

Evidence based patient/public voice: a Patient and Public Involvement Audit in  
the field of Sexual Health.

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## Abstract

### Background

The NHS constitution enshrines the central role of Patient and Public Involvement (PPI) in order to place patients as its heart. The sexual health field presents unique challenges for PPI in the tension between current PPI practice vs the need for confidentiality/feelings of shame/stigma. However, there is little evidence around the goals, evaluation measures or theoretical underpinnings of PPI.

### Objective

In order to improve current PPI practice in the sexual health field, audits were carried out on PPI plans in both service and research sectors.

### Methods

18 sexual local health service contacts completed the audit through snowballing. The tool was refined and 5 research projects completed the audit from the Health Protection Research Unit (HPRU) in Blood Borne and Sexually Transmitted Infections. Responses were collated and a thematic analysis by 2 independent researchers carried out. Common areas for improvement were identified.

### Results

Audit tool responses evidenced wide variability in practice. Issues include: conflation of PPI work and qualitative research; limited 'patient satisfaction' approaches; lack of PPI goals; methodological reliance on 'visible' methods such as focus groups; lack of responsiveness around patient needs; poor resourcing of PPI work. Research specific issues included 'late' PPI after key decisions had been made and poor lay summary validity.

### Discussion

Two audits evidenced a range of areas for improvement of PPI practice in sexual health. Clear definition of 'what PPI is for' aligned with evaluation measures would begin to build an evidence base for the contribution of patient voice.

## Introduction

Patient and public inclusion is increasingly recognised as vital in both healthcare and research, but means many different things to different groups. It can be used to define a range of activity under the banner PPI (Patient and Public Involvement) from patient feedback to co-production in which patients play an active role in planning and delivering work. This heterogeneity poses significant challenges for communication, implementation, and quality assurance of PPI initiatives. This article discusses PPI as it applies to sexual health work in the UK, framing the need for improved evidence based practice within the framework of the inherent challenges of patient's need for privacy within sexual health which mitigates against a willingness to share experiences.

Extensive guidance around how to carry out PPI in healthcare is available from INVOLVE and the service standards within the sexual health field repeatedly reference the need for PPI, e.g. NHS England<sup>1</sup>, BASHH<sup>2</sup>, DoH<sup>3</sup>, FRS<sup>4</sup>. However, it is also the case that there is little practical guidance on how to translate these national PPI policies and guidelines into methods and processes that are appropriate to Sexual and Reproductive Health (SRH) services 'on the ground'. Moreover, there is little published in this area, and therefore little evidence of what PPI is taking place or its likely impact/effectiveness. The most useful specifically for sexual health, and endorsed by the DoH<sup>3</sup>, was the London Sexual Health Programme (SHAPE: Sexual Health<sup>5</sup>); however this website has been discontinued. What good PPI looks like sexual health services is unclear.

Patient and Public Involvement (PPI) in research is a UK health research funding requirement<sup>6</sup>. It is also embedded in the NHS Constitution<sup>7</sup> and is a statutory duty of health services (Health and Social Care Reform Act, 2009) which aims to place the patient at the heart of the NHS. Systematic reviews of the literature have evidenced a lack of conceptual and theoretical underpinning to PPI, and the evidence base for the use and impact of PPI work is limited. Theoretical work around PPI in research is beginning to develop<sup>9</sup>, including calls for use for the robust measurement of impact<sup>10, 11</sup>. However, studies have also found that there is little agreement around what PPI in research is for<sup>12</sup> or what theory is used.<sup>13</sup> As evidenced by the authors own ad hoc survey of those involved in PPI work. A short

survey at an INVOLVE (lead organisation to promote PPI in the UK) annual conference<sup>14</sup> showed that of (n=33) workshop participants, definitions of its goal varied, including: listening to patient voice, improving the quality of services, tailoring services, improving patient experience, making work more relevant to the recipients. PPI may be trying to achieve all or none of these outcomes which are themselves probably overlapping but assessing PPI 'success' depends at least on defining what PPI is for and then measuring this.

This lack of clarity around what PPI is for, may makes it vulnerable to tokenism or a 'do it because we have to' approach. The lack of evidence of good PPI also prevents evidence based improvement. More worryingly, it could prevent us identifying where it may cause harm. Amplifying patient experience should improve services, improve patient experiences and ultimately improve health outcomes<sup>15</sup>. However, this requires an evidence base.

In order to address this gap and address the unique challenges of securing patient voice within a service where embarrassment/shame mitigate against visible involvement, the authors developed a short audit tool for PPI, structured in such a way as to ensure PPI work is defined in terms of goals and clearly measurable outcomes. The tool was designed to both capture current practice in order to identify key common areas for improvement but also induce better practice as respondent were required to articulate their concept of what PPI is for and how success could be measured. Two audits were carried, one examined service PPI in a local sexual health specialist service, the second audited the research plans across the National Institute for Health Research Health Protection Research Unit (NIHR HPRU) in Blood Borne and Sexually Transmitted Infections programme of research. The uniquely challenging context of sexual health patient engagement<sup>8</sup> within which the tool was developed is the focus of a wider portfolio of research.

This paper both outlines the tool itself and presents key areas requiring improvement from its use within both sexual health service delivery and research.

## Methods

Two audits were carried out one within delivery of sexual health services and one across a large programme of research projects around sexual health. Detailed information on the audit tool and its development is presented later. The audit tool was initially developed from the key concepts of audit, good PPI and data from patients<sup>13</sup> and modified after each use.

The service audit tool was electronically circulated amongst a body representing all the sexual health services within the area (the Sexual Health Improvement for Population and Patients, Health Improvement Team/ SHIPP)<sup>i</sup>. Recruitment took place through snowballing of the SHIPP contacts and 18 participants filled in the anonymous online audit tool. Reach of the audit was checked against both organisations and levels to ensure a good range of data<sup>13</sup>. Returns were collated and a thematic analysis carried out independently by 2 researchers. Key common strengths and weaknesses were identified across PPI activity. Comparison against best practice was not possible as no such standard exists, however, both researchers were familiar with the range of current PPI and PPI in sexual health guidelines. Key findings were shared with the SHIPP/ HIT including sexual health services commissioners.

The research audit was commissioned by the lead of a large and varied research programme (NIHR HPRU) around sexual health, to drive improved PPI. 5 of 9 individual research projects filled in the audit tool and submitted PPI plans electronically. Audit tool returns were again collated and thematically analysed independently by 2 researchers for common strengths and weaknesses. Each project received individual feedback and cross cutting improvement recommendations made for the programme as a whole and reported here.

#### Patient and Public Involvement in developing the audit tool

Patient and Public Involvement informed the development of the audit tool itself through survey work with young people around their experience of PPI across sexual health services<sup>13</sup>. The work was also shaped by the Health Integration Team (HIT) which represented recipients of the audit (all organizations working in sexual health across

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<sup>i</sup> <http://www.bristolhealthpartners.org.uk/health-integration-teams/sexual-health-improvement-hit/>

Bristol). Furthermore, the authors are working on a 'Story-based PPI' approach to capture the definitions of how a variety of vulnerable patients across sexual health services (Sexual Assault Referral Centre, Abortion Services etc.) want to contribute to PPI and how they define success criteria.

### The PPI Audit Tool\*: Questions that improve practice

This series of 12 questions, examining 3 areas, was developed to build users' understanding of what they were trying to achieve with their PPI work, as well as some assessment of the organisational resourcing of the PPI work itself. The questions were developed in the first instance to capture the range of PPI work taking place within different sexual health organisations and drew from existing guidelines on what PPI should look like from INVOLVE<sup>15</sup> as well previous research work carried out to explore the particular needs of users accessing sexual health services<sup>13</sup>.

The structure of the tool aimed to ground respondent's understanding of their PPI work in the goal they were trying to reach (Question 1) and use this to encourage them to not only define but measure that success (Question 8). At the same time the questions needed to capture the full range of activities that might be seen as PPI and focus on the building blocks of good PPI planning<sup>11</sup> such as resourcing, policies, name roles etc.

#### Identifying PPI work

1. What is PPI for?
2. How could the voice of patients or the public change the work you are undertaking?
3. What is your current activity to involve service users and potential service users?
4. What plans or policies do you have for PPI work, can you submit with this audit?

#### Effectiveness of PPI work

5. What is the goal of your PPI?
6. Who is involved (how diverse) in PPI work at what stage, in order to achieve what?

7. How will PPI shape your service/research?
8. From the goal already identified can you select outcomes or measures that demonstrate the impact of the PPI work?

### Resourcing PPI work

9. Who looks after PPI in your organisation?
10. What is their role?
11. What resources do you have for PPI work (finance, time, patient groups/ collaborators)
12. Do you have the resources you need? What more do you need?

\*The authors request citation of this paper if the tool is used or adapted

The common issues and areas for improvement were identified across services and research projects are reported below.

## Results

### Service Audit

Findings from the use of the audit tool within a regional delivery of specialist sexual health services are reported elsewhere<sup>8</sup>. However, the key themes that emerged from the input of N=18 individuals, representing all levels of service (CCG commissioners sexual health services themselves including primary care, clinics and charitable providers) fall into five areas (in bold):

A varied programme of some interesting and innovative PPI work was evidenced. The audit tool identified areas for improvement including wide **variability** around PPI practice, with many reporting no PPI policy and others submitting advance patient centred work. In terms of the key aim of the tool itself, encouraging clear identification of **PPI goals**, many had not conceptualised what PPI was for, often conflating PPI work with qualitative research involving patients. This meant there was no way of measuring how successful work had

been in reaching any goals. Change in the logistics of service delivery (appointment times, availability of information etc.) was often cited as a key outcome, which reflect a minimal **'patient satisfaction approach'** to PPI. Methods also demonstrated a lack of **responsiveness** to patient groups/confidentiality concerns, and there was some reporting of innovation being undermined by standardised 'NHS' PPI systems. Finally, the audit tool also highlighted a lack of **training** as a key barrier to PPI, although 8 out of 10 services reported offering PPI training to staff.

The audit tool successfully identified areas that required improvement and, in reporting back results across the SHIPP HIT group, enabled areas of the service to benchmark their PPI work against those of others and begin to improve this aspect of their work.

### Research Programme

The use of the tool to audit at the National Institute for Health Research Health Protection Research Unit (NIHR HPRU) in Blood Borne and Sexually Transmitted Infections large programme (3 themes, 9 projects) of research work within the sexual health field, enabled us to identify some key overlapping issues around PPI but also some key themes that were specific to research, as opposed to service delivery. 5 of the 9 projects returned audit data.

Overall, evidence was submitted of valuable PPI work being done but again, there was some variability in approaches to conceptualising PPI, captured by the audit tool. They included ideas such as: quality of the research, democracy, ethics, understanding the context of the research, engaging people, relevance, and transparency. So, again, there was wide **variability** and, in some instances, PPI was conflated with qualitative research (double badging original qualitative research undertaken for the project as patient involvement work). Projects had difficulty identifying their **PPI goals**. **Resourcing** of PPI was seen to exist only at a project level which, within a larger programme of work, suggested that wider organisational roles, training and policies could be put in place to support frontline PPI work. Information around specific funding for PPI was often vague and suggests that clear financial support for PPI work could have been better defined. **Methodological approaches** relied heavily on the use of face-to-face groups, which within the specific context of sexual



health makes recruitment very difficult, as stigmatized patients require confidentiality and anonymity<sup>12</sup>. The proposed **timing** of PPI planning was often after key decisions of focus and methods had been decided by researchers and therefore its scope was limited to elements such as the tailoring of materials. PPI work should be planned from the outset of a project and allow patient input into the research question and methodology. Finally, the quality or true accessibility of **lay summaries** was clearly identified as an issue. Findings were fed back to the organisations concerned.

## Discussion

The audit tool led to the identification of key areas of improvement that in many areas chimed with findings from an existing systematic review<sup>10</sup> whilst at the same time signaling areas of good practice within PPI. The audit work demonstrated a need to push PPI work to be clear about where on the continuum of involvement their work sits (patient and public voice at the heart of both service and research design (ideal), to projects that simply require tailoring of communications or logistic service delivery (often the reality). The full scope is required, and the goals of each would be very different, so defining these at the outset of work is both logical and desirable.

Within the specific context of sexual health, the need for greater variability in methods around patient engagement emerged as a way to cater for the sensitivity and anonymity required by the field. Likewise, the need for greater diversity in the types of voices heard by research and services in this area, as well as the need to build trust with seldom heard groups, points to the need to offer a range of different contact approaches, and to ask patients and the public how they would like to contribute. However, this is not only the case for sexual health: the principle of greater variability in method, tailored to patient expectations and experiences, can be seen as key to successful engagement with PPI across a range of different health fields.

There was little evidence of any measurement or quality control in any of the PPI work that was audited here. Our recommendation that this area is developed not only to better evidence the effect on patients giving their time, but also to scope and maximise this benefit

whilst minimising potentially harmful, tokenistic approaches. It is our ethical duty to report back to those giving their time and above all and show then what their contribution has truly achieved . Measurement should be theory-based, using a concept of Theory of Change as used in evaluation. Theory of change approaches, explained briefly, define the pathway or causal linkages from activity to desired change<sup>13</sup>. Using such approaches will challenge projects to articulate their PPI assumptions, but also to ensure that PPI goals are clear and make sense within a given context and problem. It will also allow researcher and services to make clear links between activities and outcomes, and to know if, when, and how PPI has benefited those involved.

A key often unaddressed issue within PPI is diversity and whose voices are being represented. The sensitive nature of sexual health work requires us to address the needs of hard to reach groups and goes to the heart of who is heard.

## Key Messages

- PPI practice in sexual health was variable and may not cater for the sensitive/stigmatized nature of the patients it seeks to give voice to.
- PPI practice struggled to define its goals and method of evaluating success in achieving those.
- PPI in sexual health needs to offer a range of involvement options (being mindful of embarrassment/anonymity) and both define and assess its own goals.

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