

Mental Health
TOGETHER

Good Practice Guide

Involving the voice of lived experience in meetings



This guide has been developed with our Experts, to help organisations plan thoughtfully and support people well, so their involvement in meetings is both enjoyable and productive

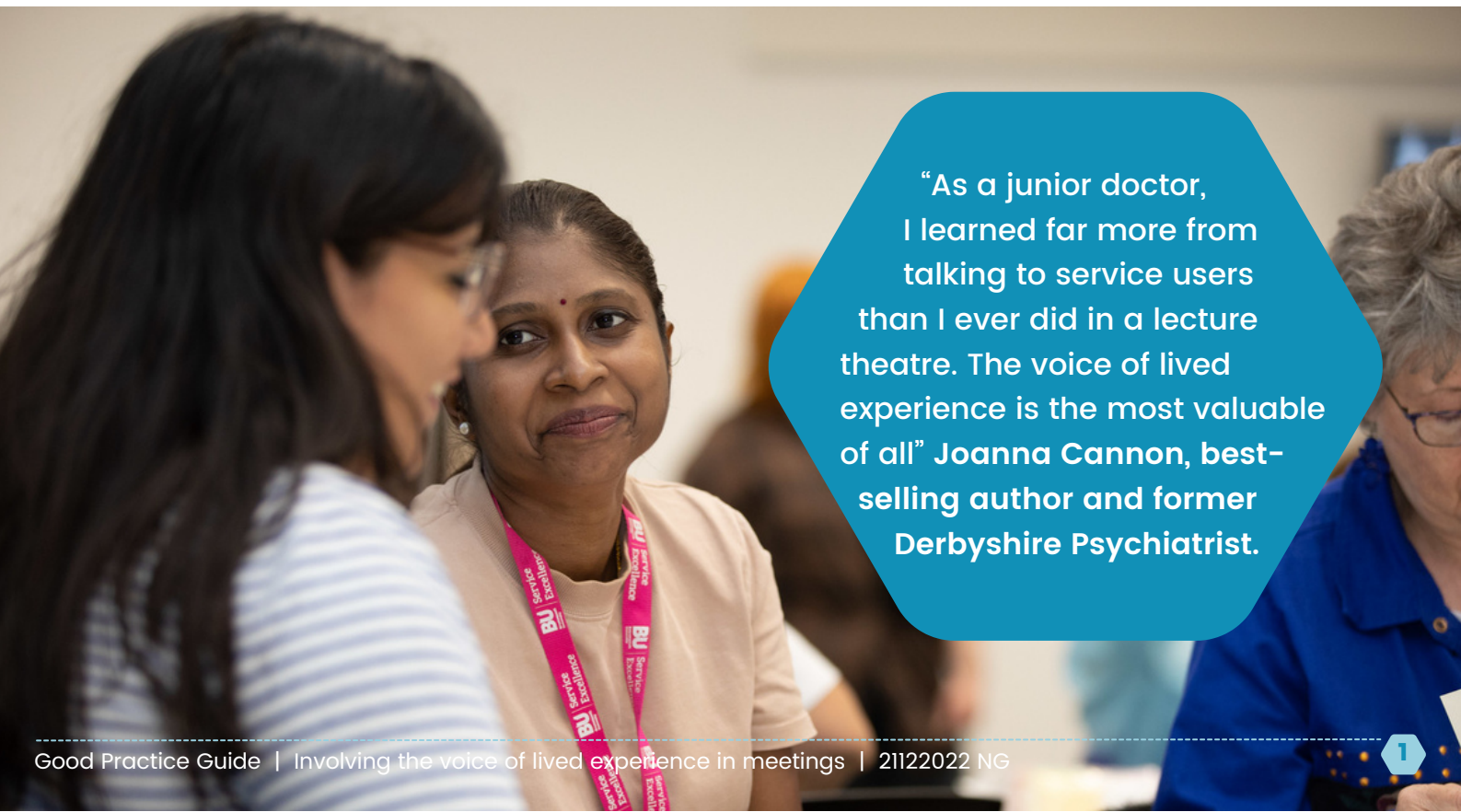
Introduction

from Experts by Experience

“Experts by Experience are people who are experiencing or have experienced mental health challenges, and their carers, who are usually family members or friends. Like you, they want to change things for the better. They are both a gift and a wonderful resource for you! By working together, listening to their experiences and knowledge with real empathy and interest, and being willing to share decision-making with them, you can make a huge difference!” **Jean**

“Because Experts by Experience truly do experience the system, it allows us to share a unique perspective which can help you improve services. Being directly involved has allowed me, for example, to help re-design letter templates for clinicians that will be more supportive to patients through an often-traumatic time. It is a rewarding feeling to know I’ve made a real difference that will benefit others.” **Matt**

“Including an expert at your table should be more than a tick box exercise if our collective voice of experience is to be truly heard and acted upon. With this in mind we’ve put together this guide to help you be genuinely inclusive. If you adhere to the guidelines in it then we can actively take part in your meetings and you will really hear us.” **Shelagh**



“As a junior doctor, I learned far more from talking to service users than I ever did in a lecture theatre. The voice of lived experience is the most valuable of all” **Joanna Cannon, best-selling author and former Derbyshire Psychiatrist.**

Purpose

“Professionals need to be clear about why they are involving people with lived experience and what impact it would have – it should never be a tick box exercise”

The first essential step to getting things right is to make sure you have thought clearly about the value of bringing people with lived experience into the project, meeting etc.

Is there a genuine commitment and potential to LISTEN to their experiences and ACT on them? Be honest with yourself and others about the scope, timescale, and budget. Are there things that will prevent this being a genuine involvement experience? If so, what can you change to ensure that it is?



It's really important that you can describe clearly the opportunity that you're offering to people, particularly what is in scope and how much they can influence the outcome. Is there already a service model or requirements that can only be tweaked or is it a full co-design opportunity?

It is great to aspire to real co-design work but the most critical thing is being clear and honest at the start about expectations and opportunity. Many Experts by Experience have felt really let down in the past when they've put time and energy into meetings or a project that appears to go nowhere or doesn't heed their advice.

Audience

“You'd get more people if they were able to contribute to subjects they feel passionately about, then they would be more likely to want to be involved.”

The next step is to think carefully about who needs to be invited to the 'table' and why. Remembering this is not just about ticking a 'service receiver' or 'carer' box. The opportunity needs to feel relevant to people with lived experience, they need to feel confident that they



have something of value to bring to the meeting. It is better to take time now making sure you have a good fit in terms of relevant experience rather than risk it ending up as a 'tick box' exercise which will do more harm than good. It's important that all the right people are round the table; this includes other organisations. It will feel frustrating and disrespectful for Experts giving up their time if there is insufficient commitment from other parties.

It's also important to consider whether you have the right ratio of people with lived experience to other attendees. Some voices can easily be overpowered, and you risk losing their knowledge and wisdom. A good balance in number ratios and in power-sharing, will help you create a successful involvement space for everyone.

Finally make sure you give yourself time to understand your audience. Who are these people who are offering to share their time and experience? What adjustments and considerations might they need to ensure they can fully participate? And what strengths and skills are they bringing? Be careful not to fall into the trap of making any assumptions simply because a person comes with lived experience of mental health services.



Environment

“Going out to where people with lived experience are comfortable helps to level the playing field.”

Before you make decisions about where and how the meetings or event will be held ask your participants what is most comfortable for them. This seems a very obvious thing to do but the responses may surprise you, you cannot always predict people's preferences.

You may need to think about accommodating varying preferences by offering hybrid meetings or rotating venues? Some people may feel too anxious to meet face-to-face but they still need a voice.

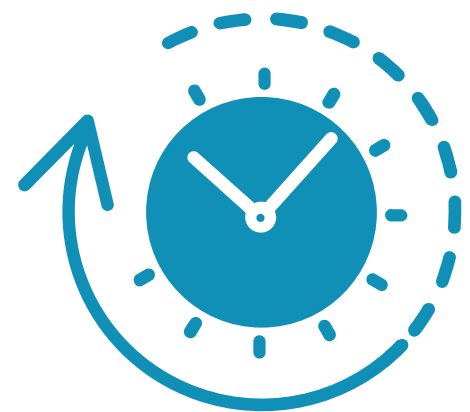
If the meeting is face-to-face, it's important to ensure the venue is fully accessible for those with disabilities, is on a good public transport route and of course is a pleasant space to be in e.g. good natural lighting, not claustrophobic etc. If in doubt invite your participants' views on the options available.



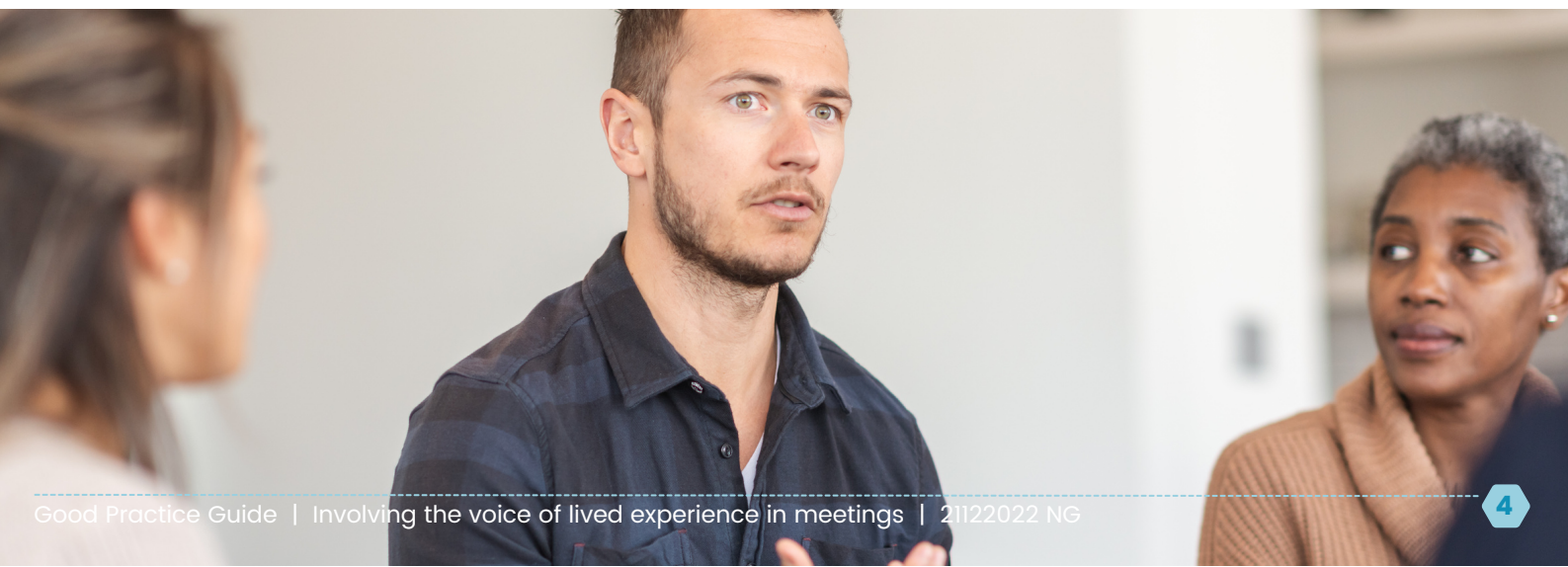
Timings

“Time and length of meetings. Mornings aren't good for some people due to medication”

Remember to consult your audience about the length of individual meetings. Most people will find meetings which last more than two hours quite challenging. Even in a two hour meeting it's important to agree the need for built-in breaks. It's also important to be realistic and clear about the overall timescale for the work planned. This enables people to make informed decisions about the commitment they can make.



Be mindful that people may have external commitments e.g. caring responsibilities or medical appointments on set days/times that cannot be changed.



Agendas and Paperwork

“Give the Experts the agenda in enough time to know if they can contribute to the meeting. If there’s a subject that could be triggering for them then they would have prior warning”

There are of course general points of importance for everyone about meeting paperwork. Receiving them in plenty of time to read, and possibly re-read, being of course a key one. We would recommend at least four days in advance. But some people will also have other specific needs around paperwork so take the time to invite people to let you know their needs.

For example, some people may need all paperwork in large print or special formats.

Some like to receive it digitally and others need a paper copy. As always ask people to let you know of any particular considerations you need to be aware of.

When planning agendas, it would be good practice to consult with people especially if they are sharing their experience or taking some other particularly active role in a meeting. When do they feel most comfortable playing their part? They may wish, for example, to speak just before a break so they have time to gather themselves, have a debrief opportunity, before re-starting.



Jargon Busting

“Someone with anxiety disorders may not feel confident enough to ask ‘what do they mean?’ in front of professionals”

Remember that to have a meaningful conversation and input we need to use a common language. This is a really important part of putting people at ease and empowering people to participate as fully as they wish to. Information is power – never forget it!

How you achieve a common language should be discussed with all attendees. You may agree to



provide an up-to-date glossary of terms in advance of the meetings. Or you may decide together that it's going to be a jargon and acronym free zone.

Whatever you choose it's important to check in after a couple of meetings to see if it's working well for people. It's generally good practice to keep jargon to a minimum and only use it when it adds value and there isn't a better alternative, which is rare!

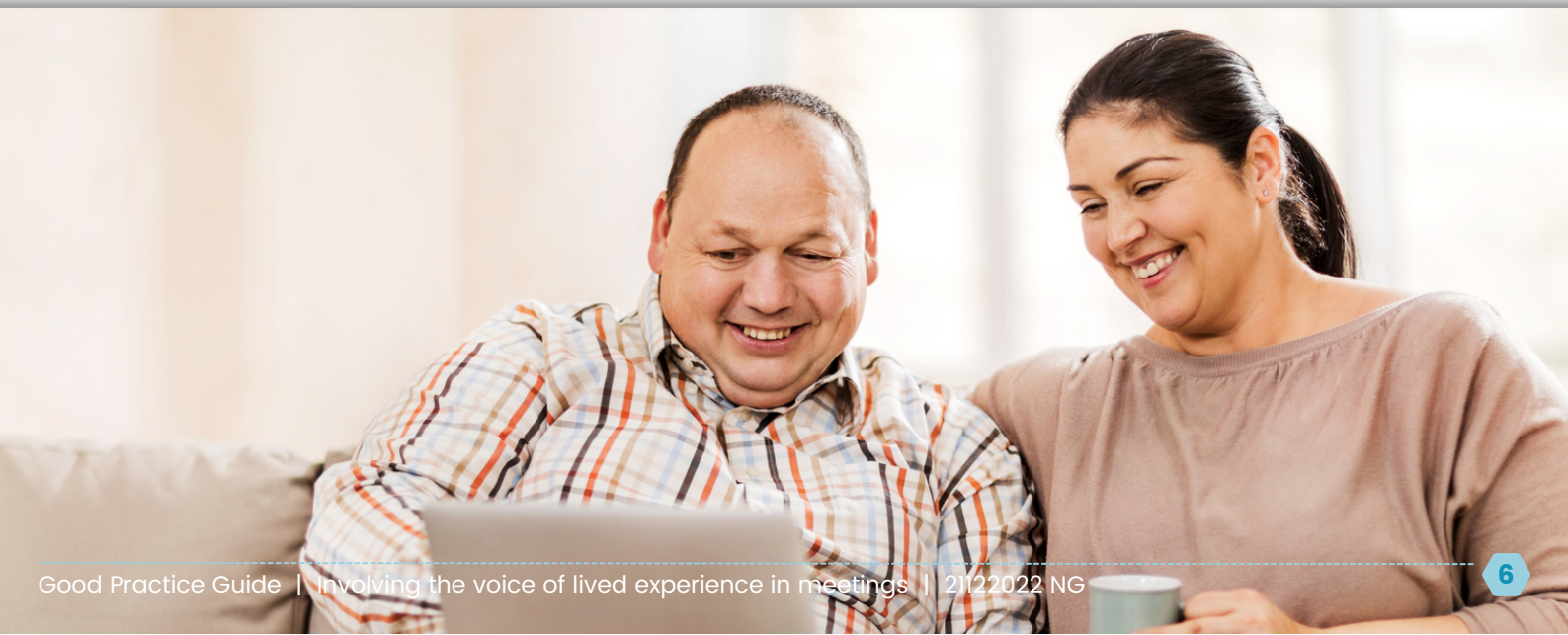
During Meetings

“One thing that concerned me was that my psychiatrist would join a group I was in and then he would think I was OK. It makes me feel vulnerable who's listening and how you will be interpreted”

We all know there are many things that can go right and wrong in a meeting! No-one expects a perfect meeting experience but the more time you spend getting to know your attendees beforehand the better. It makes people feel valued from the very beginning.

On a practical level, if you plan to use break out groups consider the members in each group – is it balanced? Are there any potential conflicts or difficulties to be aware of e.g. a person could find themselves in a group with their CPN or Doctor. If it's a virtual or hybrid meeting, give people the option of keeping their camera off when needed if that makes them feel more comfortable. And don't force people to introduce themselves unless you have checked they are comfortable with that. People could have the option of dropping their name into the chat box instead.

Be sure to provide some refreshments and to build in mini breaks to help with concentration levels. Think about the pace of the meeting in order to be fully



inclusive. Don't speed ahead if some people need further clarification and allow time for a debriefing session afterwards to check how things have gone for everyone.

Before you close the meeting make sure you advise on next steps. Will there be further meetings or do you need to go away and try things out based on their input? Either way it's important to let people know when you expect to give them feedback. Finally remember that sharing personal experiences can trigger painful memories so take time to check in with Experts and see if anyone needs some support before leaving.

Remuneration & Reward

“Maybe a few options could be offered based on need e.g. one service I worked with decided they would offer money or vouchers or training as three options for remuneration”

How will you show that you value the input Experts bring to your meetings or project? This is critical because we all deserve to be valued for our time and experience.

You may have an existing policy in your organisation that provides a framework for reward and remuneration. Be sure to familiarise yourself with it and make sure you have the relevant budget allocated to enable payment or other reward. Make sure that all Experts understand the policy and have the chance to ask questions about options and possible impact of payment on benefits.



If you have no policy or budget for payment, then think about how else you can show appreciation for people's time and input. Not everyone will be able to accept payment, but they still deserve to be rewarded and valued. This could be meals/refreshments, gifts of thanks, certificates of appreciation etc. People are very different so ask them what they would prefer. It's important to think about how much time you are expecting people to give up especially if you are not able to pay them.

Out of pocket expenses will need to be paid promptly because failure to do so may exclude some people from being able to participate. Costs of household bills including electricity are going up sharply which has practical impacts such as, charging of laptops and phones for meetings.

Feeding Back

"How will I know that what I've shared will help others like me in the future?"

If there is one thing above all others that most Experts by Experience want to know it is – **"what difference has my involvement made?"** This is usually because their own experience has been hard earned and they really want to make things better for others. It is not easy sharing very personal and often painful experiences and what makes it worthwhile is knowing that you have made a difference in some real way. It's an important aspect of reward and very important for motivation.



So, it's important to give careful thought to how you will feedback to people about what difference they have made. What has actually changed as a result of their involvement? How will you monitor and review those improvements? This should be approached seriously and form part of your official project plan. There are many different ways you could do this as long it makes a very clear connection between Expert input and eventual outcomes.





Good Practice Guide – Checklist

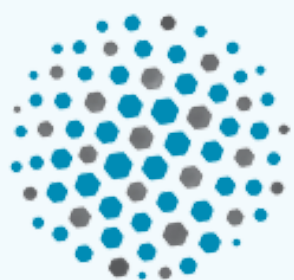
Purpose	Tick if complete	Action still needed? Make a note of what you need to do
Am I clear about why I am asking for lived experience input?		
Am I able to describe the potential impact that Experts involvement can have?		
Have I been clear and honest about the scope, timescales and budget right from the start?		
Do I need to address any barriers to genuine coproduction?		
Audience		
Am I clear about who needs to be at the table and why? Are the voices that we most need to hear from present or still missing?		
Do I have the right ratio of people to make sure the voice of lived experience isn't overpowered?		
Who are these people who are offering to share their time and experience? What adjustments and considerations might they need? What strengths and skills are they bringing?		
Are there any power-sharing issues that I need to consider and address?		

Environment	Tick if complete	Action still needed? Make a note of what you need to do
Have I asked where people would be most comfortable participating in meetings?		
Have I checked that meeting spaces are fully accessible for those with disabilities, on public transport routes, have good natural lighting etc?		
Do I need to provide the option of a hybrid meeting for those who feel unable to meet face to face?		
Timings		
Have I consulted my audience about the length of individual meetings and the overall timescale for the work planned?		
Have I built regular breaks into the agenda?		
Does anyone have external commitments eg caring responsibilities or medical appointments that cannot be changed?		
Paperwork and Agendas		
Am I clear about how people would prefer to receive the paperwork?		
Does anyone need large print copies or other special formats?		
Does anyone need different approaches due to concentration difficulties or dyslexia?		
Can I ensure that people receive the paperwork at least four days in advance?		

Jargon Busting	Tick if complete	Action still needed? Make a note of what you need to do
Have I consulted attendees about how we'll ensure that language and information is accessible?		
Do I have a glossary of relevant terms ready if I need to share one?		
Have I made a note to remind people regularly to avoid jargon and acronyms?		
During Meetings		
Have I taken the time to familiarise myself with the people I will have around the table?		
Have I thought about different approaches that might work for different people who want a voice?		
Are there any potential conflicts or difficulties to be aware of during meetings and/or break-out sessions?		
Have I allowed time for a debriefing session afterwards to check how things have gone for everyone?		
Have I thought about potential next steps to discuss with everyone at the end of the meeting/project?		
Do any Experts need some support after sharing personal/painful experiences?		

Remuneration and Reward	Tick if complete	Action still needed? Make a note of what you need to do
Should I be paying people for their time and input into this project and/or meeting?		
Is there an existing policy in my organisation for paying Experts?		
Have I made sure that all Experts understand the policy and the options they have for payment or other forms of remuneration?		
Do I need to advocate the need for a policy in my organisation?		
If I'm not able to offer payment, have I asked people their preferred option for showing appreciation for their time and experience?		
If paying expenses only, do I have budget and process in place to ensure prompt payment?		
Feeding Back		
Have I built into my official plan a means of feeding back to Experts and colleagues the difference it has made to have them involved? Outcomes and learning.		
Do I also need to plan in extra debrief sessions between meetings for more in-depth feedback opportunities and further understanding as we go along?		





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Mental Health Together,
Suite 14, Riverside Business Centre
Foundry Lane,
Milford,
Belper,
Derbyshire
DE56 0RN



healthwatchderbyshire.co.uk/mental-health-together/



01773 880786



enquiries@mentalhealthtogether.org.uk

 @MHTDerbys