

Commissioned by Health and Social Care Alliance Scotland

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

October 2022



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Foreword

Amplifying the Voice of Lived Experience - Sara Redmond, Chief Officer, the Health and Social Care Alliance Scotland (the ALLIANCE)

There is a growing practice in Scotland to ensure that people's expertise and knowledge through their lived experience is valued and, and that people's voices are at the centre of policy and practice through meaningful involvement in decisions which affect them. Yet, this is a culture shift which is still developing, and currently there remain occasions where people are being involved with insufficient time or resources being allocated, and where the scope to influence feels predetermined and somewhat limited to those involved.

If we are to realise the ambition where people are meaningfully able to share their lived experience to influence decisions and actions taken at a policy level, it is essential that we understand what good looks like, what the barriers and enablers are to engaging with people with lived experience, and develop robust evidence about the difference it can make when individuals are active and equal partners in the development of policy and practice.

As an organisation, the Health and Social Care Alliance Scotland (the ALLIANCE) is committed to contributing to the realisation of this ambition and we have been involved in a range of work internally and with members on this issue. This research by the Democratic Society (Demsoc) was commissioned to explore the existing evidence on best practice for the meaningful involvement of those with lived experience.

There is already great work which can be built upon across Scotland and internationally. This research helps to bring some of this together and will be a useful resource to groups and organisations seeking to develop and assess their own practice. It also helpfully highlights that more research is needed to evaluate the impact of involving people with lived experience on policy and practice. It is imperative that we invest in this evidence base to ensure there is accountability as well as the opportunity for learning and improvement. For our part, we are committed to ensuring that the ALLIANCE utilises this research in our continuing work to collaborate with members in supporting this culture change which we see as integral to embedding a human rights-based approach.



Executive summary

This report documents the findings from a research study conducted by The Democratic Society (Demsoc) for the Health and Social Care Alliance Scotland (the ALLIANCE). 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 literature review was complemented by a workshop with people with lived experience in Scotland, a feedback questionnaire, and interviews with policymakers working in Scotland.

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

- KLoE 1) Best practices in engaging people with lived experience
- KLoE 2) Barriers and enablers in engaging people with lived experience
- KLoE 3) Inclusion and quality of participation
- KLoE 4) Impact achieved

We have identified the following key learnings on meaningfully engaging with people with lived experience. It is important to involve people at each stage of work or policy cycle; setting clear goals and expectations for an engagement; making participation accessible and inclusive; and providing adequate support and training for participants were given as examples of meaningful participation. The UK political system and other systemic barriers, such as lack of funding, were highlighted as hindrances to meaningful work with lived experience. Monitoring and evaluation was mentioned in the policy interviews as being important to learn from the engagements and understand their impact but its use is limited because there is no clear system in place for it. More specifically, we identified the following insights:

Workshop participants expressed wanting to be more meaningfully involved. This means being a **part of each stage of the process** rather than being consulted once without follow-up. Sustained involvement, at the ideation, design, and implementation stage, allows people with lived experience to raise key issues that affect them, recommend changes and solutions to policies, help implement them, and evaluate their effectiveness in the long run. **Follow-ups** enable those who were involved in policy work to be informed about the impact of their contribution to policy and decision-making. Participants from the workshop conveyed how they are often consulted but are not kept informed of the effects of their involvement. The literature and case studies often mention the 'participation ladder' framework (see Arnstein, 1969) as an example of the different levels of involvement and the various methods and stages relevant for each level of involvement.

Setting **clear goals** and **expectations** for a process help ensure that participants are aware of what is expected of them and what their work entails. It can also help avoid disappointment in the outcomes of policy work as individuals are made aware of what the outcomes are likely to be or how decision-making processes are likely to work. A clear timeline of the engagement also informs those involved what is expected of them and for how long. Participants from the workshop and feedback questionnaire also expressed that they want to be told the truth of what is feasible. Those working in policy also expressed a willingness to be truthful and manage expectations. **Clear communication among** those involved minimises miscommunication and fosters an environment of open communication. Such practices also encourage new voices to be heard.

Participation should be made **inclusive and accessible** to allow different means of participation. **Paying people with lived experience for their contribution** provides an opportunity for everyone to be involved. Although currently there are restrictions imposed by the current systems that can make it challenging to provide monetary remuneration for participation (McLean, 2021). **Different needs should be represented and valued** by adopting methods to support participation. Some may have other commitments or may not be able to attend online or offline due to health or accessibility needs. Holding accessible meetings and different types of engagement and providing tailored support for those who need it enables meaningful participation. **Diversifying target groups and communities** that the government and other bodies work with ensures that decision-making processes are informed by different people. It can also reduce the pressure that people with lived experience may face if they were to contiguously work on the same issues.

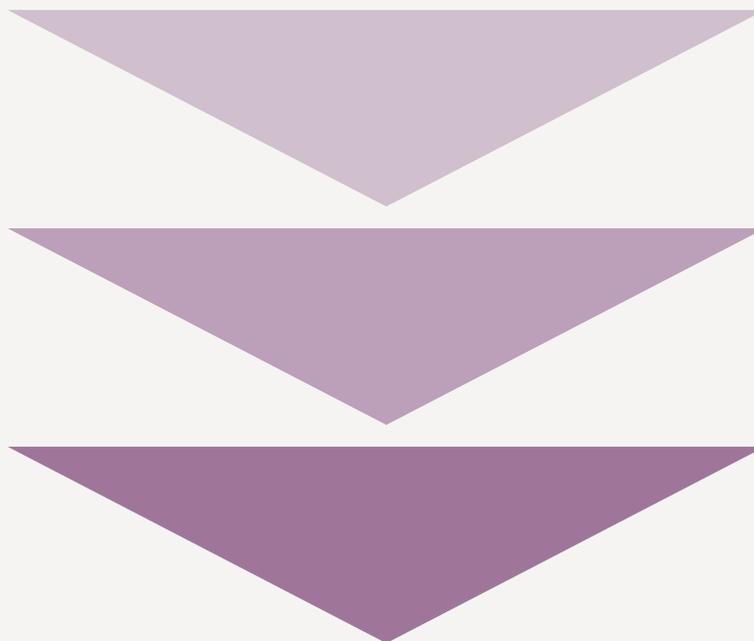
Participation should be accompanied with **adequate support and training** for people with lived experience taking part in the work. Appointing **appropriate and well-trained** staff to work with lived experience ensures that proper support is given to people and that the work is well executed. Training and support can encourage participants to **feel more comfortable** about their contribution and help them **develop and gain new skills** which they can transfer to other employment. In addition to feeling comfortable, creating a welcoming and trusting environment can minimise harm for participants and establish a **safe space**.

Participants from the workshop and comments from the feedback questionnaire expressed that the UK **political system and other systemic barriers** prevent many from maintaining an adequate standard of living. "Westminster" was mentioned in this context as a barrier to decision-making that meets the needs of participants, and the Department of Work and Pensions (DWP) was referred to as a barrier to receiving adequate care that meets their specific needs. It was heavily emphasised that not everyone has their needs met and care should be tailor made. Interviews with people working in policy in Scotland highlighted barriers that exist in their workplace that **hinder their ability to do what they think is best**. They expressed that in the public sector there are many employees who are passionate about their work and want to do lived experience work meaningfully but the lack of trained staff working with lived experience and the system that is in place make it harder to do meaningful work.

Lived experience is put at the centre and core of policy and decision-making processes by valuing people with lived experience as **individuals** who have their own **unique experiences**. This ensures that the outcomes **reflect their needs and their inputs**. Organisations should provide training and support for staff working with people with lived experience to further develop their understanding of people's experiences.

The need for proper **monitoring and evaluation** processes to be put in place was emphasised by some of the interviewees, in order to identify the impact of involving people with lived experience and to learn from the work that has been done. The literature and case studies reviewed highlight the benefits involving people with lived experience has for participants and for organisations and policy. People working with lived experience can better address biases and misconceptions; design and implement strategies and policies that are relevant to real needs and more effective; and improve the communication of services and policies. However, evidence on the long-term impact of involving people with lived experience is limited.

Finally involving people with lived experience requires **communication, time**, and **resources** for a meaningful, inclusive, and impactful engagement.



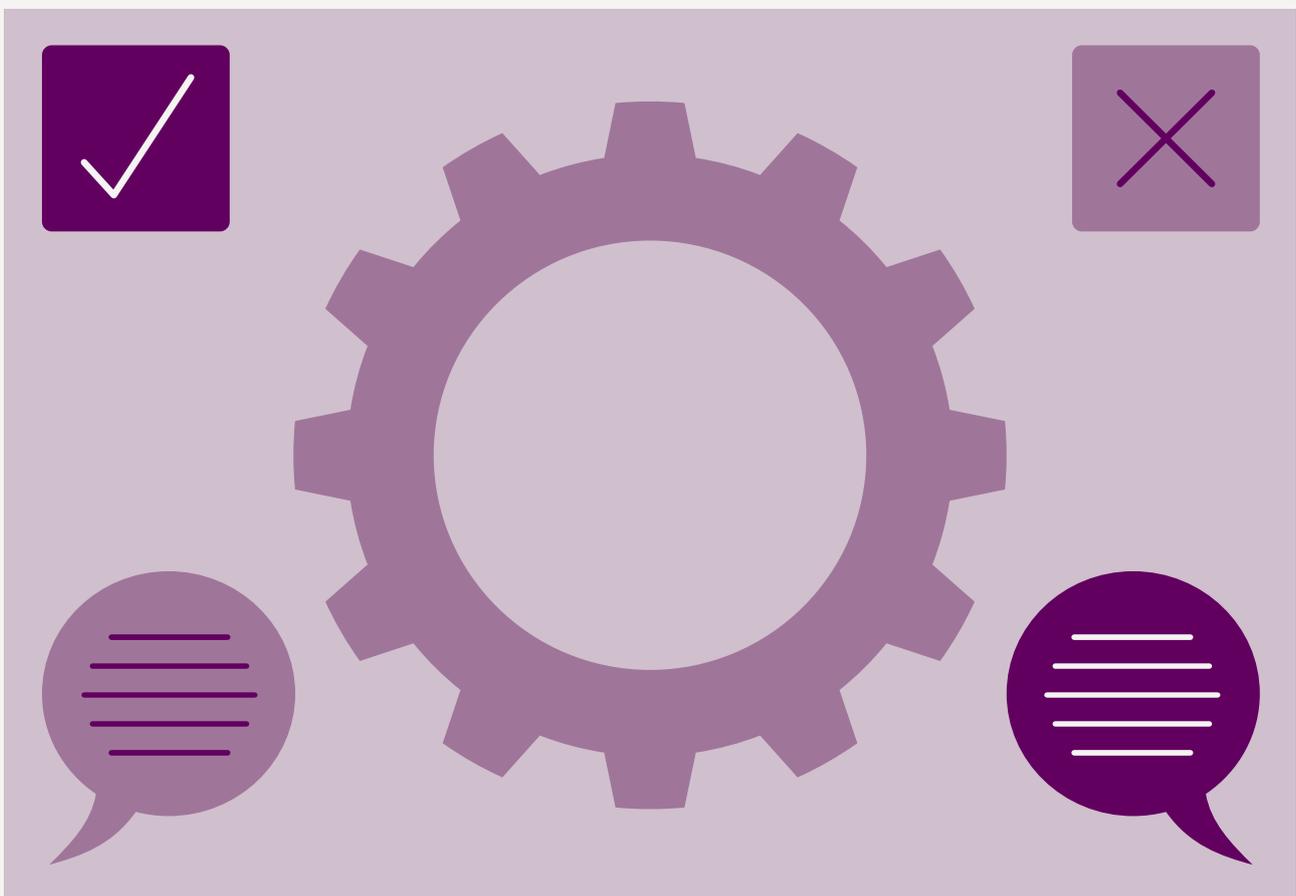
Introduction

This research has been commissioned by the ALLIANCE with the aim to identify and share best practice and evidence on including people's lived experience in health and social care policy and practice. Key learnings from this report will provide an evidence base to inform decision-making processes and the design and implementation of policy.

Specifically, the study sought to identify best practice of meaningfully engaging and involving people with lived experience as well as to document the impact achieved and understand how to plan for successful involvement.

The report is structured as follows. First, we introduce the key lines of enquiry that have guided the research. Then we explain the research scope and methodology, including the desk-based research, workshop and feedback questionnaire, and the interviews with policymakers. Following this, we provide a definition of lived experience in this report. Subsequently, we analyse the findings from the literature, workshop, feedback questionnaire, and the policymaker interviews. Finally, we outline the limitations of the study and future research and recommendations on the best ways to involve people with lived experience in decision-making processes.

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 the participants during the third week of June. The interviews with people working in policy were conducted in the last two weeks of July. The report was completed at the end of August.



Research scope and methodology

The core of this research consists of a literature review, including practical case studies and research as well as academic literature. The desk research has been supplemented with 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.

There are four key lines of enquiry (KLoEs) that have guided this research. The first key line of enquiry (KLoE1) has focused on identifying lessons from best practice on how to design spaces for meaningfully including lived experience. KLoE2 aimed at exploring barriers and enablers to meaningfully including lived experience and KLoE3 focused more specifically on what inclusion and quality of involvement looks like and what it means for participants and organisations. Finally, the fourth key line of enquiry aimed at exploring the impact that meaningfully including people with lived experience has on policy and practice in health and social care.

KLoE 1 - Best practice

What are the lessons from existing practice in engaging people with lived experience in health and social care in relation to:

- What approaches, design features and tools (including digital and platforms) are used to engage with people with lived experience, and what makes them effective?
- Meaningfulness of engagement: what can ensure that people with lived experience have the confidence and opportunities to tell their stories and that these stories are heard? (e.g., focusing on inclusiveness and emancipatory potential of engagement)



KLoE 2 - Barriers and enablers

What are the barriers and enablers to engaging people with lived experience on issues related to health and social care:

- 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?
- What type of support can help overcome these barriers to enable participation?
- What approaches ensure long-term engagement?

KLoE 3 - Inclusion and quality

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?

- How are systemic barriers to participation tackled?
- What evidence is there of reported long-term positive outcomes and benefit for those who participated beyond the initial engagement?

KLoE4 - Impact

What is the impact on policy and practice of including people with lived experience in decision-making processes related to health and social care?

- The impact of engaging people with lived experience in policy and practice (e.g., how has the engagement been used across the input, process and output phases of a decision-making process)
- How are expectations set and what is the role of people with lived experience?
- How is the success defined (e.g., what was the perceived added value) – how can it be measured and what counts as good engagement?

Desk research

The desk-based research included a review of academic sources and case studies from non-profit organisations and service providers on the inclusion of people with lived experience in decision-making processes on health and social care. The search was done using a series of keywords in different browsers. The keywords 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. We also consulted Google Scholar and Participedia, a crowdsourced database of participatory case studies.

Relevant sources came from organisations working on health and social care, -including toolkits, evaluation or learning reports, and policy documents -, and academic literature. The main findings were analysed thematically according to the KLoEs. In total, we explored 31 sources (15 research studies and 16 case studies).

In terms of geographical spread, 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. Table 1 shows the geographical spread across the 31 sources that were explored.



Table 1. Geographical spread of sources explored.

Out of the 31 sources explored, 16 case studies were particularly relevant in addressing some or all of the KLoEs and have thus been summarised with key insights in a separate document. This final list includes the case studies that have been used for the analysis and which will be referred to in this report.

Workshop and feedback questionnaire

In addition to the desk research, 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. All participants were recruited through the ALLIANCE. Six people participated in the online workshop. An additional four people who could not attend the workshop provided feedback via an email questionnaire. Two participants who attended the workshop also gave additional feedback in the questionnaire. 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. Given the small number of participants, we are mindful that this group cannot represent the views of all people with lived experience in Scotland. Therefore, the insights recounted below reflect the views of the participants in the workshop and are not generalised claims. However, when triangulated with the literature, they provide a consistent answer to the KLoEs.

Those who gave feedback through the questionnaire (n=6) self-reported a physical long-term condition, chronic pain, disability, mental health problem (such as depression, anxiety, bi-polar etc.) or none. They were from the northeast, south, southwest, and west of Scotland. They were between the ages of 35 and 75.

For the workshop, it was agreed in advance that an ALLIANCE representative would not be present, in an effort to mitigate possible power dynamics and ensure that participants felt they could speak openly. At the start of the workshop, two researchers from Demsoc presented an overview of the desk research insights. They also took notes and observations during the workshop. A research assistant also attended and provided summarised live captions to support participants who were hard of hearing or had connectivity issues. Two facilitators from Demsoc guided the participants through key conversations points, focusing on:

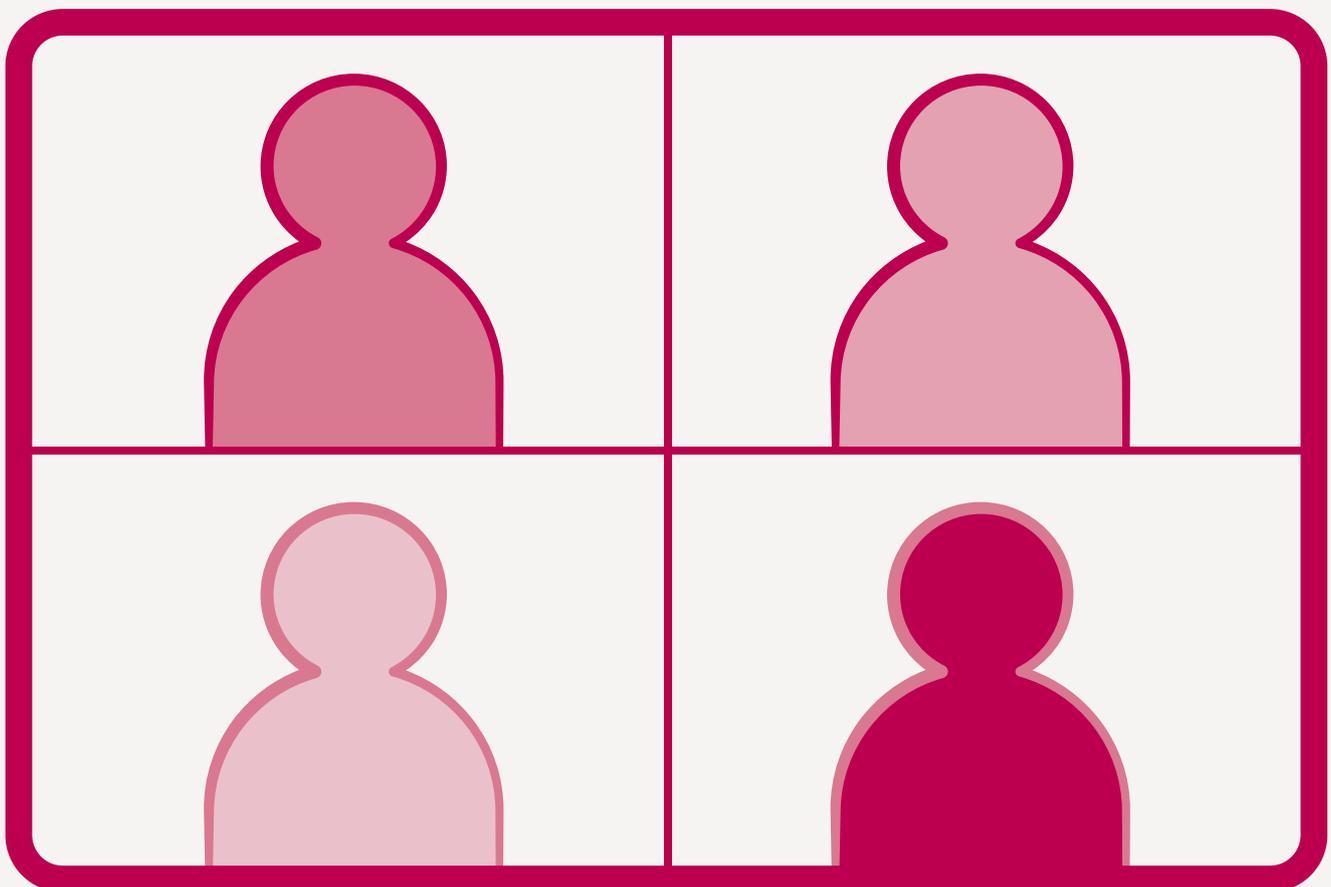
- Experience of barriers and enablers to participation
- Experience of being involved in decision-making
- What could organisations do to enable people to participate meaningfully?
- What would a positive impact look like for decision-making in Scotland?

The insights gained from the workshop reflected many of the key findings from the literature and case studies we identified. However, talking to participants also generated additional valuable insights that were new to us. These included the lived experiences of systemic barriers such as governance and government policy and gendered impacts of health and social care needs and services. In addition, workshop participants sharing their experiences vividly illustrated the very real and concrete struggles that people with lived experience face. This in itself is evidence of the value that people with lived experience bring, including into this report. We are grateful to the participants for giving us their time and sharing their insights so candidly.

Policymaker interviews

Four interviews with people working in policy in health and social care were conducted after the workshop to get a better understanding of the policy landscape in Scotland and discuss the potential barriers and enablers in shaping policy and practice on health and social care. The ALLIANCE gave Demsoc a list of people working in health and social care policy, and they were contacted. Through snowballing, other contacts were reached out to and four interviewees were found. The interviews lasted between 30 to 50 minutes and were conducted online, on Microsoft Teams. The interviews were recorded for the purpose of analysis.

The insights gained from the interviews with people working in policy reflected the findings from the literature and workshop but added nuance on the barriers faced on the policy side. They specifically focused on monitoring and evaluation, diversifying target audiences, reaching out to individuals and community groups rather than organisations, and the systemic barriers that can prevent government staff from doing meaningful work with lived experience.



Lived experience: A definition

Before presenting the findings, it is important to clarify what is meant by lived experience in this report.

Some of the case studies analysed include definitions in their reports or toolkits. For example, CFE Research (2020, p. 6) defines lived experience as:

...direct, personal experience of a particular issue or service. In the case of this report this includes experience of homelessness, substance misuse, contact with the criminal justice system and mental ill health.

Sandhu (2017, p. 2) explains lived experience as:

The experience(s) of people on whom a social issue, or combination of issues, has had a direct impact.

Chandler and Munday (2016) define it as follows:

Personal knowledge about the world gained through direct, first-hand involvement in everyday events rather than through representations constructed by other people.

It is common for lived experience to refer to personal and direct experiences of difficult social issues, often related to ill health or discrimination. However, as seen in Sandhu, and Chandler and Munday's definitions, lived experience can also have a broader meaning. It 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. The Scottish Social Services Council (2019), for example, refers to people with "lived experience of social services" (p. 3) specifically and defines it as "people who use or have used social services and people who are carers" (p. 3). Lived experience thus also entails the experience of using a service as different from the experience of those who might be designing or delivering the service.

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.

Key findings

The following sections present the main findings identified from the desk research of sixteen case studies, the workshop, the feedback questionnaire, and the interviews with people working in policy. All findings are presented according to the KLoEs. When insights came directly from the workshop and questionnaire, this is acknowledged, as well as when they came directly from the policy interviews.

Table 2 below shows the findings at a glance.

Themes	Findings
KLoE 1 - Best practices of involving people with lived experience	<ol style="list-style-type: none">1 Have meaningful levels of participation and involvement2 Ensure clear expectations and communication throughout3 Do monitoring and evaluation4 Provide resources, training, support, and account for risk of involvement5 Recognise the worth and value of participants as individuals and reflect their needs and outputs6 Work to create a trusting and welcoming environment7 Ensure projects are well funded and resourced8 Have appropriate and well-trained staff and networks



Themes

KLoE 2 - Barriers and enablers to participation

Findings

Barriers

- 1 Systemic and political barriers
- 2 Tokenistic involvement of people with lived experience
- 3 Not enough information about opportunities to participate / Information about participation not reaching the target population
- 4 Practical barriers / lack of inclusive spaces
- 5 Lack of language and cultural sensitivities
- 6 Lack of funding and time
- 7 Reliance on organisations for participants

Enablers

- 1 Use time and effort to build trust
- 2 Build a collaborative foundation to continue planning
- 3 Eliminate financial and practical barriers
- 4 Diversify target groups
- 5 Share accessible and clear information about participation

Themes	Findings
<p>KLoE 3 - Inclusion and quality of participation</p>	<p>An engagement that is inclusive and high-quality means:</p> <p>To practitioners/policymakers</p> <ol style="list-style-type: none"> 1 Strengthen effectiveness of services 2 Staff development 3 Workplace inclusiveness <hr/> <p>To participants</p> <ol style="list-style-type: none"> 1 Share experiences and listen to others' stories 2 The opportunity to directly influence policy and services is meaningful to participants 3 Participants can gain transferable skills <hr/> <p>To both practitioners and participants</p> <ol style="list-style-type: none"> 1 Improve knowledge and reduce stigma around the topic and life experience
<p>KLoE 4 - Impact on policy/decision-making</p>	<ol style="list-style-type: none"> 1 Hard to identify impact on policy and decision-making potentially due to limited research on policy impacts, long term benefits or limited meaningful engagement of lived experience 2 Credibility of work recognised

Table 2. Key findings described briefly.

KLoE 1) Best practices in engaging people with lived experience

This line of enquiry focused on exploring lessons of **best practice** in engaging people with lived experience. A key element of this KLoE was identifying the different **approaches** that organisations took to engage with people with lived experience. Below we present the learnings from best practice identified in our research, with a focus on these different approaches.

1 Have meaningful levels of participation and involvement

There are different degrees of involving people with lived experience with increasing levels of empowerment. Some of the case studies illustrated these levels through a **participation ladder** (Arnstein, 1969; Mind, n.d.; Suicide Prevention Center, 2020), shown in Table 4 below. There are also different practices in engaging people with lived experience such as peer research, inclusion in committees, working groups, or consultation. These practices enable different levels of engagement. For example, consultations through surveys or focus groups are less empowering and meaningful than approaches that involve sharing decision-making or sustained engagement.



Level of participation	Description
Leading	Processes designed, developed, and run by people with lived experience
Collaborating	Partnership between stakeholders and people with lived experience
Working and doing together	Decision-making shared as much as possible. Common goals and fixed roles for those involved
Consulting	Gain insights from people with lived experience about improvements
Informing	Inform people with lived experience about opportunities to be involved

Table 3. Illustration of the different levels of participation. Adapted from Arnstein (1969), Mind (n.d.) and Suicide Prevention Center (2020).

Table 3 shows that the lowest level of engagement is informing people. This means simply relaying information to people with lived experience about policies or services, with no opportunity for further involvement. A higher level of engagement includes consulting people with lived experience by gathering opinions and views on issues, topics, or services. Data can be collected through surveys, focus groups and interviews. Consultation activities mean that people with lived experience are asked to share their views and feedback, but there is not necessarily an obligation for decisionmakers to act on it. Participants in the workshop mentioned how disappointing it was to be consulted but never hearing back on the results. This also illustrates the short-term nature of consultations (see Figure 1 below). Most of the people working in policy expressed that they try to avoid doing consultations and aim to involve participants in other forms of engagement such as working groups and panels. They also expressed that often consultations repeat the same themes and participants feel frustrated.

To involve people with lived experience in work requires organisations to listen and update their practices to ensure that needs are met. This can be performed by people with lived experience volunteering and participating in peer activities and supporting delivery of sessions. Collaboration is good practice and involves working in partnerships with people with lived experience and organisations to develop services and programmes. People with lived experience can be part of steering groups to make decisions on issues that affect them. The highest level of engagement, 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). For people with lived experience to have an impact on decision-making, they should be leading initiatives and decision-making process (Activity Alliance, n.d.; Quintero, Murray, Connelly, & Ballantyne, 2015).

Short-term involvement

Method			Overview
Level 1	Consultation	Questionnaires and surveys	An effective and simple way to gather feedback from a large group of people.
		Interviews	A useful method to gather more personal and in-depth responses that can be used as personal stories or case studies.
Level 2	Working together	Discussion and focus groups	An effective way to engage a small group to get feedback on a specific topic. Focus groups are helpful in developing ideas, because the group can explore and reflect together.
Level 3	Doing together	Formal groups	Useful when you need to gather views and influence the shape and direction of a particular project. For example, service user forums enable people to make decisions about the service they use or help guide the organisation that runs it.

Longer-term involvement

Method		Overview
Level 4 Deciding together	Working and steering groups	Brings together people with specialist skills and expertise to a project including people with lived experience. It is their responsibility to identify and complete tasks, and make decisions.
	Trustees	Trustees who have lived experience can offer valuable input on strategy at local and national levels. They can use their specialist knowledge and skills to influence the organisation at a strategic level.
	Co-design	Designing something together such as training materials, a new service or organisational policies. Decision-making is shared equally and everyone has an equal say.
	Co-production	Developing and delivering something together. This approach allows an equal and mutually beneficial relationship between staff and people with lived experience.
	Service design	A way to create new or improve existing services. We believe that people with lived experience should be a part of every stage of the service design process.

Figure 1. Screenshot of the levels of involvement from Mind's guide (n.d., p. 11) on ways to involve people with lived experience of mental health problems in physical activities.

During the workshop, participants emphasised that practitioners do not truly understand the experiences of people with lived experience, thus they need to be included in decision-making processes.



People doing these reports, really don't have the faintest idea of the experiences of what people like us go through every day.

(Workshop participant)

Participants from the workshop and the feedback 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. Additionally, 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. They want to be involved in the ideation of policies, drafting of them and throughout the life of policies. This way they can raise issues in services, suggest alternatives and solutions, and have a longitudinal role in the process. Actively including people with lived experience at all stages of projects helps ensure that different perspectives and experiences are taken into account when designing an engagement plan (Samaritans, n.d.). Through this, they can give constructive feedback on processes and have an influence on the content of engagement. They are also kept updated on the development of the project which improves communication between participants and organisers (Samaritans, n.d.).



After all, that's what a democracy is supposed to be: a system where everyone has a voice.

(Feedback questionnaire)

Communication between stakeholders and policymakers is important in relaying information and communicating the development of projects. Follow-up was heavily emphasised by the participants in the workshop and the questionnaire. For them it was important that surveys, workshops, meetings, and other processes include feedback to ensure participants are informed of the various steps after the consultation and have a chance to input on any developments. Follow-ups encourage communication with the target population. Individuals are made aware of how the developments are going and what has changed (Homer, 2019). This shows that initiatives that involve people with lived experience are not short term and aim for actual impact in people's lives.

Community development is an example of an approach that engages with the affected communities, from identifying issues to co-producing outcomes. Community development helps set up networks, activities and support forums that enable people to work across community and organisational boundaries. It actively works on issues of social exclusion and discrimination that deter some people from participating in decision-making processes and activities to be included. It is aimed at achieving particular outcomes (Community Development Foundation, 2006).



Community development - which specialises in encouraging and empowering people to gain control over the conditions in which they live gives us a very powerful way of turning alienation into engagement.

(Community Development Foundation, 2006, p. 1)

Establishing a community development approach that also influences policy enables working groups of people with lived experience to identify issues, prioritise these issues and develop action plans, build relationships with policymakers and stakeholders, further develop these relationships by attending meetings and contribute to strategies, and finally reflect on the outcomes on the work done by the working group (see Figure 2 below) (Quintero et al., 2015). In addition, community development approaches have shown that involving people with lived experience positively affects people's sense of community and sense of autonomy in the process of identifying issues and drafting action plans.

Through **co-production**, organisations help people with lived experience adopt appropriate methods to approach the issues, design, review and prioritise issues that affect them. Such practices are beneficial to individuals as they feel that their voices are heard and that they have direct impact on policies.

In Scotland, the Refugee Women's Strategy Group (Quintero et al., 2015) employed a community development approach. The group aimed to represent the views of refugee women in Scotland. They held a conference for women in Scotland seeking asylum, wrote a report on the group's progress, delivered an employment seminar, and developed an engagement which included focus groups and interviews. They were able to have direct communication with policymakers which increased their knowledge of their rights. Their contributions have influenced activities and integration strategies.

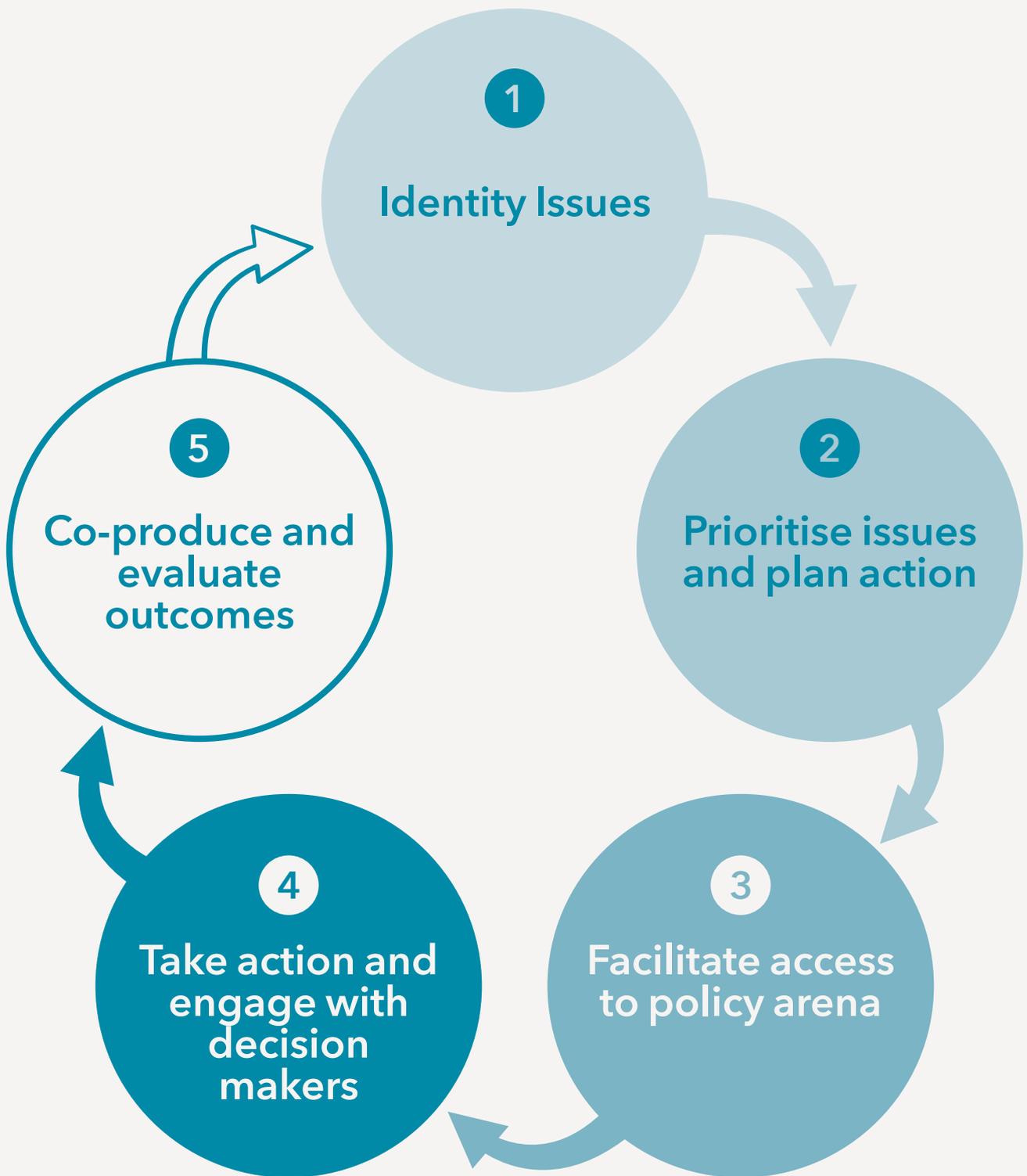


Figure 2. Screenshot of the stages of work done by the Refugee Women’s Strategy Group (Quintero et al., 2015, p. 8) using a community development approach that combines policy influencing.

Other case studies included **policy and systems change recommendations** generated by consulting and working with people with lived experience and relevant organisations (CFE Research, 2020; BEMIS, 2016; Quintero et al., 2015). In BEMIS' project (2016), participants first identified key barriers of their life situation, then project leads and community organisers reflected on the policy landscape relating to the issues and made recommendations based on the key issues. Policy recommendations can also come from people with lived experience (BEMIS, 2016).¹

Peer research projects include people with lived experience in the development of projects (British Red Cross, 2019; de Wit, Kvien, & Gossec, 2015; MacIntyre et al., 2018). Peer researchers' role can involve fine tuning language to make it accessible, generating interview questions, facilitating workshops with people with lived experience and helping establish trust with participants. They are involved in facilitating workshops and are encouraged to reflect on their own learnings and give recommendations on how to develop research processes (British Red Cross, 2019; de Wit et al., 2015; MacIntyre et al., 2018; Samaritans, n.d.). Peer research can help organisations working with people with lived experience to design methods that meaningfully engage participants. Literature shows that such initiatives do not necessarily directly engage participants in decision-making processes, rather, they give them the ability to shape research methods and develop professional skills (British Red Cross, 2019; Samaritans, n.d.). Involving peer researchers at each stage of preparation can help in recruiting participants and provide local knowledge on the issue that may not otherwise be available (MacIntyre et al., 2018). Additionally, the outcomes of projects can better reflect the needs of people with lived experience if they are engaged at all stages of the process. They can also highlight the key topics for the research which helps in developing the project (Samaritans, n.d.).

Another method of engaging people with lived experience in decision-making processes is establishing **Advisory Committees** to develop guides for best practices (Homer, 2019). Participants can be involved in drafting guides for organisations to better engage people with lived experience in their activities (Homer, 2019). There are opportunities for them to come together to form groups and discuss best practices. By working together, they can develop a guide on addressing an organisation's readiness to engage people with lived experience in their activities, reflections, and developments. One participant from our workshop suggested having a "consultative panel" in which various people with lived experience represent as many different needs as there are. These panel members would hold the post for a fixed amount of time to have meaningful involvement but also to allow for the development of varied ideas and feedback.

Examples given during the policy interviews of initiatives where people with lived experience are actively being involved include setting up **Working Groups**. An interviewee gave an example of the BSL (British Sign Language) Linguistic Access Working Group. The working group consisted of the Scottish Government Equality Unit, NHS Health Scotland and organisations working with BSL users to contribute to the British Sign Language Scotland Act 2015. The working group also comprised of native and first language BSL users who talked to

¹ Some examples of these barriers came from The Afghan, African and Nepalese communities in Scotland. The Afghan community in Glasgow expressed that isolation and the lack of premises to develop community cohesion were areas that they reinforced. The Nepalese community in Aberdeen highlighted that many individuals' immigration status prevents them from seeking employment and social security. The African community in Inverness described racism in the workplace and public environment, and the lack of understanding of school curriculum negatively impacting their life situation (see BEMIS, 2016).

the Parliament about what they needed. These individuals were coached on how to talk to government officials and were supported to deliver their work. The interviewee said: “Have the people with lived experience at the front”. Another person working in policy is overseeing and supporting a working group with civil society around open government. The working group gives civil society an opportunity and space to talk about the ways they are being engaged efficiently as part of the open government commitment. The interviewee emphasised that for it to work well, it needs proper communication, time, and resources.

A policy officer explained that when doing public engagement, they try and avoid asking the same questions which have been asked before as the answers are readily available online. For one of their public engagements, they conducted a literature review to identify the areas that have already been covered and compiled their own findings of where the gaps were. In such a way, they avoided asking repetitive questions.



Follow up, clear expectation setting, like a clear understanding from the participants about what can be influenced and what cannot be influenced. All those things will be discussed if that, if that co-production is happening properly.

(Policy interview)

The quote above summarises well the good practices of working with people with lived experience. The interviewee described that an engagement plan should be clear and well planned for its entirety. Furthermore, power should be less focused on the Scottish Government and its ways of working that feel comfortable, and more on the negotiation between the parties involved. They said that it is important that they listen to people with lived experience and “involve them in decisions that matter to them”. As a result, the interviewee commented that such involvement gives people the opportunity to participate beyond every four years (in reference to the electoral cycle) but it also helps decision-makers to understand the challenges people face:



People who have a direct experience of a proposed policy, a situation, a circumstance in their life that they have a right to participate in decisions that are being taken about that. And, actually, it's to the benefit of those decisionmakers to understand in as much depth as possible the complexity of these challenges.

(Policy interview)

One participant who responded to the questionnaire commented that, when they moved to Scotland from England, they were surprised at the extent that they could shape policies. They felt that in England policy making decisions are shaped by charities, with less consulting of those affected by the policies compared to Scotland. This view implies that the **policy landscape** in Scotland is amenable to greater involvement from people with lived experience – a valuable opportunity to build upon.



I think it's because the politicians up here are more in touch with people

(Policy interview)

An interviewee echoed this sentiment by mentioning that the Scottish policy system works faster and more efficiently than Westminster. They gave an example of Social Security Scotland which was created with the involvement of people with lived experience by setting up user panels to work on social security and it was driven by the Scottish Government.

2 Ensure **clear expectations and communication** throughout

No matter which methods are selected, and the level of engagement, 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.

Managing expectations and clear communication about roles and process helps all those involved understand what is expected of them and how much they need to commit to the role (Samaritans, n.d.). From the interviewees with people working in policy, an interviewee emphasised that setting expectations helps inform participants of what is possible and what cannot be done. **Appointing different roles** among people with lived experience working on issues that affect them is also an efficient way of organising the work they do (Homer, 2019). **Setting clear goals** for an initiative is important to manage expectations and includes answering questions of what the work aims to do and what is its purpose (Mind, n.d.). This can be done by giving detailed and clear information in advance (CFE Research, 2020). People may have different understandings of what the success of an initiative or decision-making process looks like. Two participants from the workshop also expressed that initiatives should have a goal that everyone agrees on and that expectations should be managed. Those involved should know what they are able to achieve with the work they do. One of them also indicated that people should not be promised outcomes that cannot be delivered. The participant wanted processes to be truthful to what they can do. Another participant expressed they want to be consulted on what they think should be changed. Then decision-makers should say if it is really possible to execute that change rather than saying “yeah we’ll do that”.

There was a view from both sides that they needed to be understood. As a workshop participant expressed: “I really feel that they need to understand us too”. Similarly, a person working in policy expressed that they would also want to be understood by people with lived experience, including the constraints that people working in policy are under and that they “answer to ministers as well as to the public”. The interviewee said that they are very open about their position and about the things that they can deliver. They said that it is good practice as it helps build trust and openness among those involved.

Adopting clear communication minimises potential miscommunication and differences of understanding. Maintaining regular dialogue among those involved and being open to hearing different experiences helps develop structure and overall flow of work (MacIntyre et al., 2018). If people with lived experience attend stakeholder meetings or other activities, they should receive information on those who are attending to allow them to prepare and understand who are going to be present.

3 Monitoring and evaluation

Implementing a **monitoring and evaluation** (M&E) process was suggested by most of the interviewees working in policy as they said it is not built in the system. 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. In addition, they mentioned that they are working on having an established M&E process. One of them 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. The interviewee mentioned The Magenta book, which is an evaluation handbook with a lot of different methods used by the Scottish Government to provide support for staff on evaluation. Another interviewee gave an example of an evaluation work from The Scottish Independence Advocacy Alliance which supports people to evaluate advocacy organisations. They expressed that because many retired and disabled people are looking for jobs, M&E could be a way to employ these individuals. They also suggested that M&E groups should be set up of “users, carers, professionals” and emphasised that these individuals work together to effectively do M&E.

4 Provide participants with resources, training, ongoing support, and account for risks of involvement

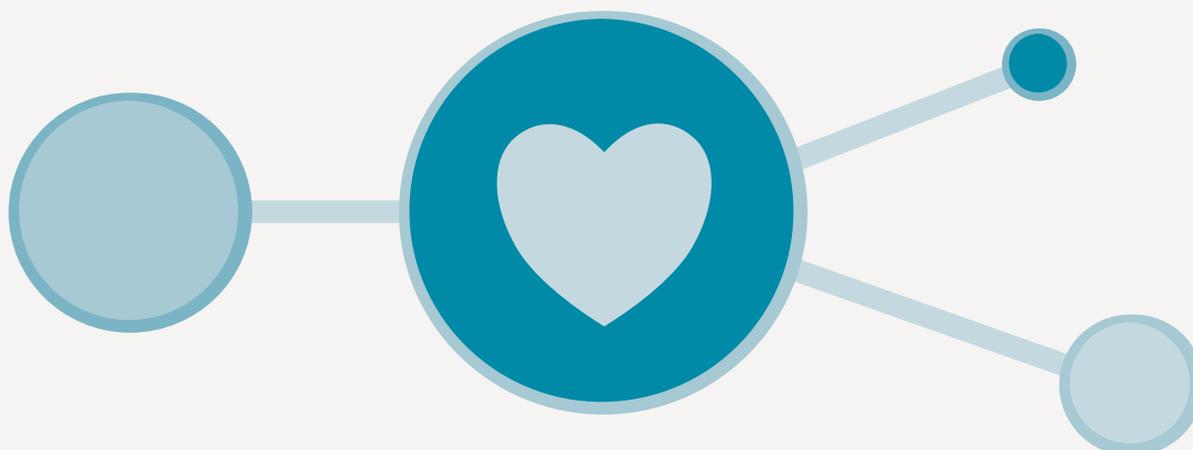
Meaningfully involving people with lived experience also requires ongoing support, which needs resources, risk management, and training.

Training can make those involved **feel prepared and comfortable** about their contribution to an activity (CFE Research, 2020) and was mentioned as important by some of the case studies (de Wit et al., 2015; Samaritans, n.d.). In the policy interviews, one interviewee explained that engagement should “upskill people on the experiences they have”. In such a way, participants are equipped, and quality lived experience work can be channelled through it. Another person working in policy mentioned spending time teaching participants about design and what co-design means. Engagements could start off by taking time for learning and not necessarily producing outcomes from the get-go. They expressed that as a result, participants can better scrutinise and question the work they do.

Training can include informing participants of different organisations relevant to the service, policy, or topic; or teaching them about widely used acronyms that they may not be familiar with related to the specific topic. When conducting participatory research with peer researchers, they should be provided training in research methods, including developing research questions, or designing and facilitating focus groups or interviews. Information on ethical considerations and practice sessions are also important to help prepare peer researchers take part in research (MacIntyre et al., 2018). Training can also involve support in community organising or engagement with affected communities. Throughout the course of a project, participants could be offered training resources that they can access online and practice. Such courses could cover topics of coaching and working effectively with equipment (Samaritans, n.d.). Training is not only useful for the specific initiative but also for the career development of the individuals who are receiving it (Samaritans, n.d.).

Any potential **risks of involvement can be mitigated** by ensuring adequate support is provided to participants. As projects often deal with difficult topics, those involved should be properly taken care of (Samaritans, n.d.). People with lived experience should be consulted on what they want and need in terms of support as needs vary. A participant expressed in the questionnaire that support should be provided for those who fill out feedback questionnaires and surveys. Some people may have “severe fatigue or cognitive issues” and may require additional support for easy reading and writing. The individual expressed that such options should be “easier to deliver”.

People with lived experience should be given autonomy to contribute to the extent that they can and want and should be supported in doing so. They should not be pressured to talk about topics that they do not want to. Another participant who completed the feedback questionnaire commented that they would want to have a **support network** while participating in decision-making processes. Another participant expressed that they want to receive support to engage with the policymakers. It is important that people with lived experience can receive support and training to build confidence and develop skills (Homer, 2019). Providing counsellors or psychologists can also support participants’ wellbeing and provide a safe space for them to speak in confidence (CFE Research, 2020). A policy officer mentioned that they have often had the support of their third sector partners and advocacy groups when engaging with people with lived experience to ensure that their workshops are safe and practical for these communities. This suggests it is both in the interest of policy officers and people with lived experience to work with partners that have developed the expertise in working with lived experience.



5 Recognise the **worth and value of participants as individuals** not only as resources of lived experience **and reflect their needs and outputs** in the process and outcomes

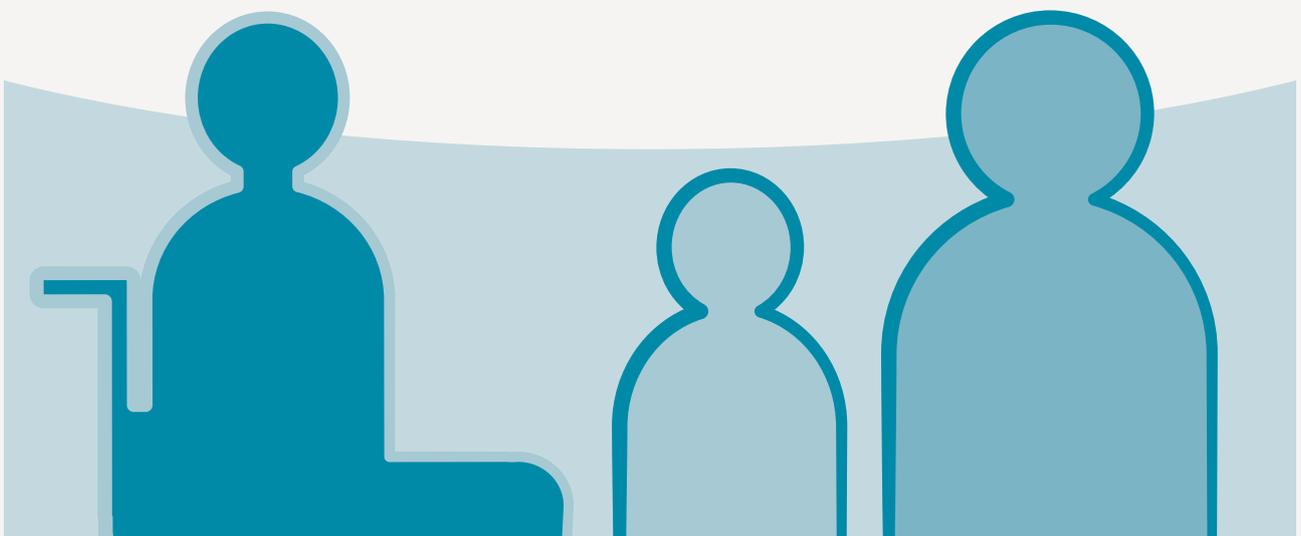
Respecting different cultures, positionings, and experiences is important when engaging with people with lived experience. People must be supported to feel comfortable and so that they can be themselves, recognising that whilst they may share some similar experiences, they are also individuals with individual experiences (Quintero et al., 2015). They should be listened to as individuals and be able contribute through their individual experiences (Samaritans, n.d., CFE Research, 2020; Homer, 2019; Samaritans, n.d.). In relation to this, a participant in the workshop regretted this lack of nuanced understanding of different realities:



Generally it's one size fits all and if it doesn't fit you then that's all too bad

(Policy interview)

With the help of involving people with lived experience, organisations can identify “cultural norms” of each individual and work collaboratively within those frameworks (CFE Research, 2020, p. 20). Ensuring that a diverse range of experiences are represented in these initiatives and decision-making processes can inform policymakers of the various ways in which they can improve their services (CFE Research, 2020). A participant from the workshop highlighted that intersectionality is important when discussing policies and that individuals from minority ethnic communities and LGBTQI+ communities, and those with different needs, must be considered when planning and drafting policies concerning people with lived experience. People who work with people with lived experience should prioritise creating a culture of recognising that participation should be tailor made and that “no concept exists that fits all” (de Wit et al., 2015, p. 6).



6 Work to create a **trusting and welcoming environment**

Meaningful participation can take place when people with lived experience have a **support network and safe** space to speak about their experiences. Building trust minimises harm and ensures that support is available. It also ensures that individuals can share their experiences and discuss issues without feeling judged (Samaritans, n.d.). To create a trusting and welcoming environment for participation, organisations can appoint key contacts that participants can keep in contact with (Mind, n.d.). Having a point of contact is also useful for check-ins and questions from organisers (CFE Research, 2020). Creating trust ensures that individuals know what their work will look like and what the outcomes are likely to be and a welcoming environment can be created using inclusive language and making time for introductions (Homer, 2019).

In addition, insights from the interviews with people working in policy highlighted the need to spend time **building relationships** with people with lived experience to understand who they are and what their needs are. They also expressed that building relationships with charities and community groups can help to better understand their needs to make services more inclusive.

7 Ensure initiatives are **well funded and resourced**

For effective and meaningful engagement to take place, organisations and projects should 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). Having a **large enough budget** would help ensure that all aspects of an initiative can be implemented (de Wit et al., 2015; MH:2K, 2017). Using cost effective methods helps to ensure that projects can deliver high quality outcomes and stay within budget. Work should be effectively planned so that processes can be completed in a timely and adequate manner, but also ensure that activities can be completed properly with enough time to reflect on them. The **timeline of projects** should be clear to illustrate resources and roles needed for each activity (MH:2K, 2017; Samaritans, n.d.). Considering the timeline of a project is also important as participation requires energy from everyone involved (de Wit et al., 2015). During the policy interviews, an interviewee also emphasised that reaching out to and working with people with lived experience takes time, money, and commitment.

8 Have **appropriate and well-trained staff and networks** working with people with lived experience

Having **well-trained staff** working with people with lived experience ensures that well-being, support, and delivery of activities are properly done. Providing staff with toolkits and training helps them be informed of the best methods to use when engaging with people with lived experience (Mind, 2017). Scanning for existing organisations and initiatives is also an effective way of building relationships with those that work with people with lived experience. Such connections can provide additional support and help establish key areas of focus for future initiatives (Activity Alliance, n.d.). Some of the policymakers interviewed expressed that well trained and skilful staff can help other staff members do participatory work and can support them to do it well.

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



Culture of, of involving people routinely in the public sector will have to shift a little bit further still so that it is truly routine to involve the public and people with lived experience.

(Policy interview)

The research has identified the following barriers and enablers to meaningfully engaging people with lived experience:

Barriers

1 Systemic and political barriers

One of the key additional insights gained from the workshop and the feedback questionnaire was the **systemic and political barriers that affect people with lived experience** and make it **difficult for them to access the services and support** they need. In a way, this takes us back a step from engagement to consider the underlying context and circumstances that people with lived experience must deal with in the first place. It is important to consider these factors because better understanding of systemic barriers can inform better ways to engage people in decision-making. People working in policy also highlighted the systemic barriers that often prevent them to do their work meaningfully.

Participants from the workshop discussed the political context, and lack of representation and awareness, as major barriers in engaging people with lived experience in decision-making and receiving adequate services. Two themes mentioned recurrently by participants relate to the **overall governance and public policies of the UK**. Specifically, the policies and culture of the Department of Work and Pensions (DWP) and UK government (which participants referred to as Westminster) were mentioned as considerable barriers in engaging in decision-making.



I am not really political but we never discuss Westminster. It's the biggest barrier for everything and everybody in Scotland and I feel really strongly about it.

(Workshop participant)

In relation to the DWP, some participants referred to its way of working as dehumanising (“they don’t take any human things into account in the system”) and a participant expressed having experienced “re-traumatisation” when using their services because of the questioning and the consequences that can result from it. Some also mentioned being put in “danger” when using health and social services.



How can you build trust when you are not actually providing the service?

(Workshop participant)

Some participants recounted that not being provided with a safe space to receive care puts people with lived experience at risk. The DWP was described as not having “dignity” in their work and “respect” for the people they served. Participants wanted the political system to change and have a complete revision of health and social care. In relation to Westminster, 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. It is important to note that while the Scottish Government is responsible for health and social care policy, some aspects of social security, pensions and other relevant policy areas are reserved by the UK Government, and some are devolved (Scottish Government’s responsibility) (Delivering for Scotland, n.d.).

There were references in the workshop to the political and governance system not being functional and needing for it to be fixed. One participant, for example, said that “the system is probably beyond repair”. Participants wished for changes in leadership and policies which they hoped would grant families the ability to have higher wages and spend more time with their loved ones. One participant wanted to see a future where families could rely on the wages of one parent and still have free time and adequate childcaring abilities.



The whole system needs turning upside down. The whole system is broken right now. There is no democracy in Britain right now...

(Workshop participant)

A person working in policy described that there might be instances where the ministers make decisions that are not informed by the voices of the public and finds it “disingenuous” especially when they are using the rhetoric “in the service of Scotland”.



Because ‘in the service of Scotland’ actually means in the service of ministers, and that clash between politics and society can be really quite overt sometimes.

(Policy interview)

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. The unfamiliarity of ethically working with lived experience and the lack of understanding of lived experience were described as challenges to meaningfully working with lived experience and said to be sources of anxiety to some staff working with lived experience. Some interviewees explained that this may lead to frustration from people with lived experience in raising issues, making engagement stressful. The person working in policy also mentioned that when there is no nurturing relationship and no ongoing level of communication, this can turn people away from participating.

Another person working in policy pointed out that there may be a fear of getting the work wrong when engaging with lived experience and thus, people “want to work at a desk, away from the hard stuff”. The lack of experience working meaningfully with lived experience may turn workers away from it. The interviewee expressed that even if people want to do the right thing, they may not have the right knowledge on how to do it. Furthermore, the interviewee expressed that often **staff are not trained and equipped** to do participation and there is not much emphasis on developing programs that teach participation. A policy officer explained that the government does not have public engagement experts or groups that can regularly engage with people with lived experience. Additionally, the person working in policy commented that staff may see the parliament as their audience, not the public and as a result, deliver outcomes for the parliament, and do not think of following up on involvement and informing people with lived experience of their impact on decision-making process.



And I do think traditionally the civil services' very much been an inward-looking machine and, so a lot of people that have been employed here think that's what they're here to do, is to talk to ministers, not to talk to the public.

(Policy interview)

All the 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”.

2 Tokenistic involvement of people with lived experience

Tokenism happens when engagement is carried out for **performative** reasons, without meaningful intention to listen or act on the input of people with lived experience. Tokenistic approaches do not place lived experience as the focus (Samaritans, n.d.). Doing the same projects with different names or consulting only a few members of a community of people with lived experience are also examples of tokenism. It can be discouraging for participants to not be informed on what has been done as a result of their work and involvement. Participants may feel that they are only consulted because of their experience and are not seen as individuals with other attributes that make them unique. Involving and consulting people with lived experience on only a few occasions may also appear tokenistic (CFE Research, 2020).

These concerns were also reflected in our workshop and the feedback questionnaire. A **lack of follow-up** to many of the initiatives that the participants had been involved in made them feel less motivated to participate in future opportunities. Attempts to include people with lived experience in decision-making processes often use surveys or workshops. Participants reported that these efforts lack impact as there is no follow-up on what has been done and people cannot see change being implemented as a result of their involvement. Such practices have discouraged the participants from taking part in future initiatives. That is why managing expectations and having a clear goal for a project are important to ensure everyone involved knows what is going to happen.



I think the most important thing is that they have to listen to us, feedback is important for that to let you know that you actually have had an impact.

(Workshop participant)

One participant from the workshop described their previous experience in a decision-making process where people with lived experience were invited to contribute, but in fact the outcomes and decisions had already been decided. The results of the initiative did not align with the results of the consultation. Such practices demonstrate the performative and “box-ticking” nature of many decision-making processes involving people with lived experience. They are invited to contribute, but their input is not applied or even listened to.



Quite often when people with lived experience come in with people with nice salaries and nice experiences...just [have] some recognition of the inequality of having the DWP breathing down your neck...it's not from malice or anything, but it's like they have conversations like we're not even in the room.

(Workshop participant)

A further concern alongside this theme relates to the experiences of participants **receiving a “one size fits all”** approach. One workshop participant expressed that “there’s an assumption that people have all the social care they need and that’s just not that true”. In a feedback questionnaire, a participant expressed a desire “that social services is able to not just provide a one size fits nobody approach to social care”.



Policy makers have no idea of the day-to-day problem that those of us who use services actually face.

(Feedback questionnaire)

There is lack of representation of different needs in the approaches and services to support the differentiated and often complex needs of people with lived experience in health and social care and policies. Some workshop participants mentioned that they are not consulted on what they need, rather they are given limited options to work with. This further demonstrates that people with lived experience are often put into one box and their needs are not represented, alluding to tokenistic engagement.

3 Not enough information about opportunities to participate / Information about participation not reaching the target population

Participants in the workshop and feedback questionnaires recounted that often people with lived experience may not be aware of opportunities about getting involved in decision-making processes and workshops catered for them. This was echoed during the policy interviews that often people are not aware, nor know how to get involved. One workshop participant mentioned how TV, newspapers, websites, and online forums could be used as platforms for sharing information regarding decision-making processes. They also added that sometimes people with lived experience do not know all their rights when it comes to receiving care. Acquiring **awareness of rights and how to claim them** needs to be made more accessible for people with lived experience. Additionally, a person working in policy commented that often policy briefs and issues are very broad, making it difficult to find the right people.

Sometimes information about participation does not reach the target population. From the experience of a policy officer, the Scottish Government's formal public consultations often reach organisations and industry rather than people with lived experience. Such engagements are posted on the government's consultation platform and the policy officer doubted that individuals go there on a regular basis. In addition, some approaches to recruit participants are mainly online which can exclude people who do not have online access from this information. Another issue the policy officer highlighted was that for the past two years the government has been "rightfully so focused on public health messaging". As a result, it has been difficult for policy officers to get their messages about their engagements on the government channels.

4 Practical barriers / lack of inclusive spaces

During the workshop, participants mentioned that being a woman was a "massive barrier" to participation in decision-making. The participants in the workshop mentioned that women are often the **caregivers for people** with health and social care needs (as well as having their own needs). This means their lived experience is particularly valuable and, yet, this also makes it more difficult for them to take part. The timing of meetings hinders many women from participating due to childcare duties. For example, one participant mentioned that if a meeting is held in the evening, those with small children might not be able to attend as this is usually bedtime. Literature also shows similar findings, where childcare responsibilities have hindered some women's ability to participate in activities (Quintero et al., 2015). One participant did note that women with lived experience do often participate in consultations as they are the most affected by the level of services and policies but participants stressed that women's voices need to be heard more. Additionally, there was a comment about the fear of having their children taken away if they voiced their concerns. This relates to the need for supportive policies and for providing support networks and safe spaces for people to voice opinions and concerns. There needs to be better opportunities for women to be able to participate in decision-making in a meaningful and consequential way. Ensuring adequate support, trust, and meaningful impact could help mitigate some of these barriers.

Participants, both from the workshop and questionnaire, 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 all the participants. They explained that 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 they take too long, it is difficult to concentrate and be engaged. Further, meetings that are in the mornings are not suitable for everyone as it takes time for them to get up from bed and set up their computers. It is also difficult for some to stay still and sit for long hours.

5 Language barriers and cultural sensitivities

Language barriers and misunderstandings between individuals and service providers have been proven to be a challenge in engagement. Difficulties in relaying issues to service providers has prevented many individuals from contacting them further. Language barriers have caused problems in accessing health care, and often individuals rely on community interpreters. Experiences of racism have also hindered, discouraged, and made many people feel hopeless about their situation. These experiences have also affected people's ability to engage with public services (BEMIS, 2016). During the policy interviews, an interviewee mentioned that policy documents cannot be "policy speak", they should be written in plain English, Scots, or Gaelic so that people can understand what they are reading.

The **language used** to describe people with lived experience may hold them back from change-making processes. For example, there are connotations of describing them as "victims or service-users" (Sandhu, 2017, p. 4).

6 Lack of funding and time for meaningful engagement

Some remarks were made from participants in the workshop and feedback questionnaire about the **lack of funding** that health and social care gets to adequately take care of people with lived experience. They expressed that even though many studies are being conducted on lived experience in health and social care, their overall situation will not improve without proper funding from the government. One of them expressed that "without finances, nothing will change". Another participant mentioned not seeing progress in their situation for half a year due to the **shortage of social workers**. They further expressed concern about the amount of work the social worker was tasked to do with limited time. Better patient care needs to be put in place where safety is the primary focus. Concerns about funding were framed as a **systemic barrier** stemming from the UK central government, as discussed above.

Many organisations working with lived experience are grassroots and non-profit organisations that struggle with funding their activities (Sandhu, 2017). There is also increased competition for limited funds that reduces their chances of acquiring funding (Sontag-Padilla, Staplefoote, & Morganti, 2012). Resourcing constraints affect an organisation's ability to compensate participants for their contribution. Lack of funding results in initiatives not being able to deliver as planned or develop their work further (Quintero et al., 2015). In addition, some funders may not understand the added value of lived experience, and as a result, may not provide enough funding for inclusive practices (Homer, 2019).

7 Reliance on organisations for participants



Because that's the problem, organisations are gatekeepers. They decide who they are getting to speak to.

(Policy interview)

An insight that came from the policy interviews highlighted an overreliance on organisations to recruit participants. The interviewees expressed that when the Scottish Government reaches out to people with lived experience, it often reaches out to **organisations** who then **decide who represents lived experience**. One of them mentioned that the “Scottish Government gets it right most of the time but relies on organisations”. They further commented that these practices can stop some people from joining these organisations. Another interviewee commented that when organisations are asked to reach out their stakeholders, they can end up being “**experts and lobbyist**” who “no longer talk from lived experience”. The others also expressed that if the same individuals are asked to represent lived experience, they may become burdened by these continuous responsibilities.

Enablers

1 Use time and effort to build trust

Building trust can take substantial amount of time from weeks to months, especially in multi-sectoral and stakeholder initiatives. A possible first step to building trust among those involved is recognising that individuals may need different amounts of support. People with lived experience can develop their own rules and note what everyone's work will look like. Additionally, being patient with one another can create a sense of comfort for participants (Homer, 2019). Setting up patterns of communication that work for people with lived experience was mentioned by one of the policy interviewees.

In the field of grassroots organisations, there should be an effort to build and foster trust between smaller grassroots organisations and larger organisations that work with lived experience (Campbell, 2018). Often, bigger organisations rely on the work done by smaller organisations and fail to properly compensate them for their contributions (Sandhu, 2017). Thus, both parties should commit time to **build trust with one another**, to properly collaborate and **share power** so that the voices of lived experience can be heard (Campbell, 2018).

2 Build a **collaborative foundation** to continue in future planning and innovation

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 (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. Working collaboratively produces positive changes which can encourage organisations to **continue working** with people with lived experience (CFE research, 2020) as it fosters connection with the community and inspires others to do similar things. In a research report by CFE Research (2020), a local authority working with lived experience of homelessness stated that consulting and collaborating with individuals with lived experience had become a standard in their practice. Additionally, this collaboration creates change that benefits people with lived experience and helps challenge prejudice (Suicide Prevention Resource Center, 2020). People with lived experience can gain further recognition in their community by working with organisations.

3 Eliminate financial and practical barriers

In social care, people with lived experience may be working multiple jobs or for low wages. Participating in decision-making processes can result in missing paid employment and, therefore, many cannot afford to participate in un-paid work (Homer, 2019). **Paying participants** demonstrates that their contributions and work are valued and recognised (Samaritans, n.d.). During the policy interviews, one interviewee expressed that participants should be recognised for their contribution and their commitment to an involvement. They see the involvement of lived experience as a “formal qualification” thus it should be given “equivalence to professional experience”.

It is however important to note the challenges of paying for participation to both participants and organisations. According to the Scottish Human Rights Commission, “...any income from participation – including in the form of vouchers – can be classed as ‘miscellaneous income’ and subject to tax, as well as potentially impacting on benefits” (McLean, 2021, p. 14). Vouchers may in some cases be considered as gifts but it is important for organisations to contact their tax office to request a ruling (National Institute for Health and Care Research, 2022). They should carefully consider that **payments could but should not interfere with participants’** income, meaning that legal requirements need to be conformed to in order to protect participants (Homer, 2019). Expenses should be reimbursed accurately and separately from payments for involvement. Those who receive Employment Support Allowance have a cap on how many hours a week they can work and a limit on how much they can earn from participation, which the DWP describes as “service user involvement” (McLean, 2021, p. 17). It is important to discuss with participants how earnings can impact their welfare support that they may receive and to provide them with independent advice through work coaches (Homer, 2019; McLean, 2021). Some initiatives have hired participants as paid interns. In addition, some individuals may not have easy access to bank accounts, thus paying them with cash eliminates this barrier. Such payments must be properly recorded (Homer, 2019; McLean, 2021).

Participation should ensure that individuals do not need to cover for “participation-related expenses” (Homer, 2019, p. 13). Participants should be provided with food and transportation, and with childcare and language interpretation. If financial compensation is not possible, participants should be given the opportunity to decide the degree of their involvement. It is still recommended that whenever possible, people with lived experience get financial remuneration for their time and effort. Organisations can include these payments in their budgets and raise funds from local governments. For example, the Refugee Women’s Strategy Group received funding which enabled women with children to take part and have their transportation costs covered (Quintero et al., 2015).



We need to meet people where they are at. We should go to places where people feel more comfortable.

(Policy interview)

A few of the people working in policy mentioned that engagements should happen in **places where people are and use** to enable as much participation as possible. Organising parties should also consider holding activities in physically **accessible and conveniently located** spaces as well as in familiar spaces to alleviate potential intimidation and anxiety (BEMIS, 2016; CFE Research, 2020; Homer, 2019). If activities are held online or with other equipment, participants who do not have the means should be provided with the needed equipment for them to participate (CFE Research, 2020). A participant from the workshop gave an example of best practice at an all-day event they attended. The organisers provided assistants to every disabled person there. The assistance included helping those who needed to get their lunch and other needs. A participant in the workshop also mentioned that these inclusion practices should be embedded in programme designs and budgets rather than asking participants about their needs every time.

Related to the **gendered nature of health and social care** mentioned by participants during the workshop, opportunities to engage in decision-making need to be held at times and in places that are accessible to caregivers. The Refugee Women’s Strategy Group also highlighted a similar point in their work. The women taking part in the strategy group expressed that a lot of refugee and asylum-seeking women in the UK fear the Home Office and worried that their engagement would affect their asylum decision. Additionally, the lack of funding from the Home Office in ensuring childcare during asylum seeking interviews affected many women’s ability to attend interviews. Thus, the strategy group was an important voice for refugee women, bringing forth the gendered aspect of the asylum-seeking process (Quintero et al., 2015).

There needs to be a **variety of options to engage** in decision-making. Some participants suggested online surveys and email responses as other ways to engage people with lived experience who may have difficulties joining online events. It was expressed in the feedback questionnaire that digital tools that enable participation have become easier to implement, especially since the COVID-19 pandemic when there was an immediate effort to shift to online interactions. While some participants could not attend the workshop as it was not suitable for them, they still appreciated that they were able to give feedback through the questionnaire. With the feedback, they could take their time writing their responses. "Giving a lot of options is one of the biggest things I can suggest" was expressed in the feedback questionnaire. Providing individuals with different means to participate whether online, in person or in feedback form can help those participate who might not otherwise be able to.

4 Diversify target groups

Another suggestion that was highlighted by the policy interviews was to diversify the groups that the government works and engages with. The people working in policy expressed that they 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**. A policy officer did caution that by creating a space for regular involvement of people with lived experience, the engagement can end up creating a routine space where only the same participants engage. The officer suggested that the pool of participants needs to be refreshed to reduce possible participant fatigue.



Someone who is furthest away from the government, you'll pick up everyone else on the way.

(Policy interview)



5 Share **inclusive and clear information** about participation

Initiatives should clearly state the level of commitment, the timeframe, and the type of communication when recruiting people with lived experience. Including the benefits of participation such as pay and new skills in the recruitment poster informs potential participants of how the initiative is laid out (Homer, 2019). Recruitment should use clear and plain language and keep information concise (Mind, n.d).



Invest in inclusive communication, accessible information and you'll get people who have never thought about being involved in policy, involved in policy. But you have to tell them why.

(Policy interview)

Those working in the field of policy emphasised the importance of sharing inclusive information about participation. By adopting an **inclusive communication** model as explained by an interviewee, practitioners share information about participation “where people are”. Supermarkets, libraries, pubs, and people’s hubs were some of the suggested places to post information about participation. Posting information that is unique and engaging can also make people interested in participating. Some interviewees also emphasised that information should not only be posted online as not everyone has online access.



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?

To projects and practitioners

1 Strengthen effectiveness of services such as projects, events, research

By meaningfully engaging with people with lived experience, organisations can more effectively **meet the needs of the people** they are supporting (Mind, n.d.; Suicide Prevention Resource Center, 2020). This was also expressed in our feedback questionnaire by one of the participants, who mentioned that for policies to be effective, they must consult the people affected by them. By involving people with lived experience, organisations can better represent diverse needs and experiences, and provide information about their activities that is more useful to the target audiences (Mind, 2017). Co-production with people with lived experience can help change how individuals and organisations think and practice (CFE Research, 2020). Organisations can add **depth to their services** and evaluation methods. Working with lived experience can help inspire innovation and implement relevant projects and services. By collecting and understanding findings from initiatives, organisations can transfer this information to learning which can help shape future initiatives and make them more effective (Activity Alliance, n.d.; CFE Research, 2020).

2 Staff development

Some of the case studies mention adopting programmes to **train employees on relevant skills and knowledge** “beyond theoretical and textbook learning” (Suicide Prevention Center, 2020) or putting in place workplace policies and toolkits for staff that helps them work accordingly and meaningfully with lived experience (Mind, 2017). Most of the people working in policy expressed wanting to have more staff members who have experience working with participation and lived experience in the government, and training for existing staff.

3 Workplace inclusiveness

Organisations become **better at representing different experiences** and this can help organisations operate more equitably and genuinely. In addition, they can minimise and restructure hierarchies in the workplace (Suicide Prevention Center, 2020).



And see all the other various, different perspectives. Because without that full range of perspectives, it, it would be virtually impossible to deliver a policy that is reasonably going to work for the people of Scotland when my views are representative of a small portion of that community.

(Policy interview)

Adopting a **reflexive approach** enables project leads to acknowledge their pre-held views and experiences and reflect on how they may influence processes. 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 policies would not be effective if they are not representative. A reflexive stance has also been valued by peer researchers as they express having greater involvement and being listened to. Reflexive meetings are a good way to collaborate on modifications and learn from one another (MacIntyre et al., 2018). A reflexive approach can also ensure that organisations set priorities for their future work and increase inclusiveness of different needs within lived experience (Suicide Prevention Center, 2020).

To participants

1 Share experiences and listen to others' stories

Sharing experiences helps individuals make sense and reflect on their own situation (Mind, 2017). 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 and meet like-minded individuals (Quintero et al., 2015). As a result of the online workshop, one participant expressed in the feedback questionnaire being **exposed to different experiences** and viewpoints that they otherwise might not have thought of. Other participants expressed wanting to have a stronger **sense of community**, a benefit which has also been mentioned in the case studies. It is important to remember, however, that individuals should not at any point be made to feel that they must share their experiences, rather are given the space to do so if they want to (CFE Research, 2020).

Some participants in both the workshop and the questionnaire had extensive experience of engaging with different initiatives, from practical volunteering in their communities to being a vocal advocate on issues like poverty, mental health and addiction through workshops, discussions, and co-design sessions. One participant, for example, mentioned that being involved in decision-making keeps them informed about processes and developments.

2 The **opportunity to directly influence policy** and services is meaningful to participants

Being able to contribute can make people with lived experience feel **valued** and respected (Mind, 2017). Working with organisations that respects, listens, and empowers people with lived experience makes a **positive impact** on people (Samaritans, n.d.). Individuals have expressed feeling empowered and having the sense of being able to tackle anything (Quintero et al., 2015). They have expressed being hopeful and aiming toward something greater as a result of being a part of decision-making processes (CFE Research, 2020). While participating in work with lived experience, individuals can gain greater knowledge of their rights and can be in direct dialogue with policymakers. Some have become more confident in voicing their opinions through public speaking (Quintero et al., 2015). People with lived experience can grow their personal empowerment by recounting and describing their lived experience into solutions for their community (Suicide Prevention Resource Center, 2020). Being involved can also increase confidence in understanding topics about lived experience and may encourage some to take additional roles such as leadership roles. Gaining confidence can also translate into the desire to raise awareness of one's situation to others (MH:2K, 2017).



Just reach out to us, we want to be involved in decisions regarding our treatment and care, and we want to be listened to.

(Feedback questionnaire)

Having committed decision makers involved in the processes is valued by participants (MH:2K, 2017) as they can see a more direct impact on change. People with lived experience want to be included in decisions that affect them (Homer, 2019; Quintero et al., 2015; Samaritans, n.d.) and their involvement also helps to identify how policies and changes impact people and further areas for development (CFE Research, 2020).

Both the workshop and feedback questionnaires echoed those processes need to involve **co-production and co-design** but, as recognised by both participants and existing literature terms like “co-production” or “co-design” are often used with varying or unclear definitions, compounding uncertainty around expectations and impact (CFE Research, 2020; de Wit et al., 2015). Co-production between stakeholders and policymakers helps them make informed decisions, but power should be distributed between parties. Participants described how these terms are often performatively used by policymakers and services when deciding on policies affecting people with lived experience. Participants in the workshop felt that their needs had not been met through such processes and that their contributions were being ignored by policymakers.



I feel often the words co-design and co-production are just banded around are just tick-box exercises. There is no point talking to people and ignoring what people are saying. (...) If you want to genuinely provide the help and services needed, you need to genuinely listen to people.

(Workshop participant)



Make it easy for everyone to contribute their ideas, highlight flaws or complaints, and just listen to what we have to say.

(Feedback questionnaire)

Participants want to be involved in decision-making processes; they want to impact their lives for the better. As shown previously, they want to implement and have a long-term impact and role in the policies that affect them.

3 Participants can **gain transferable skills**

Engaging in decision-making process and working with different stakeholders helps participants to gain **transferable skills**, which can support people to take up other opportunities as a result. For example, through networking and working opportunities, participants have become chairs of organisations and policy forums (Quintero et al., 2015). They can also gain new skills when contributing to meetings, editing and writing documents, and leading meetings (Mind, 2017). Practicing public speaking and gaining practical knowledge of topic have helped some to do well in future job interviews and have helped them get new jobs (MH:2K, 2017; Homer, 2019).

To both practitioners and participants

1 Improve knowledge and reduce stigma around the topic and life experience

Working effectively with people with lived experience can **deepen and develop staff's knowledge** and understanding of lived experience (Mind, n.d.; Suicide Prevention Resource Center, 2020). It can also 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.). Such interactions can **reduce stigmatising perspectives**. Interactions can help make discussions of lived experience more human and less abstract by having the impact statements from people with lived experience (CFE Research, 2020). People with lived experience participating in decision-making processes and peer research have expressed feeling less stigmatised (Quintero et al., 2015; Samaritans, n.d.). They can help “demystify” what it means to have lived experience through interaction with organisations and policymakers (CFE Research, 2020, p. 18).



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

1 Hard to identify impact on policy and decision-making

Case studies did mention the impact that involving people with lived experience has on organisational practice, service design, or staff knowledge and attitudes, as mentioned in the previous section. However, 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. This was also highlighted in the policy interviews. A policy officer did note that engagement can take place over several months, even years and participants can feel that their contribution has no impact, especially when they are consulted at the early stages of an engagement. Being able to identify the results of policy and strategy can take time (CFE Research, 2020), meaning that evidence may not be available yet. This does not mean the impact does not occur, as it may be that 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). A policy officer did note that they have in place a “You said, we did” feedback exercise on their channels. Individuals can access this feedback and reflect on their participation and see what other participants have said as well. The officer explained that they want to be transparent about the engagements that are being done, thus individuals can see all the different engagements that are happening.

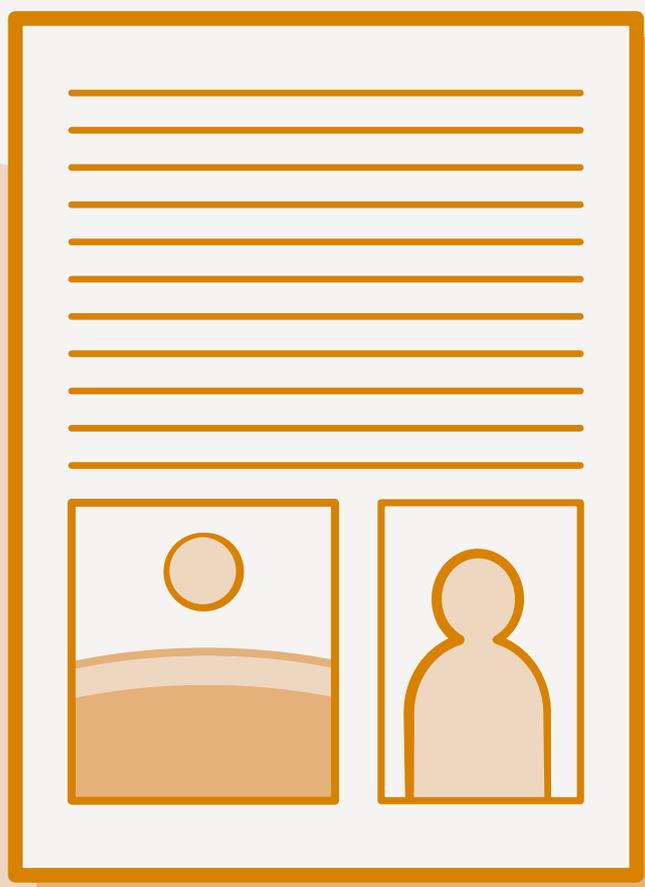
Similarly, in the workshop and the feedback questionnaire we did not gather much evidence on the impact and benefits on decision-making of engaging people with lived experience. This may be because, as found in the literature, there is simply not much evidence on impact. In addition, it became apparent during the workshop that participants needed to express their experience of barriers to meaningful engagement which suggests that the impact may be limited or not experienced due to the lack of follow-up.

Participants did however share the personal impact – outlined in KLoE 3 – that they had experienced from having taken part in previous decision-making processes. This is also reflected in the literature on participation more widely where impact on participants is better documented than impact on policy. Both the workshop and literature 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. Policymaking is a complicated process with multiple influencing factors and stakeholders. The engagement must be taken up and carried through this policy process (Goodin & Dryzek, 2006) so that people’s involvement is not only advisory but has an impact on policy and service delivery.

People with lived experience **should be involved in policy implementation and evaluation**, since there can sometimes be a gap between intention and implementation, and engagement in these later stages (Quintero et al., 2015). Additionally, there is a disparity with the work being done and seeing the results of that work as policy change and adaptation may take time (CFE Research, 2020; MH:2K, 2017). The need for monitoring and evaluation was highlighted during the policy interviews, as covered previously.

2 Enhanced credibility of work done by organisations and participants

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). Through its work engaging people with lived experience, the Refugee Women's Strategy Group was perceived as a group who could provide credible first-hand insight and evidence. The group was valued as representing people with lived experience in decision-making processes and were relied upon to represent the needs of refugee women in an increasingly difficult political context. 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). 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 et al., 2015).



Recommendations

Based on the synthesis resulting from the literature review, the workshop, the feedback questionnaire and the policy interviews, Table 4 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

Best practice

Examples

Provide training and support for participants

- 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

- 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

- Effectively planned
- Budget for expenses such as training, support, payments, venue
- Clear timeline

Value participants as individuals and reflect their needs

- Different experiences
- Listen to individuals, collaborate together
- Lived experience at the centre

Create a trusting and welcoming environment

- Minimise harm
- Safe space
- Inclusive language and spaces

Table 4. A summarised list of best practices in involving and engaging people with lived experience.

Decision-making processes should adopt levels of participation where people with lived experience can design, produce, facilitate, and evaluate projects and policies. They should be involved in all steps of decision-making and policy processes and be informed on how their contributions have affected outcomes of initiatives. Monitoring the impact of their contribution and evaluating the work being done are also ways to do meaningful lived experience work. Furthermore, appointing clear roles, goals, and outcomes, and having clear communication with one another can contribute to meaningful and well executed work, and managed expectations.

Participants should be provided training where appropriate. If work is specific such as peer research or workshop facilitation, participants should be trained to carry out such work. In addition, ensuring that they get adequate support for their needs is important as well. Staff working in policy or services also need training and support. Third sector organisations can help government staff to safely and practically work with people with lived experience but this should not be in detriment to reaching diverse groups of people and those who have never engaged in decision-making processes.

Organisers should value participants as individuals who each have unique attributes to them, and the outcomes of the work done should reflect their needs. They need to create a trusting and welcoming environment by fostering awareness and understanding of differences. Harm to individuals should be minimised by providing tailored support and by listening. Adopting inclusive language and spaces also minimises harm and places lived experience at the centre. Fostering relationships between those involved is also important to establish openness and trust.

Initiatives and decision-making processes should be well-funded and resourced to cover expenses of training, support, and payments to participants. Participation takes energy and resources; thus, organisations should appropriately manage the timeline of projects. Finally, appointing enough resources, well-trained, and appropriate staff to work with lived experience is important to ensure safety and proper support for participants.

Our workshop participants illustrated the weight of the systemic and political barriers that they face. These barriers are intimately linked to their lived experiences. Engagement must create space for these 'big picture' challenges to be discussed and acknowledged. People working on policy also highlighted the systemic barriers they face when working with lived experience.

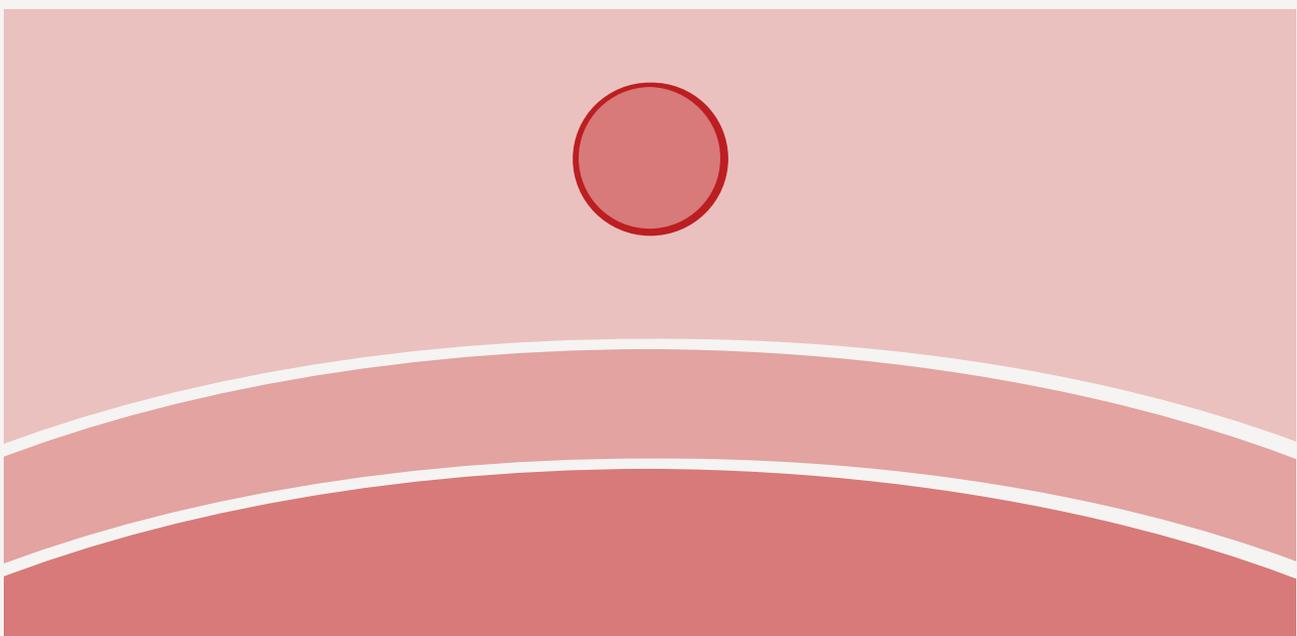


This study also has some limitations. We were not able to speak with as many policymakers as we intended due to the low response rate and scope of this study, so insights from this perspective are limited. Similarly, the number of participants in the workshop and questionnaire was also lower than expected. We learned from our own research that participation should be supported through multiple routes. In our case, this meant offering both the online workshop as well as a questionnaire, but more could be done in this regard such as offering two workshops at different times, or other modes of participation. Despite these limitations, we still gained valuable insights from all participants, which added value to the desk research and created consistent insights alongside the key findings from the literature.

Our desk research highlighted some further limitations in existing evidence and research on certain issues. The literature that we found to be most relevant was limited to a few sources and were referenced more frequently. Information about the policy impacts of engaging people with lived experience was limited. This is mirrored in other literature on participation which has to date mainly focused on the impacts on participants themselves (Jacquet & van der Does, 2020). Future research should pay attention to the impacts of engaging people with lived experience on policy and decision-making, and on resulting changes to health and social care services.

A further gap in our knowledge is the role of long-term engagement, and the potential of engaging people with lived experience in later stages of the policy process such as implementation and evaluation. For the most part, only a few case studies focused on policy development, and most of the cases studies were recommendations and guides for organisers and decisionmakers to adopt to meaningfully involve people with lived experience in their work. More research and practical work need to be done in these regards to understand if and how the impact of engaging people with lived experience can be strengthened and sustained.

People with lived experience are time after time encouraged to contribute and share their experiences, but often feel their contributions go nowhere. As expressed in the workshop and the feedback questionnaire, 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, in an inclusive and consequential manner and, as one workshop participant said, doing “design based on dignity and respect”.



References

- Activity Alliance. (n.d.). *Effective engagement*. Retrieved from https://www.activityalliance.org.uk/assets/000/002/883/Engagement_factsheet_2_-_Effective_Engagement_original.pdf?1557928886
- Arnstein, S. R. (1969). A Ladder of Citizen Participation. *Journal of the American Planning Association*, 35(4), 216-224. doi:10.1080/01944366908977225
- BEMIS. (2016, January). *Agenda and policy development in Scotland – Lived experience of ethnic and cultural minority communities*. Retrieved from <https://bemis.org.uk/PDF/bemis-poverty-and-ethnicity.pdf>
- British Red Cross. (2019). *Co-production case study – RSRFL Glasgow peer research project*. Retrieved from <https://communityengagementhub.org/wp-content/uploads/sites/2/2020/04/Peer-research-%E2%80%93-Glasgow.pdf>
- Campbell, S. (2018, October 24). Are people with lived experience of poverty finally being heard? *Joseph Rowntree Foundation*. Retrieved from <https://www.jrf.org.uk/blog/are-people-lived-experience-poverty-finally-being-heard>
- CFE Research. (2020, September). *The role of lived experience in creating systems change. Evaluation of Fulfilling Lives: Supporting people with multiple needs*. Retrieved from <https://www.bht.org.uk/wp-content/uploads/2021/03/The-role-of-lived-experience-in-creating-systems-change-2020-1.pdf>
- Chandler, D., & Munday, R. (2016). *Oxford: A dictionary of media and communication (2nd ed.)*. New York, NY: Oxford University Press.
- Community Development Foundation. (2006, December). The Community Development Challenge. *Department for Communities and Local Government*. Retrieved from <https://www.bl.uk/collection-items/community-development-challenge>
- de Wit, M. P. T., Kvien, T. K., & Gossec, L. (2015). Patient participation as an integral part of patient-reported outcomes development ensures the representation of the patient voice: A case study from the field of rheumatology. *RMD Open*, 1(e000129), 1-7. doi:10.1136/rmdopen-2015-000129
- Delivering for Scotland. (n.d.). *Devolution*. Retrieved from <https://www.deliveringforscotland.gov.uk/scotland-in-the-uk/devolution/#:~:text=Scotland%20has%20two%20governments%2C%20the,over%20matters%20that%20affect%20them.>
- Goodin, R., & Dryzek, J. (2006). Deliberative impacts: The macro-political uptake of mini-publics. *Politics & Society* 34 (2): 219–44. doi:10.1177/0032329206288152

Homer, A. (2019). 10 Engaging people with lived/living experience. A guide for including people in poetry reduction. *Tamarack Institute*. Retrieved from <https://www.tamarackcommunity.ca/hubfs/Resources/Publications/10-Engaging%20People%20With%20LivedLiving%20Experience%20of%20Poverty.pdf>

Jacquet, V., & van der Does, R. (2020). "The Consequences of Deliberative Mini-Publics: Systematic Overview, Conceptual Gaps, and New Directions." *Representation*, 57(1), 1–11. doi:10.1080/00344893.2020.1778513

MacIntyre, G., Cogan, N., Stewart, A., Quinn, N., Rowe, M., O'Connell, M., Easton, D., Hamill, L., Igoe, M., Johnston, G., McFadden, A-M., & Robinson, J. (2018). Understanding citizenship within a health and social care context in Scotland using community-based participatory research methods. *SAGE Publications*, 1-13. doi:10.4135/9781526484918

McLean, R. (2021, March). Paying people with lived experience for their participation. A review of legislation, literature, and practice. *Scottish Human Rights Commission*. Retrieved from <https://www.scottishhumanrights.com/media/2251/paid-participation-report-vfinal.pdf>

MH:2K. (2017). *MH:2K final evaluation report*. Retrieved from https://s3.amazonaws.com/participedia.prod/20f033ef-756c-4da3-9335-177b26bd36b1_MH2K-Oldham-final-evaluation-report.pdf

Mind. (2017). *Lived experience influence and participation policy: Ensuring people with mental health problems drive all that we do*. Retrieved from <https://www.mind.org.uk/media-a/4743/mind-lived-experience-influence-and-participation-policy.pdf>

Mind. (n.d.). *Mental health and physical activity toolkit. Guide 3: Involving people with lived experience of mental health problems in the design and delivery of your work*. Retrieved from <https://www.mind.org.uk/media/7595/mind-mental-and-physical-activity-toolkit-guide-3.pdf>

National Institute for Health and Care Research. (2022, July 13). *Payment guidance for researchers and professionals*. Retrieved from <https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392#in-brief--information-for-staff-who-are-administering-payments-and-key-issues-for-payments-to-people-who-receive-benefits>

Parry, L. J., & Ercan, S. E. (forthcoming). In The Eyes of Beholders: Rethinking the Impact of Deliberative Mini-Publics. In Jacquet, V., Ryan, M. van der Does, R. (Eds.) (forthcoming). *The power of democratic innovations. The impact of participatory and deliberative institutions*. ECPR Press.

Quintero, M., Murray, N., Connelly, E., & Ballantyne, F. (2015). Raising refugee women's voices. Exploring the impact of Scottish Refugee Council's work with the Refugee Women's Strategy Group. *Scottish Refugee Council*. Retrieved from https://www.scottishrefugeecouncil.org.uk/wp-content/uploads/2019/10/Scottish-Refugee-Council_s-Women_s-Project-Impact-Report.pdf

Samaritans. (n.d.). *From 'they' to 'we'. Reflections on working as lived experience advisors.* Retrieved from https://media.samaritans.org/documents/Lived_experience_advisor_FINAL_I7MmpzN.pdf

Sandhu, B. (2017, July). *The value of lived experience in social change: The need for leadership and organisational development in the social sector.* Retrieved from thelivedexperience.org/report/

Scottish Social Services Council. (2019). *Learning from lived experience. People, partnership and planning for involvement.* Retrieved from file:///C:/Users/itseme/Downloads/Council%20meeting%20of%2026%20March%202019%20Papers%20Item%2010%20Involving%20People%20Plan%202019-20%20Appendix%201%20(8).pdf

Sontag-Padilla, L. M., Staplefoote, L., & Morganti, K. G. (2012). Financial Sustainability for Nonprofit Organizations. A Review of the Literature. *Health and Rand Education.* Retrieved from https://www.rand.org/content/dam/rand/pubs/research_reports/RR100/RR121/RAND_RR121.pdf

Suicide Prevention Resource Center. (2020). *Engaging People with Lived Experience: A Toolkit for Organizations.* Retrieved from <https://www.sprc.org/livedexperiencetoolkit/about>

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of over 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers. Many NHS Boards, Health and Social Care Partnerships, Medical Practices, Third Sector Interfaces, Libraries and Access Panels are also members.

The ALLIANCE is a strategic partner of the Scottish Government and has close working relationships, several of which are underpinned by Memorandum of Understanding, with many national NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims. We seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.



ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

