

Commissioned by Health and Social Care Alliance Scotland

Learning Report

Engaging people with lived experience:
best practice, challenges, and opportunities



A research study on involving people with lived experience into health and social care policy and decision-making



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Contents

Introduction	1
Lived experience: A definition	1
Research scope	2
Desk research	2
Workshop and feedback questionnaire	3
Policymaker interviews	3
Key findings	4
KLoE 1) Best practices in engaging people with lived experience	4
KLoE 2) What are the barriers and enablers in engaging people with lived experience?	5
Barriers to engaging people with lived experience	5
Enablers to engaging people with lived experience	7
KLoE 3) What does inclusive and meaningful participation mean to practitioners and participants themselves? What does it look like and how can it impact on the project and participants?	8
KLoE 4) Impact/benefits on policy and decision-making of engaging people with lived experience	9
Recommendations	10
Conclusion	12
References	12

Introduction

This learning report provides a synthesis of a research study commissioned by the Health and Social Care Alliance Scotland (ALLIANCE) with the aim to identify and share best practice and evidence on including people with lived experience in health and social care policy.

The core component of the research consisted of a literature review, with the objective to understand the latest evidence and learning on how to meaningfully include people with lived experience in decision-making processes on health and social care. The desk research was supported by a workshop and feedback questionnaire with people with lived experience of health and social care. In addition, we conducted four interviews with people working on health and social care policy in Scotland. The purpose of the interviews was to understand the policy perspective and further probe points that arose from the desk research.

The desk-based research started in mid-April 2022 and the workshop was held on the 13th of June. The feedback questionnaire was completed by participants during the third week of June. The policymaker interviews were conducted in the last two weeks of July. The report was completed at the end of August.

Lived experience: A definition

Lived experience can refer to knowledge from having experienced something first-hand rather than through others' interpretations or representations, regardless of whether it is a difficult and traumatic experience or not (Chandler & Munday, 2016). For this research, which relates to health and social care specifically, the definitions of lived experience relate to first-hand experiences of social issues like care, health or discrimination as well as of services providing social and health care.



Research scope

The research has been guided by the following key lines of enquiry (KLoE):

- KLoE1: What approaches, design features and tools (including digital and platforms) are used to engage with people with lived experience, and what makes them effective? What can ensure that people with lived experience have the confidence and opportunities to tell their stories and that these stories are heard?
- KLoE2: What barriers can we identify during different phases of engagement? What are the mechanisms for incentivising/disincentivising engagement that are more successful to engage people with lived experience each phase?
- KLoE3: When people with lived experience are active and equal partners, what does that look like? What do people with lived experience perceive as the value of involving people like them?
- KLoE4: What is the impact on policy and practice of including people with lived experience in decision-making processes related to health and social care?

Desk research

The desk-based research included a review of academic sources and case studies from non-profit organisations and service providers the inclusion of people with lived experience in decision-making processes in the context of health and social care.

The desk-based research included the following search terms: 'lived experience', AND 'decision making' AND / OR 'policy' AND 'Scotland'. Specific searches for 'inclusion in policy Scotland' and 'including vulnerable groups in policy Scotland' were also included.

In total, we explored 31 sources (15 research studies and 16 case studies). The sources feature a mix of UK and international examples. This mix was seen as important to broaden learnings beyond Scotland, whilst retaining a focus on the Scottish context. Out of the 31 sources explored, 16 case studies were particularly relevant in addressing some or all of the KLoEs.¹



¹ Not all case studies are referenced in this summary but the full list can be accessed in the long report.

Workshop and feedback questionnaire

We facilitated a two-hour online workshop with people with lived experience of health and social care to learn from them and examine the extent to which their insights were reflected in the existing literature.

Six people out of the total who accepted an invite from the ALLIANCE attended the online workshop. Two facilitators from Demsoc (Democratic Society) guided the participants through key conversations points, focusing on:

- Experience of barriers and enablers to participation
- Experience of being involved in decision-making
- What could organisations do to enable people to participate meaningfully?
- What would a positive impact look like for decision-making in Scotland?

The feedback questionnaire was sent to all participants who signed up to the workshop, irrespective of whether they participated in the workshop or not. In total we had six responses to the feedback questionnaire.

Policymaker interviews

To build on the insights from the desk research and the workshop, it was decided to interview policymakers. The aim was to get a better understanding of potential barriers and enablers from the point of view of those designing or implementing policies. We followed a snowballing approach to identifying interviewees, starting from an initial list provided by the ALLIANCE. We interviewed four policymakers.



Key findings

All findings are presented according to the KLoEs. Here we share the main findings from the case studies, workshop, questionnaire and interviews.

KLoE 1) Best practices in engaging people with lived experience

To meaningfully involve people with lived experience in work requires organisations to listen and update their practices to ensure that needs are met. The highest level of engagement (and impact), and an example of best practice, enables people with lived experience to **lead and design decision-making processes** (Activity Alliance, n.d.; Arnstein, 1969; Mind, n.d.; Suicide Prevention Center, 2020).

Participants from the workshop and the feedback questionnaire mentioned that it is important that they **take part in all the steps of policy and decision-making**. They highlighted that it is important that they are being listened to and they want to be included in highlighting issues, formulating recommendations, and evaluating new changes. This implies that there needs to be **more meaningful** involvement of people with lived experience, beyond consultation. This way they can raise issues in services, suggest alternatives and solutions, and have a longitudinal role in the process.

Methods and approaches must be fit for purpose, well designed, have a clear rationale and structure, and be well executed. Key to this is having **clear roles and boundaries**, and therefore clear communication in the process to ensure meaningful participation. Communication between stakeholders and policy makers is important in relaying information on the development of projects. **Follow-up** was heavily emphasised by our participants, for them, it was important that processes include feedback to ensure participants are informed of the various steps after their input and have a chance to further contribute on any developments. This indicates to participants that the initiative aims for actual impact in people's lives.

Implementing a **monitoring and evaluation** (M&E) process was suggested by most of the interviewees working in policy. A few of them did express that evaluation is challenging to implement as there may be different degrees of involvement of people with lived experience, and it can be difficult to identify the impact these different levels have. An interviewee said that evaluating is a big part of **ethical work** as it helps assess whether the work that has been done has had an impact and it demonstrates to participants how their contributions are being used.

Meaningfully involving people with lived experience also requires **ongoing support**, which requires **resources, risk management and training**. People with lived experience should be provided a **support network and safe space** to speak about their experiences. Building **trust** minimises harm and ensures that individuals can share their experiences and discuss issues without feeling judged. Participants may share some similar experiences, but it is important to recognise that they are also people with individual experiences (Quintero, Murray, Connelly, & Ballantyne, 2015; Samaritans, n.d.).

For effective and meaningful engagement to take place, organisations and projects should also have **proper funding** for their initiatives (Sandhu, 2017). Funding enables adequate support for participants and staff members, reimbursement of people with lived experience for their time and effort, training opportunities, and equipment (MH:2K, 2017; Mind, n.d.; Sandhu, 2017).

Finally, having **well-trained staff** and providing them with toolkits and training to work with people with lived experience ensures that well-being, support, and delivery of activities are properly done (Mind, 2017).

KLoE 2) What are the barriers and enablers in engaging people with lived experience?

Barriers to engaging people with lived experience

There are several **barriers** in engaging people with lived experience in decision-making, but one that was mentioned strongly by participants in the workshop is related to **systemic and political barriers**. Participants emphasised that the systemic and political barriers make it **difficult for them to access the services and support** they need. The Department of Work and Pensions (DWP) and UK Government (which participants often referred to as Westminster) were mentioned as considerable barriers in engaging in decision-making and in receiving adequate social care. Participants wanted the political system to change and have a complete revision of how health and social care is provided. Participants referred to the overall UK Government and direction it has set, as a barrier to the development of policies in Scotland that are suitable to the needs of people with health and social care needs.

During the policy interviews, an interviewee said that the biggest barrier is the “established ways of working that the public sector can get stuck in”. The **lack of experience of working with people outside of the government** was described to have led to the lack of nurturing relationships with stakeholders and the lack of communication. All the policy interviewees did highlight that there are people within the public sector that are **passionate about their work** and are trying to improve how the sector works with lived experience. Their remarks highlighted that the system that is in place has often been a barrier for individuals or groups to deliver what they want to with the evidence they have. They expressed that there are significant levels of working that need to change that “puts lived experience in a proper central role”.

Workshop participants with lived experience mentioned the **lack of follow-up** to many of the initiatives that they had been involved. This made them feel less motivated to participate in future opportunities because there is no feedback on what has been done and people cannot see change being implemented as a result of their involvement.

There may also be a **lack of information of engagement possibilities**. Participants recounted that often people with lived experience may not be aware of opportunities of getting involved in decision-making processes and workshops catered for them.

Participants also highlighted that the **accessibility of meetings** affects how people with lived experience can engage in decision-making processes. They described that for example, in-person meetings are not accessible for everyone as leaving the house may be painful, time consuming, it costs money and there are concerns about wheelchair accessibility. For others, hour long online meetings are not feasible as it is difficult for them to concentrate and be engaged. This means different spaces of engagement need to be enabled to cater for different people and needs. Furthermore, the workshop participants mentioned that women are often the **caregivers for people** with health and social care needs (as well as having their own needs). This lived experience means they have very direct insight on what needs to change in health and social care, but the timing of meetings makes it more difficult for women to take part.

Some case studies highlighted **language barriers and misunderstandings** between individuals and service providers as a challenge in engagements. In addition, the difficulties in relaying issues to service providers has prevented many individuals from contacting them further (BEMIS, 2016).

Participants also flagged the **lack of adequate funding** for health and social care services impacts the ability of people to get adequate care. They expressed that even though many studies are being conducted on lived experience in health and social care, people's overall situation will not improve without proper funding from the government.

The interviewees working in policy highlighted an overreliance on organisations to recruit participants. When the Scottish Government reaches out to people with lived experience, it often reaches out to **organisations** who then **decide who represents lived experience**. Another interviewee commented that when organisations are asked to reach out to their stakeholders, they can end up being "**experts and lobbyist**" who "no longer talk from lived experience". Power dynamics and issues of representation are therefore also important.



Enablers to engaging people with lived experience

There are multiple ways to **enable** the involvement of people with lived experience in decision making processes, one of them is taking time to **build trust**. It is important to create safe inclusive spaces with adequate communication. The literature suggests also the value of co-creating these spaces where people with lived experience can develop their own rules and note what everyone's role will look like (Homer, 2019).

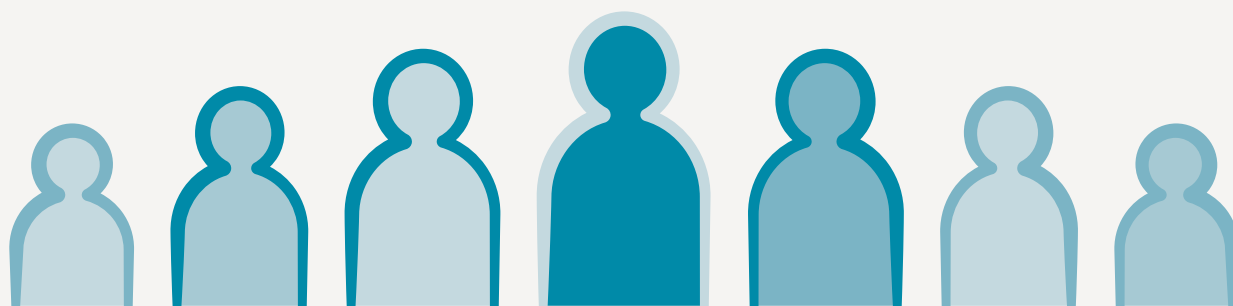
Working in collaboration with people with lived experience is mutually beneficial, as organisations and policymakers are informed about the lived experience perspective and people with lived experience are recognised for their work and contribution (Quintero et al., 2015). A policy officer expressed that by **creating a routine space** for meaningful involvement, policymakers can more regularly and easily access public opinion.

Participants need to be **recognised for their contribution** and their commitment. A participant said they see the involvement of lived experience as a "formal qualification" thus it should be given "equivalence to professional experience". At the very least, organisations should ensure that individuals do not need to cover for "participation-related expenses" (Homer, 2019, p. 13) and participants should be provided with food, transport, childcare support, and language interpretation. Those involved should also discuss together the individual needs of participants and barriers in order to effectively involve them in initiatives.

Other practices that can help people become involved, mentioned in the policy interviews with policymakers and case studies, were to hold engagements in **accessible, conveniently located** and **familiar** spaces to alleviate possible intimidation and anxiety (BEMIS, 2016; CFE Research, 2020; Homer, 2019). There should also be more than one type or space for engagement to cater for different needs, be it online, in person and through different approaches. A participant expressed in the feedback questionnaire: "Giving a lot of options is one of the biggest things I can suggest".

Furthermore, the people working in policy expressed that the government should work more with people who have not engaged with the Scottish Government before, and that there should be a system in place to **reach those who are the most removed from government**.

Lastly, initiatives should **clearly state** the **level of commitment, and the timeframe** of an engagement, and use plain language when recruiting people with lived experience. Including the benefits of participation such as pay and new skills in the recruitment poster informs possible participants of what to expect (Homer, 2019; Mind, n.d.).



KLoE 3) What does inclusive and meaningful participation mean to practitioners and participants themselves? What does it look like and how can it impact on the project and participants?

Meaningful involvement of people with lived experience can help organisations adopt a **reflexive approach**. A policy officer explained that it is important to remove oneself as “your own point of view is inherently biased” and understand the different perspectives that exist. They expressed that for policies to be effective they need to be representative of the needs in society.

Working effectively with people with lived experience can help staff understand the **day-to-day experiences** of people with lived experience. They will be more connected and familiar with the issues people face. With this increased familiarity and experience of lived experience, staff become more comfortable in addressing these issues (Mind, 2017; Mind, n.d.). Furthermore, people with lived experience can help “demystify” what it means to have lived experience through interaction with organisations and policymakers (CFE Research, 2020, p. 18).

Being involved in decision making processes also enables people with lived experience to share their experiences and reflect on their own situation (Mind, 2017). As a result of the online workshop, one participant expressed being **exposed to different experiences** and viewpoints that they otherwise might not have thought of. In addition, individuals may feel isolated in their situations and experiences, and when they join activities that are aimed at them, they may feel more **connected to their local communities** (Quintero et al., 2015).

Being able to contribute can make people with lived experience feel **valued** and **respected** (Mind, 2017) and working with organisations that respect, listen, and empower people with lived experience makes a **positive impact** on people (Samaritans, n.d.). When this meaningful participation takes place, individuals have expressed feeling empowered and having a sense of being able to tackle anything (Quintero et al., 2015), as well as being hopeful and aiming toward something greater as a result of being a part of decision-making processes (CFE Research, 2020).

Finally, engaging in decision-making process and working with different stakeholders also helps participants gain **transferable skills**, which can support people to take up other opportunities as a result (Quintero et al., 2015).

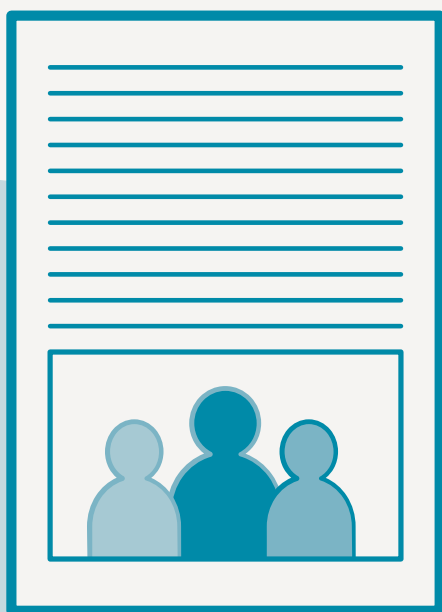


KLoE 4) Impact/benefits on policy and decision-making of engaging people with lived experience

Despite all the benefits recognised in the literature, workshop and interviews as outlined in the previous KLoE, the research also demonstrated that there is **a gap in knowledge on the external impact of involving people with lived experience**. Whilst there are many potential benefits such as building policies that better reflect the needs of people that use health and social care services, it is difficult to establish if and how this happens. Some of the case studies in our desk research identified **enhanced credibility and visibility of people with lived experience** as an important impact (Mind, 2017; Mind, n.d.; Quintero et al., 2015). This credibility and legitimacy can be further enhanced when people with lived experience are directly involved in producing reports of their work which can be utilised by policymakers (Quintero et al., 2015). But workshop participants expressed a need for radical change in the services that are provided to them, and most studies do not explicitly identify policy impacts of involving people with lived experience.

Tracking the impacts of participation is complex and may occur over time (Parry & Ercan, forthcoming). Even when changes in policy occur, it is difficult to establish causality on the influencing factor to the extent where one can claim it came down to a specific engagement initiative (Quintero et al., 2015).

It is still important to note, as mentioned in the literature, that a small group of people with lived experience can never be fully representative of all perspectives (de Wit, Kvien, & Gossec, 2015). In addition, there are barriers that may not be solved by involving people with lived experience, such as the lack of funding and resources to implement the policies and practices they have helped to inform or design, and other systemic or structural barriers mentioned in this report.



Recommendations

Table 1 below summarises the best practices for engaging and involving people with lived experience in decision-making processes.

Best practice	Examples
Meaningful levels of engagement	<ul style="list-style-type: none">• Inclusion of people with lived experience in all the steps of decision-making (design, implementation, and evaluation)• Listening and implementation• Co-production and collaboration• Feedback and follow-up• Embed inclusive practices and spaces in design and budgets
Ensure clear expectations and communication throughout	<ul style="list-style-type: none">• Clear roles• Having a common goal and clear expectations• Clear communication
Do monitoring and evaluation	<ul style="list-style-type: none">• Identify the impact of participation on policy and services• Indicate how contributions are being used• Incorporate learnings from past work

Provide training and support for participants	<ul style="list-style-type: none"> • Help participants prepare for tasks • Accessibility • Online and/or offline engagement and in multiple forms (diversity of options) • Tailored emotional and practical support
Have appropriate and well-trained staff and networks	<ul style="list-style-type: none"> • Training for staff working in policy and services • Ensure staff can properly support participants • Create trust with appropriate skills • Build relationship with existing networks
Ensure funding and resources	<ul style="list-style-type: none"> • Effectively planned • Budget for expenses such as training, support, payments, venue • Clear timeline
Value participants as individuals and reflect their needs	<ul style="list-style-type: none"> • Different experiences • Listen to individuals, collaborate together • Lived experience at the centre
Create a trusting and welcoming environment	<ul style="list-style-type: none"> • Minimise harm • Safe space • Inclusive language and spaces

Table 1. A summarised list of best practices in involving and engaging people with lived experience.²

² A table with pink outlines and two columns. The left column is named best practice and the right column is named examples. They have grey background and the text is in bold font. The right column has eight rows. The right column has eight rows giving examples to the best practices. These text are in black, Verdana font size 11.

Conclusion

People with lived experience want to be listened to, want to contribute, want to design, produce, and evaluate changes made to policies that affect their lives. They must be given the opportunity to do so meaningfully, which means in an inclusive and consequential manner and, as one workshop participant said, doing “design based on dignity and respect”. There are many benefits to people, organisations, and policies of involving lived experience in meaningful ways. However, more research needs to be done to understand if and how the impact of engaging people with lived experience results in improved health and social care or how this impact can be strengthened and sustained. Other systemic barriers related to governments’ interests or ideologies, funding and resources, and ways of working will also need to be overcome for people’s involvement to translate into social change.

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