Shared Learning Group on Involvement

**Involvement, volunteering and supporting:
A discussion paper**

1. Introduction

1.1 This paper reflects the discussions of the Shared Learning Group on Involvement about 'involvement', 'volunteering' and 'supporting'. This is a working document that has been (and will continue to be) developed over time – it does not reflect the views of all members of the Shared Learning Group.

1.2. This paper was originally written in 2006, and reviewed and updated in 2009, 2011, 2014 and 2019. We're making this latest version publicly available in case it is of use to people and organisations outside our membership.

2. Terminology used in this paper

2.1 Many terms are used to describe the people who our member organisations exist to support. These include 'people with lived experience', 'people affected by…', 'service users' as well as other terms that are specific to an organisation (e.g. 'young women' at the Young Women's Trust). There is no one term that is acceptable and appropriate to all of the people our organisations exist to support. In this paper we have used the term 'service users' to describe people our organisations aim to support and people who directly benefit from our services. This includes people with lived experience of a condition or issue, carers, friends and family. We want to distinguish between the involvement of this group of people and the involvement of other stakeholders (e.g. staff or clinicians).

2.2 We've used the term 'involvement' to describe the active participation of service users in an organisation's decision making. Again, we recognise that many other terms are used, including 'participation', 'engagement', 'lived experience leadership', 'influence and participation', 'voices', 'shaping' and 'insight'. We have chosen to use the term 'involvement' as it is the term used by most of our members.

2.3 For us, the term 'involvement' includes approaches such as co-production and co-design, but is broader than these, as it also covers approaches such as consultation and service user led activities.

3. Defining involvement, volunteering and supporting. What are the key differences?

3.1   Service user involvement refers to any activity where services users are meaningfully involved in decisions which influence, shape and change the work of an organisation. This requires service users' views to be respected and valued, and for them to be part of decision making processes. When organisations involve service users they are inviting them to share power, control and influence and therefore also to share accountability and responsibility. Service users may or may not be paid for their involvement.

3.2   The key aspect of 'volunteering' is the willingness of individuals to give their time (free of charge) to help an organisation to do its job. Volunteering is often covered through a volunteering policy, and volunteers may be asked to sign up to certain conditions. Volunteers do not need to have lived experience of a condition or issue.

3.3.   'Supporting' involves people giving money, gifts in kind, resources, expertise or time (e.g. to support campaigns). Some organisations use this term to describe people who support a friend or family member to take part in an involvement activity. Supporters do not have the same formal relationship with an organisation that volunteers do. As with volunteers, supporters are not necessarily affected by a health condition (or disadvantage) and may not require any particular expertise.

Example

An organisation might offer a particular service.

Involvement means that service users will have the chance to influence the design, delivery and/or review of the service.

Volunteers may help to deliver the service, but will not usually have a say about how the service is designed or delivered.

Supporters may help to raise money to fund the service.

3.5.   The differences and similarities between service user involvement, volunteering and supporting are summarised in the table in Appendix One.

4. When is it important to recognise the differences?

4.1   It can be helpful to make a clear distinction between service user involvement, volunteering and support when there is a misunderstanding (particularly amongst staff) about what service user involvement really means.

> **Example**
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> Some staff may believe asking service users to take part in a campaign is 'involvement' – but this would only be genuine involvement if service users are involved in deciding what the campaign should be about and how it should be run.
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> Asking service users to help out at a pre-arranged campaign event that is planned and organised solely by staff is better described as seeking volunteers.
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> Asking people to send money to support a campaign, or asking family of friends to support a service user to get involved in a campaign, may be better described as seeking supporters.

4.3 It can be helpful for staff teams who have traditionally focused on volunteering or supporting (e.g. fundraising) to understand what makes service user involvement different. It's also important that senior leaders understand the difference between involvement and volunteering, because they set the cultural tone of an organisation, and they are the people who can ensure that service users can have more of an influence on an organisation.

5. What are the similarities between involvement, volunteering and supporting?

5.1 The overarching similarity between involvement, volunteering and supporting is the willingness of people to give their time to help an organisation, regardless of what task or role they take on. This is often linked with a wish to support the goals of an organisation, or a 'thank you' in return for help received.

5.2 Organisations are likely to value every contribution that is made and may wish to avoid appearing to value the contribution of one group of people over another.

6. When is it important to recognise the similarities?

6.1 For service users, volunteers and supporters the distinction between these different activities may not be obvious and the label may seem unimportant. But it can create tension and confusion if some people are paid for their work when others are not and the reasons why are unclear. Similarly, the same person may be paid for one activity but not for another, which they see as part of a whole – what they do to help an organisation.

6.2 Service users may prefer to define their role themselves. Some people have more than one role, or a role that changes over time. What is essential is that the organisation and the people involved have clarity about the purpose of any activity, the expectations of both sides and how much say the service user can have.

7. Overlapping and blurring boundaries

7.1 Service user involvement, volunteering and supporting can sometimes be blurred in organisational thinking. It is therefore important that organisational policies around supporting, volunteering and service user involvement are developed in parallel, with a clear understanding about the differences. For example a payment policy or a policy on criminal record checks may not uniformly apply to all of these roles. However, areas of overlap must also be kept in mind. This is particularly important from the service user's perspective.

7.2 Any one activity is not clearly always a voluntary task or an example of service user involvement. For example, a person who runs a support group could be a volunteer if they only deliver a service on behalf of an organisation. They could also be considered as an 'involved service user' if they decide how the group will run and/or provide feedback from their group to help shape the work of their host organisation. The case is similar for peer supporters.

7.3 Trustees are a special case. Some Trustees may be service users and their work considered to be part of an organisation's commitment to involving service users. Other Trustees who are not service users may be considered to be 'volunteers', particularly as they are not paid for their work. However, as they have considerable influence over the direction of an organisation, their role does not fit with the definition of volunteering described in this paper. Trustees could therefore be seen to fall into a separate category.

7.4 Organisations may need to give more thought as to how they describe the different ways in which people can work with them. For example, the 'get involved' section on the website of many organisations often only links people to fundraising information. However, this could be a way to inform people about the wide range of opportunities for volunteers, and for service users who would like to be 'involved' in influencing the organisation.

8.   The challenge of shifting an organisational culture to one where there is genuine involvement

8.1   An organisation that has previously only seen service users as volunteers or supporters will need to work hard to shift towards a culture of involvement. Even organisations that have been trying to work in partnership with service users for many years will still find it hard to genuinely share power with service users.

8.2   A lack of genuine involvement (or tokenistic involvement) may reflect a reluctance to share power with service users, or simply a lack of awareness or skills on the part of an organisation. Helping staff to understand the distinctions between service user involvement, volunteering and supporting is therefore important to help shift the balance of power and to find ways to support and enable staff to meaningfully involve service users in their work.

9.   Where should involvement staff be placed in an organisation?

9.1   There is no one right answer to this. Our members sit in a variety of teams within an organisation, including:

- Services (where organisations offer services)
- Volunteering
- Human resources/people
- Policy
- Campaigns
- Quality
- Regions

9.2   There are advantages and disadvantages to each of these options. For example, placing involvement within or alongside volunteering can be helpful, as it can help to ensure that involvement is supported through appropriate policies and procedures (e.g. expenses and data protection policies). But it can also lead to confusion if other staff see service users as volunteers who do not have any influence.

9.3   If an organisation provides services, it may be most appropriate for involvement to sit within the services directorate, to ensure that service users are meaningfully involved in the development, management and review of services, as the directorate is operationally focused on services.

10. Conclusion

10.1 Service user involvement, volunteering and supporting are all important roles within voluntary organisations. We think it's helpful for organisations (and especially staff) to be clear about the similarities and differences, so that they can interact with people appropriately. But we also recognise that the boundaries between these definitions can be blurred. For us the important thing is that service users are seen as partners, and that they have the opportunity to influence and change our organisations.

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Appendix One: Distinctions between service user involvement, volunteering and supporting

	Service user involvement	Volunteering	Supporting
Definition	The active participation of service users in decision making that takes place in our organisations.	The help people provide to deliver the work an organisation has already decided to take forward. There is usually a formal relationship between the organisation and the volunteer.	Those who give money, gifts in kind, knowledge, skills and/or time. There is no formal relationship between the supporter and the organisation.
Payment	Service users/carers may be paid for their time to attend meetings etc and their expenses are reimbursed.[1]	Volunteers provide their time for free. Usually their expenses are reimbursed.	Supporters provide their support for free. Expenses are not usually paid
Who does it?	People our organisations aim to support - this includes people with lived experience of a condition or issue, carers, friends and family.	Anyone	Anyone
What do they provide?	Expertise and knowledge based on life with a health condition or issue, and/or their experience of using services, as well as their other life experience or skills.	Time. May also offer expertise and knowledge from any area relevant to the work being taken forward e.g. fundraising, accounting.	Money or time. May also offer expertise and knowledge from any area relevant to the work being taken forward.

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[1] Some member organisations believe that service users *should* be paid and are doing this or working towards this, whilst recognising that this may have implications for the financial situations of some service users.

	Service user involvement	Volunteering	Supporting
Where do they do it?	Usually work directly with staff to plan, deliver or review the work of an organisation. May join existing planning groups or work independently as an advisory group or steering group.	Can work anywhere inside or outside the organisation – e.g. fundraising (external) or helping with admin (internal).	Can work anywhere inside or outside the organisation.
How are they supported?	Service users may be offered training and support to ensure they can participate meaningfully in decision-making.	Volunteers may be given training and support but are often 'managed' more closely to enable them to undertake work that helps the organisation.	Supporters are provided with information (from the public domain) which is relevant to their area of interest of activity.
When do they do it?	May be a one-off or ongoing.	May be a one-off or ongoing.	May be a one-off or ongoing.
Outputs/ outcomes	Views feed into decision-making, in order to influence those decisions and shape future direction.	Volunteers usually have no further influence on an organisation once they have helped to deliver a particular piece of work. They may of course be asked for their views on what an organisation does.	Supporters have no further influence on the organisation once they have helped raise funds or completed an activity. They may of course be asked for their views on what the organisation does.