

## York HS&DR Evidence Synthesis Centre

### Service user engagement and health service reconfiguration: Protocol

#### Background

The need to fully engage staff, patients and public in discussions and decisions about changes to the way health services are delivered has been recognised for many years. 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, e.g. NHS England's *Planning and delivering service changes for patients*<sup>1</sup> and *Transforming participation in health and care*.<sup>2</sup> Proposals for service changes by commissioners and other bodies are required to pass four tests, one of which is to be able to demonstrate evidence of strong public and patient engagement.

While much of the guidance appears to be simple common sense, there is a need to establish the strength of the evidence base, for example around different approaches to public engagement and involvement and evidence of impact. Proposed changes to health service delivery are often controversial locally and sometimes nationally but effective public engagement may minimise controversy and result in a broad consensus on the way forward. On the other hand, inadequate consultation may result in lack of agreement, leading to proposals being delayed or referred to the Independent Reconfiguration Panel (IRP) or ultimately the courts. Any evidence that can clarify factors associated with positive public engagement will be of value both to NHS decision-makers and society as a whole.

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 citizen 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. Recent systematic reviews have looked at the impact of patient and public involvement on UK health care in general<sup>3</sup> and at strategies for interactive public engagement in development of healthcare policies and programmes.<sup>4</sup> Turning to the primary literature, examples of the type of evidence that might be relevant include an academic study of a 'decision conference' including patients and caregivers to consider eating disorders services;<sup>5</sup> general discussion of the issues in a journal aimed at health service managers;<sup>6</sup> and a number of case studies published by the NHS Confederation.<sup>7</sup>

The objective of this project is to bring together evidence from published and grey literature sources; to assess what is known about effective patient and public engagement in reconfiguration processes; and if appropriate to identify implications for further research.

## General approach

The project is 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. We intend to carry out a review that will use 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 anticipate that the process will be less exhaustive and the outputs somewhat less detailed than might be expected from a full systematic review, especially given that we expect to find limited evidence in the peer-reviewed primary literature.

## Research questions

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

Given the nature of the research questions, we will adopt a service-facing approach. In doing so, we anticipate that the process of locating and assessing evidence for inclusion will be iterative and will involve consultation with outside experts as well as discussion among the research team. Outside experts may be a particularly valuable source of help. They may be able to provide (for example) one-off advice on the draft protocol, on-going advice, and rich sources of material in relation to examples of current practice.

The focus of the review is reconfiguration of health service provision in the NHS. We will consider evidence on health services delivered by non-NHS providers (e.g., voluntary sector/private sector) and the joint provision of health and social care where this impacts directly on NHS provision. Similarly, we will only consider international evidence from other health systems which are comparable and relevant to the NHS.

We will consider inclusion of empirical evidence and theoretical work from fields other than health where this provides high-quality independent research that addresses questions where evidence from health research is lacking or deficient. However, such evidence will not be the main focus of our review and its inclusion will be guided by expert opinion.

Reconfiguration includes large-scale system change (for example relocation of hospitals; (re)location of specialist care; changes in provision of

urgent/emergency/out-of-hours care) as opposed to small-scale change (for example, at hospital ward-level, within a GP practice).

Patient/public engagement or democratic involvement (the terms engagement and involvement are often used interchangeably) includes 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). The scope includes existing patients, carers and their representative groups; and the general public and their representatives (for example, local councillors and MPs).

## **Inclusion criteria**

We expect to find potentially relevant evidence in three main areas:

- Systematic reviews of methods of/approaches to patient/public engagement. We will only include reviews that are relevant to patient/public involvement in decisions about health service reconfiguration. Reviews of patient/public involvement in research will be excluded.
- Empirical studies of any design that evaluate methods of/approaches to patient/public engagement. Studies that focus on involvement in research will again be excluded.
- Case studies that have examined how patient/public involvement has worked in specific examples of system change in the recent past. We anticipate that these are more likely to be found in the grey literature than in peer-reviewed publications. Case studies of this kind are likely to provide a biased sample of 'successful' rather than typical patient/public involvement but as such are more likely to provide useful data to inform future practice. We will also search for case studies where public involvement has failed to produce an agreed way forward or has resulted in unintended consequences, using the web site of the IRP as a starting point.

## **Excluded**

'Emergency' reconfigurations triggered by failure of a service provider, e.g. a NHS Trust

Consultation/involvement of NHS staff

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., PALS, Healthwatch independent advocacy arm)

## **Searching**

A search strategy will be developed to identify systematic reviews and overviews of systematic reviews of patient/public engagement. The following resources will be searched:

The Cochrane Database of Systematic Reviews (CDSR)  
Database of Abstracts of Reviews of Effects (DARE)  
Health Systems Evidence.  
EPPI Centre databases - Database of Promoting Health Effectiveness Reviews (DoPHER) and The Evidence Library  
Campbell Library

A search strategy will also be developed to identify primary studies. The following databases will be searched with a date limit of 2000 and restricted to English language:

MEDLINE  
MEDLINE in process  
Health Management Information Consortium  
ASSIA  
Social Care Online  
PsycINFO  
Social Science Citation Index

In addition, websites relevant to UK health policy, health service delivery and organisation and patient engagement in health will be searched to identify any policy documents, reports or grey literature (see Appendix 1). We will also search the Internet using a general search engine such as Google to locate UK reports on service reconfiguration published in pdf format.

## **Study selection, data extraction and quality assessment**

Search results will be stored in a reference management database (EndNote). Final study selection will be carried out by two reviewers independently, with disagreements resolved by discussion or involvement of a third reviewer if necessary.

We are planning to use EPPI-Reviewer software to record decisions about study selection and for data extraction and quality assessment. We will develop data extraction forms to record key information which we expect to be different for different evidence sources. Unpublished case studies containing limited information will be recorded but not data extracted. Data extraction will be performed by one reviewer and checked by a second.

Quality assessment will depend on study design. We will assess systematic reviews for methodological quality and reliability using the approach of the Database of Abstracts of Reviews of Effects (DARE). Published primary research studies will be assessed using appropriate design-specific tools in line with CRD's guidance for

undertaking systematic reviews in health care (2009). Unpublished case studies and non-peer-reviewed reports will not be formally assessed for quality (risk of bias) but we will seek to identify any instances of more rigorously conducted and fully reported case studies. Issues to be considered might include, for example:

- The extent to which an appropriate diversity of perspectives (e.g., across service user and NHS) were considered in assessing the impact of patient/public engagement.
- To what extent the case study was conducted and reported with transparency. Reflexivity on any specifically adopted perspective, together with adequacy of reporting on intervention context, methods, and impact, will be issues for consideration.

We anticipate that further issues related to the reporting quality and usefulness of case studies may be identified as the project progresses through further development and consultation with experts.

## **Synthesis**

We will carry out a narrative synthesis with the objective of identifying key themes that can be used to inform future practice in public involvement/engagement and identify key areas of uncertainty and research needs. We will seek to identify exemplars from different UK settings, ideally where an independent evaluation is available. Given the resources available for the project, we expect to focus on only a small number of exemplars. Other case studies will be dealt with more briefly, for example by tabulating brief details and/or providing bibliographic references.

## **Timetable**

A timetable for the main stages of the project is presented in Appendix 2.

## References

1. NHS England. *Planning and delivering service changes for patients*. Leeds: NHS England; 2013.
2. NHS England. *Transforming participation in health and care*. Leeds: NHS England; 2013. Available from: <http://www.england.nhs.uk/wp-content/uploads/2013/09/trans-part-hc-guid1.pdf>
3. Mockford C, Staniszewska S, Griffiths F, Herron-Marx S. The impact of patient and public involvement on UK NHS health care: a systematic review. *Int J Qual Health Care* 2012;24:28-38. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/22109631>
4. Abelson J, Montesanti S, Li K, Gauvin F-P, Martin E. *Effective strategies for interactive public engagement in the development of healthcare policies and programs*. Ottawa: Canadian Health Services Research Foundation; 2010.
5. Airoldi M. Disinvestments in practice: overcoming resistance to change through a sociotechnical approach with local stakeholders. *J Health Polit Policy Law* 2013;38:1149-71. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/23974471>
6. Clarke R, Rozansky D. Engaging the public early in service reconfiguration. *Health Service Journal* 2013. Available from: <http://www.hsj.co.uk/home/commissioning/engaging-the-public-early-in-service-reconfiguration/5058185.article#>
7. NHS Confederation. *Service redesign case study: Redesigning maternity services in Sandwell and West Birmingham*. London: NHS Confederation; 2013. Available from: <http://www.nhsconfed.org/Publications/reports/Pages/Service-redesign-case-study-Birmingham.aspx>

## **Appendix 1: Potential websites to search for grey literature for patient voice and system change rapid review**

Health Services and Delivery Research (HS&DR) Programme  
<http://www.nets.nihr.ac.uk/programmes/hsdr>

NHS England  
<http://www.england.nhs.uk/>

NHS Wales  
<http://www.wales.nhs.uk/>

NHS Scotland  
<http://www.show.scot.nhs.uk/>

Department of Health  
<https://www.gov.uk/government/publications>

NHS Confederation  
<http://www.nhsconfed.org/Pages/home.aspx>

NHS Institute for Innovation and Improvement  
<http://www.institute.nhs.uk/>

NHS Improving Quality  
<http://www.nhsiq.nhs.uk/>

NICE  
<http://www.nice.org.uk/>

Social Care Institute for Excellence (SCIE)  
<http://www.scie.org.uk/>

Healthcare Improvement Scotland  
<http://www.healthcareimprovementscotland.org/>

Independent Reconfiguration Panel  
<http://www.irpanel.org.uk/view.asp?id=0>

The Picker Institute Europe  
<http://www.pickereurope.org/>

<http://investinengagement.info/>

National Voices  
<http://www.nationalvoices.org.uk/>

Joseph Rowntree Foundation  
<http://www.jrf.org.uk/>

The Kings Fund  
<http://www.kingsfund.org.uk/>

The Health Foundation

<http://www.health.org.uk/publications/>

RAND corporation  
<http://www.rand.org/>

The Nuffield trust  
<http://www.nuffieldtrust.org.uk/>

Center for Studying Health System Change  
<http://www.hschange.org/>

Foundation Trust Governors Association  
<http://www.ftga.org.uk/>

Healthwatch England  
<http://www.healthwatch.co.uk/>

Health Services Management Centre, University of Birmingham  
<http://www.birmingham.ac.uk/schools/social-policy/departments/health-services-management-centre/index.aspx>

## Appendix 2: Project timetable

Action	Start date	Finish date
Develop draft protocol	3 March	21 March
Comments on protocol	24 March	4 April
Protocol to HSDR for sign-off		4 April
Search for systematic reviews, grey literature and primary studies (iterative)	17 March	14 April
Study selection, document acquisition and data extraction (iterative)	15 April	30 May
Data synthesis and writing draft report	2 June	11 July
Comments on draft report from wider team/advisers	14 July	8 August
Prepare final report and other outputs	11 August	1 September