"*It's the organisation's responsibility to promote Patient Opinion...subscribers have the responsibility to disseminate the data ... It's their area, they know what works best etc. We've never had the budget to do sales campaigns. We're always at them but not as a huge marketing plan."*

Publicity and promotion (subscribers)

When exploring this ‘contractual obligation’ across the four case study sites, we found a range of practices from those that were very engaged and proactive, to those that were initially engaged but overtime were less active, to those that either did very little or nothing to promote the service.

For one PCT, who were very engaged, they worked hard to roll out the feedback service across the services in their patch:

“ I started with 4 GP practices and 4 health centres in a similar geographic area and Patient Opinion worked with these practices (by phone) and encouraged them to take up the information packs. This year we have rolled this out across the city. I had a meeting for locality support managers (who manage health centre buildings and reception staff), then did a distribution of information. We bought 5000 marketing packs.”

A mental health trust used a range of activities to promote the service:

“The Involvement officer emails all staff and tells them about Patient Opinion. We hold workshops (more in future) where service users and involvement members attend. The Involvement Leads promote it in their Departments. Articles have been in the Positive Magazine (to service users and staff)...”

This contrasted with a PCT who admitted that they are doing little to publicise the web-based service:

“ We could do more to promote it, particularly with contractors – at the moment we are a kind of a post box for the acute trusts – picking up their postings and passing them on. It could possibly be built into the contracting with these that they have a subscription but this hasn’t been discussed so far.”

The low levels of subscriber marketing and publicity activity was mirrored in interviews with conference members:

“ They wouldn’t find out from us currently, there’s a link on the website, just have a logo. Not many members of the public look on their own PCT website. So it’s wouldn’t be a great source of feedback. As commissioners we haven’t done too much promotion.” “The promotion of Patient Opinion is weak at the moment...”

For some of the sites, while there was excellent initial engagement and publicity by both Patient Opinion and the subscriber, supported by training and development, this was not on-going, and seemed to tail off; reportedly due to the lack of resources e.g. leaflets, time:

“numbers go up after they have done a promotion.”

“we have a slow trickle and then sometimes a flurry (after Patient opinion workshops)”

“...Sense of tailing off... we signed up and had a lot of corporate buy in and [the acute trust] also subscribed and we did a lot of publicity. We got approached by others asking how we got so many. NHS alliance still do a lot of publicity and the provider arm do too. As commissioner’s now we’re not doing much. Because of lack of resource really.”

Patient Opinion felt that it was also about attitude:

“ It’s the procedural mentality again, they believe that once the box is ticked…”

For some subscribers, it was a matter of building knowledge about and trust in, the feedback service:

"The more staff know about it [the service] the more they will use it and respond. This will happen by word of mouth, my emails and the workshop ...we will need more PO workshops for the staff."

"We need to raise awareness, staff need to know it's not about blame and we need to change the complaints culture."

"...it has become more embedded since we invested in doing a lot of promotion in GP and Health Services. We also built a good working relationship with Acute Trusts to make them see Patient Opinion as important as PALS. The team are always trying to raise the profile of Patient Opinion."

While there seemed to be areas with targeted activity, there seemed to be some assumptions by subscribers, that Patient Opinion should be responsible for publicity and should do more to get the service known; consequently a lack of feedback was down to Patient Opinion. This was recognised by Patient Opinion, who often found themselves frustrated:

"On the promotion thing, Trusts think that magically loads of opinions will come – they have high expectations, then they become confused and angry."

The *dependent variable* in this process seemed to be the level of engagement across the boundary between Patient Opinion and subscriber organisations; activity exponentially increases with engagement. But that engagement was also dependent on the subscriber's lead role (champion). One subscriber champion argued this clearly:

"Promotion of Patient Opinion is highly resource intensive. Posters and leaflets will not sell it by themselves. I firmly believe in Patient Opinion, which is lucky for our services. P[boss] believes that I sell Patient Opinion well and am a 'champion."

Active agents at organisational boundaries (subscribers)

The Patient Opinion service model is a complex cross-boundary intervention i.e. the feedback provided by a patient needs to traverse across a number of organisational boundaries from the website to the Patient Opinion team, to the subscriber organisation and from there to the staff involved in service delivery[31]. This is depicted in Figure 8 below:

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[31] some subscribers are commissioners (PCTs) looking to improve the quality of services a third party provided, which means there are several boundaries (actual and psychological) across which feedback needs to traverse to have impact.

Figure 8: Complex cross-boundary intervention

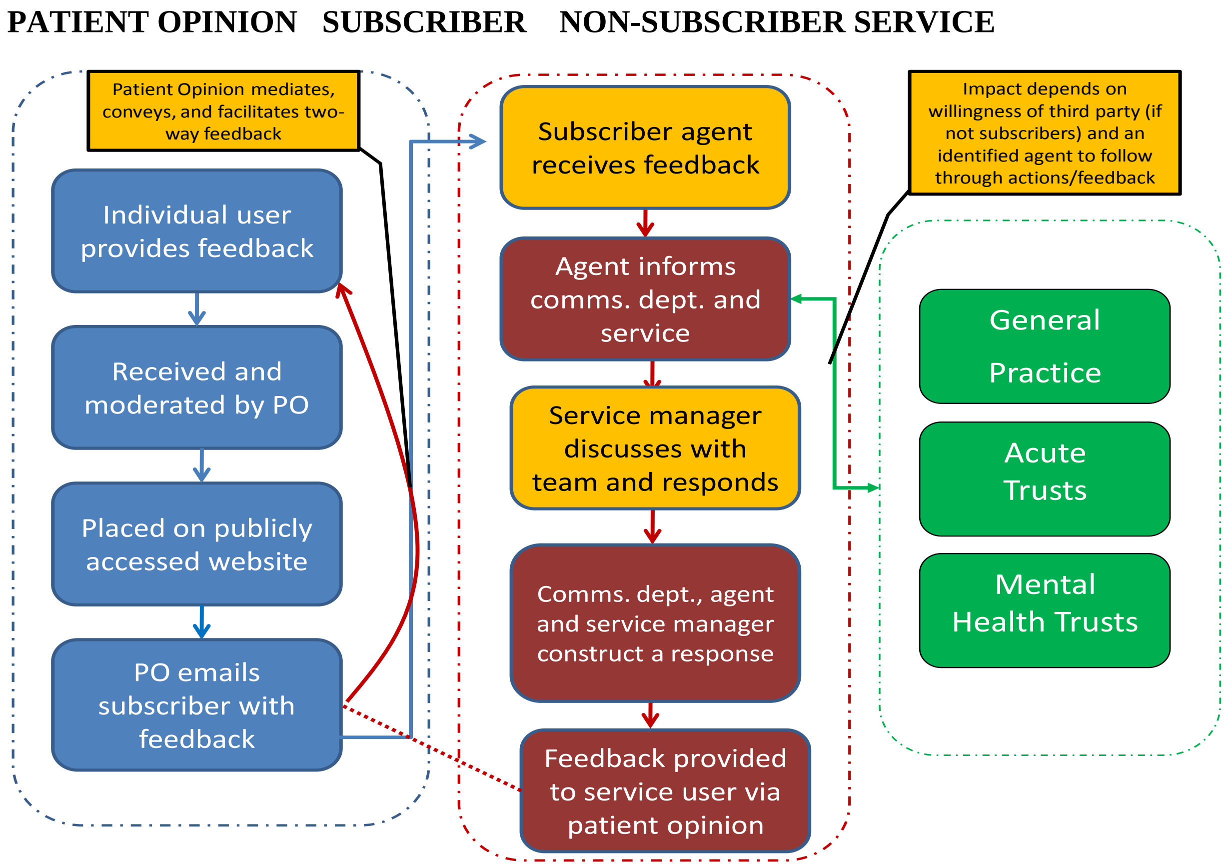

Figure 8 shows that for feedback to have real impact, there needs to be *active agency* at the interface of each transaction boundary.

The first active agent is that of the Patient Opinion team and website, receiving feedback, automatically acknowledging receipt, and once moderated, being published on the web with a simultaneous alert to the subscriber organisation.

The second active agent is the person in the subscriber organisation who first receives the email alert and patient feedback. They are the catalyst for a process which will determine impact and ultimately the satisfaction of the responses received by the patient.

As the quote in the preceding section suggests, there is a significant amount of work involved in making this work, but not just the intensity required for marketing and engaging staff and service users. It also includes:

- providing a timely and sensitive holding response;
- alerting communications/complaints/PALS as required;
- alerting the implicated services (managers);
- seeking a response from the service and follow up where this is not forthcoming;
- constructing a public response[32] to the patient and posting that on the website;
- being the conduit for further feedback on actions taken and chasing as needed;
- collating data on types of feedback/resolutions and coordinating reports with Complaints and PALS through existing quality improvement reporting mechanisms.

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[32] As previously indicated this is most likely to include the Head of Communications moderating all public messages

These ‘agents’ are the most crucial link in the whole service model, without which impact would not be effective. Such an agent requires a passion and commitment to drive quality improvement; as the quote above suggests a *local champion* is key to making this a success.

During the case study site visits we interviewed these local champions to explore their role and tasks, where they were located in the organisation and how integrated their role and activities were in the organisation’s quality improvement processes.

In the main, local champions were situated within a directorate that encompassed Patient and Public Involvement (PPI), communications, PALS and Complaints. Three of the four were dedicated roles supporting patient involvement and feedback which operated separately from PALS and Complaints. In most cases attempts were made to ensure that these different functions were coordinated, either in terms of working arrangements, data collation and coordination or reporting; Patient Opinion feedback in all but one of the sites seemed generally more peripheral to the organisations interests that information from PALS and Complaints.

Three of the four local champions were middle managers or at more junior levels in terms of authority. Only one had the Director of Nursing as the lead champion, who had his PA and another person to assist with some of the day-to-day processes. Of the former champions, all were in part-time posts and two out of the three were on short or fixed terms contracts and awaiting news of whether funding would be continued. The paucity of resources available in this function was reflected during interviews:

“ If I’m away for a few weeks it can all wait....the financial situation has meant that we can’t fund vacancies and we double up on what we do so can’t do as much we hope.”

One of the local champions who was on continually renewed short-term contracts and was waiting to hear if her contract would be renewed in March 2010, said she felt that if she was no longer in her role then Patient Opinion [feedback] would not get done, and her impression that more senior people would help embed the process:

“I am waiting to hear if I have a job after March. There is a lot more work to do to get [this] embedded. If I wasn’t here I would have to make sure others were involved as administrators of Patient Opinion. It would be helpful if one on the Executives was involved or one of the General Managers. I want all General Managers and Directorate Leads to be signed up [to Patient Opinion]. One General Manager said he would not sign up unless he was required too as he was too busy.”

This contrasts with the Director of Nursing:

I am the champion, the willing champion but if I wasn’t here my boss would find someone else like S [another Director] or someone lower down in the organisation.”

As with the previous interviewee, he also identified seniority as important, but more in relation to how responses are experienced by patients:

“ I’m on the board so that gives my responses a level of authority. I don’t think people want to hear from the matron, they want to hear from the boss.”

The third active agent is at the interface between the subscriber organisation and the services or the non-subscriber organisation. Where the services are within the subscriber organisation this is more straight forward, as there is a designated lead role in the service and there is the potential to use line management authority to elicit a response and change. However eliciting a response from non-subscriber organisations and services, is more complex. This is because (i) there often is not an obvious link to receive feedback; (ii) an inherent tension already exists between commissioners and services providers because of money, contracts, targets and expectations, in the main imposed to meet policy requirements; (iii) because a psychological contract (relationship) has not been developed locally in relation to the quality of the patient experience beyond policy requirements such as PROMS, CQUIN and quality accounts; (iv) while there is the potential for a formal 'contractual' obligation to be inserted in Service Level Agreements [SLAs]) against which sanctions could be imposed, PCTs were not doing this; and (v) PCTs would have to manage the boundary with numerous different services. This is reflected on by one PCT:

" The most challenging thing for us as a Trust is working with multiple small organisations, how much can we really influence the culture of so many organisations; each different?"

In those cases where responses from non-subscribers was positive, it was because the subscriber's local champion had been pro-active in engaging the services and building up a relationship and trust that then elicited an on-going responsiveness.

This further strengthens the finding that the *local champion* is a crucial factor in the effectiveness of such a service; the dependency on local champions when the precariousness of their funding and longevity is in questions seems an important finding.

Embedding feedback into mainstream quality mechanisms

In this section, we examine the activities that subscriber organisations have established to embed Patient Opinion generated feedback into mainstream quality improvement mechanisms.
The parameters examined are derived from:

- the results of a literature review (box 1) on key features of complaints and feedback approaches
- the results of interviews with key participants (those with an in-depth knowledge of Patient Opinion and similar initiatives)
- the results of the comparisons analysis of initiatives from both health and non-health sectors which represent good practices in user feedback, identifying the key success factors in the cases analysed.

This enables each service to be mapped and subsequently compared against a standardised set of analytical constructs, either in terms of key bench-learning criteria or organisational processes or both. These criteria were applied to Patient Opinion in the systems analysis above. Here we apply them to subscriber organisations. The six criteria are:

- Management and governance are transparent, involved and open to learning;
- Information and processes are established and systematised;
- Customer focused behaviours are established and actively promoted;
- Feedback is captured and channelled to appropriate person for action;
- Feedback is acted upon as 'business as usual';
- Good customer relations with clients are managed and maintained on an on-going basis.

As the two dimensions - feedback is captured and channelled to appropriate people for action and feedback is acted upon as 'business as usual' have been discussed in 3.4.3.1 above this is not repeated in this section. In addition the last dimension - Good customer relations with clients are managed and maintained on an on-going basis – is addressed in section 3.4.3.3 below.

Management[33] and governance are transparent, involved and open to learning

Strategic accountability for quality improvement generally was located in a *designated role* – at Board, senior or middle management levels - and through *regular reporting mechanisms* where information on Complaints, issues raised through PALS, and any PPI activity including surveys, patient feedback etc was collated and formally reported. Some of these reports were publicly available, some for internal use.

In the case study sites, strategic accountability was located in a number of different roles, most not at Board level: a Patient and Public Involvement Manager, a Head of Involvement, a Clinical Director and a Medical Director (Board level).

For one site, progressive medical leadership was seen as an essential element:
"In here and other hospitals the medical director's attitude is crucial. We have our third medical director now since I've been here – we'd never have had old medical directors agree to what we're doing now. The new one is far more prepared to look at all the things that affect the patient experience. He's extremely committed, unwilling to accept excuses. He's very patient focused – if you have the wrong medical director it's very difficult to get changes embedded at all. In one or two other areas it's made a lot of difference when the medical side are on side."

For reporting mechanisms, all sites had some form of clinical governance process. In addition, reports on complaints, PALS and incidents were regularly generated as Boards reports. Patient Opinion feedback was integrated into this latter report in three of the four sites. Beyond this they also reported on PROMS, CQUIN and other surveys undertaken.

For one PCT, they also assessed and reported clinical quality on a monthly basis to their Board and a yearly quality strategy. Providers were expected to generate a monthly quality audit. They reflected on the commitment of the Board:

"The board are very involved in these issues and get to hear everything."

Another PCT held monthly meetings with providers with a focus on patient experience every quarter.

The mental health Trust had a well developed infrastructure for embedding quality, from the Board to the front-line and across the different directorates:

- Board level overview of performance, targets, quality and involvement;
- A Quality oversight group;
- An Involvement Strategy group
- Clinical Governance groups in each clinical area with action plans, complaints systems and reports;
- Involvement leads and groups in each of the 15 directorates
- Involvement report with yearly plan which goes to the 15 clinical directors in the different directorates
- An involvement lead, council and volunteers in each directorate
- involvement standards:
    - To ask people their views
    - Service users to be involved in planning
    - Effective communication
    - Respect and dignity

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[33] Boards/CEOs need to be accountable

The local champion recognised more could be done:
"it is a useful structure for involving people...we are still working on it..."

Generally, it was difficult for Quality Leads to identify organisational activities that 'created' a culture of openness and learning.

"...not done anything specific to develop a culture of openness. We are currently restructuring the organisation and are taking feedback from staff and senior managers about what works well etc. This will affect how we develop the Organisational Strategy (behaviour, values and training) in 2010."

However, they were able to identify activities that reflected a shift to more democratic practices and targeted efforts to bring about change. Three categories of activities emerged:

- *Increased transparency:* reporting of patient safety issues, risks and critical incidents. Breadth of transparency varied with the type of data; sharing information across departments, with the board (some open to the public and some not), with members (Foundation Trusts) and with service users;

- *Dedicated meetings:* of the Board, directorate meetings, constituency (staff) or involvement meetings (service users); but it was felt that at times it was hard to link this activity with actual improvements;

- *Focussed campaigns or projects*: picking up on aspects of feedback, surveys or inspections and working to enhance these areas e.g. dignity, signage, protected meal times, where staff and patients (sometimes) would be involved.

In some organisations the openness and ability to learn seemed to be down to a faith in staff as opposed to evidence:
"In P's area, I feel reasonably confident that the staff know that when something has gone badly they know to own up to it and report it and discuss what to do about it with colleagues."

What seemed clear was that quality improvement was valued by some staff and the intent and desire existed but there was little to no evidence of patient feedback being consistently addressed as part of organisational wide practices. Inconsistency in practice was raised by one site:

"I can find pockets of fantastic quality but also poor practice where they do not talk to the patients ...there is a need for consistency."

Customer focussed behaviours are established[34] and actively promoted
On 26th February, 2009, *Listening, Responding Improving: A guide to better customer care* was published. This document outlined best practice in terms of resolving and learning from complaints, and provided a detailed guide on complaints handling. There were a number of significant shifts in focus set out in this policy. First, it placed patient experience rather than service provision at the centre. Second, it approached complaints handling from the perspective of *customer focussed behaviours* shifting the way in which staff should engage with patients.

Third, it acted as a step-by-step guide to staff behaviours and actions in handling a complaint (particularly the early stages[35]). Fourth, it focussed on improving through learning.

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[34] Training and development in customer focussed competences
[35] This was because the Health Care Commission's report: *Spotlight on Complaints, 2009* identified that one of the

Given that the publication of this policy coincided with our evaluation, it seemed possible that case study sites were beginning to focus on standards of behaviour of handling complaints.
In addition, the subscriber training carried out by Patient Opinion emphasised the importance of engagement, the need to respond quickly, and how best to respond that encouraged continued dialogue; we also looked for evidence of the impact of this training on staff.

Our findings indicate there are few[36] organisational-wide approaches specifically focussing on standards of behaviour in relation to engaging patients and working with feedback, but there was evidence of training having taken place for specific roles e.g. PALS, Complaints and Patient Opinion feedback. There was evidence of Trusts developing customer service strategies.

"We do not have a systematic approach yet but are working on a customer service strategy, which will outline standards and staff expectations to treating patients/customers (early 2010 work)."
"We evaluated and audit PALS (not Patient Opinion) through patient questionnaires and held focus groups (focusing on the themes from the questionnaires).... This will all link to the development of a customer service strategy."

It was difficult to ascertain the effectiveness of the different trainings on standards of behaviour without gathering feedback from individual patients who used PALS and the complaints process, but observational data and data from interviews showed that:

- Those involved with PALS and Patient Opinion and PPI appeared more engaging and responsive and their practices and systems reflected a more customer-oriented approach;
- Those involved with complaints appeared more guarded and their practices and systems reflected a more judicial-oriented approach.

The main training provided, generally related to professional development and professional values as part of the induction and on-going development of each clinical speciality, which were cited as well developed, but also that more could be done.

Some sites focussed on additional attitudes and behaviours beyond those covered in professional development programmes:

"The main competencies are respect and compassion. Also being welcoming and culturally sensitive are important."

There were no organisation-wide frameworks for example, on customer focussed behaviours, working with patients or handling patient concerns; these were limited to those in lead roles for PPI, PALS or complaints:

"We do not have a systematic approach yet, but we are working on a customer service strategy, which will outline standards and staff expectations to treating patients/customers."

One quality lead reflected that learning was part of their culture although not embedded, and were looking to develop this further in a different way:
" There is a culture in the organisation… expectations to learn about feedback. However, it is not in staff contracts...we are looking into providing regular involvement training sessions, where staff can meet with patients etc. working with people is more effective than training days. We need passionate staff who can then sell the values to their teams."

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biggest issues was the poor initial handling of complaints.

[36] The involvement standards developed by the Mental Health Trust could be viewed as organisational-wide standards for engagement and customer focussed behaviours

Information and processes are established and systematised[37]

Monitoring of quality was primarily exercised through routine reporting of data. Provider Trusts were involved in collecting and reporting of a range of quantitative and qualitative data including mortality rates, clinical incidents and risk, complaint and trends, use of PALS, National Patient Survey and other survey feedback, Patient Reported Outcome Measures (PROMS) and Commissioning for Quality and Innovation Framework (CQUIN) activity.

PCTs as commissioners were primarily involved with collating data from PALS, complaints and clinical incidents. Practices varied in terms of number of reports and reporting cycles, but generally information was regularly collated and fed back to provider organisations and independent contractors and less frequently to PCT Boards. At times these reports included governance issues e.g. requests for access to patient records.

" We do monthly quality reports which have the different feedback elements mentioned ...providers also provide a quality audit and we do a yearly quality strategy at PCT level. The board are very involved in these issues."

All those interviewed recognised that more could be done, with differing perspectives of where systematisation could be improved:
"We need to improve our reports and not just look at outcomes but also impacts and changes. But how to evidence it?" "[we are]good at establishing systems but not so good at keeping things going - it takes five years to embed something...[there is] initial buy-in... [then] drift in the medium term."

It was evident that all the case study sites were involved in a number of monitoring and reporting processes that they were *required* to do; collecting, analysing and reporting data related to policy. The follow-on from these reports beyond serious incidents or inspection reports – the change processes – did not seem to be systematically built into the quality improvement processes; there seemed to be no internal 'ward to board' requirement for the implementation of change across all aspects of quality improvement, that was systematically embedded in the organisations' quality improvement processes, nor was the implementation of change outside of the 'required' areas as rigorously monitored.

Practices varied in terms of how or whether, directorates and staff teams received feedback on quality. There was some recognition that this needed to be purposeful and effective:
"The measurements need to be fed back to the right people."

In the main, there were directorate and service level activities, cascading practices, and sometimes direct reporting to services where particular events had taken place or practices were being monitored. However, only one of the case study sites had a systematic and organisation-wide process that had a coherence from the front-line to the Board and across directorates. Even here however, this was limited to a focus on involvement; it seemed to have a real potential to move beyond involvement to also address impact.

Patient Opinion generated feedback

We have added this section – although not in the theory of change framework - as specific data emerged relating to the mainstreaming of Patient Opinion generated feedback which warranted highlighting.

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[37] There are planned processes of coordination and change, performance is monitored and reported, and feedback is provided to directorates and staff teams

In some cases Patient Opinion generated feedback was seen as mainstream and data was integrated into PALS, Complaints and survey feedback reports, but this was not a consistent picture and there were varied practices which, while positively viewed by PPI leads, suggested that it generally was viewed in the same way as policy requirements:

"We have got a quality director; I don't think Patient Opinion feedback does go to him. The feedback did get reported to the board but that was only when we were making a case to re-subscribe. As the complaints process goes up I don't think it has much Patient Opinion data with them."

"If we have a lot of feedback on one particular issue then I would feed this back to the relevant commissioner – but this has rarely happened – no particular trends have emerged from the postings... Just one post could be enough. However, commissioners generally look for themes. Half a dozen posts on the same issue would be a theme... the Quality team are aware of Patient Opinion but don't require contractors to subscribe to or use this...this could be taken on board later, but isn't at the moment..."

" Patient Opinion needs to be linked up with PALS and Complaints. It is early days….over time it will link. PALS and Complaints data goes to the Board, Risk Management committee and clinical governance. I receive a copy. Patient Opinion needs to be balanced with PALS and Complaints. It needs to link more with them- this is key. We don't want 20 action plans!!"

"Patient Opinion data doesn't go into any report. It doesn't go anywhere, it's not something we manage, and we don't want to start the idea and don't want people to start soliciting the Patient Opinion responses. If you get a complaint on Patient Opinion it doesn't go into the complaints reports. We don't want to create the impression that it's a facility to use for people to set up. Don't want to make it bureaucratic. I think people think it's more beneficial as it is."

Two key questions emerge from these responses – one raised by a commissioner and one raised by a provider – are worth exploring:

How many times does an issue need to be raised for action to be taken and change to be initiated?

Interviews with a number of PCT subscribers - both through the case study sites visits and through the discussions at a Patient Opinion Regional Event – were consistent in thinking that there needed to be a critical mass of postings with common themes for this to be followed up. It could be that the general tension and sometimes adversity that existed in the relationships between commissioners and providers[38] would likely make PCTs more sensitive to when and how they raised issues regarding quality where there was sufficient evidence.

How to retain the independence of the service provided by Patient Opinion on the one hand (not to bureaucratise it) while being able to mainstream use of the data for quality improvement?

There is an inherent tension in bringing in innovative, responsive and more engaging (less formal) processes and embedding them into public service structures and processes which are bureaucratic, rule-bound and usually require (long) lines of authority.

Evidence from elsewhere would suggest that this can be done to some extent where organisations devolve authority and enable services to own and work with these processes more directly.

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[38] Acute provider organisations tend to be much larger, more robust and effective in contract negotiations than PCTs and PCTs have come under sustained attack for ineffectiveness both fro providers and from government.

However, this then requires the Trust hierarchy to let go of control; this can be difficult when they are ultimately held to account. The consequence of devolving authority would mean having:

- a systematic two-way process of communication, monitoring and reporting;
- very effective engagement from the Board to the front-line;
- identified leads in each service that were held to account;
- shift in service attitudes to actively engaging with patients and soliciting feedback for quality improvement

3.4.3.3 *Impact*

In section 3.3.4.1 above, we identified the *desired impacts* Patient Opinion were looking to achieve through their service model was:

i) To create conditions for learning[39] by recognising staff does a good job; and
ii) Patient feedback is heard and leads to improvements in the quality of care; and

Create conditions for learning by recognising staff does a good job

Evidence from the analysis of *activities* (3.4.3.2.) showed that one[40] of the four case study sites had more of a systematic process for engaging and involving patients and encouraging staff to work differently and learn through their work with patients. There is also some evidence to show that the other provider Trust recognised staff does a good job. For commissioners, being at a distance from patients and staff in the services (unless directly contacted), this was not possible. The engagement and relationships PCTs have to work with are mainly with provider organisations; given the main transactions take place around contractual obligations and Service Level Agreements this is complex and problematic, although not impossible.

However, creating the conditions for learning – through engagement, relationship and positive feedback - is far from being the norm across all the organisations and their the services. While the usual organisational artefacts were evident (newsletters, awards, events, etc) these are viewed by staff as outside of the day-today routine. For learning relating to patient feedback, there was an over-reliance on the PPI leads and staff to champion this way of working, and a dependency on the attitude and responsiveness of service managers to whom patient feedback is given.

Furthermore, the monitoring and reporting culture which is inculcated in public service processes, seemed to distance management (senior and middle) from engagement and relationship with patients and staff - both physically and psychologically - rather they acted as recipients of information for decision-making and instruction.

In this way learning through engagement, relationship and positive feedback can be seen to be *extra-curricular* and *detached;* something that happens over there and is left to a minority rather than owned and embedded by all.

Patient feedback is heard and leads to improvements in the quality of care

Evidence from the analysis of *what the service seeks to address* (3.4.2.) demonstrates that Trusts are working towards ‘hearing’ patient feedback by positively acknowledging and responding to feedback. There is also evidence of feedback being passed on to services and some evidence of action being taken. There was also some evidence of patients being informed of what changes had been made.

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[39] Through engagement, relationship and positive feedback

[40] It is not surprising the Trust’s focus was Mental Health, as user engagement and involvement has a long history in mental health and learning disability services.

However, to fully assess impact on the quality of care, we tracked the feedback of eight patients from the point of posting through to its reception in the subscriber organisation and any subsequent actions taken. Below in Box 7, is a summary of the process for all eight patients. We then provide three stories to illustrate different experiences of using web-based feedback.

Box 7: Assessing the impact of patient feedback on quality improvement

Site and feedback post	**Type of feedback**	**Received response from Trust**	**Passed on to staff team**	**Action taken as a result of feedback**	**Patient informed of changes**
A1	Thank you	Yes	Yes	Unclear as this was positive feedback and staff member has left.	No evident follow-up response
A2	Concern	Yes	Eventually. Originally passed from PCT to (non-subscriber) acute Trust who seemed to be unclear if it was their responsibility. Then regional lead got involved and acute Trust did eventually respond through PCT PPI link.	Action was stated to have been taken, but could not be substantiated as staff never responded to requests for interviews.	Patient informed of actions in first response
B1	Concern	Yes	No. Passed on to PALS to follow up as service was not part of the PCT Difficult to trace service as was not named.	Subscriber did not know if this had been passed on or if any action had been taken.	Unknown
B2	Thank you	Yes	Subscriber unclear what happened to the feedback hereafter: *“ I don’t know what was done as a result of the feedback, we don’t generally call them [providers services or GPs] and ask what happened.”*	Unknown	Unknown
C1	Thank you	Yes	Yes	Yes	No changes needed, and Patient engaged with further and is in contact
C2	Concern	Yes	Yes (has direct contact now)	Yes a number of actions have been taken as there is continued contact and this has led to more strategic changes in patient information across the Trust	Yes. Patient engaged with further and actively Involved with the services now, and said to be a great advocate of Patient Opinion.

Site and feedback post	Type of feedback	Received response from Trust	Passed on to staff team	Action taken as a result of feedback	Patient informed of changes
D1	Concern	Yes	Yes	Yes	No, but patient engaged with Trust initiative as a result of feedback.
D2	Thank you	Yes	Yes	Unknown	None beyond first response

We provide three case studies to illustrate in more detail three of the eight experiences of patients interviewed; one that worked well, one that did not work as well and one of mixed experiences.

A heartening story

Feedback: THANK YOU FOR HELPING MY SON AND ME
After caring for my son for over 20 years and receiving a new psychiatrist, I am now finally getting the services for my son that I have wanted as a carer. He has listened to me and acted on it. He has new ways of working as he has listened to my son and listened to us. He has shown a lot of interest in us and now my son has been referred for a dual diagnosis.

Response:
Thank you very much for your comments. We are pleased to hear that you have been listened to as a carer and that new ways of working have enabled the referral to the dual diagnosis service. We will pass your comments on to this service and hope this proves to be a positive experience for your son and your family.

Impact:
The involvement manager already had contact with the person:

"She gave her feedback [posted on the web] after she attended a Patient Opinion workshop at the Trust. She wanted to say thank you to the Trust and let us know that we had made a difference. Since making the post, she has continued to connect with us. She is in greater communication with us now. I think Patient Opinion has helped her to feel more confident in approaching the Trust, has raised awareness of what it is like to be a carer and awareness of our services. It may help more people to feel confident to have their say. It is not easy for everyone to give their feedback.

Since, the carer gave her feedback she has contacted us more and asked for our support. She has had a problem since (related to her son, not the service). Her contact with us through Patient Opinion has highlighted who can help her in the Trust. We have then been able to sign post her to services to help her son with the issue. I think she has improved confidence in us.
The carer wanted to share her story to help show others what it is like to be a carer and to help break down stigma. We have since put her in touch with the Breakdown Stigma group, who do marketing about anti stigma. She may also wish to be involved in Living Library, where she can tell her story of being a carer. The General Manager is contacting her."

A less heartening story

Feedback: NOT LISTENED TOO
Early May I was measured by the practice nurse for compression stockings as the ones I wear are too tight and cause pain, I was later told that I could not have them until I had a 'D' I explained that for the past seven years since having an heart bypass I had worn the stockings. However on returning from the Fire services rest home in Devon I made arrangements to be measured yet again and when the stockings arrived they were the same size as before.

I have to await the return from holidays of the nurses who did the test so I have been told.

Why do some medical staff not listen to patients? At 77 I have never known things so disorganised. If patients were listened to and doctors advice listened to perhaps things would be better.

Response:
Thank you for taking the time to share your story. I am very sorry to hear that you had problems with the stockings that were sent to you and that you had to wait to see the nurse who had done your test. If you would like to discuss your story in anymore detail please do not hesitate to contact the Patient Advice and Liaison Service (PALS) on freephone...

Impact:
I sent it to PALS because the PCT doesn't have a Health Centre: The post didn't have enough information to do anything about it. I always tend to apologise in my replies. I worked in Comms. before so I try to reply in the same way.

A story of mixed experiences

Feedback: IGNORED ON A SURGICAL WARD

I was due to be admitted for a cholesystectomy in Nov and the day prior to my admission, it was cancelled. I was informed it was due to lack of beds.

I was then informed to go to the surgical ward at 7.30am on the Friday. I turned up at the time requested and was informed to wait in a small waiting area in the middle of the ward. I was with 8 other patients, some elderly. I sat there for 5 hours before I was taken to a bed and prepared for theatre, where I was then taken about 30mins after getting in my bed. it was literally one out... one in. for most of the morning there were more patients on the ward than beds which I felt was not acceptable. no one came to see who I was, so I had to ask if they knew I was here. no one seemed bothered that we were sat on very uncomfortable chairs which were in the way of staff. I could have been anybody with a bomb/gun/or stealing patients things etc as no one checked who I was. I felt this was poor safety management.

some of those waiting were not that lucky. several were taken to the toilet and asked to change into a gown and their dressing gowns and taken to the theatre from there. some of these patients were again elderly. their bags were taken to another ward whilst they went to theatre and were waiting for them in this ward. after my surgery, I asked several times for pain killers and eventually my husband had to ask the staff after 2 hours.

During the night I wanted something to eat as I felt sick due to being starved for nearly 24 hours and had no call bell to call for staff.

during the night, no staff came to see if I was ok, and if I needed anything, so I had to wait for staff to come nearby and shout to them. in the morning, there was only 2 staff on the ward as it was originally a Monday to Friday ward and there were no beds for the ward patients to go to on other wards. the staff were very busy dealing with several poorly patients and I had to get up and have a wash on my own following surgery. I had to wait till tea time before staff had time to discharge me back home. I felt that:

1. staff had no time for patients as there were too many patients on the ward
2. we were on a conveyer belt
3. it was not acceptable for patients to be admitted in a corridor and to change for theatre in a toilet
4. no adequate staffing levels
5. poor security

Response:
I am very sorry to hear of your experience during your time at the Hospital.

When emergency demand for beds significantly exceeds capacity, we have to make the difficult decision to cancel planned patient admissions. We do this very reluctantly, as we appreciate the distress and inconvenience this causes. When we are in a position when we have no alternative but to cancel admissions we obviously try to give patients as much notice as possible.

Our Surgical Elective Facility (SEF) usually takes only elective admissions. We plan how we utilise our beds very carefully. Unfortunately on this occasion, emergency patients were admitted to the beds on the ward that would usually be reserved for elective patients. The result of this was too many patients for the number of beds available at that time. However, the ward was expecting to discharge patients so that we could accommodate patients such as yourself.

As patients on SEF are usually admitted directly to a bed, we do not have a large waiting area. Consequently, patients were asked to wait in a small “sub waiting” area. I acknowledge that this is far from ideal. However, following your comments I have asked the ward to purchase some suitable chairs so that if the situation ever arises again patients are made as comfortable as possible.

I am sorry that you were not greeted and kept informed by ward staff in the way that I would expect. This has been addressed with the staff concerned and I do not expect this to reoccur. Asking patients to change in toilet facilities occurs only as a very last resort and only occurs if the patient consents to this. Again, I would like to reiterate that this only occurs in exceptional circumstances and is offered to ensure a patient’s operation is performed rather than cancelled.

I am very sorry that you had to wait for pain killers after your surgery. Without specific patient details it is very difficult for me to comment on this as on some occasions it is not always possible to administer pain killers. This is dependent on for example, what pain killers have been given in the theatre environment and how long ago they were given.

Following your comments, I had asked the housekeeper on SEF to ensure all bed areas had a call bell available. I am reassured that all beds have one in place. I have also asked the housekeeper, as part of her daily checks, to ensure every bed as a call bell available at all times.

It is correct that SEF is usually a Monday to Friday ward. Additional staff were secured for the Saturday morning in question and arrangements were made to transfer the patients who required higher levels of care to more appropriate areas. I apologise that this took priority over facilitating your discharge. However, I am sure you will be pleased to hear that at the hospital we are now performing laparoscopic cholesystectomy as a day case procedure. Patients are now discharged home 4 to 6 hours after their procedure. Research suggests that patients recover better at home following this type of procedure.

As a Trust we recognise that it can be difficult at times of pressure to balance elective admissions with emergency admissions. The hospital is working extremely hard to ensure that both patient pathways are managed effectively at times of peak pressures.

Impact:

“ We did all the things that we said we were in a position to do. Obviously we can’t change external things like the demand. My secretary sent follow-ups on the chairs etc. I get a reminder in my email to ask whether it’s been done which stays there until it’s done.”

The patient however did not know whether the changes had taken place:
“I thought about having a wander round. I suppose that’s the only thing, how do you measure if anything’s been done? It can just be someone saying they’ve made changes – other than going back there’s no way of knowing.”

3.4.3.4 *Positive psychological impact*

Interviews with patients provided a rich description of their experiences of using healthcare services and of their motivation for using the web to feedback to the services. Two of the eight patient’s stories are discussed below because unanticipated positive psychological impacts emerged in interviews which are worth reflecting on:

Veronica’s story[41]

Veronica is a 70 year old, who had problems with her knee. The nurse at her GP Practice referred her to X Centre for Health. The centre is away from the Hospital but in the centre of the town. This service meant that Veronica did not need to go into Hospital, which she thought was brilliant. *“I didn’t have to see a doctor once, which was amazing...brilliant that I saw nurses and physiotherapists and not doctors.”*

The patient said her *“treatment was second to none”*. She liked that she was seen by Nurses who had gained extra relevant qualifications and by trained physiotherapists. *“They had extra knowledge and were absolutely brilliant”*. Veronica was impressed as she thought the service was making the most out of its staff, resources and health services; *“it takes the burden off the doctors. I didn’t need to see the doctors so I didn’t have too. I didn’t waste their time. If I had needed to see a doctor then I would have been referred. The Centre makes the most out of staff’s skills”.*

It was Veronica’s first time at the Centre, and away from the hospital where Veronica had not always had a pleasurable experience. The *“Centre was so different and I felt I just had to tell others how good it was”.* The Centre *“didn’t seem like a clinic, if felt like a private hospital. It was beautiful, relaxed and not hospital like”*. Veronica was also sent for X-rays and scans in a portable cabin in a car park, which she said was also a good experience. She then went back to the Centre for extra physiotherapy. Veronica was also impressed with the follow-up care as the Centre called her to check that the appointments were still suitable, they made changes easily and sent her results to her GP and to her. She felt that she was *“kept in the loop, it was not a secret like some NHS experiences. I knew what was happening, which was excellent”*.

Veronica could not remember how she came to provide feedback on the Patient Opinion website. She wanted to give feedback so that others would realise how good her experience was. She had told her friends and family via emails but wanted more people to hear her story. Some of her friends and her husband had also had good experiences with the Centre.

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[41] Pseudonyms are used to protect the confidentiality of the patients.

Veronica thought she chose to give web feedback as it was accessible. She is always on her lap top and thought it was easy to post. She would not ring the Centre up to give feedback; she was not sure why. Veronica thought that it maybe because that is not anonymous, whilst Patient Opinion is. She also liked that Patient Opinion was independent to the NHS. She chose the web as more people would see her post.

Veronica felt satisfied that she had voiced her story. “*It was good as I had done what I wanted to do. It got to people involved and they were grateful”.* She also was very satisfied by the response and speed of response; she had not expected a response. Veronica felt that there would be no changes as her post was positive. She did not want them to make any changes. She just wanted to let them know that she had found the service good.

Veronica was nervous about the media’s negative coverage about how some NHS services treat older people. She worried how old people are treated. This experience helped *“take the fear away”* as it was a good service. She was *“not treated as a pensioner but as a person”*, which was great. *“I was treated normal”*. *“I was not patronised or treated as a second class citizen”* (she seemed surprised and very happy about this). She said that *“at my age I can be invisible sometimes. This can be hard as I had a professional job at the PCT and I am a person”*. Veronica wanted to give her story a high profile and let her friends know, so that it takes their fear away. She is now not as nervous about going to the Hospital.

Contextual antecedents

Veronica:

- had been previously employed by the local PCT
- was nervous about the media’s negative coverage about how some NHS services treated older people;
- knew of friends and family who had had a good experience at the same centre; and
- is always on her lap top

Trigger for giving feedback

- the experience was both different *(“not like a hospital”)* and [therefore] empowering.

Associated motivations

- Veronica wanted to give feedback so that others beyond her friends and family,so they would realise how good her experience was;
- it would take others’ fears (of NHS care) away; and
- Veronica liked Patient Opinion because it was anonymous, independent and would be seen by more people.

Psychological impact of the whole experience

Veronica:

- is now not as nervous about going to hospital;
- feels satisfied from doing what she wanted to do (giving feedback); and
- is happy that staff received her feedback and that they were grateful.

Gerald's story

Gerald is a 78 year old ex-firefighter and ex-magistrate, living in sheltered accommodation. He said that when he goes into hospital he feels that he is not always listened too. *"They talk like you're not there and they don't always listen. It is wrong. They talk about their own social lives, like going to play golf. Some are good. I am lucky with my new GP who is very concerned for me. He really listens and cares about his patients. He said I should always ask for him. He even does follow ups. He has made a vast difference."*

"I would use Patient Opinion again to tell them about how good my new GP is. It is good as no names are mentioned on it, as that wouldn't be fair to your doctor. I don't trust some consultants. They're maybe good in their field but not in person. We are human and they sometimes lose track of this. We are not just numbers."

Gerald used Patient Opinion as he was concerned about his treatment and what others may receive. *"Mistakes have been made and they need to be rectified".* Gerald said that he has mistrust of the NHS as they misdiagnosed his insulin and took a long time to admit that they were at fault and because he got MSRA but was not told what was happening. They then could not find any reference to him having the bug. *"It was swept under the carpet"*.

"I am bothered about others. Others (people) matter to me. I don't want others to face what I faced."

Gerald cannot remember how he heard about Patient Opinion; he may have been told by medical students who come to his house every October; he also helps at the School of Nursing on their Ethics and Law course.

Gerald uses PC's a lot even though he doesn't fully understand them. He gets a lot of emails, which he finds useful. *"PO is alright to use but you have to be careful on the internet. The whole world can see so don't put your name or address". He likes that you can make up a name on Patient Opinion and that it is anonymous. He said that he was not worried about who sees his Patient Opinion post as it has no names on it. "No names and it is alright. I would be worried if they asked you for your name and address."*

Gerald knows of PALS but did not want to use them. He explained that he used to sit on the Patient Involvement Team and is upset that PALS took over. He felt that the Patient group allowed patients to come together and that it is sad that it no longer exists. *"The group had authority and could make changes and act."*

As a result, Gerald is not keen on PALS as it is controlled by the NHS. *"Patient Opinion is good as it is independent unlike PALS. Patient Opinion gets true facts, studies facts and can act on them."*

Gerald thinks that changes were possibly made due to his feedback but he does not know. *"They have taken notice, they have listened and this will help the doctors".*

"I feel more positive about the NHS. I just wanted to help others, it does not matter who they are. I was brought up like that." Gerald also seemed happier with his health care since giving feedback.

Contextual antecedents

Gerald:

- was mistrustful of the NHS due to a previous misdiagnosis, subsequently contracted MSRA, was not kept informed an records were lost;
- Was on a Patient Involvement Team that was *"taken over"* by PALS and subsequently perceived to be "*controlled by the NHS"*
- was aware of Patient Opinion possibly through contact with junior doctors; and
- used his PC a lot; got lots of emails

Trigger

- the experiences left Gerald feeling that he was not being taken seriously and that issues were being ignored. *"It was swept under the carpet"*.

Associated motivations

- Gerald just wanted to help others – this was how he was brought up and part of his value system.

Psychological impact of the whole experience

- Gerald feels more positive about the NHS as a result of giving feedback; and
- also is happier with his health care.

In both of these examples we can see that the patients felt more positive about themselves and about the NHS, and that this arose as a result of being engaged with; for Veronica as an involved person who had a contribution in her care process, and for Gerald, being taken seriously and listened to, through feeding back his concerns.

Feeling engaged is evident in the experiences of patients in two other sites above[42] (Box 7: examples C2 and D1) where both went on to become involved with PPI activities and became great local advocates for the NHS. The common factors in both examples was that the Trusts had been responsive; passed on the feedback to staff, and had taken action. In addition, both patients had been engaged with, and involved in, the process. To do this staff had to be willing to form a relationship, because on-going involvement is dependent on this.

In her seminal work, Menzies-Lyth (1988) showed that over time, professionals developed ways of defending against the difficulties and anxieties inherent in the nature of their work, by introducing routines, systems and procedures that took them away from having to relate with patients' experiences. She suggested that these *social defence mechanisms* develop over time through collusive interaction and agreement, and are often unconscious.

The development of new technology is providing innovative and enabling ways in which the human services such as healthcare can be more person-centred, responsive and improve the quality of care, and that is evident from the analysis so far. However, in an era of increasing *customer-supplier* models of public service provision, and a concomitant decrease in sense of purpose for staff, as policy drivers obscure what motivates clinicians to get up every day and go to work, there is a danger that technological solutions can become a proxy for human relatedness and another social defence mechanism.

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[42] An acute trust and mental health trust

3.4.3.5 *Additions to the service model's theory of change*

In re-mapping the theory of change, we need to add in two new dimensions to Patient opinion's mission centric market-linkage model, which emerged through the evaluation activity:

- Local marketing and promotion, and on-going management and maintenance of good customer relations with subscribers; and
- Patients feel more empowered and more positive about the NHS as a result of giving feedback

3.4.3.6 *Areas for development in the service model's theory of change*

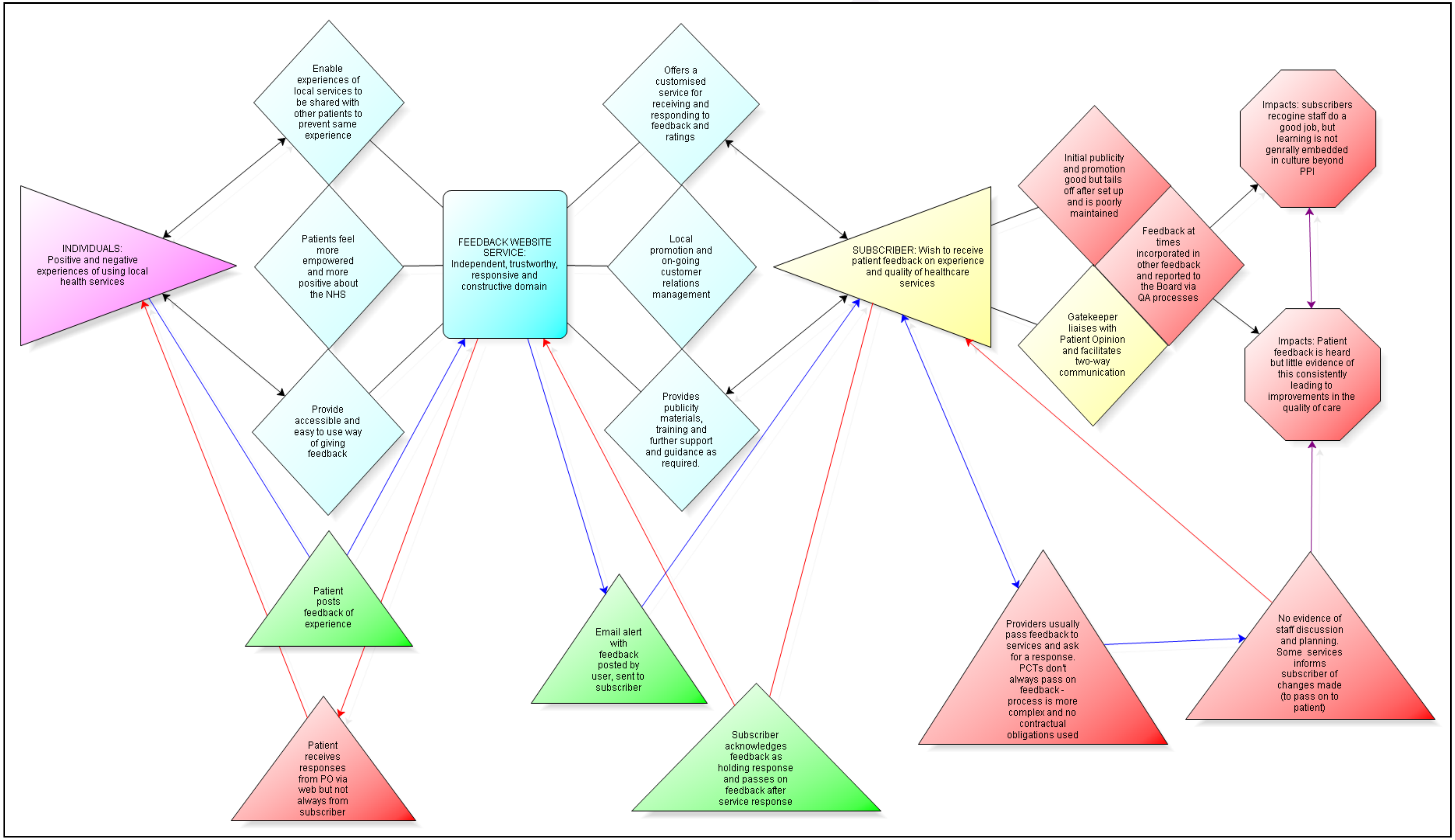
The Patient Opinion theory of change depicted in figure 4 (p43), shows the causal pathway in their service model, i.e. the relationship between the *intended* impact and the activities undertaken to achieve that impact. Having examined the practices throughout this chain – in particular through tracking each of the eight patient experiences - we found that it is possible to achieve that impact (see site C in box 7 above), however more often than not the intended outcome differed from the *actual* experience.

By no means all experiences had been negative for patients, even when the desired outcomes and impact were not achieved (discussed further in 3.4.3.4 below). There were however, trends in activities and responses that were common in most of the case study sites examined that would suggest these are areas to develop further. The six particular areas for development are:

- Subscriber publicity and promotion
- Engaging responsiveness
- Passing on feedback to services concerned and monitoring that action is taken
- Service staff rigorously discussing and using feedback to improve quality
- Services closing the loop by communicating to patients the changes made or how positive feedback was used
- Including web-based feedback in mainstream quality reporting and dissemination practices

Below in figure 9 we have added the two new dimensions and highlighted those aspects of the theory of change that require development by subscribers:

Figure 9: Areas for development in the service model’s theory of change



3.5 Research question 4:

What factors need to be present in a healthcare organisation for platforms like Patient Opinion to allow both user objectives and quality improvement objectives to be met and how far is the impact of such a platform within any particular healthcare organisation dependent on potentially vulnerable factors, such as key individuals or a favourable organisational context?[43]

3.5.1 Factors that need to be present in healthcare organisations

When it comes to looking at whether giving feedback impacts on the quality of care, then there are differences between the *theory of change* and the *actual experience*. What is clear from the analysis, is that much of the progress required to fully realize the potential of web-based feedback mechanisms in healthcare, lies with NHS organisations.

As the causal pathway depicted in Figure 9 above shows, the factors that need to be present in relation to user objectives are systematic processes for:

- Subscriber publicity and promotion
- Engaging responsiveness
- Passing on feedback to services concerned and monitoring that action is taken
- Service staff rigorously discussing and using feedback to improve quality
- Closing the loop by communicating to patients the changes made or how positive feedback was used
- Including web-based feedback in mainstream quality reporting and dissemination practices

In section 3.4.3.2 we examined the activities undertaken by both Patient Opinion and subscribers that were established to deliver the theory of change, with a particular focus on embedding quality improvement. From this, the factors that need to be present for impact to be realised are:

- Promoting and role modeling a culture that goes beyond *required* practices (we do what we have to) to *desired* practices (we want to do this because it is important to us), by focusing on purpose, patient experience and learning;
- A shift in focus from feedback (the process) to impacts and changes (the outcomes)
- A systematic and organisational-wide quality improvement infrastructure that involves effective engagement from the Board to the front-line and across all directorates and services with two-way processes of communication, monitoring and reporting;
- Establishing customer focussed behaviours in relation to engaging patients and working with feedback, and providing focussed training beyond that offered as part of normal professional development;
- Identified leads in each service that are held to account;
- Shift in staff attitudes to actively engaging with patients and soliciting feedback for quality improvement rather than the cited *conveyor belt mentality* one patient referred to[44]

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[43] The second part to this research question - How far is the causal chain between receipt of feedback and steps taken to improve the quality of care sustainable, strong and replicable across the constituent parts of each NHS organisation and between NHS organisations? – is dealt with in research question 5 as there is overlap with being an independent provider.

[44] An important issue to examine further would be whether the way in which the target culture and productivity drives have been implemented nationally and locally, has created a conveyor belt mentality where there is ‘no time’ to stop and ‘relate’ to people (staff and patients) .

3.5.2 Factors that enables both user objectives and quality improvement objectives to be met

Engagement and *relationship* were found to be the most crucial factors in enabling both patient and quality improvement objectives to be met. They[45] were central to transforming patients' negative perceptions of the NHS, to one of advocacy and support for the organisations.

Engagement in particular, was discussed at length by the Patient Opinion Team as being central to their approach to build trust with staff, and central to the values embedded in their approach.

3.5.3 Dependent variables

A number of *dependent variables* in the service and business models emerged during the study that potentially make this process vulnerable. Some of these relate specifically to Patient Opinion[46] while some are more generic to this form of web-based feedback mechanism:

Volume of feedback

Although reputational theory would suggest even micro-conversations can lead to change and some subscribers state that it only needs one post to make a change, in practice, we found that most subscribers wanted a critical mass of postings to remain confident and engaged in the process themselves, to persuade staff to work with the feedback and to persuade bosses to renew the subscription. In addition, for commissioners it was difficult to persuade providers to work with the feedback (particularly if they were not subscribers themselves) without being able to show trends and patterns in services; this requires a larger number of feedback posts that is currently the case.

"The way I see it - I think it's an excellent tool but the problem is not a lot of people know about it."

"When you've got a critical mass of postings we can make a much better case. It gives better leverage – otherwise the bosses would say 'come on, this is only one person'."

Patient Opinion were very clear about this themselves:

" The key obstacle which we will fail on and deserve to fail on if we can't solve it in the next few years, is generating more postings, more stories and finding out what the psychological reasons are for posting and what people want…profile and pr is now the biggest problem"

Two aspects emerged from the evaluation, which affect this factor:

- Patient Opinion marketing practices at a local level, needs to also target local staff and patients; and

- an assumption by many subscribers, that the generation of feedback was down to Patient Opinion, as the work involved was intense and on-going, and there were limited resources provided by NHS Trusts. Contrary to this, the evaluation shows that subscribers need to be proactive on an on-going basis and use a range of approaches to promote the service to engage staff and patients. This work cannot be done by Patient Opinion as they sit outside of organisational lines of authority and operational processes, to influence staff, and have limited funds[47] to support all Trusts in this activity.

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[45] Found in the care and feedback processes.

[46] Patient Opinion are already aware of many of these vulnerable factors.

[47] unless Patient Opinion offers this as an additional service with costs to cover activity and materials.

Generating subscriptions and renewals

Records shows that there is a high turn-over of subscribers (50%) and staff reported a huge amount of internal resources are spent on generating new subscriptions. Retention rates are reported as issues to do with cultural or communication problems, but the feedback from subscribers shows that they usually stop due to a low volume/lack of posts.

As subscriptions were initially purchased by Strategic health Authorities (SHAs) on behalf of providers and commissioners, a number of NHS Trusts did not renew their subscription when they had to subsequently pay for it. One problem with this model was that no (psychological) ‘contract’ between Patient Opinion and the budget holders in subscriber organisations had been developed. Other subscribers preferred to use NHS Choices because it was free.

The comparisons analysis advocates the benefits of managing customer relations with participating organisations on an on-going basis. While there was continued engagement with subscribers, some reported little contact with Patient Opinion once the service was set up as they were well trained to operate autonomously. This raised the question as to whether Patient Opinion needed to prioritise proactive on-going customer relations management activities to maintain engagement of subscribers and work with them on how to engage their staff and service users and promote the service.

Small, enthusiastic and engaging team

Patient Opinion was highly valued by both staff and patients for the quality of their support, their engaging approach and their willingness to respond. This worked effectively to bring people on board and build confidence in the feedback mechanism. In part this was down to the values, practices and size of the Patient Opinion Team. However, it was also possible because of the relatively low volume of feedback, which enabled the team to provide a bespoke approach.

One subscriber who valued this bespoke approach asked: *“How will they evolve if they do get more posts?”*

This raises a question as to whether the quality of the engagement and bespoke service valued, would reduce as the numbers of posts increase in line with Patient Opinion ambitions?

Local champions

Local champions were identified as being the most crucial link in the whole feedback service model, without which impact would not be effective. However, they mostly lacked organisational authority, secure funding and support resources to continuously engage patients and local services, and carry much of the work to be done. It was clear that the service often relied on these individuals and that this vulnerability was a significant issue.

Active ‘agency’ by subscribers

Analysis of the Patient Opinion model (see figure 8 on p54) shows that there are a number of ‘boundaries’ to navigate for feedback to have real impact, and there needs to be *active agency* at the interface of each transaction boundary; with patients, with subscribers, and between commissioners and non-subscriber providers.

Where the services are within subscriber organisations, eliciting a response (in theory) is more straight forward, as there is a designated lead role in the service and there is the potential to use line management authority to drive a response and change. However, where active agents are outside the organisation e.g. external to Patient Opinion, the only authority they have is influence and persuasion, and as we know from experience of leading change within the NHS, this in itself is insufficient to bring about the desired change.

3.6 Research question 5:

Is there any evidence that there are particular advantages or disadvantages to an independent as compared with an NHS-run feedback platform?[48]

3.6.1 Advantages and disadvantages

When looking at the particular advantages and disadvantages of an independent feedback mechanism compared with an NHS run feedback platform, it is clear that the advantages identified, relate to patient experience and the disadvantages relate to quality improvement:

ADVANTAGES	DISADVANTAGES
Perceived as trustworthy, independent and transparent.	Service is dependent on high volumes of posted feedback for subscribers to feel confident and renew subscriptions
Provides opportunity for people to offer their experiences anonymously reducing fear of reprisal and intimidation.	Having impact on quality improvement is difficult as Patient Opinion is not part of the system of action
Provides opportunities for people to tell others about their experiences, whether good or bad; this fulfils a function that is cited as not being available via other sites.	Potential for subscribers to see the service as outside of the organisation and not understand their responsibility to promote and publicise service as an 'external' body is providing the feedback mechanism.
Experienced by patients as more satisfying because it is engaging, responsive and timely.	Over-reliance on individual PPI champions who are generally under resourced and often structurally isolated from operationally-based quality improvement processes to promote and drive the process.
People feel more positive after providing feedback, both about themselves and the NHS, and in some circumstances, have gone on to become advocates for the NHS.	Reliance on subscribers to drive the follow-through on feedback and implement change. If there is no follow-through and subsequent impact, this leaves the independent feedback service vulnerable to non-renewal of subscriptions.
Staff feel more trusting of the service because it is more engaging, feeds back both praise and concerns, maintains their anonymity and approaches feedback as learning not blame.	If no action taken by provider or commissioner, difficult to know whether there was impact and follow-up.

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[48] How significant are the underlying values and positioning of the platforms in determining the value of different feedback sites to patients and NHS stakeholders? Is there any evidence of a differential impact on feedback as a driver of quality improvement?

3.6.2 Meeting patients and staff needs

There is much to commend the service provided by Patient Opinion, and it seems to be addressing many of the limitations patients experience when using existing complaints mechanisms. The evidence suggests that the values articulated and practised by Patient Opinion are significant features in meeting the needs and satisfaction of patients wanting to give feedback about their healthcare experiences, and of staff receiving and working with that feedback.

Patients prefer using Patient Opinion because they feel safer (anonymity), trust them because they are independent, are more than satisfied with responses and the speed of responses, like to show their appreciation of staff, tell stories of their experiences where this was a concern so that others don’t have the same experience, feel empowered by the positive experience of being heard and feel more positive about the NHS. Staff, once they know about Patient Opinion and are involved in the process, also feel that it is more credible because it is independent, more engaging and less threatening because they also have anonymity, they are not exposed in public and that the focus is on learning.

3.6.3 Embedding quality improvement

These positive values and approaches are insufficient however, to bring about impact in the services; there are problems influencing change across the organisational boundary into the NHS.

Any independent provider may experience difficulties of this nature, where they are dependent on the subscriber to follow-through on the causal chain of activities, and there is no evidence that a national or local NHS run-platform would necessarily be able to overcome these same disadvantages, while at the same time delivering the advantages.

It seems that this platform’s service model is limited when impacting on quality improvement, because it leaves the challenge of using the data and driving change, to the internal world of the NHS. This would suggest that the theory of change that *stories about the quality of services appearing in the public domain that affect an organisation’s reputation will* ***automatically*** *become a driver for quality* is currently difficult to realise in the NHS.

Given the evidence about the lack of quality improvement impact in the NHS (Davies and Cleary, 2005) and evidence from this evaluation of the dependence of Patient Opinion’s feedback mechanism’s service model on *active agency* at the interface of each transaction boundary (see figure 8 on page 60), this would suggest that there a different form of active agency (and service model) is required at the boundary between Patient Opinion and subscriber organisations.

The answer may lie both in shifting the focus from feedback to impact and from being wholly external to the NHS, to working in partnership for change across the whole system. This could be done by exploring aspects of the service model *Iwantgreatcare.com* provides, which recognises that the NHS requires assistance to develop the capability and culture required to embed quality improvement, for this to be effective and sustained.

While the service model of *Iwantgreatcare.com* might be viewed as focussing on *performance management*, this could be adapted to focus on *organisational development*, with a dual focus on impact and learning, while nevertheless drawing on some of their *activities* that seem better designed to deliver Patient Opinion’s desired outcomes:

- Contracting with the Board and senior clinicians where authority and accountability for implementation ultimately lies;
- Fully engaging the organisation (Board, management, front-line staff and patients) to create a shared purpose and strategic vision of positive patient experience and embedded quality

improvement;
- Using existing (or establishing new) cross–organisational working groups including patients to drive and monitory quality improvement;
- Linking feedback to operational priorities and mechanisms for quality improvement;
- Providing workshops to review, analyse and agree on actions; and
- Establishing web-based quality dashboards[49] that regularly keep staff informed of both positive feedback and concerns.

In addition to these activities we suggest it might be useful in the early stages of subscriptions, to:

- work with the cross organisational working group to assess of the ability of the organisation to use feedback to improve the quality of the services; this might take an *appreciative inquiry* approach to actively and positively engage staff as part of bullet point 2; and
- establish a series of cultural and structural indicators, against which these activities can be continually assessed which is the responsibility of the Board to implement and review.

3.6.4 Sustainable, strong and replicable model

The final elements to be discussed in this evaluation - how far is this model sustainable, strong and replicable across the constituent parts of each NHS organisation and between NHS organisations – is not straight forward, particularly in a changing landscape following administration change and the publication of the white paper *Equity and Excellence: Liberating the NHS* (DH, 2010)

3.6.4.1 *Sustainable and strong model*

The evidence from this evaluation suggests that those organisations and services that already embed user involvement in their clinical and care practices and have an infrastructure for quality improvement, are more likely to effectively use patient feedback for quality improvement. Not surprisingly, Mental Health and Learning Disability organisations were more developed than mainstream healthcare organisations, as user involvement has been embedded into clinical and care practices since the late 1980s.

The evidence also suggests that the model works more effectively for providers than commissioners as there is one less boundary for feedback to traverse and there is more authority within the same organisation for improvement to be driven.

Commissioners argue that they need a critical mass of data (trends) to be able to act, particularly given the complex commissioner-provider dynamics involved, and they would also need to build requirements into contracts. We also identified that they would need an identified active agent managing the boundary between commissioner and provider, to have any effective impact. It is unclear however, even with these mechanisms in place, whether there can be any real leverage where a provider has choices over which system to use e.g. NHS Choices, and feedback is not actively monitored by commissioners who have very little capacity due to staffing levels.

As GP consortia become a reality, it is unlikely most will have the organisational capacity and tacit knowledge to establish and manage these systems from the outset. Furthermore, it will take some time for the new commissioner-provider dynamics to settle down. However, they may well be in a good position once properly established to advocate for patients in services commissioned.

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[49] Based on and potentially drawing on Darzi's recommendation for *Clinical Dashboard*s - toolset developed to provide clinicians with the relevant and timely information they need to inform daily decisions that improve quality of patient Care.

3.6.4.2 *Replicable*

We know that there are a number of different web-based feedback mechanisms that are used by both patients and NHS organisations. This together with the increasing expansion of technology, would suggest that there is good potential for replicability in the service examined, but some of the survey data suggests that Patient Opinion is particularly fulfilling the unmet needs of some patients.

As we can see above, some activities would need to be changed for this service model to be fully realised. However, the essential elements that facilitate this model working for both patients and quality improvement are *independence, engagement and relationship*. While independence is replicable, engagement and relationship are not easily replicable, without transformative work on organisational cultures.

That is not to say that it cannot be done; there needs to be strong leadership from the Board, role modelling to others a commitment to responding to, and acting on, feedback about patient experience and a commitment to developing a culture of praise and learning that helps staff move from a defensive position to one of being open and engaging with feedback.

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