



Beyond consultation: a guide for health commissioners

How staff and service users can work together to improve health services

Acknowledgements

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Naz Project London provides sexual health and HIV prevention and support services to selected black and minority ethnic communities in London, see www.naz.org.uk

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An effective engagement process can reveal the hidden reasons why seldom-heard groups are reluctant to use health services.

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Real engagement is the result of investing time and resources. Here, Robin Vincent of Panos London hears the concerns of service users.

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Engaging not consulting: introduction

‘My GP used to mark any of my test results – like even my eye test – with HIV, regardless of whether it was relevant. I spoke to him about it and now he doesn’t do it. I wouldn’t have known to question this without Beyond Consultation.’

**African female
service user**

This guide suggests different and practical ways for health commissioners to encourage real engagement between service users and staff so that health services can adequately address the needs of seldom-heard groups. The guide provides lessons from previous experiences of work in this area and outlines key steps in an effective engagement process.

Bringing service users and health staff together to shape and improve services and to identify and test practical changes is no easy task, but it is a valuable process. If you commission health services or work directly with service users, you understand very well the challenges of working with constrained resources in a changing NHS landscape. Effective engagement between staff and service users can lead to more relevant services, greater uptake of services and ultimately better value for money. The process can turn service users from being passive to active in their healthcare choices and encourage them to better maintain their own health, which can in turn improve health outcomes.

Engagement with health service users to inform health services is also a statutory requirement that is reflected in the NHS Constitution. The NHS wants service users (including seldom-heard service users) to take more responsibility for their healthcare. Such changes can be encouraged by engaging users to shape services.

Key principles outlined in the NHS Constitution include:

- NHS services must reflect the needs and preferences of patients, their families and their carers (principle 4)¹
- The NHS is accountable to the public, communities and patients that it serves.²

A good engagement process can result in practical changes to make services more relevant and better used. It also builds the confidence of service users to articulate their own experiences and priorities. Done well, it can strengthen working relationships between service users and staff, providing the basis for more fruitful and longer term engagement.

Engagement can support positive changes in health services so that:

- Services such as sexual and reproductive health and HIV services become more responsive, relevant and better used by seldom-heard groups
- Seldom-heard groups become more confident and able to convey the issues that affect them
- Staff members have opportunities to articulate their own concerns, issues and constraints and reflect on how to address them
- Mutual understanding and trust between staff and service users grows. This can lead to increased uptake of services
- Sustainable links between service users and health staff are established, which helps ongoing service improvement.

¹ NHS (2010) *NHS Constitution*, p6, available from <http://bit.ly/pNEV08>

² *Ibid*, pp6–7. See also: UK Department of Health (2010) *Healthy lives, healthy people: our strategy for public health in England*, available from <http://bit.ly/pNEV08> and National Institute for Health and Clinical Excellence (2008) *Community engagement to improve health*, available from <http://bit.ly/zNfsDI>

About this guide

This guide is one output from an engagement process designed and piloted by Panos London and Naz Project London. The project, Beyond Consultation, brought together African women, African men who have sex with men and staff from sexual health and HIV services in South East London. The three-year project aimed to improve the uptake of sexual health and HIV services by African migrants living in South London by enabling them to consider, discuss and address their concerns and priorities with staff from NHS services.

The project tackled concerns around the confidentiality of personal information, insensitive questioning during health consultations and service users' reliance on doctors to provide letters to support their housing and other social needs. The aim was to increase overall use of services and ultimately improve health outcomes. You can read more about this project and its outcomes at www.panos.org.uk/beyondconsultation

Many of the lessons and practical examples in this guide come from the Beyond Consultation project and are included to illustrate how an effective engagement process is put into practice. The steps of engagement included here are designed to encourage genuine participation and engagement between staff and service users. They have wider relevance and application in encouraging service users to take an active role in their health and shaping health services. For each step there are questions to guide decisions, useful practical methods and tools, and potential challenges.

If you wish to read more, there are links to relevant resources alongside specific sections.

Moving beyond consultation

‘Taking pictures helps to look at things differently and bring out new issues... We can express ourselves in other ways than talking – there are better ways to get things across, like with drawing and pictures.’

African female service user

The Beyond Consultation project was designed to encourage genuine engagement between staff and service users, particularly seldom-heard groups. The aim was to move beyond traditional consultation such as questionnaires and occasional public meetings to a much deeper process of engagement. The project piloted approaches which brought together health staff and service users, allowing service users to articulate their perspectives, experiences and priorities in ways that suited them.

The following points are drawn from this project and previous experiences of trying to stimulate engagement processes in health services.

Listen to service users

The expertise of service users is essential in engagement processes. They bring knowledge of the patient experience within the service and can identify how their experience may be shaped by factors beyond the service. Service users may have their own distinct priorities which are different to those identified by health professionals.

An open approach to listening to service users builds mutual respect and trust. The process can highlight issues or misunderstandings that impede service effectiveness and can introduce new ideas for improvement. This contrasts with consultation processes that start from the perspective of the service and limit engagement to an agenda based on professional understandings and clinical needs.

Use a range of methods to be as inclusive as possible

Creative methods help service users to identify and articulate their experiences, meaning staff can explore beneath the surface of common problems. Together, they are able to look at experiences in new ways and understand underlying causes. Methods might draw on different media such as drawing, role-play or storytelling, which can be powerful ways of engaging people who are not confident in group discussion or writing. A mix of individual and collective work allows everyone to contribute, agree priorities and identify common and current issues.

Managing health is an emotional experience so methods should take into consideration both how people feel and what they think. This approach is different from written consultations or public meetings that inevitably exclude particular groups who may not feel confident or able to take part.

Engage with staff as well as service users

Health staff members have experience, expertise and concerns that are invaluable in improving health services. Involving staff early in the process and employing the open, inclusive and mixed creative methods also used with service users can encourage staff insights and knowledge about services and practical constraints. It is effective to conduct this work in parallel groups, bringing staff and service users together once they have had the opportunity to reflect openly on their own experiences.

More traditional consultations tend to follow a model where the health service or NHS trust defines the issue and asks service users to comment. Later, staff members at different levels are expected to address this feedback to improve the service. This is a less interactive and responsive process that can overlook vital staff input.

Work together for change

When staff and service users talk to each other and work to develop understanding and trust, they are able to pool their collective knowledge and make improvements to existing services. Identifying how these services can address key challenges is helped through a mutual understanding of the many factors that influence service users' health and their access to services. Such collaboration helps to identify and test practical changes and importantly it builds relationships for future collaboration.

Emphasise 'live' rather than representative issues

Working with a group of service users and staff on immediate concerns relating to their lives and work can lead to small practical changes. When people work to find practical solutions for immediate problems, trust and the motivation for further engagement becomes stronger. Rather than conducting a large 'representative' survey of issues, this approach focuses on building a robust involvement process over time, providing the potential to tackle a range of further issues.

Service user engagement takes time and needs flexibility

Ideally engagement should be integrated into services, with a commitment to working with service users over time. Longer-term engagement can build service users' confidence and encourage them to feel comfortable articulating the issues that matter to them. They should be able to express their own concerns, and not just respond to consultations on existing services. They might also be motivated to enquire further into practical solutions for the issues they identify.

Processes need to be flexible to accommodate these factors. This demands time and resources plus the ability of staff and commissioners to listen, respond, and adapt plans and schedules when needed. It may be a challenge to work in this way given the institutional and financial constraints of the NHS but investment in building longer term engagement leads to more relevant and effective services in the long run, as well as meeting statutory requirements.

Outline of steps in an engagement process

An effective engagement process works through the stages outlined below. These stages can be adapted to become a cyclical and ongoing process over time and be built into commissioning and service reviews for continuous improvement.

Steps in an engagement process	Description
Planning	Decide which groups your engagement process is going to include, over what period of time and with what resources. Consider ethical implications (see page 9) and any exit strategy
Evaluation and learning plan	Build evaluation and learning into the process from the planning phase and address it regularly throughout, so you can track important changes and make improvements as the project progresses
Recruiting service users and staff	Recruit service user and staff participants, ensuring the engagement process fits with their availability and needs
Prioritising issues	Use a range of alternative and creative methods to help service users and staff (initially in separate groups) to identify, explore and convey key issues. Produce materials to share these findings with other groups as a basis for cross-group dialogue (see page 13)
Cross-group dialogue	Bring together service users and staff engaged in the project and a wider group of staff and service users, to review materials and issues and identify systemic issues that can be addressed
Peer enquiry	Support staff and service users to reach out to a wider network of their peers to test assumptions, or to look deeper into opportunities for practical change.
Collaborative design	Bring staff and service users together to make and test practical service changes
Sustainability (and project exit strategy)	Link the project, networks and relationships into broader public and service user engagement processes

Planning

When planning an engagement process, consider:

- ethical issues
- the scope and timescale of the engagement
- which groups of service users and staff to involve
- who will manage, facilitate and evaluate the process
- how issues emerging from the process will be recorded and managed.

In addition to the collaborative work between service users and staff that is central to any engagement project, there will be opportunities to feed emerging issues and insights into other planned consultations and service reviews. Even with limited resources, engaging even a small number of service users in a meaningful way can generate important insights to improve services.

Ethical considerations

Engaging service users raises a number of ethical concerns. Commissioners and staff should discuss ethical guidelines clearly at the outset and then revisit them throughout the process. Clear agreements are needed for how people engage with the process and how any materials produced (posters, meeting notes, videos and so on) are shared and attributed.

The following are of critical concern:

Consent

Participants need to consent to participating in the engagement project and associated activities. This should be informed consent: the extent and implications of taking part should be made clear before consent is given.

Materials produced that include personal perspectives or images of individuals should only be used with the informed consent of participants. This should be given separately to consent to take part in the project as a whole.

Confidentiality

Respect for confidentiality is key. The default position should be to keep all participants' identities confidential unless they agree otherwise. Steps should be taken to make sure materials produced during the project (for example meeting notes, posters or videos) are anonymous where required.

Referral arrangements

Individual participants are likely to raise issues that need referring to relevant services or expertise. The project should be prepared to respond to these issues and have referral arrangements in place.

Respecting people's time

Engagement can make considerable demands on people's time over an extended period. All parties should take responsibility and have mutual respect for each other's time commitments. Clarity about the commitment being made, what expenses will be covered and the potential benefits for both individuals and groups is important.

A commitment to participatory monitoring and evaluation means taking the time necessary to work with participants to ensure they understand the project process and involve them in generating indicators and monitoring the project.

Flexibility in planning and delivery

It is always necessary to adapt objectives, timetables and working processes to respond to participants' needs, rhythms of life and work so they feel comfortable with working methods. The project may not be able to pursue the fixed timetable often expected in project planning and management.

Managing expectations

While the aim of the engagement project is to make practical changes to improve services, people need to be realistic about what can be achieved during a particular timeframe. It is particularly important to avoid raising the expectations of service users.

Checklist

Scope and timescale

- 1 Decide if the engagement process is to be integrated into the management of a service, or if it is a one-off process connected to a review or restructure. If the latter, plan an exit strategy or consider building partnerships with other organisations, to provide continuity.
- 2 Find out what resources you have available.
- 3 Decide how the project will:
 - involve and recruit service users and staff
 - manage a series of meetings to identify and communicate issues
 - recommend changes to services.

Who to involve

- 4 Assess which groups are not being reached by the service you are reviewing, and therefore need prioritising.
- 5 Identify how you will know whether you are successful in reaching these groups.
- 6 Identify who needs to know about the project as it progresses. For example, what kind of staff you need or want to involve (clinical, support, commissioning and/or managerial).
- 7 Decide who will manage, facilitate and evaluate the process (in-house or with external support such as trainers and facilitators).

Useful methods

- 1** Recruit an advisory group with expertise and insight into both the service user and staff groups you will work with and the networks and contacts your initiative can draw on.
- 2** Develop a clear plan of the process and a sense of the methods, tools and resources required over a defined timeframe. Be prepared to be flexible and to adapt the process to the group's ways of working and issues that arise.
- 3** Plan the evaluation at the start of the process and involve project participants in deciding on criteria for/indicators of success (see next section).
- 4** Keep others informed about the engagement process through, for example, a website or blog where updates and materials can be shared. Updates can also be shared through text and email updates.

Challenges

People's experiences of health and the factors that affect their health may go much wider than the focus of particular health services. The results of the engagement process may highlight social problems which are beyond the scope of health commissioners. Emerging findings from the project will likely have relevance beyond the immediate services in focus, so links with relevant support organisations are worth developing.



Relationships are key to the success of an engagement process. Involving participants in evaluation can help to improve its quality
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Learning and evaluation

Evaluating engagement projects means looking at their practical impact on services and the quality of the engagement process itself, including relationships built between service users and staff. Decide which evaluation methods you will use at the beginning of the project and adapt indicators with project participants.

Checklist

- 1 Decide how you will show the impact of the engagement process on services.
- 2 Agree the best ways to capture the quality of the engagement process and its potential for supporting further service improvements.
- 3 Identify who will do the monitoring and evaluation.
- 4 Assess regular opportunities for monitoring and reflection throughout the project.

Useful methods

- 1 Look at services before and after the engagement process to assess relevant practical changes that may increase service user uptake or service improvement. Assessing or adapting existing user surveys may be helpful in this.
- 2 Evaluate staff and service users' experiences and perceptions of their participation in the process and how this changes over time. To what degree, for example, did they feel they shaped the topics under consideration and the agenda for change?
- 3 Track changes in relationships and networks between service users and staff, and between the project and other organisations involved in the issue. Such relationships can be important to building project sustainability and influence. Network evaluation tools can help to identify evolving relationships and how these contribute to changes in practice and behaviour (for more on network evaluation tools see www.mande.co.uk/special-issues/network-models/).
- 4 Regularly monitor and document activities to support potential improvements to the project and responses to issues as they emerge. Such documentation can also form the basis for lessons that can be shared with others who work with engagement processes.

Evaluating the experience of participation

Beyond Consultation adapted the use of 'most significant change' stories to understand the impact of the project, including service users' perceptions of participation (for more information on most significant change, see <http://mande.co.uk/special-issues/most-significant-change-msc/>).

African women involved in the Beyond Consultation project gave personal accounts of changes brought about by the project. From these, the group identified a number of changes that were important to them. The kind of changes identified included: being listened to by NHS staff, improving their own communication skills, having more confidence, and the ability to draw on support from other project participants. Stories of change in these areas were gathered at intervals throughout the project and helped to convey and demonstrate service users' changing experiences of participation.

Challenges

Monitoring and evaluation often risks being neglected in the push to get on with project activities. Early on, it is important to involve the participants in developing indicators for the changes they would like to see. Collectively, you should find manageable ways of documenting progress against these targets as the project goes along, all of which takes time.

Even if project managers have a good idea of what they want to evaluate, working with service users and staff on the evaluation plan at the beginning of the project can add new insights. The sense of ownership this creates is important for honest evaluation and learning.

Recruiting service users and staff

Do not underestimate the time and effort needed to recruit participants. At an early stage, identify appropriate service users and staff and ask them to commit to participate for the duration of the project. Find ways to involve them that accommodate their life and work demands and which keep them engaged and interested. When you recruit service users, think about how best to organise their engagement. For example, it may be appropriate to work separately with men and women or with different age groups.

Checklist

- 1 Find out how you can best reach the people you want to engage (both staff and service users).
- 2 Identify existing networks, organisations and spaces through which individuals and groups can be reached.
- 3 Decide how to convey the aims of the engagement process.
- 4 Be clear about what you think individuals and groups of service users could get out of the project.
- 5 Identify existing opportunities and initiatives for staff to engage with service users.

Useful methods

- 1 Identify existing groups and organisations with a track record of working with the service user groups you are interested in and seek their support in recruiting participants.
- 2 Identify existing patient engagement initiatives and staff who are committed to working on patient engagement.
- 3 Develop a clear, one-page description of the project. It should outline what service users and staff will gain from engaging as individuals and as a group.
- 4 Take time to go and talk to people as well as using a variety of communication channels used by different groups (texting, social media, leaflets etc).
- 5 Ensure participants understand what commitment is expected and what expenses or other support is available.

Challenges

Identifying and recruiting participants might be difficult and could take considerable time at the inception of the project. Recruitment needs to be done carefully. When recruitment draws on participants engaged in existing initiatives, you will need to recognise their existing time commitments and understand how their ability to engage may be affected by their prior involvement.

Service users already linked to organisations and initiatives will not be the most marginalised, but you have to start somewhere. Successive rounds of the engagement process over time may allow you to engage a wider range of participants, building on the networks and trust developed over the course of the project.

Participants may not be a representative group in scientific or epidemiological terms but they can bring a range of experiences and backgrounds to the process.

Finding participants through existing networks

The Beyond Consultation project focused on sexual and reproductive health and HIV services. Stigma and discrimination limited the number of African men and women who were ready to be open about their HIV status or sexuality and therefore willing to participate in the project. Building on existing relationships and trust developed by Naz Project London (NPL) and the African Advocacy Foundation (AAF) was central to finding willing participants.

Different approaches were needed to recruit African men who have sex with men and to recruit women. Young men from an existing NPL project were invited to take part in Beyond Consultation. Although 10 men volunteered to join the project it was difficult to find consistent meeting times that suited the group. When the other project ended, their involvement in Beyond Consultation dwindled.

It was initially more difficult to recruit African women, until AAF invited women from their existing support group for Africans living with HIV. The women who joined Beyond Consultation had more consistent and sustained involvement and were more ready to take on responsibility for work in the project. It helped that meetings were initially held on the same day and in the same place as their existing support group.

Recruiting staff for the project began with key enthusiastic individuals, but constantly hit the difficulty of staff time and availability. Much more time had to be invested in reaching out to individual staff to draw them into the project.

Prioritising and communicating issues

‘It was a good experience to learn about ourselves with drawings – to reflect on our background and understand it.’

African female service user

Creative methods help participants to build confidence and trust, explore and reflect on their experiences and start expressing the issues that are important to them. Methods such as drawing or role-play can unlock experiences and perceptions in a way that gets behind received wisdom or the usual way of talking about things.

Producing a range of communication outputs – posters, photos or short films – can then help to capture experiences and concerns in a way that conveys them to others more easily. Service users and staff work separately at this point, but the outputs subsequently provide the basis for better understanding and dialogue between staff and service users.

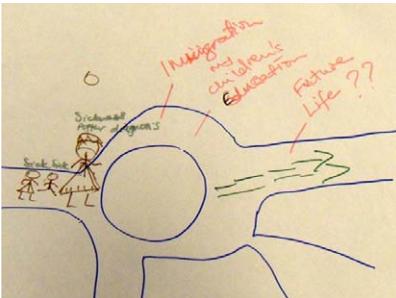
Checklist

- 1 Select methods that will help:
 - each group build trust and feel safe to convey their experiences
 - to identify issues from people’s experiences
 - to collectively prioritise issues
 - to produce materials about key issues to share with others.
- 2 Pursue an open approach that listens to people’s personal concerns and life context, as this can reveal unforeseen barriers to maintaining good health, as well as barriers to accessing health services.

Useful methods

- 1 Use trust-building exercises to help individuals gain confidence and build group rapport.
- 2 Start with service users’ or staff experiences of health and support, drawing out the factors influencing their health and wellbeing over time. These will go much wider than the particular health issue and services in question but will be a useful starting point.
- 3 Get an understanding of users’ knowledge of services to identify issues of awareness or barriers to access. You could use a service mapping exercise to ask users to list all the services they are aware of, those they use, and their experiences and perceptions of those services. See www.panos.org.uk/bccommunicating
- 4 Look at the micro level of what happens when services are used to identify issues. Drawing exercises can be particularly useful to explore personal experiences and form the basis of further group discussion to identify common challenges. See box overleaf.
- 5 Use a similar range of creative methods with staff. Start with their experiences of challenges, constraints and successes in providing services for the service users involved.
- 6 Move from individual experiences to collective agreement on priority issues that the group will work on together. Consensus building exercises can be useful here. See www.panos.org.uk/bccommunicating

- 7 Explore these priority issues further. Methods such as a 'problem tree' can examine a range of factors, the causes behind them and also the consequences. See www.panos.org.uk/bccommunicating
- 8 Once issues have been explored in detail, support participants to depict their concerns and experiences through creative communication methods such as photographs or short films. Captioning photographs, making posters of quotes and images, making digital or audio stories can capture experiences and be used as the basis for further cross-group dialogue.
- 9 Provide training to service users and health staff who may have different levels of familiarity and skills with communication tools. Encourage participants to help each other develop and share skills.



Building trust through sharing experiences

In the Beyond Consultation project, service users were asked to draw their life experience as a road. Using symbols of junctions, signs and other road metaphors, they highlighted key moments that had an impact on their sexual and reproductive health. This allowed people to get to know each other, build trust and situate their sexual and reproductive health needs in the broader context of their lives and relationships.

Participatory photography

The Beyond Consultation project used participatory photography to help capture and convey issues that arose during the project. Participants received digital cameras and some basic photography training. They discussed the prioritised themes and planned and took photographs for the project over several weeks.

Project facilitators and participants reviewed and discussed the photographs and developed captions for them. Some photographs were used to produce posters with quotes or captions from the participants about themes such as medication or a clinic visit. Some were used to make digital stories. See examples of posters and digital stories at www.panos.org.uk/bcresources

Challenges

It is important to avoid trying to present a definitive or representative picture at this stage of the project. This stage of the process is designed to open up and explore experiences to promote discussion.

Posters and films can be misunderstood as advocating for a particular issue, rather than conveying experience in order to promote discussion, so they need to be presented and disseminated with care. In addition, individual identities may need to be protected when developing materials, in particular films and photographs. It is worth revisiting discussions about where materials can be used and to discuss and agree consent processes.

Cross-group dialogue

After working separately (but in parallel), bring service users and staff together to share and explore issues, build mutual understanding and identify possible practical changes. A larger group of health stakeholders should then review the issues raised to see which resonate with them, to both validate the issues and add further insights.

Multi-stakeholder dialogues and system-mapping build on the experiences of all the participants and enable broader perspectives and reflection. The aim of this step is to see how the issues relate to the different people present, rather than looking for a representative or complete picture. This helps to highlight opportunities for practical change emerging from people's daily activity, and identify the constraints that affect health and health services.

Checklist

- 1 Share the materials produced in the previous stage.
- 2 Analyse which issues resonate across the whole group of service users, staff and health stakeholders.
- 3 Assess what is causing and driving these issues.
- 4 Identify opportunities to make practical, positive changes to health services.
- 5 Seek out additional perspectives from people not involved in the project to broaden understanding of the issues.
- 6 Identify where existing services can take account of these wider needs and where they cannot.

Useful methods

- 1 Hold a 'dialogue day' to bring together service users and staff who have been involved in the process with a wider group of service users and health stakeholders. Together they can review what the project has found and reflect on these findings.
- 2 Gather all the materials produced so far, and allow the larger group of participants to review them. Include any quotes, audio recordings, posters or collages, digital stories and short films.
- 3 Draw a 'system map' with the assembled participants to identify priority concerns and their causes and consequences. Begin to identify who and what may need to change to address them (see overleaf). See www.panos.org.uk/bcdialogue

Using a system map to investigate key issues

Working with staff, service users and other stakeholders, the system mapping process in the 'Beyond Consultation' project began with concrete experiences of sexual and reproductive health and HIV services. Exercises helped participants view problems as being part of a system. The process explored how social issues previously identified by participants affected service users' experiences and the practical concerns of staff.

The importance of GPs and consultants providing support letters for immigration or benefits claims was one concern raised during this process. The issue of continuity of relationships and trust with healthcare professionals emerged strongly. Also stressed was the need for better two-way communication around appointments and health needs, and greater appreciation of the costs of transport and telephone calls for many service users.

Challenges

Mapping requires expert facilitation to manage the range of confidence levels and communication styles of the group and to navigate the issues that emerge in discussion.

Peer enquiry

Up to this point, the engagement process has built a picture of priority issues for service users and staff. Further detailed information and experiences are needed to identify concrete opportunities for change.

Peer enquiry is a way to gather a bigger pool of experiences and stories. It helps to understand the range of different life circumstances that affect people's health and access to health services. It is also an opportunity to test assumptions and gather further detail. Reaching out to a wider network through service users and staff can extend the project to people who are otherwise unwilling or unable to engage in the process. Various methods and communication channels (texting, interviewing, online surveys) can help to reach different people.

Participants will need support and training to conduct peer research. An accessible introduction and guide to the ethics of doing research is useful. See www.panos.org.uk/bcenquiry

Checklist

- 1 Identify with participants what else you need to know about key issues.
- 2 Decide who else you need to talk to, in order to address the gaps and get a good picture of each issue.
- 3 Assess how best peer enquiry methods can be used to gather experience from people who would not otherwise engage in the process.

Useful methods

- 1 Support participants to talk to their peers and contacts to gather more information and experiences on key issues.
- 2 Methods could include interviews, diaries of activity, online surveys or text messages to feed back experiences of services or regular appointments. See www.panos.org.uk/bcenquiry

Peer inquiry on confidentiality

The Beyond Consultation project supported African women living with HIV to interview their peers. Together, service users and staff developed a set of questions about how personal information is – and should be – kept confidential. The project developed guidelines to help them introduce, document and conduct the interviews. The service users practised interview techniques and audio recording. Collectively they agreed how to identify interviewees to extend understanding of the issues. Then each participant interviewed at least two other people.

Challenges

It is important to preserve direct insights and experiences, even if these appear to be misunderstandings or incorrect. Distilling the material or summarising too much can take out richness and detail; this is needed to provide a good basis for collaborative design discussions. **Furthermore, it is useful to document misunderstandings and misapprehensions as addressing them may be key to improving service uptake.**

Collaborative design

‘We might think that being open and direct in our questioning is helpful to someone, but if you come from somewhere where being open is not acceptable, then is it right for us to ask these questions?’

Health advisor
NHS

After detailed information has been gathered through peer research, mixed groups of staff and service users should work together to review findings. Their aim should be to identify potential areas for change and decide which changes to pilot, test and review. Having service users and staff work together helps to manage constraints and opportunities on both sides and means changes are much more likely to be effective and sustainable.

Changes to health services can take different forms. Service users and staff might work together to design information or training materials to help address misunderstandings or deepen understanding about cultural or other issues. They might devise changes to reception arrangements to reduce waiting times. Or they might revise how sensitive questions are asked during consultations.

Checklist

- 1 Assess what the peer enquiry has revealed about options for practical changes.
- 2 Identify which changes the group will work on together.
- 3 Work together to detail what those changes involve and what their implications might be.
- 4 Identify who needs to be involved in trying out the suggested changes.

Useful methods

- 1 Hold a one-day dialogue event to bring together service users and staff to review findings from the peer enquiry and identify achievable changes. Prioritise ideas of how to bring about practical changes and decide who can work together to try them out.
- 2 Create smaller sub-groups or working groups that can work out the detail of the suggested changes. Decide who needs to be involved and agree how to test practical changes.
- 3 Organise a multi-stakeholder review event to bring all the participants back together. People can review piloted changes and consider together what may be needed to further the work. They can also address new emerging issues.

Challenges

Once some practical changes have been identified, the staff involved will need to negotiate how and when the changes can be tried out. This negotiation may take some time.

Deciding on the practical changes will inevitably be a balancing act between issues and priorities raised by service users, those raised by staff, and the type of changes possible within current services and constraints.

The experience of making changes can help to identify further improvements or other possibilities for collaboration, rather than always being an end in itself.

Sustainability

‘Some of these issues have come up before, but it makes such a difference hearing directly from service users about the detail of their experiences and what it really means to them.’

Health advisor
NHS

Engagement is not just about making practical changes. An engagement process aims to increase the confidence and motivation of service users, as well as improving relationships between service users and staff.

Sharing project lessons about useful engagement methods is helpful to others – trust and relationships built during the engagement process provide the basis for further work on a potentially ongoing basis. Where possible, a project’s work should be linked to existing public engagement structures. Further cycles of collaborative mapping and design may form part of ongoing service improvement.

The communication materials developed throughout an engagement process may appeal to other health staff who were not involved in the process and can provide useful awareness-raising and training materials.

Checklist

- 1 Identify how the work of the project can link to existing service user engagement structures.
- 2 Explore opportunities for further collaboration on issues the project has raised.
- 3 Identify sources of funding and resources in order to continue similar work.

Useful methods

- 1 Create a list of contacts during the engagement process, so that staff and service users can remain in touch for future collaboration, even in the absence of resources for continuing the project.
- 2 Gather communication materials developed throughout the project on a website (subject to ethical considerations and confidentiality) so that external people can access key information. A selection of the materials could be used to support training and awareness-raising among other staff. Materials produced during the Beyond Consultation project can be found at www.panos.org.uk/bcresources
- 3 Run the project process in repeated cycles to look at successive issues and opportunities for practical changes with a gradually widening network of staff and service users.

The value of personal accounts for staff training

The Beyond Consultation project took audio stories and short films about stigma to share with staff at a hospital clinic as part of training. Staff found the personal accounts very compelling. Two members of staff said that they would approach their consultations with people coming for testing very differently after hearing a young man’s account of being upset by insensitive questioning.

Challenges

Identifying funding to continue and expand the engagement process before the project cycle has finished can be difficult. However, it is worth pursuing as it allows each engagement cycle to build most effectively on the previous one, in terms of contacts, relationships and shared understanding of the issues. If the engagement process is not to be continued, an exit strategy needs to be developed.

Beyond consultation: a guide for health commissioners suggests practical ways for health commissioners to encourage real engagement between service users and staff so that health services can adequately address the needs of seldom-heard groups. The guide provides lessons from previous experiences of work in this area and outlines key steps in an effective engagement process.

Effective engagement between staff and service users can lead to more relevant services, greater uptake of services and ultimately better value for money. The process can turn service users from being passive to active in their healthcare choices and encourage them to better maintain their own health, which can in turn improve health outcomes.

‘Finding effective ways to engage service users in shaping NHS services is important, and the *Beyond Consultation* guide provides a useful framework for doing just that.’

Hong Tan
Director
London Sexual Health Programme

Cover image

Pictured Doctor Marita Koumettou with a patient at an NHS doctor's surgery in North London. Bringing together seldom-heard service users and health staff can help to improve the uptake of health services.

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