

# Service User Involvement in DIALOG



## Case study and good practice recommendations



Service User (SU) Involvement in the implementation of DIALOG as a patient reported outcome measure (PROM) is critical to ensure that the use of the outcome is meaningful and supports personal recovery.

London Mental Health (MH) Trusts have agreed to use DIALOG as the London PROM.

All of the Mental Health Trusts in London have been working to implement DIALOG so that it is routinely used in practice and can inform service user needs and the services that are provided.





# What is in this document?



The purpose of this document is to ensure that service users are actively involved in all aspects of DIALOG implementation.



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To read more about DIALOG and its use across London Mental Health Trusts click on the icon >>>>



Glossary of terms & appendix



# General Principles of Service User Involvement

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## What is service user involvement in mental health?



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Service user involvement is about making sure that mental health services, organisations and policies are led and shaped by the people best placed to know what works - people who have used the services or ‘experts by experience’

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**All of the information in this report has been collated from service users groups including:**

- ✓ Pan London DIALOG events
- ✓ Individual Trust workshops
- ✓ Conversations with individual service users
- ✓ Service user focus groups

# Working Together: Co-Production and Involvement



There are a number of ways that service users can be involved in DIALOG implementation- all of them are fundamental and add value.

## CO-DESIGN

People who use services are involved in designing services, based on their experiences and ideas. They have genuine influence but have not been involved in 'seeing it through'.

## CONSULTATION

People who use services may be asked to fill in surveys or attend meetings; however this step may be considered tokenistic if they do not have the power to influence or affect change.

## EDUCATING

The people who use services are helped to understand the service design and delivery so that they gain relevant knowledge about it. That is all that is done at this stage.

## CO-PRODUCTION

Co-production is an equal relationship between people who use services and the people responsible for services. They work together, from design to delivery, sharing strategic decision-making about policies as well as decisions about the best way to deliver services.

## ENGAGEMENT

Compared to the consultation step below, people who use services are given more opportunities to express their views and may be able to influence some decisions, but this depends on what the people responsible for services will allow.

## INFORMING

The people responsible for services inform people about the services and explain how they work. This may include telling people what decisions have been made and why.

## COERCION

This is the bottom rung of the ladder. People who use services attend an event about services as passive recipients. Their views are not considered important and are not taken into account.

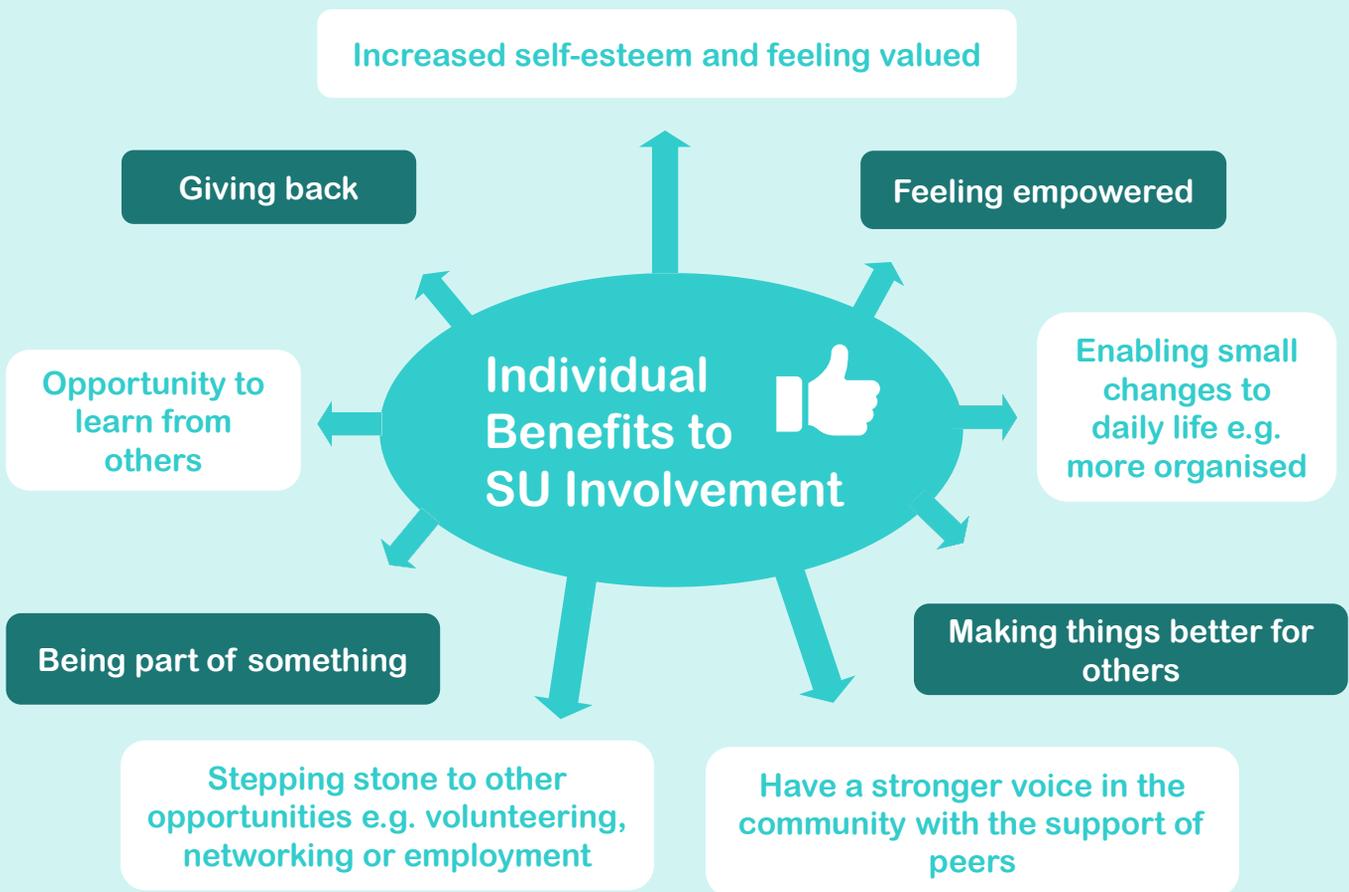


This ladder can be used to assess where the Trust/organisation is at with SU involvement.



For more info visit:  
Think Local Act Personal  
(TLAP)

# Benefits and barriers to service user involvement



## Common Barriers to Service User Involvement



Trying to do too much at one meeting e.g. asking loads of questions or trying to cover too many topics in one sitting



Fear, lack of understanding and uncertainty– feeling rushed due to a lack of preparation to enable people to actively participate e.g. asking important questions on the spot



People missing out on opportunities because they do not have the technology (this however can be a positive aspect)



Not being informed of what it has contributed to



Using specialist terminology and acronyms



Negative perspective from staff such as feeling as though being scrutinised



Not acknowledging different perspectives and expertise through experience



Not receiving feedback on contributions and decision-making processes or getting involved in something and then it stops



Not being clear why service users have been invited to a meeting

# Top Tips to Encourage Involvement from Service Users

- 1 Provide information about user groups e.g. ways in which they can get involved through information packs
- 2 Give an option of how they can be involved e.g. the type of activities that they might engage with - it won't be the same for every person
- 3 Provide reasonable adjustments / Being adaptable and flexible to peoples' needs
- 4 Send information / prep materials to service users ahead of meetings
- 5 Be honest and transparent around what can and cannot be achieved
- 6 Provide support throughout the involvement process
- 7 Enable people to develop a rapport
- 8 Provide opportunities to share views in a range of ways
- 9 Address the use of jargon and acronyms
- 10 Encouraging working with (and not to)

There are a number of ways that SUs can be involved in DIALOG implementation. These are some of the ways that SUs have suggested they would like to be involved:

- 1) Train service users on DIALOG to help spread and share learning and support others to complete DIALOG
- 2) Actively involve service users on steering groups and advisory Boards
- 3) Use their networks to socialise DIALOG information
- 4) Have service users involved in training and development of staff across the Trust
- 5) Establish DIALOG service user 'champions'



It will be important to ask your SU groups how they would like to be involved.

# Creating a service user culture

Staff and service user colleagues from South London and the Maudsley NHS Foundation Trust have shared learning on how they have created a culture for service user involvement and co-production

SU involvement is about creating a community



Having a common understanding that everybody adds a different perspective - with equal value



People feeling comfortable to share and learn from each other whether they are a staff member or a Service User



Service user involvement is a journey and is often multi-layered - understanding where SU involvement is present in all of the work, from engagement to co-production



A bottom-up and top-down approach is important for meaningful SU involvement

Some examples where SU have been involved include:

1

## Shaping strategic discussions

- Involved in Board discussions
- Engaging senior leaders
- Service user governor role

2

## Shaping Trust conversations at every level

- Being a part of focus groups or committee meetings
- Active involvement in the quality centre

3

## Established paid roles

- Employment of people with lived experience e.g. peer support
- Peer Support Workers in every borough

4

## Voluntary roles

- Pilot 'people panel' – ad hoc service user feedback on a specific topic

# Shared experience from an Expert by Experience Consultant at SLAM



## The value of service user involvement, from an Expert by Experience Consultant perspective .....

I enjoy the chance that my involvement offers to be creative and to work as part of a team with other service users, carers and staff

Involvement in a wide variety of activities has given me the opportunity to recover part of my identity, use my personal and professional experience and skills to contribute to the SLaM community

Involvement gives me the opportunity to be the person who I am despite my mental health challenges

I have particular interest in service development and training and my involvement at SLaM has given me the opportunity to contribute to these

I have not only felt that my experience and contribution is valued but I have overwhelmingly been welcomed as a member of a team

## To read the full blog see below....

**Sarah Davenport is an expert by experience consultant at SLaM. She is involved in supporting DIALOG implementation at The Trust by shaping and delivering the DIALOG training for staff across Southwark community MH teams. Sarah says....**



I have been involved in delivering training, co-design and co-production of training programmes for staff, student nurses and other service users. I have particular interest in service development and training and my involvement at SLaM has given me the opportunity to contribute to these.

I enjoy the chance that my involvement offers to be creative and to work as part of a team with other service users, carers and staff. Involvement in a wide variety of activities has given me the opportunity to recover part of my identity, use my personal and professional experience and skills to contribute to the SLaM community. The aspiration is that the Trust is a dynamic, safe, inclusive organisation offering the best possible and most equitable care. I have not only felt that my experience and contribution is valued but I have overwhelmingly been welcomed as a member of a team.

There have been some hurdles and experiences which have been less satisfactory. I hope that the Trust aspiration for service user and carer involvement to be axiomatic throughout the organisation will help allay the trepidation that I have felt that some members of staff have felt about working with service users. It would be a more satisfactory experience if there was a more formalized system of feedback on performance in individual activities from both the commissioning manager and the service user.





# A service user perspective on how to promote DIALOG



## What do I want to know about DIALOG as a service user?

- ❓ What is DIALOG/+ ?
- ❓ What is the purpose of it?
- ❓ How can it benefit me? – why does it matter to me?
- ❓ How do I use it? - what is the Likert scale?
- ❓ When and where do you use it?

You can find this information by clicking on this link >>>>>



Sharing this in a clear and simple way will be important if DIALOG/+ is socialised across service user groups. Some things to consider include:



What format to share the information (video, leaflet, posters, social media, etc)



Using images or breaking up text with pictures



Using language that is familiar to the person. Making information as simple as possible- breaking down information when there is a lot



Providing good stories - feedback of positive comments or videos made of success stories



Holding workshops to reiterate the relevance and importance of DIALOG

A SLaM SU consultant has developed a DIALOG leaflet, click on this link >>>



## What role can SUs play to spread and promote DIALOG?

## Improving DIALOG completion – a service user perspective

### Service user engagement

- ❖ SU sharing knowledge of DIALOG
- ❖ Drive DIALOG in the Trust (service user led)
- ❖ Help to engaging seldom heard groups
- ❖ Develop presentations, posters, video clips, leaflets etc.

### Existing groups and forums

- ❖ Take DIALOG to Trust quality forum / patient quality forum
- ❖ Information, advice and guidance (IAG) workers and existing links to promote and share DIALOG
- ❖ London-wide DIALOG workshops
- ❖ SU alliance reps to promote DIALOG and share information
- ❖ Communicate staff and SU commitment to implement

### Staff engagement

- ❖ Raise awareness from management – co-produce presentations to the Board
- ❖ Helping to create a culture that promotes co-production
- ❖ Internal messaging system for staff through comms teams
- ❖ Change DIALOG from admin task
- ❖ Bottom-up and top-down approach to DIALOG promotion
- ❖ Promote DIALOG whenever and wherever bottom-up and top-down across the board
- ❖ Share good practice between SUs and staff from different Trusts

- ❖ Give service users the opportunity to ask questions
- ❖ Being able to prepare before going to see specialist
- ❖ Having an expert by experience explaining how it has had a positive effect in their lives
- ❖ Reminding SUs that they can ask their clinician about how DIALOG can be used as a part of your care
- ❖ Service user sharing knowledge of DIALOG – training sessions led by Service users on their experience and how to complete it, answering any questions
- ❖ Choice and control over how DIALOG is completed
- ❖ Recommendations on making the conversation person-centred
- ❖ Getting feedback - being able to review the DIALOG notes after the session has ended
- ❖ Offer alternative means/tools to complete it (e.g. paper copy, digital, verbal)



The following slides provide some examples of ways that MH Trusts in London have been involving service users to shape DIALOG in their Trusts

## 1 Training and development service user leads



- East London NHS Foundation Trust
- South London and Maudsley NHS Trust

## 2 Informing care plans



- Camden and Islington NHS Foundation Trust
- Oxleas NHS Foundation Trust



## East London NHS Foundation Trust South London and Maudsley NHS Trust

ELFT and SLaM have both involved service users in developing and delivering the training and development roll out to the Trust staff and teams.



### What is the role of service user in delivering DIALOG training in the Trust?



The service user DIALOG training 'lead' or 'consultant' that is an active member who equally delivers the training alongside other Trust training staff.



The SU lead attends **all** training sessions with a dedicated slot to deliver an element of the training session to staff.



Both Trust roles are paid roles in line with the persons preferences.



The SU lead has received 'training' on DIALOG using the London HLP training and development resources. Further training on delivering remote training may need to be considered for the SU lead.



The service user lead is involved in the development and scheduling of the training sessions.

### How can SU come to be involved in training?

At SLaM the SU consultant was recruited through the PPI lead in the Trust and involvement in the Trust 'Service User Advisory Group'. The service user had been involved in other activities in the Trust and it was raised as a helpful way to engage clinicians in DIALOG training as it was noted that the other training when involving a SU was 'richer and more meaningful'. A job role was developed and the SU consultant was recruited to the role.

For example, at SLaM the role of the SU is to plan, learn, engage and co-deliver DIALOG training within Southwark community teams. The SU lead attends the same meetings as the lead matron who delivers the training so that it can be co-produced including planning meetings with additional staff such as the head of psychology and psychotherapy, community matrons, clinical service lead and head OT to understand and plan how this can be delivered locally. After the training sessions, the training leads (including the service user) have a debrief to discuss what went well, how it can be improved and provide feedback to one another.

#### The service user DIALOG training consultant at SLaM says:

“ I as a service user feel and have been treated as a full and equal member of the team delivering DIALOG training with the added contribution of giving a service user perspective on DIALOG which I believe adds power to the presentation. ”

### What impact has a service user lead had on the delivery of the DIALOG training in the Trust?

SLaM and ELFT training leads (including a service user lead) have said:



The importance of being heard, being seen as a person and not their condition.



Hearing directly from a service user provides a unique 'lived experience' of care demonstrating the importance of owning their care plan throughout the course of their treatment, how DIALOG can impact on their care and the relationship between the person and the professional team.



A service user involved in the delivery of DIALOG training can have a bigger impact and power on the training.



Directing clinicians away from risk focussed management approach towards a service user-central model that acknowledges the different aspects of a person's life that can help or impact their mental health.



By giving a service user perspective on the pros of the DIALOG tool and guidance on how to engage service users in this can provide a more holistic, person-centred approach.



**Feedback from service user consultants is vital to improving collaboration and involve service user consultants in all the meetings throughout planning, training, co-delivering and evaluation.**



## Templates and resources

For additional templates and resources please click on the link [here](#)

# Case Study: Shaping care plans



Camden and Islington NHS Foundation Trust  
Oxleas NHS Foundation Trust

Oxleas and Camden and Islington have both involved service user groups to inform care plans around DIALOG+

Click



A service user group at Oxleas were asked to review the existing Trust documents to take a view on how easy they were to read and use. Some alternative options were discussed and the care plan that was written in a letter format was chosen as it was considered to be more user friendly. Physical health information can also be pulled through and printed with the care plan if required.

Click



An alternative easy read care plan was also created with the help of the Trusts learning disability focus group for Trust information, using images to support the text.

East London Foundation Trust have also produced an 'easy-read' document created by service user group. Click on the icon >>>>>>>>>



Your Trust may want to produce their own using service user groups to help shape it. The above documents can be used as templates.

Camden and Islington engaged service user groups to get their perspective on what they wanted from a care plan document. This is some of the feedback that they gave:

“ Everyone can see what the plan is – transparency is important ”

“ It should be an A4 sheet of paper ”

“ Mine is on the bedroom door and it reminds me of the number 1 things I need to do ”

“ It would be great if it wasn't so concrete – if it could be a 'living document' that was flexible and updated whenever needed in sessions ”

“ My day to day life - the little things sometimes ”

“ A snapshot in time but also records where they've been so they don't have to go through things all over again with people they don't know ”

“ A care plan should be a way of starting the conversation. Filling in that form is a way of opening of that conversation ”

“ It sits on my fridge and it prompts my nurse to ask me where we are on something ”

“ It needs to be pragmatic - we need to be flexible on what we call a care plan - but it needs to be done in collaboration with the service user and be agreed upon ”

“ Our clients find paperwork overwhelming - they need friendly, open, simple language ”

What do people want?

What should go in it?

And staff say.....



Sidney says: 'Compared to the old care plan, DIALOG is different in the sense that I am involved from the very beginning and the DIALOG cannot be completed without me, my hopes, my dreams, what's important to me'

To see the full video, click on the icon >>>>>>>>>





## Acronyms used in this document



- Service user (SU)
- Mental Health (MH)
- Patient Reported Outcome Measure (PROM)

## Glossary of Terms

**User leadership** - service users have a majority say in decisions at every level within groups, projects or organisations.

**Peer support** - people with lived experience of mental health issues offering support to someone else.

**Co-production** - people who use services and people responsible for services working together from design to delivery of services and policies.

This document has been produced by Healthy London Partnership in collaboration with service user groups, London MH Trusts and voluntary sector partners.

The information included in this document has been collected from a number of PAN London events and workshops with participation from: experts by lived experience groups, clinicians and informatics from London MH Trusts.

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