

Involving patients and the public: a view from the public gallery

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Abstract

Title

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Summary

The structure and organisation of the NHS does not make it easy for patients and the public to contribute their experiences and knowledge to the many elements of a patient journey through the service. Clinical leadership is critically important in enabling patients to make their contributions heard and felt in order to drive and contribute to continual quality improvement - a key NHS goal.

In order for patients and the public to shape a complicated system, it is helpful to break the processes down into small sections and then support people to contribute their experiences and knowledge to each stage.

The choice and use of medicines is an example of the need to optimise the approach. By having a transparent structure and process, patients and the public will be helped to add considerable value and benefit to service design and improvement.

Good quality care is the result of designing and then delivering effective and safe patient-centred services.

Keywords: patients, public, medicines optimisation

Introduction

NHS organisations have a legal duty to involve and consult the public about the running of local health services. Patients should be listened to and actions taken to meet their concerns (see NHS Choices website at

<http://www.nhs.uk/NHSEngland/thenhs/about/Pages/getinvolved.aspx>).

The division of the NHS into separate 'boxes' for the purposes of commissioning and organising services does little to help people who use, or may need, those services contribute to them. What is more, how services are commissioned and managed is of limited interest or value to anyone when they are actively seeking planned or unplanned care.

In addition, social care has many links and interdependencies with health care so there is yet another separation that does not assist users of services to navigate, make sense of and, importantly, contribute their personal knowledge and experiences into the design and evaluation of the services they have received or will receive in the future.

The growing role, impact and influence of those involved in the provision of primary care in the commissioning of health and wellbeing services means that having a clear and explicit description of what good public and patient involvement looks like will be an

enormous asset to citizens, health professionals, managers and the sustainability of the NHS. The benefit will be to enable everyone who contributes to good quality care, and the patient is a major contributor, to have a focussed conversation about shared goals, albeit from their valuable and different perspectives.

Achieving authentic patient and public involvement

The achievement of authentic patient and public involvement is often hampered by failing to enable the right conversation at the right time. The three main factors that contribute to this are not knowing exactly what the question is, not preparing people to be able to contribute to honestly answering that question and, finally, not asking the questions in the right order.

Why involve people? Because that is the only way to design, develop and deliver good quality services i.e. services that meet and strive to exceed the needs and reasonable expectations of those for whom those services exist in the first place. Involvement activities therefore need to concentrate on helping to enable the right service to be provided to meet individual needs at the right time. With finite resources this means making sure that the process optimises the application of those limited resources in as fair and equitable a manner as possible.

For many organisations, the incorporation of the patient story with the medical, nursing, managerial, and other health professional perspectives becomes a challenging deliverable; particularly as it is expected to guide transparent decision making and prioritisation across the whole organisation. Add into that the mixed outcomes of professional, patient and public involvement experiences, ranging from the very good to occasionally being quite confrontational and having no apparent value or benefit despite the investment of professional time, and the barriers get higher.

Take anticoagulation for the prevention of stroke in a person with atrial fibrillation as an example. Effective treatment requires very good adherence to a tablet taking routine, and that may include occasional changes and adjustments. Safety includes significant dietary and lifestyle changes as well as changing to the threshold for seeking urgent and emergency care. The person will have to attend far more clinics and organise other activities to ensure continual treatment for life. The patient is by far the most important stakeholder; making sure that they can play their part in this means involving them at every stage in the choice, design and implementation of their care in order to achieve the objective of greatly reducing the likelihood of suffering from a stroke. If patients who take anticoagulation treatment for life are involved in the design of that service it is more likely to be an effective and safe service that is as positive an experience as possible.

Failure to achieve authentic patient and public involvement will lead to services being designed to meet interests rather than needs, services that are less and less accessible by those with greatest need and constantly worsening outcomes as users become less engaged and thus make a diminishing contribution to their own health and wellbeing. The same principles apply to all staff involved in service delivery.

Desirable outcomes from patient and public involvement

Ideally, what would really effective patient and public involvement help deliver? This can be summarised as:

- a better informed understanding of the diverse needs of the population
- insights into the appropriateness and efficiency of service delivery
- collaborative service design leading to improved effectiveness, experience and safety
- evidence of the experiences and outcomes of services being delivered
- opportunities and ideas for continual improvement
- transparency and openness in decision making and prioritisation
- robust challenge to traditional methods and approaches
- good quality and continually improving health and care services.

In a nutshell, this means good quality and continually improving health and wellbeing.

With the current trends of demand for services growing faster than the growth in funding available for health and social care services it is necessary, now more than ever, to have an effective solution to the authentic involvement puzzle.

Incentives to become involved

A further issue to take into account is the varying degree to which people are prepared to become involved, compounded by the fact that those with the greatest needs and potential to benefit seem less likely to participate. This leads to consideration of the incentives that are necessary to encourage and reward meaningful participation.

For many, the reward is seeing how personal effort leads to a direct and tangible difference to themselves and others. Evidence of the actual difference that involvement has made is sufficient reward for most people if that evidence is effectively communicated to those who contributed. Failure to complete this aspect as fully as possible leaves people less interested and willing to take their time to share views in the future, and less likely to have belief and faith in the outcome of the work that has been completed.

Medicines

Medicines are the most common intervention used by the NHS to prevent illness and improve health and wellbeing. The scope for improvement in the effective use of medicines is considerable and widely documented.

Patients have a direct and clear role in achieving a good result because they can choose to take their medicines or, indeed, choose not to take them. As Benjamin Franklin said, "Tell me and I forget. Teach me and I remember. Involve me and I learn". The goal has to be for patients to learn how to use medicines to the greatest benefit. This learned behaviour will serve them for the rest of their lives.

Someone diagnosed with diabetes is a good example to illustrate the importance of involving the individual in their care. Effectively controlling risk factors through the appropriate use of medicines and taking action to improve diet and exercise make a huge difference to life expectancy and quality of life. This is largely in the hands of the individual and the coaching and the support they receive to help make this happen.

How can an involvement processes be designed and structured to achieve all that?

The starting point is to organise all the involvement opportunities into clear and discrete actions, based on a simple structure of three stages of involvement and on three levels of involvement.

The three stages are:

- involving people in understanding the problem by contributing their lived experience
- involving people in the design of the solution because they are part of that solution

- involving people in assessing how well that service has delivered on what it was designed to achieve, as that is what is most important.

There is usually a lot of information and insight to take into account in truly understanding the problem to be solved. That insight comes from a wide range of stakeholders and needs to be assimilated into a clear articulation of the problem and then shared back with everyone who has a contribution to make to the design of the solution. Then, and only then, can the design of the solution begin with everyone working to design and coproduce a solution to the same agreed problem. Once the solution has been designed it is relatively simple to identify what needs to be measured to ensure that the solution is effectively and consistently delivered and implemented, and to test that it delivers exactly what it was designed to deliver.

Levels of involvement

The three levels of involvement are from an individual, community or population perspective.

In this context, community means a group of people with one or more similar characteristics; for example they may live in the same geographical area, have the same clinical diagnosis or have other similar needs.

These considerations may be combined into a framework of involvement that enables the importance of sequence and asking the right questions to become more apparent (Table 1).

It is now clear that:

- different questions need to be asked in each clear and distinctly different situation for patients and the public to be able to make their lived experience contributions
- the process needs to be followed in sequence for it to make sense and enable the next stage to build on the agreed findings of the previous stage
- the process needs to be followed left to right and back to the start to deliver the purpose of involving people if services are to be continually improved
- if the right question is not properly crafted, the responses will be unhelpful to the purpose

- authentic involvement is fundamental to good quality care and its continual improvement.

Individuals

Involvement of an individual in their care is very much about professional skills and competence and their genuine belief in the value that an individual brings to the outcome of the services provided for them. The diagnosis and initiation of treatment for a long term condition such as hypertension is an example of the importance of making sure that the individual is genuinely committed to lifelong daily treatment that may have a negative impact on their quality of life but may extend their life expectancy. As the interest in outcome measures of service provision grows, the effectiveness of individual involvement and supporting and enabling that individual to become a valued and valuable contributor to their own health and wellbeing will grow. Social prescribing and supporting individuals to address wider determinants of their own health and wellbeing is an example of how this individual involvement is being incorporated. This is arguably the greatest opportunity for primary care to have the most far reaching impact and benefit of patient and public involvement.

Communities

The involvement of communities is heavily dependent on clinical and medical leadership in particular. It is about the willingness to seek to improve the quality of services i.e. the effectiveness of services, the safety of services and the experience of services by those for whom the service exists to help. This is often about secondary care services and the relationship between primary and secondary care and how that relationship is improved to enable more efficient delivery and fewer interface issues and problems e.g. patient flows and shared responsibility. For example, the gap between a hospital consultation and actually receiving the prescription for the treatment from primary care can take weeks to complete the process. During this time the diagnosis has been made, the clinical need agreed and yet the treatment has not been started, resulting in unnecessary suffering for those concerned. This is the area where the most rapid change is feasible and where the most radical differences can be achieved. It is highly dependent on meaningful and practical clinical leadership, enabling patients to bring their lived experience to bear on pathway redesign and coproduced improvement.

	Understanding the Problem	Designing the solution	Judging the quality
Individual	e.g. telling their story and agreeing the diagnosis with a doctor	e.g. reaching an agreement on the choice and use of the treatment	e.g. reviewing the results of the tests together and agreeing next steps
Community	e.g. identification of access to services issues with users of crisis mental health services	e.g. coproduction of a solution that better meets user needs	e.g. evaluation of the degree to which access has improved and the anticipated benefits have been achieved
Population	e.g. gaining insights into the concerns of potential users of out-of-hours services	e.g. designing and prioritisation of options for service developments	e.g. reviewing the outcome of wide stakeholder involvement and conclusions

Table 1: Framework of involvement

Populations

The involvement of populations is all about the wider public health and service design strategies such as urgent care, making decisions about what should be created and what should be stopped, what should be developed and what should be phased out. It is about involving people in the strategic development of service provision across health, social care and third sector provision. It is more difficult, more time consuming, more costly and has more serious consequences. This is the biggest challenge as it requires coordination across many agencies and will involve primary care clinicians in the decisions. This requires to be led by people who are competent strategic thinkers.

Key points

Primary care involvement will play a vital part but is by no means the whole story. How will any piece of community or population involvement be judged in terms of the validity of the conclusions drawn?

Whilst there will be case by case considerations there are a few key points to consider:

- **Timeliness.** The involvement work must be completed in time to be able to inform the decision making process and not used to validate the process or otherwise after the decision.
- **Demonstrating and evidencing** that the work has involved a group that is representative of those who are likely to be affected by the decision.
- **Clearly reporting** on the specific questions asked, avoiding any misrepresentation in the conclusions drawn and avoiding misleading the decision making.
- **Demonstrating** that a diversity of techniques has been used to reach people in the way that best suits the needs and requirements of the specified audience.
- **Making available and actively sharing** a summary of the findings that is easily and widely accessible, in particular to those who have contributed their views to the work.
- **Providing feedback** on the final decisions and action taken as a result of the involvement work so that there is clarity and transparency in decision making.

Summary

In summary, this article describes the structured approach that would enable people to make a valued and valuable contribution to the continual improvement in the quality of the health and wellbeing of the local population.

It is about people; the value they have and the value they bring.

It is not about an involvement activity, it is all about enabling the lived experiences of people who use or may use local services to contribute their knowledge and experience to helping services become more effective, more efficient and better able to meet the needs of the people it is there to serve.

Declaration of interests

Mr. Prestwich reports Action to Support Practices Implementing Research Evidence (ASPIRE), member of the Patient and Public Involvement Panel, Leeds Area Prescribing Committee, lay member.