

How to...

Recruit and support people with lived experience

1. Is this the best approach?

Inviting people with lived experience into the governance of your projects and programmes and/or onto a specific lived experience group has many benefits, including increased accountability to local people, hearing directly from recipients of the service areas you are looking to develop and co-creating solutions together.

However, supporting people with lived experience can be resource intensive and may require you to adapt the way you and the rest of your team work. It is not a tick box or an alternative to wider engagement.

People with lived experience can represent their own views and experiences and bring wider reflections if they are part of a group or network and are actively encouraged to seek views from these contacts. They cannot be expected to comment on behalf of entire populations or groups. They may have their own agendas and perspectives, based on their own backgrounds. It is, therefore, important to consider this as part of your recruitment processes.

Make sure you have considered wider methods of engagement that can support your project/ programme of work in addition to having people with lived experience as part of your governance.

2. What kind of involvement opportunity is this?

- **One-off or short term** - i.e. a task and finish group or a sub-group within a project, focussed specifically on understanding people's experiences
- **Ongoing** – i.e. participating in a steering group meeting or board
- Working in an **advisory capacity** or as **part of decision-making** processes

Do the voices of those with lived experience carry equal weight to professional view/vote?

There are no right answers here. But it's important to be clear with people what their participation will entail and influence.

Who do you want to involve?

Consider who you want to involve. Is it:

- People recruited from and representing a group?
- Individuals bringing their own experience and views?
- Users of particular services?
- Carers?
- Members of the public?



- Residents of particular areas or people who have particular characteristics (eg age, gender)?

It is always recommended to have **at least two people, as well as deputies**, with lived experience working with you. This creates mutual support, ensures consistency of participation and continuity if one person is unable to participate occasionally. Having only one individual involved can cause isolation and may seem tokenistic. Having an odd number can be helpful if users share a “vote” or are working together to reach a score they agree on, e.g., procurement panels. Having deputies who receive papers helps to develop a wider pool of people for future projects and programmes.

If aspiring to co-design and co-produce, consider equal numbers of ‘users’ and professionals.

4. Is the group/panel ready?

Involving people with lived experience in your work will require some adjustments. It’s important everyone working on the project is in agreement and understands the value of involving people with lived experience.

Things to consider include:

- Ideally, you will recruit people with lived experience to join the group/project as it starts. It may sometimes be the case that they will be joining a pre-existing group and the reasons why should be made clear to them.
- Having clear terms of reference and outlining whether any roles have voting rights.
- Creating a role outline (example can be found in Appendix A) for people with lived experience, so people understand the expectations of the role.
- Working with the chair of any meetings to carefully plan the agenda so that there is enough time for everyone to have their say, and to ensure people with lived experience are proactively invited to share views and ideas.
- Considering how different views and conflicting feedback will be resolved, fairly.
- Creating an agreement around how the group will work together. This should include avoiding jargon and assumptions that everyone will understand what is being discussed; and allow space for questions and clarifications before, during and after sessions.

5. How will you recruit people with lived experience?

Outlined here is a best practice approach. However, not all of these steps will be required for smaller/ short-term projects.

- **Create a role outline.** This document explains what the opportunity is; what experience/ particular requirements you are looking for; what support will be offered to those who express an interest; and the application process and deadline.

- **Create an application form and an open and transparent selection process** (an example application form can be found in Appendix C). It's important this process is light touch for voluntary roles. You need enough information to be able to decide what strengths the applicant will bring to your project, and what support they might need to participate (for example if working with people with additional needs). Use a demographic information form as part of the application process (the engagement team can provide you with one). Consider how you will select people and the process of short-listing if you have too many volunteers/applicants. Once applications have been received, consider the value of bringing those who have been short-listed in for an informal chat before offering them the opportunity.
- **Hold an information webinar** as part of the process for people to attend and find out more about the role, understand what's involved and can ask questions
- **Publicise the opportunity** – create an advert (an example can be found in Appendix B). This could be shared through existing channels, local networks and provider organisations with direct access to service users. Or you may need to use more targeted (and potentially paid for) recruitment if your project is about a specific community/ condition. This might include commissioning a trusted community organisation to recruit people for you or promoting via social media/ specific publications

We have already recognised that involving small numbers of people with lived experience can never truly be representative. But, through your recruitment process, you can be mindful of the range of experiences and backgrounds different applicants might bring to your work.

6. How will you support participants' involvement?

In addition to setting out a clear role outline, it's important that people with lived experience are supported to participate. This includes:

- **Training and induction:** Provide a general induction to the programme and to the specific work people will be involved in. This will help familiarise people with their role, project aims, activities to date, key terms and documentation. It will help people working together to get to know one another and avoid misunderstandings. Induction should include an opportunity to meet key people, understand each other's roles and ask questions before the first meeting. Consider if any mandatory training is required or whether they need to complete a register of interests form – for example if they will be involved in procurement, do they need training on any computer systems to access documents and score bids?

- **Meeting set-up:**
 - **Chairing:** The chair will involve those with lived experience and give them space to share views, ideas and provide challenge. At their first meeting, participants should be introduced and welcomed. To help manage time and contributions, you may want to consider having a specific slot on the agenda for those with lived experience and/or encouraging participants to co-design the agenda with you.
 - **Briefing and de-briefing meetings:** These should be offered before meetings and after participants have had chance to read the papers for the meeting to ask any clarifying questions. They should also take place after the meetings, in the first instances, to discuss how the meeting went, to seek any further clarification and to explore whether participants felt able to contribute and how working together could be improved for next time. Remember, participants are not ICB employees and therefore do not have access to “insider” information about how the ICS works – this is one of the benefits of their contributions.
 - **Logistics:** Plan meeting days/times well in advance, or in collaboration with those who have lived experience. Ensure papers are received with enough time for people to read and absorb the key points. Participants may be comfortable reading documents on screen, but be prepared to provide printed copies if needed/ reimburse the cost of printing
- **Jargon busters:** jargon and acronyms should be avoided as much as possible but a glossary of terms for easy reference can be useful
- **Valuing people’s time:** reimbursement of out-of-pocket expenses and other payments: seek advice from your engagement team for involving people with lived experience
- **Contact person:** there should be one named contact for any queries or concerns that arise before sessions / between meetings.

Take time to regularly review what is working well and what could be improved (from everyone’s perspective) so that any adjustments can be made.



Appendix A – example role outline

[insert name of project / programme]
Lived experience member role outline

1. Background

The ICS a partnership that brings together the organisations responsible for health and care services in south east London, to make the greatest possible contribution to the health and wellbeing of people living in our six boroughs.

This includes our Integrated Care Board, our NHS health services, our six Local Authorities and organisations from the voluntary, community and social enterprise sector. Together, we are responsible for allocating public money as well as planning and delivering a wide range of health and care services.

We use our combined resources to tackle of some of the biggest health issues affecting local people in Bexley, Bromley, Greenwich, Lambeth, Lewisham and Southwark.

We aim to keep people well, prevent ill-health and support people to thrive and live healthier lives.

As part of this, we are working with partner organisations to improve the health outcomes of people and reduce health inequalities. [Project leads to add further context e.g. around differential outcomes].

The ICS has set up a project steering group. The purpose of which is to

- [Project leads to insert further details in plain English (taken from terms of reference)]
- Plan and deliver further work with people with lived experience, local people and communities in the programme within the ICS engagement approach, working with people with lived experience, including using the ICS online engagement platform [Let's Talk Health and Care South East London \(letstalkhealthandcareselondon.org\)](http://letstalkhealthandcareselondon.org) to gather wider insight and views.

[Project leads to expand on working with people with lived experience, local people and communities by addressing questions below]:

- What is the scope and aim of working with people with lived experience, local people and communities. Why you are engaging? E.g. service review or transformation, identifying priorities for to inform development / transformation, feedback on different options for service development, statutory requirement, etc.
- What are the programme priorities that you are engaging on?



- What information/ feedback you require and how feedback and insight will be used?
- What you would like to achieve working with people with lived experience, local people and communities and other stakeholders?
- Can any of the partners or other organisations support the engagement?
- How the insight gained will influence the decision-making process?

The project steering group meets [insert frequency] on [insert day of the week and time] for [insert number] hours.

It is anticipated that these meetings will be on-line using MS Teams for the foreseeable future.

As face to face meetings begin to start again, we intend to offer the opportunity to continue offering the option of taking part on-line to minimise travel for members.

2. Membership

[Project leads to insert from terms of reference]

All members of the board are expected to adhere to the [Nolan principles of public life](#): selflessness; integrity; objectivity; accountability; openness; honesty and leadership. These are the basis of the ethical standards that board members should adhere to in their roles.

3. Lived experience member role

The ICS is looking for [insert number] of local people who have experience of using [insert service area] services within [insert geographical area, if relevant]. The role of the members with lived experience is to reflect on their experience of using and accessing the service to inform discussions and support the improvement outcome and help design further engagement. Where lived experience members are part of a wider resident, patient, carer or users groups or wider relevant networks they will be expected to feedback key issues to these groups and reflect the wider experience of other members of the group in discussions at the working group where relevant. However, these roles are not formal representative roles.

The members with lived experience roles are not paid roles but agreed reasonable expenses will be able to be claimed. Benefits of being a member include developing a range of skills and experience and access to development and support which could be included in your CV.

Experience

- Uses health services and has used [insert relevant service area] services in the last year, in particular, in [insert name of borough]

Skills

- Ability to speak in a formal group/ meeting and be able to constructively put forward views and to ask questions
- Ability to work with a range of people including those at a senior management level
- Ability to understand and assess a range of information and data, such as formal reports, graphs, charts and financial information, with support
- Be able to demonstrate integrity, good judgement and objectivity
- Be able to demonstrate an understanding and commitment to equality, diversity and inclusion

The lived experience member roles are offered for [one or two years] with an option of extension. We anticipate the role to require the equivalent of [one day a month] for reading papers and attending meetings, with the possibility of more time for development and support.

Papers for meetings will be distributed [at least a week] before the meeting so that community members have time to read and absorb them. On occasion there may be sensitive or confidential items to discuss and the chair will determine how these items are handled

4. Support and development

The ICS is committed to supporting and developing lived experience members of the project steering group.

The ICS will:

- Offer telephone or on-line conversations with anyone interested in finding out more about the role.
- Offer an induction meeting to lived experience members with the chair of the steering group and the key contact person prior to the first meeting lived experience members attend.
- Link members into any training put on by partner organisations such as NHS England and Improvement (NHSE&I).

The ICS is developing an expenses policy so that members can claim for agreed expenses in the future.

5. Benefits

Being a member of the steering group will provide a range of benefits which could be added to your CV including:

- Helping to improve the outcomes and experiences of using [insert service area]
- Understanding how the ICS and wider the NHS work
- Access to support and training
- Developing skills and knowledge in [insert service area]
- Understanding and experience of working on a strategic steering group



Appendix B – example advert

Advert - call for lived experience members on our steering group

Are you passionate and enthusiastic about the future of your NHS and health and care and want to help us shape the future of services?

We are currently seeking volunteers to play a key role in helping us shape the future of services for our local health and care services including the NHS.

As a member with lived experience your role will be to attend meetings and speak from the perspective of having lived with [insert], used services or a carer perspective, acting as a critical friend

Do you have an interest in [insert service area]?

We would like to invite you to help us to develop and transform [insert service area]. To do this, we have set up a patient, public and carer representative group, which helps shape the work of our steering group. Being part of this will give you the opportunity to contribute to discussions about [insert service area] and share what is important to you, based on your own experiences.

The main focus of the work is to lead transformations and improvements in [insert service area/ location]. Our steering group, which this group will feed into, is made up of staff, including clinicians, from the ICS, NHS England and [insert other partners involved in the work].

What does the role involve?

Your role will be to attend meetings to bring in the voice and experience of patients/carers to discussions, acting as an independent critical friend.

Meetings will be held every [insert frequency] and will usually take place in [insert location] at [insert timings of meetings, if known]. Reasonable travel and alternative care expenses will be paid. We will support you to participate through: training; induction meetings and one to one support.

Interested?

You can apply if you:

- Are over 18
- live in [insert geographical area] or have experience/knowledge of using [insert service area], and
- can commit to [2 hours] every [month] to attend meetings (out of pocket expenses will be reimbursed); and
- are passionate and committed to improving the quality of care for local people

How to apply?

For more information or to request an information pack please contact **XXXXXXX**.
Deadline for applications will be **XXXXX**

Appendix C – example application form

Name	
Organisation (if relevant)	
Contact address	
Telephone	
Mobile	
e-mail	
Preferred method of contact:	
Do you have any access needs we should be aware of, in order to fully participate	

Please give us a brief overview (250 words) of any relevant experience and why you are interested in this voluntary role. Please bear in mind that in order to ensure a fair process, selection will be based on responses given to points raised in the role description and person specification.

--

