

Future Requirements and Possibilities for Public Involvement in Health and Social Care: Summary of Key Findings

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This report summarises the key findings of research which explored the future possibilities for public involvement in Scotland, in the context of planned integration between adult health and social care services. It was produced by ODS Consulting for the Scotlish Health Council in spring 2013.

The research involved; six discussion groups with members of the public; 40 telephone interviews with health and social care practitioners; an online survey of practitioners which generated 41 responses; and telephone interviews with five equalities organisations and six national organisations. We also developed four case studies of public involvement in health and social care in Scotland – involving interviews with an NHS staff member; a local authority staff member; and at least one (and up to four) members of the public. The research was supported by a Reference Group and also involved a workshop with 30 research participants, to discuss initial findings.

This report sets out the key findings from this research, and the key issues it raises for the future. This report is accompanied by a separate 'think piece' which develops these issues and gives further consideration to the options and possibilities for public involvement in adult health and social care.

Key findings

Context

- 1.1 The Integration of Health and Social Care Bill aims to integrate adult health and social care services in Scotland. It will create Health and Social Care Partnerships which will be the joint and equal responsibility of NHS Boards and local authorities.
- 1.2 The current arrangements for public involvement in health and social care services in Scotland vary between the NHS and local authorities. The NHS has a more formalised and nationally consistent approach. NHS Boards are required to involve people; there is a national Participation Standard which Boards must self assess performance against; and Boards have a specific responsibility to set up Public Partnership Forums connected to Community Health Partnerships.
- 1.3 The arrangements for involving people in discussions about social care services are very varied across Scotland. Local authorities are encouraged but not required to work to the National Standards for Community Engagement. Local authorities have lead responsibility for Community Planning Partnerships, which among other things aim to support community involvement in planning and delivering local services. All local authorities have locally determined, different, mechanisms for involving communities.
- 1.4 Integration of health and social care services has taken place in Northern Ireland; in England there is an integrated approach to public involvement in health and social care services; and in Wales a draft Bill is currently being considered which among other things would encourage integration of health and social care services. There are a number of key lessons from these approaches, which echo experience in Scotland:
 - there are pockets of good and poor practice in public involvement;
 - there are concerns about representativeness of organisations which coordinate the views of the public – and how this can be achieved;
 - there are concerns that the most disadvantaged communities may not have the same opportunities to participate;
 - there is recognition of the need to use a range of methods to involve different people in different ways;
 - senior leadership has been essential in promoting public involvement particularly in clinical rather than community settings;

- integrating public involvement in decision making, rather than seeing it as an add on, has enhanced its value;
- coordination of involvement opportunities has helped to reduce competition between different representative organisations; and
- change has resulted in some concerns about public involvement.
- 1.5 There is also some concerning evidence from the Francis Report (2013) which suggests that while there have been a range of routes through which patients and members of the public in England can link into health services and hold them to account, these have been largely ineffective.

Existing experiences of public involvement

- 1.6 There was overwhelming agreement that current practice in terms of meaningful public involvement was varied and that there were pockets of good practice. Some members of the public felt that practice was improving, but others had not seen any change as a result of their involvement.
- 1.7 Generally, there was a feeling that the NHS approach was more formalised and structured. This was positive in that it provided consistency, but was seen as a more bureaucratic approach. There was also some concern about a medical approach to health rather than a social model, which some felt could result in 'top down' decision making. Generally, local authority strengths were seen as in taking a community development, 'bottom up' approach to involvement with strong skills and experience in this area. However, some felt that local authorities did not always meaningfully involve and consult, and were not always happy to work in partnership with others. Local authorities often mentioned working to the National Standards for Community Engagement, and NHS consultees often mentioned the Participation Standard.
- 1.8 The barriers and challenges of meaningful public involvement were very consistent across consultees, and included:
 - achieving representative involvement with varying views on what representative meant, and whether this could actually be achieved;
 - supporting members of the public to take part in complex discussions about services – with complex language often used;
 - fear and power the power imbalance between service users and institutions making people concerned about providing their real views;
 - action and decision making ensuring that views are built into decisions and action is taken swiftly and in a way which is apparent to communities;

- staff attitudes with some challenges to ensuring staff recognise the value of involvement and their role in supporting involvement as an ongoing activity; and
- practical barriers including travel and transport, money, time and jargon.
- 1.9 Overall, local authority and health consultees strongly felt that it was vital that lessons learned from these successes (and challenges) were built into future systems. Many cautioned not to "reinvent the wheel" or "ditch" the good work that organisations and communities have invested in.

Future Possibilities for Public Involvement

- 1.10 There was strong consistency in terms of views of what meaningful public involvement should feel and look like. It should be clear and honest about purpose; involve 'the right people'; be routine and ongoing; take place at different levels; use different methods; be respected and respectful; involve listening and changing as a result; and be accessible and informed
- 1.11 Many consultees were unsure about the implications of integration on public involvement. This research took place in late 2012 and early 2013, just before the Scottish Government published its response to the consultation on the ideas that would inform the draft Bill. This meant that many were unsure exactly what was being proposed and how this would impact on their area. Many felt that integration wouldn't impact too much on public involvement, as there was not much existing duplication and previous work to integrate activities had not made much difference in this area. However, a number of opportunities were identified, including a higher profile for public involvement; opportunities to integrate involvement; shared and pooled resources; and opportunities to develop local approaches which build on lessons learned.
- 1.12 Many felt that there were significant challenges too, including:
 - an internal focus due to organisational restructuring
 - a potentially limited extent of real integration
 - challenges sharing information
 - reducing resources
 - how to match scales of operation between health and social care
 - concern about significant change although at the same time some concerns about weaknesses in some existing structures, and
 - the NHS and local authorities working towards different standards.

- 1.13 There was strong agreement that different types of involvement opportunity were required for the future including formal, permanent involvement structures; ad hoc issue-based opportunities; and ongoing routine community development work. Building relationships on an ongoing basis was seen as a key way of involving 'seldom heard' participants which consultees believed was important in order to fully reflect the views of the public.
- 1.14 The case studies of experiences in four parts of Scotland highlighted the opportunities and challenges of integration and public involvement. Leadership, communication and capacity building were key success factors; with shifting organisational cultures and successfully managing transition periods being key challenges. Ultimately, however, the case studies demonstrate that there are opportunities for integration to strengthen and raise the profile of public involvement.

Key issues for debate

- 1.15 This research found a strong appetite for gradual change and building on existing approaches in relation to public involvement. However, lessons from elsewhere in the UK provide a range of ideas about how public involvement could be integrated. We wished to test some of these ideas further, to determine whether there was any appetite for change while recognising the strong message that lessons learned from existing approaches need to be built in.
- 1.16 We developed the findings into three main questions for further exploration, in relation to future public involvement in health and social care. These did not involve radical change as research participants suggested but offered opportunities to standardise and bring together the two existing different systems within health and social care. The questions we were keen to explore were:
 - Should there be a single formal structure which Health and Social Care Partnerships should use to involve the public?
 - Should there be a shared standard for public involvement, which Health and Social Care Partnerships would be asked to meet?
 - Should there be a shared framework for assessing outcomes of public involvement, which would be used to assess the performance of Health and Social Care Partnerships in this area?
- 1.17 These ideas were discussed at a workshop involving 30 research participants, including members of the public, NHS staff, local authority staff, national

organisations and equalities organisations. This explored the range of options under each key area, using a 'sliding scale', as outlined below.

Structures for Public Involvement					
Different	Guidance or case		Recommended model		Single structure for
structures across	studies on options		for involvement –		involvement which
Scotland as	for structures		comply or explain		all areas need to
decided locally					use
Standards for Public Involvement					
Two separate	Guidance which		A single shared		A single shared
sets of standards	links the existing		voluntary standard for		standard for public
for health and	two separate		public involvement		involvement
social care work	standards				enforced by law
Assessing Outcomes of Public Involvement					
Locally decided with		A Scotland wide self		A Scotland wide framework	
help from guidance		assessment framework		assessed by a national	
(pilots, case studies, etc)				organisation	

- 1.18 Discussion of these options with workshop participants identified a strong consensus around broadly where we should be aiming in relation to all three of these options. The discussion suggested that that:
 - there is a strong appetite for developing a recommended model for public involvement within Health and Social Care Partnerships – with a requirement to comply with this model or explain why it is not being adopted;
 - there is a strong interest in developing a single shared standard for public involvement, which would be enforced by law; and
 - there was agreement that the approach to assessing outcomes for public involvement should sit somewhere between a Scotland-wide self assessment framework, and a framework assessed by a national organisation – this could include a self assessment which has to be submitted to a national organisation; which has to be validated by community organisations; or which must involve members of the public in the assessment process locally.
- 1.19 This discussion took place with only a small sample of those who would be impacted by these changes just 30 people from across Scotland. It is important to note that there was a strong steer from those who participated in the interviews, focus groups and surveys as part of the research that public involvement should build on existing approaches and structures, and should not involve radical change. However, there is scope for each of these three

- proposals to be developed in a way which complements rather than disrupts or negates existing approaches.
- 1.20 These ideas and issues are developed further in our 'think piece' on possibilities and opportunities for public involvement in health and social care in Scotland, produced as a separate document. This is intended to initiate debate, providing some ideas for discussion in moving forward with public involvement in health and social care.

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