



The SUN Network Co-production and Involvement Best Practice Guidance

**Co-produced with people with lived
experience, carers, services, and
commissioners.**

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The SUN Network Co-production and Involvement Best Practice Guidance

Introduction:

The aim of this Best Practice Guidance that has been co-produced by people with lived experiences of mental health, drug & alcohol challenges, and learning disabilities, carers, service staff, and those that fund services is to:

- a) help create an understanding of the meaning, differences and benefits of **co-production, collaboration, and involvement**

and:

- b) Promote best practice around co-production, and support service providers, those that fund services, and those with lived experience to utilise co-production in its truest sense, alongside involvement and collaboration

It will also be The SUN Network's own guide to working with people with lived experience.

It is planned that this Best Practice Guidance will have the greatest relevance in the areas of all age mental health and substance misuse services. But a wider range of services under the broad heading of social and community care are expected to benefit from this approach too.

Please note:

For ease of reading, this document which is intended for commissioners, service staff, people with lived experience and carers, is written in plain English.

The term 'Lived Experience' refers to people who have personal experience of mental health, learning disabilities, addiction etc. (it can be applied to any area of life)

There is a jargon buster and a 'who's who' at the end of the document which may be useful to look at prior to continuing.

Co-production, Collaboration, and Involvement: The Meanings and Differences:

There are lots of ways that services and those that fund services are involving people with lived experience from designing to reviewing services. All of these ways of involvement are very welcome, however, sometimes, a service or those that fund services think they are co-producing when they are involving people or collaborating. As we would like to see co-production happening as often as possible and ideally be embedded in the culture of services and those that fund services as a way of working, it is helpful for everyone to know the difference.

It is important for people with lived experience to know if they are truly involved in a co-productive way or in another way entirely. The following section explains what Co-production, Collaboration



and Involvement are and will help you to understand if you are working **co-productively**, **collaboratively** or are **involved** in a project.

Collaboration

Dictionary Definition	Best Practice guidance Definition
'The action of working with someone to produce something'	Those who fund services, and those who work for services working together

Collaboration – often called 'joint working' or 'partnership working' happens a lot and works well to see what is missing from services or see if more than one service is offering the same support. Collaborating means services are not working alone where no-one knows what they are doing. (sometimes referred to as silo working) It can help identify where services might be needed but are not being delivered, and also where people are delivering services already and what it is that they are delivering so work is not being duplicated. This in turn can result in money being saved so that it can be used in the best possible places where it is most needed.

Typically, collaboration will involve those who fund services and those who deliver services working together. There is likely to be a service or services representing lived experience.

Involvement

Dictionary Definition	Best Practice Guidance Definition
'The fact or condition of being involved with or participating in something'	People with lived experience being involved either a lot or a little alongside those who work in services and those who fund services.

Involvement is good because there are lots of different ways that people can be involved. (examples listed below) A service like The SUN Network can help services or those that fund services to use involvement in their work.

Involvement can be Encouraged and Supported by:

- Those that work in services and those that fund services can go out of their way to create opportunities for people to be involved.
- Understanding how important lived experience is and how it can help.
- Helping people be an important part of an on-going project.
- Making sure that opportunities are offered to everyone and that no-one is left out for any reason. Also, that the opportunities are accessible to all so that those who wish to be involved can be.
- Offering opportunities that are important to those involved, and that those people are happy with their involvement and feel a sense of pride or achievement.



- Being open to listening to other ideas and points of view and create opportunities for people to be involved based on how they would like to be involved, not based on how a service thinks they should be involved.
- Just because it hasn't been done before, doesn't mean it can't be done now. Welcome the challenges and embrace change.
- It's the right thing to do.

Types of Involvement Opportunities with Positive Practice Examples

There is a wide range of different ways to involve people, and we have listed some of the ways below and shared local examples of how these methods have been used to great effect locally.

Consultations – When services or those that fund services have conversations with carers and people with lived experience about those services, or a new service they are thinking about creating. **The Recovery Coach service was developed after consultation with people leaving mental health support services, to find out what they needed next.**

Meetings – People with lived experience and carers attending decision making meetings on a regular basis to learn about and have their say about the work. **The SUN Network have people with lived experience at all decision-making mental health meetings in Cambridgeshire and Peterborough representing the voice of themselves and others.**

Tender Scoring – When services are applying for money to run a service. People with lived experience and carers may ask them questions to see how they will run the service and give them scores based on how well they answer. **The Cambridgeshire County Council invite service users and carers to participate in their tender panels through The SUN Network.**

Workshops – Those that fund services, service staff, people with lived experience and carers attending workshops together to share ideas and move work along. **The Exemplar mental health service project in Peterborough designed their services this way.**

Blogging and Vlogging – Writing a blog or making a vlog (video blog) to raise awareness and inspire other people to be involved. **Change, Grow Live (CGL) Cambridgeshire invite people to share their blogs, poems, recipes, art, photography and more.**

Training (1) – Services and those that fund services offering training to support people with lived experience and carers to be involved. **Illuminate Charity offer Confidence for Change training.**

Training (2) – People with lived experience, carers, services, and those that fund services designing and delivering training together. **The SUN Network and Recovery College East have both designed and delivered training together with people with lived experience.**

Interview panels – People with lived experience or carers being a member of an interview panel when someone applies for a job. Asking their own questions, giving a score to the responses of all questions, and having an equal say to help select the best person for that job. **All of The SUN Network interview panels have a lived experience representative on them.**

One off Projects – Services and those that fund services offering different choices of projects and involvement opportunities so that people can select one-off projects that they are interested in. **The Cambridgeshire and Peterborough Clinical Commissioning Group (CPCCG) ran a**



series of workshops and leaflet design opportunities for the Eating Disorder service and asked people how they wanted to do the work.

Reviewing services and apps – Carers and people with lived experience using a service or an app on their phone and sharing their experience to help others understand what to expect. **David Lee who has lived experience of mental ill health reviewed the Lifeline service and CPSL Mind, and CPFT used this review in their communications strategy.**

Feedback – Carers or people with lived experience offering feedback about a service that they have used. **Rethink Carers support, The SUN Network, and Healthwatch Cambridgeshire and Peterborough work together to share their feedback at regular meetings with the those that fund services.**

Surveys – People with lived experience and carers answering questions in a survey to share their thoughts and ideas **Healthwatch Cambridgeshire and Peterborough regularly run surveys to hear what people think of local health services.**

Telling Your Story – People with lived experience and carers sharing their personal journey including the good bits and the more difficult bits to help raise awareness and let people know they are not alone. **Recovery College East offer training to empower people to tell their story. The SUN Network have a series of Addiction recovery Stories told by people who have experienced addiction.**

Boards – Having people with lived experience or carers on the Director’s board or Trustee panel. **The SUN Network have a Directors board which has people with lived experience on it. Other services offer similar opportunities (Lifecraft, CPFT, CPSL Mind etc).**

Evaluations – People with lived experience and carers checking if a service is doing what it is meant to be doing by using a set of questions to hear the experience of staff in that service or people who have used the service. **The SUN Network Five Values Patient Experience which was co-produced with The SUN Network, evaluates patient experience based on the Five Values chosen by people with lived experience and carers. (Empathy, Inclusion, Honesty, Working Together and Personalisation).**

Innovation – People with lived experience or carers may have a fantastic idea that people who fund services or people that work in services can help bring to life. **Kim Laidler who has lived experience of mental ill health raised the concept of a Toolbox Café and CPSL Mind developed the idea with Kim to make it widely available to others.**

Co-production:

Dictionary Definition	Best Practice Guidance Definition
‘The production of a recording, theatrical work, television programme, etc. jointly with another or others’	A partnership of people, some who have Lived Experience or are Carers, working equally with the people who fund and run the services that we all use. A useful and relevant experience using everyone’s skills to share decision



	making from the very start to the finish, including continuous feedback
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Co-production is not something that can happen overnight. It can use all of the involvement opportunities listed above, however, there is a depth to the work that cannot be captured through involvement alone. Co-production must start at the very beginning of any idea of a service, a review, or a consultation process.

Opportunities Need to be Planned in Advance to be Able to:

- Let people know that there are opportunities to be involved
- Put money aside to spend on co-production
- Learn about what co-production is and how to support it
- Get to know people and build positive relationships so everyone feels part of the team
- Let people know what the involvement opportunity is and how it has come about
- Make sure that there is enough time and opportunity to get it right
- Make sure the opportunities are open to all
- Find out if people need any support to be involved and provide that support

The Benefits of Collaboration, Involvement and Co-production

Benefits of Collaboration:

- Everyone works together, not separately, so people are not doing their own thing that no-one else knows about
- If people share, we find out who is already doing what so people don't do something that is already being done
- It can help us find out what works well and what doesn't work so well by talking to others and sharing our experiences
- It helps us work towards a shared goal
- It can help people see the bigger picture and check if anything is missing or if there are people that need support, but that support isn't being offered
- It can save money to support more people who need it
- It can make sure everyone is treated fairly, and included
- It helps people to work together to use money wisely and where it is needed most
- It doesn't matter who you are. Those that fund services, service staff, carers, or someone with lived experience. We can all work together

Benefits of Involvement:

- Involvement can take place at a later stage of the planning process and even after a service has already been established
- Sometimes there isn't a lot of time, so co-production isn't possible, but there may still be time for involvement opportunities
- People with lived experience and carers can still have their say and make a difference



- There are lots of good reasons to be involved such as increased confidence, sense of achievement, or feeling heard
- Lots of people can be involved – there is no need to limit numbers
- People can have a choice of different ways to be involved
- People can learn about how decisions are made and why things happen the way they do
- With input from lots of different people's points of view – a better decision can be made
- Helps those that fund services know what is important to those that use services

Benefits of Co-production

Co-production includes all the benefits listed above and more besides. It is the ideal way to work.

Anyone from any sector can experience the following benefits of co-production, whether they are someone who funds services, someone with lived experience, a member of staff from a service, or the general public.

- Save time, money, and other resources getting it right first time
- If a service is based on all the different people's input, the service is likely to last longer
- Co-production can pull everyone together with a shared vision
- Making sure that the service delivers what people want and need can prevent costly redesigns or service closures
- A positive co-production experience can boost confidence in the process and in people, meaning you will most likely do it again
- There can be a feeling of being equal and creating something together
- Everyone benefits by supporting the process and each other
- There are no sides because everyone works together
- Positive and effective communication means people become better connected
- People can feel empowered to make shared decisions and share their own opinions
- The decisions made make sense to everyone as they are joint decisions
- The process can help people in charge make the right decisions
- It can be an inspiring, creative, and motivating experience for all
- Hearing from people who use services can help people who fund or deliver services understand how it feels to receive support from that service
- It can help people continually look to make things better than before
- People feel happier with the service they use if it has been co-produced
- People are happier in their work as they feel they are doing a better job because people using services are happier
- Co-producing services means that people stay well for longer because the service is helping in a way that is needed
- It can be a really positive experience to listen to and understand different perspectives and ways of thinking
- People feel like they are creating something together
- People are creating new relationships and connections
- Everyone feels a part of something and is there from the start
- Hearing what people who use a service think of that service
- Learn about the needs and wants of people who use services



- Services and those that fund services can learn about all the benefits of co-production
- It can be a way for people with lived experience and carers to say thank you for the support they received from services
- People can feel important and valued and know that someone cares
- Carers and people with lived experience can speak on behalf of others who may have had a similar experience
- People will follow in the footsteps of those involved and consider getting involved themselves
- People can use personal skills they already have and learn new ones
- People may feel like they want to be involved in other things if they have a good experience
- There may be recognition for people's time and input
- Confidence may grow and people may want to volunteer or look for paid work
- There is a feel-good feeling because people are achieving something together

Differences Between Collaboration, Involvement, User-led and Co-production

Co-production, Collaboration, User-led, and Involvement overlap one another, and it can be easy to confuse them and not be entirely sure which one you are doing. Below are some explanations of how they differ.

Understanding what they all mean should help you to recognise the differences between them and see whether the work or project you are doing is co-produced, collaboratively produced, you are involved in a different way, or it is a service user led project.

Collaboration
Collaboration is working together, however everyone may not get to have an equal say on decisions.
Involvement
Involvement can happen at any time but may not be at the beginning or happen for all of the project. Also, involvement does not mean everyone will get an equal say in decisions. People also may not get to use their skills and expertise in involvement.
User-led
User-led is when people who use a service also run the service and make the decisions, which means they may be the only ones making decisions.
Co-production
Co-production is when people who fund services, people who deliver services, and people who use services all work together having an equal say on designing and delivering the service.

Potential Barriers or Limitations to Involvement and Co-production

As with everything in life, there are sometimes barriers and obstacles to overcome, or that get in the way of how we would like to do things. Here are some examples of barriers and limitations to involvement and co-production.

- Sometimes there is no time for co-production, but services and those that fund services should try to involve people in other ways such as collaboration and involvement
- Sometimes it is hard to keep up with how quickly the work is moving
- It might be that no-one thought about involving people with lived experience, or carers
- It might be that people don't know what co-production is or how it can be helpful, or how important it is to work with people who may have used the service
- If all the meetings are during the day, those that work during the day can't attend
- People may not know how to find out about how to be involved in something
- Services and those that fund services may not know the best place to advertise involvement opportunities
- Not all services and those that fund services are aware of how to offer inclusive opportunities so everyone can be involved
- Services and those that fund services may not have a skilled or trained facilitator who can help people to be involved and work together
- Services, those that fund services, people with lived experience and carers may have expectations of what they think is going to happen or not know what is expected of them
- There may be services, those that fund services, people with lived experience or carers that are expecting people to do something that they can't or are unable to do
- Services may be asking for a formal application or be looking for a specific skillset which may exclude some people from being involved
- The project may be too much for some people or expect too much of their time
- Some services or those that fund services may not know how to ensure people are supported to be involved
- Some services might not promote co-production or create opportunities. Also, some may want to do it but not do it very well
- Finding people with lived experience who want to be involved can be difficult
- Some services or those that fund services may not have put the money aside to pay for involvement or co-production
- People may have been involved or done co-production before and it wasn't a good experience and has put them off
- Some people involved may not stay for the entire project so the group may get to know someone and then they leave, and the group may have to start again with someone new
- There may not have been consideration given to making sure everyone has the whole teams contact details
- Worries about how confidential the people involved in the work are able to be
- Company policies and procedures (rules) may prevent work happening quickly



- Some people who don't have a car may find it difficult to get to a meeting, or someone who doesn't have IT will find it difficult getting to an online meeting
- Language, initials, and words that are only familiar to the service where the work is based may not be understood by other members of the group
- People may not know the background or reason for the work
- Someone outside of a service probably doesn't understand the way it normally works
- Sometimes people feel really rubbish about themselves and don't see that they have lots of valuable skills to offer
- Sometimes services or those that fund services don't realise that people have lots of valuable skills to offer

Fears and Myths Around Involvement and Co-production

It is possible for everyone involved in Co-production to experience fears or be worried about how it will work.

Some fears identified in the creation of this Best Practice Guidance included, but are not limited to the list below, however, all of these fears can be mitigated or removed completely with careful planning, good communication and an excellent facilitator.

- Saying the wrong thing and upsetting people
- Being patronised or condescended
- People not seeing or valuing your skills
- Not feeling good about letting other people share the decision-making
- Not being able to control what other people say and do
- Thinking you already know how a person, or a group of people will be and what they can do
- Sometimes, if you have a bad experience with something, it puts you off doing it again
- The people that volunteer to be involved may not always be the ones that are able to represent others
- Worrying how to support someone if they become upset whilst talking about the work
- If the work is complicated, it may mean less people can join in
- If you don't work at the same place, you may not understand what is being talked about
- There may be an expectation around what skills people may or may not have
- Not enjoying the work, and not feeling like you are supported to make a difference
- Struggling to see it how someone else sees it
- Struggling to get your point across
- Not understanding why the work is happening
- If people with lived experience or carers are not brought into the work at the start, they sometimes can feel like everyone else already knows each other, and they are the odd one out
- You don't always know what might happen next
- Everyone wanting different things or not being able to agree
- Too much is going on at once
- People may not like to hear things about their service or themselves that is not good



- Not being allowed or able to have your say (being shut down in meetings)
- Having to slow down the work to enable people to be involved
- When someone with lived experience is only there to talk about their own experience and doesn't talk on behalf of lots of people
- When someone is not letting decisions be made as a group, but maybe wants the final say or the only say
- Worries about getting it wrong

Myth Versus Reality: A Real-Life Example

The SUN Network invited a lady with lived experience of mental ill health to be involved with the crisis care meetings in Cambridgeshire and Peterborough by attending and participating in the decision-making meetings with service staff. The lady was very nervous and expecting the professionals and service staff to not value her, not be interested in what she wanted to say, and only be concerned about saving money rather than the interests of the patient. After attending several meetings with the crisis care meeting participants, our lady had the following to say:

'I wasn't sure how I would feel meeting Commissioner's, Contract Managers etc. I think I must have had some kind of weird expectation or assumption which is truly awful, especially as I had not had any experience with meeting anyone from the CCG before. I was basing my view on the many people I speak to with mental ill health and how difficult accessing services is for them, and also not really having a clear understanding of how in practice, the bigger picture is.

It was lovely to meet Modestas, (meeting manager) he is such a warm person and I felt so welcome at the meeting. I would like to thank him for that. I felt included from the off and that was lovely even though I am not a professional within the mental health field.

In the meeting I saw passion, dedication and commitment which was almost palpable in the room on Wednesday, and I almost bounced out of that room.

Thank you. I am blessed to have found you and The SUN Network and the rest of the team making it all happen Being involved with The SUN Network has given me the opportunity to feel included, valued and informed on key decisions being undertaken by the CCG and CPFT'

Steps to Success: A Commissioner and Services Co-production Plan for Achieving Success:

People who fund services and people who deliver services can create opportunities for people with lived experience and carers to be involved or co-produce work, but sometimes don't realise how much planning might be involved and miss out on opportunities as a result.

The following steps are guidelines to help plan co-production:

Step 1: Plan Ahead so You Can Make Sure You Are Able to Co-produce a Service

This may include:

- Learning about and understanding co-production and the differences between co-production, collaboration, and involvement



- Putting money aside to pay for co-production
- Working with other services to involve those with lived experience and carers
- Asking a service with co-production experience to help you with co-production
- Making sure that you have plenty of time to include co-production. A timeline of the work would help
- Including people from the very start of the project
- Valuing co-production and understanding the importance and benefits

Step 2: Working Together

- Value lived experience as a skill in its own right. Any other skill offered is an added bonus
- Ask if anyone needs additional support to be involved, and support people to be involved if they need it
- The responsibility of a good facilitator is to make sure everyone is being heard and move the work along. Pay for a facilitator if needed
- Appreciate the different ways people may see things and know that it is ok to have different opinions or thoughts, and that all of these opinions and thoughts matter
- Make sure people are happy and enjoying the work
- Keep people involved. Ensure everyone is included
- Consider paying someone who is an expert in co-production to do the co-production work for you so that it is a good experience for all involved

Step 3: Shared Decision-Making

- Everyone must get an *equal* say for this to be true co-production
- Help people to have a say and share their thoughts
- Make sure that you value every contribution, whether you agree with it or not
- Make sure everyone is and feels an equal part, and doesn't feel they shouldn't say what they think, or that any one person has the final say on decisions
- Be reflective and positive about *all* feedback, as it's important to hear the good and not so good

Step 4: Communication

- Make sure everyone knows what is happening at all times throughout the process
- Let people choose the way they would like to be involved or updated – email, phone, text, face to face, social media etc
- Ensure that you use plain English – no initials or words that people may not understand
- Check that everyone in the group has everyone else's contact details and is included in all group communication
- Advertise your opportunities well in advance and as widely as possible

Step 5: Inclusivity

- Make sure that opportunities are open to all so as not to be a barrier for people to be involved
- Support individual needs to help people be involved. This may mean a lift to a venue or easy read format



- Value lived experience as a genuine skill that people can bring to the table
- Be clear when you are communicating with people. Don't use any ways of talking or writing that may make people feel left out
- Don't assume people won't be interested in the more strategic work. Offer involvement opportunities as broadly as you can

Step 6: Continuity

- Make sure that relationships can develop by having the same staff involved for the whole project
- Make sure to keep everyone in the loop and up to date with the work
- Make sure that there are no changes without everyone's input
- Ensure payment and involvement policies are clear and readily available
- Have a dedicated point of contact so people can check in if they need to

Step 7: Ending a Piece of Work

- Make sure everyone is valued and thanked for their contribution
- Make sure all payments are prompt and that people are not out of pocket
- Have a clear ending and celebrate the work achieved
- Where there may be ongoing evaluation or review, ask if people want to remain involved
- Maintain connections and relationships

Celebrate

Achievement

Partnership

Together

Teamwork

Participation Versus Attendance

The SUN Network are keen that people with lived experience are supported to participate and not simply attend (although attending whilst confidence is built, and an understanding of the work is gained should be encouraged)

Ways to support participation:

- Explaining to people what the work is, and checking that people understand what you are telling them
- Check if anyone has questions and make sure there is time to ask questions before and during the work



- Make sure everyone knows what is expected of them, and what people expect to be doing
- Make sure everyone knows why we are doing this co-production together and how the service hopes it will help
- Make sure you listen to and use ideas and feedback from everybody to decide how the work will be done
- Understand how important and valuable co-production is and value the individual skills from everyone involved
- Don't wait for someone to ask you what something means, make sure that you are explaining everything along the way and not using language or words that may not be understood by everyone
- Make sure that meetings have a space on the agenda for people with lived experience or carers to talk
- Share contact details of all group members with every group member (once they have told you that is ok to share)
- Make sure you are sending any paperwork or communication to everyone in the group
- Offer lots of ways for people to have their say, maybe offer post it notes or a way of sharing thoughts creatively or in a group, or smaller groups/pairs
- Make the time to get to know everyone involved
- People with lived experience and carers can speak on behalf of lots of people as well as their own lived experience
- Explain why the work is happening. What the reason for it is
- Make time for people to ask questions, and give answers. If you don't know the answers, find out and come back to the person who asked and the group
- Be clear on what the work is about. Is it just one thing? Or more than one? Is it ongoing or linked to other work?
- Help people to understand how meetings usually happen and what behaviour is helpful to know and use. For example – not interrupting when someone else is talking, refreshments or seating plans*

*(The SUN Network guidelines for those with lived experience attending meetings is attached as an example Annex A)

The Power of The Lived Experience Story

It is really hard to fully understand what having lived experience of mental health challenges, a learning disability, or a drug or alcohol addiction must feel like if you haven't experienced it yourself.

Possibly it may be difficult to feel empathy for those that have or are experiencing it.

It is possible to form judgements or assumptions about people or stigmatise them without meaning to, based on what little we know about them.

It can be easy to work in a job supporting people for so long that you don't attach as much feeling to your work and become quite business-like in the way you work with people. Especially if there are time limits to your work.



The SUN Network have always encouraged people to share their stories to help others gain a better understanding of what it is like to access a service, or sit in front of a member of staff, or even contact that service in the first place. What it feels like to not get help and wonder if there is help out there.

Also, what it is like to receive help and support and possibly a diagnosis. What impact does this have on someone's feelings? Their relationships? Their Life?

We have heard some truly inspirational stories about people's experiences and how their lives have improved beyond recognition both by becoming unwell and also by becoming well again.

We've heard about tragic losses, and joyful gains, the real rollercoaster journey behind the person, and facilitated lived experience involvement sharing experiences or telling their story in the Eating Disorder pathway, Severe Mental Illness Specialist Health Care Assistants, Crisis Care Pathways, Dual Diagnosis meetings, Trauma Informed Care and many more. Always to really positive reviews from all involved around the value of the experience of telling or listening to the story.

The SUN Network also have a link to our Youtube channel with more inspiring stories.

[The SUN Network - YouTube](#)

Measuring Progress and Success

The Feedback Loop

It is common for services or those that fund services to ask for feedback to find out what is going well and what is not going so well. This feedback is then used to shape the service and make changes to improve things where needed.

If a service or those that fund services are asking people for feedback on behalf of their service, it is good practice to let people know how their feedback is making a difference to how the service works. The feedback wheel below shows how this could look in a 'You said – We did' style.

Feeding back to people to let them know how their feedback has made a difference to services means people will feel listened to and valued and will encourage future participation.

If a service or service funder is unable to use the feedback offered, then they should let people know that they haven't used the feedback and why they haven't been able to use it. It's important to be honest and transparent.

All feedback is good feedback. With ever evolving needs from people who may need a service, the services will need to evolve too. This means accepting and reflecting positively on feedback that is not so good and looking at whether there are any themes emerging and what the potential solutions could be. Quite often, the people with the best solutions are the people who use or need the service. Hence why co-production is so important.

Feedback also helps services and those that fund services to see what is working and celebrate successes.



How Will You Know if You Are Being Involved or Co-producing?

If you look at the participation jigsaw picture below created by the Best Practice guidance group, the pieces show you how involved you are in co-production. If there is no engagement, or if you are being given information, you are still not being very involved. If you are offering feedback or being involved, you are having more of a say. If you are on the last piece of the jigsaw, you are co-producing. These jigsaw pieces match up with the co-production ladder for services and those that fund services. (below)

Participation jigsaw





How do services and those that fund services know if they are co-producing?

Services and those that fund services can see where they are on the **Ladder of Co-production**. The higher up the ladder they are, the closer they are to reaching good levels of co-production.

It is fair to say that most services will be somewhere between steps one (No Engagement) to step three (Involvement) the majority of the time.

The key words to ensuring co-production is embedded into the work of services and those that fund services are **valuing** and **understanding**.

By understanding the importance, benefits, and role of co-production, services can then value the process of co-production and the individuals within.

If we value something, then it becomes a priority for us. If services and those that fund services value co-production, then it will become a priority for them, and they can ensure that it is embedded in the culture of the service and service staff, so that when a staff member joins, the service instils the importance of co-production in the new member of staff. It's a cultural thing, not a personal thing.

Services and those that fund services should not be asking 'Why would I co-produce?' They should be asking 'Why would I NOT co-produce?' There is no good reason not to co-produce.

Being honest and identifying where a service is on the ladder of co-production can help that service identify what needs to be done to ensure co-production is happening. The fears and barriers above can assist in identifying any issues, and the steps to success can support steps towards ensuring co-production is embedded.

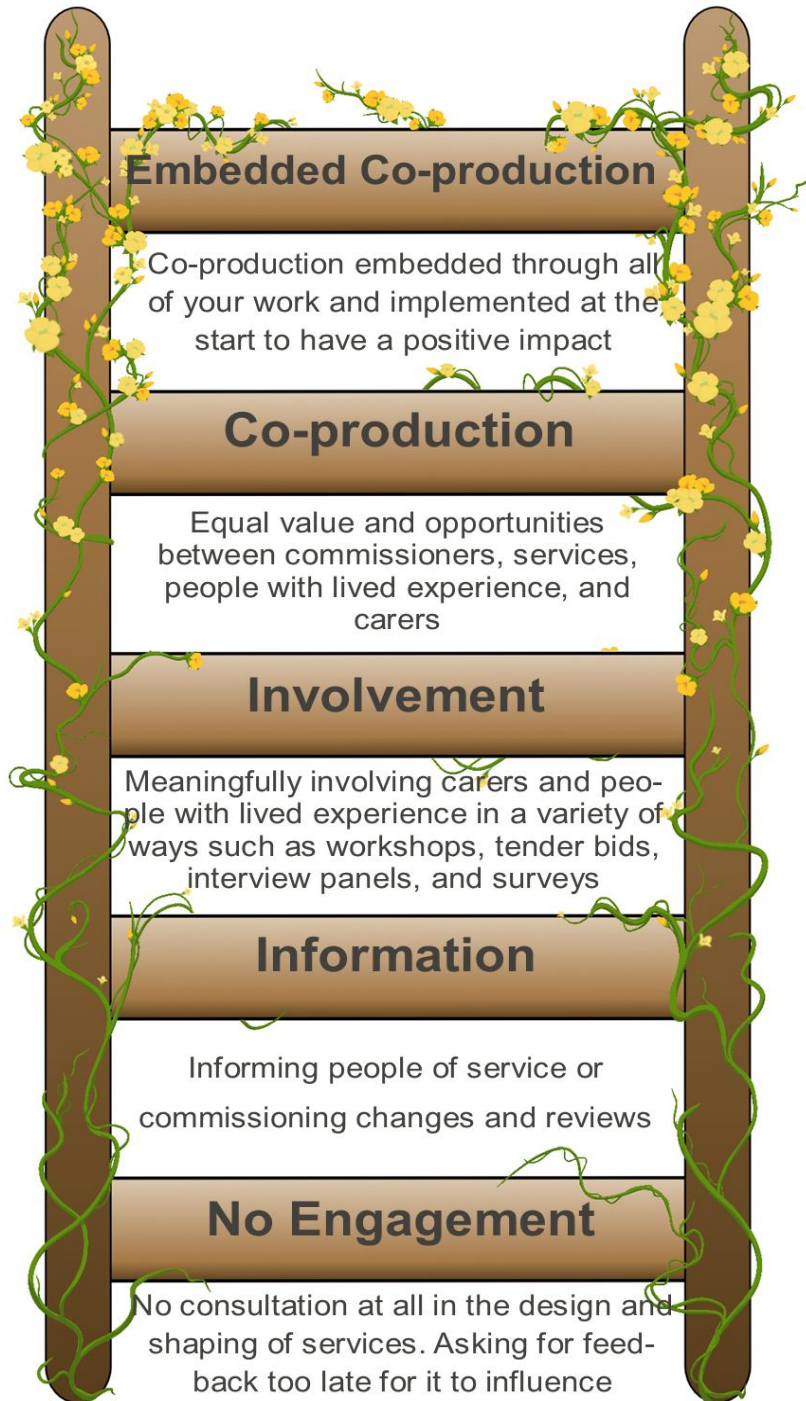
Working on one project co-productively is great, but if it is just one project, then your service will still be between rungs three and four on the ladder. The aim is to reach the top of the ladder and stay there.

Those that fund services can really lead by example. They can use co-production throughout their own work, and also make it a contractual obligation for all funded services to utilise co-production and for those service to be prepared to pay for it, and evidence their ongoing use of co-production.

Asking the following questions can support a service journey up the ladder:

- Where do we currently sit on the ladder?
- What is the current staff knowledge and confidence of using co-production? (maybe do a little staff survey or quiz)
- How many co-production or involvement opportunities have we completed in the last year?
- Did we have any successes that we can learn from or celebrate?
- Are there any barriers to us using co-production? (If yes, analysis for solutions)
- On a scale of 1-10 how committed have we been do far to embedding co-production?
- Are we prepared to pay for co-production?
- Who do we know that we can work with to facilitate co-production?
- How can we address cultural attitudes towards co-production?
- Where do we want to sit on the ladder?

The Ladder of Co-production



Cultural Attitudes Within the Workplace:

Over time, services, those that fund services, and any person can, without meaning to, become set in their ways and do things a certain way because it has always been done that way.

Some services may not have heard of co-production or have not typically used it before, so are not thinking about using it now. This way of thinking is known as cultural attitude.

In a 2018 report from the Social Care Institute of Excellence (Breaking Down the Barriers to Co-production) 36% of respondents felt that in their area or organisation's professional attitudes are a major barrier to co-production whilst only 21% felt that there is a good understanding of good practice in co-production in their organisation or area.

In the same report 76% of respondents felt that if there was a legal duty to co-produce it would strengthen co-production in their area or organisation.

Only 32% felt that in their area or organisation senior leaders lead co-production by setting an example and only 40% felt that in their area or organisation people have the skills and knowledge to support co-production

When asked what would help/or was important to strengthen co-production the most – the top two answers were: more support from senior leaders and developing practical guides.

It is important for staff working in services or commissioning to think about whether there are cultural attitudes or traditional ways of working that could be preventing co-production from happening.

- Look for new and exciting ways to involve people
- Don't wait for a chance for people to be involved, create an opportunity
- Challenge any stigma or traditional ideas that prevent people being involved
- Don't assume things have to be done the same way they have always been done
- Embrace change and new ways of working
- Embed co-production in the work culture so that when people leave, co-production doesn't stop

What do You Need to Think About Before You Get Involved?

As a carer or someone with lived experience, you may want to think about the following things before you get involved.

- Think about why you would like to be involved. Are you interested because you want to improve services? Or give something back? Speak up for yourself and other people? Share your experience? Or something else?
- How would you like to be involved? Do you want to attend meetings or workshops? Do you want to work creatively and design leaflets and posters? Do you want to help write policies or something else?



- How much time can you realistically offer without over-committing yourself? Think about how this is going to affect your spare time. Can you spend 1 hour a month or 5 hours a week? Be realistic so you don't take on too much
- Is it important to you that you be paid for your time either with money or training opportunities? Or are you happy to volunteer?
- Consider if you need any help or support to be involved? A lift to a meeting, or easy-read documents or something else?
- Can you think of any possible training that may help you to be involved? Confidence building? Learning about the NHS, understanding co-production etc?

Representative Involvement

If somebody with lived experience or a carer are asked to represent (speak on behalf of) others with lived experience or carer experience the following is important to know about:

- Think about your experience and the experience of everyone else that you are there to represent. They will all be varied so try and represent all these people as well as yourself
- Be aware that the meeting or workshop that you are in may not be the right place to make complaints or observations about certain services or personal experiences
- Each meeting will have an agenda or a list of things to be talked about. Sticking to the agenda means more work can get done
- Make sure the service and the piece of work that you are involved with are a good fit for you. Are you the right person to be representing the voice of people with lived experience?

Who Can Support Services and Those that fund services With Involvement and Co-production?

Sometimes those that fund services and service staff are really keen to carry out co-production in their work but are just not set up to do so. They may not know where to find carers or people with lived experience or may not have a facilitator who can carry out the co-production for them. They may not really understand co-production and how to get started.

The following are people and services who can support co-production:

- Organisations such as The SUN Network (Cambridgeshire and Peterborough) Viewpoint (Hertfordshire) and Suffolk Users Forum (Suffolk) are all extremely experienced in co-production, involvement and collaboration and can facilitate the process and also have a network of people with lived experience that would like to get involved
- Local User led services such as Lifecraft Cambridgeshire can also support sourcing people with lived experience
- Carers support groups such as Rethink Carers, Making Space, or Pinpoint have lots of carers within their networks
- Cambridge and Peterborough Foundation Trust (CPFT) have a Participation and Partnership Forum (PPF) that are happy to support co-production, involvement, and collaboration



- Recovery College East can also support the process and help source people with lived experience
- CPSL Mind have their own Co-production group and other services will have similar feedback groups, such as VoiceAbility who have the Speak Out Council
- Training – The SUN Network offers training around co-production that has been co-designed with people with lived experiences, those that fund services, carers, and service staff

How Services and Those that fund services Can Use and Support Involvement and Co-production

- Aim to build co-production into your work until it is THE way of working
- Partner work or fund services that already have relationships with the people of lived experience you are looking to engage
- Write into contracts, the requirement for co-production
- Be prepared to pay for co-production
- Train staff in co-production
- Write or adopt a co-production strategy and be accountable for co-production happening
- Aim to move from 'You said – We did' to 'We said – We did'
- Share positive examples of your own co-production work
- Follow the feedback wheel model of closing the feedback loop
- Develop two-way beneficial relationships
- See people as assets with valuable skills
- Encourage peer support networks
- Facilitating not delivering to. Working together

Who Can Support People with Lived Experience be Involved and Co-produce?

The easy answer is that anyone can support people with lived experience to be involved and co-produce. However, it is important that those that fund services ensure that they are requesting that those that provide services co-produce them. Those that fund services should also look at what co-production opportunities they themselves can offer.

There is also a responsibility for those that provide services to co-produce these services as much as possible and ensure that there is the time and money set aside to do so. Staff members can support and involve people with their work to create new or improved services and ideas.

Services such as The SUN Network exist to ensure that co-production is encouraged and used as often as is possible. Our staff are experienced at facilitating co-production.



The important thing is to be really open to involvement opportunities within your service and advertise these opportunities to that people who may like to be involved, know that they are welcome.

Recognition of Contribution:

Payment for involvement can be a very difficult area to navigate as there are many different opinions and thought around payment.

The chances are that everyone involved in a workstream or project is being paid to be there and it seems only fair that any lived experience involvement has an option of being paid too.

Some companies don't have a budget for involvement or a very limited budget.

Some people don't want to be paid to contribute. Just knowing they are giving something back or making a difference is rewarding enough.

Some people are not in a position to take payment as it may affect their benefits claims.

It is possible to recognise people's contribution in several ways, including:

- Payment – ensure you have a budget for involvement when bidding for money
- Vouchers – these could be used as a thank you at the end of a project or for ongoing payment
- Training opportunities – offering training and upskilling/refresh can be a reward for involvement
- Volunteering roles – having volunteer roles to support people in the workplace
- Awards – recognising contributions by celebrating with an award or celebration

It is important to have a payment of the public policy to clearly define what can be paid and how it can be paid. And outline any responsibilities and where they lie.

Training Opportunities:

Please contact us to find out about our co-produced training opportunities to help your service to learn more about how to support and utilise involvement and co-production or how to participate in involvement or co-production opportunities.

Or visit our website www.sunnetwork.org.uk

Jargon Buster and Who's Who

Those That Fund Services. Often called Commissioners or funders. Local commissioners in Cambridgeshire and Peterborough include The Cambridgeshire and Peterborough Clinical Commissioning Group (CPCCG), The Cambridgeshire County Council (CCC) Public Health (PH)



and The Police and Crime Commissioners (PCC) There are other commissioners, and these are just some of the local ones.

The SUN Network. A non-profit organisation who exist to amplify the voice of those with lived experience of mental health, drugs and alcohol support, or homelessness in Cambridgeshire or Peterborough and facilitate co-production and involvement. [Home - The SUN Network](#)

Recovery Coach Service – A service offered by The Primary Care Mental Health Service (PCMHS) to support people who are coming out of mental health services into the care of their

The Exemplar – A service to improve mental health care in Cambridgeshire and Peterborough. They operate community website pages and Facebook groups HAY Peterborough and HAY Cambridgeshire [About – How Are You Peterborough \(haypeterborough.co.uk\)](#)

Change Grow Live (CGL) – Drug and alcohol support service [Cambridge - Drug & Alcohol Service Cambridgeshire | Change Grow Live](#)

Illuminate Charity – Mental health support charity [Coaching and training Cambridge | East of England - Illuminate Charity](#)

Recovery college – A collaborative learning environment supporting mental health learning. [Recovery College East | CPFT NHS Trust](#)

CPFT- Cambridge and Peterborough Foundation Trust. Delivers the NHS mental health services in Cambridgeshire and Peterborough [Home | CPFT NHS Trust](#)

Lifeline – A mental Health support helpline based in Cambridgeshire Lifecraft service [Lifeline - Lifecraft](#)

Lifecraft – Mental health support service based in Cambridge [Welcome - Lifecraft](#)

CPSL Mind – Cambridgeshire Peterborough and South Lincolnshire Mind – mental health support service [Cambridgeshire, Peterborough, and South Lincolnshire Mind \(cpslmind.org.uk\)](#)

Healthwatch Cambridgeshire and Peterborough – A service that gathers feedback on all health matters [Healthwatch Cambridgeshire | Your spotlight on health and social care services](#)

VoiceAbility – An advocacy and involvement service that also run the Speak Out Council with people who are autistic or have learning disabilities [VoiceAbility | Advocacy and involvement](#)

Rethink Carers Support – A support service for carers of those with mental health challenges [Rethink Carer Support: Cambridgeshire and Peterborough](#)

Recovery College East – A CPFT collaborative learning environment [Recovery College East | CPFT NHS Trust](#)

Making Space – A support service for carers of adults with mental health challenges [Cambridgeshire and Peterborough Carer Support Service, Church Street - St Neots, Cambridgeshire | Making Space](#)

Pinpoint – A parent led organisation that gives help and information to parent carers of children and young people aged 0-25 with additional needs and disabilities [Parent Carer Support in Cambs from Pinpoint Cambridgeshire \(pinpoint-cambs.org.uk\)](#)



Participation and Partnership Forum – The CPFT service user forum [Participation and Partnership Forum | CPFT NHS Trust](#)

Viewpoint – A voice organisation for mental health and addiction. Based in Hertfordshire [Viewpoint \(hertsviewpoint.co.uk\)](#)

Suffolk User Forum – An independent mental health user led, involvement, peer support and advocacy organisation [Mental Health and Wellbeing in Suffolk - Your Voice Matters \(suffolkuserforum.co.uk\)](#)



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Annex A:

Guidance for Participating in Meetings – for Those with Lived Experience

Here at The SUN Network, we believe that people with lived experience of mental health or addiction challenges can offer valuable input into how services operate at every level.

The mental health and drug and alcohol services and those that fund services meet regularly to ensure that services are delivering what is needed.

Our aim is to ensure that people with lived experience are also attending and participating in these meetings and sharing their thoughts and opinions.

The following are some guidelines to support people to participate in these meetings:

Training:

We are happy to provide support and training identified by the individual to enable them to participate in meetings. This may be around some of the subjects contained in this document or it may be around confidence and assertiveness, or you may require a jargon-buster to help you learn the acronyms that are commonly used, or a background on the work stream. Whatever, you feel may help, we will do our best to provide it.

Stigma:

A big part of our work is around challenging stigma. The way we do this is to accept everyone at face value without judgement or preconceived ideas. We avoid using derogatory or slang words for mental health and drug and alcohol such as 'druggie' 'nutter' etc and would ask you to consider the same. We value all participants around the table equally. You may have some preconceived thoughts around how you think others at the meeting will be. We invite you to come and see for yourself.

Support and Feedback:

We will support you during and after the meeting if required, inviting you to have your say and ensuring that you feel involved to a level at which you feel comfortable. We will most likely check in with you after the meeting to hear your feedback around how it went and if there is anything we can do to support future participation.

Representation:

We ask that people with lived experience that participate in meetings with or on behalf of The SUN Network are representative of all those who may use services and ensure that they are seeing the bigger picture. The meetings are not a place to bring your own agenda and we do have other platforms for hearing your story. That is not to say that your story is not relevant or important, of course it is, just that the meetings cover a wider agenda, and we are speaking about larger more prevalent issues/successes within the system.

Payment:

The likelihood is that most people around the table will be there in a paid role and we believe that you should not be an exception to this. We pay reasonable travel expenses for you to get to the



meetings if it is a physical meeting. We cannot pay claims that are not supported with receipts. We also pay £10 per hour for participation at the meeting. We do not pay travel time. If it is a virtual meeting, we pay for the time that you are participating in the meeting.

We will provide you with a claim form to complete and return to us. We can assist you to complete the form if needed. Claims are usually paid the same week they are returned, but to allow for staff being on annual leave, please allow up to 14 days.

Table of Expenses:

Bus or train journey	Keep the receipt for reimbursement (cheapest fare option)
Car journey	45p per mile – shortest/most direct route taken
Hourly pay rate	£10.00 per hour for participation. (Not to include travel time) This can be paid via bank transfer or as shopping vouchers

The SUN Network accept no responsibility for management of benefits for those participating. It is your responsibility to ensure that any payment does not affect your benefits claims.

- Provide background information and history of the project, ensure that context is added where needed and obtain understanding of the purpose and aim of the work
- Allow for and answer questions
- Be clear about the expectations of all parties
- Explain what you hope to gain through co-production/involvement – all parties
- Ensure that all contributions are valued equally to encourage participation
- Positive attitudes around co-production and involvement – appreciating the value and benefits – all parties
- Create jargon busters explaining jargon, 'clinical speak' and acronyms. – Try not to put people in a position where they have to ask as many may not have the confidence
- Agenda items – Ensure that the agenda reflects co-production. Have an agenda slot for lived experience reflections or thoughts
- Access to appropriate people. Ensure that people outside your organisation have the correct details for the appropriate people
- Access to appropriate paperwork. Ensure that the people outside your organisation are on the distribution list (consent gained for sharing their email address) Are you able to print or post documents if necessary?
- Accessibility – are meetings and paperwork accessible?
- Varied choice around how to be involved. – Do you have post it notes or a chat function to enable voices to be heard if confidence doesn't permit speaking in a group?
- Get to know the lived experience participants – can you tell when they would like to say something? Do they need time and space to speak? Do they prefer to contribute in a different way?
- Being representative – Do you have the ability to represent more than just yourself?



References and Bibliography:

Thinklocalactpersonal.org.uk. 2020. *What Is Co-Production? - In More Detail - Co-Production - Co-Production In Commissioning Tool - Think Local Act Personal*. [online] Available at: <<https://www.thinklocalactpersonal.org.uk/co-production-in-commissioning-tool/co-production/in-more-detail/what-is-co-production/>> [Accessed 1 December 2020].

Engage.hscni.net. 2020. *Benefits Of Involvement – Personal & Public Involvement (PPI)*. [online] Available at: <<http://engage.hscni.net/what-is-ppi/benefits-of-involvement/>> [Accessed 2 December 2020].

Roberts, A., 2020. *Resources*. [online] Coalition for Personalised Care. Available at: <<https://coalitionforpersonalisedcare.org.uk/resources/>> [Accessed 2 December 2020].

co-production, S. and barriers, B., 2020. *Breaking Down The Barriers To Co-Production*. [online] Social Care Institute for Excellence (SCIE). Available at: <<https://www.scie.org.uk/co-production/supporting/breaking-down-barriers>> [Accessed 9 December 2020].

Bank of Information. 2020. *11 Advantages / Benefits Of Employee Involvement*. [online] Available at: <<http://bankofinfo.com/advantages-and-benefits-of-employee-involvement/>> [Accessed 2 December 2020].