

Service user engagement and health service reconfiguration: a rapid evidence synthesis

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Scientific summary

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Background

The need to fully engage staff, patients and the public in discussions and decisions about changes to the way health services are delivered has been recognised for many years. In England, local authority health overview and scrutiny committees must be consulted by local NHS bodies about proposals for substantial changes to services. Committees can refer proposals to the Secretary of State for Health if they are not satisfied with the consultation process or consider that the proposals are not in the interests of the health service in their area. The Independent Reconfiguration Panel (IRP) provides independent advice to the Secretary of State in such cases. More recently, the Health and Social Care Act 2012 established a new mechanism (Healthwatch) to drive patient involvement locally and nationally across the NHS. Best practice guidance is available from several sources, for example NHS England's *Planning and Delivering Service Changes for Patients* (Leeds: NHS England; 2013) and *Transforming Participation in Health and Care* (Leeds: NHS England; 2013). Proposals for service changes by commissioners and other bodies are required to pass four tests, the first of which is to be able to demonstrate evidence of strong public and patient engagement.

While much of the guidance reflects common sense, there is a need to establish the strength of the evidence base around different approaches to public engagement and involvement and in terms of impact. Proposed changes to health service delivery are often controversial locally and sometimes nationally. Effective public engagement may help resolve controversy and result in a broad consensus on the way forward. In contrast, inadequate consultation may result in lack of agreement, leading to proposals being delayed or referred to the IRP or ultimately the courts.

A wide variety of approaches to public engagement and involvement are available. Examples include surveys, face-to-face and telephone interviews, public meetings, focus groups, online consultations (including use of social media), local referenda and citizens' juries (also known as citizen panels or stakeholder dialogues). The available literature describing and evaluating how these approaches have operated in practice appears to be disparate and widely scattered. Any evidence that can clarify factors associated with positive public engagement will be of value both to NHS decision-makers and to society as a whole.

Objectives

To assess what is known about effective patient and public engagement in reconfiguration processes and to identify implications for further research. The specific research questions were as follows:

1. How have patients and the public been engaged in decisions about health service reconfiguration in the past?
2. How has patient and public involvement affected decisions about health service reconfiguration?
3. Which types of patient and public involvement have had the greatest impact on these decisions?
4. Which methods of patient and public involvement are likely to be sustainable/repeatable?
5. How have differing opinions about reconfiguration between patients, public, and clinical experts and other senior decision-makers been negotiated and resolved?

Methods

Scope and definitions

The project was resourced as a rapid evidence synthesis. There is no generally accepted definition of this term and a number of other terms have been used to describe rapid reviews incorporating systematic review methodology modified to various degrees. Our intention was to carry out a review using systematic and transparent methods to identify and appraise relevant evidence and produce a synthesis that goes beyond identifying the main areas of research and listing their findings. However, we foresaw that the process would be less exhaustive and the outputs somewhat less detailed than might be expected from a full systematic review. Added to this, we expected to find limited evidence on the subject in the peer-reviewed primary literature.

The focus of the review was reconfiguration of health service provision in the NHS. Reconfiguration includes large-scale system change, such as relocation of hospitals, (re)location of specialist care and changes in provision of urgent/emergency/out-of-hours care. We did not consider small-scale change, for example at hospital ward level or within a general practitioner practice.

We defined patient/public/user/carer engagement or democratic involvement as including any means of seeking and responding to the views of patients and the wider public at any stage of the process of reconfiguration (including identifying possible options for change). We have not attempted to standardise the varied terminology used to indicate service user engagement across the included studies. In our search strategy, terms included 'user' and 'carer' engagement and involvement. The scope included existing patients, carers and their representative groups, and the general public and their representatives (e.g. local councillors and Members of Parliament).

Data sources

We carried out separate searches for systematic reviews, primary research studies and grey literature. Searches were limited to material published in English from 2000 to March 2014.

We looked for relevant evidence in three main areas:

- Systematic reviews of methods of/approaches to patient/public engagement. We included only reviews that are relevant to patient/public involvement in decisions about health service reconfiguration. Reviews of patient/public involvement in research were excluded.
- Empirical studies of any design evaluating methods of/approaches to patient/public engagement. Studies that focus on involvement in research were excluded.
- Case studies that have examined how patient/public involvement has worked in specific examples of system change in the recent past.

The following databases were searched for systematic reviews: the Cochrane Database of Systematic Reviews (CDSR), the Campbell Library, Database of Abstracts of Reviews of Effects, Database of Promoting Health Effectiveness Reviews, the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre), Evidence Library and Health Systems Evidence (www.mcmasterhealthforum.org/hse/). For primary research we searched MEDLINE and MEDLINE In-Process & Other Non-Indexed Citations, Applied Social Sciences Index and Abstracts, Health Management Information Consortium, PsycINFO, Social Care Online and the Social Science Citation Index. In addition to the database searches, a wide range of websites relevant to UK health policy, health service delivery and organisation, and user engagement were searched to identify any policy documents, reports, case studies or grey literature.

The following were excluded:

- 'emergency' reconfigurations triggered by failure of a service provider, such as a NHS trust
- consultation/involvement of NHS staff, except as part of a broader consultation where staff and patient/public involvement could not be separated
- patient/public representation on bodies where reconfiguration is part of the remit but is not the main focus
- patient/public engagement methods where complaints management is the focus (e.g. patient advice and liaison service and the Healthwatch independent advocacy arm).

Review methods

Records were managed within an EndNote library (EndNote version X6, Thomson Reuters, CA, USA).

Final decisions on study inclusion were made by two reviewers independently. We used EPPI-Reviewer 4 (Evidence for Policy and Practice Information and Co-ordinating Centre, University of London, London, UK) to record decisions and for data extraction and quality assessment. We carried out a narrative synthesis using multiple frameworks (including pre-specified research questions and current guidance). In synthesising the case studies, we selected a number of 'exemplars' based on quality of reporting and some evaluation of the process of engagement.

Results

The searches identified 2322 potentially relevant references, of which 1896 were excluded based on title and abstract and 15 were unobtainable. Following screening of full texts and websites, eight systematic reviews, seven empirical research studies and 24 case studies (six exemplars) were included. The evidence contributed to answering research questions about methods of engagement and effects on decision-making. Evidence was less substantial in relation to research questions about the differential effects of methods, their sustainability and the means of negotiating differences between stakeholders. Methods of engagement were varied in nature and intensity, and generally involved a mixed methods approach. Engagement programmes were conducted across a range of health services with diverse audiences. There was no evidence on the isolated impact of any particular engagement method or collection of methods. There was little detail about their sustainability.

The impact of engagement was variably measured and demonstrated. Impact was more frequently defined in terms of process measures rather than success or failure of reconfiguration. Key process factors identified were organisation readiness and commitment to service user engagement, clarity of aims and adequate resources. Although the overall quality of evidence was mixed, key factors specifically associated with positive service user engagement were identified from the exemplar case studies. Indeed, the exemplars identified may represent what good evidence looks like. Clearly reported objectives, methods, contextual detail and reflective reporting are key elements to achieving good-quality evidence in the future. Little was reported on the potential negative impact of service user engagement, but the variable effect of media coverage (which may encourage polarised views) was highlighted; lessons from past referrals to the IRP appeared potentially helpful.

Conclusions

This review has identified that meaningful engagement is hard to achieve, and research to evaluate its impact is difficult to conduct.

Nevertheless, our review demonstrated that it was possible to address these difficulties. Great advances have been made to set out frameworks for engaging users in discussions and decisions about service reconfigurations. We found a number of exemplar case studies which showed meaningful engagement could be achieved. Our review also demonstrated that present NHS England guidance goes some way to providing a helpful working framework for future engagement activity. Moreover, although the evidence base was not large, we found studies that provided insight into the value of user engagement and its impact on shaping service reconfiguration. In particular, this review has succeeded in clarifying some of the factors associated with positive service user engagement.

Patients and the public could be engaged through a wide variety of methods ranging from public meetings and distribution of information to the use of modern social media. People could be engaged as individuals, in small groups and in larger groups. In selecting which methods to employ locally, decision-makers will need to take into account the nature of the local population and of the proposed service changes. In general, engagement was most likely to be successful when the process started at an early stage of planning service change, offered opportunities for genuine interaction, and was led and supported by clinicians involved in delivering the relevant services. Interactive methods involving small groups, such as citizens' juries, could be very successful, although there may be difficulties in recruiting genuinely representative samples.

Our review also highlighted the importance of engaging with public representatives (in England primarily in the form of local authority scrutiny committees). The committees were important because of their power to refer disputed reconfiguration proposals to the IRP, an outcome that NHS decision-makers should seek to avoid. The IRP's summary of lessons from its reviews is an important resource, as is the availability of informal advice from the IRP.

The IRP report noted that problems often arose because NHS decision-makers paid insufficient attention to issues considered important to the public. There was evidence from case studies and public opinion research that many people were unwilling to accept longer journey times in return for the promise of better care at specialised centres. Since reconfiguration often involves centralisation of services, tackling these issues may warrant consideration by the leadership of the NHS at the national and local levels. There were potentially divergent issues to consider across other challenges to the NHS, such as decentralisation of services across several locations or moving services from one location to another.

Given that service reconfiguration dominates the health policy agenda in almost all countries, it is essential to build upon the practical and research foundations that have already been laid.

Implications for health care

The NHS England stages of reconfiguration may provide a helpful framework on which to base plans for future service user engagement programmes. However, this framework should not necessarily be considered as a linear process or a set of distinct elements. The 'ladder of engagement and participation', based on the work of Sherry Arnstein (Arnstein SR. A ladder of citizen participation. *J Am Inst Plan* 1969;**35**:216–24), seemed to offer less practical value. The four-dimensional framework developed by Gibson *et al.* [Gibson A, Britten N, Lynch J. Theoretical directions for an emancipatory concept of patient and public involvement. *Health (London)* 2012;**16**:531–47] may be worth further evaluation.

Within the NHS England framework, some key factors contributing to successful engagement and/or service reconfiguration appeared to be:

- ensuring a clear understanding of the local context
- early engagement; consulting widely
- demonstrating clinical-led case for change, with focus on service improvement rather than cost savings
- demonstrating openness and developing shared understanding of change through local partnership working
- promoting ownership of the change model and feedback results of engagement
- implementing strong managerial leadership
- using mixed approaches, particularly deliberative methods of engagement, targeted where necessary for different population groups
- considering access and transport issues as part of service change
- evaluation; follow-up
- expecting the unexpected.

Of these key factors, the one aspect that seemed most pressing was the striking need for robust evaluation and follow-up in user engagement programmes. Where evaluation had taken place – and particularly in relation to some potentially valuable case studies – it was largely poorly reported and therefore difficult to appraise from a research viewpoint. Quality of reporting may be limited by time constraints in health-care practice and naturally less concern for academic rigour. However, present reporting made it difficult to learn and move forward. Evaluation of user engagement in future health service reconfiguration is vital if we are to avoid reinventing the wheel each time public interaction is required. Ideally, evaluation should be conducted independently of those directing the engagement programme and should be embedded throughout the entire process from planning to implementation. Specific attention should be paid to explicitly and consistently describing the contextual characteristics of the situation, methods of engagement, outcomes measured, overall impact (including positive and negative impact, and differential effects of engagement methods), sustainability of efforts (through appropriate follow-up) and lessons to be learned. The need to publish evidence on methods and impact of patient and public voice activity was touched upon in NHS England's *Transforming Participation in Health and Care* (NHS England. *Transforming Participation in Health and Care: 'The NHS Belongs to Us All'*. Leeds: NHS England; 2013).

Implications for research

The NHS England guidance on stages of reconfiguration may be of value in providing a generalisable approach and basis for user engagement in practice. The guidance may also provide a foundation for the design of future research on the evaluation of user engagement in service reconfiguration. These aspects were recommended areas of future research, together with an exploration of how the guidance might apply beyond the NHS setting.

In addition, further longer-term evaluations are needed to test the sustainability of methods of engagement and their impact over time. More research may also be warranted on the specific impact of interventions in negotiating and resolving differing opinions between patients, the public and clinical experts. Cost-effectiveness evaluation of engagement methods would be beneficial.

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