

Personal and Public Involvement (PPI)



Guidance for Service Users and Carers when sharing their lived or living experience

This guide will support Service Users and Carers when they are invited to share their journey/experience with others. Telling your story can play a positive role for the person sharing their experience and in supporting others or highlighting the positive impact Service Users and Carer Involvement can make to the Health and Social Care system. For some, it can be an anxious experience and we want to keep people safe and reduce the chances of someone over sharing sensitive or personal experiences. We hope you find these tips helpful.

Step 1: Pre-planning stage

- Have a clear understanding of who has invited you to speak i.e. their name and contact information.
- Clarify the audience in advance i.e. will it be other Service Users and Carers or health care professionals you will be speaking with?
- Will it take place online or in person?
- If online, try and ensure you have a good internet connection and the meeting link in advance.
- If in person, try and make your self aware of the address, building and meeting room.
- Will my story be recorded? If yes, I would like to see the finished recording before I am comfortable with it being shared.
- How long am I being asked to speak?
- Do you want to use a PowerPoint presentation or would you prefer a more informal and relaxed conversation?
- Can I leave the meeting after I speak or am I required to stay the duration of the meeting?
- Do not rush into saying “Yes/No”; allow yourself some space to think and then respond.
- If it does not feel right, you do not have to do it.
- If the time and date does not suit or puts you under extra stress or pressure you can decline the invite.
- Do not agree to being recorded if you do not want to.
- If you previously agreed to tell your story and something has come up at the last minute i.e. GP appointment, you can cancel to another time that suits you.

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Step 2: The Purpose of your story

- Think about *why* you are telling your story, and *what* you want people to do after they have listened to your story.
- What impact do you want your story to make? i.e. change clinical practice, raise awareness of Service User and Carer Involvement, take action, change behaviours or organisational cultures .
- Try and keep to “I” or “me” as this will keep the focus on you.
- Have a clear start, middle and end.
- 5-6 minutes is the perfect amount of time to share your story.
- Your personal story is not intended to impress or shock your audience.
- Try and be brave in sharing your experience.
- Almost everyone has either heard or could have a negative experience when using a service.
- Try and avoid using this method, and do not share another person’s story.
- Avoid blaming or placing guilt upon others, organisation and services. You want your story to promote awareness and positive change for the future.

Step 3: Connect with your audience

- During your story describe the emotions, sounds, smells and how you felt, this will make your story more memorable.
- Protect yourself and know when to take a break.
- Keep your message simple and clear.
- Use language like, “together we can”, “we have all experienced”.
- Look up and smile at your audience.
- If you feel overwhelmed you can stop at any time.
- Don’t panic, if it does not go according to plan.
- Take a breather and remind yourself this is a good opportunity.

Step 4: Practice and prompt notes

- Keep a watch on the time or ask someone you know in the audience to support this.
- Enjoy the experience.
- Encourage your audience to ask questions.
- Practice, Practice, Practice.
- Avoid preaching to the audience.
- Don’t disregard difficult moments of being a Service User and Carer.
- It can be difficult to remember everything you want to say, have some prompt notes in front of you.

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Step 5: Self Care

- Telling your story can leave you feeling fatigued. Give yourself permission to take care of yourself.
- Take some time out afterwards and do something positive for you, go for a nice lunch, dinner, meet up with friends.
- It is important that you take care of your physical, emotional and mental well-being after you have shared your personal experience with others.
- Re-telling your story can bring up emotions and thoughts that can be difficult to manage, if this happens ask for help.

We hope you found these tips helpful, good luck and enjoy the experience.

For more information on Involvement, Co-Production and Partnership Working, please visit the Engage website:

<http://engage.hscni.net>

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