

# How to engage with people with lived experience

## Why is engaging with people with lived experience important?

Involvement and collaboration are two of The Five Ways of Working set out in the Wellbeing of Future Generations Act. While this also refers to engagement with stakeholders, there is an onus on health, social care and the third sector to involve and collaborate with patients and the public to improve the wellbeing of the population in Wales.

Engaging with people with lived experience can have a positive impact on the work that we do and can inform changes to services and the way we work. To do so meaningfully, it's important to understand what works well, what the challenges and barriers might be and how to overcome them.

In this article, we'll look at how to engage people with lived experience in planned engagement activities, but there are other ways you can use lived experience to create change in health and social care too, for instance, employing people with lived experience, responding to situations you see in your service area, helping people with lived experience share their story to encourage change and involving people in their own care.

## What do we mean by lived experience?

Lived experience refers to having direct experience of an issue, situation or service. In our context, lived experience means having personal experience of our health and social care services or having experience of a health and social care issue, such as being a person or carer of someone with dementia or a learning disability.

There are many different terms used to describe involving people with lived experience, such as consultation, engagement, participation, partnership and co-production. Generally, these words are used to denote different levels of influence, involvement and power. The main distinctions these models use is whether an involvement activity is done to, for or with services users and members of the public. You can find out more about the distinctions in this great resource from [Co-Production Network for Wales](#).

## What does good look like?

There are many resources and frameworks that look into best practice when engaging with people with lived experience. We've gone through some of these and pulled together common themes to help you to engage with people with lived experience in a meaningful and effective way. You can find all of the resources we've looked at on the 'Additional Resources' page of this guide.



# Expectations, communication and choice

It is important to establish what the purpose of an engagement activity is, what can be influenced from the engagement activity, who will be involved and what you expect from the people you are engaging with prior to an engagement activity. This needs to be clearly communicated in an accessible way to the people you are engaging with, which will make the engagement more meaningful and helps people to decide whether it's something they want to be involved in or not.

By working through these types of questions, you can decide whether you've opted for the appropriate level of participation for the circumstance. This will result in a better experience for the people you're engaging with, by ensuring it is true engagement rather than information giving and reducing the risk of tokenism. You could use pre-existing engagement frameworks, such as Cardiff and Vale Regional Partnership Board's [Engagement Checklist and Plan](#) or Participation Cymru's [Engagement Project Initiation Document](#).

## Reciprocity, trust and respect

Power dynamics and trust can play a huge part in whether an engagement activity is successful or not. When there is an imbalance of power, people can feel uncomfortable and may give you answers they think you want to hear, rather than sharing their true lived experience. Establishing mutual responsibilities and blurring the distinctions between professionals involved and the people you are engaging with can help with this.

Spending time building trusted relationships and making it clear that you respect and value the ideas and views being shared with you can make the engagement more meaningful. You could draw on existing regional assets, such as community groups and third sector organisations, where trusted relationships have already been developed.

## Representation, equity and accessibility

Making sure the right people are represented is important. Hearing from a wide range of people will ensure the results of the engagement are robust and reflective of the population, though it is good practice to be mindful that people from within the same community have their own individual experiences.

To make sure everyone has an equal opportunity to engage, we need to understand barriers people might face, such as language barriers, cultural preferences and ease of access in terms of transport, sensory impairments and disabilities. These can be overcome by identifying and addressing these barriers when planning an engagement and working with the people you're engaging with to ensure they can take part.



# Development and skills

Engaging people with lived experience is a great way for us to find out what's meaningful to people, but it can also be an opportunity for the people we engage with to learn new skills and engage with their community. By engaging with people with lived experience, we can build confidence, reduce isolation, increase community cohesion and ensure people are treated like assets, rather than burdens on our health and social care system.

Where possible, offer training opportunities to the people you engage with and inform people about any policies, services and acronyms they might not be familiar with. This can help people feel more valued and involved in the process and develop skills and knowledge they can use in other areas of their life. Further to this, training staff in how to engage with the public is important, as it makes staff feel better prepared to engage with people with lived experience and can ensure that the people we engage with feel supported and safe.

## Feedback and keeping participants informed

Providing feedback to the people we engage with is essential as people have the right to know how their involvement has been used and if it has led to positive changes and decision-making. This will allow the people involved to see the difference and can ensure the positive impacts seen in the previous section. Be mindful of how you report this feedback to the people you've engaged with, ensuring the information is clear and accessible.

Not all engagement activities will be acted upon, and if so, explain why this is the case. By doing so, we can build or maintain the trust we have with the people we've engaged with.

## Monitoring and evaluation

In a similar sense to the above, it's important for us to reflect on the engagement process itself. This will help you to understand if the engagement activity was worthwhile and if there was anything you could've done differently. Cardiff and Vale Regional Partnership Board's Engagement Plan referred to above has a debrief section that you can use to make it easier to review how well the engagement process has been undertaken once it's completed.

You can also seek feedback from everyone involved in the process to see how well participants think the activity has gone. As well as being important for us doing the engagement activity, it is also helpful to share the evaluation of the process with the people you've engaged with, which again builds trust and makes people feel valued.



## Additional Resource

### National Principles for Public Engagement in Wales

This set of principles for public engagement in Wales has been produced collaboratively with organisations across health and social care. It aims to ensure that engagement is good quality, open and consistent.

### Children and Young People's National Participation Standards

This is a set of national participation standards focussing on children and young people, created by Welsh Government and Young Wales.

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

This research study commissioned by Health and Social Care Alliance Scotland, looks into involving people with lived experience in health and social care policy and decision making.

### NHS England: Working in partnership with people communities

While this is statutory guidance for NHS England, it contains some great information that is transferable to health and social care in Wales

### Co-Production Guide: Connecting and Realising Value Through People

In this guide, North Ireland's Department of Health discuss co-production at various levels, from policy makers to communities and people with lived experience.

### Involve: Nine Principles of Effective Deliberative Public Engagement

Involve is the UK's leading public participation charity and in this article, they set out their Nine Principles of Effective Deliberative Public Engagement.

### IAP2 Core Values for Practice of Public Participation

In this article, Involve summarises the recommendations set out in The International Association for Public Participation's Core Values.

Visit the [Regional Innovation Co-ordination Hub website](#) to see more of our work or get in touch by emailing [Dylan.John4@wales.nhs.uk](mailto:Dylan.John4@wales.nhs.uk) if you have an idea you'd like to explore together

