

How can we involve people in shaping diabetes services, care and treatment?

Introduction and context

This document sets out guidelines for involving diabetes service users in a meaningful way in order to inform and improve services. It is a result of contributions from people with lived experience, healthcare professionals and NHS decision makers in the Northern regions working together to agree on what is important to them through a number of engagement events. Diabetes UK collated the outputs of these to form this set of guidelines.

It contains six pledges which set out what we will do as NHS decision makers and healthcare professionals to effectively and meaningfully involve people with lived experience, and how people with lived experience can expect to be involved. Following each pledge is a set of actions which specify how to deliver it.

What is involvement?

Involvement is often described as doing things **with** or **by** people, rather than **for** or **to** them. In this context, involvement means giving people who use diabetes services the opportunity to influence how they are run. It needs to be embedded in all aspects of our work, rather than being seen as an optional extra.

We asked people with lived experience to tell us what the being involved means to them – the figure on the right shows some of the key words they used in their answers.



Where do these guidelines apply?

Involvement can exist on a number of levels. Here, we will be considering:

- 1) **Strategic level** - co-designing, planning and giving feedback on services.
- 2) **Individual level** - shared decision-making where people with lived experience and healthcare professionals work in partnership to plan an individual's care and treatment.

The following guidelines apply to **both these levels** and should be used by **anyone who works with or for people with, or at risk of, diabetes**. This includes NHS England, Public Health England, CCGs, clinical networks and NHS Trusts, and applies to the whole of the Northern region (North West and North East & Yorkshire).

Terminology

Using the right language is important to ensure we are clear and inclusive. Those involved in the development of these guidelines preferred the term *people with lived experience* to *service users*, *diabetics* or *people with diabetes*. Throughout this document, we will refer to *people with lived experience*; this can be read as anyone with, or at risk of, diabetes as well as their family, friends and carers - all of whom will have valuable insights and experiences to share.

Guidelines

Theme 1 - Culture and systems to support user involvement

Pledge 1

We will create an environment that supports, values and promotes user involvement, increasing and improving awareness and knowledge, with support and buy-in at all levels.

Actions:

- 1) Make sure that the voices of people with lived experience are heard in every service, project and other key decisions, at all levels.
 - Ask the question “How have people with lived experience been involved?” of **every** proposal, request and discussion, including at board level.
 - Ensure their views are **represented** on project steering groups and at planning stages.
 - Ensure people with lived experience are involved in key decisions about their care.

How have people with lived experience been involved?

We will make it the norm, not the exception to involve people with lived experience.

We acknowledge that it may not be appropriate to involve people with lived experience in **every** decision. However, we will try to approach everything from this perspective and **we must have good justification as to why they shouldn't be**, rather than having to give reasons why they should be.

- 2) Provide access to user involvement training and resources for staff.
 - Train **patient involvement champions** to monitor progress and motivate others.
 - Signpost to resources and organisations to support with involvement (for example Diabetes UK, NHSE Involvement Hub).
 - Integrate into **Continued Professional Development** (CPD). For example, introduce a minimum recommended number of hours spent on user involvement per month.
- 3) Share and spread good practice.
 - Use and promote **good practice libraries** and resources and **make them accessible through existing systems** (such as the intranet).
 - **Celebrate** good examples of involvement and those doing it well.

Pledge 2

We will ensure that people's engagement experiences are positive, not tokenistic, they feel valued, and their contribution results in tangible outcomes and improvements.

Actions:

- 1) Be **open, honest and realistic** about how people can contribute.
 - Create clearly defined roles that allow a **shared understanding** of what the role is going to include, and let people know what to expect.
 - Be clear about **what will happen** to the feedback.
- 2) Follow up with participants after involvement opportunities.
 - Share clear **minutes and actions**.
 - **Get feedback** on the involvement opportunity to see if it was a positive experience.
 - Communicate to participants **what happened next** as a result of their contribution - "you said, we did".
 - **Thank** people for their time and celebrate projects' progress.

Pledge 3

We will make better use of what's already available – for example by linking with existing Patient Reference Groups (PRGs) and other relevant organisations.

Actions:

- 1) Work in **partnership with other organisations** who have shared goals (such as community groups, pharmacy, Diabetes UK, Healthwatch & NHS England).
 - Check what these organisations are doing and identify opportunities to work together.
- 2) **Improve communication** with existing Patient Reference Groups and partner organisations and make the most of their knowledge and resources.
 - Involve them in producing audience appropriate communications and sharing it with the people they are in contact with to raise awareness.
 - Communicate with them regularly to exchange ideas, gain their feedback and share outcomes.
- 3) **Increase diversity of PRGs** by conducting a review of existing groups.
 - Establish where the gaps in representation are and address these.

Theme 2 - Increasing Diversity

Pledge 4

We will remember that one size doesn't fit all and provide opportunities for everyone to be involved - across all demographics and in all services.

Actions:

- 1) Understand who is currently underrepresented in involvement opportunities and make a targeted effort to reach out to them.
 - Establish involvement champions locally to encourage people in their communities to get involved.
- 2) Open up meetings and panels to a range of people with lived experience to ensure broad representation.
 - Publicise such opportunities through a variety of methods, including social media.

See the person, not just the condition

Not everyone with diabetes is the same. There are lots of other factors such as the type of diabetes they have (or maybe they're a carer), their age, gender, culture, personality and experiences that will influence their views. Rather than having one 'token' person representing everyone with lived experience, we will strive to involve multiple people from a range of backgrounds where possible.

Pledge 5

We will improve accessibility by offering a variety of engagement methods.

Actions:

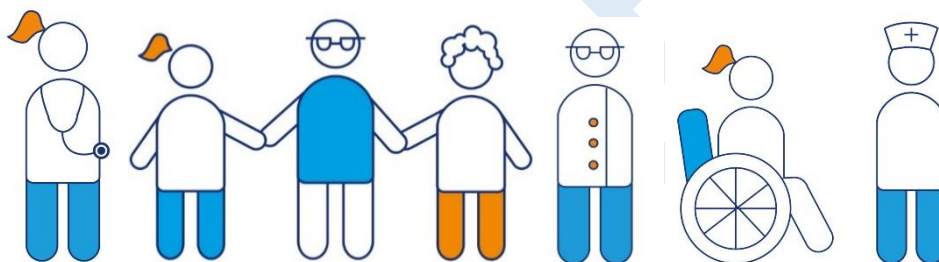
- 1) Use a 'menu of methods' for example face to face, online or telephone, and offer an appropriate combination of these depending on need.
- 2) Involve people with lived experience and healthcare professionals in developing engagement communications such as surveys, adverts and role descriptions, to ensure their suitability and appeal.

Pledge 6

We will embed the use of clear language ('Plain English') across the region to make sure everyone is included.

Actions:

- 1) Where more complex language must be used, provide a [glossary of terms](#) to refer to that is accessible to all.
- 2) [Share guidance and resources](#) to encourage and support the use of plain English.
- 3) Integrate clear communication into staff [training](#).
- 4) [Challenge unhelpful language](#) practices such as unnecessary acronyms and jargon.



Quick reference summary of guidelines

Theme 1 - Culture and systems to support user involvement

Pledge 1

We will create an environment that supports, values and promotes user involvement, increasing and improving awareness and knowledge, with support and buy-in at all levels.

- Views of people with lived experience always represented
- Provide training in user involvement
- Spread good practice

Pledge 2

We will ensure that people's engagement experiences are positive, not tokenistic, they feel valued and their contribution results in tangible outcomes and improvements.

- Be open and honest about what to expect
- Follow-up with next steps and outcomes
- Thank those involved

Pledge 3

We will make better use of what's already available – for example by linking with existing Patient Reference Groups (PRGs) and other relevant organisations.

- Work in partnership
- Communicate

Theme 2 - Increasing Diversity

Pledge 4

We will remember that one size doesn't fit all and provide opportunities for everyone to be involved - across all demographics and in all services.

- Target underrepresented groups
- Involvement 'Champions'
- Variety of communication methods

Pledge 5

We will increase accessibility by offering a variety of engagement methods.

- Menu of engagement methods
- Variety of opportunities

Pledge 6

We will embed the use of Plain English across the region to avoid excluding certain groups.

- Glossary of terms
- Resources to support
- Challenge unhelpful practices