

INTRODUCTION

Sexual and reproductive health and HIV services face unique challenges around accessing patient experience.

We have taken a multi-dimensional approach to this challenge, including auditing PPI (Patient and Public Involvement) in sexual health services, surveying potential patients around their experience of PPI in services. We are now building on this through specific targeted work with different groups to establish the diversity of need and experience.

Current PPI often centres on patients who are happy to be identified. Sexual health services are unique due to the circumstances that lead to attendance which require assurance of anonymity and confidentiality. Patients often access services sporadically, due to a crisis or risk behaviour. This can generate feelings of shame or embarrassment (1,2).

A first step to build upon current PPI guidance in sexual health (3,4,5,6) was to begin building an evidence base through a snap shot audit of current practice in the region and to compare that with patient's reported experience of PPI.



Design

Mixed Methods.

Audit

Sexual, reproductive and HIV services in the Bristol region were sent an audit questionnaire 8-11/2013 requesting details of PPI work and policy but also asking for goals and measures of PPI success. Respondants were from services, primary care, commissioners and charities.

Survey

n = 96 participants from UWE responded to an open call to N= 500 students and snowballing of contacts and completed an anonymous online questionnaire. Mean age = 23.5, all had used services. 89% hetero, 5% gay/lesbian, 5% bisexual.

Results

Audit

VARIABILITY - there was very different practice across services, many reporting no PPI policy and use of minimal 'patient satisfaction' approaches.

TRAINING - 8 of 10 services responding offered PPI training.

GOALS - many had not conceptualised what PPI was for, often conflating PPI for research and service delivery.

METHODS - responsiveness and innovation were undermined by standardised 'NHS' approaches to PPI.

Survey

Only 3 respondents had ever given feedback to sexual health services they used, 20 had wanted to, 13 with positive comments.

30% reported not being asked for their feedback and 40% did not want to give any feedback.

None, no one. 0 agreed to take part in further research.

Results reported in Meyrick et al (2016)([7])

Why

Trust is key to being open about risk behaviour, sticking with treatment and comprehensive partner notification. Those with the greater burden of ill health are often the hardest to reach. Putting patient voice at the heart of services may reduce barriers.

How

Don't ask if you don't want to know
- be clear about what PPI is for and what it can or cannot change.

One size does not fill all
- different groups may want different things
- a range of methods should be offered.

Measure the difference it makes
- have a theory of change for the patient sharing and for the service listening.
Use this to find theory based measures of impact of hearing and listening.

Patient Involvement in Sexual Health Service Delivery

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



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



Conclusions

- Services should aim to gather good quality data from a representative sample of patients using a variety of methods.

- Services should have a clear theory of what PPI data is for, evaluate its' success in reaching those goals and evidence its' impact on services and patients.

- a variety of methods (including online) should be offered and tailored for different groups with a focus on anonymity.

Research Directions

Vulnerable Groups

Research has begun around the particular needs of patients within a Sexual Assault Referral Centre as they represent a vulnerable group. Other groups for which research funding is being sought are women undergoing Termination of Pregnancy and Black and Minority Ethnic Men who have sex with Men (BME,MSM). These groups have been chosen on the basis of need and anticipated difference in contact preferences.

Experimenting with contact methods

A range of innovative methods need to be tried out with different groups of patients using sexual health services, online and anonymous contact methods in order to secure more representative samples.

Theory based outcome measures

The impact of PPI work should be measured to evidence its' impact both on services and patients. Such impact data should be grounded in theories of how the process works and theoretical approaches to PPI are fundamental to our ongoing research aims within a health psychology approach.

References

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- [7] Meyrick, J. Gray, D. & Jones A. (2016) Assessing the possibilities and challenges of patient involvement in sexual, reproductive and HIV/AIDS services. *Sexual Health* 13(3) pp 213-220.

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