Strengthening the public voice in shaping sexual and reproductive health services - Changing relationships

Executive Summary

1. Introduction

Patient and public engagement (PPE) comprises involving, consulting and listening to patients and the public, to make services responsive to patients' needs, improve clinical outcomes and patient experience, add value to services and support good governance. PPE is a key priority for the NHS, featuring in all recent policy drivers. One particular challenge for the NHS is to embed PPE in quality improvement initiatives, commissioning, decision making and contracting, through WCC, QIPP and CQUINS.

PPE presents particular challenges for sexual and reproductive health and HIV/AIDS (SRHH) services due to stigma and confidentiality issues, especially in London which has the highest UK prevalence of sexual ill-health. People at risk of poor SRHH are least likely to have their voices heard, particularly: ethnic minorities, young people, sex workers and those with mental illness, substance misuse problems and disabilities. One of the 2010 London Sexual Health Strategic Framework standards is to involve users in the design and delivery of SRHH services and measure service users' experience. Despite a long history of patient advocacy in HIV/AIDS, systematic PPE in SRHH is limited.

2. Aims and Methods

This project, commissioned by the London Sexual Health Programme, aimed to review current policy, guidelines and practice on PPE in SRHH and produce recommendations on how to effectively engage patients and the public in SRHH services in London in order to inform SRHH strategies. Four data collection phases were used: a literature review of 59 documents/journal articles/websites; an email survey of all PCTs in England; an online survey of 72 stakeholders; and in-depth interviews with 25 stakeholders including commissioners, managers, voluntary/community organisations (VCOs) clinicians and patients.

3. Key findings

A number of methods of PPE currently used in SRHH were identified; mixed methods were often employed. Levels of engagement (and frequency) ranged from fairly common 'one-off' consultations to collecting feedback (audit, surveys and comments boxes) and in-depth views (online, qualitative interviews, HIV user forums and participatory action research), to user-delivered/designed methods (mystery shopping, patient representatives, teen pregnancy peer education and peer interviewers in at-risk groups). More meaningful engagement, either with management (reps on committees, volunteer staff) or with policy/decision-making (users developing SRHH strategy or prioritising spending, leadership programs in HIV), was less common. Ideally methods were innovative, flexible, validated and user-designed. Twenty-nine examples of best practice in SRHH PPE were identified (detailed in main text).

PPE in SRHH was often driven by policy, as well as answering clinical questions such as effectiveness of sex education or reasons for late testing for HIV. PPE driven by patient-centred values of an organisation was less common, most frequent in HIV services. The most significant challenge was organisational commitment, and associated lack of dedicated staff, time and money. The second most important barrier was lack of patient motivation; particularly avoiding only engaging 'passionate', 'vocal' 'volunteer types', for example HIV advocates, rather than at-risk groups such as men, older people, ethnic minorities and those with disabilities. The absence of an ethos of customer satisfaction in the NHS was another key barrier. Provision of information to patients/public, including factual information on SRHH, raising awareness of PPE opportunities, feeding back results of PPE, and training for PPE was felt to make PPE less tokenistic, more sustainable and address stigma. PPE was often associated with existing community engagement such as public awareness campaigns (e.g. on causes and treatment of HIV/AIDS), health promotion, leadership initiatives (e.g. Africans living with HIV), peer education (e.g. on teen pregnancy), and patient advocacy (e.g. facilitating direct contact between the public and decision makers such as YP and MPs). The stigma of SRHH, especially for ethnic minorities, was a barrier to PPE, although this was given less priority than organisational and motivational barriers. Using VCOs' expertise and their membership base was a predominant method of engagement, including churches, schools, youth clubs, local councils and health forums.

PPE can improve patient satisfaction, increase service uptake and reduce inequalities, all key priorities in SRHH. In addition, PPE can identify innovative ideas for service delivery and challenge knowledge and guidance based on theory and management.

4. Recommendations

Although the following recommendations emerged from the data, many are not specific to SRHH, but apply to PPE in all health sectors. The key recommendations for those designing PPE activities are:

- Use PPE approaches which avoid tokenistic involvement and promote meaningful engagement by obtaining in-depth views and integrating these into service planning and by providing incentives. Ensure methods are convenient and easy for participants.
- Consider using user-designed, and even delivered, methods to give ownership and encourage participation.
- Empower participants rather than ‘using’ them, e.g. by providing them with the skills and confidence to be involved.
- Actively involve non service users and hard to reach/at risk groups, through collaboration with VCOs, providing incentives, and using peer researchers.
- Use methods with important, measurable, strategic and significant outcomes, e.g. informing NHS resource allocation or policy, as well as practical changes such as clinic opening hours or location. Outcomes should have a demonstrable impact and be based on patient priorities.
- Ensure that participants are informed of the results of their engagement and are able to participate in further PPE.

Organisational recommendations are:

- Engage the community to help overcome stigma by working with self-management programs, community organisations and religious leaders and using peer education and leadership training.
- Link PPE with existing drives towards self-management and patient centred care.
- Develop an organisational policy specifically on PPE in SRHH.
- Provide training and information for staff at all levels, and dedicated money, resources, staff and time to develop organisational commitment.
- Systematic PPE needs to be the norm for every service, with an associated change in ethos or a ‘culture shift’ where PPE is embedded at all levels, including commissioning, decision making and policy and not just in logistics of service delivery.
- Use the expertise of colleagues and other sectors where customer service is implicit.

Recommendations for potential future work in this area include:

- Systematic scoping of policies, guidance and practice related to these recommendations.
- Exploring development of an audit tool to measure the impact of PPE in SRHH.
- Training/information packages on PPE in SRHH, for both staff and patients/public.
- Establishing a network for sharing of best practice in SRHH PPE.

There is now a need to determine how these recommendations apply practically to SRHH services in London, in particular guidance on methods, processes and standards, building on best practice rather than ‘reinventing the wheel’. A short life strategy working group will be convened consisting of stakeholders to develop a strategy to practically implement the recommendations, identify outcome indicators and potential training needs.

5. Conclusions

This project has identified barriers to PPE in SRHH but has also found evidence of tremendous will, belief in and commitment to PPE in SRHH, as well as numerous examples of excellent projects striving to overcome these barriers. With further effort to use creative methods and embed PPE in organisations, PPE can be used to create innovative, high quality SRHH services and save costs by improving access, as well as tackling stigma through community engagement.