Review & Proposals for changes to:

The Patient and Public Involvement (PPI) Trust-Wide Internal Structure

&

The Involvement Register

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This Review will be distributed to the following groups:

- All people signed on to the Involvement Register

- Mental Health Service User Organisations which operate across Lambeth, Southwark, Lewisham and Croydon

- SLaM staff with a responsibility for PPI

- SLaM staff who have made bookings on the Involvement Register between 2012 – to date

It will also be available to a wider audience via the SLaM Internet site, TWIG Ops Blog and the SLaM weekly email.

Introduction and purpose of the document

This document has been prepared by the Trust Patient and Public Involvement Team with support from the CAG leads on Patient & Public Involvement.

It aims to:

- Describe the current Trust Wide PPI Structures and mechanisms for making payments via the Involvement Register
- Identify the gaps in the above
- Make proposals to address the issues
- Tell you how you can give us feedback on the proposals

This paper consists of two parts. Part A will first consider the overarching PPI Structure within SLaM and Part B then look at the Involvement Register.

Please note: This paper does not cover CAG PPI structures, TWIG Blog, or PPI activities which do not attract payment such as volunteering. The role of Link workers will also be reviewed separately and will not currently be affected by this review.

Background

What is involvement?

South London and Maudsley NHS Foundation Trust (SLaM) is committed to involving service users, carers and members of the local community through meaningful consultation, engagement, planning, delivery and development of our services. This has been clearly emphasised in the Francis Report which outlines how partnerships between health professionals and patient groups; should aim to go "over and above nationally required minimum standards".

An individual's experience of using our services gives them a unique individual perspective of what worked well for them and where necessary, improvements can be made. SLaM recognises the importance of this experience and wants to use this to continually improve the services that it provides.

As a Trust we also have a legal obligation to consult and involve with the public, communities and patients (service users). This is set out in a number of key documents such as the NHS Constitution, Patients' Preferences Matter, The Francis Report, The NICE Service User Experience in Adult Mental Health, The Health and the Social Care Act 2012.

Involvement can be mutually beneficial, service users often report that becoming involved helps with their recovery, providing meaningful participation which feels productive and useful. This in turn enables service users to reintegrate back into the wider society.

Within SLaM, there are different ways people can get involved, to share their experiences and provide feedback this includes (but is not exhaustive):

- Being a member
- Volunteering
- Completing patient experience (PEDIC) surveys, complaints or compliments
- Participating in public meetings, focus groups or forums
- More formalised involvement through the Involvement Register

PART A: Trust Wide PPI Structures in SLaM

Current PPI Structures in SLaM

Within SLaM currently there are a number of groups which are responsible for the implementation and management of PPI activities. This paper is only concerned with those groups which operate at a SLaM wide level – CAG Service User Advisory Groups (SUAGs) are not within the scope of this paper.

There are three key Trustwide groups relating to involvement and/or improving patient experience which operate across SLaM:

1. The Patient Experience Group (PEG). This is chaired by Dr Martin Baggaley (Clinical Director) and was initially set up to explore how the Trust could improve its scores on the National Patient Survey. This focus has remained, in addition to also looking at issues relating to Patient Experience (PEDIC) surveys, Patient Experience CQUINs and Patient Experience related Quality Standards. It is attended by representatives from PPI, Clinical Governance, Nursing, Psychology and the chair of TWIG Ops. It meets on a bi-monthly basis for one hour. It does not feed into any other meetings in the Trust and operates as a stand-alone group.

2. **Trust Wide Involvement Group (TWIG) Strategic**. This group is chaired by an elected Service User Consultant and co-chaired by the Strategic Lead for PPI. The aim of TWIG Strategic is to create and oversee the continual development of PPI within SLaM. It meets quarterly and meetings now last for two hours. Membership of the group is primarily made up of service users who are were originally selected as representatives from other service users groups, both internally and externally, and from the Council of Governors. Without any structural governance this often left the group limited in its' objectives.

3. Trust wide Involvement Group (TWIG) – Operations. This group is also chaired by an elected service user and co-chaired by the Strategic Lead for PPI. The aim of TWIG Ops is to work on service improvement issues identified by staff and service users. It meets on a quarterly basis and meetings last up to 3 hours. The group aim was to follow a co-productive approach and to work in partnership with staff to improve services in SLaM. Members are overwhelmingly service user consultants. As with the reasons for the above without any structural governance, the group was often unable to respond to Trust-wide patient experience priorities.

These three groups are managed and co-ordinated by the Trust PPI Team, which is managed by the Strategic Lead for PPI.

Why Review the Existing PPI Structure in SLaM:

1. The development and update for the PPI Strategy was initially delayed until after the outcomes from the NICE Service User Experience in Adult Mental Health (December 2011). This resulted in 3 focus groups with the TWIGs and the Council of Governors (from February to June 2012) the discussions were 'how do we take account of the Guidance'. A range of objectives were suggested including 'wider involvement at all levels' and 'effective communication'. A draft PPI strategic response was developed however this also coincided with the Francis Report, it was considered as prudent to await the outcomes of Francis.
2. To take account of the NICE Service User Experience in Adult Mental Health published in December 2011
3. To take account of the Francis Report published in 2013, ensuring the Trust has the structures and systems in place to allow it to adopt the key recommendations from the report.
4. A number of service user participants from the Involvement Register indicated inequity of involvement opportunities and favouritism

Findings from the review:

The themes below are based from feedback gathered at a series of workshops on the PPI Strategy. These workshops were attended by staff, service users, carers and two members of from the Council of Governors. More detail can be found in the Consultation Document. They also reflect comments received from a previous draft PPI Strategy which was circulated in 2012.

The key messages were that SLaM needs to:

1. To widen participation
2. Challenge the culture for patient experience so that it is everyone's responsibility
3. To ensure that PPI is real and honest

Gaps identified within the current PPI structure are identified in the table below:

Gap	Description
Need a strong governance structure	Currently the Trust does not have an overarching PPI governance structure. This means there is no one has an overview of all the PPI activity being undertaken within SLaM. PEG, TWIG Strategic, TWIG Operations work along side each other, but they all act independently of each other and other groups within the Trust. In practical terms this means that there is no central function which has an overview of all patient experience activity, data and findings. It also means that there is no formal route to share patient experience outcomes and knowledge with Trust senior staff or to the service user community. This makes it extremely difficult to assess the true extent and impact of PPI activities within SLaM
Need to widen Participation	One of the key recommendations from the Francis Report was for the need to widen participation. Feedback from the workshops strongly indicated that work needed to be done to widen the number of people involved in opportunities and the breadth of opportunities available. The current model has has narrowed participation.
Issues with TWIG Ops and TWIG Strategic	Staff and service users have raised concerns over the current structure of the TWIG meetings and the extent they encourage wider participation. The current model has been accused of hierarchical. The meetings also put considerable pressure on the service user chairs.

Proposals:

Introduce a new 'flatter' trust-wide group that is chaired by Senior Executive and Co-chaired by a service user or carer. This will replace all existing trust wide groups (PEG, TWIG Ops, TWIG Strategic).

The membership (highlighted Fig 1) for the new patient experience group will be made up of staff and service users and carers representing internal and external bodies.

The new group will meet monthly and have four main functions

1. To ensure that all patient experience data, information and involvement activities are centrally collated and assessed
2. To understand SLaM patient experience data (from surveys and focus groups) and communicate findings and recommendations
3. To support, advise and evaluate all trust wide patient experience priority projects for CQUINs and service improvements
4. To formally report to the Trust Executive and the Quality Committees
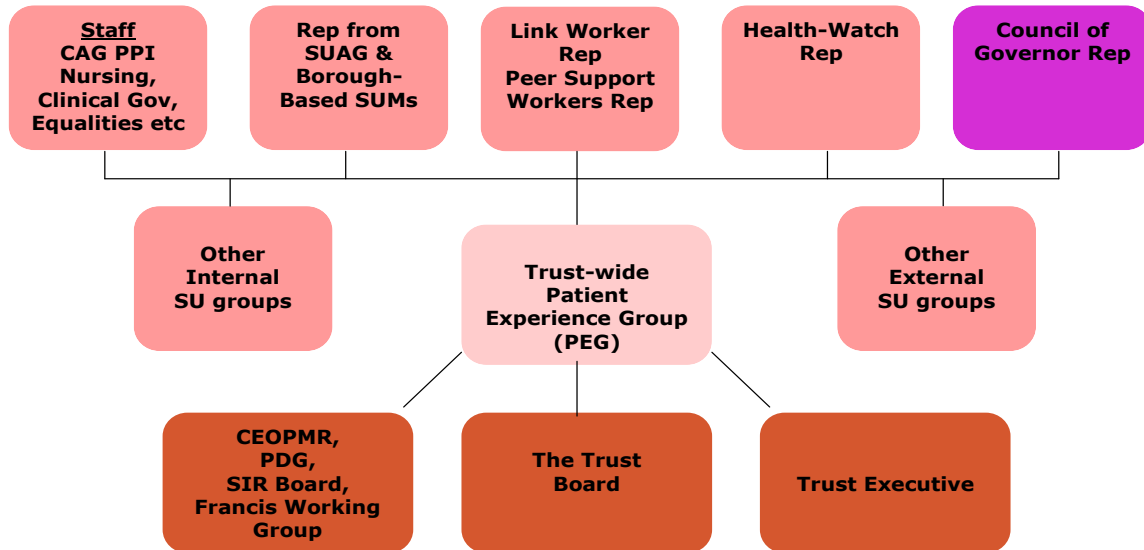
This new approach will bring the following benefits:

- A consistency of style, approach and philosophy to user involvement throughout the Trust making involvement fairer, more collaborative and streamlined
- Different types of activities will be treated with the same importance
- Provides strategic coordination and drive
- Provides an effective method of reporting to Trust Senior Management
- Provides fair and robust structure for all activities to thrive within
- Promotes and supports each CAG's SUAG
- Encourages embedding of involvement practices
- Provides professional and supportive governance

The new proposal will ensure that:

1. No one service user or carer should be made to feel that they are left with massive tasks of organising meetings or be put in positions where they take on responsibilities beyond their capabilty.
2. No one service user or carer will be in an elected or unelected position of authority without any formal direction.
3. Membership will be for individuals who represent another body (either internally or externally) - this will widen participation, increase communication, and open transparency.
4. Service users and carers will be much closer to the decision-making body and therefore have direct involvement in the decision making process. Each member will have a clear role and set of responsibilities

Fig 1

Internal PPI Governance

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│    Staff     │ │  Rep from    │ │ Link Worker  │ │ Health-Watch │ │  Council of  │
│  CAG PPI     │ │   SUAG &     │ │    Rep       │ │    Rep       │ │ Governor Rep │
│  Nursing,    │ │  Borough-    │ │ Peer Support │ │              │ │              │
│ Clinical Gov,│ │ Based SUMs   │ │ Workers Rep  │ │              │ │              │
│ Equalities etc│ │             │ │              │ │              │ │              │
└──────────────┘ └──────────────┘ └──────────────┘ └──────────────┘ └──────────────┘
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Other Internal SU groups

Trust-wide Patient Experience Group (PEG)

Other External SU groups

CEOPMR, PDG, SIR Board, Francis Working Group

The Trust Board

Trust Executive

PART B: The Involvement Register

A description of the Involvement Register

The Involvement Register (IR) was set up in 2007 in response *to Rewards & Recognition 2006 Guide - The principles and practice of service user payment and reimbursement in health and social care.*

At this time, it was felt that people should receive a financial reward for their contribution to specific work streams. The IR was set up to as a method to achieve this.

The IR provides payment in recognition for a person's input, experience or expertise. The payment is for ad hoc work. The IR is not intended to be or should be seen as formal employment. To join the IR an individual needs:

- To be sponsored (usually by their care co-ordinator),

- To undergo an occupational health check

- To be CRB checked.

There are three pay rates: £7 an hour, £10 an hour, £15 an hour. The rate assigned depends on the complexity of the activity. The Trust has no legal obligation to reward financially service users and the rates are more generous than many other comparable NHS Trusts.

Opportunities are assigned by HR depending on a person's experience and abilities. Some opportunities are also advertised on the TWIG Ops Blog.

Additional training on specific areas (such as attending meetings, running focus groups, taking-part in interview panels) is provided if required.

Currently there are 240 people signed up to the IR, with approximately 50-60 undertaking regular involvement activities. In 2012-13, the Trust paid £97,092* to individuals through the IR – *this figure is without taking NI contributions and travel expenses into consideration.

The IR is co-ordinated by an administrator in the HR department, who is allocated 12 hours per week for the role, which includes processing applications, supporting people through the application process, allocating opportunities and processing timesheets.

Why review the Involvement Register?

1. The number of people joining the IR has increased significantly since its inception. While it is heartening to see this increase, at the same time, both service users and staff have raised concerns about whether the current mechanisms within it are now fit for purpose to support this.
2. The IR was a new concept and it has not been comprehensively reviewed since it began.
3. The financial climate is changing significantly and although there is less money generally the IR changes are not financially driven, the monies available will go to a significantly wider group of people

The Involvement Register Review

The process has been a 'rolling review' whereby discussions have been held both formally and informally over a considerable time-period. Staff and service users were asked for their views about what works well with the IR and what could be improved. People were asked for feedback via email and at meetings. There were also 3 Involvement Register Review focus groups in 2011, which lead to the Involvement Register research led-by Psychologist student the outcomes of which were published in 2012. As with the PPI Strategic development it was considered as prudent to delay while awaiting external recommendations. However, the key findings are highlighted below which also acknowledges the input of the MAP advisory group, TWIG Ops and TWIG Strategic.

Key findings from the review

The process of joining the register	Many service users reported that the process of joining the register was onerous, citing the occupational health and CRB checks as lengthy and off-putting. The lack of resource allocated to the co-ordination of the register has lead to lengthy delays for people wishing to join The role of 'sponsor' or referee is unclear. More people who do not have a care co-ordinator are joining the register. There is an increasing need for non-clinical staff and external agencies to act as referees. This means that the notion of sponsor offering ongoing support is unrealistic. Service user welcomed access to the welfare benefits advisor.
Allocation of Opportunities*:*	Many people signed up to the IR are not being allocated opportunities. A relatively small number of service users are very active, across the boroughs and across the CAGs. These people are now highly skilled and very capable, whilst other people have not had the same opportunities to develop and practise skills. There are several reasons for this: • Many arrangements are made directly between staff and service users without the knowledge of the IR co-ordinator who should hold an overview of access to opportunities. Often, one opportunity leads to another as individual staff members develop good ongoing working relationships with the same service users. • Without specific criteria for joining the IR, there are no requirements in terms of confidence level or ability to contribute. Services are reluctant to pay for involvement where service users are less able to make an active or appropriate contribution. • For some, there are no limits on the amount of activities that people can undertake or timescales during which they can be active in any individual project.

Pathways through Involvement	Many service users expressed interest in using their experience gained through the IR to move into more formalised employment opportunities. They highlighted difficulties within the benefits system and lack of appropriate opportunities as barriers. There was concern that access to benefits and vocational support should not be reduced.
Involvement Work being	The IR was set up to pay for ad hoc pieces of work. However, some of the opportunities paid for through the IR are ongoing – either weekly or monthly. Without time limits, this has meant that

seen as a job	some people have been regularly involved in specific projects for many years. Some people have also developed a portfolio of projects that they are regularly involved in, meaning that they consistently undertake more than 30 hours a week involvement work. These cases can lead to service users becoming dependant on the income, with the arrangement feeling more like a 'job' rather than ad-hoc involvement activities.
Pay rates	The three hourly pay rates were set a number of years ago. Some individuals receiving payment through the IR believe that the pay rates should be increased to reflect the work they are undertaking. It has also been argued that the rates should be increased in line with inflation. Individual services and CAGs have been encouraged to identify budgets for payment of service user. There is a lack of consistency in this between and within CAGS. Some services are happy to pay for the expertise of service user – others are unable to identify the resources. Some staff and service users argue that payment should not be made for involvement activity and that it should all be undertaken on a voluntary basis with out of pocket expenses paid only.

Support	There was consensus that it is important that people are offered appropriate support whilst taking part in IR opportunities. There is an expectation that the individual's initial sponsor would provide this support, however, in most cases this has not taken place. This gap has affected some people's mental wellbeing. A few people who are engaging in a number of involvement projects have been offered or requested mentoring and supervision from SLaM staff to help them manage their work loads. It is not clear whether staff members are unable to meet this demand on an on-going basis, especially if demand grows. Some staff have expressed confusion around support, supervision and accountability mechanisms with those people undertaking involvement activities.
Training	It was agreed that IR members may need some training in order for them to develop their skills around certain tasks. Currently, there is no capacity within the IR for training to be provided as a matter of course. Some training for service users has been developed and delivered through TWIG Ops, but funding for this is not agreed for future trainings. Individual CAGs have offered some training opportunities, but there

	is no co-ordinated approach to training for service user across the Trust.
Overall Management	Although the IR is co-ordinated by a member of staff from Human Resources, it does not have an identifiable management structure. This has affected the speed at which changes can be introduced and issues being addressed. It is also acknowledged that the IR is understaffed which has contributed to a backlog in people registering.

Proposals

The proposals below were developed following a meeting between key SLaM staff which was held on 16th April 2013 to discuss the next steps.

Work previously undertaken on the IR as detailed in this document informed the discussion and recommendations below. This included feedback on the IR from staff and people being paid through it, the creation of a risk register which identified and rated concerns about the IR and a presentation given to the executive by the Chair of TWIG Ops and the Strategic PPI Lead.

1. The process of joining the Involvement Register

The current criteria for joining the register is simply that people have direct experience of services, through using them or via a caring role.

Additional criteria will be developed so that those for whom it may be appropriate to initially engage in voluntary involvement activities can be signposted to more appropriate opportunities.

Occupational Health assessments will continue to be required to ensure that people are offered appropriate opportunities and support where needed. CRB checks will also continue to be required to ensure individuals are placed appropriately.

The role of the 'sponsor' or referee will be made more explicit, and particularly the expectation that they provide contact and support around involvement activity. (Further discussion will take place about people who are not in contact with clinicians within the service – for example those who have been treated in primary care, or carers or family members).

2. Opportunities that can be paid for

Individuals on the IR will receive payment where a specific outcome or contribution is required such as:

      a. Delivering training
      b. Making specific contributions to meetings
      c. Undertaking LINK working or facilitating focus groups
      d. Undertaking audits, service reviews, evaluations
      e. Taking part in recruitment panels

Each opportunity will have a clear description covering:

- what is expected from the role
- skills required,
- any supervision structure
- support and training

This will enable people to be matched to opportunities appropriately.

Attending training will no longer attract a payment as people are rewarded and recognised appropriately by gaining skills and knowledge.

3. Allocation of Opportunities

In order to encourage wider participation from IR members and increased 'flow through the system' the following restrictions will be introduced:

- The total number of hours an individual can work through the IR will be limited to 30 hours a month.
- Individuals can work on a specific project for up to 2 years unless the specified number of hours has not been exceeded. This is designed to ensure that opportunities are shared throughout the IR.

For some people these restrictions will represent a significant reduction in hours of paid involvement work or involvement in opportunities coming to an end. In order to help people plan for this change there will be a notice period so that people can make necessary adjustments. However, most will not be affected and the increased numbers of people able to take opportunities is desirable overall.

4. Pathways through Involvement Register

As more formal volunteering opportunities and training programmes are developed within the Trust,

- work will be done within the IR and within the PPI teams to link appropriate volunteering opportunities with IR opportunities.

In this way, people may gain confidence and skills as a volunteer and progress to some ad-hoc paid involvement work within the IR.

For those on the IR:

- signposting to existing vocational services within and external to SLaM will continue
- access to the welfare benefits advisor will continue.
- relevant employment opportunities as they arise within the Trust will be highlighted to those on the IR.

5. Payment

Two rates of payment will be introduced. A flat rate payment of £10 an hour will be introduced for all people aged 16 and above.

Ten pounds is proposed as it is mid-way between the current three rates and is the rate which is currently paid for the majority of involvement work. The proposed payment rate exceeds that of comparable Trusts and is greater than the minimum wage and the London Living Wage.

A higher rate of £15 an hour will be introduced for a small number of service users who take on more complex work such as chairing meetings, presenting at conferences. A very strict set of criteria will be developed to ensure this higher pay band is used appropriately. People paid on this higher rate will be those who are moving towards being job ready and seeking employment.

For some tasks, this will represent a reduction in payment. In order to help people plan for this change there will be a notice period so that people can make necessary adjustments.

Removing all payment was discussed but it was felt that financial reward should be given for some work streams due to the time commitment and expertise required. However, the Trust's position will reviewed in 12 months' time.

6. Support and supervision

It is acknowledged that involvement activities can be perceived as 'therapeutic' and a contribution to people's recovery journey. However, the IR as a mechanism does not provide a therapeutic intervention and staff organising involvement activities are not expected to have clinical support skills. Support and supervision associated with involvement activity can only be around the content of the involvement activity, not someone's mental wellbeing.

Therefore,

- For members of the IR who are currently using SLaM services, sponsors (limited to clinical staff) will be expected to offer the necessary therapeutic support.
- We will explore other systems for supporting members of the IR who are no longer linked formally to SLaM services. This could include encouraging staff to take on a mentoring role with people, or peer support systems which may be external to the trust
- All members of the IR will be asked to complete a brief 'Wellbeing Recovery Action Plan' (WRAP) which they will be invited to share with staff for whom they are undertaking activities. This will be a way of communicating informal support needs around physical and mental wellbeing.
- As is current practice, staff engaging service users in involvement work have a responsibility to offer adequate supervision for the work being undertaken, this will be mainly linked to the work itself and will form part of the Real Reward and Recognition Policy (in development).
- Supervision, mentoring and coaching will no longer **be paid for via the involvement register**.

7. Training

It is recognised that a co-ordinated approach to training for service users needs to be developed across the trust. There is currently no funding identified at a Trust level that can be allocated to a training component of the IR. Whilst some training is available via CAGs and through TWIG Ops it would be more efficient to integrate 'core training' across the Trust, particularly as many service users engage in involvement work across different CAGs.   For this reason:

A work stream will be developed to explore training for service user, bearing in mind existing activity such as TWIG ops Training, volunteer training programmes and forthcoming opportunities such as the Recovery College

8. Next Steps

Over the next 6 weeks there will be the opportunity to feedback into this process (contacts below) there will also be an Engagement Process Group who will review the process set out below.

Please give us feedback on the proposals:

The proposals have already been agreed by the Trust Executive and PPI Leads from each CAG. We now want to hear from you

Feedback Period

There will be a 1 month period for people to give feedback to this review. We would like to hear your thoughts on:

- What you like about the ideas proposed,

- Your concerns

- Any ideas to make it work even better

How to give feedback on the proposals

Feedback may be given by:

Attending our feedback event, planned for Thursday 14th November at the Ortus Centre from 10am to 12pm followed by lunch. Booking is essential. To book a place or for more information please contact Mariana Bakewell – Tel: XX email mariana.bakewell@slam.nhs.uk

Email – PPITeam@slam.nhs.uk .

In writing by sending an e-mail or letter to:-

Dr Ray Johannsen-Chapman
Strategic Lead for PPI
South London & Maudsley NHS Trust
Maudsley Hospital
Denmark Hill
Camberwell
London

Fax:
Email: ray.johannsen-chapman@slam.nhs.uk / PPILeads@Slam.nhs.uk

Or by speaking to one of the PPI Leads, contact details are listed below:

The deadline for feedback is *Friday 22nd November 2013

All feedback will be considered. Within 4 weeks, We will then issue a final paper detailing the themes from the feedback and any alterations to the proposals

Contacts

Name	Position	Contact Details
Dr Ray Johannsen-Chapman	Strategic Lead for PPI Please also contact if you attend services under Addictions	Tel: 0785490099 Email Address: Ray.johannsen-chapman@slam.nhs.uk
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