

TITLE: Assessing the Possibilities and Challenges of Patient Involvement in Sexual, Reproductive and HIV/AIDS Services

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ABSTRACT

Background

Patient and public involvement (PPI) is a key feature of the commissioning and delivery of healthcare services, particularly in the UK. Sexual health and reproductive services face unique challenges when it comes to PPI, as the anonymity and confidentiality required by service users, and the sensitivity of the issues dealt with, can be a barrier to drawing in people to shape services. PPI should help to create high quality sexual health services, which in turn should result in increased trust in services and help to tackle sexual health inequalities. However, specific practical guidance on how to address PPI in sexual health, and the evidence base to support this, is sparse

Methodology

This research aims to begin building an evidence base for PPI in sexual health services through two routes: 1) an audit of PPI in sexual and reproductive health and HIV services (SRHH) in Bristol, North Somerset and South Gloucestershire (BNSSG) and 2) a parallel survey of potential users of sexual health services about their experiences of PPI. For the audit, all organisations involved in sexual health service delivery or management in BNSSG were invited to complete a short online survey. In total, 18 organisations responded, representing a range of different service providers. For the survey, a convenience sample was recruited through the University of the West of England and through social media. Participants were invited to complete an anonymous online survey of their experiences of PPI in the sexual health services they had attended. In total, 96 people responded, affording a unique insight into PPI from a service users perspective.

Results

The findings from both the perspective of service providers and their potential service users are discussed together under the headings of **Levels of Involvement** and the **Challenges of Engagement**. Results suggest a reliance on questionnaire 'customer satisfaction' approaches in services and that potential patients commonly report never having been asked for feedback. Whilst challenges from the perspective of services focus on under-resourcing and a lack of time, potential patients emphasise the need for a range of approaches and clarity about what PPI is for.

Conclusions

Findings point to some basic steps in improving the use of patient's voice in SRHH such as clarity of purpose (potentially measured against data outcomes), the importance of communication, and the need for flexible methods. Trust, safety, confidentiality and anonymity characterise sexual health services, they therefore must also underpin patient involvement efforts in this field.

INTRODUCTION

Public and patient involvement (PPI) is defined as any activity that comprises involving, consulting and listening to patients and the public. PPI is a core policy in the NHS in the UK, and is seen by many as essential to improving patient satisfaction, reducing inequality, and enhancing accountability and good governance^{1,2}. In sexual and reproductive health and HIV services (SRHH), there is wide recognition that PPI is important – albeit challenging – in terms of increased use of sexual health services and access to effective contraception and the management of sexually transmitted infections.³ There is an understanding that PPI may help to create high quality sexual health services⁴, which may help to tackle sexual health inequalities and improve outcomes for many different groups of patients³.

Extensive generic and field specific guidance and service standards for PPI exist, e.g. NHS England⁵, BASHH⁶, DoH⁷, FRS⁸. 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 SRHH 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 DoH⁷, was the London Sexual Health Programme (SHAPE: Sexual Health⁹); however this website has been discontinued.

Underpinning the lack of more specific 'how to' PPI guidance in sexual health may be a lack of evidence on which services can base their activity, this could drive variability in the way PPI is implemented¹⁰ and a lack of PPI as a mainstream activity¹¹. In this article, we attempt to address this gap by exploring the possibilities and challenges of PPI in SRHH, drawing on evidence from an audit study that we conducted with service providers and a survey carried out amongst potential service users.

METHOD

The audit study was conducted to inform the work of a Bristol Health Integration Team (see (<http://www.bristolhealthpartners.org.uk/health-integration-teams/sexual-health-improvement-hit/>)). All organisations involved in SRHH in the HIT area (which includes Bristol, North Somerset and Gloucestershire) were invited to complete a short online survey between September and November 2013, covering PPI activities and policies, as well as barriers, challenges and best practice (see Appendix 2). An email invitation was circulated to key services and HIT members, and forwarded by them to wider SRHH contacts. SRHH services in this area are provided by a range of organisations and professionals, including hospital-based specialist sexual health services providing integrated Genitourinary Medicine (GUM), Sexual and Reproduction Health (SRH) and SRH Community clinics (10 clinics) and dedicated Young People's clinics (YPC) (9 clinics). Other types of specialist providers include Brook, specialist HIV hospital services, Terrence Higgins Trust and the Sexual Assault Referral Centre (SARC). Sexual health services are also provided in general practice. All levels of SRHH services and experts were contacted, including key Public Health Teams (at the time transferring to the Local Council) and key academics working with services. The respondents were checked against service providers to ensure each type of service was included in the audit. In total, 18 organisations responded, including GUM, contraception and sexual health clinics, pregnancy advisory services, young people services, HIV services and general practitioners. An overview of the reach of the PPI audit is provided in Table 1 below.

In order to establish the patient perspective, we invited a group of sexually active young people, as actual or potential service users, to complete a short online survey (see Appendix 1) covering their experiences and views of providing feedback to SRHH services. An

invitation was circulated amongst Psychology undergraduate students at the University of the West of England (N= 500), via the departmental participant pool, which allows students to sign up to complete studies in return for course credit. In addition, an invitation was circulated on social media (Facebook), to the contacts of the postgraduate researcher (n= approx 150). In total, 96 responses were received. The demographics of this sample can be found in Table 2 below.

RESULTS

The following section sets out the details of participants for both the PPI practice audit and proxy patient group survey. Results from the two sources are then reported together as two perspectives on issues such as challenges and barriers.

Table 1 below shows the range of services reached by the PPI practice audit.

Table 1: Services represented by participants of PPI Audit.

	N=18
Sexual Health SRHH	8
Primary Care	3
Commissioner of SRHH services (CCG, Public Health, City Council)	5
Other Sexual Health organisation (Brook, Terrence Higgins Trust)	2

The mix of front line staff (Consultants, Nurses, GPs, outreach workers) with commissioning level respondents (service level managers, PPI leads) means that the reach of the audit was good and services covered all types of organisation providing SRHH services. However, the overlapping roles and levels of responsibility render sub-analysis, e.g. by organisation type, unreliable. This is discussed further in Study Limitations below.

The online survey of potential sexual health service users included:

Table 2: Demographics of survey participants

Age	<i>Range</i>	18-53
	<i>Mean</i>	23.60
	<i>Median</i>	21.86
Sexual Orientation	<i>Heterosexual</i>	89% (86/96)
	<i>Gay/Lesbian</i>	5% (5(M)/96)
	<i>Bisexual</i>	5% (5(F)/96)
Ethnicity	<i>White British</i>	87% (84/96)
	<i>Mixed Ethnicity</i>	4% (4/96)
	<i>Asian</i>	1% (1/96)
	<i>Other</i>	5% (5/96)

	<i>Did not answer</i>	2% (2/96)
Gender	<i>Female</i>	76% (73/96)
	<i>Male</i>	24% (24/96)

All of the respondents to the survey stated that they are, or have been, sexually active 74/96 (77%) and had used some form of sexual health service in the past. Of the 22 not using services, half were male and half were female, meaning 12/23 males did not use services. The sample was primarily female (73 of 96), which is consistent with the over-representation of females in local community sexual health service use (88% F 12% M - CASH)¹², but male preference for integrated SRH services (50 F 50 M - GUM) and research^{12,13}. The sample was also predominately heterosexual (89%), with 5 male participants disclosing their sexual orientation as Gay and 5 female participants as Bisexual. The limitations of this sample are discussed further below.

PPI Practice in Services

The audit suggested that organisations are primarily reliant on (often) routine quantitative surveys – and specifically questionnaires, see Table 3 – as their method of engaging patients in services design and development (see Table 3), There were some examples of more participatory approaches, e.g. the use of PPI groups, patient representatives and mystery shoppers. However, these were primarily situated in young people and HIV/AIDS services, (e.g. young people’s representation on recruitment panels for young peoples’ services) and were much less common in contraceptive and GUM services. Least common, was the use of more in-depth methods such as interviews or focus groups, as well as methods that promote ownership, e.g. by allowing services users to design their own forms of PPI. Only one organisation had used online methods, e.g. social media or online forums. Some of the examples of good practice were driven by commissioner level initiatives such as the 4 YP (for young people) a mystery shopping exercise or the complex needs of clients groups (focus groups with sex workers).

Table 3: PPI Methods Used by SRHH Services Audited (n=18)

Online methods	1
Interviews or Focus Groups	3
Community Events/Outreach	5
Patient Participation Groups	7
Patient Representatives	7
Mystery Shopping	7
Using Comment Boxes	8
Providing Information to Patients	9
Surveys	14

Patient Perspectives on Involvement:

Most survey participants 68/96 (70%), stated that they had not provided feedback about SRHH services. Only 3/96:(3%) participants stated any form of involvement with services, in terms of giving feedback to services about their experiences of using services or their views on how services should be run. Interestingly, 17 participants did have feedback and this was not only negative, 13 participants said that they wanted to provide positive feedback to services that they had used.

Many felt they did not want or need to give feedback, of the 77 who gave reasons, 32/77 (41%) said that they did "not want" to give feedback, 32/77 (41%) identified the barriers of opportunity /time constraints and 13/96 (17 %) said there was another reason. Many of these 'other' reasons related to a sense that feedback was for the purpose of criticism or that it would not make any difference.

"I didn't feel my feedback would be beneficial as there was no criticism that they would be able to do something about and improve on"

All 96 participants declined any research involvement beyond the anonymous online survey (when asked if they would like to participate in either a face to face or online group).

The Challenges of Engagement

Levels of specific PPI resourcing

Many audit respondents reported concerns about a lack of training and a lack of understanding and awareness amongst staff around PPI (and the potential to get it 'wrong'). Interestingly, most of the organisations we surveyed (15) did not have (or were not aware of) a specific policy on PPI, and only two organisations reported having a specific policy relating to PPI in sexual health. Eight organisations that responded offer staff training on PPI.

Audit respondents often referred to time constraints as a key barrier from the perspective of services providers:

"time; staff members can be wary of really involving patients"

Barriers to patient involvement

When asked why they did get involved with services, 43% (32/96) of participants stated that they had never been asked:

"Never given the opportunity also it is too much effort to bring it up."

"Didn't strike me as somewhere that would want or care about my feedback"

"There wasn't a place to give feedback, and it's a fairly private matter"

"I was not aware feedback had to be given, not offer was presented to make feedback's".

Thus, It seems that the efforts of services to gain even limited feedback may not be perceived by patients.

Many of the service users also reported embarrassment as a key reason for not getting involved.

"I felt embarrassed enough whilst I was there, without complaining about it too"

"It is a sensitive and sometimes embarrassing subject"

"I generally don't give feedback, almost feel as if I did the anonymous relationship would be broken"

Their need for anonymity is emphasised by the following quote:

"I found the aspect of anonymity very helpful as I was very embarrassed to actually go to a service."

This needs for anonymity is also reflected in the fact that although a large proportion of our respondents suggested ways to improve involvement in SRHH services, not one of the 96 were willing to discuss the issue further in an online or face to face group, suggesting that resistance to non-anonymous methods is high.

Audit respondents acknowledged that a key challenge was reaching the non-attenders:

“It is hard to engage those who do not use services and they are often the most interesting groups as we want to know why they don’t use.”

The quotes below detail the suggestions that participants gave for how they think services could increase patient feedback. The data suggests services should specifically ask patients for feedback and provide a range of easy and anonymous methods for this.

“Make giving feedback more accessible, do it online”

“They could mention how it would benefit them in improving the service”

“Show they are interested in my feedback. Leaflets or posters etc.”

Discussion

Audit reporting of the range of methods used, and resourcing/policy support for PPI in SRHH services, suggests PPI practice is variable and often limited. Methods have been defined on a continuum of engagement – ranging from more ‘tokenistic’ and consultative methods like patient surveys and audits, to what are often described as more ‘meaningful’ methods such as interviews or focus groups and/or more participatory methods¹⁴. Such methods allow services users to input directly into decision-making practices, to consult directly with commissioners, or to design their own forms of PPI.

The PPI activities reported in this audit reflect a variable and often more basic ‘patient satisfaction’ approach, focused on issues such as waiting times, access and patient complaints about services^{10,11,13}. This is not to say that such approaches are not useful. Indeed, all of the organisations that used patient surveys did report PPI as leading to helpful changes in the type and nature of information provided to patients, to appointment systems and waiting times, and to the clinic environment. However, the dominance of this approach does mean that the service, rather than the service user sets the agenda, and that patients are often involved in feeding back about the logistics of service delivery, rather than in commissioning, decision-making, and policy. As evidenced by one of our audit participants, patient questionnaires are not always helpful, “*as (we) don't get their views on what is important, just what the organisation thinks is important*!”. In contrast, more ‘meaningful’ and engaging PPI methods are seen as having a greater impact² in the sense that they allow for the direct exploration of patients’ experiences of services, and also involves the transfer of power to patients, promoting a form of ‘citizen control’ that can drive up quality. Best practice PPI should be about the empowerment of participants, and may require extended community engagement (or collaboration) to aid in reaching non-service users and hard to reach/at risk groups.

Meaningful PPI takes time and considerable dedicated staff resource – both of which were described in our audit missing. Likewise, many services had concerns about a lack of training and a lack of understanding and awareness amongst staff around PPI (and the potential to get it ‘wrong’), this extended to specific PPI policies. Thus, while it was clear that PPI – and particularly more engaging PPI - was seen to be of considerable importance to services, the practical and supportive mechanisms that would enable this to take place were not always in place.

Many survey respondents reported a desire to feedback to services and yet cited a key barrier as embarrassment. Stigma and embarrassment are key challenges in securing meaningful engagement in this context. There are real challenges within SRHH services about levels of engagement that are possible to achieve, and the levels of engagement patients want to have in this context. Service attendance may involve particular life events that people may be reluctant to bring up (e.g. sexual assault/infidelity). Issues of confidentiality (and the desire for anonymity) often run at odds with plans to have patients be visibly involved. Indeed, the challenges of getting people to be involved in groups (as is traditional in other health settings) are well recognised by services and illustrated by the blanket refusal of our survey participant to joining such a group.

Some service users' understanding of the role of feedback seemed to be around criticism or that it would make no difference. It may be that they did not know why information was being collected or what it was used for, and that this significantly impacted on their decision to be involved. Likewise, many service providers had an understanding about the importance of PPI, but lacked a clear sense of the impact of PPI on their service, or what 'successful' PPI would look like in this context. What seems important from both service providers and service users is that a clearer statement about the goals of PPI in SRHH is needed to ensure engagement, to situate current and on-going activities, as well as to provide measurable, strategic and significant outcomes, against which to assess the effectiveness of PPI work.

Study Limitations

The representative nature of the proxy patient group is limited to that of a convenience sample of students. While this sample is likely representative of the sexually active student population, the sample is not necessarily generalisable to the range of diverse population groups who attend SHHH services, or to the wider general population of younger people. Their capacity to represent their own views to services was felt to probably be better than average. However, despite this, these respondents do provide insight into sexually active young people's experiences and views of PPI, which is very rare in the PPI literature. Crucially, they also provide both a service user and a non-service user perspective, and represent a more general population of sexually active young people, than perhaps current services users already 'through the door'. Future work hopes to address the PPI needs and preferences of specific user groups within the service with tailored contact methods

The service audit was undertaken at a time of service wide reorganisation, when roles/contacts were in flux. The audit attempted to take this into account, by ensuring that all services and levels of service in both old and new structures were contacted and represented at some level by the range of respondents. The range of reports was checked to ensure information from at all major providers, services and service levels. However, it was impossible to tie down a denominator for all services, and some commissioning-level responses included a cross service view. For this reason, sub analysis was felt to be unreliable.

Both pieces of work were carried out in 2013/14 during a time of service reorganisation, the focus on sorting out roles and responsibilities at that time may have pushed out room for wider PPI work and ever increasing emphasis on PPI may mean this snapshot of services has changed. The work of the researchers themselves via their programme of PPI work within Health Integration Team may also have increased PPI practice in SRHH since this work was completed.

Conclusions

This study underlines the difficulty faced by those trying to bring patient voice into sexual health services. Findings suggest that PPI work in this field is being attempted, but that these efforts may not be clearly perceived by the patients themselves; therefore, making current PPI more overt would be a clear improvement. Clarity around the identified aim of any PPI, not only to demonstrate both to patients what their involvement is for but also to enable evaluation to measure, by clearly identified impact data, the effectiveness of PPI and improve staffs' ability to see the value in PPI

From a patient perspective, findings suggest that anonymity and ease are central to the ways in which they made decisions about services, but also about how they would like to feedback into services. The challenge for services is therefore to develop a range of diverse methods, with anonymous and non face to face being particularly important in this context. This conclusion is supported for generic PPI work by the latest guidance from NHS England⁶. There seems to be much scope to develop more innovative ways of engaging patients – moving beyond the more traditional methods of patient groups and towards methods that allow patients to get involved in the ways that 'match' their expectations. The development of digital forms of PPI could help with this – at least for some patient groups – as it allows for patients to get involved in ways that are anonymous, easy and fast^{14,15}, and INVOLVE publish useful guidance¹⁶s. It also fits with changing priorities for collecting information from patients and service users in as near to real-time as possible so that results can be assessed quickly. This approach offers a clear opportunity for services to make improvements.

Trust, safety, confidentiality and anonymity characterise sexual health services, they therefore must also underpin patient involvement efforts in this field.

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Appendix A: Survey Questions

Q 1. What is your age?



Q 2. What is your gender?
Female/Male/Transgender



Q 3. What is your ethnicity?



Q 4. What is your sexuality?
Heterosexual/Homosexual/Bisexual



Q 5. Have you ever been sexually active?
Yes/No



Q 6. Have you previously used any sexual health services?

Yes - please answer questions
7-14

No - please answer questions
15-17



Q 7. Where have you accessed sexual health services? (tick all that apply)
University health service/GP/NHS sexual health clinic/Non-NHS sexual health clinic/Other

Q 15. Why have you not used sexual health services?
Not needed them/Not aware of suitable services/Other barriers-please specify



Q 8. What services have you used? (tick all that apply)
Information and advice/contraceptives/STI testing/HIV or AIDS testing

Q 16. Do you feel informed about sexual health services?
Yes/No



Q 9. Why did you choose this service?

Q 17. Do you think you are likely to use a sexual health service in the future?
Yes/No/Unsure



Q 10. How would you rate your experience?
1-Terrible/2-Poor/3-Average/ 4-Good/5-Excellent



Q 11. Did you let the service know what you thought about your visit?
Yes - please give details/No



Q 12. Is there anything else you would like to let the service know about your experience?
Yes - please give details/No



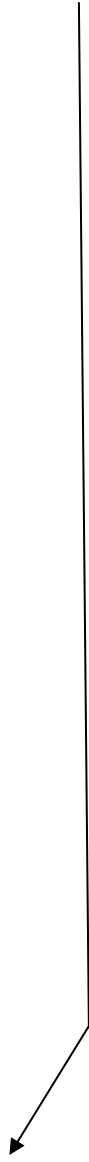
Q 13. What stopped you giving further feedback to the service?



Q 14. Have you got any suggestions of ways that services could help you to feel more comfortable in giving feedback?



Q 18. Is there anything else you would like to tell us about sexual health services?



_Appendix B. Audit questionnaire outline

Individual /Organisational details

Name individual lead on PPI?

Organisational PPI policy (if yes send copy)

External PPI collaboration

Which groups of patients working with and type and range/type PPI.
Rate success of engagement.

Rate usefulness of PPI
Results – direct change

Examples of useful and less useful practice (why)

Barriers to PPI in SRHH

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