Patient and public involvement review of strategy 2018 to 2020
‘Patient and service user involvement apart from providing patients with feelings of safety, by being actively involved in issues that affect us, signifies a direct hit on the stigma and discrimination that surrounds mental health patients. It is indeed very painful to hear mental health patients speak about other members of the public as ‘the normal people’.

That can only be changed on a larger scale if more professionals and organisations embrace the PPI example not just as a scheme, idea, theory but as an everyday practice and culture. Many organisations have a patient and public involvement group. However, in the nine years I have been in the NHS for my physical health problem and the five years of my mental health issue it is only the Tavistock that first gave me the feeling of equality and acceptance and later established the feeling through my involvement.’

Advisory forum member 2018
Contents

Context and background 4
Introduction 5
Mission statement 5
PPI values 5

1. The policy and legislative context to patient public involvement 6
2. Pan London mental health PPI forum and its role in our strategy development 8
3. The team structure 9
4. The work for which we retain direct responsibility 10
5. What we provide in collaboration with the directorates, department of education and training and as consultants to the trust 13
6. A model for running forums and support to establish, embed and maintain new groups 14
7. Good practice examples in adult and forensic services (AFS) 15
8. PPI good practice examples in children young adults and family services 17
9. Role descriptions and contracts for patient /service user reps for different activities and roles within the trust 19
10. Development and review of reward and recognition policy for patient / service user reps 19
11. Collaborations with the communications team 20
12. Business development 21
13. Future developments 22

Appendix 24
Context and background

To place our current patient and public involvement work in context, we refer to a significant piece of research in this area. The Eurobarometer study (2012) examined perceptions of patient public involvement (PPI) across health care organisations in 15 European Union member states. Among its key conclusions was the finding that the term patient and public involvement was not generally well defined or understood, either by patients or professionals.

A useful definition of patient and public involvement and one that we use at the Tavistock and Portman NHS Foundation Trust, is that PPI is work with communities, patients/services users, families and carers, which specifically refers to their rights and benefits in having a say in their health care. This:

• influences service design and development
• supports staff recruitment
• consults to the development of policies, procedure and practice

This document will review and further clarify the strategic direction of patient and public involvement in the Trust to develop best practice in collaboration with and in support of our directorates, whilst they develop their own involvement strategies in line with our Trust objectives.
Introduction

This strategy builds on the work of the previous PPI strategy (2003) and subsequent reviews. It has been produced by the PPI team based on our learning and experience. We have consulted on and included our patients / service users’ views and it is produced in collaboration with our service users, team and colleagues within and external to the Trust.

Experience informs us that patient involvement within our Trust is a relational activity. Flyers and posters advertising involvement opportunities have limited effectiveness, whereas a recommendation from a clinician, who has explored and considered their patient’s potential interest in involvement, is most effective in sustaining engagement in the work.

Mission statement

The purpose of delivering our strategy at this juncture is to examine and reflect on involvement work already undertaken in the Trust, to recognise and share examples of good practice and to share a vision of embedded involvement. It is important to emphasise the need for this to be recognised and owned by all Trust staff and not seen as a stand-alone activity in relation to the PPI team. Understanding of and engagement with patient involvement has historically been variable across the directorates, there is still more to be done to develop consistent appreciation of the importance of listening to our patients views and enabling them to share in decision making processes.

Our stated aim is to increase involvement in all aspects of service planning and delivery. We will undertake this by working collaboratively with our patients and public stakeholders and our colleagues to ensure that we consistently deliver services that are representative of and accountable to the people we serve.

PPI values

There is evidence that involving users in service development, running and evaluation; is of positive benefit to the services and to the users.

- meaningful involvement requires partnership working and co-production
- users (and staff) need to be able to see the value of their contributions
- engagement needs to be managed in such a way that it does not cause harm
1. The policy and legislative context to patient public involvement

The *Five Year Forward View* outlines a vision for a shift in power to patients and the public, which NHS England states it is striving toward:

‘One of the great strengths of this country is that we have an NHS that – at its best – is ‘of the people, by the people and for the people…we need to engage with communities and citizens in new ways, involving them directly in decisions about the future of health and care services.’

‘A significant element of NHS England’s work involves commissioning, and, in this regard, there are specific legal requirements. NHS England has a legal duty under section 13Q of the *National Health Service Act 2006* (as amended by the *Health and Social Care Act 2012*) to properly involve patients and the public in its commissioning processes and decisions.’

*NHS England Five Year Forward View 2014.*

In the Tavistock and Portman Foundation Trust’s patient and public involvement team, our strategy and practice have been underpinned by national service user 4Pi good practice principles, by legislation, by the Trust’s mission statement and values and importantly by principles of co-production. Co-Production emphasises more equal partnerships between people who use services, carers and professionals.

These principles are founded on grassroots mental health and disability service user movements. Arnstein’s (1969) ladder of citizenship participation is fundamental to good practice in involvement work; this ladder was originally based on citizen involvement in planning processes in the United States. An applied version of the ladder is used in our team to identify and clarify our PPI roles and tasks, and we also utilise it in our Trust induction presentation and in INSET day programmes as a training tool, to inform staff of the principles of involvement work. In this way we can support our colleagues and help them to identify which activities support the development of our Trust services and involve sharing in our decision-making processes. The ladder helps us as a team to identify the role and level of involvement needed for each PPI project, in addition to determining a gold standard in relation to co-production. We are working toward co-production in so far as is possible keeping in mind the ethos behind the disability rights movement slogan ‘nothing about us without us’.
The ladder of participation

- **Full control**: Service users control decision making at the highest level
- **Sharing power**: Service users share decisions and responsibility influencing and determining outcomes
- **Participation**: Service users can make suggestions and influence outcomes
- **Consultation**: Service users are asked what they think but have limited influence
- **Information**: Service users are told what is happening, but have no influence
- **No control**: Service users are passive consumers
2. Pan London mental health PPI forum and its role in our strategy development

As a part of developing our strategy in the Trust, the PPI team coordinates hosts and administrates the Pan London Mental Health PPI Forum which meets quarterly. This forum enables service users and PPI staff from across mental health services in London and the home counties, to meet and share knowledge and experience of involvement issues. This has proven to be mutually beneficial in developing, sharing, and upholding good practice in PPI, as well as in creating a supportive and influential involvement network.
3. The team structure

The patient and public involvement team is a small team with a Trust-wide remit. We currently employ:

- three PPI co-ordinators, one part-time, two full-time
- PPI assistant part-time
- PALS officer part-time,
- lead for adult and forensic services part-time
- lead for children young adults and family services part-time
- team manager part-time
- director for quality and patient experience,
our representative of PPI on the Board

Workstreams

For the purposes of this strategy document it is significant that we have divided the work into two streams; that for which we retain direct responsibility as a team, and the work in which we consult to and collaborate with Trust and community colleagues and stakeholders. These are important distinctions to make which will enable our colleagues to better understand the course of development in PPI, moving toward a model of shared ownership and embedded good practice. We will give examples of current good practice in involvement work to further illustrate this thinking.
4. The work for which we retain direct responsibility

Experience of Service Questionnaire
The PPI team report on quarterly quantitative findings from the experience of service questionnaire (ESQ), the more detailed area of work on the ESQ findings is collating, analysing and theming the free text qualitative patient feedback.

This information is broken down at team level and provided to clinical directors. The team are working to have an accountable method of providing this feedback to service users and commissioners. A procedure for this is being worked on with clinical directors and team leads, essentially ‘closing the loop’ for feedback.

Objectives and action planning
Major areas for improvement for 2018/19 have been identified as:
- estates and trust accommodation
- access to sites and parking
- communication and Information. This work feeds into the clinical quality and patient experience work plan
- the team also collaborates with the quality team in providing written updates on the progress of CQUINS, KPI’s and clinical improvement targets
- we are now examining the varied ways in which we collect feedback through the ESQ across the Trust and aim for standardisation of this procedure

Quality improvement (QI) in PPI
Coordinators in PPI have already begun to support and advise on QI projects and the team manager sits on the QI committee. The PPI team will consult, support and guide on quality improvement (QI) projects for the improvement of service user experience.

The team has a trust wide remit and PPI work should be embedded from the outset in all patient / service user related QI projects.

The team will help consider the benefits of the service user involvement, as well as consulting on the appropriate channels to involve patients sensibly and thoughtfully.
Service user representatives (SUR’s) on interview panels

Employing service users on our interview panels has been one of the most successful pieces of work for patient and public involvement to date. This work embodies principles of co-production and the process recognises the value of lived experience within mental health development. We have seen a shift in organisational culture as Trust staff have become more familiar with the benefits and rewards of having service users’ input on panels. The training of service users and families is undertaken by the PPI team, the training is very well received, and feedback shows that it has empowered service users to upskill themselves for external interviews and prepare for work opportunities. By being on a panel the SUR’s have direct influence on shared decision making.

HR acknowledge the value of this process and the PPI team keep in close communication with the HR representative for each interview to ensure the patient is kept in mind with scheduling and to ensure their mental wellbeing is considered on the day.

Objectives and action planning

The PPI team take collective responsibility for ongoing communication with clinical colleagues in the Trust to remind them of the need to refer into this service and to keep it on the agenda. It is positive to see that there are increased requests to include our service user representatives on panels, but we do not yet consistently see a corresponding increase in referral rates from clinicians. This should link with adult and forensic services’ and children young adults and families directorates’ service line objectives in relation to PPI.

Bid for Better

In 2011 the PPI team launched the Trust Bid for Better scheme and continue to run the scheme each year. The scheme offers awards of up to £400 to support bids for activities or equipment which will improve the patient / service user experience, promote mental wellbeing and / or make our services more accessible. The scheme started as a membership engagement project and bidders do still need to be members of the Trust. The scheme has become a valued annual event and is used as an opportunity to try creative projects and schemes that may not otherwise be possible due to budget constraints. Bid for Better enables the PPI team to make links with external organisations as it is open to the public and we have supported several external projects. Allocation of the awards is decided by a panel made up of service user representatives and Trust staff.
Objectives and action planning
This work is ongoing and is being refined year on year.

Pan London PPI MH Forum
– see p.8 of this document

Newsletters
The team produce a quarterly newsletter in collaboration with the communications team, updating service users on all activities that have occurred within the past few months, also to let people know of all upcoming activities they can become involved in. This includes art projects, and stakeholder groups, training for interview panels and signposting to other community activities. The newsletter is distributed across the Trust throughout waiting rooms. This was a progression and improvement from this information previously forming part of the Annual report, which reached internal staff but not service users. The newsletters are well received and there has been positive feedback about the content and presentation.

Objectives and Action Planning
Ongoing – the team ensures that this newsletter is reviewed and updated regularly.

Patient Advice and Liaison Service
The Patient Advice and Liaison Service (PALS) is part of the PPI team and the PALS officer works alongside the PPI team to think about patient involvement and feeds back on issues concerning the patient clinical experience and contact generally with the Trust. PALS also feeds directly into the complaints process and communication between members of PPI and complaints helps PALS to highlight and resolve issues that relate to involvement and patient care more widely.

The PPI team members provide cover for the PALS when the PALS officer is on leave. The PPI team structure has been vital for ensuring that PALS operates a good service and that staff members have adequate support.

Objectives and action planning
Ongoing – to continue to support the work of the PALS officer

Future Directions – the PPI team is to offer support to the newly appointed complaints, PALS and PPI co-ordinator at the Gender Identity Clinic. This work to be undertaken in July 2018 and will be ongoing.
5. What we provide in collaboration with the directorates, department of education and training and as consultants to the trust

DET learning and teaching committee sub group
The PPI team have been collaborating with the Learning and Teaching Committee since 2016. Our input began with a scoping exercise which highlighted that the level of involvement initiatives was varied across training portfolios. Our role going forward is to support portfolio managers to explore opportunities for increased involvement in their courses.

The PPI team have supported the M80 course to introduce service user representatives on their interview panels for placements.

This year the PPI team in collaboration with DET colleagues ran a parallel session at the Learning and Teaching Committee annual conference. The session was initially focused on a Literature Review of PPI in learning and teaching. We launched a film we had produced with ex-students and service user lecturers discussing the benefits and challenges of having service users delivering training.

In addition, the conference launched a repository for PPI resources, this contains literature reviews as well as videos and podcasts of service users’ films to be used in learning and teaching and is available to all Trust courses. This resource is live and is being updated.

Objectives and action planning
This is to be discussed in the sub group in relation to CPD training.

We have undertaken to support a service user advisor role in DET as a pilot for this year, to see if and how we can sustain and grow this work in DET in the future. This involves a service user employed as a visiting lecturer, who teaches across social work programmes and is working in an advisory capacity on D55.
6. A model for running forums and support to establish, embed and maintain new groups

The key aims in developing this work have been toequip the directorates and teams to think about the value of involvement in a way that enables them to learn from their patients and understand their perspectives on service provision. In this way they can see what works well and what can be improved.
7. Good practice examples in adult and forensic services (AFS)

The TAP service user advisory group
This well-established forum is co-facilitated by Team Around the Practice (TAP) and Camden MIND, with input from PPI and consults to the TAP team and Camden commissioners, to embed good practice and influence decision making processes in Camden. Here is what one of the group members has to say about the group:

‘From my perspective the work of the advisory group has been highly significant because it has given me a way to contribute to decisions that affect my healthcare, and the care of people in a similar position to me who may be affected by changes. People making decisions can’t always have the perspective of a service user, so it is important that the group exists and has a voice. We are often considered as being unable to form opinions on important matters, but we know that with this group our views are taken seriously as we have been invited to contribute our thoughts to some difficult decisions, and we have been told of changes made because of what we have recommended.’

City and Hackney getting together forum
This forum was formed in 2017 on the suggestion of an ex – Primary Care Psychotherapy Service (PCPCS) patient who had asked to make a film with the PPI team, to raise awareness of the complexities of living with physical and mental health conditions. She worked with one of our coordinators to develop a flyer encouraging others to come forward and join the group was involved in its inception and sat on the steering committee to establish the forum. The forum is now up and running and is held in a garden project in Hackney called the Secret Garden. It is run and administrated by the PCPCS with consultation and input from PPI.

‘Now done with individual therapy I look forward to joining the groups at St Mary's Secret Garden...Not only do we have a chance to share our experiences and knowledge of what it feels like to receive therapy from the Tavistock, we also get some free refreshments.’

Founder member of the forum advertising its benefits to potential members.
Objectives and action planning
Getting together forum for the Complex Needs Service – the group disbanded due to low numbers in late 2017. A new forum is currently in the planning stages with the head of Complex Needs. Support advice and consultation about these forums is ongoing within the PPI team. It is noted that complex needs and The Portman can be supported to increase involvement opportunities for their patient populations.
8. PPI good practice examples in children young adults and family services (CYAF)

Collaboration with the Refugee Service
The PPI team have a good collaborative working model with the Refugee team.

The Recipe of Life project was introduced to the trust as a successful Bid for Better project between both teams in 2015. The teams have worked together to deliver the project which has elicited a very positive response from staff and service users. The project brings together some of our most isolated patients to share experiences of culture. This supportive forum integrates people who may not otherwise be drawn into involvement activities. The ongoing development of the project has meant the PPI team have been able to support funding for this work as it has developed. A young female aged 17 from Ethiopia said:

‘It is the first time since arriving in this country that I have sat down to eat with so many people. She said that it was those around her that enabled her to maintain hope.

Small Green Shoots
The team are working with a charity ‘Small Green Shoots’ for young people in Camden, co-designing and facilitating a ‘positive mental health’ young people’s programme. This has been in collaboration with a Child and Adolescent Mental Health Services (CAMHS) psychologist from our CYAF services and will be delivered in schools, youth hostels and community centres. This project was conceived by young people who asked for the team’s involvement which promotes our user lead principles. The project will enable the team to share information about access to our services to disadvantaged members of the community and those with protected characteristics. Young ambassadors from the charity will act as stakeholders for the Trust, promoting our services and advising where the Trust requires community consultation. They have already consulted to the development of the forensic CAMHS service.

https://www.youtube.com/watch?v=a2fuYkKkuY8&t=22s

Pizza sponsorship to PPI groups in CYAF
A local pizzeria offers free pizza to involvement forums and groups monthly. This year an example of a few CYAF services that have benefited from this offer have been:
• a focus group of young people in Camden giving feedback on the Green Paper on mental health legislative review
• a project working with parents of primary school age children in Camden
• parents contributing to a CQC forum feeding back on their experience of services.
• GIDS stakeholder group
• the planning group for the Recipe of Life in the refugee service involving young people in the planning process

The director of CYAF has provided the PPI team with PPI objectives for each of the seven teams in her directorate.

These include the following examples of good practice:
• the family drug and alcohol team’s plans to involve parent user groups in development of post proceedings support work including recruitment of parent mentors by August 2018
• the fostering, adoption and kinship care team are to recruit an honorary research assistant to work on building on the feedback themes from current experience of service questionnaires
• the refugee team are to take on two young people mentors who graduate from their fast feet forward programme
• other initiatives are taking shape across the directorate and are included in the various current service line reports

Gender identity Development Service
The team links with and supports quarterly GIDS stakeholder groups, consulting patients on service improvement for gender identity services. The GIDS services have been involved with training young people and their families to sit on interview panels for the Trust.
9. Role descriptions and contracts for patient / service user reps for different activities and roles within the trust

One example of this is the role of our art board members with lived experience, who have a time limited role advising to the art board. Keeping to a year’s contract reduces the risk of unintended consequences associated with over involvement and allows people who are interested in the work of the art board to take up this opportunity in turn.

10. Development and review of reward and recognition policy for patient / service user reps

This is currently being discussed and reviewed within a pan-London framework. However, the Trust has a robust and efficient procedure for service users on interview panels which is reviewed regularly with HR.
11. Collaborations with the communications team

We have continued to develop closer links with the communications (Comms) team at the Trust. We attend their team meeting when possible and a Comms representative has attended ours, so that we are aware of developments and can link effectively between the two services. Comms oversee the PPI newsletter and assist us with tasks such as publicity for groups and other PPI related activities. We have ongoing collaboration in relation to patient information.

A successful collaboration with service users and multidisciplinary colleagues including Comms was the development of the Frame of Mind Exhibition. This involved two service users, a senior TAP clinician, our resident artist, a senior Comms officer and members of the PPI team.

This exhibition followed on from the display of the work of a therapeutic community photography project run by a primary care clinician who had exhibited their work at the Tavistock Centre. The idea was to extend the project so that the photography group members from the two boroughs of Camden and Hackney might visit and view their photographs in an accessible and free community space. The first part of this project involved mounting, displaying and exhibiting the photographs at a large Hackney library. This enabled the photographers not only to showcase their work but also to raise the profile of the photography group and the work of the City and Hackney primary care service. The group chose to donate the money from any sales to their nominated charities. This exhibition was also able to raise awareness of mental health issues through therapeutic art. The exhibition has had good publicity thanks to the skilled work and support of our Comms team. The two photographers who were involved in putting on the exhibition have gone on to be involved in forums and other PPI activities. The exhibition was originally planned to run for a month – this was extended to a seven-week run due to popular public demand.

Objectives and action planning
The plan is to extend the work of the group, include more service users and take the exhibition to a community venue in Camden. The work will begin in autumn of 2018.
12. Business development

The Director of Commercial at the Trust has met with the PPI Director and manager to discuss the need to include patient involvement and consultation in bids for future clinical contracts so that principles of good practice in PPI are embedded in service design and development.
13. Future developments

‘Patient centred care, patient led involvement...cannot be a thing apart, if it’s a thing apart it’s not going to be taken seriously and it’s not going to have traction’

(Cornwell, J. 2013)

We are moving toward co-creation from the inception of projects within the Trust and are strengthening our relationships with local community organisations, such as Healthwatch, Voluntary Action Camden and MIND, as well as working more closely with groups with protected characteristics in line with the Trust's equality strategies.

Our Gender Identity Clinic has recently employed a PPI/PALs coordinator to work within the specialism, supported by and linked to the PPI team. Our GIDS team have been proactive in running forums and providing their own interview training for young people with gender identity development needs.

The emphasis on collaborative working with Trust and community colleagues ensures that PPI is everybody’s business and responsibility. To embed this message, we request the active support of the Board, Executive management Team and staff at all levels in the Trust, to work with the PPI team to ensure that the voices of our service users are effectively heard and considered. Most important is that that their influence is valued, as we continue to develop ever more effective systems of service improvement through feedback and collaboration.

Claire Kent PPI Team Manager July 2018
## Appendix

Table of objectives

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Timeframe</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Quality</strong></td>
<td></td>
</tr>
<tr>
<td>Major areas for improvement for 2018/19 have been identified as:</td>
<td>Ongoing collaboration</td>
</tr>
<tr>
<td>• Estates and trust accommodation</td>
<td></td>
</tr>
<tr>
<td>• Access to sites and parking</td>
<td></td>
</tr>
<tr>
<td>• Communication and Information. This work feeds into the Clinical Quality and Patient Experience work plan</td>
<td>Within the next year</td>
</tr>
<tr>
<td>• The team also collaborates with the Quality Team in providing written updates on the progress of CQUINS, KPI’s and Clinical Improvement Targets</td>
<td></td>
</tr>
<tr>
<td><strong>Quality Improvement</strong></td>
<td></td>
</tr>
<tr>
<td>• The team will help consider the benefits of the service user involvement, as well as consulting on the appropriate channels to involve patients sensibly and thoughtfully</td>
<td></td>
</tr>
</tbody>
</table>

Quality

Major areas for improvement for 2018/19 have been identified as:

- Estates and trust accommodation
- Access to sites and parking
- Communication and Information. This work feeds into the Clinical Quality and Patient Experience work plan
- The team also collaborates with the Quality Team in providing written updates on the progress of CQUINS, KPI’s and Clinical Improvement Targets

Quality Improvement

- The team will help consider the benefits of the service user involvement, as well as consulting on the appropriate channels to involve patients sensibly and thoughtfully
<table>
<thead>
<tr>
<th>Objectives</th>
<th>Timeframe</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Interview panels</strong></td>
<td>Ongoing</td>
</tr>
<tr>
<td>The PPI team take collective responsibility for ongoing communication with clinical colleagues in the Trust to remind them of the need to refer into this service and to keep it on the agenda. This can link with Adult and Forensic Services’ and Children Young Adults and Families Directorates’ service line objectives in relation to PPI.</td>
<td></td>
</tr>
<tr>
<td><strong>Bid for Better</strong></td>
<td>Ongoing</td>
</tr>
<tr>
<td>This work is ongoing and is being refined year on year.</td>
<td></td>
</tr>
<tr>
<td><strong>DET</strong></td>
<td>Review by May 2019 advisor role to begin Sept. 2018</td>
</tr>
<tr>
<td>We have undertaken to support a service user advisor role in DET as a pilot for this year to see if and how we can sustain and grow this work in DET in the future. This is a lecturer who teaches across social work programmes and acts in an advisory capacity to students.</td>
<td></td>
</tr>
<tr>
<td><strong>CYAF and AFS</strong></td>
<td>Ongoing</td>
</tr>
<tr>
<td>Continue to collaborate with the Directorates. To ensure that PPI is well understood and embedded, and that tokenism is avoided. Forums Support advice and consultation about these forums is ongoing within the PPI team.</td>
<td></td>
</tr>
<tr>
<td><strong>COMMS Team</strong></td>
<td>Ongoing collaboration</td>
</tr>
<tr>
<td>To continue to work closely with Comms colleagues. In relation to the exhibition project the plan is to extend the work of the group, include more service users and take the exhibition to a community venue in Camden.</td>
<td></td>
</tr>
<tr>
<td><strong>Business Development</strong></td>
<td>Ongoing collaboration</td>
</tr>
</tbody>
</table>