

# **Patient focus and public involvement in the Scottish Public Health Network**

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## Introduction

This section will provide a brief overview of the context in terms of public engagement policy and legislation in Scotland and the Scottish Public Health Network (ScotPHN) as an organisation. There will be a particular focus on current engagement recommendations for NHS bodies.

### About ScotPHN

The Scottish Public Health Network (ScotPHN) was launched November 2006 and is hosted by NHS Health Scotland, a Special Health Board. It works across Scotland and its remit is around co-ordinating work around selected national priorities and strengthening networks.

ScotPHN remit:

*“Undertake prioritized national pieces of work where there is a clearly identified need*

*Facilitate information exchange between public health practitioners, link with other networks and share learning*

*Create effective communication amongst health professionals and the public to allow efficient co-ordination of public health activity”*

Work on national priorities is wide ranging and has included needs assessment for clinical topics such as HIV, or populations e.g. looked after children through to support for policy and strategy and a public health function review.

ScotPHN has an Executive Board (formed April 2009) with representation from key areas of public health and usually chaired by a Scottish Director of Public Health(DPH). This provides governance and quality assurance. It also creates a link between ScotPHN and the Directors of Public Health (DsPH) to whom ScotPHN is ultimately accountable. A lead consultant is responsible for ongoing management of the network and it is staffed by a small team of a researcher, a co-ordinator and administrative support.

To date monitoring at ScotPHN has followed the indicators set out in the NHS QIS (tailored as appropriate). An annual report was submitted in 2008 to the DsPH and a further self assessment was conducted in 2010 and was submitted to the DsPH.

Whilst ScotPHN does not directly provide services to patients and public there are many aspects of its work that impact on patients and public. Therefore it is pertinent to explore how current policy in patient focus and public involvement relates to its work and what needs to be in place for the organisation to comply meaningfully with this.

## Public engagement in Scotland

There has been increasing recognition and formalization of the role of patients and public in the Scottish NHS. NHS board responsibilities to involve the public in the design, development and delivery of health services were outlined in the document *Patient Focus and Public Involvement* in 2001 (Scottish Executive, 2001). The NHS Reform (Scotland) Act 2004 made the duties of public involvement and equal opportunities a requirement for health boards (2004). The Scottish Health Council, established in 2005, was tasked with ensuring NHS boards meet their *Patient Focus and Public Involvement* (PFPI) responsibilities by supporting and quality assuring these processes. The Scottish Government *Better Health Better Care Action Plan* (Scottish Government, 2007) championed a shift towards a mutual NHS with the public as partners. It underpinned this with the commitment to developing a "Participation Standard" to ensure that patient focus and public involvement were integral to how boards work. The Participation Standard (Scottish Health Council, 2010a) and a framework for assessment (Scottish Health Council, 2010b) were issued in August 2010 and NHS Boards will be expected to report on it early 2011.

Guidance on how boards should involve the public was outlined in "*Informing, engaging and consulting people in developing health and community care services*" (Scottish Government, 2010). This document also encouraged boards to follow the *National Standards for Community Engagement* (Scottish Community Development Centre, 2005). Additional guidance was provided by the Scottish Health Council for actions needed for major service changes. (Scottish Government, 2010)

A key issue around public focus and patient involvement is the equity and diversity of these processes and ensuring that potentially marginalised groups are adequately involved. This is described by as including:

- Disabled people
- Faith and religious groups
- Minority ethnic communities (including gypsy travellers, refugees and asylum seekers)
- Older people, children and young people
- Lesbian, gay, bisexual and transgender people
- Both genders

Some markers of equity are not included in this list. This includes place of residence, occupation, education, socioeconomic status, and social networks and capital. (Evans and Brown, 2003) Other groups may be marginalized according to these additional factors and may need to be given additional support accordingly.

## The participation standard

The participation standard has 3 core components: patient focus, public involvement and corporate governance for delivering PFPI. From next year, NHS Boards will be required to report against these. However not all areas covered by the participation standard are appropriate for special boards and these areas will need to be agreed.

## Public engagement practice in ScotPHN

The annual review 2007-2008 stated that the results of the self-assessment showed development of processes for public and patient involvement and equality and diversity assessment for projects should be developed as a priority. These were reflected in the work programme 2008-09. (ScotPHN, 2008) The 2010 self-assessment included examination of how well ScotPHN performed against the indicator “Ensure appropriate and effective patient and public involvement” within both the network and individual projects. The former attracted a low score as this is still under development but patient and public involvement in health needs assessments has been extensive and scored highly. To date there is no formal policy or strategy for patient focus and public involvement within ScotPHN.

The aim of this piece of work was to develop policy and strategy on patient focus and public involvement in ScotPHN.

## Aims and objectives

The aim of this document is to provide options for stakeholders on how we should ensure patient focus and public involvement in ScotPHN

The objectives include:

- Overview of patient focus and public involvement as it relates to ScotPHN’s work
- In depth exploration of stakeholder views on Patient Focus Public Involvement in ScotPHN
- Review of available standards for monitoring and previous involvement
- Provision of options for PFPI in ScotPHN based on current best practice and analysis of stakeholder input

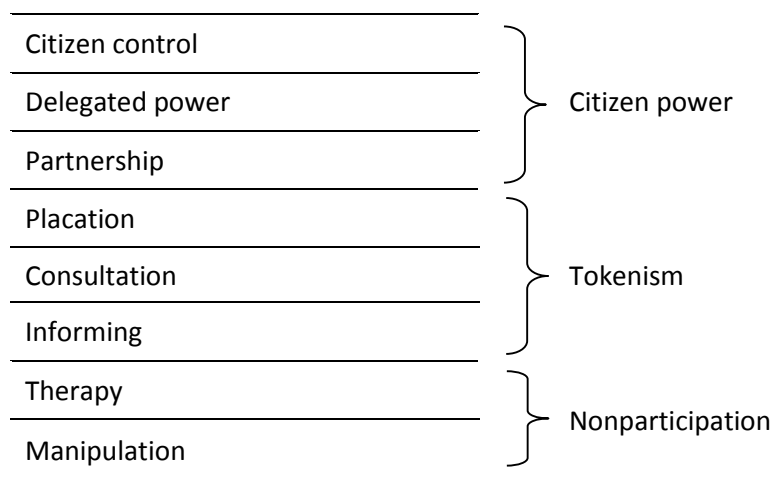
## Involvement

Current policy explicitly expects health providers to involve patients and public. This extends beyond healthcare to local services.(Scottish Community Development Centre, 2005) Patient focus and public involvement (PFPI) as defined in the participation standard.

“NHS Boards have a responsibility to focus on the needs of patients by listening to them and responding to their needs, and to involve people in the planning and development of health services.”(Scottish Health Council, 2010a)

However PFPI can encompass a number of different distinct concepts. There have been a number of different typifications of involvement. The best known is Arnsteins’ Ladder of participation (Figure 1).(Arnstein, 1969) A number of alternatives have been suggested most reiterating the view that the top rung of the ladder i.e. citizen control is inherently the most desirable state.

Figure 1 Arnsteins’ ladder of participation



Source: "Ladder of participation" Adapted from Arnstein 1969

Tritter developed a conceptual framework of involvement for healthcare that is able to characterise involvement in more detail. He introduces 5 different categories of involvement that correspond to the different arenas in which involvement might occur, and uses 3 dimensions to describe it. (Tritter, 2009) This more detailed characterisation of involvement has the advantage that it is able to provide a more detailed description of the involvement without applying an inherent value judgement on the involvement.

Figure 2 Tritter's conceptual framework of involvement for healthcare

Categories	Dimensions
Treatment decisions	Direct vs. Indirect
Service development	Individual vs. Collective
Evaluation of services	Pro-active vs. reactive
Education and training	
Research	

*What are the benefits of patient and public involvement?*

Governments in many developed countries have increasingly promoted the involvement of patients and public. This has been through patient rights, regulation and policy. However the stated aim of patient and public involvement in services often extends beyond improving effectiveness and efficiency of services. Other

proposed benefits include improved quality of services, more appropriate services, improving public perceptions, enhancing accountability and empowering marginalised service users. The reasons for involving patients or public may also be purely democratic or ethical.(Crawford et al., 2003, Crawford et al., 2002)

### *Potential drawbacks of patient and public involvement*

It is important to consider what the objectives of patient and public involvement are as there may be trade-offs between greater responsiveness of services, equity and efficiency. Other key issues include tensions between democratic and local accountability. (Florin and Dixon, 2004)

### *Relevance of ScotPHN work to patient and public involvement*

Similar to many special health board services ScotPHN does not deliver directly to the public and there can be a lack of awareness and an obvious group of stakeholders. (Scottish Health Council et al., 2009) This is difficult as there is not necessarily a geographical community that can be active as a group. This makes some aspects of the guidance and standards, developed for health boards difficult to apply. The question how should ScotPHN involve patients and public in the activities it does undertake. These map to the following areas for public and patient involvement as identified by Tritter.

- Service development: including planning, development
- Evaluation of services
- Research methods (though not necessarily research itself though this too may form part of the input of needs assessments)

Though the two other areas of “Treatment decisions” and “Education and training” may potentially be contained within the focus of ScotPHN work but would not ordinarily be the direct focus of the work conducted by ScotPHN. An additional area that has been identified as being important for health boards by the Scottish Health Council is governance.

## **Stakeholder analysis**

### **Introduction**

There is a diverse range of opinion in how we can and should involve patients and public and where and why we should be doing this. ScotPHN structure and purpose is unique and therefore it is

essential that the views of stakeholders were ascertained in developing a coherent approach to involvement.

## Aims

The aim was to gain insight into how ScotPHN can and should involve public and patients in its work. In particular this relates to the both the discrete pieces of work that it undertakes and the overall functioning as a network.

## Methods

Two interview guides for the semi-structured interviews were developed iteratively through discussion with members of the ScotPHN team (Andrew Millard, Researcher, Ann Conacher, Co-ordinator and Phil Mackie, Lead Consultant) and review of the relevant background literature (Appendix 1). One guide was used for people familiar with ScotPHN and the other was an adapted version for interviewees with no previous knowledge of ScotPHN. These covered definition of patient focus and public involvement, the interviewee's personal experience and expertise, benefits and drawbacks of involvement, methods, facilitators and barriers. They also explored possible future scope of ScotPHN work and asked where involvement was relevant and needed, what was needed to achieve this and how we should determine whether we have been successful. The interview guides were piloted and refined.

An outline of the proposed work and the interview guide was sent to the appropriate ethics committee (West of Scotland Research Ethics Service). It was confirmed that it did not require ethical approval as it relates to service development. Informed written consent and assurance of confidentiality was obtained from participants.

Relevant stakeholders were identified by reviewing previous membership of the steering group and the current Executive Board. Additional expert view on patient focus and public involvement in Scotland was also sought. Stakeholders were contacted and asked to take part in an interview or identify another potential interviewee. Of those contacted 17 were able to take part or provide the contact details of another person who was either more suitable. All interviews except one were individual, which was conducted with a group of 2 people.

A series of 17 semi-structured interviews was conducted with stakeholders between October 2010 and March 2011 by a single person. The interviews were transcribed and entered onto NVivo (a qualitative data management and analysis software programme). Analysis was conducted by a single person. This was done using a framework analysis approach and thematic analysis. The themes here are presented as they relate to the work in ScotPHN.



## Results

### Defining patient and public involvement and its purpose

There were a range of definitions, in some cases patient focus and public involvement was defined as one entity and the general approach it represented was characterised. In other cases specific aspects were highlighted. Patient focus and public involvement was justified both in terms of its positive impact and its importance as a right. One definition of patient focus and public involvement was that it was the genuine inclusion of the perspective of patients and public in approach and decisions.

Definitions that concentrated on patient focus were concerned with both individual patient care and changes to services. For individual patient interactions this included ensuring their voice was heard and listened to in clinical care, giving information and supporting involvement in their own health, well-being and care. Other definitions included putting the patient and their needs at the centre of planning, commissioning, delivering and evaluating care. Important aspects of this identified included asking the right questions and using information from patients' experience to improve healthcare and ensure it is effective, efficient and appropriate.

Patient involvement was felt to be particularly important in needs assessment or service development and it was highlighted that it is a requirement from the Scottish Government to involve patients in service change. Public involvement was perceived to encompass different groupings of people including public, carers, patients and staff. Some felt public involvement was more appropriate in the delivery and development of services at the strategic level and ensuring transparency and scrutiny. It was related to the focus on co-production and mutuality in Scotland. It was noted that this was a more pro-active practice and that it was important to consider how to involve the wider public in public health.

Other related terms that were mentioned included engagement (defined as helping people to arrive at their own solutions) and co-production (which should be used as the full version).

### Levels of involvement

There were varied responses to the question around what level of involvement should ideally be pursued. Some people referred to well characterised hierarchies or classifications of involvement such as Arnstein's Ladder, others used a descriptive approach. The range of involvement described spanned information giving to decision making, with potential for multiple levels to be used. The view was often expressed that the level of appropriate involvement depended upon the issue and that there may be some areas where it may not be appropriate or beneficial. The need to be transparent about the level of power and the role of the patient was felt to be important regardless of the level.

Some respondents noted difficulties in finding the right level and that there may be drawbacks of too much power depending on the groups and motivations of those involved. Others felt that involvement needed to be balanced against the evidence base or that shared decision making and responsibility is not feasible.

Opposing views were that patients and public should have at least an equal say as those who have responsibility for resources and those with expertise or that communities should be in control.

Some respondents stated that people often do not have power, they are not listened to and their priorities not reflected in the way that money is used. It was felt that it was difficult to ensure that views influence decision making and that professionals need to concede power to allow changes.

### **Impact of involvement**

Both benefits and detrimental consequences of involvement were described. Some were inherent in involvement others were potentially associated with particular methods. Often there was no clear division between which elements of patient focus and public involvement the impact arose from.

### ***Benefits***

The benefits of involvement identified focussed on improved understanding, ownership, improved services, increased acceptance of change and harnessing patient and public skills.

Informing and increased understanding of different points of view was seen not just as an advantage for staff but for patients too. The opinion was expressed that people feel positively about being involved and individual patients will respond better if involved as a partner in their own care. For patients and public the advantages were felt to be increased awareness and understanding of the work being conducted. The wider benefits of this were felt to be that this gave an opportunity for misconceptions to be addressed and facilitated a greater understanding of difficult choices. Communicating what public health is and getting support for legislative action was also identified as a possible gain. Some advocated involvement as a means of increasing patient/public ownership of work. This was felt to be particularly important for determinants of health work.

Involvement in projects was felt to help the process and the outcome because of patient expertise and ability to identify issues that professionals miss. Learning points from patients good and bad experiences were reported as being useful in improving services and the patient experience. The dual perspective was recommended as providing a more relevant response when developing services. This was felt to be more likely to lead to appropriate and therefore more effective and efficient services and greater satisfaction though there was recognition that it does not guarantee the perfect service. Additional benefits mentioned included patients setting up services themselves such as cardiac rehab groups and promotion of the notion of volunteering.

Driving forces identified for involvement included financial drivers, growing demand due to demographic changes and expectations and the need to do things smarter. Where involvement was perceived to lead to appropriate care and address issues such as patient safety, sustainability, diverse needs and inequalities then it was felt that it may also be more efficient. The potential for patient choices to be cheaper was also mentioned.

Overall involvement was felt to improve the quality of a piece of work (such as a needs assessment) not only because of the knowledge but because an independent person can ask the uncomfortable “daft laddie” question or may come up with completely new ideas or have particular skills.

## *Drawbacks*

There were a range of drawbacks identified. These were often portrayed in terms of a balance – i.e. a negative feature was compared to the alternative or a method of mitigation was offered. Key issues included high public expectations, representativeness, impact of involvement on resources, areas where involvement is inappropriate, drawbacks of the involvement process and motivations behind involvement.

Public expectations were expressed as a concern as it was perceived that they could exceed what is achievable or not be compatible with the range of options actually available. Some stated that it was important to manage public expectations to avoid this leading to resentment and cynicism if people subsequently feel the involvement was tokenistic.

An opinion frequently expressed was that those involved may not be representative of the cohort the services are being developed for. It was a concern that the people who least need it tend to be the most vociferous and get their needs heard and that some involvement methods select for this. There was also the perceived risk that vocal groups may oppose change without good reason or may push for issues that they have a personal interest in and that it can be challenging to get meaningful, representative contributors. A counterpoint view was that this is equally true if you just involve professionals. Some respondents highlighted a potential tension between having a layperson that has the skills and experience to be involved and their not becoming professionalised or part of the organisation.

Particular aspects or consequences of the involvement process that may cause difficulties were identified. This included large amounts of discordant input or vested interest which could lead to conflict. Further issues highlighted included difficulties managing the involvement process if there were no mechanisms for dealing with unacceptable behaviour or the amount of support required had been underestimated. It was felt that involvement had a risk of being tokenistic or failing unless the right people, time and methods were used.

Many respondents identified an impact on timescales if involvement is to be done properly, however the opinion was voiced that this depends on starting points and whether good engagement already exists with the community the quality of the involvement process. Involvement was acknowledged by some as to require more resources and logistically difficult. It was felt that it was important to anticipate this as otherwise it could place a strain on resources meaning the work might not be completed.

Some respondents identified areas where involvement may not always be appropriate, in particular patients or public may have a opposing or misleading view of some services which are less popular (e.g. Needle exchange, Carstairs, Cinderella services). However others felt that there may still be potential benefit in involving the public to ascertain their views so that these can be addressed. Areas of concern raised, were what the public want may not be consistent with the evidence base or good care and that therefore their interests are important but may not always be the deciding factor. There were also some concerns that involvement could be used as a way of justifying cost cutting or falsely legitimise decisions.

## Standards and monitoring

Current monitoring and standards were sometimes felt to be prescriptive and not as relevant to non-territorial health boards. The view was expressed that it was important to ensure that the standards and monitoring are not met in a tokenistic fashion. The existing community engagement standards were felt to be useful. One approach suggested was to make a quality measure to build in the thinking into every piece of work prospectively and retrospectively. Even though involvement might not always be appropriate this would ensure that it is always considered and justified. A further suggestion was to have a default position of co-production and a set of co-production principles that you could measure against.

## Involvement in ScotPHN work

In some cases people commented on their direct experience of ScotPHN work, in others the typical sorts of work that ScotPHN might do were discussed and the potential role for involvement. The opinion was voiced that involvement was very relevant to ScotPHN work particularly where it impacts on patients. One approach suggested was that whilst it might not be relevant or appropriate for every piece of work it should always be considered. It was recommended that the purpose and suitable approaches should be considered early in the process. One concern raised was whether this would fit in with ScotPHN requirements in terms of project timelines.

In terms of discrete projects, involvement in needs assessments was highlighted. The expectation was expressed that there should be involvement in every needs assessment unless there is a reason for it not to be. Another view was that it should be considered for every needs assessment. The framework for needs assessments was highlighted as this sets out that you should be involving patients and public. It was also suggested that needs assessments could be developed in partnership with relevant patient or public groups.

Other respondents proposed involvement in decision making between options for prevention and treatment. Another view was that at the public is increasingly seen as co-producers of own health and involvement is needed to determine what is acceptable.

There were a range of views on whether patient and public involvement was appropriate at the governance level and what the role and benefit would be. Benefits were felt to be keeping a link with the public group, establishing confidence and a different perspective. Drawbacks identified were that an individual member might not be representative or that the involvement has the risk of being tokenistic. If there were a public member they would need to be right for the role in ScotPHN and adequately supported. Other views were that the current format with Voluntary Health Scotland (VHS) as part of the Executive Board and involved in the governance process was a good alternative. An additional measure that was proposed was to develop an independent panel of commentators on a project group to provide quality assurance.

Varying opinions on involvement in identifying potential projects for ScotPHN were expressed. Though some felt there might be a potential role this contrasted with the view that ScotPHN is a professional network and issues come from professionals. It was suggested that issues raised by patients and public can be brought to it by professional sources. A potential role for involving

patients and public in deciding which projects to take forward was identified. However it was felt that this could be challenging and you would have to consider what the added value was and if there was to be involvement in this area then a tool and transparent process would be needed. Additional roles identified for ScotPHN that could relate to patient and public involvement including recording needs assessment activity across Scotland to facilitate sharing of information and skills, becoming the means of a public voice in public health in Scotland and acting on public health priorities and major service change.

It was noted that identifying the appropriate patients and public for involvement was particularly difficult for national bodies, non-territorial health boards and networks. It was highlighted that it was important to find methods of involvement that were context appropriate rather than being prescriptive. One potential resource mentioned was the skills throughout NHS Boards in Scotland, as the ScotPHN was designed to draw on resources across boards. Other potential sources of expert guidance on best practice were identified including numerous examples from 3<sup>rd</sup> sector, NHS and government agencies. The view was expressed that it was important to raise the profile of ScotPHN by publicising its activities more widely; one suggestion was that this could be done by sending bulletins to relevant bodies.

## Methods

Respondents emphasised the importance of having a consistent approach to involvement at the planning stage and some advocated formalising this in their commissioning process for new work. It was stressed that it is important to consider who you are involving and the time needed for the process factored in to ensure adequate resources and processes at the outset. It was stressed that involvement should be an open, transparent and robust process with clear objectives and clear roles for involvement. The point was made that it should be integral to the work rather than an 'add-on'.

Many felt that a range of tools and methodologies may be needed for each piece of work as different methodologies suited different starting points, timescales, contexts and people. There was some acknowledgement that it can be difficult to find the right method to ensure the involvement is not tokenistic and that particularly patient and public involvement may require different strategies.

Numerous approaches to getting input were described including using a representative or independent facilitator for a community or organisation, community development approaches, stakeholder days, patient scrutiny panels or groups to review outputs such as reports and consultation. Taking meetings out to the community such as public meetings or local events were also felt to be useful. Other particular methods highlighted were ethnography, social media, focus groups and case studies. It was felt that existing information around patient needs or views could be used if available. Various survey methods e.g. survey monkey were proposed.

One view was that it was preferable to have involvement from early on whereas others felt that it could be done at multiple different points or advised waiting until you had ascertained the evidence base, initial recommendations or other basic information.

It was felt to be important to develop the appropriate skills for those conducting the involvement or have other resources such as health boards or 3<sup>rd</sup> sector which could be drawn on. In some cases it

was proposed that it might be more appropriate for the third sector to conduct part of the involvement process such as focus groups.

## People

One issue raised was that it is important to identify the right group to involve and whether it is patient or public input that is needed. This may entail different people involved at different stages. The point was made that even if views are outrageous you should still be asking!

Using relevant intermediary bodies that already work and have a trust relationship with patients and public to talk to their communities to get a broad and representative view was recommended. Examples given included voluntary organisations, representative groups, community organisations, self-help groups, patients associations, service users, NHS and public health providers. A potential role for involvement was also identified for the key support workers or leads from these organisations. It was proposed that expert bodies such as Voluntary Health Scotland could help advise on this. Another possibility suggested was to go through NHS structures such as primary health care or local public partnership forums. It was suggested that there may be benefits from using multiple organisations. However there was some concern that difficulties may arise if groupings are left out or that there be conflict between some groups. A potential added benefit was identified that sometimes these organisations may already have done some relevant work which may be able to feed in. There was uncertainty expressed as to how useful it is to have individual members of the public unless they have networks behind them.

A further option proposed was to develop and support a specific group of people that could be drawn on. For sensitive topics solutions suggestions included the creation of an advocacy group which can feed in to the main project group or anonymised scrutiny panels or otherwise a group of volunteers could be trained and recruited. However it was commented that this required careful planning and required an adequate volume of work and support to sustain it. Concerns included a tendency for the same person to be used leading to them becoming part of the organisation. Regular turnover of individuals was proposed as a means of reducing this risk. Particularly those able to contribute at national level were noted to often have a professional background but then are no longer representative. It was perceived to be important to get the balance right between giving participants enough skills and information and keeping the public perspective. It was felt to be important to have the right contacts and networks to ease access to the right people.

Being proactive and thinking of innovative means of reaching out into the community such as going out to job centres or shopping areas were described as being very effective. Another potential avenue described was getting the patient voice through staff though views diverged on the degree to which health care workers could provide insight into the patient's viewpoint. Some felt that this was not at all possible whereas others felt this was in some situations appropriate though often only in conjunction with patient views. The staff or staff groups identified as being able to act as the patients advocate included Managed Clinical Networks (MCNs) or specialist care staff. Others advocated using local expertise such as PFPI teams so you do not have to start from scratch.

There was divergence of views on where and when and even if representativeness is always needed and appropriate to the purpose of the involvement and if so how to achieve it. Some respondents noted that communities are not homogeneous and that to get a breadth of views you needed to select representatives from different sections of the community and support them to be representative. One recommendation was to make sure all the important groupings are considered at the outset.

Some felt that having a single patient on a group was unlikely to be representative; often the people that come forward are atypical e.g. retired doctor. Ways identified to avoid this were to ask organisations to send a representative though even some organisations may be more representative than others. The importance of thinking about why you are engaging with a particular person or group rather than a tokenistic person from each subgroup was raised. Respondents recommended considering sociodemographic criteria to ensure a diverse mix in groups of people but this was countered by the view that even then it is important to recognise that there are limits to how representative this is. Other respondents voiced the opinion that it was preferable to have someone involved who is more interested in the mechanisms than the topics for public representation to get people who can contribute appropriately and see beyond their own personal issues - i.e. the bigger picture or that staff as proxy may be able to represent a range of views.

Some respondents stated that it might be necessary to capture local views even for work at the national level as these will vary so widely whilst others felt local groups might find it difficult to get the national perspective.

One concern that was repeatedly raised was that those most in need were often those least likely to be involved which raised issues around equity. Groups identified included men, young people, and older people, those from areas of social exclusion or with addictions. It was felt to be important to proactively seek involvement from such groups and consider different methods.

A further issue was that some people or even groups may have vested interests and that people may have the wrong motives for getting involved. It was felt to be easier to get involvement on issues that the public are familiar with or interested in eg service closures.

## Facilitators

Particular ways of working that were reported to be conducive to involvement were being clear about what you want to achieve from the beginning (including with patients) and having an open, consistent and transparent process for involvement with agreed objectives. It was felt to be important that involvement becomes part of the process rather than an 'add-on'.

The importance of supporting people who are involved was emphasised as processes may be highly technical and the support this requires is often underestimated. An infrastructure to support people who are involved was advocated. Practical support measures identified included interpreters, childcare, financial and making involvement as accessible as possible. Alternative methods suggested included phone conferencing or web based measure. Another recommendation was to check implementation of support measures. Other areas identified as needing input included capacity building or training around the skills or knowledge base needed to meaningfully engage.

Other respondents highlighted the importance of the provider having the appropriate skills and choosing a conducive environment. Other more general attributes for those leading involvement that were mentioned included being open-minded, fair, anticipating sensitivities and demonstrating that those involved are valued. It was felt to be important that structures were in place to support the involvement process such as guidelines for involvement or access to experts. This also included having internal policies to manage issues such as confidentiality.

## Barriers

Practical barriers for patients such as travel, skills, language, financial (even where expenses are reimbursed patients can be transiently out of pocket) were identified as being significant. People may not be able to fit involvement in with their other activities such as school/college/work etc. Some respondents noted that it can be difficult to find people that are interested in involvement particularly for some areas such as public health or that there may be some difficulty understanding concepts such as finite resources. However a counterpoint to many of these arguments was that it is not about people being hard to reach it is that we are hard to access.

Others described barriers as occurring due to the professionally dominated hierarchical NHS with performance assessed on speed and efficiency and safety. Some felt that involvement could be seen as being problematic and the language used around "PFPI" could be a barrier. One view was that we need to change the way in which we work in order for greater involvement to occur and it needs to be seen as an opportunity. Other obstacles mentioned were that people may not be empowered enough to voice their opinion even where they are involved or even where they were it still did not ensure that this would influence decisions.

Often the view was expressed that involvement can be limited by resources, confidence, skills and time. However some felt that this should be managed by anticipating and planning for it. It was also noted that there is a duty to engage so that this gives the backing to ensure that involvement does occur.

There were particular difficulties identified for national bodies as they may not readily have access to the same structures and groups as the territorial boards or topics may not generate a lot of interest e.g. health improvement, or the type of work strategy and policy.

Some respondents reported that particular conditions may require special consideration either because they are sensitive (e.g. HIV) and there are issues around confidentiality or because there are issues around the definition of illnesses and their treatments. Also for some conditions there may be particular needs which will need additional consideration e.g. learning disability.



## Standards and monitoring of PFPI in Scotland

In order to support and monitor involvement in ScotPHNs work a standards tool was sought that represented current best practice and was appropriate for an organisation without NHS Board status and no patient contact. Previous self-assessment of ScotPHNs work in 2009 ([Appendix 2](#)) used adapted NHS QIS standards. These have the advantage that there is already a historical comparison, they have already been used for assessment and been found fit for purpose and appropriate. A further source for a validated audit tool is the participation standard and its assessment (Appendix 3). This is primarily intended for geographic health boards though it is stated that it can be adapted for non-geographic health boards. As this is the standard against which NHS Boards are now expected to measure their performance and in this respect it supersedes the previous NHS QIS reporting for this area of activity it was reviewed for potential use.

Areas covered by the previous self assessment include:

- Ensure appropriate and effective patient and public involvement.
- Ensure an Equality and Diversity Impact Assessment on work carried out as appropriate.

In the participation standard areas covered include:

- Care and services are provided in partnership with patients, treating individuals with dignity and respect, and are responsive to age, disability, gender, race, religion or belief, sexual orientation, and transgender status.
- There is supported and effective involvement of people in service planning and improvement.
- Robust corporate governance arrangements are in place for involving people, founded on mutuality, equality, diversity and human rights principles.

The participation standards are identified as key points against which reporting takes place which are fairly detailed and some relate only to geographical boards. The first participation standard is more closely related to providers of direct clinical care which does not form part of ScotPHN's remit. For national boards without patient survey data the recommendation from the Scottish Health Council indicates that self-assessment can reflect improvement work conducted in geographical boards supported by the national board. Therefore this standard can be embedded where the work being conducted is such that it is relevant to patient's clinical care. On this basis the second and third standard could be adopted to form the basis of standards and an audit tool, however, it may be difficult to meaningfully adapt the first standard. An example of a potential adapted tool has been included (Appendix 4).

## Discussion

Participation had clearly been identified as an integral component to many aspects of work throughout the NHS. Much of ScotPHN's activity impacts on patients and public and as such it is essential that the role of involvement is explored and that transparent and consistent approach is developed. The options outlined are based on the views expressed in an extensive series of in-depth interviews and existing policy and standards around involvement. Those which would clearly not be tenable have not been included here. Some of these options are mutually exclusive – others are not. When determining which options to pursue it is important to consider the implications for resources in terms of time scales, finances, staff and skills.

## Options

### Level of involvement

- The appropriate level of involvement should be determined following assessment
- Patients and public should be always be involved at the highest possible level

### Standards and monitoring

- Use of existing participation standard with appropriate modifications
- Development of alternative standards
- Use of standards prospectively when planning or commissioning work
- Use standards retrospectively to monitor work

### Involvement in needs assessments

- There should always be involvement
- Involvement should always be considered but may not always be appropriate

### Involvement in governance

- Involve an individual member of the public
- Develop a panel of public members
- Continue to use a representative of the public voice

### Involvement in priority setting

- Involvement only through professional sources
- Develop a direct path for involvement for patients and public

### Accessing the patient and public voice

- Use intermediary organisations to reach patient and public groups
- Develop own network or group of volunteers
- Use existing networks of volunteers developed by other organisations

### Supporting the involvement process

- Develop expertise within ScotPHN
- Use expertise from geographical health boards
- Use expertise from the third sector

### Semi-structured interview schedule

This interview is about patient focus and public involvement in ScotPHN work. The interview will be recorded and notes will be taken. Anything said during the interview will be anonymised in the report i.e. any direct quotes will not be attributed to person or position. The interview will last a maximum of one hour. You may stop the interview or the recording of the interview at any time. Following the recording the interview will be transcribed.

- What do you understand by patient focus and public involvement?
  - *Probe: What are the most important aspects, benefits, drawbacks? Why? Think about levels, types and methods of involvement.*
- What is your involvement with ScotPHN?
  - *Probe: has there been any patient focus or public involvement in this work, should there have been?*
- Do you see patient focus and public involvement as having relevance to ScotPHN work and if so where and why?
  - *Probe: Are there particular areas where it is more or less relevant?*
  - *Probe: What are these judgements based on e.g. past experience etc?*
- What is the potential scope for the different types of work that ScotPHN might undertake in the future?
  - *Probe: How might this be relevant to patient focus and public involvement?*
- How do you think patient focus and public involvement should occur in ScotPHN?
  - *Probe: Are there particular types of work that you think are suitable or unsuitable, outline reasons why?*
  - *Probe: Do you feel the public should be involved with ScotPHN as a network?*
  - *Probe: Do you think there should be public input into priority setting?*
- What are the advantages or benefits of patient focus and public involvement in ScotPHN work
  - *Probe: Benefits to the public?*
  - *Probe: Benefits to ScotPHN/ ScotPHN work?*

- What are the drawbacks or risks of patient focus and public involvement in ScotPHN work?
  - *Probe: General issues and problems in particular areas? Why / for whom?*
  - *Probe: In particular are there areas where you feel these drawbacks could be managed or would they preclude you from patient focus and public involvement?*
- What are the barriers to patient focus and public involvement in ScotPHN work?
  - *Probe: How able do you feel to involve the public?*
  - *Probe: Are there training needs, financial, barriers?*
  - *Probe: Is there anything else that you can think of that would need to change to have patient focus and public involvement?*
- What are the facilitators to patient focus and public involvement in ScotPHN work?
  - *Probe: How, why and when are these things useful?*
  - *Probe: What additional facilitators can you think of?*

## Appendix 2: Self Assessment for the Scottish Public Health Network

July 2007 to November 2009 (with update on lower scores February 2010)

Scoring: (Translated from NHS QIS Standards)

1.	Not yet developed: <ul style="list-style-type: none"> <li>• Not started</li> <li>• Not achieved</li> </ul>	Score 1
2.	Developed but not yet implemented: <ul style="list-style-type: none"> <li>• Started but still in development.</li> </ul>	Score 2
3.	Implemented but not everywhere: <ul style="list-style-type: none"> <li>• Projects: Work clearly underway but not yet completed</li> <li>• Network: developed and partially achieved</li> </ul>	Score 3
4.	Fully implemented across all areas: <ul style="list-style-type: none"> <li>• Network: fully completed / achieved</li> <li>• Projects: fully completed and widely available</li> </ul>	Score 4

Ensure appropriate and effective patient and public involvement		
Network	1	Voluntary sector representation on Executive Board. Identified in 09/10 work plan for action
Explanation / Action for 2010/11		Low score: due to lack of development Action: Consider how recent Scottish Government guidance should be incorporated into ScotPHN work methodology Consider volunteering to ScotPHN work.
Projects	3	Extensive voluntary sector and patient/carer involvement in projects: ME-CFS – voluntary sector representation on project group; focus groups; scrutiny panel review of report. HIV - voluntary sector representation on project group; focus groups; scrutiny panel review of report. (Documented procedure for scrutiny panel involvement.)
Ensure an Equality and Diversity Impact Assessment on work carried out as appropriate		
Network	1	Identified in 09/10 work plan for action
Explanation / Action for 2010/11		Low score: due to no formal process being developed Action: Development of process 09/10

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Ensure appropriate and effective patient and public Involvement		
Network	3	As inclusive as possible Stakeholder Group Scottish Health Council
Projects	2	Thinking, but not embedded in process
Ensure an Equality and Diversity Impact Assessment on work carried out as appropriate		
Network	1	Not developed

Projects	1	Not developed
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### Appendix 3: Participation standard

<b>STANDARD Section 1 Patient Focus</b>
Standard Statement: Care and services are provided in partnership with patients, treating individuals with dignity and respect, and are responsive to age, disability, gender, race, religion or belief, sexual orientation, and transgender status.
CRITERIA
<p>1.1 <i>NHS staff provide information and advice to patients in response to individual needs and preferences throughout the journey of care enabling and supporting informed patient choice and shared decision making.</i></p> <p>1.7 <i>The NHS Board provides information about services in a range of formats, and has clear systems for responding to the specific communications needs of individuals.</i></p> <p>1.8 <i>People are treated with dignity and respect, in ways which recognise and respond to diverse cultural and social values.</i></p>
<b>STANDARD Section 2 Involving people in service planning, improvement and change</b>
Standard Statement: There is supported and effective involvement of people in service planning and improvement.
CRITERIA
<p><i>The six elements of the Informing, Engaging, and Consulting Guidance are covered by the criteria: planning; informing; engaging; consulting; feedback; evaluation.</i></p> <p>2.1 <i>The people who may be affected by the proposed service development or change are identified and their support needs assessed (planning).</i></p> <p>2.2 <i>The people who may be affected by the proposed service development or change are provided with relevant information and other appropriate communication aids that meets identified support needs (informing).</i></p> <p>2.3 <i>The people who may be affected by the proposed service development or change take part in developing, and appraising options, and are consulted appropriately (engaging and consulting).</i></p> <p>2.4 <i>Feedback is provided to the people involved on decisions made and how their views are taken into account (feedback).</i></p> <p>2.5 <i>Evaluation of the involvement is planned and carried out on an ongoing basis (evaluation).</i></p>
<b>STANDARD Section 3 Corporate Governance of Participation</b>
Standard Statement: Robust corporate governance arrangements are in place for involving people, founded on mutuality, equality, diversity and human rights principles
Criteria
<p>3.1 <i>The NHS Board is assured that systems and processes are in place to enable it to meet its statutory requirements in relation to the participation agenda.</i></p> <p>3.2 <i>The public feed into governance and decision-making arrangements.</i></p> <p>3.3 <i>The NHS Board is assured that a culture is encouraged throughout the organisation where participation forms part of the day to day planning and delivery of services.</i></p>

Appendix 4: Modified participation standard

STANDARD Section 2 Involving people in service planning, improvement and change
Standard Statement: There is supported and effective involvement of people in service planning and improvement.
<p>CRITERIA</p> <p><i>The six elements of the Informing, Engaging, and Consulting Guidance are covered by the criteria: planning; informing; engaging; consulting; feedback; evaluation.</i></p> <p>2.1 <i>The people who may be affected by the proposed service development or change are identified and their support needs assessed (planning).</i></p> <p>2.2 <i>The people who may be affected by the proposed service development or change are provided with relevant information and other appropriate communication aids that meets identified support needs (informing).</i></p> <p>2.3 <i>The people who may be affected by the proposed service development or change take part in developing, and appraising options, and are consulted appropriately (engaging and consulting).</i></p> <p>2.4 <i>Feedback is provided to the people involved on decisions made and how their views are taken into account (feedback).</i></p> <p>2.5 <i>Evaluation of the involvement is planned and carried out on an ongoing basis (evaluation).</i></p>
STANDARD Section 3 Corporate Governance of Participation
Standard Statement: Robust corporate governance arrangements are in place for involving people, founded on mutuality, equality, diversity and human rights principles
<p>Criteria</p> <p>3.1 <i>ScotPHN is assured that systems and processes are in place to enable it to meet its requirements in relation to the participation agenda.</i></p> <p>3.2 <i>The public feed into governance and decision-making arrangements.</i></p> <p>3.3 <i>ScotPHN is assured that a culture is encouraged throughout the organisation where participation forms part of work impacts on patients and public.</i></p>



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