Public Involvement in NHS Inquiries

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Abstract
Opportunities for engaging the public have changed over the fifty years since the inquiry into the Ely Hospital, Cardiff. NHS inquiries, and inquiries more widely, tend to be called where events have led to public concern and loss of public confidence. Involvement of the public could therefore be assumed to form a part of restoring that public confidence. This paper explores the mechanisms for public involvement in NHS inquiries over the past fifty years, assessing the roles played by the public. It uses the framework outlined by Geoffrey Howe to examine how members of the public have been involved in four NHS inquiries. Findings suggest that the roles and mechanisms have varied, but that understanding the extent of public involvement is a dimension to assessing each of the potential functions of an NHS inquiry.

Keywords: NHS inquiries, public inquiries, public involvement, public participation, Community Health Councils, healthcare disasters

WHAT ROLE do members of the public play in NHS inquiries? NHS inquiries themselves vary: they may be held in public or in private, may be independent, and may have judicial powers.1 This paper considers the roles played by members of the public in four NHS inquiries that varied in the extent to which they were conducted in public, and in the public involvement mechanisms available to support the inquiries.

Geoffrey Howe, himself the chair of the Ely Hospital inquiry, which is widely regarded as the first modern NHS inquiry, proposed six main purposes for inquiries: establishing the facts; learning from events; catharsis or therapeutic exposure; reassurance; accountability, blame and retribution; and political considerations.2 These purposes are used here as a framework for reviewing the roles played by members of the public in NHS inquiries. The public could be assumed to be an audience for the ‘catharsis’ and ‘reassurance’ elements in the framework, but the framework is applied here as a means to consider whether members of the public have also taken or have been expected to take more active roles in ‘establishing the facts’, ‘learning from events’, ‘accountability’ or ‘political considerations’.

This article discusses the role and expectations of the public as expressed in four NHS inquiries over time: Ely Hospital, Cardiff, 1969; Normansfield Hospital, Teddington, 1974; Bristol Royal Infirmary, 2001; and Mid Staffordshire NHS Foundation Trust, 2010 and 2013. This is a purposive sample, reflecting times when different public involvement mechanisms were in place. The inquiries also take different forms, which may impact on the extent to which members of the public are able or willing to be involved.

As context, the article opens with an overview of the role played by the public in the NHS, including changes over time to statutory public involvement institutions.

Public involvement in the NHS
The relationship between members of the public and the National Health Service in Britain is complex. As patients, individuals are dependent upon the NHS for care. As citizens and consumers, members of the public seek to ensure that the NHS is held to account for providing high quality and cost effective care. The dependency of members of the public on the NHS for care may limit their ability to raise concerns. In Hirshmanian terms, they do not have an ‘exit’ option unless they have financial means, and ‘voice’ may be inhibited by reliance upon and
loyalty to the NHS. Rather than individual treatment decisions, the phrase ‘public involvement’ refers to ‘involvement of members of the public in strategic decisions about health services’. Public involvement is a contentious term, leaving open issues of the level of engagement and who sets the agenda in which the public are involved.

There are four principal forms of public involvement in the NHS. Firstly, NHS-led consultation on proposed changes, particularly section 11 consultations under the Health and Social Care Act 2001. Secondly, involvement of voluntary sector organisations or interest groups, which tend to focus on a particular health condition or sector of the community. Thirdly, crisis-formed groups, where local members of a community come together in response to a disaster or local concern. Lastly, statutory public involvement institutions, or state-funded mechanisms for members of the public to be engaged in decision making within the NHS. The history of this last type of involvement forms part of the history of NHS inquiries.

In the early years of the NHS, public involvement in NHS decision making was through the lay members of Hospital Management Committees. Each committee oversaw several hospitals and members were local authority appointees, who tended to be significant figures in local communities. This changed in 1974 with the introduction of independent Community Health Councils (CHCs) in England and Wales, with statutory powers under the National Health Service (Community Health Councils) Regulations 1973. The CHC members were also appointees, but through a mixed appointment process: half of the members were appointed by local authorities; a third by local voluntary organisations; and a sixth by the regional health authority covering that district. Guidance issued with the regulations (NHS Reorganisation Circular: Community Health Councils HRC (74) 4) ensured that interest groups, particularly those representing more vulnerable communities, were included as members of the CHC.

Under the National Health Service Reorganisation Act 1973 and subsequent statutes, CHCs had rights to ‘enter and inspect’ NHS premises across a district and to appeal to the Secretary of State if ‘reasonably required’ information was declined. They also had statutory rights to be consulted and most offered support to complainants, providing the CHC with insights into problems in the local NHS organisations. These powers gave CHCs the potential to identify problems and refer them on before they became major issues, in the style of a ‘fire alarm’. Members of CHCs referred to themselves as being ‘watchdogs’ for patients in the NHS.

In 2003, CHCs in England were replaced by Patient and Public Involvement (PPI) forums, whilst in Wales the CHCs were retained. Unlike CHCs, the remit of PPI forums was confined to a specific NHS organisation, rather than a geographic district. They were also directed nationally by the Commission for Patient and Public Involvement in Health. The PPI forums within primary care trusts could ‘enter and inspect’ the NHS institutions within that primary care trust’s authority; other PPI forums could only visit the hospitals or other NHS institutions in which they were embedded. Whereas CHCs had a statutory right to be consulted, the arrangements for PPI forums and subsequent statutory public involvement institutions shifted into a requirement placed on NHS organisations to consult the public, under the Health and Social Care Act 2001, and to determine whether they would do so through the statutory public involvement institution or through some other mechanism.

The Department of Health replaced PPI forums with Local Involvement Networks (LINks) in 2008, as a structure to align with a more integrated approach towards health and social care, rather than remits restricted to specific NHS organisations. Under the Local Government and Public Involvement in Health Act 2007, LINks were established by local authorities and had rights to ‘enter and view’ social care premises and premises in which NHS-funded care was taking place. They could refer issues to their local authority’s Overview and Scrutiny Committee. In common with PPI forums, LINks did not have statutory rights to be consulted by NHS organisations.

LINks were replaced in their turn in 2013 by Healthwatch. Established under the Health and Social Care Act 2012, they have a clearer corporate structure than the LINks had, with
a national body, Healthwatch England, providing insights to the Care Quality Commission (CQC). Local Healthwatch groups do not have statutory consultation rights, but local NHS-funded organisations must allow authorised representatives to ‘enter and view’ premises and observe ‘the carrying-on of activities’ under The Local Authorities (public health functions and entry to premises by local Healthwatch representatives) Regulations 2013.

Whilst there have been extensive changes to statutory public involvement institutions in England, as mentioned above, CHCs in Wales have been retained. In Scotland and Northern Ireland, changes in 2005 and 2009 respectively centralised processes from local councils to the Scottish Health Council and the Patient and Client Council in Northern Ireland.

The changes to these institutions interconnect with the changes in how the public have been involved in NHS inquiries. The forms of public involvement, and the nature of the inquiries reviewed in this paper, are summarised in Table 1.

### Ely Hospital, Cardiff, 1969

The Ely Hospital in Cardiff was a long-stay psychiatric hospital for adults and children, many of whom also had physical disabilities. Public involvement in the hospital was through the Hospital Management Committee. The Ely inquiry found that committee members did not ask patients or more junior members of staff about their experiences when they made their formal visits to the hospital.6 The Committee of Inquiry criticised the rota mechanism that meant that

### Table 1: NHS inquiries and associated public involvement institutions

<table>
<thead>
<tr>
<th>Date</th>
<th>NHS body</th>
<th>Inquiry type</th>
<th>Statutory patient and public involvement institutions</th>
<th>Other patient and public involvement groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>1969</td>
<td>Ely Hospital, Cardiff</td>
<td>Committee of inquiry set up by Welsh Hospital Board. Held in private with public report.</td>
<td>Lay members of Hospital Management Committee</td>
<td>None involved</td>
</tr>
<tr>
<td>1978</td>
<td>Normansfield Hospital, Teddington</td>
<td>Committee of inquiry set up by Secretary of State under section 70 of NHS Act 1946. Held in private with public report.</td>
<td>Community Health Council</td>
<td>None involved</td>
</tr>
<tr>
<td>2010</td>
<td>Mid Staffordshire NHS Foundation Trust</td>
<td>Independent inquiry set up by Secretary of State. Hearings in private, but with summaries of evidence on website. Public report.</td>
<td>Patient and Public Involvement Forum Local Involvement Network</td>
<td>Cure the NHS</td>
</tr>
<tr>
<td>2013</td>
<td>Mid Staffordshire NHS Foundation Trust</td>
<td>Public inquiry set up by Secretary of State under the Inquiries Act 2005. Held in public.</td>
<td>Patient and Public Involvement Forum Local Involvement Network</td>
<td>Cure the NHS</td>
</tr>
</tbody>
</table>
Hospital Management Committee members visited Ely on average once every twenty months. The Ely inquiry reported concern about the lack of representation for vulnerable patients. Despite including two psychiatric hospitals in its remit, none of the lay Hospital Management Committee members had been recruited from a group with an interest in mental health, and none of them were ‘battling for’ Ely. When Richard Crossman, as Secretary of State, presented the Ely Hospital report to the House of Commons, his summary was that ‘the main recommendation of the Report is that a new system of regular visiting and inspection is needed. I agree’.7

The first element in Howe’s framework for the purposes of inquiries is ‘establishing the facts’. At Ely, as chair, Geoffrey Howe hoped to be able to use patients as a source for gathering information, but ‘because of the severe disabilities of most of them, little assistance was derived from this source’. The Ely inquiry was held in private and did not draw more widely on the public to help with establishing the facts. Public involvement was very much a part of the second element in the framework, ‘learning from the event’, at Ely, as the inquiry is credited with the later incorporation of visiting, referral and consultation rights into the CHCs.8 As a structured form of public involvement, the recruitment mechanisms for CHCs ensured that the interests of vulnerable groups would be represented.

Catharsis is hard to achieve unless there is direct involvement of those affected. At Ely, the difficulties with engaging patients and the private inquiry process meant that there were no opportunities for catharsis. In the aftermath of the Ely inquiry, the Secretary of State, Richard Crossman, established the Hospital Advisory Service, which could be seen as a public ‘reassurance’ mechanism in promoting best practice in hospitals. Both at a professional level and in creating a mechanism for structured public involvement, including rights to visit services and refer problems, the Ely inquiry generated reassurance mechanisms.

Organisations held to account, in the ‘accountability’ aspect of the Ely inquiry, included the lay members of the Hospital Management Committee, who were criticised for being too close to the management to represent the interests of patients. Finally, public involvement at Ely was also incorporated into the last of Howe’s proposed inquiry functions, ‘political considerations’. Geoffrey Howe was part of a policy committee in the wake of Ely that led to the introduction of the CHCs, incorporating the public into a formal role in monitoring health services. This monitoring role placed public involvement in NHS organisational decisions within the political arena for the NHS locally.

Normansfield Hospital, Teddington, 1978

Public involvement at Normansfield Hospital was through the Kingston, Richmond and Esher CHC. Like Ely, Normansfield was a long-stay hospital. It was founded by Dr Langdon Down, the physician who first identified the condition that has come to be known as Down’s syndrome. Shortly after the CHC was established in 1974, it started to raise concerns about conditions at Normansfield. The CHC copied the Secretary of State, then Barbara Castle, into communications with the area health authority and issued a press release, but the inquiry was only established when staff at the hospital went out on the first strike in the history of the NHS. The Normansfield inquiry was held in private with a public report. The Secretary of State in post when the report was published, David Ennals, praised the CHC in his introduction to the final report for ‘its tenacity in exposing and reporting on the situation it found at the hospital’.9 Whilst the CHC did not trigger the Normansfield inquiry, it was heavily involved in the inquiry process.

At Normansfield, the CHC played a major role in ‘establishing the facts’. A member of the CHC was included in the Committee of Inquiry, chaired by Michael Sherrard, and one of the twenty-two chapters in the inquiry report is devoted to the activities, reports and views of the council. The CHC was the sole mechanism for gathering input from the public into establishing the facts at Normansfield. Acknowledging the value of visits to identify problems early, the merit of CHC insights was a ‘learning’ for the
Committee of Inquiry. As a formalised representative body, however, the CHC inhibited ‘catharsis’, as it limited opportunities for therapeutic exposure of family members more closely affected by the quality of care at Normansfield.

The Normansfield inquiry continued to emphasise the need for the public to be involved in inspecting services, with the overarching theme being that the needs of patients override those of staff, and the assumption that poor care would be visible to lay inspectors. Normansfield did not change the structures for either involvement or inspection, but emphasised the value of existing mechanisms as part of ‘reassurance’ to the public. ‘Accountability’ following the events was placed in the hands of local organisations, under the observation of the CHC to bring a public involvement perspective.

Whilst the Ely inquiry contributed to the development of public involvement institutions with the legal powers that enabled them to act as ‘fire alarms’, the role of the CHC at Normansfield reinforced the political value of these powers in providing light-touch political oversight of problems managed locally and distanced from national politicians.

**Bristol Royal Infirmary, 2001**

The public inquiry into the Bristol Royal Infirmary investigated a comparatively high death rate from 1984 to 1995 among babies in the thirty-day period following open heart surgery. The public inquiry, chaired by Ian Kennedy, was triggered by the concerns of an anaesthetist at the hospital who had collated his own statistics and compared them with those for similar services. Bristol Royal Infirmary was ‘awash with data’, but ‘little if any of this information was available to the parents or to the public’. CHCs are described within the report as being ‘on the outside’, or seeking to find someone to blame rather than resolving an issue internally.

At Bristol, the anomaly in the number of children’s deaths was only identifiable through comparative statistics, rather than being observable by members of the public visiting the premises. The Committee of Inquiry did not involve the CHC in the process of ‘establishing the facts’ or ‘learning from events’ and described the councils as ‘tolerated mechanisms for venting public concern, because ultimately they could do nothing’.

A group of parents whose children had undergone heart surgery at Bristol Royal Infirmary created an action group, the Bristol Heart Children’s Action Group, which submitted evidence and became an audience for some of the debate. The Bristol inquiry was held in public, conducted workshops and provided transcripts of hearings online, increasing the opportunity for catharsis.

The ‘reassurance’ role after events at the Bristol Royal Infirmary took a different slant, with a greater reliance on data collection and comparative analysis. The Bristol inquiry led to Ian Kennedy’s direct involvement in the Commission for Health Improvement, the precursor to the Healthcare Commission and later the Care Quality Commission, as a reassurance mechanism on the comparative statistics, as well as a professional visiting mechanism. Like Ely, therefore, Bristol strengthened the inspection mechanisms as a means to reassure the public that structures were in place to reduce the risk of similar disasters.

The ‘accountability’ and ‘political considerations’ at Bristol explicitly excluded statutory public involvement institutions, as the inquiry report emphasised the need for a ‘no blame’ culture. Ten of the 198 recommendations related to public involvement, bringing involvement into NHS processes and leading to weaker statutory public involvement institutions as CHCs were replaced by PPI forums. It was assumed that issues would become identifiable through statistical returns and regulation. Events at the Mid Staffordshire NHS Foundation Trust were to show that external mechanisms for observation by the public and sharing of patient experience were still needed.

**Mid Staffordshire NHS Foundation Trust, 2010 and 2013**

During the period covered by the independent and public inquiries into Mid Staffordshire NHS Foundation Trust, the statutory
Public involvement institutions were the PPI forum and then the Local Involvement Network. Whilst these bodies had statutory rights to 'enter and view' premises, neither used these powers to raise concerns about the quality of care. Quality of care issues included insufficient staffing on the wards to ensure that patients were fed or hydrated, very poor hygiene, a culture of hospital staff not engaging with patients, and triaging of patients by receptionists. Issues would have been visible to observers, so the statutory public involvement mechanisms had powers that would have enabled them to identify issues and to raise concerns. The independent and public inquiries into Mid Staffordshire NHS Foundation Trust were both led by Robert Francis. He included examining the role played by statutory public involvement institutions within the issues to be explored in the public inquiry. Local people formed the group Cure the NHS and raised concerns through the Healthcare Commission that led first to an independent inquiry and then to the public inquiry.

Considered in terms of 'establishing the facts', events at Mid Staffordshire demonstrated that information sources are not just statistical. In the absence of strong statutory public involvement institutions, Cure the NHS was formally involved in the independent and public inquiries, supporting the call for evidence from members of the public. Public involvement was integrated into 'learning from events' through a role in visiting services, with the Mid Staffordshire public inquiry leading to a stronger public involvement mechanism through Healthwatch.

The processes for the Mid Staffordshire public inquiry were designed to facilitate direct involvement by members of the public, providing a forum for catharsis as an inquiry function. Members of Cure the NHS had been affected by the problems at Mid Staffordshire and were direct participants within the inquiry process. Public schedules of the witnesses were issued, and included senior NHS personnel called to give evidence, and full transcripts were published online within twenty-four hours of each hearing. Members of Cure the NHS and the public more widely therefore knew who had been summoned and could either hear or read their responses, as well as submitting evidence themselves.

Cure the NHS raised concerns initially with the Healthcare Commission and then called for a public inquiry. The group welcomed the independent inquiry, but continued to call for a public inquiry. Part of the political rationale for agreeing to undertake the public inquiry is likely to have been public 'reassurance' where the previous inquiries had failed to provide this. The recommendations from the public inquiry incorporated cultural change to increase openness, including a 'duty of candour', and strengthening of the Care Quality Commission's role.

In evidence to the public inquiry, the former Secretary of State, Andy Burnham, indicated that he had not initially accepted the call for a public inquiry as the PPI forum had not expressed concerns about the Stafford Hospital. Formalised public involvement was therefore held accountable for failing to raise a 'fire alarm' at Mid Staffordshire.

Formalised inspection structures did not distance national politicians from accountability for the problems in a local hospital. The 'political considerations' in the Mid Staffordshire public inquiry included responses to strengthen regulation alongside public involvement to keep the Secretary of State and the new Care Quality Commission advised of issues, with Healthwatch England reporting in to the CQC as well as having political referral mechanisms.

The Mid Staffordshire inquiries demonstrated the need for patient experience and public involvement alongside data to manage issues, and that members of the public will continue to call for a public inquiry if other inquiry mechanisms have not addressed their concerns.

Public roles in NHS inquiries

These four NHS inquiries demonstrate a shifting relationship between public involvement and inquiries in the NHS. The selected set of NHS inquiries have had implications for the powers and operation of statutory public involvement: the creation of CHCs after Ely; the reinforcement of a fire alarm...
oversight role at Normansfield; the disbanding of CHCs after Bristol; and the reinforcement of the visiting oversight role of Healthwatch after the events at Mid Staffordshire. In these examples, the relative strength of statutory public involvement institutions has had implications for the roles played by the public.

The first potential purpose of an inquiry in the Howe framework is ‘establishing the facts’. In this context, the visiting rights of statutory public involvement institutions could be seen as a means to create a ‘fire alarm’ or ‘watchdog’ to alert authorities to issues before they become disasters. This treats public involvement institutions as an oversight mechanism, in the terms of McCubbins and Schwartz, as an alternative to more formalised ‘police patrol’ surveillance. Public involvement may in this context be formalised to enable authorities to act on problems before the need for a formal inquiry arises, but may also provide insights as part of gathering facts during the inquiry process.

Public involvement in ‘establishing the facts’ is associated either with a strong statutory public involvement mechanism, as at Normansfield, or with a passionate group of local people who are keen to resolve issues, as at Mid Staffordshire. In both instances, the involvement with ‘establishing the facts’ related to issues that were visible to patients and the public, rather than the statistical basis of insight at Bristol. Involvement in ‘establishing the facts’ is dependent either on a public process or explicit engagement mechanisms. The Ely inquiry team attempted to involve members of the public in ‘establishing the facts’, but the severe disabilities of patients and lack of engagement by the lay Hospital Management Committee meant that this was not possible. The public can therefore have a role in ‘establishing the facts’ where they are empowered to do so, and where the issues are apparent either by visiting services or through patient experience.

‘Learning from events’ is closely allied to establishing facts in the case of public involvement, as the monitoring that provides insight into what has happened can also form part of the process for reducing the likelihood of similar events in the future. The creation of CHCs after the Ely inquiry, and their ongoing role following Normansfield, enabled lay members of the public to alert authorities promptly to observed problems, following a fire alarm surveillance model. Statutory public involvement was not seen as part of the process of distilling lessons or reducing the risk of recurrence at Bristol, contributing to the weakening of statutory public involvement institutions. This weakening of mechanisms meant that the statutory mechanisms were criticised for not having alerted authorities to problems at Mid Staffordshire.

On the basis of this small sample, public expectations of catharsis seem to have increased over time and to be dependent on a public process. Catharsis was not part of the design at Ely and a strong, corporatist structure for involvement through the CHC reduced the opportunities for catharsis at Normansfield. It was not the statutory public involvement institutions that increased the catharsis element in this sample, but the combination of public processes and groups creating themselves in response to local crises in Bristol and Stafford. Opportunities for catharsis have also increased through the growth of online sharing mechanisms, with online engagement forums, shared lists of interviewees and either broadcast or rapid online transcription of inquiry sessions.

Whilst this is a small sample, the ‘reassurance’ role of NHS inquiries has been a strong element in creating structures or increasing powers to restore public confidence that events will not reoccur. The direct role of these specific inquiries in the shape of statutory public involvement institutions is atypical, but shows a general trend of lay visiting being part of reassurance up to the Bristol inquiry, followed by a greater dependence on data that was overturned by the Mid Staffordshire inquiries.

The counterbalance to a reassurance role is that statutory public involvement institutions are also subject to ‘accountability, blame and retribution’. At Ely and Mid Staffordshire, the formalised involvement mechanisms then in place were blamed for not doing more to alert authorities to problems. By contrast, the desire in the Bristol inquiry to create a ‘no blame’ culture meant that the CHC was criticised for being seen to be outside the NHS.
and potentially seeking to blame NHS staff rather than seeking to resolve issues within the NHS.

‘Political considerations’ and a sense of something being done have generated changes for the statutory public involvement institutions, whether in the creation of CHCs after Ely, the reinforcement of their role at Normansfield, or the changes following both Bristol and Mid Staffordshire. In this function particularly, the public are not just an audience, but their involvement is one of the changes associated with the politics of NHS inquiries.

The functions framework developed by Howe was not created to consider the functions of the public in NHS inquiries explicitly. This application, however, demonstrates that public involvement may form a part of any of the six proposed functions of an NHS inquiry. The public are therefore participants in NHS inquiries, not simply an audience for the inquiry reports.

During the fifty years since the first modern NHS inquiry, digitisation and development of online resources have changed the process for some of the aspects of public involvement in NHS inquiries. Notably, catharsis can be broader and less structured with the development of online forums and broadcasting or sharing of transcripts during the inquiry process. Digitisation has also created opportunities for comparative data to be used to identify problems in NHS organisations, rather than observation through public involvement institutions or regulators. The experience at Mid Staffordshire shows, however, that personal experience and observation of care are needed as well as statistics to understand performance in the NHS.

The public are therefore an active part of the process for NHS inquiries. This reflects the wider involvement and engagement of the public in organisational decision making within the NHS.

Notes