

## Abstract

**Background** Patient involvement in the design, planning and delivery of health services is acknowledged to be a local and national priority. **Aims** To improve health service quality through a quality improvement initiative to explore patient preferences for involvement in health services design, planning and delivery. **Methods** A questionnaire was developed to assess patient preferences for involvement in hospital service development; and to explore difference in responses between patient sub-groups. **Findings** 162 patients were recruited. Most were positive about the importance of involvement in all service developments, not just those used personally. Questionnaire involvement with infrequent email communication was favoured over attendance at public meetings. Time was a greater barrier to involvement than distance or remuneration. **Conclusion** Patients valued involvement in health service development, but finding free time during working hours was difficult. There were no differences in preferences for involvement between sub-groups defined by gender, ethnicity, home situation or health.

## Keywords

Patient and public involvement (PPI)      Patient Preferences      Service Development  
Questionnaire Development      Quantitative Analysis

## Key points

- Patients valued involvement in health service development
- Infrequent (annual) email communication was the preferred method of involvement.
- Time was the key barrier to involvement; distance and remuneration less so.
- No patient sub-groups are more or less discernibly different in their willingness to be involved.

## Reflective questions

- Are patients willing to be actively involved **in** design, planning and delivery of health services, and how can the patient perspective on involvement play a role in these developments?
- Are certain groups of patients more willing to be involved than others?
- What means of involvement are preferred by patients who are willing to be actively involved design, planning and delivery of health services?
- **What approaches can I use to involve patients and their families in service development?**

## Introduction

Whilst there is no real consensus on the precise definition of Patient and Public Involvement (PPI), patient engagement and involvement can be conceived as two different but closely related concepts (Goodwin et al. 2011). Patient engagement refers to the degree to which people participate and connect with a range of activities linked to health. This may include health behaviours linked to when and how people seek health advice, self-manage their health and access health information. In recent years, there has been an increased policy emphasis upon the importance of patient engagement. This is, in part, in response to the significant health burden caused by the epidemic of lifestyle-related non-communicable (NCDs) diseases, which place an unprecedented burden on current health services across the globe and are largely preventable. Involvement specifically refers to the involvement of lay individuals in the design, planning and delivery of health services (Goodwin et al. 2011).

## The policy context

Western European and North American government health policy emphasises the need for patient and public involvement (PPI) in the design, planning and delivery of health services (Crawford et al. 2002; Armstrong et al. 2013; NHS Constitution 2013; Abelson et al. 2015). The NHS Constitution specifies that:

*‘You, {the patient}, have the right to be involved in discussions and decisions about your own health care, service planning, implementation and evaluation; the manner and range of services delivered and available to you or other people and, where appropriate, the inclusion of family and carers’* (NHS Constitution 2013, p.69 – 70).

Various arguments exist to justify PPI in healthcare and why they are required for quality service improvements. Rationales include listening to the ‘patient’s voice’ as service users and funders of health care, who remain at the ‘heart’ of the health service. Patients are regarded as legitimate stakeholders of health care in a consumerist society who are entitled to make a positive impact on, and to shape, with professional health carers, quality health service improvement for the public at large (Armstrong et al. 2013). Additionally, The King’s Fund (2011) refers to the current climate concerning the public’s higher expectations of receiving a more individualised and responsive service designed to meet their healthcare needs.

Current NHS and government policy documents strongly advocate the involvement of the public, patients, family and carers in the assessment, design, delivery, and the commissioning of health services responsive to their needs (NHS Five Year Forward View 2014; NHS Engaging Local People 2016; PPI in Commissioning Health and Care 2017; Patient and Public Participation Policy 2017). These policies suggest, anecdotally, that PPI enables improvement in all aspects of health care, patient safety and health outcomes such as health-related quality of life. The inclusion of patients and public in having a stake and voice in the services they expect is

a key aspect to maintaining quality in health care; defined as: “patient safety, clinical effectiveness and patient experience” (NHS Five Year Forward View 2014, p.8). Through a partnership approach with patients, the role of NHS healthcare professionals and NHS leaders is to serve patients, their families, carers and communities in a service that should be “of the people, by the people; and with the people” (NHS Five Year Forward View 2014, p.9).

### **Patient Involvement: mechanisms and theoretical framework**

To implement the health policy in practice we need to consider which 'involvement mechanism' might be the most effective to facilitate participation by local patients in service development. There is rather limited literature on this topic, but a typology of effective mechanisms to support involvement provides a useful starting point (Crawford et al. 2002; Rowe and Frewer 2005). These authors re-iterate the variation of the definition of 'public participation' in both the existing literature and at the point of practice development. Rowe and Frewer (2005) point out that this lack of clarity has impeded the development of robust research at organisational level coupled with the lack of implementation of effective public participation practices. However, more recent guidance (REF) explicitly defines the principles and benefits of patient involvement and the extent to which CCGs and NHS England should engage and promote both public and patient participation in decision making. ([www.england.nhs.uk](http://www.england.nhs.uk) 2017)

To enhance definitional clarity of PPI, Rowe and Frewer advocate three types of mechanisms of involvement used to facilitate the participation of patients and citizens in service improvement. Firstly, they argue that '*public participation*' rests at the institutional agenda at the policy-driven decision-making level. Secondly, '*public consultation*' occurs where information is conveyed from the public to sponsor-initiated developments where no formal dialogue exists between the public and the sponsors or the commissioning group / party. In this situation, information is exchanged between the public members and sponsors in a typical group setting, for instance. Finally, '*public communication*' refers to any setting where information is conveyed from the sponsors of the service development to the public members. When combined, these three concepts are referred to as the broader construct of '*public engagement*' (Rowe and Frewer 2005) which has provided a theoretical framework for the researcher-generated questionnaire in relation to this research work.

In summary, PPI is here to stay; as reflected in international policy. However, less is known about how to implement it in healthcare settings. In this quality improvement study, we aimed to understand the attitudes and preferences of our local population about their involvement in health service development through the distribution of an anonymous e-survey. Findings were to be used to improve our approaches to involving patients in health service developments.

The objectives of the study were to determine:

- (a) PPI preferences in the design, planning and delivery of local health services;
- (b) PPI preferences in communication strategies;
- (c) Associations between PPI willingness to be involved and demographic characteristics.

## **Setting**

The setting for the quality improvement was a single NHS Foundation Trust based in Northern England (United Kingdom). The Trust provides a full range of acute hospital and community services to a relatively large geographical area with a combined population of approximately 607,400 people. Close to one quarter of the population (22%) who live in the Trust catchment area are 18 years and under; 62% of the population are aged between 18 and 64 years, and, similar to many areas in the UK, there is a growing population of older people in the area where 16% are aged 65 years and over. Life expectancy, both at birth and at age 65 years in the study area is slightly lower than the national average.

## **Design, methodology and questionnaire development**

A descriptive, anonymous research-generated quantitative e-survey questionnaire design was selected to ascertain patients' preferred ways of local service involvement and their preferred means of communication. The quality improvement study was conducted in 2015 at a local NHS Trust. The time lag or delay in reporting the findings from this study was due to time consumption and logistical difficulties experienced in collating and analysing the extensive data sets received. The participating patients were helped to complete the questionnaire, if required, by a Research Nurse in the Outpatients Department (OPD) by using information technology which facilitated a relatively high response rate. Additionally, the survey design ensured that the views of a relatively large sample of the population surrounding the Trust were included to gain wide and diverse views regarding PPI in service development (Polit and Beck 2014).

We wanted to obtain numerical or factual data using Likert scale items to explore patients' preferred methods of involvement in service development and their modes of communication to sustain their interest in local PPI activities. A literature review related to PPI revealed that no rigorously valid and reliable quantitative questionnaire tool existed. However, themes extracted from the literature were used to inform the development of this survey questionnaire (Appendix 1).

The identified literature themes included:

- The importance, value, and interest of PPI in 'I' having a say in how hospital services are run or the appropriate hospital services that 'I' use.
- Preferences on how "I" get involved in order to have a say in service improvement e.g. small and large public meetings or filling out a questionnaire.
- 'Getting involved' – 'my' convenient time, travel, pay and geographical distance from my local hospital
- 'My' preferred method and frequency of communication with the hospital personnel
- 'My' preferred type of electronic device usage (and problems) used to complete the Questionnaire (e.g. ThinkPads, mobile phones, personal computers or other devices) (Greenhalgh 2009; Goodwin et al. 2011; Armstrong et al. 2012; Meetoo 2013; Abelson et al. 2015)

The tool was installed on a Lenovo ThinkPad Tablet to facilitate patient use. A Research Nurse approached patients attending an Orthopaedic Clinic and invited them to complete the questionnaire whilst they waited. Patients who agreed to take part were given an introduction explaining the background to the study and details of the questionnaire content. The Research Nurse noted how well patients engaged with the completion of an anonymous questionnaire and was available to give assistance as required. Participants completing the questionnaire, either in or away from the clinic were given an individual username and password to access the questionnaire whilst in clinic to ensure anonymity.

## Ethics

The Research and Development Department was consulted at the participating Trusts and confirmation given that the proposed initiative qualified as a quality improvement initiative designed to understand how we can match our patient engagement strategies, for the involvement of patients and members of the public in health service development, with their personal preferences. Implied consent is defined as "when surrounding circumstances exist which would lead a reasonable person to believe that this consent had been given, although no direct, express or explicit words of agreement had been uttered" (<https://dictionary.law.com> 2018). In the context of this improvement work, implied consent was as obtained from willing participants by requesting them to complete an anonymous questionnaire completed in the OPD or at the patient's home accessed on-line. A specific statement was included in the survey indicating that completion of the survey was taken as their consent. There were no identifiers or links to any clinical data. Anonymity was maintained by providing each participant with an individual unique

username and password to access the questionnaire from any of their preferred personal computers, smartphone, ThinkPad or tablets.

## Data Analysis

Data analysis was largely descriptive. Non-parametric statistical tests were performed to evaluate associations between demographic characteristics and willingness to be involved in service development. For this analysis, ethnicity was dichotomized into categories corresponding to *White* and *Other*, due to low frequencies of all categories other than *White*; and overall assessment of general health was classified into either *Very Good, Good, or Excellent*; and *Poor or Fair*.

## Results

Data were collected over a 13-week period in 2015. 229 consecutive patients attending an orthopaedic OPD clinic in the Trust were approached to complete our questionnaire; 36 declined and 193 verbally agreed to complete the questionnaire, either in clinic, or at home. Of this sample of 193, a total of 172 patients returned the questionnaire. From the 172 respondents, ten failed to complete the questionnaire and were subsequently deleted from the data set. Hence, the final analysis was conducted on 162 respondents which yielded a 71% response rate which is considered a good response when using an online questionnaire (Richardson 2005).

Demographic characteristics of participants (age, gender, ethnicity, home situation, employment status, health literacy and self-reported health status) were elicited. A typical participant was aged 50 years, white Caucasian, employed full-time, living with a partner, high level of functional health literacy and 'good' to 'very good' self-reported health. Males and females were almost equally represented in the sample. Full participant characteristics are summarised in Table 1.

**Table 1: Sample characteristics**

Categorical Variable	Frequency (valid %)
<b>Gender</b>	
Male	83 (48.3%)
Female	89 (51.7%)
<b>Ethnicity</b>	
African	4 (2.3%)
Asian/ Asian British	11 (6.4%)
Chinese	1 (0.6%)
Mixed	9 (5.2%)
White	147 (85.5%)

<b>Home situation</b>	
Living alone	52 (30.4%)
Living with partner	35 (20.5%)
Living with husband/wife	65 (38.0%)
Other	19 (11.1%)
<b>Employment situation*</b>	
Employed full-time	59 (34.7%)
Employed part-time	25 (14.7%)
Retired	48 (28.2%)
Student	8 (4.7%)
Unemployed	13 (7.6%)
Self-employed	17 (10.0%)
Unpaid or voluntary work	4 (2.4%)
<b>Health literacy – help needed with medicine instructions</b>	
Never	139 (81.8%)
Rarely	16 (9.4%)
Sometimes	6 (3.5%)
Often	4 (2.3%)
Always	5 (2.9%)
<b>Assessment of overall health</b>	
Poor	14 (8.2%)
Fair	24 (14.1%)
Good	67 (39.4%)
Very good	43 (25.3%)
Excellent	21 (12.4%)
Unknown/unsure	1 (0.6%)
<b>Numerical variable</b>	<b>Mean (SD; range)</b>
<b>Age in years</b>	50.9 (17.0; 18 – 89)

\*more than 1 response could be selected; percentages are based on cohort providing 1+ valid responses to item; missing data not imputed (n=170)

Responses to all items are summarised in Table 2.

**Table 2: Summary of responses to all items**

<b>Item Description</b>	<b>Frequency (valid %)</b>
<i>Being involved in having my say about how hospital services are run is worthwhile</i>	
Completely agree	
Agree	58 (34.3%)
Neither agree nor disagree	86 (50.9%)
Disagree	22 (13.0%)
Completely disagree	2 (1.2%)
	1 (0.6%)
<i>To have my say about my local hospital is important to me</i>	
Completely agree	61 (36.1%)
Agree	85 (50.3%)
Neither agree nor disagree	22 (13.0%)
Disagree	1 (0.6%)
Completely disagree	0 (0.0%)
<i>I am only interested in having a say about the hospital services I use</i>	
Completely agree	12 (7.1%)
Agree	50 (29.6%)
Neither agree nor disagree	38 (22.5%)

Disagree	48 (28.4%)
Completely disagree	21 (11.7%)
<i>My preferred way of having my say about local health services would be through attending a small public meeting consist of 5 to 10 people</i>	
Completely agree	9 (5.3%)
Agree	46 (27.2%)
Neither agree nor disagree	50 (29.6%)
Disagree	37 (21.9%)
Completely disagree	27 (16.0%)
<i>My preferred way of having my say about local health services would be through attending a fairly large public meeting consist of 40 to 50 people.</i>	
Completely agree	7 (4.1%)
Agree	41 (24.3%)
Neither agree nor disagree	52 (30.8%)
Disagree	44 (26.0%)
Completely disagree	25 (14.8%)
<i>My preferred way of having my say about local health services would be filling out a written questionnaire.</i>	
Completely agree	25 (14.8%)
Agree	100 (59.2%)
Neither agree nor disagree	26 (15.4%)
Disagree	10 (5.9%)
Completely disagree	8 (4.7%)
<i>Finding time between 9 am till 5 pm to get involved would be difficult for me</i>	
Completely agree	41 (24.3%)
Agree	60 (35.5%)
Neither agree nor disagree	23 (13.6%)
Disagree	34 (20.1%)
Completely disagree	11 (6.5%)
<i>Getting to a meeting place from my home would be easy for me</i>	
Completely agree	19 (11.2%)
Agree	66 (39.1%)
Neither agree nor disagree	43 (25.4%)
Disagree	24 (14.2%)
Completely disagree	17 (10.1%)
<i>Being paid for my time spent getting involved would be important</i>	
Completely agree	7 (4.1%)
Agree	13 (7.7%)
Neither agree nor disagree	51 (30.2%)
Disagree	57 (33.7%)
Completely disagree	41 (24.3%)
<i>Please select your preferred method of communication.</i>	
Phone call	35 (20.7%)
Text messages	32 (18.9%)
Email	54(32.0%)
Website	3 (1.8%)
Skype	0 (0.0%)
Face to face communication	9 (5.3%)
Letter by post	36 (21.3%)
<i>How often you would like to be contacted by us?</i>	
Fortnightly	8 (4.7%)
Monthly	46 (27.2%)
Six-monthly	50 (29.6%)
Annually	65 (38.5%)
<i>What electronic device you used to complete the questionnaire?</i>	
Thinkpads	159 (95.2%)
Mobile phones	6 (3.6%)
Personal computers	2 (1.2%)

The proportions of respondents *Strongly Agree or Agree* to specific items was considered to indicate a positive attitude with respect to that item. Under this assumption, the majority (144; 85.2%) of participants were positive about being involved in hospital service development, and felt that having their say was important to them with reporting (146; 86.4%). Participants were more interested in being involved in services across the hospital, rather than just in the services they used themselves.

The majority of participants (125; 74.0%) favoured questionnaire involvement with smaller proportions of respondents expressing willingness to attend large or small public meetings. However, given that the information was being elicited from an optional questionnaire, the sample may be self-selecting in this regard.

Time was considered to be more of a barrier to involvement than either distance from the hospital or remuneration; 101 participants (59.8%) reported strong agreement or agreement that they would have difficulties in getting involved during working hours. By contrast, distance and lack of payment appeared smaller barriers to involvement than time: 85 participants (50.3%) and 20 participants (11.8%) respectively stating that these would be barriers to their involvement.

Several different preferred methods of communication were selected by substantial numbers of respondents. Email communication was the most popular option, selected by 54 respondents (32.0%); but significant numbers also opted for phone calls, text messages and letters. A strong preference for infrequent communication was reported with increasingly greater numbers of respondents reporting preferences for increasingly infrequent communications; 115 respondents (68.0%) requested communication at intervals of 6 months or more.

Almost all respondents (159; 94.1%) who completed the survey preferred using the *Thinkpad* electronic device with negligible numbers using mobile phones, computers or other devices. Ten respondents (5.8%) reported experiencing a problem with the device used which consisted of difficulties accessing the internet / Wi-Fi, logging on with the username/password, and general lack of familiarity with usage of the ThinkPad device. These issues were resolved at the point of questionnaire completion by the Research Nurse in the Orthopaedic OPD.

There were no associations between the variables of gender, ethnicity, home situation and health, and willingness to become involved ( $\chi^2_{(1)}=0.045$ ,  $p=0.833$  for gender;  $\chi^2_{(1)}=0.219$ ,  $p=0.639$  for ethnicity;  $\chi^2_{(3)}=4.74$ ,  $p=0.192$  for home situation;  $\chi^2_{(1)}=0.865$ ,  $p=0.352$  for health).

## Discussion

Several factors are known to enhance patient and public involvement in health service development. Some include the existence of the wider political, cultural and organisational climate that values the inclusion of PPI in their policies. For example, this is evident in health care governance, resource allocation, and patient decision-making about their own care processes and services (Meeto 2013). This wider positive health government policy seems to permeate downwards to fuel local developments in order to create a unique PPI identity. At Trust level, the host organisation too needs to value PPI input, not from a tokenistic point of view or paying 'lip service' to the concept but from an open communication and meaningful dialogue system that operates between health service managers/leaders and patient inclusion groups (Meeto 2013).

Moreover, several different organisational initiatives seem to attract PPI *vis-à-vis* the development of consumer involvement interest groups, small or large working groups, stakeholder dialogue with PPI and use of various survey designs to engage public/patient interest including the views of senior and junior staff of the organisation *per se* (Meeto 2013). Findings from our quality improvement initiative supports the work of Gauvin et al. (2011); particularly in terms of the way local services and organisations value the importance of consumer involvement for their input, opinions, judgements and decisions in how services are delivered and managed.

Our findings suggest that demographic characteristics such as gender, ethnicity, home and employment circumstances were not associated with preferences for involvement. It should be mentioned that our study had a large sample of white British participants (85%) with only a small proportion of participants deriving from ethnic groups (15%). Despite this context, our findings are congruent with the cited literature where demography, ethnicity or class structure are not linked to barriers or obstacles to PPI involvement in healthcare organisations (Gauvin et al. 2011; Gagnon 2011). In contrast, other authors mention that the reality of PPI involvement in clinical commissioning reflects that lay member representation tended to be semi-retired or retired, white and middle class (O'Shea 2016). Their ethnographic study unsuccessfully attempted to recruit representative lay members from across the social strata in terms of ethnicity, gender, age and geographical area to avoid marginalising minority group involvement. They argue that PPI representation in terms of demographic characteristics is a hotly contested area relating to "whose voices, what representation is or what it should be" (O'Shea et al. 2016)

Important mechanisms to facilitate effective PPI in various organisations were participants' genuine and meaningful lines of communication between organisational personnel and PPI groups by a variety of communication methods, which included: survey methodologies, working groups, various committees and service user groups (Meeto 2013; Gauvin et al. 2011; Gagnon 2011). The concomitant use of non-hierarchical power bases and jargon-free language was seen as an important issue at various meetings and for fostering authentic positive relations between both sets of parties.

Findings from our quality improvement study showed that approximately 45% of participants indicated no real preference for one communication strategies between telephone calls, Skype technology, or face-to-face dialogue. Over half of the participants (55%) preferred e-mail as a means of communication and the majority of patients preferred infrequent communications between the Trust and themselves by a timeline of at least six months. Possible explanations for these findings may be the 'unconscious bias' introduced by the researchers in terms of their own preferential selection of electronic devices and methods (*ThinkPad*) used to collect data on PPI (Polit and Beck 2014). Moreover, this group of participants preferred e-mail communication to other communication forms which may reflect a higher level of computer literacy. Over 80% of participants reported never needing assistance with reading health information which suggests that they had a high level of health literacy. It is not clear why the participants preferred a 6-month time gap of communication with the Trust, but this may be related to personal issues, for instance, lack of time, distance from home to the Trust; or perhaps their own perceived satisfaction that their PPI work was well done over that time span.

It is recognised that barriers or obstacles exist towards the implementation of PPI in NHS health services to enable service users to contribute positively to organisational/service developments (Gauvin et al. 2011). An argument exists towards the absence of a theoretical foundation upon which to base the concept of PPI moving forward at local or national levels. It is suggested that tensions may exist about the value of PPI. There is considerable emphasis upon a medical model which relies upon relatively instant numerical assessments, measurements and statistics to justify cost-effective health care services (Gauvin et al. 2011). This strategy reflects the dominant positivistic paradigm evident in the Cochrane Collaboration and the evidence-based medicine movement which emphasises the experimental method, systematic reviews and meta-analysis of 'nearly all things' and activities related to patient care and NHS services (Gauvin et al. 2011). All in all, this may serve to dichotomise PPI from the more powerful professional medical groups, and thus, may give rise to negative attitudes, communication systems and unhealthy lay-professional relationships which may stultify PPI service in relation to organisational development.

Other obstacles are more pragmatic in nature associated with finances, time, travel and personal commitment to PPI initiatives. Evidence suggest that patients and public commonly refer to the expense, and mostly, the relatively long periods of time taken for even modest PPI work (Gauvin et al. 2011). This supports our findings in which participants perceived time resources as the biggest impediment to PPI work as opposed to financial cost or travelling time to various PPI meetings. The majority of participants in this study suggested on the questionnaire that they would have difficulties with contributing to PPI work scheduled during working hours, but unlike some of the literature, did not consider remuneration or travelling times as a real barrier to PPI activities (Gauvin et al. 2011).

### **Strengths and limitations of the study**

The sample was relatively large ( $n=172$ ) but was selected from one clinical setting, which may limit the generalizability of findings. Participants had a relatively high level of health literacy, which may mean that the preferences of those harder to reach individuals may have been missed. Although formal checks for internal validity and reliability of the tool were not conducted, face validity was established by gleaning the concepts of the published literature to inform the contents of the questionnaire.

### **Conclusion**

In summary, the key findings from our quality improvement initiative demonstrate that the majority of patients attending our orthopaedic OPD wished to have their views heard. This concerned the way local health services were managed and led and not just the specific services that they had used. From the outset, careful consideration should be given to PPI involvement mechanisms in health service development. Once patients and public are involved, healthcare professionals need to value their time, efforts, insights and experiences in an organisation which genuinely listens to the patient's voice in service development (Crawford et al. 2002; Rowe and Frewer 2005; Gauvin et al. 2011; Gagnon 2011; Meetoo 2013; Patient and Public Participation Policy 2017)

In the final analysis, this quality improvement initiative has provided valuable information to help us to understand local patients' preferences for involvement in health service development and any potential obstacles that they may face. These data can inform our future approaches to the involvement of patients to ensure that our patient engagement strategy matches patients' preferences and that we are aware of specific demographic groups who may be less well represented.

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