Trust Wide Involvement Operational Group
Meeting Minutes

Monday 14th May 2012
11AM – 3PM, Maudsley Boardroom

In Attendance:

Ray Johannsen-Chapman (**RJC**)	Co-Chair Strategic Patient & Public Involvement Lead
D Rosier (**DR**)	Co-Chair Service User Consultant
Anne Kirby (**AK**)	PPI Lead, Psychosis CAG
Bill Berry **(BB)**	Minutes
Carmine De Rosa (**CD**)	Service User Consultant
Vanessa Bray (**VB**)	Vice Co-Chair TWIG Ops and Food lead, Southwark
Liz Dalton (**LD**)	Food Project Service User Consultant
Martin Saunders **(MS)**	Southwark Link
Gillian Ashwood (**GA**)	Recruitment and Selection Training Project Worker
Bridget Jones (**BJ**)	Service User Consultant – Operational Lead Food Project
Andrea Woodside (**AW**)	Recruitment & Selection
Reagan Edminston **(RE)**	PPI Lead B&D CAG (part-time)

Apologies:

Alice Glover (**AG**)	MAP/Psychological Med CAGs
Nick Hervey (**NH**)	Head of Social Care
Kim Clarke (**KC**)	PPI lead for Addictions CAG
Stefano Peria (**SP)**	Psychosis SUAG
Nuala Conlon **(NC)**	PPI Lead Older Adults CAG

Item	*Business Item*	*Action by*	*Date*
1.	**Apologies** Received as above.		
2.	***Matters Arising*** Minutes of the meeting on were agreed as an accurate record		
3.	**SLaM TWIG Ops Blog** D asked group to submit articles for publications – not many postings means that Blog not used to its maximum. RJC suggested that the Blog could be used to share academic on a wide range of topics. An 'Academic category could be added		
4.	**Members Council** Paul Paterson unable to attend - RJC write to the Members Council asking for a rep for TWIG Ops	RJC	Before next TWIG Ops

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5.	**Report TWIG Strategic** Caroline Hough elected as the interim Chair of TWIG Strategic – next 3 meetings are monthly, current focus is the PPI Strategy. **RJC** added PPI Strategy had been delayed as the NICE Service User and Clinical Guidelines expected in October 2011, was delayed until 2012 - the Trust are expected to take account of them.		
6.	**PEG (Patient Experience Group) Meeting** **VB** outlined that PEG concentrated on CQUIN targets and PEDIC survey questions **RJC** gave an outline of PEG – why and how it started, the areas it generally focuses on, and highlighting the strength of its membership. PEG does not formally report to any body within the Trust – but the Medical Director is the Chair and that determines its power. PEG and both TWIGs need to find a formal route for reporting.		
7.	**Blog postcards and poster** **D** provided Blog postcards and posters offering members to take what they needed – D suggested postcards on every ward.		
8	**Project updates - Food Project (non borough)** **BJ** fed back about the training day on the 24th May to provide training to more people survey service users. Following food presentation the group was linked up with Yorkshire and Humberside Service User group who have done a report on food, Bridget happy to share presentation and reports to the group. **RJC** suggested it would be interesting to compare Humberside reports with SLaM outcomes **Southwark Update: (VB)** **VB** Meetings scheduled once a month on wards and working on action plans. Difficult to get the wards to respond. We need a refresher training course to refocus what we are doing. Things need to made clearer with staff and reinforced as the issue and process is not taking this seriously e.g JBC and AL3 ward not responding as they should when trying to organise monthly meetings. There are Helpline posters for any issue with the food staff should contact Aramark and let them know where issues. **RJC** Asked Bridget and Vanessa for their views of Aramark, are they responsive? **VB** there are some issues they won't budge on e.g. portion sizes. They fundamentally won't move on portion sizes they say they have been agreed with the nutritionists this is what you are going to get but people on the wards say that it's not enough for me. However things have improved.		

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	RJC understood that service users were quite happy with food in Lambeth and Lewisham where the food is not supplied by Aramark, might be worth benchmarking portion sizes **Lambeth Update:** Results from the bench marking survey for Lewisham and Croydon to be circulated asap		
9	**Content Analysis** **D & LD** trained 9 service users. The training starts by asking questions about the value of being a service user, receiving more positive comments than negative. We then did a fake content analysis, using D&P on the ward survey. The analytical feedback D&P was engaging, the respondents found it interesting and challenging.		
10.	**Information Stalls** **JA** explained that she has worked under the supervision of Ros Byfield run a number of stalls in GP practices. The Practices had little information on mental health awareness only information on physical health. We gave out information leaflets about mental health awareness. Very positive feedback from patients and staff – highlighting the need for greater collaboration between SLaM and GPs. Ros Byfield is compiling a report together for Trust Leads on the outcomes. **RJC** added the importance for Service Users to enquire whether their GP Centre and Patient Participation Groups (PPGs) as it could be avenue to further promote mental health awareness. **MS** stated that PPGs play an important role in Southwark, each commissioning GP practice must have a patient group and each is grouped to a locality group, this in turn sends representatives to the wider commissioning group. This is part of the Commissioning Board which feeds directly into the commissioning. **DR** We should put this on the blog and encourage people to join a participation group where available and encourage people to set one up where there isn't one. Martin and Ray to put something together	RJC and MS	Before next TWIG
11.	**Nightline** **(BJ)** Things have gone a bit quiet at the moment Derek Nichol is putting together a business proposal to present at PEG. Awaiting further nightline meeting		

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12.	**Recruitment and Selection** **VB**. Vanessa has been appointed as Andrea's mentor we are also looking for a project worker to join that team. We don't have any service users trained to sit on recruitment and selection panels.		
13.	**Borough reports** **SWIG** we ran another SWIG workshop although it was meant to be for all psychologists in Lewisham the only attendees were psychologists from the psychosis CAG. The feedback was very good and we hope it will motivate some psychologists to go out there and undertake more user involvement work, that's what the purpose was. Report to be put on the Blog **RJC** asked **CR** if he felt this was the right forum to discuss why he resigned as Link Worker in Ladywell. **CR** one main reason when you have a mechanism for collecting SU feedback if there's no structure or mechanism to receive that feedback then the whole thing becomes meaningless and frustrating. D asked whether RJC could write a paper on how TWIG Ops can relate to Link workers. **Focus Group Training** **VB** explained that 11 people are attending the next training session. After they are fully trained they are passed over to D who allocates them to focus groups.	RJC	Before next TWIG Ops
14.	**CQUIN's** **RJC** The Trust has to meet CQUIN targets, one domain is patient experience; SLaM's targets are, nationally the most demanding. There is money attached so we have to hit them. RJC explained the CQUIN demands. RJC to discuss with Paul Calaminus and Julia Gannon what would be the most appropriate way for TWIG Ops to be involved.	RJC	
15.	**PPI Leads Update** BAD CAG very new to this and Reagan only in post a few months prior to my appointment there wasn't a dedicated PPI Lead in the CAG, it was only part of some ones role. What is good is that now we have a Service user and Carer Advisory Group which is small in numbers but doing some excellent work. **B&D Projects include:** Reworking our patient information leaflets to ensure the language and content is right, the aim of the information group is around language accessibility		

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	Improving use of visiting suites in forensic services, we are holding focus groups in June to begin this assessment. There are special challenges for our CAG e.g. our forensic services and the long length of stay, for some this can be two years. There is a lack of opportunities to be to be formerly involved in things like the involvement register. We are trying to create opportunities for patients to become involved as they move through the service and are nearing the point of discharge. Another area we cover is learning disabilities, again a tricky area, to have people that are functioning well and able to communicate well enough to be able give feedback consequently we have a lot of carer involvement. There are a number of Learning disability forums outside SLaM so we may not be running something locally. I have just discovered a criminal justice user forum as well which is made up of ex-offenders some of whom may have used our services not just our forensic services. We hope to link in with them. **VB** added when she went into River House to run an art club she wanted to thanks Sharon Wellington who was brilliant and instrumental in supporting this work, it was one of the most rewarding we have done. **Psychosis CAG** D asked if anyone from the SU advisory group could provide an update. **CDR** feedback on the pathway focus groups. Some of it is complete but the bit still outstanding is the early intervention pathway. Psychosis CAG is consulting in four areas; Acute, community, early intervention and complex care. **MAP CAG** MAP recent consultation event at Cambridge House. At the event both Steve Davidson (Service Director) and Jonathan Bindman (Clinical Director) discussed future plans for psychological therapies. Alice Glover is in the process of compiling a report		
16.	**My Health Locker** **D** introduced David Newton who is the Trust's Project Manager for My Health Locker. **DN** asked how many people around the room had heard about Health Box (since renamed to My Health Locker) only a small number were aware of it. My HealthLocker is an environment where SUs can be actively involved in every element of the care and treatment they receive. It can also be used by SUs to keep a record of their personal wellbeing, which can help them afterwards to figure out what made them unwell. It shifts the emphasis al little bit away from the clinician. DN provide a presentation to the group – which will be circulated		

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	RJC had a comment about who in reality might use this system and that there is the danger of creating a gap between the information rich and the information poor – in other words the very vulnerable who might be "information poor", and therefore lose out on the empowerment process. DN replied that the Health Locker links can be accessed across all libraries and the Trust are looking to support service users. Presently, the system is being piloted with two services you can put information there about every day staff like the		
17.	**Benefit changes** Carol Waylett (Trust Welfare Lead) and two welfare advisors, Shelley Leckey and Sian Edwards presented to the group about the benefit changes. CW explained that as everyone knows that the government were making significant changes to the benefit system that will impact SLaM SU's, some key points: • Working age DLA for new claimants will be abolished from April 2013. • Replacement is "Personal Independence Payments" (PIP) – May eventually apply to younger and older claimants • After some pressure, the government agreed to a staggered introduction of PIP from April 2013 • Government is seeking 20% reduction in spend by 2015/16 – Government seeking £2.1 billion, savings' – Possibly 577,000 current/new refusals needed to reach £2.1 billion – Latest projections say claimant caseload may reduce by 23% • Second draft regulations were published in November 2011 • Draft PIP Activities, Descriptors and now known asThresholds • Consultation period on second draft regulations ended on 30.4.2012 • There may be more changes, the extent is not known • Those on Attendance Allowance are unaffected The issue of housing benefit was discussed and how it was to be paid, there were issues around benefits being paid into bank accounts and where there is multiple occupancy of buildings. The themes discussed caused real anxiety for some people and Carol apologised if she was unwittingly caused upset. All acknowledged that it wasn't Carol's fault it was the realisation of the potential		

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	impact. CW also mentioned that there was a belief that the anxiety and fear caused by the changes could result in more inpatient admissions and that there was some evidence of that around the country. CW asked that if there was evidence in SLaM it should be sent to her as all dealings with the Department for Work and Pensions end up in the call for evidence to support the impact the a changes were having. D asked to group to bear that in mind. **NB (there are two documents attached, Disability Rights Fact Sheet and Main points about changes from Disability Living Allowance (DLA) to Personal Independence Payments (PIP)**		
18.	**Advance statements** VB outlined the work she put together on Advanced Statements: An Advance Statement is a written expression of the wishes of a person who experiences mental illness regarding their treatment and care. It is drawn up when the person feels they are well and competent, to be taken into account in the event of them facing a crisis (Rethink, 2007). Advance Statements differ from Advance Directives as they are broader. An Advance Statement includes active and positive suggestions whereas an Advance Directive is a refusal of certain types of treatment. As the Mental Health Act can override the directive, a statement is more commonly used for people with mental health difficulties. Many SLaM CMHTs will have Crisis Plans and many service users will carry crisis cards. It is recommended that when completing an Advance Statement for TWIG ops that the individual also takes these documents into account and that their care co-ordinator is aware of the statement in order to avoid any contradiction in requests. It is legally binding if written when the person is understood to 'have necessary capacity'. However it can be overridden by a section under the Mental Health Act. Doctors also have the right to replace one treatment with another if the first request is not available or if it is illegal or may cause harm. In conclusion, Advance Statements are worth having in conjunction with crisis plans as they are user led. They can increase the likelihood of a person's wishes being adhered to and therefore reduce their level of distress. Copy of a draft Advance Statement is attached in the appendix.		

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	Potential for the AS being on EPJs – RJC and VB to discuss at future date D could we take two minutes to think about how we can encourage people to fill this in.. For the next meeting you have this as a target for a launch.		
18.	**Any other business** None		
19.	**Dates of *next* meeting:** 6th August 10am to 2pm in the Board Room		

Advance Statements for TWIG ops

An Advance Statement is a written expression of the wishes of a person who experiences mental illness regarding their treatment and care. It is drawn up when the person feels they are well and competent, to be taken into account in the event of them facing a crisis (Rethink, 2007). Advance Statements differ from Advance Directives as they are broader.

An Advance Statement includes active and positive suggestions whereas an Advance Directive is a refusal of certain types of treatment. As the Mental Health Act can override the directive, a statement is more commonly used for people with mental health difficulties.

Many SLaM CMHTs will have Crisis Plans and many service users will carry crisis cards. It is recommended that when completing an Advance Statement for TWIG ops that the individual also takes these documents into account and that their care co-ordinator is aware of the statement in order to avoid any contradiction in requests.

An Advance Statement is intended to be an act of empowerment, where service users can feel more confident that their wishes will be implemented when they are unwell. This will be more likely if doctors and care co-ordinators are informed and involved. Also, a study at the Maudsley in 2005 showed that people who had an Advance Statement experienced a reduction in the number of compulsory admissions under the Mental Health Act (Rethink, 2007).

It is legally binding if it is written when the person is understood to 'have necessary capacity'. However it can be overridden by a section under the Mental Health Act. Doctors also have the right to replace one treatment with another if the first request is not available, or if it is illegal or may cause harm.

In conclusion, Advance Statements are worth having in conjunction with crisis plans as they are user led. They can increase the likelihood of a person's wishes being adhered to and therefore reduce their level of distress.

I include an example containing the information as recommended by the British Medical Association's Code of Practice. Copies should be retained by the individual, TWIGops and the person's care co-ordinator. It is also recommended that the people who have been named on the form are aware of the fact. They should be signed and witnessed, and able to be withdrawn or altered at any time at the person's will.
VKBray 23/04/12

Advance Statement for TWIG ops

Name: Mary Bloggs

Address: 85 Southwark Street, Southwark, London SE22

Phone: 0207 7777777

Care co-ordinator: Judy Smith, Central Team CMHT, Southwark, 0207 6666666

GP: Dr Jones and partners, Southwark SE22

IN THE EVENT OF A CRISIS (with details):
I would like you to contact :
Joe Bloggs, brother, 07788 999333

I nominate the following individual/group as my advocate:
Mental Health Club, Southwark

My next of kin:
Joe Bloggs, brother

If I am treated I would like the following:

- **What has worked:** Codeine, Amisulpride
- **What has not worked:** Clormazepam

My physical health needs:
I have asthma and need to have an inhaler

My cultural/spiritual needs:
I need to be allowed to pray at X time
At home I would like the following to happen:
(Children/pets/security etc)
Ask my brother to feed my cat

I would also like the following to be taken into account:
No restraints as I will panic and have an asthma attack
DATE: 23/11/11
SIGNED:
WITNESS: