QI in CITY & HACKNEY FACTSHEET 3: Service user, carer and customer involvement

Jen Taylor-Watt, Improvement Advisor

"To involve service users, you must listen to what they are saying, and be seen to be acting on their feedback with support. This in turn will empower them to take more control of their destinies especially when they see positive change taking place"

Steve Terney, Patient Liaison Worker, City & Hackney

"I feel I am on an even pegging and feel just as valued member of the `team in my experience"

Feedback from a Service User member of a C&H QI project, QI Evaluation 2016

It's really important to involve the customers of the issue you are working on in your QI project as much as possible. In most cases this will be service users and carers within your service. This is important so that the work of projects is shaped by the views, experiences and perspectives of the people who are the customers of our services, as well as that of staff.

In what ways do we involve service users and carers in QI?

We have 2 different levels of involvement in QI:

- Involvement with a **little i** means asking the people who use your service, have they noticed the improvements. This can be done via survey, focus groups etc.
- Involvement with a **Big I** means involving service users and carers directly in your project and Qi development and delivery.

In most cases you should strive for Big I involvement in your project, so you have service users and/or carers working alongside you in the project team, co-producing what the project is doing. That way, you ensure you have a service user's perspective within all decisions you make as a team and to help you see things from this perspective. Big I involvement can be transformative for QI projects and for individual members of the team.

It can also be really helpful to undertake Little I type consultation periodically as part of your project, so you get broader perspectives of service users and carers on the work of your projects. You can use tools like Nominal Group Technique within existing service user and/carer forums to do this, or use other types of feedback mechanisms, such as surveys.

As you can see from the Gold Standards Project case study in box 5, projects can utilise lots of different types of service user involvement to determine the ongoing direction of their project – in this case it was totally critical to the project existing at all.

Your People Participation Lead (PPL)

People Participation Leads play a key role in supporting and enabling service user and carer involvement in all respects across ELFT, including QI. Ways in which the PPL can support project leads and teams are outlined in the below section. The PPL for City and Hackney is Helena Maine.

Box 5: Case Study – Service User Involvement at the heart of the Gold Standards Project

The Gold Standards project is focused on improving the environment on Gardner Ward in City and Hackney Centre for Mental Health. We are working on this because being cared for in a positive environment is really important to people's recovery. A project team for this work meets fortnightly and includes the Ward Manager, Life Skills Recovery Workers, Head of Art Therapies, Psychologist, Improvement Advisor **and Big I involvement of a Patient Liaison Worker and a service user, who joins the meeting by teleconference.**

To understand what the project needed to focus on, the team started with **focus groups with service users**, discussing what was important to them in the ward environment. This identified 10 main areas: safety, being occupied, information, privacy, getting help, homeliness, personal care, supporting recovery, independence and sufficient resources.

To understand whether changes are leading to improvement, **service users are completing surveys about their experiences across these 10 areas**. Gardner Ward's **patient liaison worker, Steve, plays a crucial role in supporting service users to complete the questionnaire**. He comments, "My reasons for getting involved in these projects were that as a long time service user, I wanted to help patients input into improving the experience of being on the ward by empowering them to honestly express how they really feel, and to improve things for themselves and others in the future".

Tests of change

So far we have tested a range of change ideas to improve people's experience of care in terms of feeling more occupied, supporting recovery and independence and supporting personal care.

Change ideas have included:
• Introducing Daily Planning meetings to boost engagement in group activities
• Enabling people to occupy themselves on their own through access to materials and support
• Creating a welcome pack of information and toiletries to give people a good experience of arriving on the ward and to facilitate personal care

Whilst in the beginning 52% of people agreed or strongly agreed they were having a positive experience of the environment, this has now increased to 65%. Steve comments, "I am getting positive feedback from patients who have noticed an improvement in their experience of being on the ward and I think they are also empowered by the changes!"

P chart: % people saying they agree or strongly agree that they are experiencing a positive environment

Successive groups of 4 responses (4 surveys per week on average)
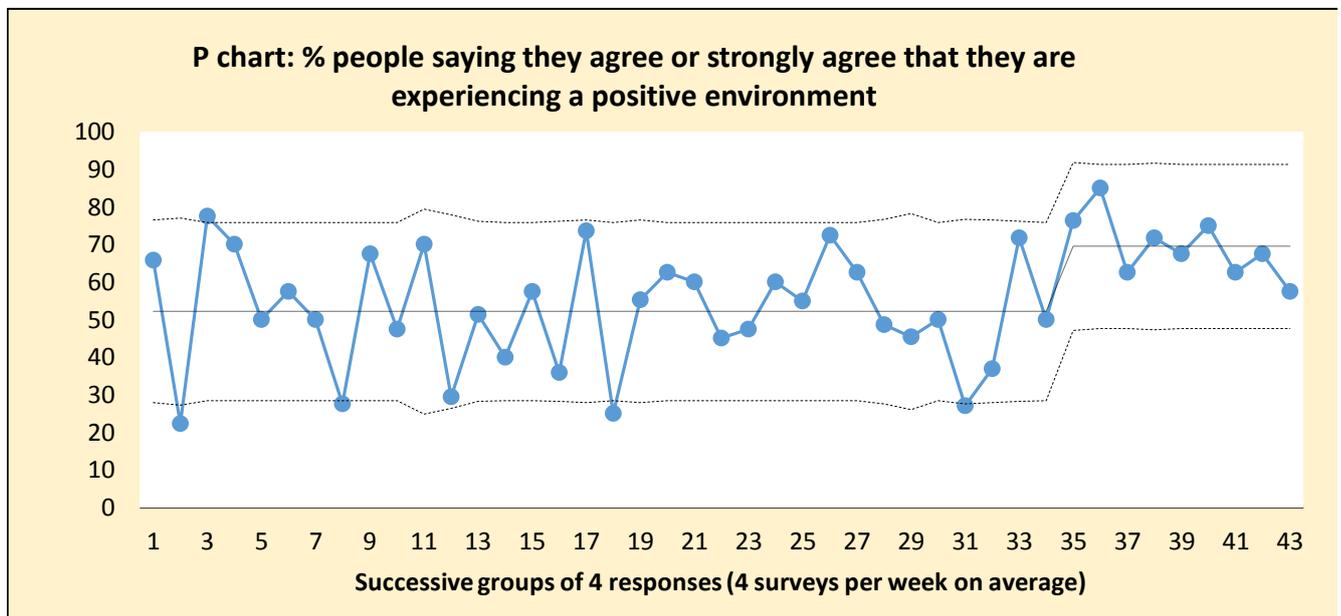
Holly Smith, Service User in the Gold Standards Project – My experiences and perspective on being involved in a QI project

Having been a patient and being on the receiving end of care I wanted to help. I know how much a few small things can make a real difference to someone when they're feeling very vulnerable and being cared for. With small changes it is easy to raise the standard of care on a ward and directly impact a person's experience of being there. Little things can go a long way to helping recovery on a mental health ward.

I also needed something to challenge me straight after being discharged, so I got involved straight away. It meant that my experiences of being a patient on the ward were fresh and I could give a unique perspective of what it is like to be on the receiving end of care and what is good or bad.

As to fitting in this extra work into my schedule – I haven't had any problems. My role is advisory and making sure the aim of the project and perspectives are right. I am able to dial into meetings too, so I don't have to make long journeys to join the team. It's quite flexible.

Professionally I have experience of project management. QI methodology is a little bit different, but it's been very interesting using these methods and there have been occasions in my own job where I have applied them; for example, in planning sessions where there have been loads of ideas floating round and it's difficult to sort them out, I have used nominal group technique with my team and analysed the ideas using an affinity diagram.

Based on my experience of QI, I believe the role of the service user should be reminding the team what the key focus is for their work and what the objectives are of the whole project. Service users can also offer a unique perspective on whether suggestions and changes will actually help, as they know what it's like to be on the receiving end of care. I think this input helps keep the team grounded and remember that they are doing this all to help the service user.

A working example of this on our project has been staff wanting to add magazines in wards. It sounds like a good idea, but some magazines sell ideas of what the ideal body image is, or how you should look, or perhaps buying or having certain things will make you happy, popular or find love.

To a vulnerable person having a tough time on a mental health ward and trying to recover, these subliminal messages are unhelpful. So it is better from a service user point of view to have magazines that focus on positive messages, such as health and wellness, hobbies etc.

My impression of quality improvement in the project I'm involved in is that staff have found and are finding this work incredibly valuable. They are not dictated to from the top. They chose to do the project, and it has all come from them. These are busy frontline staff who are passionate about their work and the care they deliver to patients. I think that's one of the most important aspects of improvement work; staff need to buy in to QI. There's a created and shared responsibility within the project team to keep things going. e.g. safety huddles; these are more likely to succeed due to created responsibility.

It's so important to get service user input in quality improvement work, project teams will find it very valuable. However, it's important to remember that service users cannot be around 24/7 and for the whole duration of an improvement project. Some may only want to help for a certain period of time, and that's OK. It's still great to use them and their skills to help you! You may want a service user to give you feedback on one survey question, or provide ideas for one particular aspect of your project. They may have a particular interest or skill with that you can utilise in the overall project. So, involve them! It'll still be a valuable and rewarding experience for them and you!

The above was an excerpt from an Interview with Holly. Read the full interview here: https://qi.elft.nhs.uk/my-quality-improvement-journey/

The earlier quotes from Steve Terney, Patient Liaison Worker, are also from another interview on the QI microsite. Read this here: https://qi.elft.nhs.uk/an-interview-with-a-patient-liaison-worker/

How to involve service users and carers in QI Projects; process, payment & clearance levels

The diagram on the following 2 pages illustrates the process project leads can take to identify service users and carers and organise their involvement in QI projects, supported by their directorate and particularly the City & Hackney PPL. Further guidance on the steps noted in the flow chart is below and further information on key points is included afterwards.

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                                              (A)

Project lead to discuss with        Initial conversation
team and/or sponsor to see if        between project
can identify SU/C for invlv or       lead and service
PPL lead to identify from            user/carer
contacts

                    ┌──────┐      ◇ Does the project ◇      ┌──────┐
                    │  No  │ ←──  ◇ lead have a service ◇ ──→ │ Yes │
                    └──────┘      ◇ user in mind? ◇          └──────┘

Abbreviation Key                 Project lead to
SU - Service User                liase with PPL
C - Carer                        lead
Invlv - Involvement
PPL - People                        ╱ New project to include service ╲
Participation Lead                 (  user/carer involvement         )
                                    ╲                               ╱
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Project lead to go through role description and ask if Service user/Carer interested in involvement with project?

A

Yes

No

Project lead to liaise again with PPL for other contacts for involvement

Project Lead to check service user/carer has clearance forms (including confidentiality and DBS) completed

No

Yes

PPL lead to liaise with HR and service user/carer for completion/process management see A agenda

Project lead to liaise with service user/carer to organise:

- Induction for service user/carer in to project team

PPL to liaise with service user/carer to organise:

- regular check-in support arrangements with PPL (3 monthly?)
- Information about SU/carer support network for project duration

Additional Notes:

- PPL to start DBS process with HR as soon as service user/carer have identified their potential future project involvement
- QI Forum to ask new project teams to check in every 3 months and to check SU/C involv and support needs

Process A

DBS Report is provided to project lead and sponsor for decision to check with Directorate lead for QI if content of DBS requires second opinion.

Key points on how to identify and organise service user and carer involvement in QI projects

- In general project teams should try to identify a service user to join their QI project, rather than asking the PPL to do this at the outset. This is because it is best for representatives to come from the team that is involved in the project. E.g. if your project is based in EQUIP, then you'll want the perspective of an EQUIP service user or carer and your team will likely be most able to identify someone. If you are having difficulties identifying someone though, the PPL and directorate QI sponsors are there to help you, so get in touch with them.

- Once you've identified someone, a first step is for the project lead to meet with the person to talk to them about the project. You need to let them know things like: what you plan to work on, why you feel it is an important priority for the team and what contribution you think they could make. You also need to hear from them about what they are interested in, what is important to them and what they can commit to. The People Participation Team have put together a short set of questions to cover. Fill this in[1] with the service user if they are happy to be involved and give them a copy of this, so you both know what you've agreed. The PPL can also join you for this first meeting.

  1. Project title:
  2. Project Leads:
  3. Time Commitments:
  4. Where will you be based?:
  5. Accountability and Responsibility:
  6. Payment:
  7. Length of project: (e.g. 6 months to be reviewed)
  8. Contact/Supervision/Support: (1:1 time, training needs)
  9. What do you hope to get from this work?

- Service users and carers involved in QI projects will need to sign a confidentiality agreement and have a DBS check if this hasn't already been carried out. The confidentiality agreement is available here[2]. PPLs will lead on organising DBS checks, so get touch with your PPL to help with this. See further guidance on Clearance Levels below.

- Service users and carers involved in QI projects need to be paid for their time. It is the responsibility of project leads to organise this, but if you have any questions/need help with setting this up, get in touch with your PPL. Please see the further guidance below.

- At the first meeting with the whole team, make sure you spend time introducing everyone and bear in mind all the content will be new, so take things more slowly. At the end of the meeting check in with the service user/carer once others have left to see how they experienced the meeting and check if they want to talk anything through with you. Do this periodically, as you go through the project, so you make it easy for service users/carers to raise questions and/or anything they are finding difficult.

- PPLs will also arrange regular support with them every couple of months for all service user/carer members of QI projects to provide them with a clear space to share their experiences and address any problems. PPLs will also provide information about SU/carer support networks.

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[1] Template available here: https://qi.elft.nhs.uk/resource/service-user-and-carer-qi-role-descriptions/

[2] https://qi.elft.nhs.uk/resource/confidentiality-form/

Organising payment for service user/carer members of QI projects

Once part of a QI project team, service users and carers need to be paid for their contribution to the work of the team

There are various options for payment for service user/carer time.

Option 1- Under Reward and Recognition Policy

If you are involving service users and carers in any meetings, focus groups or any regular commitment then:

Under 2 hours- £10

Over 2 hours – £20

Payments are made via BACS and no cash payments should be made.

BACS forms and user payment forms are available to download[3].

Option 2- Permitted Work (for people on benefits)

If you require more and sustained input into a QI project (someone to regularly measure satisfaction on a weekly basis for example) then the People Participation Team can help support the QI project to place someone on Permitted Work (via the Job Centre). Your local PPL is listed on this page.

This allows a service user to earn up to £104 a week (work up to 15 hours a week) without affecting their benefits so that people can be given a regular task or project.

Payments are made via BACS and no cash payments should be made.

Option 3 – Employment by the Trust on temporary/bank contract (for those people not on benefit, retired and in employment)

Initially graded an AFC Band 3 employee.

A temporary bank contract.

This would be regarded as taxable earnings

Making payments

All costs related to the above are to be met via budget code related to the host team for the QI project (unfortunately we do not have central funds for this).

All completed BACS and payment forms should be sent to SUC-payments@elft.nhs.uk for processing, except Bank payments which will be made in the usual manner.

If you have any questions or problems with these processes, get in touch with your PPL, or Paul Binfield, Head of People Participation.

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[3] https://qi.elft.nhs.uk/resource/weekly-payment-form-for-service-users-and-carers/
https://qi.elft.nhs.uk/resource/bank-details-form-for-service-user-and-carer-involvement/

Managing clearance levels for service user/carer involvement

The following is taken from a brief guidance document for QI Projects and QI Forums around service user/carer involvement in QI work and the level of clearance/checks required to fit with Trust policy.

We need to organise for the appropriate level of clearance, depending on the sensitivity of information that the person is subject to, as set out in the table overleaf. Project Leads need to review the table to decide on level of clearance required then let PPLs know who will support with organising DBS checks. Templates and instructions are available via hyperlinks below.

Once you have reviewed the below, if you have any uncertainties about the level of clearance required, talk to your project sponsor. If you don't know who your project sponsor is, get in touch with your Improvement Advisor.

Please note, although your current project tasks may be at level 1, you may still want to process a DBS in case this changes in future. It can sometimes be hard to predict what will be involved in your project at the beginning and this will avoid delays/awkwardness if the nature of information changes and becomes more sensitive.

The results from DBS checks will be returned to directorates, who will be responsible for reviewing and making decisions about whether someone can proceed with being involved in the QI project. It is up to directorates to establish appropriate structures and processes for managing this. The costs of processing DBS checks for directorate QI work will be met by directorates.

Please note, this guidance is not designed to replace that related to clinical work within teams. Please see the note after the table about QI involvement, which is closely linked to clinical practice.

Level	Description & Example Tasks	Clearance required
1 – Generic/ Involvement (no sensitive information)	Tasks and project team discussion does not involve any personal or sensitive information, nor 1:1 contact with service users and carers; e.g. • Contributing to generic project strategy (discussion of measurement approach, discussion of drivers of problems, change ideas, process mapping) • Reviewing/commenting on generic materials (patient information leaflets, template appointment letters) • Being involved in sessions at Away Days to promote service user involvement	• Confidentiality agreement[4]
2 – Handling sensitive information & patient identifiable information	Tasks and project team discussion involves handling sensitive/ patient identifiable information and/or 1:1 contact with service users and carers; e.g. • Contacting/interviewing service users and carers or carers to get their views on a service (thereby having access to contact information) • Hearing case examples of service users and carers' experience of services • Having access to patient identifiable data in project datasets or other materials	• Confidentiality agreement • DBS check[5]
3 – Handling patient records (Peer Support Worker)	Not usually required for QI projects, but PSW tasks are noted below for information: • Have access to RIO, handle patient sensitive info and writing in progress notes	• Confidentiality agreement • DBS check • Formal role as Peer-support worker

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[4] https://qi.elft.nhs.uk/resource/confidentiality-form/
[5] Let your PPL know this is needed and they will help with processing this

Service user QI Involvement linked to clinical practice

Sometimes you may be working with service users, as part of clinical care and include discussion linked to QI projects; for example, running discussions during ward community meetings about experiences of violence and aggression. In these cases, because the nature of involvement is part of standard clinical practice, it is unlikely you will need to get service users to complete formal written confidentiality agreements, but you should instead follow your normal clinical protocols (e.g. requests that service users not to discuss others experiences outside of a therapy group, etc).

In all such cases it is good practice to be clear about how feedback/content of discussion will be used in relation to the QI project; e.g. that notes of themes from the safety discussion will be kept for us to learn from, but these won't be attributed to individuals. You should also make clear that involvement in this consultation is voluntary.

Where a current service user or carer within a clinical setting is intended to be directly involved with a project team as a core ongoing project member, working directly with materials as part of a QI project team role, then confidentiality would need to be obtained as suggested above. If in doubt around the need for a confidentiality agreement or enhanced DBS checks the project sponsor needs to be contacted.

Supportive service user and carer involvement

Since meetings were alien to me, I really did not know the "rules" of a meeting and felt I couldn't leave the room when I needed to

A simple matter: meeting rooms not being very welcoming with no windows and dark rooms

I didn't have any personal reference or training to know how to behave and I felt like an actor, not truly being myself.

I feel this is positive work and we should not have to feel like its "Them and Us", these barriers are slowly eradicating. It's "Us and We", staff, service users and carers are all looking after the mental health and emotional wellbeing of each other. I found the interactions are wonderful and very positive. It is about being human and thinking outside of the box.

Feedback from service users on experiences in QI projects - Trustwide

As with elsewhere in the Trust, within QI projects it's important to reflect on how to effectively support service users and carers well within your project team. Above are some comments from service users across the Trust, which reflect both positive and negative experiences and should prompt some thinking. Below are some key principles and tips to bear in mind, based on our learning over the first 3 years of QI.

It is acknowledged that many of these will be common-sense to staff - but at the same time, it can be easy to slip up sometimes and forget about them when we're busy and they make a real

Top Tips for Supportive Service User Involvement

- Try to avoid QI jargon and acronyms in project meetings – most things can be explained my simply, but if not, take the time to explain what QI terminology means

- Make sure you introduce everyone in the project team to new service users and carers

- Be aware of how intimidating meetings can be in terms of the environment and not having met and/or worked with people in what can feel like quite a formal format before; think about what you can do to make things more comfortable

- If you're going to use papers for meetings, make sure these are explained

- Check in with service users and carers periodically, to make sure they feel comfortable. PPLs will do this too separately, but it's important that project leads take a lead on this when service users/carers attend meetings, etc.

- Provide clarity to service users about the length of time they will need to be involved in the project and what they role is at the outset

- Make sure you have a main contact in the team for service user/carers members, who are responsible for ensuring they are supported in meetings, and with logistical stuff like getting paid, etc.