

INVOLVING PEOPLE IN THEIR CARE

Your guide to including
people in shaping their
diabetes care and services

Working in partnership with



Public Health
England



DiABETES UK
KNOW DIABETES. FIGHT DIABETES.

Working in partnership with



Public Health
England

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FOREWORD



Diabetes UK is delighted to have worked with the NHS Diabetes Programme to produce these practical guidelines to involving people with and at risk of diabetes.

People value being involved in their care, and we've seen over many years how doing so makes for better services. However, we often hear that it can feel hard to involve people – these guidelines can help. By working in partnership with people affected by diabetes, as well as healthcare professionals and commissioners from the outset, we have developed a series of pledges, along with some clear actions and top tips, that are practical and achievable. It's a key step forward in ensuring the voices of those people that matter the most can be put at the heart of service delivery.

We would actively encourage you to try these out – put these pledges to the test and let us know what you think. We're here to support you to make person-centred diabetes care a reality.

A handwritten signature in black ink that reads "Bridget Turner". The script is cursive and fluid.

Bridget Turner
**Director of Policy, Campaigns and Improvement
Diabetes UK**



I am delighted to support this initiative. Within the 10 year plan for the NHS, service users are integral to our development and we must learn from their experiences as we design services and move forward. We strive to promote their increased involvement in developing services, capturing their views and experiences of care. These principles will promote service user participation and will build upon the many strong relationships with existing user groups. We hope to support patients, carers, voluntary organisations and health care professionals, thus encouraging all in the Diabetes community.

As a clinician specialising in Diabetes I am very keen to share this learning with others. On behalf of the North Regional Diabetes Programme Board, I would like to take this opportunity to thank those involved in the development of these principles especially all the service users and healthcare professionals who have attended our workshops, events and meetings. It is now up to all of us to ensure these principles and pledges of care are embedded into our system. I ask that all of us take the time to reflect on how we achieve this as we move forward.

A handwritten signature in black ink that reads "Tim Butler". The script is cursive and somewhat stylized.

Dr Tim Butler
**GP Specialist in Diabetes/Member of North Regional
Diabetes Programme Board
NHS England & NHS Improvement (The North East & Yorkshire)**

INTRODUCTION

This is a set of guidelines outlining how you can involve people affected by diabetes in a meaningful way to inform and improve services.

It's a result of contributions from people affected by diabetes, healthcare professionals and NHS decision makers in the northern regions. We worked together during a number of engagement events to agree the priorities for these guidelines.

What do we mean by 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're run. It needs to be embedded in all aspects of our work, rather than being seen as an optional extra.

Who are we involving and how?

You can involve people with diabetes in a variety of ways. This could be co-designing, planning and giving feedback on services, or on a more individual level, where the person affected by diabetes and their healthcare professionals work in partnership to plan their care and treatment. These guidelines are about how to involve people with diabetes, those at risk, and family, friends and carers.

As part of this work, we heard how important language is to making people feel included. So rather than speaking about service users, we will use 'people affected by diabetes' to include all of these groups.

Who should use these guidelines?

The following guidelines should be used by anyone who works with people living with, or at risk of, diabetes. This includes NHS England, Public Health England, Clinical Commissioning Groups (CCGs), Clinical Networks, Local Authorities and NHS Trusts, and applies to the whole of the Northern region (North West and North East and Yorkshire).

How should these guidelines be used?

There are six pledges that we've summarised as The 6 Ps of Involvement. Under each pledge is a set of suggested actions to help you deliver them.

The pledges cover changes needed in both the systems and culture to make sure involvement can happen, as well as ensuring that there is diversity in representation and that everyone who wants to be involved is given the opportunity to.

There are also some top tips to help healthcare professionals to involve people affected by diabetes as part of their care.

Involving children and young people

Whilst it's also important to involve children and young in their care and treatment, these guidelines have been designed specifically with and for adults. There are many other resources available which can support you to involve children and young people. For example, from the NHS Youth Forum and the Royal College of Paediatrics and Child Health.

THE 6 Ps OF INVOLVEMENT

These guidelines introduce the six pledges you can make to meaningfully involve people with diabetes in shaping their care and services.

Below is a simple checklist for reference:



1

Promote involvement

Make including the views of people affected by diabetes the norm not the exception.



2

Positive experience

Make all experiences of involvement as positive and meaningful as possible.



4

Participation for all

Provide opportunities for involvement that work for everyone.



5

Practical support

Reduce the barriers that are stopping people being involved.



3

Partnership working

Make use of what's out there and link with existing groups.



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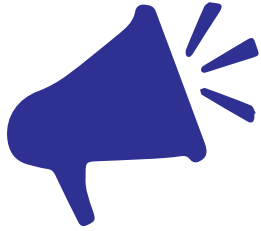
Plain language

Use language that's clear to everyone.



Pledge 1

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PROMOTE INVOLVEMENT



We'll create an environment that supports, values and promotes the involvement of people affected by diabetes and increase our awareness and knowledge of how to do it well.

What can you do?

Make sure that people affected by diabetes can contribute in every service, project and other key decisions, at all levels.

- Approach everything from the perspective of involvement first. Where it's not possible, there must be a good reason for why they shouldn't be involved in a decision, rather than having to give reasons why they should be.
- Ask the question "How have people affected by diabetes been involved?" of every proposal, request and discussion, including at board level.
- Make sure their views are represented on project steering groups and at planning stages.

Top tip

Involve people affected by diabetes in key decisions about their own care and treatment by working with them to produce their own care plan.



Provide access to resources and training to support with involvement.

- Train individuals to champion involvement, so that they can motivate others and monitor progress.
- Signpost to resources and organisations to support with involvement, for example Diabetes UK, NHSE's Involvement Hub and Engagement Practitioner's Network.
- Integrate involvement into yours and others' Continued Professional Development. For example, by regularly discussing in your appraisals how you involve people affected by diabetes in your work.

Share and spread good practice.

- Use and promote good practice examples and make them accessible through existing systems such as the intranet.
- Celebrate good examples of involvement and those doing it well, for example through awards.



Pledge 2

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POSITIVE EXPERIENCE



We'll make sure that people's involvement experiences are positive, not tokenistic, and that their contributions lead to clear actions.

What can you do?

Be honest and realistic about how people affected by diabetes 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 their feedback.

Follow up with participants who have been involved.

- Share clear minutes or actions, including outcomes and next steps.
- Get feedback from the participant to see if it was a positive experience.
- Update them with what happened as a result of their involvement "you said, we did".
- Thank people for their time and celebrate progress.





Pledge 3

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PARTNERSHIP WORKING



We'll make better use of what's already available, including creating partnerships with existing patient groups and other relevant organisations.

What can you do?

Work in partnership with other organisations who have shared goals. These could include community groups, local Healthwatch branches and Diabetes UK.

- Contact them and find out what they're doing to involve people and identify opportunities to work together.
- Communicate with them regularly to learn from each other's experiences, and use their networks to reach more people.

Make the most of the knowledge and resources of existing Patient Participation Groups (PPGs) and existing Patient Reference Groups (PRGs).

- Involve them in producing and sharing user-friendly communications.
- Communicate with them regularly to exchange ideas, gain their feedback and share updates.
- Increase diversity of patient groups by reviewing their current membership. Establish where the gaps in representation are and address these.

A **PPG** is a group based at every GP surgery to provide feedback to the practice.

In April 2015 it became a contractual requirement for all practices in England to form a PPG, engage with them regularly and to make reasonable efforts for it to be representative of the practice population.

A **PRG** is usually based at CCG level and is made up of patient representatives from multiple PPGs, as well as CCG governing staff, community representatives and voluntary sector organisations.



Top tip

You can maintain links with these groups and gain feedback for improvement through attending meetings, or asking for regular updates.





Pledge 4

PARTICIPATION FOR ALL



We'll provide opportunities for people from all backgrounds to be involved in all services and remember that one size doesn't fit all.

What can you do?

Identify whose views are not currently being heard and make a targeted effort to reach out to them.

- Work with people who can champion involvement locally to encourage people in their communities to get involved.

Open up meetings and panels to everyone to make sure there is a broad range of views from people affected by diabetes.

- Publicise ways to get involved through a variety of channels, including social media, newspapers, community centres and at surgeries and hospitals.
- Work with people affected by diabetes and other healthcare professionals to develop suitable and relevant surveys, adverts and role descriptions.

See the person, not just the condition

Everyone's experience of diabetes is different. There are lots of factors that will influence their views, so it's important to involve a diverse range of people where possible.

What do we mean by diversity?

Diversity means having a mixed community from many different backgrounds including, but not exclusively:

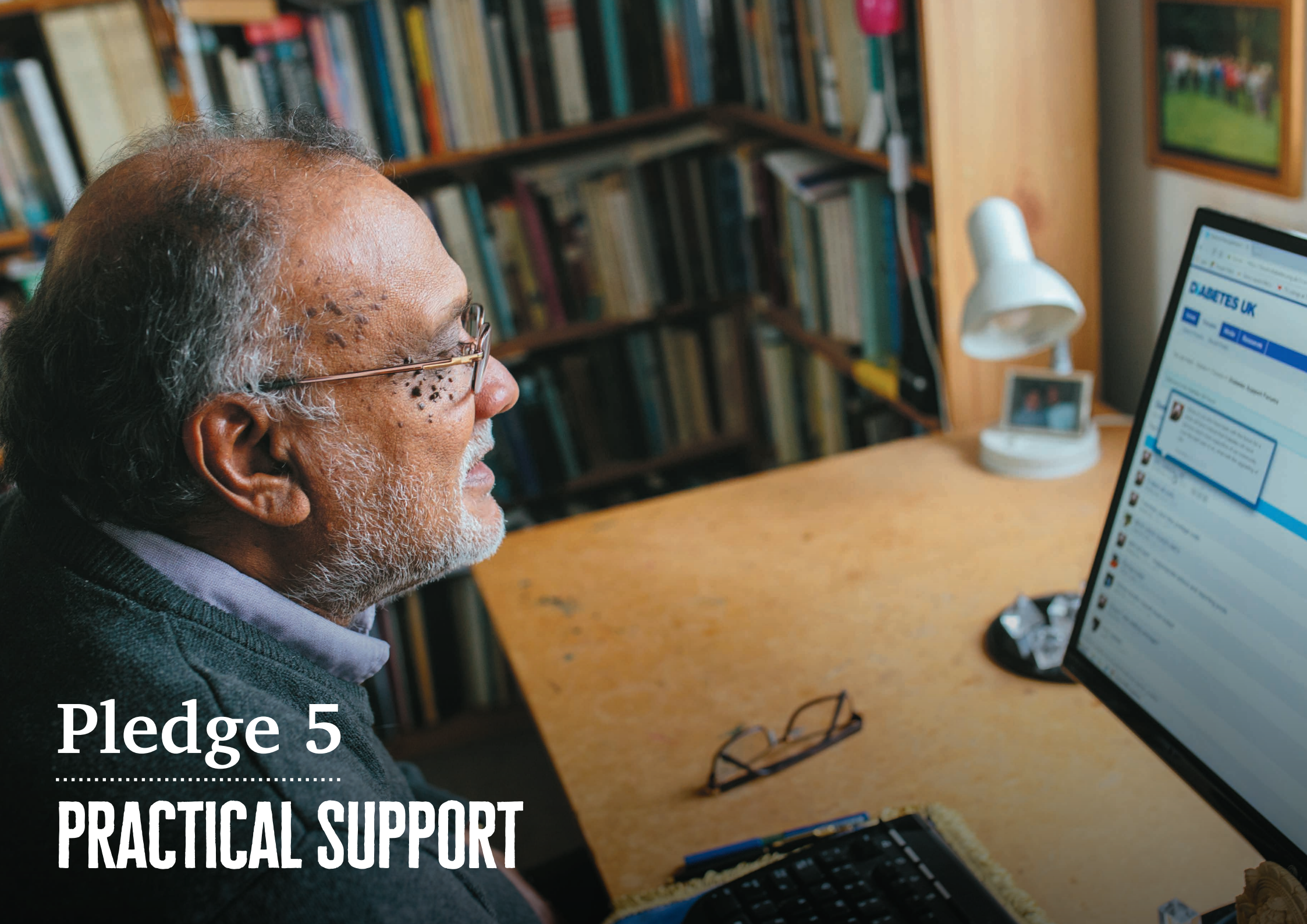
Type of diabetes (including those at risk), gender, ethnicity, age, rural and urban populations, LGBTQ+, religion, learning disabilities, physical disabilities, mental health conditions and long term conditions.



Top tip

When seeing a patient, ask "What matters to you?" and don't make assumptions about what they want from their care.





Pledge 5

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PRACTICAL SUPPORT



We'll make it easier for people to be involved by addressing some of the barriers that are stopping them.

What can you do?

Offer a variety of ways to be involved, to make it as easy as possible:

- Different methods – include face-to-face, online or telephone, or a combination of these depending on need.
- Different roles to suit all levels of skill, experience and commitment.

Consider practical arrangements when inviting and involving people:

- Travel, expenses, access needs and timings that might affect someone's ability to attend events.
- Interpretation or translation needs, access to technology and inclusive messaging to avoid excluding people when you communicate.



Top tip

Find out what opportunities there are to be involved in your own area, so you're aware of the options available to your patients.





Pledge 6

PLAIN LANGUAGE



Renal threshold

Blood glucose
12 mmol/L

▶ No glucose in urine

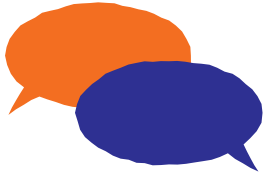
Blood glucose
above 12 mmol/L

▶ Glucose in urine

Insulin

Quick acting insulin (QI)

Soluble	eg. Actrapid, Humalog
Analogous	eg. Humalog, NovoRapid
	Onset
Soluble	30 min
Analogous	5-15 min



We'll always use clear language that everyone can understand.

What can you do?

Where more complex language must be used, provide a glossary of terms to explain what it means.

Make sure staff understand how to use clear language.

- Provide supporting resources and guidance, for example the NHS Language Matters guide. Go to www.england.nhs.uk and search 'Language Matters'.

Challenge unhelpful language such as unnecessary abbreviations and jargon in meetings, appointments and patient information.

Top tip

When talking to patients, avoid using technical language where possible, and recap at the end to check you've both understood each other.



SO WHAT NOW?

These pledges were co-produced by commissioners, people affected by diabetes, healthcare professionals and Diabetes UK.

Now it's time to work together to make them a reality:

Think about how you can adopt each of the pledges in your everyday work.

Share what you are doing to involve people affected by diabetes with your colleagues, your local network and with us.

For guidance on user involvement, visit www.diabetes.org.uk/user-involvement or get in touch at involvement@diabetes.org.uk.

For local support on working with people affected by diabetes in the Northern region, contact your local Diabetes UK office: northyorks@diabetes.org.uk or n.west@diabetes.org.uk 01925 653281



For more information

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