



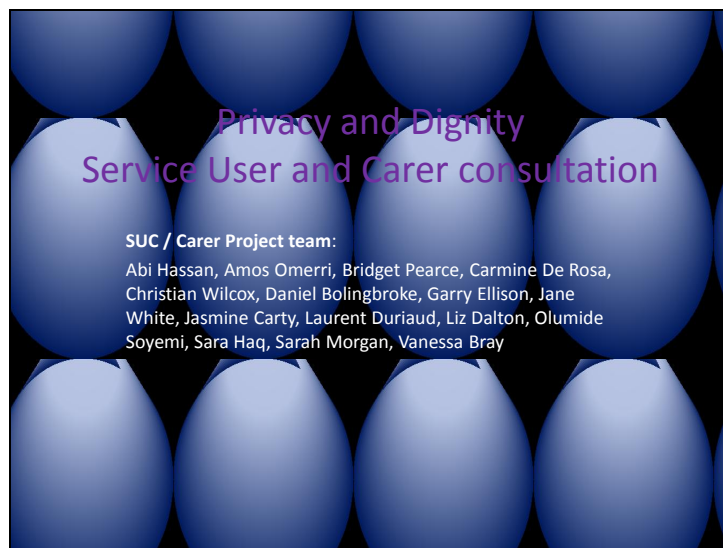
Privacy and Dignity Service User and Carer consultation

Commissioner:

Natalie Warman (Assistant Director of Nursing with responsibility for physical healthcare)

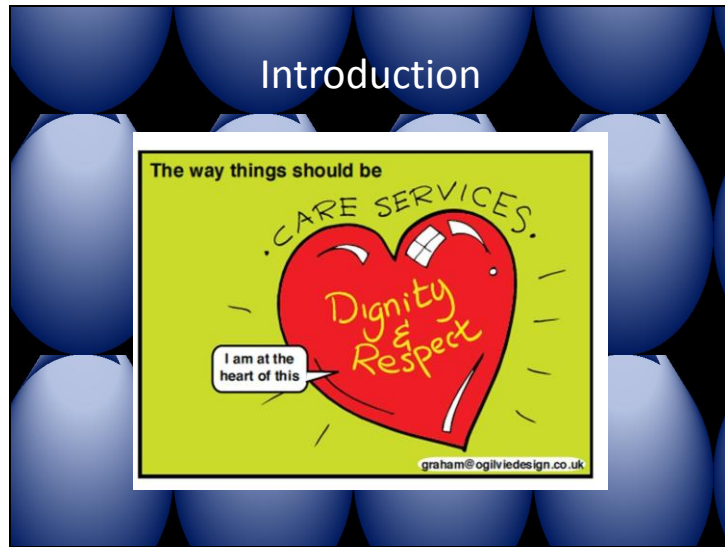
Project co-producers:

D Rosier (Service User Consultant) and Alice Glover (Patient and Public Involvement Lead: MAP CAG)



16 Service User Consultants in total, including some new to involvement.

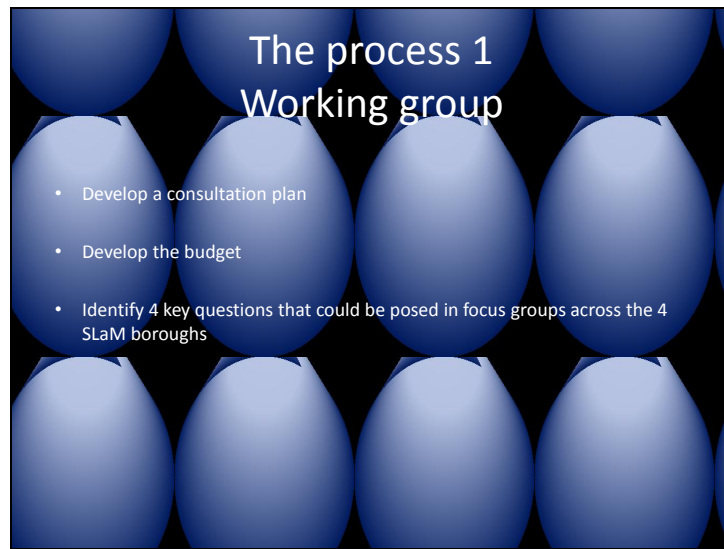
Introduction



As part of the development of a Trustwide Privacy & Dignity Strategy, Natalie Warman approached the Operational Trustwide Involvement Group in Summer 2011.

The operational arm of the Trust Wide Involvement Group is designed to ensure that a wider range of service users are involved in the improvement and development of SLaM services, and to look across the Trust and externally to influence and develop good practice, innovation and service user research.

The aim of this consultation was to engage people with experience of using SLaM services in the process of identifying what is important to service users and carers about privacy and dignity.



Whilst staff were available to support the process where necessary, the management and co-ordination of the project was led by people with experience of using services. A working group was established where service user consultants worked alongside staff to:

Develop a consultation plan ,

Develop the budget,

Identify 4 key questions that could be posed in focus groups across the 4 SLaM boroughs.

They were: What does it mean to have your privacy maintained?

What does it mean to be treated with dignity / respect?

Are there any barriers that prevent you having your privacy and dignity maintained?

What are your suggestions for improving the privacy and dignity of people that use our services and family / carers?

The process 2 TWIG Ops role

- Ensuring service user consultants were recruited, trained, briefed & supported to run a series of focus groups
- Ensuring the project ran to time
- Managing & overseeing the content analysis
- Writing the report

The process 3

Admin, publicity, training

- A service user consultant co-ordinated the arrangements for the focus groups, contacting the venues and overseeing booking details including refreshments
- A service user consultant and a carer jointly developed publicity for the focus groups
- A service user consultant and staff member delivered a training session on facilitating focus groups

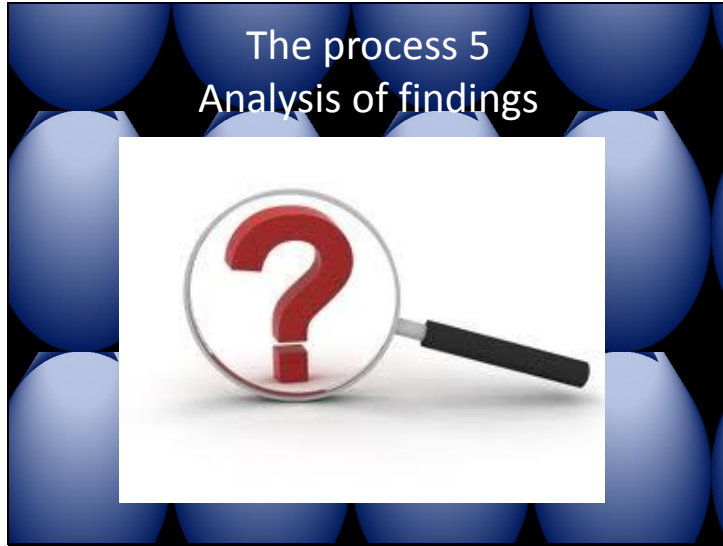
The process 4 Focus groups



We ran 10 focus groups, with at least one in a community setting and one for inpatients in each Borough, as well as one specifically for carers.

Twenty-eight people attended, and one person gave feedback by email.

The process 5
Analysis of findings



Done entirely by Service User Consultants, trained from previous projects.

Emergent themes

- Environment
- Stigma
- Patients' Rights
- Communication
- Interfaces
- Treatment
- Staff
- Carers

Dignity comes not from control, but from understanding who you are and taking your rightful place in the world.

Theme 1: Environment



A number of participants felt that the ward was not a therapeutic place, and one participant reported: "It is hard to feel dignified in an environment where people are agitated."

A number of participants reported issues related to leave: "consistent and clearer leave" was needed, and it was desired to "have a more flexible form of hospital care."

A number of participants commented on issues related to the fabric of the building: "some of the buildings are terrible. The environment is a question of dignity."

In terms of visitors participants reported a number of issues related to improving access and space for visitors. The participants commented on children visiting. One suggested "more space for visitors".

In terms of the cleanliness of the environment a number of participants reported issues with cleanliness. The toilets and bathroom need improvements: it was desirable "to have clean toilets and facilities", and it was felt that "having clean quarters, i.e. toilets, bathrooms etc, is important."

Theme 2: Stigma



One participant reported that the disclosure of mental health problems in employment was an issue as “relapse may result in losing your job.”

Regarding assumptions, one participant said “it should not always be assumed that you are lying.” Another said that it was desired and important “to be regarded as innocent until proven guilty, rather than the other way around.” It was also cited that “being believed” and “having credibility” was a big issue.

In terms of labels there were a lot of comments around the negative effects of labelling, for example one person said it would be good “not to feel identified by your diagnosis.” “Labels like borderline personality disorder are a stigma and a barrier.” Also it was said that “being labelled by your mental health problem is unhelpful”.

Theme 3: Patients' Rights



In terms of spirituality participants felt that their religions were not being respected. Others also felt ignored when they asked to see a vicar: "When I first went into hospital my diagnosis was paranoia. I asked to see a Priest but was ignored."

One participant made a positive comment about dignity and the support their family member received: "Dignity is difficult to balance. The support systems in place in [Borough], and the Consultant and Care Plan Worker's vision have been tremendously helpful in maintaining an inner calm and dignity. And [x] himself is a remarkably resilient person. The above all has helped us to understand things."

"Being physically restrained can be very undignified. Better options should be considered."

In terms of basic rights most participants commented that they are not being valued: "I felt I wasn't treated like a human being." "I felt like I did not exist. I did not feel valued". Others felt that they didn't have a choice, and were being forced to do things: "patients are not kept informed and have no choice." It was desired "not to be forced to do things."

In terms of gender, some participants commented that they prefer to have a mixed ward rather than a single sex ward, while others said they preferred "not to have male staff on a female ward." Another commented that "male staff not to be involved in forcible actions, i.e. stripping, drugging, and so on of female patients, and vice versa."

In terms of physical space, participants said, "A patient's bedroom should be their private space – where possible no one else allowed in, not even staff." It was also desired "to be treated fairly and respectably, to be able to wear decent clothes that aren't too revealing," whilst another said "everyone should have a key to their own room." Also, another participant preferred "being asked, helped, and encouraged instead. People should not be forcibly stripped and washed."

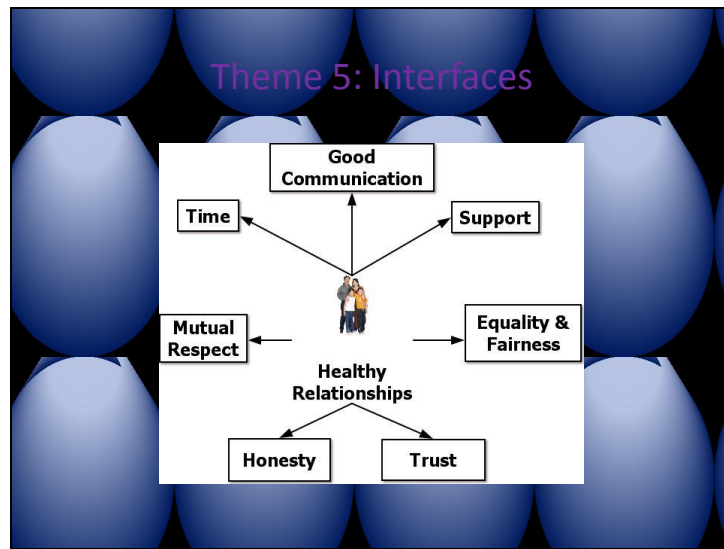
In terms of emotional space participants felt that they should be treated with respect, whilst others felt they are being treated like children: "Having respect for when someone wishes to remain silent or be alone" was desired, and not "being belittled".



There was a lot of general feedback about “unclear communication” and a “lack of information.”

In terms of verbal communication, the main issues were concerning how staff spoke to patients and general communication between staff and patients. It was reported that there were language barriers when staff spoke “poor English” and it was “frustrating.” A suggestion was that more training was needed. One person said they were spoken to in a way that made them feel disrespected. Another view cited was that there should be regular meetings “between patients and staff regarding privacy and dignity.”

In terms of formal communication, it was reported that practices were sometimes unsatisfactory for instance one person said the “GP doesn’t always have my notes up to date” and another said that “assessment can be very repetitive and sharing personal information with mental health professionals can be frustrating when agencies don’t pass information on.”

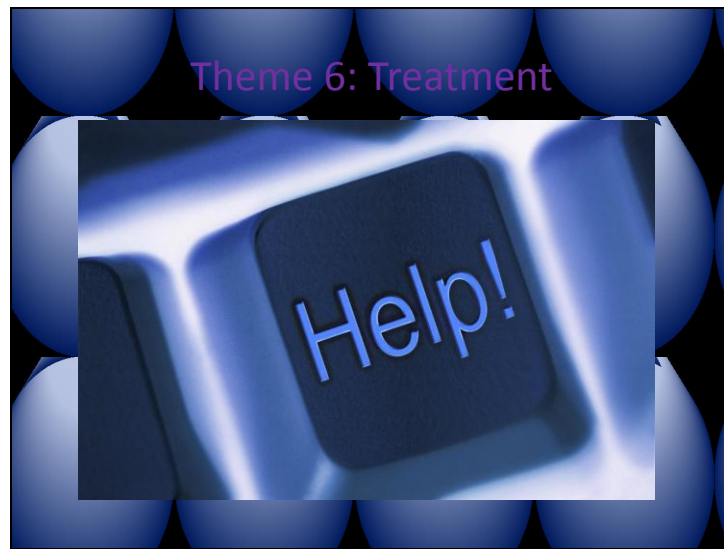


Participants reported that it is important to remember to respect that some people “with mental health problems also experience physical health problems and vice versa.” Also to note that as a mental health patient going into A&E for a physical problem it is often assumed that the matter is mental health related.

Regarding GPs, a positive comment was that the participant’s GP “knows when I’m becoming unwell and makes the appropriate referral ASAP.” A more negative comment was that sometimes when service users get “passed between GPs and A&E” and that this results in the participant feeling “unwanted and un-valued.”

One participant suggested “if taken to hospital under a section, to be allowed to pack a bag and take it with you.” Also another participant reported the desire not to automatically always have one’s mobile phone taken away regardless of the particulars of the case on triage. One participant was treated indignantly by the police “(violence).”

The question of a participants personal dignity came into the comments; “[Borough] no longer has an out of hours advice line, now being advised to contact the Samaritans,” which impacts on a participant’s dignity.

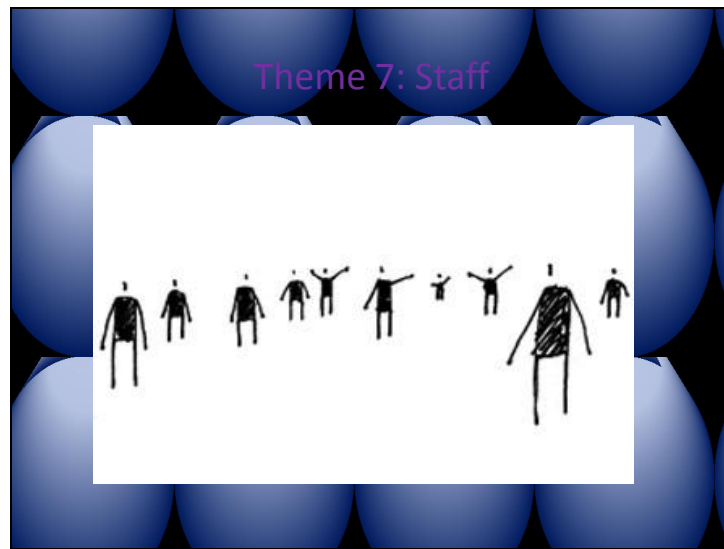


In terms of medication, most comments from participants were negative, “not to have to queue for medication” and “medication to be kept confidential from other patients.” Only one positive comment was mentioned that, “medications brought to patients rooms. Observations done in privacy.”

Generally participants felt that there was a lack of involvement in their own care and they were not encouraged to get involved. “Asked my care coordinator a question about my medication and the care coordinator blew his top saying are you challenging my professionalism?” It was also mentioned that there is a lack of one to one meetings and “inconsistent regimes on the wards.”

The overall report was that participants felt a more person-centred and more holistic approach to treatment should be implemented. While they felt life and should get better, two participants commented on respect and value, “valuing each other” and “respect is reciprocal.” One participant asked for “help outside of hospital to put or remedy the possible external causes off ill-health”.

Some participants felt they are being forced to take medication and treatment. “Medication is regulated without consent” and “patients still being forced and held down to be given medication.” Other patients felt that they should be encouraged or helped to do things, as opposed to being forced.



Participants reported that mutual trust, listening skills and politeness were of paramount importance. Staff should take “direct responsibility” when questions are asked and a few participants commented that “trust needs to go both ways.” Compassion and empathy are necessary for staff to “respect the boundaries of patients.” One participant reported that staff should “not always be in a rush.” “To be treated with courtesy” meant that it was possible for participants to “respect staff due to being treated well.”

There were a large amount of comments by participants on the ill-treatment by staff. Issues ranged from “staff interfering in our business” to “being ignored”, to “confrontational in exercising their authority” and “being threatened with the section system by staff.” Participants were concerned by a lack of respect, with staff “kissing their teeth”, “barging in without knocking” and “being told what to do by staff who are much younger than me.” It was recognised, however, that some problems were due to “not enough staff” and “staff overstretched.”

There was also the feeling “as though aspects of your case might be getting discussed at the pub.”

There were many comments about staff training , which fell into three categories: general training, service user training to staff and involvement (SUCs).

It was reported that there was a lack of training. It was suggested that there should be “a minimum of one day training on treating patients with dignity – mandatory.” Also that there should be more “awareness from non mental health medical staff.”

Participants also stated that there should be “attitude and awareness improvement” and “training in cultural awareness.”

Participants made many comments regarding service user to staff training e.g. “service user lead training”, “training delivered to staff by service users.” Also that training should be given to all non clinical staff including cleaners, and that they should have training “from service user consultants re: dignity.” One participant suggested that “receptionists to have SUC and mental health awareness training.” Another suggested that staff should experience what it is like to be an inpatient, and that the “leaders of the CAG teams to receive training from service users.”

In terms of the role of SCU involvement, one suggestion was that “service users trained as secret shoppers on wards and in CMHTs.” One participant said “patients find it easier to talk to linkworkers, not the nursing staff.”



In terms of communication, most participants commented that carers should be better informed by staff and also informed about medication and diagnosis etc.

Others commented “visitors and family members not informed that they can take service users off the ward even if they are sectioned.”

A participant was “indignant to receive standard letter (to family) stating that ‘carer/ family member has mental needs.’ ”

In terms of visiting, participants commented “no definite defined private space for visits from family and carers.”

It was also noted that there were “unflexible visiting times” and “visit delays are provocative.”

In terms of recovery, participants commented that they would like to have family and carers involved as much as possible “to allow patients to have family/ carers involved at important stages throughout treatment and care.”

It was also suggested “to have minimal amounts of your case discussed with carers (medication & diagnosis) but not intricacies such as self-harm.”

Full report

Available to download at:

<http://slamtwigops.wordpress.com/2012/04/28/slam-trustwide-privacy-dignity-strategy/>



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