

Discovery Interviews: a mechanism for user involvement

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Abstract

Discovery Interviews have become widely used in the UK National Health Service as a service improvement tool and patient involvement mechanism. This first paper in a series of three explores the development of Discovery Interviews in the NHS in the context of explicit central government policy of the development of patient-centred services and user involvement in shaping health service organisation and delivery. It draws on the published literature on Discovery Interviews to date, including that on evaluation.

Introduction

Discovery Interviews were developed by the NHS Heart Improvement Programme in 2000 and have since become widely used in the UK National Health Service as a service improvement tool and patient involvement mechanism. They are conducted by practitioners and others, trained in the technique, involved in service delivery with patients who have been or are still in receipt of care, typically but not always from the interviewer's own organisation. Transcripts from the Discovery Interviews are reflected on by local clinical and service teams to inform service improvements through a process of identification of issues and or processes of concern.

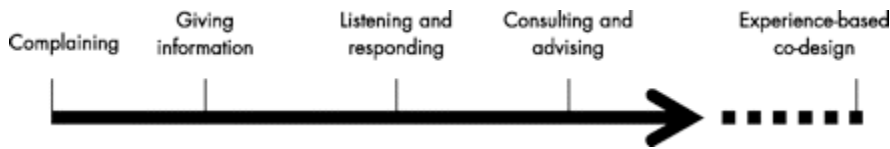
This paper explores the development of Discovery Interviews in the NHS in the context of explicit central government policy of the development of patient-centred services and user involvement in shaping health service organisation and delivery. It draws on the published literature on Discovery Interviews to date, including that on evaluation.

UK policy context

The NHS Plan (Department of Health 2000) set the stage for widespread modernisation of the NHS. It focused on redesigning services around patient need, in contrast to the portrayal by the Plan's authors of services at the time being designed around organisational need. A wide range of reforms were thus launched. The notion of 'patient-centredness' was given serious policy attention (in spite of a lack of agreement as to which interpretation of the term was to be used (Kendall & Lissauer 2003)) and its influence can be seen in efforts to reduce waiting times, to promote patient choice of health care provider, and in a growing interest in patient experiences and preferences while in receipt of health care (Department of Health 2005; Department of Health 2001; Department of Health 2003). The NHS Plan also sowed the seeds for what was later to become policy aimed at promoting active service user involvement in shaping the delivery of services.

Bate and Robert (2006) set out a continuum of patient influence that reflects the development of NHS policy in this area (Figure 1). Prior to the NHS Plan, policy was reflective of the first two stages of the continuum, and focused on responding to service user complaints, and providing information to service users. The NHS Plan shifted policy along the continuum by requiring that all organisations providing health care ask patients and carers for their views on services received. This practice was not widespread at the time, so its inclusion in the NHS Plan represented progress, but it fell far short of recommending active involvement of patients in shaping service delivery.

Figure 1 Continuum of patient influence



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In 2001, the high profile of several cases of serious failings of care, for instance Bristol Royal Infirmary undermined perceived public confidence in the NHS and this led to a number of central government measures, including promoting a more active role for patients and the public (Kennedy 2001). New, legally enforceable duties were placed on NHS bodies (Section 11 of the Health and Social Care Act 2001) to involve patients and the public in every stage of the planning and delivery of services and a range of techniques were developed or extended to comply with that requirement. However, while a range of structures to promote patient and public involvement have been introduced, the processes by which patient involvement might happen are less clear (Fudge, Wolfe, & McKeivitt 2008). This is perhaps because different understanding exist of what user involvement is, and evidence that user involvement is still ultimately controlled by service providers (Bate & Robert 2006; Fudge, Wolfe, & McKeivitt 2008; Robert et al. 2003). Bate and Robert make the case for experience-based design that places “the experience goals of patients and users at the centre of the design process and on the same footing as process and clinical goals” (p. 308). In this approach, service users and providers are co-designers aiming to design experiences rather than services.

A further issue in current user involvement strategies is the representativeness of the service users who are invited and/or agree to be involved (Fudge, Wolfe, & McKeivitt 2008). There is general agreement that some groups, including older people, are harder to involve than others. There are positive published accounts of involving older people in service development (Forshaw 2007; Greene 2008; Hayes & Dearnley 2007), but a wider lack of involvement may reflect their low status in society and thus the lack of interest from organisations in what they have to say. In addition, practical concerns such as impaired hearing, speech, cognition or physical ability may be perceived by older patients and/or service providers as a barrier to involvement. Finally, ageing may lead to lower expectations of care, and this, coupled with an increasing sense of dependency on existing care providers, can affect older people’s willingness and/or their capacity to evaluate their care (Owens & Batchelor 1996), let alone become actively involved in shaping local health services.

It may be that some user involvement mechanisms are better than others at involving seldom heard groups. This paper next presents Discovery Interview technique as a user involvement mechanism and assesses its potential to involve older people in shaping health service organisation and delivery.

Understanding Discovery Interviews

There are a large number of techniques for involving patients and the public in healthcare. Selecting a technique depends upon the aim of the work being undertaken i.e. feedback of patient views, supplying information to patients or involving patients in dialogue and decision-making. As policies that promote patient and public involvement take root, interest is growing in how patient and carer experiences can be captured and explored, with a view to informing service improvement. New techniques are emerging that provide a framework to achieve this and the use of Discovery Interviews is one such technique.

Part of the modernisation work of the NHS has taken place through the development of national condition-specific 'collaboratives' for particular patient groups that aimed, through national teams that co-ordinated national learning and disseminated good practice, and local project managers, to examine care delivery processes and systems and make improvements where these were needed optimising care delivery across the whole integrated pathway of care. (Bateson et al. 2003; Robert, Hardacre, Locock, Bate, & Glasby 2003). One of the tools built up by the coronary heart disease collaborative in particular (now the NHS Heart Improvement Programme) has been the development of Discovery Interview technique a method that helps to gather patient and carer stories to inform service improvement and which is now a mainstream service improvement methodology across cardiac networks. The use of the technique is based on the principles of continuous quality improvement (CQI) and the Nolan framework (Langley et al. 1996). CQI uses knowledge to identify changes for improvement, plans a test and learns from the results (CHD Collaborative 2004). The 'Building Knowledge for Improvement' Nolan framework enables changes to be built systematically into improvements through small changes being quickly implemented and tested, with larger improvements are achieved through a cumulative effect (CHD Collaborative 2004; Langley, Nolan, Nolan, Norman, & Provost 1996; NHS Modernisation Agency 2004). 'Plan-Do-Study-Act' (PDSA) cycles are used to test improvement ideas, so that new ideas can be implemented with a greater chance of success (CHD Collaborative 2004). Discovery Interview technique uses knowledge gained through interviews with patients and carers to stimulate improvement activities such as PDSA cycles. Discovery Interviews "are based upon a philosophy that puts patients and carers at the centre, and values listening to their experiences as a way of gaining insight which is unavailable elsewhere" (Matrix 2005). The approach seeks to help teams understand what it is like to be a person – rather than a patient – or carer of a person, with a particular condition or in receipt of a particular set of services. Discovery Interviews are one-to-one face-to-face interviews, using open questions and supplementary probing, that aim to enable patients and their carers to directly tell their story. The framework of a 'spine' is devised with input from local service users prior to the interview stage and is used to guide interviewees through key stages of their experience. The spine reflects the whole pathway of care from the point of learning that something is wrong through to living with the condition, and aims to encourage storytellers to weave in descriptions and interpretations of their experience of this illness journey. Skilled use of the spine by the interviewer is intended to encourage a natural discussion about the patient/carer experience that triggers significant memories and thoughts. The open-ended nature of the

interview echoes narrative methodologies in qualitative inquiry, and serves as an antidote to the limitations of patient satisfaction surveys (Bateson, Brown, Wilcock, Carver, & Machin 2003). Discovery Interviews are based on principles of giving the storyteller the control (because there are less questions from interviewer) and Bateson et al argue that interviewees are therefore more likely to share private accounts better reflecting personal experiences and their impact on thoughts and feelings that accompany them. Access to an individual's private account of experience is encouraged through telling stories rather than answering questions.

In addition to the potential merits of a one-to-one, semi-structured interview, Discovery Interview technique has other notable features. Introducing the use of Discovery Interview technique to an organisation requires executive level support, a process of embedding the work at a strategic level within the wider service improvement and patient and public involvement strategies. This requires each organisation to go through a period of preparation to ensure that key stakeholders understand and support the technique and can play their part in integrating it with wider organisational strategy. This approach is supported in the literature by research that has highlighted the importance of organisational context in change efforts (Bridges, Fitzgerald, & Meyer 2007; Dopson et al. 2002).

Use of the technique is typically led by individuals who are locally employed, in for example, local patient advice and liaison services, audit departments, or who are practitioners or managers involved in providing services. These individuals receive two days training in approaching and consenting interviewees, conducting the interview, sharing the transcripts locally, and dealing with ethical issues should they arise. They may not otherwise have had interview, research or service improvement experience. Involving local staff serves two purposes. Both the impact on the interviewer of listening to the stories first-hand, and any existing credibility that interviewer has with local colleagues, may optimise the chances of success of any improvement activities. Using Discovery Interview data to stimulate service improvements draws on the recognized power of stories in stimulating reflection and service change (Bate 2004; Hatem & Rider 2004; Hurwitz, Greenhalgh, & Skultans 2004; Newman 2003). Interview transcripts are used in their 'raw' form by local teams to stimulate reflection and service improvement. No attempts are made by the interviewer to identify themes in the interviews. Rather the information is shared in its original form to act as a catalyst for discussion and change management.

Contribution of Discovery Interviews to user involvement

Formal evaluation of Discovery Interview technique to date is limited to one study. Matrix (2005) used document review, stakeholder interviews (n not given), questionnaire survey (n=450) and case study fieldwork (n=7 sites) to explore the impact of Discovery Interview technique on services targeted in two national programmes: coronary heart disease and whole health communities. Matrix identified a number of influencing factors for the success of Discovery Interviews. These included a commitment and leadership by the organisation's Discovery Interview lead to the technique; full and early engagement by key local stakeholders; administrative support; establishing strategic links at Trust

managerial level and clinical team level; and ensuring that service improvement activities take place after patient narratives have been gathered. Matrix (2005) also claimed a range of benefits from using the Discovery Interview process including alteration of personal attitudes and/or behaviours as a result of hearing or reading a Discovery Interview. Forty five percent of respondents stated that Discovery Interviews had led to changes in care, services or facilities at the clinical team level, 32% at the departmental level and 22% at Trust level.

Other authors have also claimed benefits to using Discovery Interview technique. Brown et al. (2004) claim improvements resulting from 40 Discovery Interviews in the national critical care collaborative ranging from “small changes in direct patient care on individual units, to influencing a change in policies throughout a whole hospital” (p. 125). Bateson et al. (2003) report on the pilot phase of the coronary heart disease collaborative and the critical care collaborative, and provide two case study examples of practice changes which they claim are among numerous examples of “narratives leading to patient-centred changes as part of a quality improvement programme” (p. 8).

Questionnaire respondents in the Matrix (2005) evaluation reflected a largely positive impact on the organisational culture of user involvement in particular. Sixty two percent of respondents agreed that Discovery Interviews had led to “changes in attitude and thinking about patient and carer involvement, service improvement and the development of patient-centred care” across the organisation (p. 30). Fifty five percent agreed that use of the technique had led to “a stronger commitment to patient and carer involvement in service improvement” (p. 30).

Conclusion

These positive evaluations are encouraging, although more detailed evaluation would now be of value, given the current use of the technique with a wider range of patient groups, and a more sophisticated understanding that has developed of the characteristics and pitfalls of user involvement. Since the Matrix report, and alongside the wider use of Discovery Interview technique, anecdotal evidence has continued to emerge on the power of Discovery Interview data in stimulating service improvements. The technique appears to capitalise on our ability to process stories in making sense of the world around us and builds on a connection to the storyteller through their accounts of events which would not be possible if the story were recounted by a dispassionate observer. Hearing Discovery Interview stories may help health care teams in to develop congruence with service users’ perceptions, expectations and needs and to provide patient centered care, but more detailed evaluative work is now needed to explore this potential, and to feed into the ongoing development of the technique.

Evaluation to date has not looked specifically at the impact of involvement on harder to reach groups, such as older people, despite their probable inclusion in the above collaboratives’ patient populations. Given the question marks about representativeness in user involvement initiatives in general (see above), it would be helpful to profile which people are being targeted for inclusion in Discovery Interviews. The third paper in this series (Bridges & Nicholson 2008) reports on the profile of older patients included in

Discovery Interviews about urgent care, and illustrates how the patient profile reflects very limited representation of individuals from ethnic minorities and no representation from care home residents. More work in this area would be of value.

Further, it is important to develop a better understanding of the generalisability of Discovery Interviews and to explore if the lessons learned in one setting can be successfully transferred to other settings, without loss of impact and relevance. If stories are indeed “exportable”, the potential of Discovery Interviews to promote service improvements will be further enhanced. It would also suggest the desirability of developing a central database of interview transcripts, provided this is consistent with ethical requirements.

Finally, while the use of Discovery Interview technique may promote strategies for user involvement in organisations it is just one approach in a required raft of such mechanisms. Service users will need to be involved in other ways and with regard to Discovery Interview technique, this may well involve thinking about how to involve users at other stages of the process, particularly in feedback to local teams and planning service improvements. In a recent example, service users drawn from Older People’s Action Groups conducted Discovery Interviews with other, older service users, and this represents a move away from a process that, to date, has been largely controlled by professionals. The findings were reported directly to the local Champions Forum for Older People, thereby incorporating a mechanism to support and monitor service improvement. If user experience is to become central to how services are shaped and delivered (Bate and Robert 2006), care needs to be taken that key patient groups are included in sharing their experiences, and for most health and social care services, this means enabling a range of older service users to have a voice.

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