

Shared Learning Group on Involvement: Stopping involvement

Introduction

In June 2022 the Shared Learning Group on Involvement talked about how to support people with lived experience to stop their involvement. Thanks to Abby Meadows from Turn2us, Nicola Lucey and Angela Slater from Mind and Derek Stewart, a patient advocate, for sharing their experience and prompting really useful discussions amongst members. This paper summarises our discussions.

Why involvement may need to stop, and how to help this to happen

There are thousands of people with lived experience who effectively, successfully and with ease move on to other projects or decide to give it all a break. But there are inevitably a very few people for whom this is a challenge.

We have identified three main reasons that you might want to support people with lived experience to stop being involved:

1. They've come to the end of a project
2. There are some unacceptable behaviours
3. There are safeguarding issues.

Below we have summarised how you might make it easier for involvement to stop under each of these broad headings.

1. They've come to an end of a project or activity

You can make it easier for people to cease their involvement by:

- Building in time limits at the beginning of someone's involvement in a project/activity, so that people are clear on when their involvement will end
- Agreeing a development plan with people so that they can reflect on their achievements and feel confident they can move on to something else when a particular activity or project ends
- At each meeting, reminding people about the parameters and boundaries of the work, so expectations are consistently clear
- Checking in with people regularly (e.g. every six months) to see how they feel about their involvement, whether their and your expectations are being met and whether they want to continue with the project/activity
- If the timeline or the work of the project changes, checking with people whether they still want to be involved
- For longer term projects, considering how to manage the end of someone's involvement – e.g. hold a group celebration or thank you event; signpost people to other roles; hold an exit interview to note the skills they have developed and what

they achieved, and/or send handwritten thank you cards. Ideally you should co-design the ending together with the people involved

- Ensuring people are asked about their experience of being involved and are signposted to appropriate support if their experience of endings is difficult due to trauma etc.
- If there is another phase of the project/activity, involving them in the preparation for this - e.g. by involving them in the development of role descriptions and recruiting or mentoring new members. Be clear how much time they will be involved for if they take on additional roles such as mentoring.
- Keeping them informed if there are further stages of the project, so they feel involved in what they helped to create. You could do this via occasional update emails or by inviting them to the launch of the product/service.
- Ensuring people understand the impact and outcomes of their involvement. It can be helpful to do this in person, but also via email so people can refer back to it.

If people stop their involvement before the end of the project, think about how to keep them informed (if they want this). This might include sending regular updates, and/or inviting them to events.

Sometimes people can feel they are sharing the same experience or raising the same issue repeatedly – and sometimes staff may feel they need to hear different perspectives. In this case people may feel uncomfortable about saying they want to stop their involvement, so it's important they feel they have permission to do this. Discussion around inclusion can be a helpful starting point (e.g. the need to involve a wide range of people, or people with different experiences/perspectives).

Sometimes it can be helpful for people to move on to roles where they no longer need to share their lived experience – this might include mentoring others to get involved, involvement in training, recruitment, evaluation, developing new involvement roles etc. These moves can be mutually beneficial, as rather than people's knowledge and experience being lost, it is given a new focus.

2. Unacceptable behaviours

Although this is very rare, we need to be ready to stop someone from being involved in an activity because of their conduct. Its best to try to prevent this happening in the first place, for example by:

- Making people aware of your code of conduct when they first get involved
- Developing a 'working together' or group agreement at the start of a project and revisiting this at the start of each meeting. And making sure members have a copy of this
- Making sure you are clear with people about the conduct you and your organisation expect, and making sure that staff who are involving people understand this too, and are consistent in enforcing this
- Building your facilitation skills – good facilitation is important to prevent and deal with challenging behaviour

If you feel that someone's conduct is not acceptable, you should:

- If possible, plan what you want to say and seek advice before you address this
- Remind them of the code of conduct
- Separating out the behaviour from the individual person – focus on what was said or done as the reason for discussion

3. Safeguarding issues

Again, on rare occasions it may no longer be safe for someone to be involved in an activity or project. If this is the case, you should:

- Use a [trauma informed approach](#)
- Be clear about the support that you or your organisation can offer if someone needs it
- Regularly remind people where they can go if they feel they need help
- Recognise that people can have good days and bad days
- Try to agree with the person you are involving about removing them from a project temporarily or permanently, and whether it's appropriate to remove them from your involvement mailing list temporarily or permanently
- Agree whether and how you will keep people informed, if they want this
- If people need to step back from a project for wellbeing reasons, reassure them that this won't impact on them being part of future involvement opportunities
- Ensure that there is a consistent approach across your organisation if someone is involved in a range of projects

Other things to think about

Recognise that for some people, involvement gives a purpose and meaning to what they have been through. Stopping their involvement can feel like a bereavement. Remember also that if you manage an ending badly there may be a serious reputational risk to your organisation. So it's important to take great care when preparing to support someone to stop being involved. It is worth chatting to a colleague about your plans before taking any action.

Even if someone has done all they can in an involvement activity, they should not feel that their lived experience is not valued. We should be leaving people feeling they have the right and power to talk about their experience and to continue to contribute this. This may be through other organisations.

Make sure you have the right policies in place before you start involving people (e.g. a code of conduct), so that you can draw on these when you need them.

Tell us what you think

We're interested to hear others' views on the issue of stopping involvement. Please share your views – email admin@slginvolvement.org.uk – and we'll look to update this paper.

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www.slginvolvement.org.uk

A personal perspective from Derek Stewart

One of the difficulties I faced in the early years of my involvement was summed up by the health professional in the group:

“We don’t know what we don’t know!”

There were clearly a number of things I wanted to change and here was a health professional asking for my opinion. It is easy to think...well, let me tell you!

I think we assume that the story and timeline of what happened to us is what is needed and wanted.

So, it took a long time to understand what parts of my journey they wanted to know about - whether it was the actual events, the time it took, how I felt and/or what I thought about it. After a time, my ‘story’ fades and becomes a fulcrum around the wider patient/carer perspective.

It was helpful when someone intervened to bring me back to the topic being discussed. It was useful to be reminded of the group agreement and our behaviours. It was valuable to be told where else I could properly address any issues I had. It was constructive to have chats outside the meeting about whether my contributions were worthwhile and how I might make a difference. It was advantageous to meet with other patients/public members to chat informally about what this was all about.

We will not really learn, move on and develop unless someone offers advice, help and support by suggesting others we might like to talk with, articles we might like to read, forums we might like to join.

It is these educational and preventative measures that help us avoid the necessity of having to intervene and ‘stop’ someone’s involvement.