



## Future Requirements and Possibilities for Public Involvement in Health and Social Care

June 2013

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# 1 Foreword

Dear colleague,

I am delighted to share with you the contents of this timely and important research, which captures current thinking around public/community involvement from a wide variety of stakeholders, and sets out options and possibilities for the future in the context of the integration of health and social care services.



As you may know, the Public Bodies (Joint Working) (Scotland) Bill has recently been published which makes provision for the integration of health and social care in Scotland.

After the consultation on the Bill during summer 2012 the Scottish Health Council commissioned ODS Consulting to produce independent research on the future requirements and possibilities for public involvement in health and social care. This research was shaped by a reference group which comprised representatives from an NHS Board, local authority, third sector, Scottish Government, COSLA, lay members as well as the Scottish Health Council.

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

The Scottish Health Council, in conjunction with its partners in COSLA and Scottish Government, will be hosting events during summer and autumn of 2013 with the aim of sharing the key findings of this report, getting feedback, and helping to develop a shared vision for public involvement within integrated health and social care services.

**Richard Norris,**  
Director,  
The Scottish Health Council

## **2 Executive Summary**

### **Introduction**

This report explores 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 Scottish Health Council in spring 2013.

The research involved a review of context; 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.

### **Context**

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.

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.

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.

## Experiences of existing public involvement

This research highlighted that current practice in public involvement in health and social care in Scotland is very varied. There are 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.

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.

Local authority strengths were highlighted in relation to 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.

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.

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**

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.

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.

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.

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.

## **Think Piece**

Overall, this research found a strong appetite for gradual change and building on existing approaches in relation to public involvement. However, the integration of health and social care does offer a rare opportunity to rethink public involvement. The findings of this research have therefore been developed into a separate short 'think piece' which provides some prompts for discussion and debate about what public involvement in health and social care could look and feel like in the future.

## **3 About this Report**

### **Introduction**

- 3.1 This report explores 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 Scottish Health Council.
- 3.2 This report is based on research undertaken during 2012/13. The purpose of this research was to develop an understanding of what effective public involvement might look like post adult health and social care integration. It explored existing practice, future aspirations and main areas for development and improvement.

### **Research methods**

#### ***A review of context – in Scotland and the UK***

- 3.3 There has been a significant amount of research into public involvement in Scotland, the UK and beyond. This research was intended to complement, and not duplicate, existing evidence. Our first stage was therefore to undertake a brief review of the context for public involvement in health and social care in Scotland, and the lessons learned about effective public involvement. This review involved setting the context for public involvement in both health and social care in Scotland; reviewing existing evidence about what works – and what doesn't; and exploring the lessons learned from England, Wales and Northern Ireland. This review of context is set out in Chapter Two.

#### ***Gathering the views of members of the public***

- 3.4 A crucial aspect of this research involved gathering the views of members of the public in relation to current practice around public involvement, and opportunities for strengthening and developing this in the future. We held six discussion groups (lasting one hour each) with between six and ten people. A total of 47 individuals were involved.
- 3.5 We wanted to ensure that the people involved in the research had some experience of participating in discussions about health and social care services, and would have views on the effectiveness of arrangements to date. We also wanted to ensure that the groups provided a range of different perspectives through being involved in different discussions using different involvement mechanisms. The discussion groups were held with:
- two Public Partnership Forums

- one Community Care Forum
- one carers group
- one community group, and
- one disabled person's organisation.

### ***Gathering the views of health and social care practitioners***

3.6 We engaged with health and social care practitioners in three different ways:

- we held telephone interviews with 40 practitioners – 22 from local authorities, and 18 from the NHS;
- we held more in depth telephone interviews with health and social care practitioners in four case study areas; and
- we ran an online survey which received 41 responses.

3.7 There are 32 local authorities and 21 NHS Boards in Scotland. All were offered the opportunity to take part in the research. This research involved 26 local authorities and 20 health boards.

3.8 We asked everyone who was interviewed whether there were other staff who may wish to take part in the research, through a short online survey. Almost all (39 of the 40) said that there were a small number of staff who may also want to give their views, and offered to circulate the survey to them. This resulted in 41 responses from across Scotland. This is a relatively small number of responses, but helped to add to and complement the detailed views gathered through the telephone interviews and case studies.

### ***Case studies***

3.9 We developed four case studies of approaches to public involvement in Scotland. Working with the Scottish Health Council, we identified four areas which had experienced different levels of integration between health and social care – Dundee, East Renfrewshire, Highland and West Lothian. In each area, we spoke to an NHS staff member with strategic responsibility for public involvement; a local authority staff member with strategic responsibility for public involvement; and between one and four members of the public – most often the Chair and other members of the Public Partnership Forum.

3.10 The case studies are included as Appendix One.

### ***Gathering the views of equalities and national organisations***

3.11 We held telephone interviews with five equalities organisations to explore their views on effective public involvement now and in the future. Interviews were held with Stonewall Scotland, Age Scotland, REACH Community Health Project, Capability Scotland and Faith in Community Scotland.

3.12 We also held telephone or face-to-face interviews with six national organisations – including COSLA, the Scottish Government, the Joint Improvement Team (a collaboration between the Scottish Government, COSLA and the NHS), the Scottish Health Council, Scottish Care and the Care Inspectorate.

### ***A workshop to discuss findings***

3.13 We invited all research participants to a workshop in March 2013, to discuss the research findings. This workshop took place as findings were being collated, and discussion helped to inform the development of the draft report. The workshop was attended by 30 participants – including members of the public, NHS and local authority practitioners and representatives from national and equalities organisations. Participants discussed the research findings, and also considered a range of options for the broad shape of public involvement structures, standards and assessment in the future. Findings from this workshop have been built into this report.

### ***A reference group***

3.14 The research was commissioned by the Scottish Health Council and supported by a Reference Group involving representatives from health and social care, members of the public, and national organisations including the Scottish Government and COSLA. A full list of membership of the Reference Group is included as Appendix Two.

3.15 The Reference Group met three times during the course of the study. It guided the focus of the research; provided feedback on key findings; and commented on the draft report.

### ***Note on terminology***

3.16 Throughout this report we use the term ‘public involvement’ to mean deliberate efforts by organisations to gather views of a diverse range of members of the public, and use these to inform decision making.

3.17 However it is important to note that a range of different terms can be used to describe this type of activity. Most commonly, the term 'public involvement ' is used within health services in Scotland, while the term 'community engagement' is more common among local authority and social care services. There are no standard definitions nationally about what these terms mean, and whether they are different or the same.

3.18 This report does not focus on activity to involve service users, patients and carers specifically in shaping their own care directly. It focuses on collective involvement to shape policy and service planning, delivery and monitoring more generally – rather than for one individual specifically. Terminology was an issue raised by many consultees, and is discussed later in this report.

### **Note on reporting**

3.19 This research was qualitative. This means that it explored the views, attitudes, experiences and beliefs of individuals. Throughout this report, verbatim quotes are often used as the most immediate way of expressing the views gathered as part of this research. These were gathered through the individual interviews, group discussions and surveys highlighted above. However, it is important to note that the quotes are used as a way of reflecting the views of individuals. The quotes are word for word what people said, and represent feelings and experiences about situations. The quotes are entirely the perception of individuals – and different people will perceive situations in different ways.

## 4 Context

### Introduction

4.1 This chapter sets the research in context in terms of the integration of health and social care, and the history of public involvement in this field. It also explains the context of integration and public involvement in England, Wales and Northern Ireland, and draws out the lessons learned from experience in Scotland and elsewhere in the UK to date.

### Integration of health and social care

4.2 The Scottish Government believes that better integration of health and social care services is needed, to ensure high quality, appropriate and sustainable services. By 'integration' the Scottish Government is referring to seamless planning and delivery of services – from the perspective of the patient, service user or carer. The aim is to achieve better outcomes and improve the experience of people using services. The Government believes that the key features of effective integration are:

- a focus on the needs of individuals, carers and family members
- strong and consistent professional leadership
- joint accountability for improved delivery, and
- flexible and sustainable financial mechanisms which give priority to the needs of people who use services.

4.3 It issued a consultation in May 2012 which set out proposals to change the way that the NHS and local authorities work together in relation to health and social care. This states that separate – and sometimes disjointed – health and social care systems can no longer be expected to meet the needs of people in Scotland, particularly with the increasing older population. The Scottish Government recognises that joint planning of services, through community planning, can help to build co-ordinated services, but believes that integration of health and social care needs to go further than this.

4.4 The consultation proposed that:

- Community Health Partnerships are replaced by Health and Social Care Partnerships. These would be the joint and equal responsibility of NHS Boards and local authorities (working closely with third sector, independent sector and carers).
- There are nationally agreed outcomes which apply across adult health and social care. Health and Social Care Partnerships would be

accountable for delivery of these, via the Chief Executives of the NHS Board and local authority.

- These outcome measures would, initially, focus on improving older people's care. They would be included in Community Planning Partnerships' Single Outcome Agreements.
- Health and Social Care Partnerships would need to integrate budgets for joint commissioning and delivery of services, to support these outcomes. As a minimum this would mean that expenditure on adult health and social care services was integrated.
- Each Health and Social Care Partnership would jointly appoint a senior 'Jointly Accountable Officer' to ensure that nationally agreed outcomes, and other partner objectives, are delivered within the Partnerships' integrated budgets.
- Health and Social Care Partnerships would make sure that there are arrangements for locality service planning which strengthens the role of social care professionals, clinicians and the third and independent sectors.
- Proportionately fewer resources (both money and staff) would be directed towards institutional care, and more directed towards community provision and capacity building.

4.5 In relation to public involvement, consultation on the proposals identified some local concerns about local democratic accountability and scrutiny for social care services, with concerns about the involvement of elected members<sup>1</sup>. There were also some concerns that the proposals focused on the role of statutory organisations, and that users, carers and members of the public needed access to information about services; and clear routes to be able to influence decision making and service planning. Some felt that Health and Social Care Partnerships should be accountable through Community Councils.

4.6 Many also felt that arrangements for involving members of the public (particularly children, young people, disabled people and people with learning difficulties) in Health and Social Care Partnership Committees should be strengthened. In addition, Public Partnership Forums were highlighted by some as good structures which could be used to build public involvement into the Health and Social Care Partnerships. Some pointed to the need for support to enable members of the public (and particularly carers) to participate. There was also a strong belief from many that any locality planning within Health and Social Care Partnerships should be based at a 'community' level, as is meaningful locally.

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<sup>1</sup> Integration of Adult Health and Social Care: Analysis of Consultation Responses, Scottish Government, 2013

- 4.7 The Scottish Health Council responded to this consultation. It highlighted the existing evidence base supporting the benefits of involving users and communities in the design and delivery of public services and how this can improve service quality. The Scottish Health Council felt that the consultation paper said little about the issue of user and public participation, creating a 'significant gap' around on the role that service users, carers and public representatives play in shaping the development and delivery of integrated services. The Scottish Health Council endeavoured to address this gap by inviting service user, public, community, carer and voluntary sector representatives in existing public involvement structures, and NHS and local authority staff to comment on the proposals, which informed their response.
- 4.8 The Scottish Health Council emphasised the need for a more joined-up approach across Scottish Government initiatives, for example linking the Integration consultation with the Community Empowerment and Renewal Bill consultation, the latter giving much more consideration to user and public participation. It felt that greater clarity was required around the potential replacement of current legal duties and guidance on user and community involvement, and what this will mean for the new Health and Social Care Partnerships. It highlighted that the future of Public Partnership Forums was uncertain and not addressed in the Integration consultation; therefore there was concern that the knowledge, experience and capacity encompassed within these forums may be lost in the new structures. It felt that clarification was also needed around quality assurance and improvement systems regarding the legal duties underpinning user and public participation.
- 4.9 The Scottish Health Council underlined support for the idea that nationally agreed outcomes for adult health and social care should be included within all local Single Outcome Agreements, but that service users and communities must be able to influence the content and local implementation of these. Further consideration is required of how statutory partners will demonstrate accountability to service users and communities, and to Ministers, local authority leaders and NHS Board Chairs. The Scottish Health Council believes that a commitment is needed to adopting a more flexible and creative approach to involving care professionals and communities, for example through participation technologies. Finally, the integration of health and social care services must reflect the valuable role played by the third sector in the planning and delivery of services, and in supporting and facilitating user and community engagement.
- 4.10 The Scottish Government produced a response to the consultation. This reflected on the consultation responses received, and summarises the government's approach to moving forward in light of these. In relation to public involvement, this response highlighted that the Scottish Government would

require, by law, Health and Social Care Partnerships to include carer, user and public interests in their Committees. It also intended to place a legal duty on Health and Social Care Partnerships to 'engage with and involve' (rather than merely consult) representatives of patients, people who use services and carers (as well as local professionals, third and independent sectors).

4.11 In May 2013, the Public Bodies (Joint Working) (Scotland) Bill 2013 was introduced to the Scottish Parliament, taking forward the plans for integration of adult health and social care. The underlying principle of the Bill is that NHS Boards and local authorities take joint and equal responsibility for the delivery of nationally agreed outcomes for health and wellbeing – specified by Scottish Ministers. In relation to involving, consulting and engaging, it:

- requires NHS Boards and local authorities to consult widely on plans for integration and meeting national outcomes, and to consult and plan locally for the needs of its population;
- requires a co-production approach to planning activities, stating that must include carers and users of health and social care services, and their representatives;
- requires public and service user involvement in significant service decisions which are made outwith the strategic plan process; and
- outlines an intention to introduce responsibilities to involve and consult carers and users of health and social care services in all aspects of integrated arrangements, through secondary legislation.

### **Public involvement in health and social care**

4.12 There is a strong history of public involvement in public and voluntary services in Scotland, and a growth in the concept of public involvement in health systems across the UK and beyond. A short review of the context and history to public involvement in health and social care is attached as Appendix Three.

4.13 Key messages which are particularly relevant to this study are:

- NHS Boards are required to involve people in designing, developing and delivering services. It describes this as 'Patient Focus and Public Involvement'. Patient Focus is about respecting and involving people who receive services in shaping their own care. Public involvement is about involving individuals, groups and communities in improving quality of care, influencing priorities and planning services more generally. Guidance on how to meet these duties is set out in the Participation Standard, which collects comparable information from Boards on a self-assessment basis. NHS Boards also have specific responsibility to set up Community Health

Partnerships, with Public Partnership Forums as networks of patients, individuals, community groups, voluntary groups and carers interested in the development and design of local health services.

- In social care, there has been a strong shift towards involving people in planning and influencing their own care. In terms of public involvement, local authorities, and other public bodies, are encouraged – but not required – to work to the National Standards for Community Engagement. These were produced by the Scottish Government and developed in consultation with communities across Scotland. Local authorities also 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.
- The Christie Commission review of the future of public services in Scotland identified empowerment of communities and individuals using services as one of four important pillars of service reform for the future. Greater integration of services is another of the four pillars identified. The Scottish Government and COSLA have stated their intention of working to achieve the Christie Commission recommendations.
- The Scottish Government plans to introduce a Community Empowerment and Renewal Bill. One of the main themes of this Bill is ‘Strengthening Participation’ – building services around people and communities, focusing both on needs and on strengths, skills and capacities. Consultation on the ideas which could be included in the draft Bill asked, among other things, whether there should be a public sector duty to work to the National Standards for Community Engagement. While some supported this idea others felt that it added bureaucracy. The responses to this consultation will inform the development of a draft Bill, which will be produced in summer 2013.

## **Integration and public involvement across the UK**

### ***Experience from England***

4.14 This section is based on a review of context and telephone interviews with two senior policy officials within the Department for Health. Both wished to participate anonymously.

4.15 In England, health and social care services are not currently fully integrated. However, there is an integrated approach to public involvement across health and social care services.

- 4.16 England has had a series of different structures to promote public involvement in the NHS. Community Health Councils were established in 1974, followed by Patient and Public Involvement Forums to 2006, and Local Involvement Networks (LINKs) established by the *Local Government and Public Involvement in Health Act 2007*. From April 2013, Local Involvement Networks will be replaced by HealthWatch.
- 4.17 Up to April 2013, Local Involvement Networks have had responsibility for monitoring and facilitating public involvement. They are made up of individuals and community groups, and seek to “ensure that the experience of people who use services is prioritised by helping them to express their views about their health and social care”. Local Involvement Networks are publicly funded through local authorities, and the UK Government has provided £27 million for their work each year since 2008/09. There are 150 across England.
- 4.18 From April 2013 this will change. The *Health and Social Care Act 2012* establishes HealthWatch, a statutory committee of the Care Quality Commission, which will replace Local Involvement Networks. The work will be divided between local HealthWatch organisations – one for each local authority area – and HealthWatch England, the overarching body. Local HealthWatch will aim to be “champions of the public” – patients, carers and service users – for all NHS health and all social care services (adults and children). They will be responsible for promoting involvement, monitoring health and social care services, assessing quality, making recommendations and influencing commissioners of health and social care services.
- 4.19 Discussion with a senior policy official in England suggested that there have been pockets of good and poor practice with Local Involvement Networks, and it is anticipated that this will continue with HealthWatch. There is some evidence that Local Involvement Networks have strengthened relationships between health and social care decision makers and some members of the public<sup>2</sup>. However, there have been some concerns about how representative Local Involvement Networks are, with one policy official suggesting that some believe that Local Involvement Networks are largely reflecting the views of more advantaged communities (white, middle class and older). It is anticipated that HealthWatch will experience the same problems.
- 4.20 There are also changes planned in relation to how health services are commissioned in England. In the past, Primary Care Trusts had responsibility for commissioning services. From April 2013, responsibility for commissioning services will fall to 230 Clinical Commissioning Groups across England – comprising largely of GPs and healthcare practitioners. However, these Groups

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<sup>2</sup> Department for Health analysis of LINKs 2010/11 annual reports, compared with 2009/10 and 2008/10 found that LINKs have established stronger relationships with health and care decision makers, and made progress on responding to social care issues.

will be required to have at least two lay members. This is a key difference from past arrangements, as to date Primary Care Trusts in England have not been required to have lay membership.

“The Clinical Commissioning Groups are required to have at least two lay members, so they can’t avoid hearing public views. The lay members should have good networks and be representative.”

(Policy official England)

4.21 Consultation with a senior policy official suggested that while HealthWatch – as a formal local structure for involving members of the public – may continue to face challenges in achieving representativeness, Clinical Commissioning Groups will be able to use a range of different methods with the aim of getting “a breadth of view” from the whole community. This flexibility in method, alongside formal representation on Clinical Commissioning Groups, may mean that there are real opportunities for public involvement in commissioning health services.

4.22 While there is a legal duty to involve the public, it is perceived to be a relatively basic duty.

“On both providers and commissioners, there is a legal duty to involve. But it sets the bar quite low. So for example, if you were changing family planning, you’d put up some information in surgeries and write to existing service users. Now that’s good, but it’s not enough. The evidence needed to demonstrate involvement is quite minimal.”

(Policy official England)

4.23 From April 2013, the support mechanisms available to support public involvement will also change. To date, the NHS Institute for Innovation and Improvement (at a national level) and the Strategic Health Authorities and the Primary Care Trusts (at a local level) all had lead staff in relation to public involvement. It is felt that there was a lot of effort and investment in training programmes. However, from April 2013 the Clinical Commissioning Groups will replace both Strategic Health Authorities and Primary Care Trusts, simplifying the landscape. The NHS Institute, which was established in 2005 to support innovation, improvement and best practice, will be replaced with NHS Improving Quality. The new body will focus on supporting a limited number of key ‘high impact, high volume, high cost area’<sup>3</sup> where there is the potential to reduce costs through improving quality.

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<sup>3</sup> [www.institute.nhs.uk](http://www.institute.nhs.uk)

4.24 Discussion with a senior policy official identified key lessons learned in relation to public involvement in England:

- senior strategic leadership has been essential – “it has been successful where it has been valued by leaders”;
- clinical leaders have not always understood the benefits of involvement, and the evidence about benefits may not be as clear in this area;
- public involvement should be an integrated part of commissioning services – not considered as an add on; and
- competition between community organisations can create unnecessary barriers, where value could be added by co-ordination or co-operation instead.

4.25 It is clear that there is some concern among public representatives about the planned changes. For example, the National Association of Local Involvement Networks Members<sup>4</sup> has highlighted potential issues and risks in moving from Local Involvement Networks to HealthWatch, including alienating volunteers; duplicating services and thus wasting resources; failing to achieve public recognition and understanding; and failing to be representative.

4.26 Concerns about public (and patient) involvement have also been raised as part of the most recent Francis Report (2013). This report was produced as a result of issues around serious and significant failures in healthcare in the Mid Staffordshire NHS Foundation Trust in England. These failures prompted both an independent inquiry (in 2009/10) and a public inquiry (in 2010/11) into the Mid Staffordshire NHS Foundation Trust. The public inquiry explored issues of organisational culture and systems in the NHS. The report produced from this inquiry is extremely critical of the arrangements in England to support patient and public involvement. It suggests that while there have been a range of routes through which patients and members of the public can link into health services and hold them to account, these have been largely ineffective. It suggested that communities were reticent in raising concerns, and those who did raise concerns were not heard or did not have a voice. And it also suggested that patient involvement structures have largely relied on goodwill to make them work, rather than support, training and guidance.

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<sup>4</sup> National Association of LINKs Members, Progress Report, July 2012

## ***Experience from Northern Ireland***

- 4.27 This section was developed through a review of context and an interview with the Chief Executive of the Patient Client Council in Northern Ireland.
- 4.28 In Northern Ireland, health and social care services were integrated in 1972. One service – Health and Social Care Northern Ireland – is now responsible for both, making health and social care far more closely integrated in Northern Ireland than in the rest of the UK. Health and social care organisations are divided between six Trusts. Five provide integrated services to their designated area, while the sixth is the Northern Ireland Ambulance Service.
- 4.29 The *Health and Social Care (Reform) Act (Northern Ireland) 2009* made personal and public involvement a legislative requirement. All health and social care organisations are required to actively engage with service users and the general public (Public Health Agency; Health and Social Care Board). Each Trust takes responsibility for ensuring that personal and public involvement duties under the 2009 Act are met. The Trust must have a Patient and Public Involvement Strategy in place, and must report on this on an annual basis.
- 4.30 The 2009 Act introduced the Patient Client Council, a body set up to ensure that “the voice of all people on health and social care is sought, listened to and acted upon”. The organisation engages in regular consultation with the public and communicates its findings to the Health and Social Care Boards. In 2011, for example, the Patient Client Council issued a survey to 401 people seeking their views on the reintroduction of prescription charges (Patient Client Council, 2011).
- 4.31 ‘Quality 2020’, Northern Ireland’s ten-year health and social care strategy, was published in December 2011. The strategy was developed through consultation with patients and staff, with input from the Patient Client Council. One of the plan’s objectives is to “promote and encourage partnerships between staff, patients, clients and carers to support decision making”. In order to do so, Health and Social Care Northern Ireland will establish standards of patient involvement, based on best practice elsewhere in the world. It will then conduct regular surveys with patients and clients in collaboration with the Patient Client Council in order to monitor practice. The strategy also aims to involve patients and clients in the design of staff training and education.

4.32 The Chief Executive of the Patient Client Council believes that in Northern Ireland, people are now able to influence how services develop. Health and Social Care Northern Ireland will now consult before drafting any new policy, which has become part of the culture of the organisation. Key success factors include:

- setting the Patient Client Council within the structure of Health and Social Care Northern Ireland – which means it can't be ignored;
- ministerial commitment to public involvement; and
- actively seeking people out to gather their views – through activities such as roadshows where Trust Chief Executives meet members of the public.

“People do know about the opportunities that exist, there's been a fairly major investment in that recently.”

(Policy official Northern Ireland)

4.33 There remain challenges, however. The system is large and it can be hard to facilitate change and respond to views quickly. It can also be difficult to ensure that people are involved in discussions about social care – as it can be easier to involve people in discussions about health services, and there can be some stigma attached to use of social care services. It can also be difficult to make sure that people are involved at the level they are most interested in.

### ***Experience in Wales***

4.34 This section is based on a review of context and an interview with the Director of the Board of Community Health Councils in Wales.

4.35 In Wales, health and social care services are not currently integrated. However, there is significant interest in integration of health and social care services, which fits with the wider policy context and shift towards collaboration and partnership working across public services. In January 2013, the Welsh Government published a draft Social Services and Wellbeing (Wales) Bill for consideration by the National Assembly for Wales. This draft Bill aims to give people a stronger voice and control over the services they receive, providing a coherent legislative system for social services in Wales. It also provides a legal framework which aims to support greater integration and joint working between health and social care services. While the Health Act 1999 allows for the NHS and local authorities to enter into partnerships and to pool budgets, take up has been relatively low. As a result, Welsh Ministers propose to introduce powers to strengthen partnership working – including pooled budgets – that will require

partnerships between local authorities; across local authority functions; and between local authorities and Local Health Boards.

- 4.36 In relation to public involvement to date, the NHS (Wales) Act 2006 placed responsibility for public involvement on Local Health Boards to ensure that those to whom services are provided are consulted on:
- “a) the planning and provision of those services;
  - b) the development and consideration of proposals for changes in the way those services are provided; and
  - c) decisions to be made by the Local Health Board affecting the operation of those services” (NHS (Wales) Act 2006).”
- 4.37 In Wales, Community Health Councils have a legal duty to represent patients and the public to the NHS. They were established in 1974 with a remit to monitor local health services. They gather patients’ views through involving people in local consultations, conducting surveys and visiting hospitals. They also provide support and advice to patients who wish to make a complaint about their care. There are eight boards in Wales, with each taking responsibility for a particular area.
- 4.38 The Board of Community Health Councils in Wales has produced an all Wales Public and Patient Engagement Strategy, with each Community Health Council producing a local strategy. They work to the National Principles of Public Engagement in Wales, endorsed by the Welsh Government.
- 4.39 The Welsh Government’s 2011 5-year plan for the NHS aims to achieve a “sea-change” in public involvement, with the relationship between the NHS, the Welsh Government and patients to be detailed in a “compact”. This compact involves the Government and NHS providing information to patients and the public so that they are sufficiently informed to make decisions. It is also stated that the Welsh Government will “strengthen support for carers”, and consult and engage with local communities on service design. The result of this report was a consultation entitled “The People’s NHS”, which closed on October 24<sup>th</sup> 2012.
- 4.40 There is a clear perceived link in Wales between integration of health and social care, and the need for ongoing public involvement. To date, there has been a strong focus on working with service users and individuals to make sure that they have the information they need to take responsibility for their own health. Health Boards in Wales have been involving members of the public in discussing and drawing up a patient compact – and they are at different stages in this activity. However, some Community Health Councils have expressed significant concerns about plans for how local services are developed. And there is recognition that there needs to be involvement more generally in service planning and delivery.

“With the continuing development of integration of health and social care, there is a growing need for local authorities/health boards/voluntary sector/Community Health Councils etc to work together to further explore shared opportunities ensuring that the services and care provided are outcome driven and patient centred.”

(Policy official Wales)

4.41 In Wales, the Community Health Councils Board believes that there are a number of key components to successful public involvement:

- it needs to be measurable (in a variety of ways) – using qualitative information about views of stakeholders, changes in knowledge, attitudes and behaviour etc and quantitative information about the number of participants, contacts or comments;
- it needs to be transparent, with regular feedback using language that is easy to understand and jargon free;
- it needs to be supported by realistic and workable resources – ideally a dedicated budget;
- it needs to involve early and ample opportunities to participate; and
- it should involve the use of technology if appropriate, but should not overlook the value of traditional involvement methods (particularly the use of written information in disseminating feedback).

4.42 However, it believes that there are also many challenges and barriers.

Particular challenges relate to ineffective communication which can lead to mistrust; and how to balance a local and national approach to understanding experiences of service users. It is believed that there are real opportunities to overcome many of these challenges through integration – pooling resources; strengthening links between partners; and working with voluntary and community organisations.

## 5 Existing Experiences of Public Involvement

### Introduction

5.1 This chapter summarises the views of stakeholders involved in this research, in relation to experiences of public involvement in health and social care to date. It draws on:

- 18 telephone interviews with NHS Boards
- 22 telephone interviews with local authorities
- 6 face-to-face focus groups with members of the public
- 5 telephone interviews with equalities organisations
- 6 interviews with national organisations (COSLA, Scottish Government, Scottish Health Council, Joint Improvement Team, Care Inspectorate and Scottish Care), and
- 41 survey responses from NHS and local authority practitioners, of which:
  - 26 were NHS practitioners
  - 5 were local authority practitioners
  - 4 were voluntary or community organisations
  - 1 was a university, and
  - 5 were anonymous.

### Meaningful public involvement – views on current practice

5.2 Consultees overwhelmingly felt that current practice in terms of meaningful public involvement was very varied. Most felt that it depended on the subject matter and team within the local authority – “there are pockets of good practice”. Some felt that good practice was happening “by chance” and not being captured or recorded, with little reflection.

“We should be looking for lessons learned and trying to share best practice between organisations and industries.”

(National organisation)

5.3 Some members of the public felt that practice was improving. However others had not seen any change as a result of their involvement.

“The process is by no means perfect, but there is more of an openness being demonstrated around public consultation decisions.”

(Member of the public)

“There has been a beneficial and fundamental shift towards co-production and user led service design.”

(Equalities organisation)

5.4 Some local authority consultees felt that there were good examples of practice in the local authority and voluntary sector, but less so in the NHS. 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 rather than a ‘bottom up’ approach.

“Public services aren’t as joined up as they could be. That needs to improve if we are to get the full value out of public engagement.”

(Local authority practitioner)

5.5 However, NHS practitioners had mixed views. Some felt strongly that the NHS had significantly more experience in relation to public involvement. Conversely, other NHS practitioners felt that local authorities were further ahead in terms of public involvement – particularly in relation to community development. Some felt that local authorities were inflexible and unwilling to share expertise and resources.

5.6 A number of organisations mentioned the terminology used around public involvement and community engagement activity. Some felt that it was important to think carefully about terminology when moving forward, as different words were used to mean different things by different organisations.

5.7 Local authority consultees pointed to a range of examples of successes, including:

- **Working with specific groups** – With examples particularly in relation to working with refugees and asylum seekers, older people (often through Reshaping Care for Older People), and people with mental health issues and learning disabilities.
- **Working with established groups** – Many pointed to the value of working with small, established local community and voluntary groups, which are trusted channels for many. Some felt that big public events were not so successful, and were particularly challenging in large and diverse geographies. Some highlighted examples of using technology to address geographical challenges – through remote video or teleconferencing.

- **Rationalising involvement opportunities** – Some areas had made “a recent, deliberative effort to tidy up some of the smaller patient and user groups to create a better structure and bring people together.”
- **Raising the profile** – Some areas had made a clear effort to raise the profile of involvement through including it as a standing item on agendas across the local authority, so that it became ingrained into people’s thoughts.
- **Using a community learning and development approach** – Ensuring communities could take the lead, building capacity (of communities and staff) and using systems such as buddying to build capacity and provide support. Consultees emphasised the value of coproduction and joint working, to establish a two way dialogue.

“The key is to keep trying, continually build relationships, listen to people and never take a defensive stance over any issue.”

(Local authority practitioner)

- **Addressing practical challenges** – Including organising taxis or crèches, simplifying language used in reports, providing interpreters/translators or providing incentives for taking part.
- **Staff training** – To help staff to understand their roles, to value public involvement and to see that some of the work they do every day – like memory books – can be involvement.
- **Committing to the National Standards** – Many highlighted that getting local authorities and their partners to sign up to the National Standards for Community Engagement helped to build a consistent approach to involvement.

**Example: Success involving people in decision making**

In East Ayrshire, there is a system of VIPs (Very Important People) who have learning disabilities. They are involved in drafting strategies and agreements about how service providers work with individuals and communities.

**Example: A successful large public event**

In Edinburgh, the local authority and NHS held a joint city centre event focusing on Reshaping Care for Older People. It targeted advertising for this event through existing networks. It also advertised through the local press and radio. The event acted as a ‘drop in’ and also meant that organisations, service users and carers could network.

**Example: Working with the voluntary sector**

In Inverclyde, Your VOICE (Inverclyde Community Care Forum) was asked by the Community Health and Care Partnership to develop and support the Community Health and Care Partnership Advisory Group and wider network, as part of the integration agenda. One member of the public felt that this made it much easier to be involved, and that she had considerably more information as a result, which enabled her to participate more effectively.

**5.8 NHS consultees highlighted examples including:**

- **Managed Clinical Networks** – Comprising of long term conditions groups and staff, found across all NHS Boards. Some felt that these had proven a successful way to engage, and some in remote areas had made good use of technology.
- **E-portals** – Allowing online discussion on key topics, and targeted information sent to interested parties.
- **Working in remote communities** – Some had invested significant time and effort in involving people in ‘fragile’ remote and island communities. This involved working jointly with elected members, community groups and NHS staff (often with support at a national level from the Scottish Health Council).
- **Local Public Partnership Forums** – One NHS Board highlighted that it had set up community-based locality Public Partnership Forums, in recognition of the large geographical area it covered, with varied community views across the area. It felt that this had allowed a focus on local issues at a local level.
- **Public and community meetings** – Some NHS Boards used public meetings as the core of their public involvement activity, holding local meetings in all instances where there was to be a change in service design or delivery. Others held regular local meetings with communities, chaired by patients, with clear action points arising from meetings and reporting to decision makers.
- **Considered ‘campaigns’** – Some NHS Boards had undertaken Patient Focus and Public Involvement campaigns, at an early stage in key decisions (such as closing hospital wards or hospitals). Some had effectively communicated the message that closure could improve services for patients, and the feedback from the public was consistent with this.

- **Annual self assessment day** – One NHS Board holds a day each year which allows the public to say what has worked well, and highlights the range of opportunities available for involvement – at different levels.
- **Working to the Participation Standard** – Some embedded this in their work, for example holding annual focus groups looking at the Participation Standard. However, there were concerns about the bureaucracy associated with assessment against this standard.

5.9 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. Most felt that integration should involve taking a joint approach to utilising existing structures, and building on these to reach those not normally involved through existing routes.

“There’s a need to build on past experience. We also need to be open and honest about what has been done right in the past, and about what’s gone wrong.”  
(NHS practitioner)

### **Meaningful public involvement – barriers and challenges**

5.10 Consultees identified a wide range of challenges to meaningful public involvement. Again, challenges were very consistent across consultees, including members of the public.

- **Representative involvement** – Many grappled with the challenge of ensuring that public involvement was ‘representative’. Most felt that it was important to gather a broad range of opinions, from a broadly demographically representative population. This would involve reaching ‘hard to reach’ or ‘easy to ignore’ groups. However, some felt that involvement should always be with communities of interest, rather than the general public, as these would be people most affected by the issues. Many felt representative involvement was a challenge as only a relatively small number of people were willing to give their views. Many local authority consultees felt that this was a particular problem for Public Partnership Forums, which often involved a small number of people who were not seen as representative. Some local authority staff had very strong views on this issue. However, others suggested that it was important to recognise that “the same faces” are “the small number of enthusiasts”. Some questioned the legitimacy of views from different types of individual – for example asking whether those involved in community

groups (who may have consulted more widely with their members) should be given more credence than those speaking simply from personal experience.

“It seems strange to give the same weight to an individual’s comment compared to the Chair of a Forum.”

(Local authority practitioner)

“There is a need for them to demonstrate that they really do speak on behalf of their community. How do we know they are representative? How do they know themselves?”

(NHS practitioner)

- **Complexity** – Many felt that health and social care was wide ranging and complex, and that to be involved fully meant understanding a significant level of detail about how services operate. It could be challenging to support people to fully understand the issues, and enable them to be involved meaningfully. Some members of the public felt that consultations could be academic in style, increasing their complexity and appearing intimidating, when they could be presented in a simpler manner. Some national organisations agreed that the language used around consultations and the setting or context they are carried out in can be confusing for individuals and act as barriers. Conversely, many (particularly NHS practitioners) felt that as people begin to understand the complexities, they are no longer truly representing the views of a ‘lay person’. And some felt that provided simple language was used, professionals should have more faith in the level of understanding of the public.

“The challenges are finding people to be involved who are representative of the public, but who understand the workings of health and social care.”

(Local authority practitioner)

“The way that the NHS is structured means that they expect the public to act as a ‘professional group’.”

(NHS practitioner)

“We should have more faith in the expertise, abilities and level of understanding of members of the public.”

(Equalities organisation)

- **Politics** – Some local authority consultees highlighted that issues can become over politicised. Sometimes this means that the most controversial

decisions are not openly consulted on – or are considered separately from other issues.

“There are some things local authorities and health boards are nervous about consulting on, so they don’t bother – which just creates problems. Full public meetings can create anxiety amongst councillors because they are often heated... it may harm their re-election.”

(Local authority practitioner)

- **Fear and power** – A small number of local authority consultees highlighted that there was a power imbalance between service users and institutions, and a reluctance to speak up about what is not working. People can be worried about what they might lose if they express their views as services are redesigned, rather than what they might gain or what might be better. People can also be worried that negative feedback will result in cuts to much needed services. Some felt that disadvantaged and poorer communities in particular may not have the confidence to speak up, or “believe they have anything of worth to say”. Some members of the public highlighted that they could be intimidated by traditional meetings or public meetings, and felt that they may be judged on their own appearance rather than what they say. Some highlighted that professionals need to be aware of the impact of language used and dress code.

“Some individuals have the ‘fear factor’ – a lack of confidence in saying what they think.”

(Member of public)

“Equal partnerships between lay people and the authorities are far from being achieved in health and social care.”

(Member of the public)

“Service users don’t have the option of taking their custom elsewhere... some tend not to feel that they have the right to speak against it.”

(Equality organisation)

- **Integrating views into decision making** – Some highlighted that some big policy decisions on health and social care continued to be taken without much consultation. Public involvement was not always undertaken, and not always acted upon. And information gathered at different stages – for example at point of assessment – was not always collated and shared effectively. Some felt that this was a particular problem as involvement was not mainstreamed into decision making, and people were not held accountable for listening to public views.

“Some big decisions are still being made without real consultation.”

(Local authority practitioner)

“It should mean that we are listened to – but this is often not the case. If it is not a formal complaint, and comes from an ‘informal’ source (such as a community group) then it is ignored.”

(Member of the public)

- **Action** – Many felt that it could take time to take action, often due to ‘red tape’ and bureaucracy, or not listening or building people’s views into decisions. This can lead to apathy and a feeling of over consultation if involvement doesn’t lead to change. Members of the public felt that apathy was a key barrier to involvement.

“People are put off because nothing ever gets done... We need to know the reasons behind decision making.”

(Member of the public)

“If I thought there was going to be a change, I would get involved more.”

(Member of the public)

- **Balancing differing views** – Some highlighted the challenge of knowing what to do when views are contradictory, and there are different perspectives. However, most felt that it was important to recognise that it is not possible to satisfy everyone, and the key is to review views and evidence, and come to a professional opinion.

“There will always be people who have clashing views, and ultimately the majority views will be acted upon more readily.”

(Local authority practitioner)

- **Practical barriers** – Almost all local authority consultees highlighted barriers for individuals in relation to practical issues, including accessibility, public transport, mobility for older and disabled people, time, timing (with many day time meetings) and money – to travel to involvement opportunities. Many, particularly those in large, rural and remote local authorities, highlighted that geography was a key challenge both for individuals (travelling to opportunities) and for staff (finding the right people with the right skills to cover remote areas). Many also highlighted the use of jargon and complicated language as a key challenge.

“The jargon by professionals...don’t accept it. If I’m in a meeting then I’ll say I don’t understand.”

(Member of the public)

“It costs the public to be involved. [The local authority] will pay for travel, but most councils will not and this excludes people.”

(Member of the public)

- **Staff attitudes** – Many felt that more needs to be done to ensure that local authority and health staff understand the importance of having the community involved. Some identified a particular issue in raising awareness among GPs. Others felt that staff could have presumptions and preconceptions about the value of involvement. For example, in one area, staff felt that young people wouldn’t be interested in a consultation, but they became involved and “they asked the most pertinent questions”. One consultee highlighted that it was important to be rigorous in gathering information as “note takers can inadvertently filter out points that they either disagree with or do not understand”. Many felt that engagement needs to be recognised as a skill in itself, as staff often feel they are “too busy doing their day job”. This was recognised as an issue in both local authorities and NHS Boards, but was raised more often by NHS practitioners in their interviews.

“Involvement is currently seen as someone else’s role, or as an add on.”

(NHS practitioner)

“Some senior staff have been making decisions without realising the impact on stakeholders, who should have been involved but weren’t.”

(NHS practitioner)

- **Resources** – Many local authority consultees felt that involvement was “very people intensive” and in this economic climate it was difficult to invest in the resources and training so that staff had the skills and capacity required. Some also pointed to the fact that health inequalities were increasing in some areas, putting increased pressure on services. Many NHS practitioners highlighted that it was resource intensive to continue trying new methods and refreshing involvement – as without constant innovation what was once innovative becomes traditional, and people don’t stay involved. And many felt that the bureaucracy and assessment around the Participation Standard was resource intensive.

“Trying to discuss investment and efficiency savings with the public is difficult – especially when the core funding is the same.”

(NHS practitioner)

“There seems to be too much bureaucracy in terms of paper filling and reporting, which takes away from quality time spent building relationships with communities of interest.”

(NHS practitioner)

## 6 Future Possibilities

### Introduction

6.1 This chapter summarises the views of stakeholders involved in this research, in relation to future possibilities and opportunities for public involvement, in the context of integration of adult health and social care. It draws on:

- 18 telephone interviews with NHS Boards
- 22 telephone interviews with local authorities
- 6 face-to-face focus groups with members of the public
- 5 telephone interviews with equalities organisations
- 6 interviews with national organisations (COSLA, Scottish Government, Scottish Health Council, Joint Improvement Team, Care Inspectorate and Scottish Care), and
- 41 survey responses from NHS and local authority practitioners.

### Meaningful public involvement – what are we aiming for?

6.2 Consultees were asked what meaningful public involvement looks like – what we should be aiming for – both generally and in relation to health and social care. A number of core characteristics were identified. Local authority and health practitioners, and members of the public, demonstrated a high degree of commonality in defining meaningful public involvement.

6.3 The core characteristics identified were:

- **Clarity of purpose** – It should be clear why people have the opportunity to be involved. Some felt that if the purpose was not clear, people could “suspect an ulterior motive”. Others felt that involvement should be outcomes focused – considering what the end result of involvement should be from the outset.

“Ensure that members of the public are crystal clear on what their role is and feel comfortable with it.”

(Local authority practitioner)

“We need to know what we are looking for, from public involvement – is it co-production, or just opinions and/or ideas? There are different levels of involvement and we need to be clear on what these are.”

(National organisation)

- **Honesty** – Meaningful involvement should be honest about its scope. It should be clear what decisions have already been made, and what constraints or limitations exist. And there should be a commitment to listen to views on all issues – not to protect organisations from views that they might not want to hear. Some members of the public felt that it was important that all key decision makers were involved, and that it should be facilitated by an independent organisation.

“There should be an independent organisation involved to ensure it was all done properly and they listened to the comments... make the council recognise the views of people.”

(Member of the public)

“It has to be planned, genuine and influence the outcome of decision making.”

(NHS practitioner)

“The public need to know what they can and cannot influence and shape, rather than give opinions on issues around which decisions have already made.”

(Member of the public)

- **The right people** – Many felt that meaningful involvement should be about engaging the people who are affected by decisions – “nothing about you without you”. This should include a range of different people. Some felt that it should be broadly representative of demographics, and should reflect equality and human rights principles. Others felt that it was important to recognise that people usually engage either if they are very happy or very annoyed – and that meaningful involvement needs to recognise this bias and account for this in decision making.

“We should be enabling people to engage by creating the opportunities for them to do so, but at the same time respecting the fact that some may not want these opportunities. It is about choice”.

(National organisation)

- **Routine** – Involvement doesn’t always have to mean new activity. Services should use the information they already have, manipulate it and share it. Some felt that meaningful involvement involves “continually gathering information on an ongoing basis”.

“It needs to be ongoing, not a ‘one hit wonder’. Relationships need to be built over time through regular engagement.”

(NHS practitioner)

“I feel we should be aiming for routing ongoing dialogue with communities.”

(Local authority practitioner)

- **Community led** – Many, particularly national organisations and local authorities, emphasised that meaningful involvement needed to include opportunities for communities to raise and take forward issues themselves, rather than simply responding to opportunities for involvement in issues determined by the NHS or local authorities.

“We need to build community capacity and capability around engagement making better use of third sector organisations and community groups.”

(National organisation)

“We need to empower local people and develop more of a grassroots involvement culture, rather than the ‘top down’ bureaucratic culture that still seems to exist.”

(National organisation)

- **Different levels** – People should have opportunities to be involved at all levels of decision making. They should be involved in planning and reviewing services. They should have the opportunity to be involved in local and strategic issues, if they so wish.

“By the time issues reach Forum level, decisions have often already been made at Committee level. It is a good channel of communication, but not effective for local decision making.”

(Member of the public)

- **Stage** – Members of the public highlighted clearly that they should be involved from “as early a stage as is possible” – not after a decision has been made. NHS and local authority practitioners echoed this.
- **Respected and respectful** – Staff (and other decision makers) should value public involvement, and build it into their decision making processes. Many felt that it was important to set up a ‘two way dialogue’, with staff respecting communities and vice versa. Some (particularly NHS) consultees highlighted the need for communities to respect staff also, and behave in a respectful manner when becoming involved. Members of the public stressed that staff need to listen and consider their ‘lived experiences’ in a respectful and considered manner.

“We should be aiming for a situation where everyone respects the importance of public involvement and does their best to make it meaningful.”

(Local authority practitioner)

“Meaningful public involvement should also strengthen public confidence in services.”

(NHS practitioner)

- **Varied methods** – Consultees felt strongly that different people like to be involved in different ways. Effective involvement was seen as requiring consideration of what the most appropriate methods are, dependent on the audience. One stakeholder described this as “reaching everyone who wants to be involved – while respecting those who do not.”

#### **Example: Range of methods**

In West Dunbartonshire, the Community Health and Care Partnership ran a six month consultation on Reshaping Care for Older People. They conducted a series of focus groups, online surveys, work with the Citizens Panel and used social media including Facebook and Twitter.

- **Listening and changing** – Many highlighted the importance of communities receiving feedback on how their views were recorded and fed into decision making. Most felt that it was important that communities had an influence as a result of involvement, and that something should change as a result. Some felt the focus should be on action at a local level – “the aim is to be able to respond more quickly, be more flexible and become more locally focused”. Others felt the people should be able to also shape outcomes at a more strategic level (if they so choose). Some stressed the need to share information across services as “sometimes you can get good information off-topic”. Members of the public highlighted that they wanted to know that their feedback had been listened to – to receive some acknowledgement of their input and know that someone had thought about it.

“It should act as a catalyst for change, where we really listen to people’s concerns and learn from them.”

(NHS practitioner)

“If people are to remain engaged they must be able to see the difference that their involvement has made, in order for them to feel heard.”

(Member of the public)

- **Accessible and informed** – Many stressed that involvement should be accessible, and that adequate time should be allowed for involvement. This could involve pre-engagement work, and the provision of information so that people can participate in an informed and meaningful way.

“We have to make sure that the public are informed and able to understand issues and decisions, as often change is perceived as loss.”

(Local authority practitioner)

6.4 Local authorities generally stated that they worked to the National Standards for Community Engagement, and felt that these were a clear definition of meaningful involvement.

“We are 100% in tune with these principles.”

(Local authority practitioner)

6.5 Health practitioners highlighted that they were required to self assess against the Participation Standard, which covers both Patient Focus and Public Involvement. Some highlighted the important distinction between patient focus (involving people in discussions about their own treatment and care) and public involvement (involving people in making decisions about changes to services). A small minority felt strongly that patient focus was considerably more important than public involvement, and that public involvement was generally not helpful.

“Public involvement is not as important as patient safety.”

(NHS practitioner)

6.6 Consultees broadly felt that meaningful involvement in health and social care shared the same characteristics as meaningful involvement more generally. However, a small number of particular issues were identified:

- links (and distinctions) between public involvement and activity to build individual capacity to take responsibility for their own health
- the importance (and challenges) of engaging carers
- the role of co-production in supporting a joint approach to involvement
- the different words used by health and social care professionals to describe their work – involvement, engagement, consultation, etc, and
- the impact of national politics on the work of NHS Boards (particularly around hospital closures).

“[A local authority] prefers the term ‘community engagement’ to ‘public involvement’ as it implies a collective aspect.”

(Local authority practitioner)

## Integrating health and social care – implications for public involvement

6.7 Many consultees were unsure about the implications of integration on public involvement. Generally, local authority consultees had significantly more to say on this topic than NHS practitioners. Practitioners within some NHS Special Boards found it particularly difficult to comment on the impact of integration. Some members of the public also exhibited some confusion about integration.

“We don’t really know what they mean. And structurally, where will it be placed? Will there need to be an equivalent of a Public Partnership Forum? It’s all up for grabs.”  
(Local authority practitioner)

“We need to know the benefits of any changes and how much it is going to cost.”  
(Member of the public)

“To the wider public, integration is still quite an abstract concept. People don’t yet understand what it means.”  
(Equalities organisation)

6.8 Many felt that integration shouldn’t impact too much on public involvement. There were two main reasons for this. Firstly, some felt that work had already been done to integrate activities, and that operational issues in relation to public involvement had remained broadly the same. Secondly, some felt that generally there was not much duplication in public involvement and that separate systems were likely to continue.

“The principle is right – but we have to remember that both organisations will retain their separate means of involving people. So it will not remove a lot of duplication.”  
(Local authority practitioner)

“There is already some joint service working in certain areas, but integration has not been achieved yet and there is more work to be done.”  
(NHS practitioner)

6.9 However, others felt that there were real opportunities to enhance public involvement through integration. This included:

- **A higher profile** – Some felt that new legislation would create more local awareness of public involvement, and that involvement may become an issue which is considered at a more strategic level. Some were already seeing evidence of this – for example involvement becoming a standing item on senior management agendas. Some felt that this would result in raised aspirations for customer experience and public involvement.

“Involvement work will be more visible, and information and ideas more easily shared.”

(Local authority practitioner)

“It is hoped that public involvement will improve with integration. It should provide more chances for people to connect as new groups are established and people are brought together within the community.”

(Member of the public)

- **Integrated involvement** – Many felt that integration should lead to integrated public involvement opportunities. This could result in a single strategy for involvement; single conversations around services; shared and triangulated information between organisations and departments – described as “larger pools of information”; reduced duplication (resulting in less consultation); shared understanding or definition of concepts; and a more holistic picture of public views on services. Some felt that some of the existing fora in place for public involvement could stop, as involvement was rationalised.

“Integration will lead to more holistic service provision, which is more effective as issues are generally interlinked and inter related.”

(Equalities organisation)

“Integration of adult health and social care could lead to shared outcomes and goals for local communities.”

(NHS practitioner)

“There are opportunities to hear a more consistent story – rather than capturing fragmented feedback from service users. This will allow for one story and picture, rather than many.”

(Local authority practitioner)

- **Shared resources** – Many felt that integration brought opportunities in sharing or pooling resources for involvement. Many highlighted that integration was linked to the need to make cuts and build efficient public services, and that ultimately resources were reducing. They felt that integration offered opportunities to share resources, to become more efficient.

“On a policy level, more joined up and partnership working is required – sharing resources and skills across agencies and organisations.”

(Local authority practitioner)

“Joint engagement activities will be possible, and duplication of activities more visible.”

(NHS practitioner)

- **Different opportunities** – Some local authority consultees highlighted that integration will occur differently in each area, and may result in different opportunities for each area and community. However, these consultees still felt that integration should reduce duplication and enhance involvement.

“We need to have best practice public involvement systems in place to facilitate this, and allow for flexible local arrangements to develop as different areas vary greatly within Scotland.”

(National organisation)

“Integration is about improving services – making them more coherent and joined up. That should make involvement easier.”

(Local authority practitioner)

- **Building on lessons learned** – Many consultees highlighted that with integration, came an opportunity to “stop reinventing things that have been done before”. Many felt that the aim should be to build on and improve the structures which are already there, including formal structures and building on the resources available across the local authority – including public involvement officers and community engagement officers. This was a very strong view across consultees – including local authority and NHS practitioners and members of the public. National organisations also highlighted the need for public involvement structures within health and social care to link to community planning structures. Some believed strongly that there should be no separate structures for public involvement in health and social care, but a single channel for engagement through community planning.

“We need to look at our current involvement structures and ensure that they enable rather than disable.”

(National organisation)

“We need to think about the community planning infrastructure, which if designed correctly should be immediate to people and communities, rather than abstract and inaccessible.”

(National organisation)

“I would definitely advocate ongoing Public Partnership Forum work. The only way to build up credibility is through ongoing dialogue.”

(NHS practitioner)

## Challenges

6.10 Consultees were asked whether integration brought any particular challenges in relation to public involvement. Many consultees felt that the challenges remained the same. However, many highlighted particular challenges in relation to integration:

- **Organisational culture** – A large proportion of local authority consultees highlighted that bringing together two different organisations to agree shared new systems and integrated objectives could be difficult. Consultees highlighted organisational barriers, with two staff groups with different cultures, terms and conditions and ethos. And many felt that staff, in all situations, could be very protective of their own practices and mechanisms. Some local authorities felt that the NHS had stricter rules in relation to public involvement than local authorities – and there was some feeling that social care may be a junior partner and may not get an “equal seat at the table”.

“The statutory requirements placed on health do not apply to local authorities. That might be a real challenge for integration.”

(NHS practitioner)

“From the health side there are Public Partnership Forums, from a council perspective the focus is on service user and carer engagement. The skills sets required for both types of engagement are very different – how are these to be integrated?”

(Local authority practitioner)

- **Organisational restructuring** – There was significant concern that public involvement would “get lost” in new arrangements, because of wider changes in terms of integration. Many highlighted previous experience of restructuring resulting in an internal focus and a “heads down” mentality, with little space for public involvement. Members of the public highlighted that most people don’t know about integration, and don’t understand what this will mean for them. However, they stressed that most don’t mind where their services come from, as long as they are provided effectively and accessibly.

“The focus so far has been on integration of budgets and governance – and not much focus on public involvement.”

(Local authority practitioner)

“So much time was spent deciding who had responsibility for what, that public involvement fell off the agenda.”

(NHS practitioner)

- **Extent of integration** – There were also concerns about the extent to which real integration would occur, generally – and within public involvement. Many felt that previous experience was of roles and remits being “divided up” rather than working together in an integrated manner. Some pointed to situations where new structures were simply added to existing structures, rather than replacing them (for example citing Public Partnership Forums running alongside Community Care Forums in some areas). Members of the public highlighted concern that the integration would initially focus on services for older people, stressing that disabled people also required joined up service provision.

“Previous experience has shown that even where social work and NHS teams are brought together there is not always integration, so duplication can be an issue.”

(Local authority practitioner)

- **Information sharing** – Many, particularly NHS practitioners, felt that for integrated public involvement to work, this would require strong IT systems to share data and strong but simple confidentiality agreements to allow information sharing. It would also require a clear desire and commitment to share information – such as contact data for local groups, or findings from involvement opportunities. It was felt that these practical issues could mean that duplication would continue to occur, because people didn’t have access to information across health and social care.

“If people protect what they have, nothing will be achieved.”

(Survey respondent)

“Unless everybody involved has access to timely and accurate information then duplication will continue to occur.”

(Survey respondent)

- **Resources** – Many highlighted the link between integration and the challenging financial environment. Some felt that there was a real challenge in maintaining meaningful public involvement in this context – particularly if the focus was on maintaining frontline services rather than strategic services.

“At times of resource scarcity there is always a risk of all focus being placed in frontline service delivery, rather than on strategic sustainable service improvement. It can therefore be difficult to get a strategic perspective.”

(Local authority practitioner)

“It’s all budget driven... to help us make public involvement meaningful it needs to be funded. It is all driven by efficiency savings, but public involvement needs to have some funding to back it.”

(Member of the public)

- **Scale** – A minority of consultees highlighted that local authorities generally worked on a smaller and more local geographical scale. There was some concern about NHS Board-wide involvement, which some felt was too large a scale and could lose the local focus.
- **Existing mechanisms** – Local authority consultees had concerns about building on Public Partnership Forums as a public involvement mechanism, with many feeling that they were not working well, involved “the same faces” and were not representative. Many local authority staff deliberately don’t work with Public Partnership Forums as they don’t see the value of this mechanism. Others felt that generally existing structures did not work well and needed to be replaced.

“Current involvement structures are not suitable for what we are trying to achieve, therefore new structures need to be established.”

(Equality organisation)

- **Standards** – There was some concern, from NHS and local authority practitioners, that both organisations were working to different standards. Some standards (such as the National Standards for Community Engagement) were voluntary, while others (such as the Participation Standard) were statutory.

“There are currently two sets of public engagement guidance for the health service (Participation Standard) and for social care (National Standards). There may still be the need to have two sets of guidance as there will be differences between the outcomes and activities required by each service.”

(NHS practitioner)

- **Change** – Consultees reiterated their strong views that it was important to build on what is already there in terms of public involvement, rather than to create new structures and standards. This was a very strongly held opinion across local authority consultees. Members of the public also strongly felt that change disadvantaged them, and prevented them becoming fully involved in decision making.

“My greatest fear about integration is that it will create new standards to work to. Understandably there will be change, but it is better to build on existing structures.”

(Local authority practitioner)

“The ideal would be to take the best of both – but the local authority is not accountable to Healthcare Improvement Scotland, and the NHS Board is not accountable to COSLA despite a shared mandate.”

(NHS practitioner)

“Constant name changes and shifting of goal posts is a way to stop lay representatives from getting to the top, where real decisions are being made.”

(Member of the public)

## Structures

6.11 Consultees were asked about the role of permanent more formal involvement structures, and ad hoc, issue-based involvement opportunities – and were unanimous that both were needed.

“Alongside a continual programme of public engagement there will always be the need for short notice, issue based initiatives.”

(Local authority practitioner)

6.12 People felt that a structured approach was needed as it helped to provide ongoing feedback, co-ordinate activities, build trust and dialogue and build understanding. One equalities organisation also suggested that permanent structures are very important so that people know what their rights are.

“The Public Partnership Forum is a forum where people feel safe and confident to air their own issues. It can ‘jump start’ more detailed work if someone raises a specific point.”

(Local authority practitioner)

“There needs to be a framework for people to work within. Without a framework there is no accountability.”

(NHS practitioner)

6.13 Consultees also felt that there was real value in issue-based and ad hoc involvement on particular issues.

“The system needs to be agile enough for ad hoc consultations to be carried out when necessary.”

(Local authority practitioner)

6.14 However, most felt that ad hoc involvement should build on ongoing smaller scale involvement – for example collating feedback gathered from people at point of assessment, and from community groups on an ongoing basis. Many suggested that there was a need to build relationships and ongoing dialogue, to build the basis for one off or issue based involvement in the longer term.

“There is a need for a level in between permanent structures and one off meetings. There is a need to go out to key groups and create relationships.”

(NHS practitioner)

6.15 However, some consultees felt that generally the types of structures in place were less important, provided there is a commitment to engage and a clear framework.

## **Using technology**

6.16 Consultees identified a wide range of different technology that they had used to involve people – including Facebook, Twitter, texting, survey monkey, websites, DVDs, online polls, voting buttons, mobile opinion meters, quiz bomb, ketso, video conferencing, web chats, mobile data capture, vox pop (gathers the views of multiple people at the same time) and e-readers for partially sighted people. Often this technology had only been used recently, and in a minority of cases organisations had not been able to sustain the resources to continue using these approaches.

6.17 Technology was seen as an excellent way of using lots of different methods to involve people in a way that suits them. It was seen as particularly valuable for involving young people and disabled people – for example using texting for

deaf people, or e-readers for partially sighted people. Members of the public were very positive about the use of technology, particularly using social media to involve young people and disabled people – provided it was alongside other methods.

“Staff can be resistant to new technologies, but surprisingly older people have taken to it quite willingly.”

(NHS practitioner)

#### **Example: Using technology**

In one NHS Board, staff were planning to hold digital focus groups so that they can try out new technologies (for example for measuring blood counts in diabetes patients) and get feedback on these approaches.

6.18 However, consultees cautioned that it is important to consider how the information gathered using these methods is used, including considering how robust the data is. They also cautioned that technology should be one of a range of options for involvement, and that people shouldn't have to use technology to get involved. This was a particular concern in relation to older people and poorer or disadvantaged communities. Some felt that technology – particularly use of the internet – could alienate those in lower income brackets. Members of the public highlighted that technology could simply involve using TV or radio – and didn't need to be something new or different.

“Technology can become a barrier if forced upon people who don't or can't use it.”

(Local authority practitioner)

“Technology should enhance our ability to involve people, not accidentally disenfranchise them.”

(Local authority practitioner)

#### **'Seldom heard' people**

6.19 Consultees also highlighted a range of other ways in which health and social care could ensure that the views of 'seldom heard people' are built into decision making. Many felt that the first step was to take time to identify whose views need to be heard and who is missing from this. Many – particularly members of the public – felt that this should be done in a routine way and integrated into public involvement opportunities, rather than holding separate consultations for specific groups of people.

6.20 Some highlighted that while many different words could be used – ‘hard to reach’ ‘seldom heard’ ‘marginalised’ ‘disengaged’ – it was important not to think of people as an entity, but as many different individuals requiring different methods of involvement.

“The right tools must be used for the right people.”

(Multiple – both local authority practitioners and NHS practitioners)

“No response doesn’t mean that respondents don’t want to respond – it may mean that they cannot.”

(NHS practitioner)

6.21 Many stressed that the most effective way to involve many ‘seldom heard’ people was through using existing organisations and professionals who have already built up trust with different groups of people. This could include visiting community and voluntary groups; or building links with professionals who already have trust – like health visitors or care workers. This was particularly important for some groups – such as Gypsy Travellers – who consultees felt could be “wary of statutory organisations” (NHS practitioner).

“We need to make a special effort to go to them.”

(Local authority practitioner)

**Example: Building relationships**

One equalities organisation highlighted that it ran a mentoring scheme, connecting six Scottish Government civil servants with six marginalised people, with the aim of breaking down social barriers between the two. This involves meetings in Scottish Government offices, and in deprived areas. The pilot programme has proven very successful.

6.22 Members of the public highlighted the need for capacity building activity, “as people are often disengaged as a result of trying to cover up for their lack of basic skills in this area.” Many consultees highlighted that the principles were the same as with all groups – for example making sure a range of different methods were used, and that costs (such as transport or childcare) were met. This was seen as a particular issue for poorer communities.

6.23 Some mentioned that people with dementia or learning disabilities can find it particularly hard to articulate their views, and that it was important to consider non-traditional involvement techniques – such as memory books or observation. This was a strong theme in consultation with some members of the public, who suggested that there is a very important task in involving people who cannot verbalise well – and have communication difficulties, learning

disabilities or mental health difficulties. They felt that independent advocacy and peer advocacy support had a key role here. Some members of the public felt that public sector funding cuts would result in an increase in vulnerable and isolated groups, requiring more effort to reach and involve people.

6.24 Others highlighted the barriers faced by people from ethnic minority communities – and the need to target involvement opportunities in areas where there were high ethnic minority populations.

“Service providers need to go into communities to engage – which is less formal but a good way to gain access to harder-to-reach groups.”

(Equalities organisation)

6.25 Some suggested that it was important to view ‘the usual suspects’ as opportunities to reach others, who do not get involved so easily. However, many highlighted that it is important to remember that ‘seldom heard’ people might just not want to be involved. While it is important to provide people with clear information about the value of being involved, consultees were clear that you can’t force people to get involved.

“We need to encourage people to participate by reminding them of the benefits of becoming involved.”

(Equalities organisation)

## 7 Case Study Examples

### Introduction

- 7.1 This chapter summarises the key themes and lessons learned from four in depth case studies of public involvement in health and social care in Scotland. These case studies were East Renfrewshire, Dundee, Highland and West Lothian.
- 7.2 The case studies are provided as Appendix One.

### Lessons learned

- 7.3 The case studies highlight different experiences of integration and public involvement across Scotland. Key lessons learned from the case studies include:
- **Communication and relationships** – Communication was a major issue identified. It can help members of the public to feel more positive and engaged, particularly if they have strong personal relationships with key senior staff and feel that they can discuss issues with them equally. Conversely, poor communication can cause fear of change, suspicion and lack of engagement. There are some examples of integration helping to build these relationships, through clear involvement of senior staff and two way dialogue. (See East Renfrewshire case study for an example of positive communication and relationships, and Highland case study for an example of where communication has caused some degree of mistrust.)
  - **Capacity building** – The case studies highlight the value of a ‘bottom up’ approach, with communities raising their own issues, as well as responding to issues raised by public organisations. The case studies also demonstrate the value of supporting people to understand the context and access the information they need. However, some case study areas experienced challenges involving new members of the public who were not ‘entrenched’ in health and social care. (See Dundee and East Renfrewshire case studies for positive examples of capacity building activity.)
  - **Profile** – The case studies demonstrate that integration can cause a renewed focus on public involvement, and can raise the profile of involvement work within organisations. It can help to challenge existing organisational cultures and staff attitudes, and in some areas there was evidence of small scale improvements in public involvement perceived

both by members of the public and staff. The case studies highlight some examples of real involvement in decision making – participation in influencing budgets, or members of the public on interview panels. (See East Renfrewshire and West Lothian for positive examples of integration raising the profile of public involvement.)

- **Organisational cultures** – The case studies demonstrate that integration can have varying impacts on organisational cultures. It can tackle historic protectionism around budgets, create a more ‘neutral’ and co-operative working environment, and result in enhanced public involvement. However, it can also cause an internal focus on restructuring and suspicion about change. There is evidence from the case studies that leadership at a senior level is vital in changing cultures as integration occurs. (See Highland and West Lothian case studies for examples.)
- **Transitions** – The case studies demonstrate that change, at whatever level, can result in uncertainty and can take time to bed in. It can be difficult for staff and members of the public to move on and let go of previous structures – whether successful or not. And it can help if members of the public see even very small differences in the extent of involvement, in a positive way. (See Highland for an example of the impact of a major transition.)
- **Standards** – In areas where there is an integrated approach, there is evidence that different standards for public involvement can result in duplication, and a view that a single standard would be beneficial. (See Highland for exploration of this issue.)

## 8 Key Findings

### Introduction

- 8.1 This chapter 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*

- 8.2 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.
- 8.3 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.
- 8.4 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.
- 8.5 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 co-ordinate 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;
- co-ordination of involvement opportunities has helped to reduce competition between different representative organisations; and
- change has resulted in some concerns about public involvement.

8.6 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***

8.7 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.

8.8 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.

- 8.9 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.
- 8.10 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***

- 8.11 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.
- 8.12 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.

8.13 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.

8.14 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.

8.15 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**

8.16 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.

8.17 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?

8.18 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.

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

8.19 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.

8.20 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.

8.21 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.

## **Appendix 1: Case Studies**

- 1a: East Renfrewshire
- 1b: Dundee
- 1c: Highland
- 1d: West Lothian

## **Appendix 1a: East Renfrewshire Case Study**

### **Introduction**

This case study explores public involvement in health and social care in East Renfrewshire. To complete this case study, we spoke to a number of health and social care professionals as well as a member of the public. These included:

- the Director of the Community Health and Care Partnership
- a Community Health Development Officer
- the support person for the Public Partnership Forum, and
- the Chair of the Public Partnership Forum.

This case study looks at joint public involvement mechanisms established in East Renfrewshire – focusing on the role of the Public Partnership Forum in shaping service design and delivery.

### **Health and Social Care Integration**

East Renfrewshire Council and NHS Greater Glasgow and Clyde took the decision to create a fully integrated Community Health and Care Partnership in 2005. The Community Health and Care Partnership has a single Director accountable to both the Chief Executive of the Council and to the Chief Executive of NHS Greater Glasgow and Clyde. The Director is on the Council's Corporate Management Team and the Senior Management Team of the NHS Board.

There is a Management Team responsible for integrated services for children and families, community care services and criminal justice. Senior Managers can be employed by either the Council or the NHS.

The whole of the local authority social work service is managed within the Community Health and Care Partnership as well as the majority of community health services. The Community Health and Care Partnership is also responsible for the prescribing budgets for local GPs and for the contracts with local GPs, dentists and pharmacists.

### **Arrangements for Public Involvement**

When the Community Health and Care Partnership was first established, a document called the 'Scheme of Establishment' was drawn up, setting out the ways in which the new Community Health and Care Partnership would work. The Scheme of Establishment set out the procedures for public involvement. The Community Health and Care Partnership was clear from the outset that the responsibility for public involvement was a joint one.

“The Community Health and Care Partnership will be characterised by.....ensuring patients and a broad range of frontline healthcare professionals are fully involved in service delivery, design and decisions.”

Scheme of Establishment, April 2005

Having public involvement ‘embedded’ into strategies has meant that there is an integrated approach to public involvement. It was described as not just about ‘informing’ the public about what is happening, but engaging them in a “hierarchy of consultation”. The aim is for consultation to be “meaningful and to achieve change.”

“We want to use the knowledge and skills of local people and this is very different to a ‘top down’ approach. As an authority, East Renfrewshire is now much more aware of the benefits of public involvement and it is seen as the right thing to do.”

Director, Community Health and Care Partnership

The Scheme of Establishment set out the ways in which the Community Health and Care Partnership could engage with the public. The Public Partnership Forum would be the main, formal component for engagement.

“...the facilitation and integration of community involvement will be core to the CHCP (Community Health and Care Partnership) through a Public Partnership Forum.”

Scheme of Establishment, April 2005

East Renfrewshire Public Partnership Forum is a network of local individuals and organisations who are interested in health and social care services and want to be kept informed and involved in how they are designed and delivered in East Renfrewshire. The Public Partnership Forum has an Executive Group which is responsible for the operation of the Forum. It has around 20 members (made up of members of the public and staff) and meets monthly to plan activity. The Public Partnership Forum Executive Group works with the Community Health and Care Partnership to get information about services to the public, and ensures there are opportunities to consult in any decision making about services. The Community Health and Care Partnership has integrated the council’s community engagement structures into the way the Public Partnership Forum works by having members representing Area Forums and Community Councils.

In addition, there is a wider contact database, where people can register an interest in the Public Partnership Forum and this group receive information bulletins every so often with invitations to events or consultations. The Public Partnership Forum also host an annual ‘open event’ where people can come along and give their views.

The Public Partnership Forum is the main way of engaging with the public, but within the Forum are also subgroups which may have a shorter life span, depending on

their focus. For example, members of the Public Partnership Forum subgroup took part in 'environmental visits' for new health clinics.

There is also a Reference Group for Reshaping Care for Older People, which is a local group made up of older people and carers, specifically invited to attend bi-monthly meetings. Senior managers sit on this group and it is chaired by a Head of Service. This group was described as "less formal" and "sometimes more effective than the Public Partnership Forum" as members of the public can come along and get their point across to very senior members of staff. Despite being "informal" the Reference Group discusses "serious and pressing issues" and has been known to "change service delivery within a short period of time". The members of the community in attendance are able to set the agenda for the next meeting.

The Reference Group also forms a 'local route' into consulting with the public and shaping service delivery. It can be daunting for the public to engage with a large organisation like the NHS and this is a more local route.

### **Effectiveness of Public Involvement**

East Renfrewshire is a relatively small local authority area. The Community Health and Care Partnership covers a population of 89,000 living in the East Renfrewshire local authority area. Some suggested that the success of public involvement in East Renfrewshire is down to the small authority, "where everyone knows everyone else".

"One of the benefits of a small local authority like East Renfrewshire is that everyone knows everyone else and the Director of the CHCP (Community Health and Care Partnership) used to be quite active in the PPF (Public Partnership Forum) before becoming director, which has helped to give the PPF some more weight and there has been more 'buy in' from staff who use it as a tool to gather public opinion."

Public Partnership Forum Support

It was suggested that public involvement has now been given more 'weight' since integration and that the Community Health and Care Partnership have more respect for it. There are examples (see later in this case study) of public involvement making a difference to the practical delivery of services.

In terms of assessing or evaluating their public involvement, the Community Health and Care Partnership believes it can evidence what people have told them and how they have responded. East Renfrewshire Community Health and Care Partnership now "plans in different ways" and has become more outcome focused. They undertake work to gather patient or service user views at the beginning of a process and again at the end to evidence impact. There is also ongoing evaluation of programmes. Reports to senior managers refer to public involvement – for example ongoing work with the Reshaping Care for Older People's agenda is assessed

through the Joint Improvement Team and case studies are written up to evidence engagement.

The East Renfrewshire Public Partnership Forum is also assessing its public involvement structures. For the first time, the Public Partnership Forum is monitoring its impact and its activities to show the difference it is making. The Public Partnership Forum also recently carried out an Equality Impact Assessment for the first time on its activities.

### **Standards**

East Renfrewshire Community Health and Care Partnership employs the National Standards for Community Engagement and has taken on board some elements of the Facing Futures Together work of the NHS. There are also guidelines set out in the Public Partnership Forum Charter, which sets out the way the Public Partnership Forum should work.

Public involvement and community engagement are discussed weekly at Council Corporate Management team meetings. It was suggested that public involvement, following integration, is now much more “on the agenda”.

### **Key successes**

The Chair of the Public Partnership Forum suggested that integration in East Renfrewshire has led to a particularly successful approach to public involvement – with the focus on communication.

“Having one director of the CHCP (Community Health and Care Partnership) is the reason why NHS and Social Work speak to one another. It is this level of communication that has led to its success.”

Chair of Public Partnership Forum

The Director of the Community Health and Care Partnership shared this view by stating; “there are lots of advantages to having an integrated system – there is no duplication, there are opportunities to maximise resources, we can draw on community engagement teams and share intelligence.”

The Public Partnership Forum believes that much of its public involvement has been very successful, particularly involvement in the new Health and Care Centres at Barrhead and Eastwood. When the plans were announced for the new Health and Care Centre in Barrhead, there was no member of the public on the Project Board. The Chair of the Public Partnership Forum raised this and was told that the Project Board was “too technical” for a lay member. But the Public Partnership Forum campaigned for a voice and was granted a seat on the project board, designing the new health and care centre. This involvement on the board by the Public Partnership Forum allowed public involvement in decision making, and this was cascaded more

widely as the Public Partnership Forum organised public consultations on all the decision making. When it came to the planning stage for the new Health and Care Centre, there were no objections from the public.

“This involvement was successful because it did not feel tokenistic. We were involved from the beginning and felt listened to.”

Chair of Public Partnership Forum

Since then (during 2012) the Public Partnership Forum has been involved in undertaking ‘environmental visits’ to local health centres. One of these visits was announced (at some point during a particular week) and then a few weeks later, a Public Partnership Forum member would return, to undertake an unannounced visit.

“They were almost ‘mystery shopping’, checking what it is like to make appointments, are the public information materials up to date? Is it clean? Tidy? How long did they have to wait? etc.”

Support person to Public Partnership Forum

The feedback from these ‘environmental visits’ was presented in a report and sent to the Care Governance Committee who were impressed with the findings. The idea now is to try and do the same in every GP clinic in the area to provide feedback on service delivery.

## **Challenges**

The Public Partnership Forum members found this ‘mystery shopping’ exercise quite challenging. There has been some development and training for Public Partnership Forum members. They also host development days to plan ahead. The next development day will cover how to collect evidence and monitor their achievements.

The community engagement team offer training twice a year and there are also Working Together events that bring together Public Partnership Forums from across the city so that they can network Glasgow wide. This has been useful for helping people to navigate around the structure of the local authority and the Community Health and Care Partnership.

A further challenge for the Public Partnership Forum is to maintain the momentum of its work and to retain membership. It can be quite a commitment to sit on the Public Partnership Forum, with monthly meetings and other sub meetings. There has, until recently been a gap in its representation of faith groups and ethnic minority groups. The Chair of the Public Partnership Forum suggested that there were barriers to involvement that need to be overcome.

“The barriers to involvement are things like – not knowing about how to get involved and thinking that you cannot make a difference or how to contribute”.

Chair of the Public Partnership Forum

A further challenge of the Public Partnership Forum is to get members to see a holistic picture and not just their own agenda, which tend to be fuelled by a particular experience.

The Chair believes that the Public Partnership Forum does make a difference. They are working towards more formal assessment, by way of an Action Plan but must also remain reactive to the Community Health and Care Partnership demands on their time.

### **Final thoughts**

Successful public involvement and integration in East Renfrewshire were thought to be due to the relationships that have developed as a result of closer working. Prior to the Community Health and Care Partnership, the NHS was described as “remote” and the Community Health and Care Partnership helped to localise the issues. The Director of the Community Health and Care Partnership indicated that “there are still some members of the public who struggle with the idea that the organisation is both health and local authority” but that they have been making ‘in-roads’ to better public involvement.

It was suggested that public involvement needs to be ‘embedded’ from the beginning and to be ongoing rather than a one-off event. It was also suggested that public involvement should not just be carried out through formal structures such as the Public Partnership Forum (although in East Renfrewshire the Public Partnership Forum is perceived as being particularly successful). There should be lots of different ways and methods to engage with members of the public. The challenge has been how to use resources to the best effect locally.

“It’s about using the right tools and knowing your community.”

Community Health Development Officer

## **Appendix 1b: Dundee Case Study**

### **Introduction**

This case study explores the extent of public involvement in Health and Social Care in Dundee and Tayside. To complete this case study, we spoke to the following health and social care professionals:

- Public Involvement Manager, NHS Tayside; and
- the Older People's Service Manager, Dundee City Council.

A member of the public was not available for comment on this case study.

This case study looks at the innovative ways of engaging with different groups of people.

### **Health and Social Care Integration**

Dundee City Council, working with Dundee Community Planning Partnership, the Dundee Community Health Partnership and NHS Tayside are responsible for service delivery. There is a history of joint management arrangements for some services such as mental health and Children's services. Recently the Council's Community Care Services and Community Health Partnership staff have co-located to strengthen their working practices.

### **Arrangements for Public Involvement**

In Dundee, public involvement is about being able to provide opportunities for getting involved to shape service delivery and ensuring that everyone has the opportunity to do so.

In Tayside, there is a Public Partnership Network. Ten years ago, Public Partnership Groups were set up, one in each of the Community Health Partnership areas. This was before the involvement of Public Partnership Forums, so that when Public Partnership Forums were introduced – Tayside opted to continue with their Public Partnership Groups (PPGs). The Public Partnership Network came from this. It is a Tayside-wide network, but is not geographically based. The network is made up of individuals interested in the NHS and local groups and organisations. The bulk of the activity is NHS instigated. For example, there are banks of people who have signed up to take part in Food Audits. These can be officers in the NHS who are responsible for food and nutrition within care homes and the audit is used so that lay people can taste and see the presentation of the food to maintain standards.

It was suggested that the Public Partnership Network is a good way of gathering patients and public feedback. NHS Tayside is tasked with trying to introduce new members to the Network. They do this through the NHS Tayside website, by

advertising at public events and with help from the Scottish Health Council who signpost interested people.

Currently NHS Tayside is developing an electronic version of the Public Partnership Network. The aim is to have over 100 people registered so that if there is a particular topic which requires an immediate response, the Network can be sent the information quickly.

### **NHS Tayside E-Portal**

NHS Tayside has also established an e-portal. This is a website which provides online opportunities for engaging and consulting with patients and members of the public. Branded “Your NHS Tayside” the website includes:

- Service redesign consultations – this section describes the background to the area of service which is subject to the redesign or change and will include a questionnaire survey.
- Patient carer feedback - this section gives people the opportunity to provide comments on their experience of using services.
- Online topic specific discussions – this can be anything but normally relates to something that it is topical at the time – e.g. inviting views on hand hygiene measures in hospitals.

The comments and responses from the public help to feed into service improvement and developments across NHS Tayside. It also captures national consultations and others from partner organisations.

### **How it got started**

NHS Tayside received funding from the Scottish Government to establish this portal. Funded initially as a pilot project, it was tried and tested by three NHS Boards that provided feedback on the portal.

### **How it was developed**

NHS Tayside worked in partnership with NHS IT specialists to develop a website which provided online opportunities for engagement and consultation.

Public involvement was key to the development of the e-portal. Voluntary organisations, youth groups, and partner organisations were consulted about the design of the e-portal and were also involved in the testing of different elements of the e-portal. Staff were also included in consultation and their views taken on board in terms of how the e-portal could be used to the best advantage of NHS Tayside.

### **How it is advertised**

Links to the portal are included on the NHS Tayside website and on social media, such as Facebook and Twitter. NHS Tayside is one of a small number of NHS

Boards using social media. Updates to topics for discussion are advertised on Facebook and Twitter and encourage people to go online to the e-portal. The 'Your NHS Tayside' branding is displayed in hospital foyers, at public events and promotional materials have been distributed to encourage people to go online and participate. The portal is also advertised through the Public Participation Network and they receive email updates about new topics and consultations.

Examples of work that have been included on the portal for consultation include:

- food and drink in hospitals
- detect cancer early campaign, and
- integration of health and social care consultation.

"All the data and background information can be added onto the e-portal and then the consultation document is there too – this means that people can find all the information they need in one place and then submit it online."

Public Involvement Manager

The portal also has a discussion zone where NHS Tayside can add "today's topic" – recent examples include 'medicines at discharge'. People can go on and give their comments. This section of the portal is moderated and comments passed onto the relevant staff for action.

There is also a general feedback section where patients can give their views on the different services.

### **Effectiveness of Public Involvement**

NHS Tayside is in the process of measuring the impact of the e-portal. Since its inception there has been a steady stream of use and data coming from it. Increased publicity about a particular topic or consultation results in a surge of activity on the portal. NHS Tayside has to plan their resources accordingly so as to manage the volume of data. Currently the work of the e-portal is undertaken within the existing Public Involvement team. The data is then fed back to the NHS department which instigated that consultation question or discussion point.

The Public Involvement Manager suggested that there was a need to strike a balance between publicising the e-portal and having staff resources to deal with the data.

"There is no doubt that the e-portal is doing what we want it to do. But there is a need to consider the resources that need to be added. If there were a full time dedicated resource it could be managed better and it could be publicised on a much more regular basis and meet demand without overwhelming the staff."

Public Involvement Manager

The benefits of an engagement tool such as the e-portal were thought to be the convenience of being able to participate and give views in participants' own time, from their own home. And the nature of the e-portal means that people can choose which topics or consultations to get involved in, depending on their interests.

Research<sup>5</sup> has highlighted that most people do not want to get involved in organised activities relating to public service delivery. In these circumstances, the e-portal and other social media can be a useful tool for gathering views from those who would not normally participate.

## **Lessons Learned**

### **Successes**

The success of the e-portal is that it is an innovative way of engaging patients and service users in giving their feedback to NHS Tayside. Its success is due to the input from different groups at the design stage.

“Stakeholder involvement has been fundamental and crucial to its development. Public partners, voluntary organisations, youth groups, partner organisations and staff have regularly participated individually, in groups and importantly online to help design and test the various elements of application.”

Public Involvement Manager

### **Challenges**

The challenge of the e-portal is to ensure it is publicised widely to make it accessible, but then to be able to deal with the amount of data generated on it. If the e-portal is to be rolled out to other NHS Board areas, the suggestion from NHS Tayside would be to consider the appointment of a dedicated member of staff.

### **Celebrate Age Network**

Dundee City Council established the Celebrate Age Network (CAN) which is a group specifically for engaging with older people. CAN was commissioned as part of the Community Strategy Statement to speak to groups of older people who receive services, such as care home residents and individuals receiving meals on wheels as well as other services. Facilitated discussions took place with different groups of older people who co-ordinated a written report back to Dundee City Council outlining the key areas they wished the Council to focus on for older people. The group are supported by a Development Worker (funded by Dundee City Council) to support their work. The development worker's role is to build the capacity of the older people and to help them be effective and confident to sit and represent older people on strategic committees and boards.

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<sup>5</sup> “If you want to walk fast, walk alone. If you want to go far, walk together”: Citizens and the co-production of public services, Dr.Elke Löffler et al, commissioned by the French ministry of Budget, Public Finance and Public Services 2008.

CAN was established around 2005 and is affiliated with organisations such as the Pensioner's Forum. Its aims are to:

- promote the involvement of older people in the planning, development, and monitoring of services across different sectors;
- actively pursue consultation/involvement opportunities for older people, by linking them with existing statutory services and resources;
- explore how older people, including those who are socially isolated, want to 'have their say';
- build feedback loops for information to be relayed back to older people; and
- improve socialisation and access to learning opportunities for older people, by enhancing activities and support, where appropriate to the project.

CAN meets once a month, but also has subgroups that meet more regularly to discuss different topics. Dundee City Council pays for the cost of their Development Worker, room hire and volunteer expenses. The group is constituted and has its own budget.

### **Effectiveness of public involvement**

The older people themselves decide on the issues they get involved in. Some recent examples include mystery shopping work for GP practices or for an independent bus company. The older people give feedback on their experiences of using these services to the service providers. This has become a recognised and effective way of engaging with older people.

"They undertook some mystery shopping about accessing public transport and then wrote a report to the bus company making recommendations."

Older People's Service Manager

### **Key successes of CAN**

CAN has been involved in work with the Dundee Independent Advocacy Service. Dundee City Council received funding through the Change Fund and involved CAN in developing an existing directory of services into a Helpline for Older People. The aim of the Helpline is to have information available on services and resources relevant to older people. For example, benefits, medical services or social networks. CAN was involved in mapping the current services they use (including exercise classes, and other resources) so that callers to the Helpline can be signposted to their nearest resource. The directory of services they compiled is in electronic format and also available to print but CAN has applied for funding to create a supporting website.

Members of CAN promote the directory of services among friends and family as well as more isolated members of the community identified through other networks such as Churches and word of mouth. These people tend to be those "unknown" to social

work and so would not be targeted by their service. CAN inform these people about resources and services from which they could benefit.

“The helpline is only useful if you know what you are looking for.”

Older People’s Service Manger

### **Key challenges for CAN**

There is only funding for one development worker for the whole of the City of Dundee. This creates lots of problems for resources as although the development worker is innovative – there are limitations to what they can do.

Another challenge is trying to maintain the interest of the older people on the group and to recruit new faces to take part.

Also there can be difficulties in trying to strike a balance between issue-based work and more general issues for older people. For example, transport is a huge issue for people in Dundee, but there also needs to be time spent on more general issues.

## **Appendix 1c: Highland Case Study**

### **Introduction**

This case study explores public involvement in health and social care in Highland. To undertake this case study we spoke to a number of health and social care professionals, along with members of the public. These included:

- The Director of Health and Social Care for Highland Council
- The Director of Adult Care for NHS Highland; Transitions Director for Integration, NHS Highland
- Chairman of the Highland Senior Citizens' Network
- Patient/Public Representative, Highland Health and Social Care Committee
- Member of the public with a background of membership on a number of health committees, including the Highland Health Council and Highland North Community Health Partnership.

This case study looks at the innovative approach taken to health and social care integration in Highland, facilitated by Health and Social Care District Partnerships.

### **Health and Social Care Integration**

On December 16<sup>th</sup> 2010, the Board of NHS Highland and Members of the Highland Council agreed to commit to planning for the integration of health and social care services. This led to the integration of Adult Community Care Services and Children's Services across the Highland Council area from April 1<sup>st</sup> 2012. The Lead Agency model was preferred, with NHS Highland being responsible for delivery of Adult Community Care Services and Highland Council responsible for provision of Children's Services. This is jointly managed by Highland Council and NHS Highland.

This resulted in the transfer of around 1,500 social care staff and £90million to NHS Highland to support the redesign of adult care. Around 250 staff and £8million was transferred to Highland Council for service redesign across social care, education and health. The aim of service integration is to improve outcomes for the people of Highland through the overhaul of the delivery of key caring services.

Health and Social Care District Partnerships, located in all nine Highland communities, are key structures for facilitating integration. These recognise the importance of the roles of elected members, including their responsibility to ensure the effective management of local public services, and for advocacy on behalf of their constituents. They are action-focused and designed to provide a clear two-way link between strategic direction and local solutions. Each District Partnership involves elected members, community representatives and representatives of professional groups including social work, nursing and GPs. They are designed to be a key element of local engagement. It has been noted that these partnerships are still in their early stages and working through issues including how best to consult the

wider public, but they seem to be proving effective, from the perspective of a local authority consultee, despite being relatively new.

### **Arrangements for Public Involvement**

Public involvement is a frequently used and accepted term in Highland, however it may be defined in different terms depending on varying circumstances.

“Different terminology is used for different groups, including older people, community and representative groups – there is no standard term and involvement is not only about the ‘public’ but all stakeholders concerned.”

Director, Highland Council

A key permanent structure for integrated public involvement in Highland has recently manifested as Health and Social Care District Partnerships, designed to be the key drivers for local engagement, for both health and social care issues. Additionally, Highland Council funds a range of specialist organisations, including the Highland Children’s Forum and Community Councils, to represent particular interest groups. Non-funded specific interest organisations also form part of the public involvement framework, for example autism and community planning groups.

Community Health Partnerships were largely abolished in Highland when the Lead Agency model and Health and Social Care Partnership were established, although the Community Health Partnerships in Argyll and Bute remains. District Partnerships were established to ensure Elected Members had a forum at a local level to communicate with staff, managers, third and independent sectors and the public, over issues relating to Adult and/or Children’s Services. District Partnerships are not decision-making forums but rather arenas for developing relations and fostering community engagement. It is acknowledged within NHS Highland that previously established, effective local groups including Public Partnership Forums should be recognised and supported, and enabled to feed into, and be heard through, District Partnerships.

“Due to the remote and dispersed nature of the population and communities in Highland, many localised groups and arenas have been established to accommodate and communicate public opinion in a variety of ways.”

Director, NHS Highland

Members of the public consulted as part of this case study, questioned the effectiveness of permanent structures for public involvement, under the integrated service system. The intention behind District Partnerships as described above is acknowledged, but there appears to be hesitancy around how effective these will be as local engagement and representative mechanisms. It is felt that it is too early to assess how successful these will be, in enabling public involvement, as they are very much in their ‘infancy’. Concerns were raised over the current lack of permanent

feedback systems for public involvement, with fears that people will become disengaged if positive outcomes of the newly integrated system do not manifest soon. From the perspective of a member of the public consulted, it is felt that there is lack of clarity around how the public can be involved in the integration agenda.

“Where previously structures including Community Health Partnerships provided a clear channel for involvement, lack of communication around integration, and newly emerging representative organisations, has confused the wider public about their options for engaging.”

Member of the Public

Ad hoc and issue-based methods for public involvement are employed on an ongoing basis by the authorities. Highland Council use tools such as Twitter, email, telephone, websites, newsletters and free newspapers, in order to communicate information on an ongoing and informal basis.

“There is currently a big issue around social networks and how to use and manage these effectively, for public involvement purposes.”

Director, Highland Council

The NHS has also addressed issue-based consultations, through local workshops involving the public on an ad hoc basis, around key area issues and priorities. They recognise that the public can generate solutions and therefore take a localised approach.

Highland Council is focused on undertaking continued stakeholder engagement activities throughout and post-integration of services, with a specific focus on users and carers. Within the NHS there has also been a phased approach to public involvement in service integration, including ward forums and public meetings. It is emphasised that the NHS and local authority do not work jointly, but in an integrated way. The Council and NHS Board have distinct remits for Children’s and Adult Services respectively, and it is highlighted that Highland is the only area in Scotland to have undertaken a large-scale transfer of staff between the two bodies in order to achieve this.

Members of the public consulted as part of this case study feel that the NHS Board and local authority have not fully considered the integration of public involvement arrangements, as the channels for ‘bottom up’ public feedback are unclear. Comments suggest that health has not encouraged open debate around co-ordinated public involvement.

“The NHS finds it extremely difficult to consult with the public.”

Member of the Public

However, it seems to be generally recognised that given the enormity of the integration task, initial difficulties are to be expected. It is conceded that change is always problematic, and time for the new system to ‘settle down’ is required. Public representatives feel that there is still ‘a long way to go’ to achieve a fully functioning integrated health and social care system, and that developments to date mark only the beginning of a much longer journey. There appears to be apprehension among members of the public consulted, about how genuine service providers are in wanting to engage the wider public. One public organisation highlights that it has not been actively involved in discussions about service integration; rather they have had to initiate their own discussions and invite professionals to explain the issues to them. Lack of communication of the integration agenda to the wider public is a theme that clearly emerged.

“It seems that it (integration) has been ‘put upon’ people and that this is a failing of public bodies to explain what integration really means.”

Member of the Public

### **Effectiveness of Public Involvement**

Within the local authority there are major developments happening around embedding public involvement both at strategic and local levels.

“At the strategic level, activity is being undertaken involving all partners around integrated children’s and adult’s service plans. At local level, councillors and the district partnerships are working on local, area-based issues.”

Director, Highland Council

Highland Council feel that public involvement is making a difference to both policy and service delivery, although is aware that the public may not always be in agreement with this. The NHS incorporates public views into the development of policy and practice in health and social care through District Partnerships and other permanent involvement structures, and believe that this has made a positive difference to public involvement. They are now much more conscious of the benefits of working closely with the public, and there has been a concerted effort to move away from the tokenistic consultation of the past, in favour of a move towards gathering and promoting real life experiences of service users. The NHS is aware that it must be continually working on developing a trusting relationship with the wider public. It is acknowledged that this is an ongoing process and there is still much work to be done.

“Positive steps forward have been taken to move towards more genuine public involvement and this is having an impact on shaping service policy and delivery.”

Director, NHS Highland

From the perspective of one public representative consulted, it is felt that the public authorities have found it difficult to let go of existing pre-integration structures and processes. This has been challenged by developments including Self-Directed Care, which offers more choice and control to service users, over their service package. It is suggested however that the authorities still have too much influence in this area, and that it is not yet fully under public ownership. Service providers must explain clearly to users how to manage their own care, before genuine public control over provision is achieved.

One public representative organisation has felt more involved in service planning since integration. The Highland Senior Citizens' Network was invited to observe and feed into the tendering process for two private care homes in Highland. The Change Fund has changed the nature of public involvement for older people, requiring the local authority and NHS Board to proactively seek engagement opportunities with the wider public.

On a local level generally, public representatives feel that effective involvement processes are still being 'worked out', particularly in relation to health. A member of the public consulted for this case study does believe that public involvement in the integrating health and social care system is making small differences. For example, it is believed that the consultation on the attempted closure of the inpatient ward at the Dunbar Hospital in Thurso, was heavily influenced by public input. The issue is still under debate, but is highlighted as an example of public representatives being treated as 'equals' in the consultation process. At a local level minimal change has been seen as resulting from the newly integrated system, but it is recognised that integration is still at very early stages.

"It may be some years before the impact of integration and the difference this makes to public involvement will become evident."

Member of the Public

### **Evaluation of and Standards for Public Involvement**

Highland Council and the NHS have ongoing performance management measures in place, and have established feedback channels around service delivery. For example, a newspaper is published every six months containing a public survey. It is now standard practice that all stakeholders must receive consultation feedback, and it is understood that this is essential for the public involvement process to be effective. Additionally external project evaluations around public engagement in service provision have been undertaken, driven by the authorities.

Highland Council acknowledges existing consultation standards and refers to these wherever necessary. It is emphasised that while the standards should inform public consultation exercises, public engagement processes must be designed flexibly, around the nature of those who are being consulted. People should be able to tell

the authorities how they want to be engaged, for the process to be genuine and meaningful for all involved.

“Joint standards would be welcomed as the NHS work closely with the Council. Staff transfer has occurred and double standards will hopefully be eliminated”

Director, NHS Highland

Public representatives interviewed for this case study were less aware of any evaluation of the effectiveness of integrated public involvement activities, standard patient satisfaction forms are used by health services, but beyond this assessment of the process “is not visible yet.” They are also aware of the Participation Standard and the National Standards for Community Engagement but have seen no evidence that these are employed as part of every consultation exercise.

## **Lessons Learned**

### ***Key Successes***

From a public authority perspective it is felt that as integrated working in Highland is in its early stages, it is hard to gauge its effectiveness at this point. Huge benefits of integration have not yet been realised, but they are witnessing a general change in attitudes and increase in cross dialogue. It is felt that having a lead organisation each for Adult Community Care and Children’s Services is beneficial, in order to avoid the historic protectionism around budgets and to provide more holistic and responsive public services. With co-location, and a more outcomes-focused approach to service delivery, authority representatives believe better provision for service users will be realised.

A public representative consulted has seen minor improvements in public involvement since integration, but believes that the new system has yet to yield any significant move forward in terms of engagement. There is a general optimism that this will happen, but possibly not in the near future.

### ***Key Challenges***

It is emphasised that the geography of the Highland area can make public involvement difficult, therefore it has been divided into nine districts, each represented by a dedicated District Partnership. Despite this development, it is believed that the remote nature of some Highland areas is still making it hard for people to participate, and therefore the ability to effectively evaluate consultation efforts, and demonstrate their impact, can be hard to achieve. From a public authority perspective, it is felt that the NHS and the Council are already at capacity in relation to engagement activities which are being undertaken.

It is highlighted by the NHS that there needs to be a shift in public attitude about health and wellbeing, for the integrated system to be successful and sustainable.

“The public have a responsibility for their own care – ‘self care’ – therefore public dialogue should be encouraged – where do the public want to be in the future and how do they want services delivered that they may not make use of currently but will do in the future.”

Director, NHS Highland

A major challenge identified by public representatives consulted as part of this case study is the traditional organisational culture within both health and social care bodies. From the viewpoint of a public representative consulted, a major challenge to successful integration lies in the need to radically change the existing mindsets of health and social care managers.

“There is an apparent resistance to change and attempts to truly engage have not been part of the culture to date, and this is a challenge to integrating public involvement.”

Member of the Public

With Highland being almost a year into integration, one consultee felt that a completely new body needed to be established to get rid of existing cultures.

Another public representative consulted felt that “putting integration into practice at a local level is the real challenge, and it is too early to tell if public involvement will make a difference to policy or delivery”. It is acknowledged by this interviewee however that integration is still in very early stages and there is hope that the system will improve.

A member of the public consulted felt that at a local level, the lack of effective top-down communication is a challenge, and that the NHS in particular is not very good at explaining to the public what is happening around to integration, and why.

“The changes resulting from integration are not understood by the wider public. Health has a lack of expertise in communicating with the wider public and the transfer of staff has caused confusion over roles.”

Member of the Public

### **Final Thoughts**

While the NHS and Council are quite clear about the integrated involvement structures in place to facilitate health and social care service planning and delivery going forward, those who are more distanced from top-level decision-making appear to lack the clarity they would like in terms of what the purpose of newly established structures for public involvement are.

The situation currently appears confusing for the members of the public we spoke to, and the general feeling is that they believe it may take some time before a more streamlined system emerges. Public authority representatives would agree that there is 'still a way to go' to achieve meaningful and integrated public involvement in service planning and delivery, but that the journey has begun and they are hopeful it will continue to positively progress.

Public representatives and members of the public consulted as part of this case study currently feel somewhat excluded from the integration process, and hope that clarity will emerge over time. District Partnerships have been criticised as not being representative of the wider public, acting more as governance bodies, and as such it is hard to raise local issues through these channels. Questions remain about what are the appropriate channels to raise public matters.

## Appendix 1d: West Lothian Case Study

### Introduction

This case study explores the extent of public involvement in health and social care in West Lothian. To complete this case study, we spoke to a number of health and social care professionals as well as a member of the public including:

- The Head of Health, West Lothian Community Health and Care Partnership
- The Head of Social Policy, West Lothian Community Health and Care Partnership
- The Public Involvement Coordinator
- The Community Planning Development Manager, and
- The Chair of the Public Partnership Forum for Health & Care (PPF HC).

This case study looks at different arrangements for involving the public.

### Health and Social Care Integration

West Lothian Community Health and Care Partnership was formed in 2005. NHS Lothian and West Lothian Council continue to work together to deliver accessible and integrated services which are jointly planned and community focused. There is a Joint Director who is also the Depute Chief Executive of the Council. The Community Health and Care Partnership manages a range of NHS and Council services including:

Community care	Personal care	Residential care	Physical disabilities
Continuing care	Mental health	GP services	Learning disabilities.
Dental	Optician	Pharmacist	District nursing
Health visiting	Children's Services		

Allied health professions (such as Physiotherapy, Occupational Therapy and Podiatry).

The work of the Community Health and Care Partnership is governed by the [Partnership Board](#) which is made up of four NHS members and four elected members from West Lothian Council, reflecting the equal involvement of health and local authority.

The purpose of establishing the Community Health and Care Partnership was to deliver a more efficient and appropriate service and to increase wellbeing and reduce health inequalities across all communities in West Lothian. And specifically to deliver outcomes and targets as outlined in the Single Outcome Agreement, HEAT targets and Community Health and Care Partnership Subcommittee work plans. Having the services co-located has made communication and information sharing “much more natural” and this has helped to establish joined-up working.

However, the integration of services did not happen overnight and it has taken some time to become established. It was suggested that initially there was some suspicion among staff about the likelihood of taking on responsibilities of the other organisation (for example, NHS staff taking on responsibilities traditionally of the local authority, and vice versa).

“It took a while to embed the structures, but it helped to have the right management on board.”

Head of Social Policy

Similarly, governance issues took time to establish. A lot of the processes are duplicated as there are governance channels to go through for both the Council and the NHS. There are often two reports; one for the Community Health and Care Partnership Board and one to satisfy the Council structures. It was thought that the integration legislation would help to iron out these structures.

This was thought to make it difficult for the wider public to understand who is responsible for service delivery.

“The public do not understand the concept of a Community Health and Care Partnership, but that is because they do not differentiate between where health stops and care begins.”

Public Involvement Coordinator

It was suggested by the Head of Health that the most important thing for the public “is that they get what they need when they need it.” And as such, the Community Health and Care Partnership has worked to try and raise its profile and the awareness of integrated services.

### **Arrangements for Public Involvement**

Community Health and Care Partnership staff agreed that meaningful public involvement includes having the public involved from an early stage and deciding whether this is purely an information sharing exercise, or engagement, which is “more interactive and gets the public to make a choice.”

It was suggested that in West Lothian, the Community Health and Care Partnership is good at getting information out to the public, patients and staff, but that there is still work to do in terms of using this information within the Community Health and Care Partnership to inform their strategic thinking.

The Community Health and Care Partnership has different ways and means of engaging with the public. The Community Health and Care Partnership’s main permanent structure is the Public Partnership Forum for Health & Care . It exists as a

co-ordinating group of about 15 people, but there are around 160 individuals who are registered as interested in its functions. The group also benefits from lots of contacts with other organisations, so for example, if a particular issue arises on a certain topic, the Public Partnership Forum for Health and Care can target groups, organisations or individuals who have stated an interest in this topic, and get information to them very quickly (mostly by email).

Community Health and Care Partnership staff praised the Public Partnership Forum for the way it involves the public in a way that they understand the mechanisms of the Community Health and Care Partnership.

“West Lothian has come a long way in the last two or three years and this is down to the strength of the Public Partnership Forum for Health and Care”

Public Involvement Coordinator

Other arrangements for engaging with the public include the West Lothian Council’s Citizen’s Panel. This panel has around 2,900 members and they are asked to respond to consultations and attend focus group discussions as well as undertake large scale surveys on local issues. Consultation and engagement also takes place with the Community Councils, and with public and voluntary groups. Currently, a Community Engagement plan is being developed as part of the key components of the Single Outcome agreement. A community engagement reference group is advising the development of the plan.

These different arrangements for public involvement were thought to be necessary in order to be flexible to the audience and the topic for discussion.

“It’s finding the right avenue, and to have it built in at the outset and to decide whether it should be a process of consultation or just information sharing.”

Head of Health

It was noted that there had been a rise in the use of social media (such as Facebook and Twitter) in an attempt to engage with people in different ways and to receive feedback on services. This has been a route taken by the local authority more than in the NHS.

Some targeted work is undertaken, through existing networks such as equalities’ networks, faith groups and disability and diversity groups to ensure that those people who might not ‘naturally engage’ with the NHS or the local authority are given the chance to have a say. For example, the Community Health and Care Partnership undertook a large public consultation on the new Community Plan for 2010-2020. The Community Planning Partnership led on gathering views from different parts of the community, for example, the Public Partnership Forum for Health and Care , Youth Congress and Lesbian Gay Bisexual and Transgender (LGBT) groups. There

were lots of different partners involved and they gathered a lot of information from people and used this to populate the Single Outcome Agreement about what the expectations were and what the benchmarks should be. This information was also used to set internal targets.

### **Effectiveness of Public Involvement**

Public involvement was thought to be about ‘changing a culture’ – not just for the public, but also changing the staff culture as they now work in a more integrated way. It was suggested that public involvement in West Lothian was starting to make a difference and was being recognised as an important endeavour.

“It is starting to make a difference. It is resources intensive and needs ‘buy in’ from senior staff to understand its value but more and more people are starting to realise the benefits of public involvement.”

Community Planning Development Manager

“Public involvement has now got to the point where people are starting to recognise the importance of involving the public at the outset, rather than a ‘we’ll do that later’ attitude.”

Public Involvement Coordinator

Staff recognised the efforts of the Public Partnership Forum for Health & Care to engage with the wider public and to put things into lay terms.

As the main permanent structure of the Community Health and Care Partnership, the Public Partnership Forum for Health & Care has conducted some work into their effectiveness as a structure. For example, in April 2012 it put together a small working group to plan new outcomes and actions for their new Action Plan 2012/14. The working group consisted of members of the Public Partnership Forum, the Public Involvement Coordinator and the Scottish Health Council Local Officer who helped to facilitate the review meetings. The Scottish Health Council Participation Toolkit was used to as the basis of the review template. The working group met three times in total and the subsequent draft Action Plan was submitted and gained the endorsement and support they were seeking from the Community Health and Care Partnership.

The Action Plan included the following objectives:

1. The Public Partnership Forum for Health & Care will support the Community Health and Care Partnership in their Patient Focus and Public Involvement duties by supporting them to ensure the public and communities within West Lothian are informed about the current and planned range and locations of health and social care services. And support and facilitate on behalf of the Community Health and Care Partnership wider public involvement in engaging

with the planning and development of local and national health and care services.

2. The Public Partnership Forum for Health & Care will endeavour to be strong, independent and balanced, ensuring that service users, carers and the voluntary and independent sector in West Lothian have a voice.
3. The Public Partnership Forum for Health & Care will ensure that equality and diversity is reflected in all of its work and the work of the Community Health and Care Partnership.
4. The Public Partnership Forum for Health & Care and the Community Health and Care Partnership will actively identify and put in place resources to support the Public Partnership Forum for Health & Care achieve its objectives.

In addition, there are plans to develop training for the Public Partnership Forum for Health & Care. It is currently comprised of ex-councillors, ex-NHS staff and people who have experience of chairing other groups and organisations. It was suggested that the members are “already entrenched” in the processes of large organisations, but training could be beneficial. A skills analysis of members would be conducted and community-based courses in topics such as mental health and first aid will be offered, as well as developing and running equality and diversity training for members.

The Public Partnership Forum for Health & Care suggested that its effectiveness was difficult to measure, but that there had been some successes in gaining more recognition locally.

“The point is not to ‘manage a problem’ but to change a culture about the benefits of public involvement. Public involvement is not just to do with evidence, but a feeling that you are part of the process, which is just as important as outcomes.”

Chair of the Public Partnership Forum for Health & Care

### **Key successes**

The Public Partnership Forum for Health & Care has had some successes in West Lothian, including involvement in NHS Lothian Clinical Strategy Board, which is tasked with managing the process of reducing budgets. Feedback from the Clinical Strategy Board is that senior management have already noted the benefits of having a lay person on the group. Least of all, having a member of the public involved ensures that ‘jargon’ is kept to a minimum.

In addition, the Public Partnership Forum for Health & Care helped to facilitate an event in October 2011 entitled ‘A Sense of Belonging’ for the West Lothian Mental Health, Adult and Older People review.

The purpose was to review the strategy for mental health for older people. There was a much larger than expected turn out and this included voluntary sector, health,

social care and the public who contributed heavily. An evaluation carried out at the event with members of the public, gave positive results, indicating the public “felt they had been listened to”. The Public Involvement Manager described this as a good example of joint partnership working.

West Lothian Council held a large consultation on their budget for the coming year. This involved a flexible approach with different methods of engagement, including an online consultation and a series of public meetings. In total, over 17,000 comments were received and these have since been categorised into eight overarching themes, with their own Action Plans which will influence the overall corporate plan.

Other good examples of public involvement in the Community Health and Care Partnership include the Young People’s Forum. This is a diverse group of young people including “young people who are looked after and have additional needs”. The Youth Health Forum allows the young people on the forum to comment on health and education issues. And they are supported by workers from health, social care and the voluntary sector in a multi-agency approach.

Although still in its infancy, some services are beginning to involve services users or carers in their interviewing panels, where appropriate. For example in mental health, carers or clients have begun to be involved in the recruitment process of key nursing staff, and young people too have been able to have a say in the appointment of some residential services’ staff.

### **Key challenges**

There were some challenges to effective public involvement identified in West Lothian. These included a willingness of the Community Health and Care Partnership to work with the public, and a motivation from the public to get involved.

It was suggested that the benefits of public involvement are just beginning to be understood by the organisation. Traditionally public involvement has been viewed as “more work” or a “burden” – and West Lothian recognises that public involvement can be resource intensive. One example given was the time necessary to ‘mentor’ members of the public to become lay members of groups at meetings. It takes time to understand the paperwork and language of the NHS and the Council.

Also, there has been a tendency for public involvement to be ‘tokenistic’ in the past and West Lothian acknowledged that they had not always been good at involving the public from the beginning.

“Too often in the past we go to the public with options appraisals and say – these are your options – but the public should be involved in setting these options. True public involvement should be embedded from the start.”

Public Involvement Coordinator

However another challenge is apathy from the public and a feeling that if “it doesn’t mean anything to you personally, why would you bother?” West Lothian agree that the first step is to get better at providing feedback, which was described as a “key failing” in the past. Feedback was thought to be one ways of encouraging people to know that their views are taken on board and what is being done as a result.

“We need to make sure we do a ‘you said...we did’ feedback, which is not always appropriate.”

Head of Health

## **Future**

West Lothian Community Health and Care Partnership indicated that when the Scottish Government proposals for integration of adult health and social care were released, public involvement was like “a sore thumb in its absence”. There are concerns that if public involvement is not specifically mentioned in integration documents that it “will not become a focus for staff.” The Community Health and Care Partnership wanted to ensure that public involvement was ‘embedded’ in all of their work.

The view of West Lothian is that until there is clear guidance about what public involvement will look like in the future, they will continue with their Public Partnership Forum for Health & Care structure. The Public Partnership Forum for Health & Care is clear about what it wants from the future of public involvement in health and social care. For example:

- recognition by the NHS and Councils on the role and value of the Public Partnership Forum for Health & Care;
- communications set up within the health and social care partnership and proper training for the Public Partnership Forum for Health & Care to be involved at a strategic level;
- health and social care strategic priorities – the Single Outcome Agreement to spell out how to engage with the public;
- senior management to give direction and motivation to the Public Partnership Forum for Health & Care and to take on a ‘champion role’ with it – promoting it where possible; and
- access to resources under integration is important to support public involvement.

## Appendix 2: Reference Group Membership

Richard Norris	Director, Scottish Health Council
Gary McGrow	Social Researcher, Scottish Health Council
Pauline Boyce	Head of Operations, Scottish Health Council
Rosemary Hill	Participation Network Manager, Scottish Health Council
Rhona Dubery	Patient Support and Public Involvement Manager, Health and Social Care Directorate, Scottish Government
Aileen McIntosh	Senior Researcher, Health Analytical Services Division, Scottish Government
Anne MacDonald	Patient Representative, NHS Greater Glasgow and Clyde
Robin Creelman	Member of Argyll and Bute Public Partnership Forum
Eric Sinclair	Public Partner, Healthcare Improvement Scotland
Beth Hall	Policy Manager, Health and Social Care Team, Convention of Scottish Local Authorities (COSLA)
Lorraine Gillies	Community Planning Development Manager, West Lothian Council
Gill Rogers	Public Participation Officer, Ayrshire and Arran NHS
Irene Oldfather	Programme Director, Health and Social Care Alliance Scotland

## Appendix 3: Review of Context

### 1. Introduction

This appendix sets out the context in which public involvement in health and social care in Scotland takes place. It sets out the legal context; the policy context; and the guidance and support available to support public involvement in health and social care.

The key changes in terms of the law, policy, guidance and support over the past 15 years are highlighted below.

<b>2001</b>	Patient Focus and Public Involvement	<b>Policy</b>
<b>2003</b>	Local Government in Scotland Act	<b>Law</b>
<b>2004</b>	NHS Reform Act	<b>Law</b>
<b>2005</b>	Establishment of Scottish Health Council	<b>Support</b>
<b>2005</b>	National Standards for Community Engagement	<b>Guidance</b>
<b>2007</b>	Better Health Better Care Action Plan	<b>Policy</b>
<b>2009</b>	Health Boards (Membership and Elections) (Scotland) Act	<b>Law</b>
<b>2010</b>	Informing, Engaging and Consulting People in Developing Health and Community Care Services	<b>Guidance</b>
<b>2010</b>	NHS Scotland Healthcare Quality Strategy	<b>Policy</b>
<b>2010</b>	Production of Participation Standard	<b>Guidance</b>
<b>2011</b>	Christie Commission	<b>Policy</b>
<b>2011</b>	Scottish Government and COSLA response to Christie Commission	<b>Policy</b>
<b>2011</b>	Patient's Rights (Scotland) Act	<b>Law</b>
<b>2012</b>	Statement of Ambition for Community Planning	<b>Policy</b>
<b>2012</b>	Community Empowerment and Renewal Consultation	<b>Consultation</b>
<b>2012</b>	Adult Health and Social Care Integration Consultation	<b>Consultation</b>
<b>2013</b>	Social Care (Self Directed Support) Act	<b>Law</b>
<b>2013</b>	Public Bodies (Joint Working) (Scotland) Bill	<b>Law</b>

In 2012, a useful literature review of public involvement in health systems was also published as part of wider work around increasing democratic accountability within NHS Boards in Scotland<sup>6</sup>. This includes a useful conceptual overview of public involvement.

<sup>6</sup> Health Board Elections and Alternative Pilots: Literature Review, Scottish Government, 2012  
<http://www.scotland.gov.uk/Resource/0041/00411336.pdf>

## **2. Legal and Policy Context**

In recent years, there have been significant changes to the law in relation to public involvement in health and social care, and public services more generally.

### **2.1 NHS Duties**

NHS Boards have specific duties to involve patients and the public in planning and developing health services.

#### ***Patient Focus and Public Involvement - 2001***

In 2001, the Scottish Government produced a framework for ensuring that Patient Focus and Public Involvement was at the heart of service design and delivery. This paper defined a 'patient-focused' NHS, outlining the key themes of:

- capacity building - of NHS employees and members of the public;
- communications - communicating effectively internally and externally;
- involvement – more patient and public involvement at local and national level; and
- responsiveness – respecting the views, feedback and needs of individuals, considering cultural appropriateness and handling complaints.

#### ***NHS Reform (Scotland) Act - 2004***

In 2004, this Act placed a statutory duty to involve patients and the public in planning and developing health services on NHS Boards in Scotland. It also requires NHS Boards to establish one or more Community Health Partnerships, covering the whole Board area. Statutory guidance for Community Health Partnerships requires that each sets up a Public Partnership Forum.

Public Partnership Forums are a network of patients, carers, community groups, voluntary organisations and individuals who are interested in the development and design of local health and social care services. They are the main link between local communities, and Community Health Partnerships. They are intended to have a formal role in Community Health Partnership decision-making processes, but still to retain an independent voice.

In 2004 and again in 2010, the Scottish Government produced guidance on how NHS Boards should inform, engage with and consult their local communities<sup>7</sup>. The guidance emphasised the importance of NHS Boards routinely involving people in designing, developing and delivering health services provided for them.

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<sup>7</sup> Informing, engaging and consulting people in developing health and community care services, Scottish Government, 2004 and 2010

### ***Patient Rights (Scotland) Act 2011***

In 2011, this Act was introduced to improve patients' experiences of using health services and to support people to become more involved in their health and healthcare. It built on previous work, such as the Scottish Government's 'Better Health, Better Care' Action Plan 2007 which sets out a vision of Scottish people as partners or co-owners in the NHS; and the NHS Scotland Healthcare Quality Strategy (2010) which stated that the health service in Scotland would become entirely person-centred with patients as partners in their own healthcare.

In relation to involvement, provisions of the Act include:

- a duty to publish a Charter of Patient Rights and Responsibilities;
- principles for healthcare provision covering patient focus, quality care and treatment, patient and participation and communication; and
- a right to give feedback or comments, or raise concerns or complaints.

### **2.2 Social Work Duties**

Local authorities do not have explicit responsibilities to involve the wider public in decisions about social care services. However, local authorities have general duties to involve communities. In addition, recent policy and legislative developments have increasingly focused on the personalisation of services, and working jointly with the service user.

### ***Local Government in Scotland Act 2003***

In 2003, this Act was introduced requiring public sector organisations to participate in community planning. While the duty to participate in community planning covers a range of public sector bodies, the responsibility to initiate, facilitate and maintain the community planning process lies with local authorities.

One of the main aims of community planning was to make sure that "people and communities are genuinely engaged in the decisions made on public services which affect them<sup>8</sup>". The Act places a duty on local authorities, as facilitators of community planning, to consult and co-operate with community bodies; and to invite and encourage community bodies to participate in community planning.

In 2004, the Scottish Government introduced statutory guidance on community planning. This highlighted that the main aim of community engagement in community planning should be to make services more responsive to the needs and aspirations of communities. It stressed that the way in which communities are involved should reflect local circumstances. This was accompanied by a detailed advice note, also produced in 2004, on 'Effective Community Engagement'.

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<sup>8</sup> Community Planning: Statutory Guidance, Scottish Government, 2004

In 2011/12, the Scottish Government reviewed community planning arrangements, in light of wider work on public service reform in Scotland. In 2012, the Scottish Government and COSLA produced a 'Statement of Ambition' for community planning in Scotland, highlighting that effective community planning would be at the heart of public service reform in Scotland. This highlighted an ongoing commitment to strengthening community engagement and participation.

### ***Social Care (Self Directed Support) Act 2013***

In 2006, the Scottish Government produced a report<sup>9</sup> which explored better ways of working for social care services. The review promoted the idea of user-centred services, based upon the concepts of individual needs assessments and the development of systems and processes enabling a quicker response from service agencies. It also stressed that there should be opportunities for people to take more of a lead in planning services.

In 2010, the Scottish Government and COSLA produced 'Self Directed Support: A National Strategy for Scotland'. This strategy aimed to promote the personalisation of social care services, with a focus on individuals and families having real choice and control over the services they receive. It formalised the concept of 'Self Directed Support' as a term that describes how people can make informed choices about the way support is provided to them. It introduced the concept of 'co-production' as a way of individuals, families and services working jointly to decide how support needs are met, and by whom.

In early 2013, the Scottish Parliament passed the Social Care (Self Directed Support) (Scotland) Act. This Act intends to embed Self Directed Support in legislation, and outlines the ways in which SDS must be offered by local authorities to those meeting assessment requirements of community care services. Direct payment to allocate available resources is the key practical concept on which SDS is based (originally introduced in the Community Care (Direct Payments) Act 1996).

Closely linked to the concept of self directed support is the concept of 'co-production' – which aims to ensure that individuals and families are at the heart of any social care service. The Scottish Government is encouraging the use of co-production in reshaping social care. This can involve co-commissioning, co-prioritisation, co-planning, co-financing, co-design and co-delivery of services and policy.

## **2.3 Public Service Reform**

### ***Christie Commission***

The Scottish Government established the Christie Commission with the intention of ensuring that plans for Scotland's public services remain "ambitious" despite the

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<sup>9</sup> Changing Lives: Report of the 21<sup>st</sup> Century Social Work Review, Scottish Government, 2006

significant pressure on public finances in Scotland. In establishing the Christie Commission, the Scottish Government stated that it wanted to ensure a focus on improving the quality of public services; redesigning services around the needs of citizens; and tackling the underlying causes of needs (as well as symptoms).

The Commission's final report (in June 2011) made recommendations about the key elements of a reform programme for public services. There were four key elements:

- building public services around people and communities;
- working together to achieve outcomes – specifically by delivering integrated services;
- prioritising prevention, reducing inequalities and promoting equality; and
- improving performance and reducing costs.

In September 2011, the Scottish Government produced a response to the Christie Commission's report – entitled 'Renewing Scotland's Public Services'. This set out the Scottish Government's priorities for reform. It identified 'engaging with Scotland's people' as an ongoing priority for public service reform in Scotland. It stressed that "public services must work harder to involve people everywhere in the redesign and reshaping of their activities."

### ***Adult Health and Social Care Integration***

There are significant changes taking part across Scotland as part of the public service reform agenda. One important current proposed change is the integration of adult health and social care services. It was initially proposed that this integration would focus on services for older people, building on the 'Reshaping Care for Older People' agenda. This programme of work focused on joining up services for older people, across health and social care – and enabling older people to live independently in the community.

The aim of the integration of adult health and social care services is that flexible and sustainable health and social care services are integrated around the needs of individuals, their carers and other family members. The Scottish Government (and its partners) believes that separate – and sometimes disjointed – health and social care systems can no longer meet the needs of the people who use them. It proposes that adult health and social care services are integrated, with the purpose of improving outcomes and delivering seamless services for individuals. It aims to introduce new legislation which will support this integration.

There have been shifts towards more integration of adult health and social care services for some time. Community Health Partnerships were set up in 2004, and one of their core aims was to enhance joint working between health and social care.

In 2011, Audit Scotland reviewed the achievements of Community Health Partnerships<sup>10</sup>. Amongst its conclusions, Audit Scotland recommended that the Scottish Government work with the NHS and local authorities to fundamentally review partnership arrangements for health and social care.

The broad outline of the Scottish Government's current proposals on integrating health and social care were announced in December 2011. Nicola Sturgeon announced the key characteristics of integration, including:

- replacing Community Health Partnerships with Adult Health and Social Care Partnerships;
- making these Partnerships accountable for the delivery of new nationally agreed outcomes – initially focusing on older people's care;
- requiring NHS Boards and local authorities to produce integrated budgets for older people's services; and
- encouraging a shift towards a larger proportion of resources being dedicated to community provision, rather than institutional care.

Consultation on the proposed new legislation (as part of the proposals for integration) was issued in May 2012. A Bill Advisory Group and six associated Working Groups were set up to inform the development of the new legislation. A draft Bill – the Public Bodies (Joint Working) (Scotland) Bill was introduced to Scottish Parliament in May 2013. The underlying principle of the Bill is that NHS Boards and local authorities take joint and equal responsibility for the delivery of nationally agreed outcomes for health and wellbeing – specified by Scottish Ministers. In relation to involving, consulting and engaging, it:

- requires NHS Boards and local authorities to consult widely on plans for integration and meeting national outcomes, and to consult and plan locally for the needs of its population;
- requires a co-production approach to planning activities, stating that must include carers and users of health and social care services, and their representatives;
- requires public and service user involvement in significant service decisions which are made outwith the strategic plan process; and
- outlines an intention to introduce responsibilities to involve and consult carers and users of health and social care services in all aspects of integrated arrangements, through secondary legislation.

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<sup>10</sup> Inquiry into integration of health and social care, Health and Sport Committee, The Scottish Parliament, 5<sup>th</sup> Report 2012, Session 4

## **2.4 Democratic Accountability**

The focus of this research is on public involvement. However, there are links between public involvement and the democratic accountability of NHS Boards and local authorities.

### ***Health Boards (Memberships and Elections) Act - 2009***

In 2009, this Act was put in place to allow for piloting a range of different arrangements for appointing non-executive directors to NHS Boards. The pilots were undertaken to assess a series of measures designed to “increase public involvement and accountability in NHS decision-making”<sup>11</sup>. While the existing system of appointed Boards was perceived to be cost and skills effective, it was potentially seen as lacking in accountability and being unrepresentative demographically.

Following on from this Act, two pilots explored direct elections of non-executive directors, and two pilots explored other methods of recruiting and selecting new Board members. The evaluation of the pilot programmes (produced in 2012) showed that “it is possible to successfully hold direct elections for NHS Health Boards”<sup>12</sup>. It found that direct elections had both advantages and disadvantages. It suggested that while members of the public are prepared to stand in considerable numbers, in general those who stood showed similar characteristics to those who were appointed under the existing system. Electoral turnout was also low. It also found that the direct election pilots were also more costly in comparison to the existing system, and that the election and profile of candidates impacted on the way Board business was conducted.

The Scottish Government has indicated that it will consider the evaluation of these pilots before any decision on the future of NHS Board elections is taken.

Research supporting these pilot programmes revealed that similar direct election systems had been trialled in Canada, New Zealand and England. However these did not produce sufficient evidence that direct election would improve public involvement in healthcare. This research also examined non-electoral models to improve public representation on NHS Boards. Public Partnership Forums were criticised for being weak in terms of lack of direct decision-making control and representative members.

### ***Elected Members and Community Engagement***

Local authorities also have a process of electing local councillors to take decisions at a local level. Elected members can play an important role in acting as a bridge between communities and local authorities. However, there can also be challenges in this role.

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<sup>11</sup> LSE Enterprise, ‘Health Board Elections and Alternative Pilots: Literature Review’ 2012

<sup>12</sup> LSE Enterprise and University of St Andrews: ‘Evaluation of the Health Board Elections and Alternative Pilots’, 2012

Research by the Improvement Service<sup>13</sup> suggests that there can be a number of challenges in the role of an elected member in relation to community engagement, including:

- The dual roles of being members of council committees and acting as council representatives for outside bodies can sometimes conflict.
- The challenge of striking a balance between being accountable to their communities and their responsibility to govern – these can sometimes conflict.
- The challenge for elected members to ensure that they seek the views of as wide a representation as possible – every community is comprised of different individuals and groups whose particular views, interests and expectations may be at odds and in some cases not reconcilable.

## 2.5 Wider Public Involvement

### ***Community Empowerment and Renewal Bill***

As part of its vision for strengthening Scotland's communities, the Scottish Government is proposing to bring forward a Community Empowerment and Renewal Bill in summer 2013. The intention of the Bill is to strengthen opportunities for communities to take independent action to achieve their own goals and aspirations, and ensure communities are able to have a greater role in determining how their local public services are delivered.

The Scottish Government held an exploratory consultation on a range of ideas to be included within the Bill during summer 2012. The consultation identified three main themes, one of which was 'strengthening participation'. This would involve building services around people and communities; and focusing on needs, aspirations, capacities and skills.

The consultation around the 'strengthening participation' aspect of community empowerment covered issues such as:

- community engagement in community planning
- a greater role for communities in directing spending in their areas
- introducing an overarching duty on public organisations to engage, and
- views on introducing a duty to follow the National Standards for Community Engagement.

The Scottish Government received almost 500 responses to this consultation, from a wide range of organisations and individuals. Themes running through these responses included:

- the isolation and lack of influence felt by communities and their representative bodies from the Community Planning process;

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<sup>13</sup> Referenced from The Improvement Service, *Elected Member Briefing Note No. 7: Community Engagement*

- a lack of genuine community engagement on the part of public sector bodies and a need to embed community engagement into public planning processes;
- the lack of representation on, or existence of, Community Councils in some areas, and the impact of this on their influence of service decision-making;
- the increasing importance of the role of the third sector in terms of acting as an interface between the community and community planning partners;
- the belief that community groups should have a greater say in the design and management of local services, rather than delivering them directly;
- the support for communities having the right to challenge service provision if unsatisfied, to ensure the accountability of service providers;
- the majority support for communities to have a greater role in budget decisions to ensure the targeting of resources to local priorities.

The Scottish Health Council responded to the Community Empowerment Bill consultation. A short summary of the Scottish Health Council response to the consultation is provided at Appendix 3a. A draft Community Empowerment Bill will be produced in late summer 2013, and a formal consultation on this Bill will then take place. It is likely that this will include either a single duty to engage, or a provision which obliges public bodies to comply with the National Standards for Community Engagement.

### **3. Support and Guidance**

#### ***The Participation Standard***

The Scottish Health Council (part of Healthcare Improvement Scotland) was established in 2005 to ensure that NHS Boards meet their Patient Focus and Public Involvement responsibilities. In 2010, it introduced the 'Participation Standard' which it requires all NHS Boards to self assess against the 'Participation Standard' which assesses:

- how well NHS Boards focus on the patient
- how well NHS Boards involve the public, and
- how NHS Boards take responsibility for ensuring they involve the public.

NHS Boards are expected to take a proactive and inclusive approach to public involvement. The Scottish Health Council has worked closely with all Scottish NHS Boards to support the use of the Participation Standard.

The Scottish Health Council summarised Boards' performance in *the 'Participation Standard National Overview 2010-2011'* report. The key findings of the report are:

- The majority of NHS Boards are involving patients in discussions on how to use patient feedback to improve services.
- NHS Boards are able to demonstrate many positive examples where patients and the public have influenced service redesign.

- All NHS Boards in Scotland have a reporting structure, measurement process and a strategy for Patient Focus and Public Involvement in place.
- It is challenging for NHS Boards to show positive differences made by patient and public involvement – evaluation approaches must be developed to ensure that benefits of good participation are demonstrated.

### ***The Participation Toolkit***

This Toolkit has been designed to support NHS staff in delivering Patient Focus and Public Involvement. The Toolkit contains 29 participation tools and outlines how to produce a report of findings. These tools can be used not only to involve members of the public as a group, but also to involve individuals in their own care. The tools include displays and exhibitions, comments cards, online surveys, focus groups, mystery shopping, social media and users' panels, and can be arranged into five categories:

1. Giving information
2. Getting information
3. Forums for debate
4. Involvement
5. Evaluation and improvement.

The Participation Toolkit outlines the most effective ways in which to present and evaluate research findings, and consider ethical and equalities issues.

### ***Informing, Engaging and Consulting***

In February 2010 the Scottish Government published updated guidance on 'Informing and engaging and consulting people in developing health and community care services'. The purpose of this guidance was to assist NHS Boards with their patient, public and stakeholder engagement strategies, regarding the delivery of local healthcare services. The guidance emphasised the importance of the requirement of NHS Boards to routinely involve people in designing, developing and delivering health services provided for them.

The revised guidance set out that alongside adopting the principles and practices endorsed in the 'National Standards for Community Planning', NHS Board service changes should follow these steps:

Steps	Description
Planning	Development of an involvement and communication plan explaining the engagement process, e.g. VOiCE (Visioning Outcomes in Community Engagement)
Informing	Provision of information to people and communities affected by a proposed service development or change.
Engaging	Open, transparent and accessible process of developing proposed options.
Consulting	Production of a consultation document outlining how options were developed and agreed.
Ministerial Approval (For 'major' service changes only)	Inclusion of Scottish Health Council report with Board submission assessing the Board's adherence to participatory expectations of guidance.
Feedback	Provision of feedback by the Board to all participating stakeholders to inform about outcomes and rationales.
Evaluation	Appraisal of how well participatory activities worked, the impact on service change and the lessons learned for future work.

### ***National Standards for Community Engagement***

The National Standards for Community Engagement are designed to help develop and support better working relationships between communities and agencies delivering public services. They were introduced in 2005, and are measurable performance statements which can be used by all involved in community engagement to improve engagement quality and processes.

The idea for developing the standards came from people on the front line of community engagement. More than 500 people from the statutory and voluntary sectors, and communities were involved. They are endorsed by many bodies including COSLA, SCVO, Association of Chief Police Officers, Scottish Health Council and Poverty Alliance.

The main principles underpinning the National Standards of Community Engagement are:

- fairness, equality and inclusion as underpinning community engagement;
- clear and agreed purposes and methods to achieve community engagement;
- improvement of the quality of community engagement, requiring commitment to learning from experience;
- building communities, ensuring practice of equalities principles, sharing ownership of the agenda and enabling all viewpoints to be reflected;
- giving all participants the opportunity to build on their knowledge and skills; and
- providing accurate, timely information which is crucial for effective

engagement.

The 10 National Standards for Community Engagement can be summarised as:

<b>National Standard</b>	<b>Planned Outcomes</b>
<b>Involvement</b>	Identifying and involving with all those who have an interest in the focus of the engagement
<b>Support</b>	Identifying and overcoming any barriers to involvement
<b>Planning</b>	Gathering evidence of needs and resources required to underpin the purpose, scope and timescale of the engagement actions
<b>Methods</b>	Agreeing and using methods of engagement that are fit for purpose
<b>Working Together</b>	Agreeing and using clear procedures enabling participants to work together effectively and efficiently
<b>Sharing Information</b>	Ensuring that necessary information is communicated to all
<b>Working with Others</b>	Working effectively with others with an interest in the engagement
<b>Improvement</b>	Actively developing the skills, knowledge and confidence of all
<b>Feedback</b>	Feeding back results of engagement to all communities and agencies
<b>Monitoring and Evaluation</b>	Monitoring and evaluating the impact and success of the engagement against pre-defined standards of community engagement

Each National Standard is underpinned by several indicators which act as characteristics about which evidence can be collected in order to assess performance.

## **Appendix 3a: Brief Summary of Scottish Health Council response to the Community Empowerment and Renewal Bill**

The Scottish Health Council:

- welcomed the proposal to consider how participation can be strengthened across the public sector;
- highlighted the need for clear objectives and a robust evaluation system;
- supported the proposal of more coherent and consistent approaches to community engagement duties across the public sector;
- suggested that there should be a single duty to engage communities placed on NHS Boards and local authorities;
- suggested that the National Standards for Community Engagement and the Participation Standard should be adapted for use in an integrated health and social care system;
- endorsed the creation of a public sector community engagement plan and the appointment of a named accountable officer responsible for community participation.

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