

## **Understanding decommissioning in the English NHS from a citizen, service user, carer and community perspective - Appendix to Original Study Protocol 12/5001/25**

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### **Case for support**

Decisions to decommission healthcare services and interventions have the potential to affect a high proportion of the population both directly as patients/ service users or carers, and indirectly as citizens and constituents of a local health economy. Recent developments such as the Joint Strategic Needs Assessment process in health and social care have stressed the importance of engaging patient/service users, carers, third sector and local community stakeholders in the planning and delivery of services (Department of Health 2011), accompanied by new mechanisms for their engagement in the commissioning cycle (Healthwatch England 2013; Local Government Improvement and Development 2011) However there is a relative dearth of published evidence on involving these groups and the wider public in the decision making, planning and implementation of decommissioning health care services.

The highly emotive, political and complex nature of decommissioning, combined with the often lengthy timescales involved, raises particular challenges and implications for engagement of patient/service user, carer, third sector and community groups (e.g. Bunt and Leadbeater 2012; Janjua et al. 2011; Robinson et al. 2013). Early findings from our current NIHR study (project number 12/5001/25) indicate that such groups need to be engaged through tailored approaches designed to both enable them to make sense of decommissioning, and to appreciate the potential benefits of sharing their perspectives. In the study we invited service users and patient engagement experts to take part in a Delphi survey of expert opinion. However responses indicated that the language and framing of the current study were inaccessible for these groups:

‘Having read the reasons for identifying me as having relevant experience, I am neither an academic nor have I been involved in decommissioning services so I will decline to take part in this survey, best wishes with it’

As well as suggesting the need for separate investigation of such perspectives, the findings of the completed Delphi survey with policy makers, practitioners and academics reinforced the sense of a gap between the rhetoric and reality of engagement in decommissioning processes. For example, although there was strong agreement that patient and public views should inform decisions to carry out decommissioning, such views were considered far less influential in practice. For example, one participant noted:

‘I’ve seen plenty of decisions that flew in the face of patient and public views’

Delphi participants highlighted this as a key weakness of current approaches to decommissioning and these results lend weight to wider literature suggesting that patient and public engagement is a neglected, but critical, perspective for informing the development of future approaches (Bunt and

Leadbeater 2012; Glasby et al. 2012; National Audit Office 2010; Sass and Beresford 2012). There is therefore a need to build on existing knowledge of best practice regarding patient and public engagement in healthcare research and practice and to apply this to the specific challenge of decommissioning.

## **Existing literature**

Below we provide a description of the main contributions to the existing literature on patient/service user and public involvement in decommissioning along with a brief assessment of contribution and ongoing gaps in knowledge.

Street, JM., Hennessy, SE., Watt, AM. et al. (2011) News and Social Media: Windows into Community Perspectives on Disinvestment, *International Journal of Technology Assessment in Health Care* 27:4: 376–383.

This paper uses analysis of internet sites – e.g. commercial media output, blogs, discussion forums and facebook - to collect community views to inform decisions on disinvestment using health technology assessment. This study particular looks at assistive reproductive technologies (ART). The authors find that social media provide a wider range of views and concerns than traditional media but they found that often those who posted had a more extreme view and those without strong views often looked but didn't post. Media and web analysis did provide a good idea of the range of different public perspectives and discourses on ART and some of the reasons behind these perspectives e.g. 'value of parenthood', 'doctors profiteering', 'factors which affect success of ART e.g. age', 'managing public money and choices' and 'human right/ lifestyle choice'. This is informative if a little narrow in focus with some limited transference to the issue of engaging service users, patients and the public in complex decommissioning processes in the English NHS.

Henshall C, Schuller T, Mardhani-Bayne L. (2012) Using health technology assessment to support optimal use of technologies in current practice: the challenge of “disinvestment”, *International Journal of Technology Assessment in Health Care* 28(3): 203–210.

This paper summarizes main points from an HTA International Policy Forum meeting on the topic of disinvestment. A key outcome was that stakeholders may have strong views on access treatments, and stakeholder involvement is essential. Prospect Theory/ Loss Aversion can help to explain why it is so important and difficult to involve public and patient groups in disinvestment. These are important insights but the paper has inherent limitations including: it is based on debate rather than research; it focuses on a relatively narrow agenda of employing Health Technology Assessment in the removal of technologies and; it covers a range of issues rather than focusing on involvement and engagement.

Robinson S Glasby J Allen K (2013) It ain't what you do it's the way that you do it': lessons for health care from decommissioning of older people's services, *Health and Social Care in the Community* 21(6): 614–622.

Drawing on local knowledge and best practice examples, this article highlights lessons and themes identified by those decommissioning care home services. Decisions to close care home services

require a combination of strong leadership, clear strategic goals, a fair decision-making process, strong evidence of the need for change and good communication, alongside wider stakeholder engagement and support. In order to give decision makers the authority to make decisions they must consider the 'authorising environment'- this means involving the public and service users to give their decision making legitimacy. This study is useful in providing a wider focus than the disinvestment literature but is confined to social care service decommissioning drawing on a small number of case studies.

Hodgetts, K. Hiller, JE., Street, JM. et al. (2014) Disinvestment policy and the public funding of assisted reproductive technologies: outcomes of deliberative engagements with three key stakeholder groups. *BMC Health Services Research* 14:204.

In this study deliberative engagement was carried out with groups of assisted reproductive technologies patients, clinicians and community members. Discussion was informed by a systematic review of ART treatment safety and effectiveness, as well as by international policy comparisons, and ethical and cost analyses. Deliberations yielded 'qualitative, socially-negotiated evidence required to inform ethical, accountable policy decisions in the specific area of ART and health care more broadly'. The study, whilst invaluable, is narrow in focus – i.e. confined to one type of decommissioning and focussing on decision making rather than implementation – and is drawn from an Australian context.

Overall there are undoubtedly insights and learning to be derived from these contributions as well as from the wider literature on involvement of patients, service users and community/public in health care decision making (see for example Charles and DeMaio 1993; Mitton et al 2009, 2011; Redden 1999).

However, we feel that there remains a requirement for specific exploration of the engagement of these groups in relation to all stages of decommissioning.

### **Summary of proposed work**

The aim of the proposed extension to our current study is to investigate the perspectives and experiences of citizens, patient/service users, carers, third sector organisations and local community groups in relation to decommissioning (that is: service replacement, removal and reduction in health care). The investigation will both complement the current study and help to address a major gap in the published literature, by addressing the following research questions:

- What are the views and experiences of citizens, patient/service users, carers, third sector organisations and local community groups in relation to health and social care decommissioning?
- How do these compare with those of policy makers, practitioners, health care leaders and researchers?
- How might these perspectives be brought together in order to improve equity and acceptability in decommissioning?

The current NIHR project has sought to collect the views of health care policy makers, practitioners and academics. The proposed additional research targets citizens, patient/service users, carers, third

sector organisations and local community groups, and is made up of the following data collection activities:

#### I. Focus groups discussions

We propose to carry out deliberative focus group discussions with a sample of citizens, patient/service users, carers, third sector organisations and local community groups to sensitise us to the issues and perspectives involved in decommissioning (Sim 1998). We will carry out three focus groups in total, each with between 6-8 participants. Participants will be sampled so as to achieve a diversity of age, gender and ethnicity (Halcomb et al. 2007). Focus group one will involve citizens/members of the public and representatives of national citizen organisations (e.g. HealthWatch, KONP). Focus group two will recruit general NHS service users and carers, as well as current users of primary, secondary and specialised care. Focus group three will involve patient organisations (general and specific), community organisations and independent third sector organisations affected by decommissioning.

Potential participants for the focus groups will be contacted through: HealthWatch England, National Voices, the Department of Health Voluntary Sector Strategic Partner Programme, Carers UK, patient representative and advocacy organisations such as the National Association for Patient Participation and Shaping Our Lives, researchers with particular expertise and interest in patient and public experience and engagement, and individuals involved in patient and public engagement identified in our case study research under the current NIHR study (project number 12/5001/25). Participants will not be required to have direct previous experience of decommissioning although it is expected that a substantial proportion will have – including for example those directly affected by service reorganisations. Questions will be open-ended, encouraging wide-ranging discussion over views and experiences of decommissioning. This will enable us to design data collection tools and approaches in subsequent phases of the research.

#### II. Delphi study of citizen, patient, carer and community groups, and third sector organisations

The focus groups will sensitise us to the major issues and perspectives of these groups in relation to decommissioning as well as to the language used when discussing this issue. To complement this, we will also use the focus groups to consult on methods for identifying potential participants and maximising our recruitment to the Delphi study, in light of the challenges we experienced recruiting service user groups to our previous Delphi study. Drawing on these insights we will design a three-round, online Delphi survey in order to elucidate consensus on best practice for the engagement of patients and the public in decommissioning processes, from the perspective of citizen, patient, carer and community groups, and third sector organisations both in the UK and internationally (Linstone & Turoff 1976; Robert & Milne 1999). This will be designed to facilitate comparison with the Delphi exercise which we have already successfully implemented as part of the current project (Robert et al. 2014). Delphi studies build consensus by collecting through iterative questionnaires and are effective in establishing consensus in complex topic areas (de Meyrick 2003). Participants will be asked to complete each round within one week. Analysis will be iterative and thematic across the three rounds and consensus will be statistically operationalised by testing for heterogeneity and inter-quartile range dispersion. The sample for the Delphi will comprise:

- Third sector organisations that provide support to, and advocacy/representation of service users and carers (including, among others, Shaping our Lives, National Voices, Carers UK, National Development Team for Inclusion, the Mental Health Providers Forum, the Voluntary Organisations Disability Group, the National Care Forum and National Association for Voluntary and Community Action)
- Other patient and public representative organisations (including HealthWatch England, National Association for Patient Participation, KONP, the Race Equality Foundation and patient expert groups )
- Selected academics specialising in public involvement and/or patient experience

There may be some focus group participants who are also invited to take part in the Delphi study and we will also ask our current advisory group for details of patient/public organisations in each of their countries. The final outcomes from rounds one to three will be fed back to all participants and further comments invited.

### **Dissemination**

Written outputs will include policy and practitioner materials, a report to NIHR and research papers in practitioner and academic journals. Other dissemination opportunities and strategies will be discussed and sought with citizens, patients, carers, third sector organisations and community groups via the focus groups early on, and we will make use of social media platforms such as twitter, facebook and linked-in in order to reach as wide a group of interested parties as possible.

### **Project timeline:**

Prior to start date Secure NHS ethics approval

Month 1-2 Arrange and conduct focus groups and design Delphi study

Months 3-5 Carry out Delphi study

Months 6-7 Compile NIHR report, disseminate

### **References**

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