



A Scottish Health Council report on improving quality through participation

A literature review of the benefits of participation in the context of NHSScotland's Healthcare Quality Strategy

Introduction

This literature review explores the potential benefits gained from implementing well designed, good quality participation and engagement activity in healthcare services and how these benefits can contribute towards NHSScotland's Healthcare Quality Strategy¹.

Summary of main findings

Patient and public participation contributes towards the person-centred ambition of the Healthcare Quality Strategy by promoting patient and public views on healthcare design and delivery. This paper concludes that participation contributes positively towards improved effectiveness, efficiency and safety within the context of a person-centred approach to healthcare delivery. However, to yield the full benefits of participation depends upon conducting good quality patient and public participation combined with NHS organisations developing a positive culture of participation.

There is strong emerging evidence that patient participation within healthcare can lead to improved patient safety. This includes:

- reducing rates of medication errors;
- reducing rates of healthcare associated infections;
- helping to identify inaccuracies in medical records;
- helping to shape improvements in the design and delivery of health services; and
- monitoring and managing healthcare treatments and procedures.

Improved safety for patients will also inevitably lead to more effective and efficient health outcomes.

There is also evidence to suggest that involving patients and the public in healthcare service design and change contributes to improving:

- service effectiveness such as improved quality of care;
- safety;
- quality of life;
- access and choice; and
- patient and staff satisfaction.

¹ The Healthcare Quality Strategy for NHSScotland, Scottish Government, May 2010, at http://www.scotland.gov.uk/Resource/Doc/311667/0098354.pdf

Evidence, from case studies in England, shows that participation contributes towards improvements in efficiency, cost benefits and a return on investment from engagement or participation. The evidence on using participation to make services timely is similar to the evidence highlighted above on effectiveness and efficiency. Involving service users to improve patient pathways to get the right treatment at the right time is also a key benefit of participation.

In conclusion, patient and public participation makes a positive contribution to NHSScotland's Healthcare Quality Strategy and should be regarded as a key activity to deliver the three quality ambitions which NHSScotland is striving to achieve.

Method

This paper summarises a short review of relevant academic literature (sourced through a systematic search) as well as web-based and grey literature² focusing on the benefits of participation within UK public services and relating the findings to the context of the health service in Scotland. These benefits are then structured into a framework using the six dimensions of healthcare quality and the three quality ambitions contained in NHSScotland's Healthcare Quality Strategy. The aim of this paper is therefore to develop an understanding of how participation can contribute towards achieving NHSScotland's Healthcare Quality Strategy.

When the term 'participation' is used in this paper it relates to literature discussing engagement, involvement, co-production of services as well as service user participation in public services. The literature mainly focuses on the benefits associated with service user (patient) participation rather than public participation in the healthcare service and includes sources and evidence from across the public and voluntary sectors as well as from healthcare. The literature is, in the main, English based with a few Scottish sources and the occasional international reference.

Background to the participation agenda and Patient Focus and Public Involvement in NHSScotland

NHS Boards are required to involve people in designing, developing and delivering the healthcare services they provide for them. NHS Boards' responsibilities in this area were initially set out in the document Patient Focus and Public Involvement (2001). To reflect the importance of their Patient Focus and Public Involvement and equal opportunities were placed on NHS Boards in the NHS Reform (Scotland) Act 2004. This Act also required NHS Boards to establish Community Health Partnerships. Each Community Health Partnership is responsible for developing a Public Partnership Forum as one important means by which it can maintain an effective and formal dialogue with its local community.

The Scottish Government's Better Health Better Care Action Plan (2007) set out a vision for the NHS, based on a theme of mutuality that sees the Scottish people and the staff of the NHS as partners, or co-owners in the NHS, giving people a greater say in the services they use.

To fulfill their responsibilities for public involvement, NHS Boards should routinely communicate with and involve the communities they serve. In February 2010 the Scottish Government published updated guidance on informing, engaging and consulting people in developing health and community care services, which is supplemented by guidance produced by the Scottish Health Council. Boards should also follow the principles and practice endorsed in the National Standards for Community Engagement.

²This term refers to papers, reports, technical notes or other documents produced and published by governmental agencies, academic institutions and other groups that are not distributed or indexed by commercial publishers.

There is now a range of mechanisms within NHS Boards for patients and the public to influence the design and delivery of services. These mechanisms have evolved locally over time, particularly through the development of forums such as Public Partnership Forums, patient groups or volunteer structures. As the focus on mutuality has grown the Scottish Government has introduced more measures (policies, guidance, and legislation) to further strengthen the participation agenda and Boards have been expected to implement and report progress on these. Some notable examples are:

- national patient experience programme, Better Together;
- service change guidance, 'Informing, Engaging, Consulting';
- pilot direct elections (to NHS Boards); and
- the Participation Standard.

Participation and the Healthcare Quality Strategy

The Healthcare Quality Strategy is the means by which the Scottish Government aims to ensure that long term healthcare challenges are addressed via a number of improvement interventions. The Healthcare Quality Strategy's improvement interventions are based on three healthcare quality ambitions - person centred, patient safety and service effectiveness. These three ambitions are based on the internationally recognised six dimensions of healthcare quality developed by the Institute of Medicine, USA. They are:

- **Person centred** providing care that is responsive to individual personal preferences, needs and values and assuring that patient values guide all clinical decisions;
- Safe avoiding injuries to patients from healthcare that is intended to help them;
- Effective providing services based on scientific knowledge;
- Efficient avoiding waste, including waste of equipment, supplies, ideas, and energy;
- **Equitable** providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location or socio-economic status; and
- **Timely** reducing waits and sometimes harmful delays for both those who receive care and those who give care.

This briefing, then, looks at how participation (Patient Focus and Public Involvement) can contribute to each of these six dimensions of healthcare quality and, in turn, how patient and public participation in health services contributes towards the three quality ambitions which the Quality Strategy strives to achieve.

Making services person centred and equitable

Clearly participation contributes positively to making services person centred; by improving communication, developing shared decision making and a mutually beneficial partnership between patients and those delivering healthcare services. However, what also came through from the literature was that to yield the full benefits of participation (including improved efficiency, effectiveness and healthcare outcomes) required participation that was conducted effectively³ or of high quality⁴. This suggests that how well people have been engaged could be a factor in delivering better outcomes as well as having a culture of support for participation (and acting on the participation feedback) in the organisation providing the service.

From the literature reviewed there is no standard definition of what constitutes effective or good quality engagement although there are a few publications which highlight good practice for effective participation. Consumer Focus Scotland produced its best practice guide to highlight examples of good practice case studies on consumer engagement while the Scottish Health Council highlights good participation case studies in the health service on its website and highlights how to conduct effective participation using a variety of methods with its Participation Toolkit⁵ resource. In addition, the Participation Standard⁶ measures

 ${}^{6}\!www.scottishhealthcouncil.org/standard.aspx$

progress with three aspects of NHS Boards' Patient Focus Public Involvement activity (patient focus, public involvement and governance) using a continuous quality improvement scale based on four levels of achievement - developing, implementing, evaluating, and improving. There are also the National Standards for Community Engagement⁷ as well as Audit Scotland's Community Engagement toolkit⁸ while the NHS in England has also developed key principles of effective patient and public engagement as part of its Engagement Cycle which is a conceptual framework for patient experience⁹.

Although Consumer Focus Scotland highlights the fact that there are a lot of good examples of engagement and participation across public services in Scotland it goes on to state that there is still room for improvement and that practice varies throughout Scotland. A Scottish Government report on public value and participation states that bad practice can lead to disengagement and therefore it is important to address the obstacles to effective participation, which include:

"lack of clarity of purpose, inconsistency, participation overload, organisational culture and power relations."¹⁰

Dr. Elke Lóffler highlights a view that the issue of service user participation in public services is simply never going to go away. This point was concluded because citizens' involvement in the delivery of public services increases with age and therefore, as the population ages, it is likely that we will see increasing levels of service user participation in public service delivery.¹¹

This therefore puts the onus on public organisations to actively accommodate and encourage service user participation in service design or improvement. There is a need for the organisation delivering a service to the public to have a culture of service user participation in order to become truly person centred and realise the full benefits of participation.

This culture of engagement could be linked to the notion of public value whereby politicians and public service managers will make better decisions (and those decisions will lead to better outcomes) regarding services if they have first of all deliberated with communities and service users. Public sector managers therefore need to genuinely believe and act on service user participation to successfully realise the benefits of participation.

Making services equitable

In terms of participation and the equitable quality dimension of healthcare, NHS Health Scotland has recently drafted a paper which highlights the business case for the importance of equality to the work of NHSScotland, supplementing the legal and moral case for equality.¹² This paper highlights the potential for equalities work to further enhance the Healthcare Quality Strategy's person-centred approach and to reduce inequality of access to health advice and inequality of health outcomes in the NHS in Scotland. The paper goes on to highlight how equalities work, such as accessible communication, community engagement and equality impact assessments, can also make services more efficient and effective by:

- reducing non attendance at healthcare appointments;
- improving clinical safety;
- reducing expensive litigation costs; and
- improving patient experience.

Person-centred conclusion

Conducting good quality participation and developing a positive culture of participation in healthcare organisations is likely to yield the full benefits of participation. This will allow health professionals to design and deliver services in line with patient and public feedback or concerns and is likely to produce better, more efficient services and contribute to improved health outcomes.

⁷http://www.scotland.gov.uk/Resource/Doc/94257/0084550.pdf

⁸http://www.audit-scotland.gov.uk/docs/best_value/2010/bv_100809_community_engagement_toolkit.pdf

⁹DHEngagement Cycle, April 2009 at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_098646.ppt ¹⁰Public Value and Participation: A Literature Review for the Scottish Government, The Work Foundation 2008, p30

¹¹"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 Lóffler et al, commissioned by the French ministry of Budget, Public Finance and Public Services 2008

¹²Draft business case for equalities work in the NHS Scotland, Gopal Lama, NHS Health Scotland, Jan. 2011.

Making Services Safe

One article¹³ which undertook a review of existing literature and evidence (at the time of writing the article in 2007) on the issue of patient involvement and patient safety highlighted a number of benefits that involving patients (or patient advocates) can contribute towards, including:

- reduced rates of medication errors;
- reduced rates of healthcare associated infections;
- help to identify inaccuracies in medical records;
- to shape improvements in the design and delivery of health services;
- to monitor and manage treatments and procedures.

However the author did point out that this did not mean that patients carry the responsibility for the safety of their care but rather patients should be viewed as a safety 'buffer' complementing existing safety mechanisms in the healthcare system.

Another more recent article¹⁴ published in American medical journal Mayo Clinic Proceedings confirms the above assertion that patient participation can improve patient safety in healthcare. The authors undertook a comprehensive summary of relevant literature from 1966 to 2008 in English and French on patient participation and patient safety in relation to decision making, chronic disease, and medical errors and cross infection. The article highlights that the concept of patient participation in healthcare has been successfully applied to improve the decision making in healthcare and the management of chronic diseases. The article also asserts that patient participation has been used in hand hygiene promotion among staff to prevent healthcare associated infection and has also been shown to reduce medical errors. The authors of the report echo the London Declaration, endorsed by the World Health Organisation World Alliance for Patient Safety, which calls for a greater role for patients to improve the safety of healthcare worldwide.

The authors highlight that there are patient-related factors which affect the acceptance of this patient role (such as lack of confidence, lack of medical knowledge and socio-demographic factors) as well as barriers put up by healthcare workers towards patient participation (such as non-acceptance and promotion of patient participation, the desire to maintain control, lack of time, personal beliefs and lack of relevant training). The authors suggest tackling the barriers to patient participation by proposing a model of patient participation to improve patient safety which includes addressing both patient and healthcare worker barriers.

This notion of a culture of engagement is applicable to the safety quality dimension of healthcare and forms part of recommendations made into the Mid Staffordshire NHS trust review in 2009 by Dr David Colin Thomé who commented that:

"I feel very strongly that a lack of good patient engagement is the key to why Mid Staffordshire hospital trust continued to provide poor care for a protracted period of time. Every part of the health system, not only A&E services could have done more to hear patients' concerns and to make changes in the system ..."¹⁵

Conclusions on participation and making services safe

There is emerging evidence that patient participation within healthcare can lead to improved patient safety. As in the section on person centredness there is the need for good quality patient participation which can eliminate patient-related barriers to participation as well as the need for a culture of patient participation among healthcare workers to eliminate barriers from staff, thus leading to improved safety for patients. Improved safety for patients will inevitably lead to more effective health outcomes and can also be potentially more efficient with less likelihood of complaints and litigation from patients and reduce the need for further healthcare procedures for patients as medical errors are eliminated and quality of care is improved.

¹⁴Patient Participation: Current Knowledge and Applicability to Patient Safety

¹³Patient involvement in patient safety - the patient as part of the safety solution: how can patients be involved? Davis, RE; Imperial College London, Nov.2007 at http://www.library.nhs.uk/ppi/viewResource.aspx?resID=273565

Yves Longtin, Hugo Sax, Lucian L Leape, Susan E Sheridan, et al. Mayo Clinic Proceedings. Rochester: Jan 2010. Vol. 85, Iss. 1; pg. 53. ¹⁵Mid Staffordshire NHS Foundation Trust: A review of lessons learnt for commissioners and performance managers following the Healthcare Commission investigation (Dr David Colin Thomé, 2009) at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/ digitalasset/dh_098661.pdf

Making services effective, efficient and timely

Discussions around participation leading to improved effectiveness, efficiency, and timely services for the patient tended to be interrelated in the literature and therefore these three healthcare quality dimensions are addressed together.

Effective

There is evidence to suggest that involving patients and the public in health service design and change contributes to improving service effectiveness. The previous section on safety has already highlighted how patient participation can improve effectiveness and health outcomes relating to patient safety. A number of pieces of literature highlighted improved effectiveness as an outcome of both patient and public participation and are cited below:

- Consumer Focus suggests that engagement can generate efficiency savings, and a more responsive service for consumers, and improve outcomes.¹⁶
- Improved service quality is highlighted as an outcome from user involvement by bringing in the expertise of service users, their families and communities.¹⁷
- "... public services that are designed around the public, that are better at building people's capabilities to be productive and healthy citizens, and so are more efficient, effective and sustainable."¹⁸
- "there is increasing evidence of a positive association between patient experience and clinical outcomes."¹⁹
- well structured engagement can focus on priorities, eliminating gaps and tackling poor and ineffective services.²⁰

Efficient

As with improving the effectiveness of healthcare services there were many examples from the literature citing improvements in efficiency, cost benefits and a return on investment from engagement or participation. Some of these assertions are highlighted below:

- A Department of Health report on LINks Annual Reports 2009/10²¹ reviewed case studies of LINks projects (aimed at involving and engaging people in healthcare service changes). The report concludes that the benefits of LINks involvement include an improvement to health and wellbeing and a reduction in costs, both to local authorities and the NHS. It goes on to state that the average benefit for each service change is £270k and that this equates to a return of £4 for every £1 spent on LINks.
- Public engagement can be used to gain useful customer insight and find efficiency savings.
- One report highlights a series of co-production case studies and states that co-production activities can improve efficiency and suggests savings of up to six times the investment made in these new approaches and better outcomes for the public.
- Getting it right first time [by involving patients] is sound business practice and a key measure of efficiency.

Timely

The evidence on using participation to make services timely is similar to the evidence highlighted in the effectiveness and efficiency sections above. A key benefit of participation is involving patients and the public to improve patient pathways to get the right treatment at the right time.

- ¹⁶Making the case for public engagement, How to demonstrate the value of consumer input, Consumer Focus 2010
- ¹⁷"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 Lóffler et al, Paris, October, 2008.
- ¹⁸Public Services Inside Out, Putting Co-production into practice, David Boyle, Julia Slay, Lucie Stephens, April 2010, p3 ¹⁹The Intelligent Board 2010, Patient Experience, Dr.Foster,p7
- ²⁰Consumer engagement in decision making: Best Practice from Scottish Public Services, Consumer Focus Scotland, January 2011
- ²¹Department of Health, LINks Annual Reports 2009/10

Conclusion on making services effective, efficient and timely

There are numerous papers and reports highlighting improved efficiency and effectiveness as a positive outcome from engagement and participation in public (and health) services. While much of the literature reports perceived benefits or notional benefit there are more recent reports citing case study evidence of improved efficiency and effectiveness as a result of participation and in some cases citing a figure of savings, cost benefit or return on investment. It must be said that this evidence is limited to a small number of local case studies. However, as more evidence emerges the focus may start to shift from whether participation does produce these benefits to how should participation be measured to determine the impact and outcomes of various types of participation?

Overall conclusions

This short literature review has concluded that there is evidence to suggest that good quality patient and public participation in healthcare services can lead to an improvement in the person centredness, safety, effectiveness and efficiency of these services. Based on the literature reviewed here the evidence would appear to show stronger benefits for service user participation than public participation and stronger outcomes for the safety and efficiency healthcare quality dimensions.

The evidence also suggests that to enhance improved outcomes from participation requires the participation activity to be of a sufficient quality and that a positive culture of participation within healthcare services can contribute to these improvements as much as, if not more than, the patient or public participation itself.

In terms of contribution to the Healthcare Quality Strategy, patient and public participation should therefore be regarded as a key activity to deliver the three quality ambitions which NHSScotland is striving to achieve.

If you wish to make any comments on this paper then please contact

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