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INVOLVING PEOPLE AFFECTED BY DIABETES IN SERVICE DESIGN AND IMPROVEMENT

27th June 2023: Discovering Leadership Involvement Module

Bridget Hopwood & Sarah-Louise Harwood – Diabetes UK

Welcome! While we are waiting for others to join, please introduce yourselves in the chat box, and write one thing that made you smile this week ☺

INVOLVEMENT CONFIDENCE

HOW CONFIDENT DO YOU FEEL ABOUT INVOLVING PATIENTS IN SERVICE DESIGN AND IMPROVEMENT? (SCALE OF 1-10)

YOUR AIMS FOR TODAY'S SESSION

CHATBOMB: USE THE CHAT FUNCTION TO TELL US WHAT YOU WOULD LIKE TO GET OUT OF TODAY'S SESSION

INVOLVEMENT ELECTIVE - AGENDA

Objectives:

- An understanding of why involvement is important
- Understand the different involvement tools and methods
- Learn tips for putting together an involvement plan
- Increased confidence in involving people

- **Welcome and introductions**

- **‘Thinking involvement’: the why…**
  - What is involvement?
  - A case study: St Helens and Knowsley dieticians
  - Q & A

- **‘Doing involvement’: the how…**
  - Tools for involvement
  - Group work: scenarios
  - Reflection

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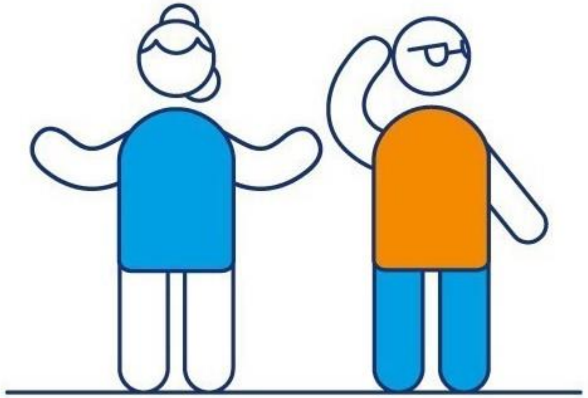
THINKING INVOLVEMENT – ‘THE WHY?’



INVOLVEMENT

What is it?

- Involvement is about **utilising personal experience** to influence the design, delivery and review of a service or activity.
- Activities done **"with or by people"** affected by diabetes not "to, about or for them"
- Working in **partnership**
- Those affected by diabetes a **leading part of the decision-making process**, driving change and improvement
- Involvement needs to be **meaningful** and with contributions leading to clear actions and impact

WHY IS INVOLVEMENT IMPORTANT?

> **It is how we should all be working – not just sometimes, but all the time.**
>
> David McNally, NHSE

- Improved health outcomes
- Better service delivery
- Patient empowerment
- More relevant, better designed, successful research
- Inspiration and motivation

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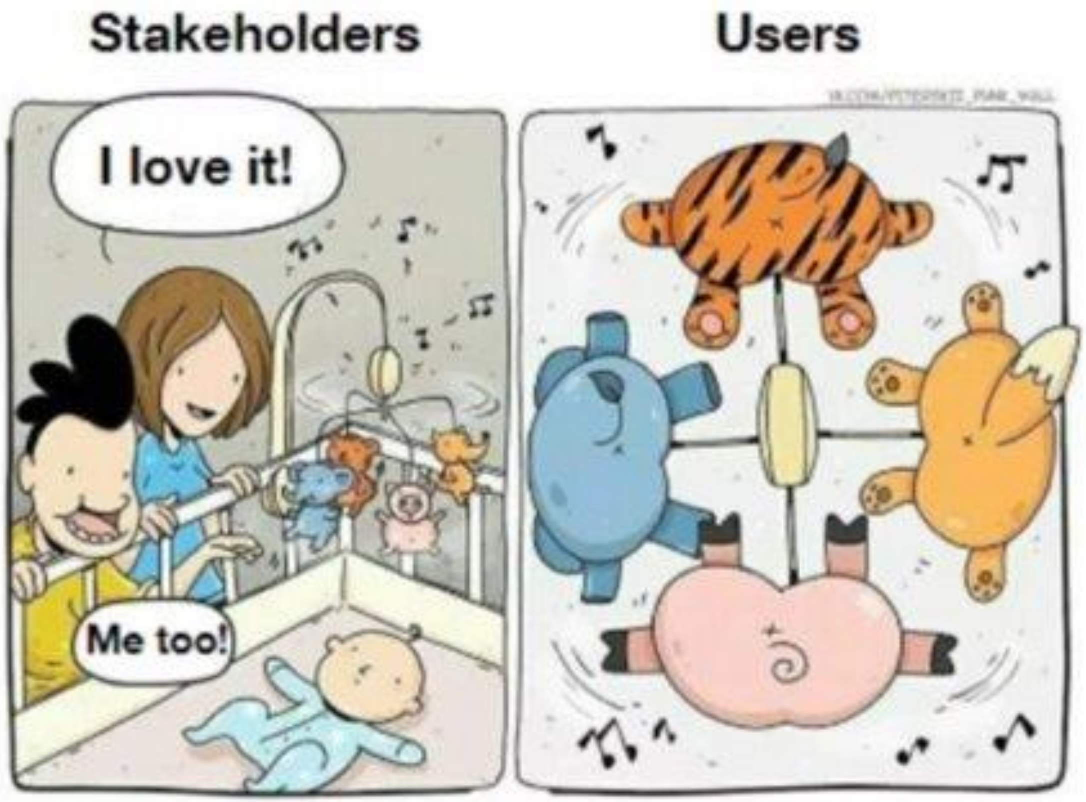
WHY INVOLVE PATIENTS?



INVOLEMENT PRINCIPLES

PERSON-CENTRED AND PERSONALISED

- Think about who you need and why – what does representation look like
- Acknowledge input: say thank you, share the impact

SIMPLICITY

- It won't be perfect, that's ok
- Make it meaningful. Should not be an afterthought, tokenistic or a 'tick box' exercise
- Embed from the start as a key stage of a project
- Don't make assumptions

BUILD RELATIONSHIP AND BE HONEST

- Be prepared to share power and decision making
- Listen and respond
- Be truthful, if you cant do something say so and why.

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INVOLVEMENT MATTERS: CASE STUDY

Diabetes Specialist Dieticians

St Helens and Knowsley NHS Trust

The importance of healthcare professionals involving people with lived experience, in diabetes research

Discovering Leadership Workshop 2023

Catherine Gallagher

Senior Diabetes Specialist Dietitian

St Helens & Knowsley Teaching Hospitals

Focus Groups to explore the views of our structured carbohydrate counting education session (2020)

INVOLVING PEOPLE IN THEIR CARE

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

Working in partnership with

NHS

Public Health England

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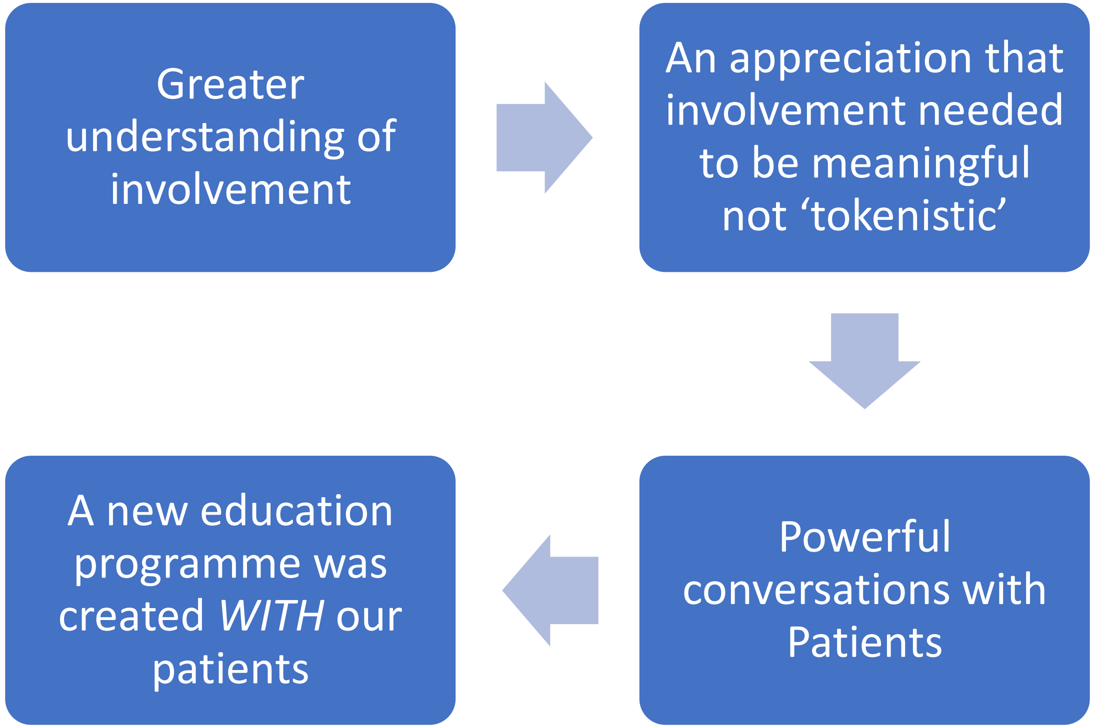
Why I got involved?

- Wanted to continue to support patients with self management of T1DM
- Gain experience in applying for a grant
- Build knowledge & skills in 'involvement'
- Curious – could I learn from patients?



Greater understanding of involvement

An appreciation that involvement needed to be meaningful not 'tokenistic'

Powerful conversations with Patients

A new education programme was created *WITH* our patients

Aim

To identify key themes among adults with type 1 diabetes about their views on insulin carbohydrate education (ICE) sessions using online focus groups.

Methods

Qualitative methodology utilising individual, semi structured, taped, transcribed and analysed focus groups with individuals who previously attended our structured carbohydrate education programme

Results

Most preferred the concept of 1-2-1 but seen merit in group education

Patients would choose face to face education over virtual

Keen for follow up after attending their initial ICE session

Discussion

Patient centred education informed by involvement is likely to be more widely accepted by patients. Patients feel valued to be involved. Recognising patients contribution is an essential component of meaningful involvement.

Take Home Messages

- Patients love to be involved
- Speak to your managers
- Equality, Diversity & Inclusion is an important consideration
- Build collaborations within the Trust
- Utilises resources available – DUK Involvement Guidelines, NIHR PPI webinars, grant opportunities

Further Opportunities for Patient & Public Involvement

- Received a public involvement fund grant from my local Research Design Services (RDS) (2021)
- Supported previous DUK Discovering Leadership Workshops (2021/2022)
- Joined BDA researchers Network & Council for Allied Health Professions Research (CAHPR)
- Currently undertaking a research internship with the Applied Research Collaboration (ARC) Northwest (2023)
- Published abstracts –BDA research symposium, Diabetes UK Professional conference, DUK pregnancy conference
- Involving patients in my future research plans

“If you always do what you’ve always done, you’ll always get what you’ve always got.”
- Henry Ford

Thank you

- Diabetes UK Involvement Team for your support & patience
- My colleague Emma Edon who was also involved in this work
- The wider diabetes team, in particular Professor Hardy & Dr Bujawansa for their support with the grant application
- The finance department for ensuring the timely vouchers for the patients involved from the DUK grant funds
- The patients themselves for their involvement

Thank you for your time!

Any questions?

INVOLVEMENT MATTERS
Q & A – OVER TO YOU

Please use either the ‘raise hand’ function to voice your question

Alternatively use the chat box function to type your question

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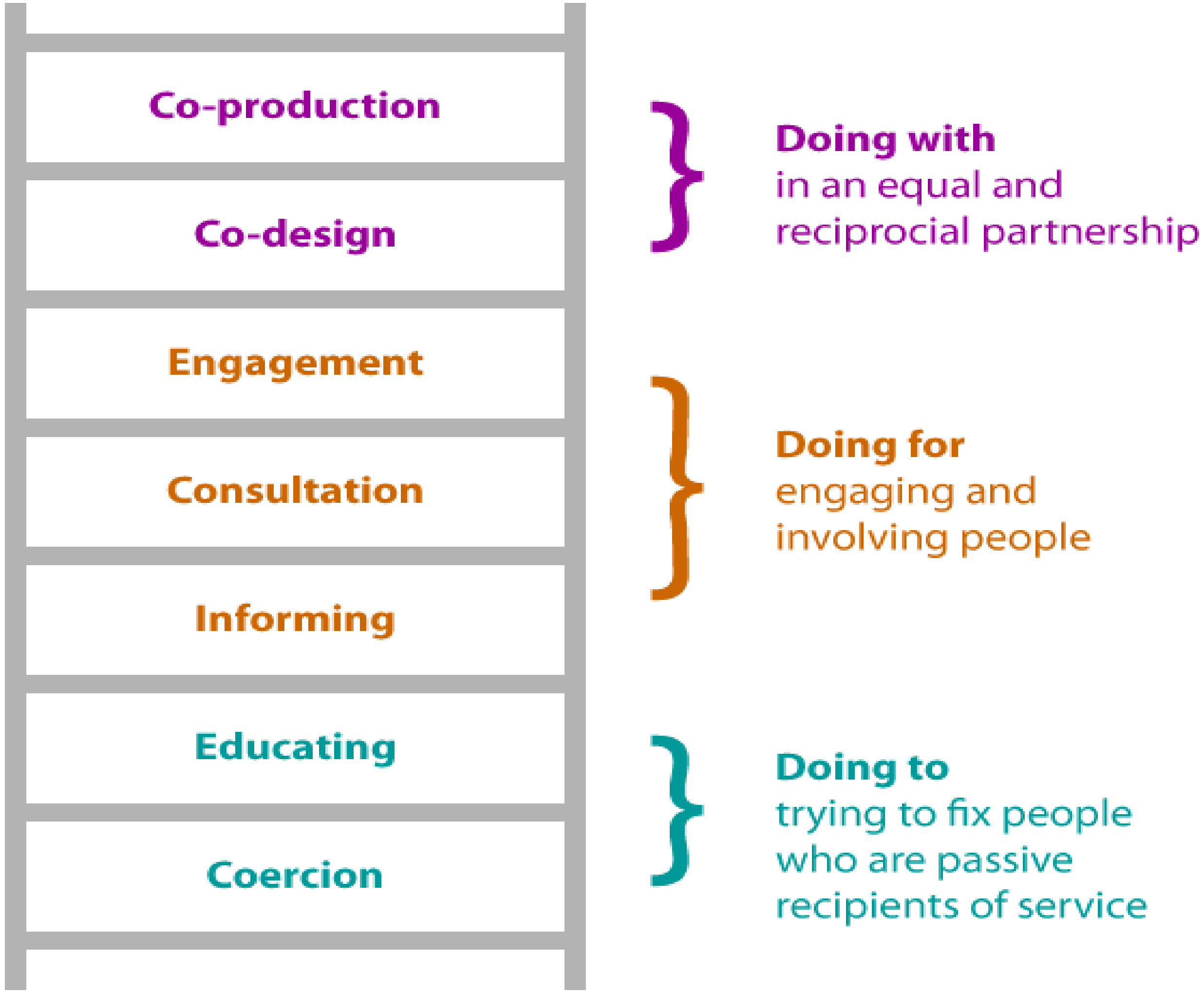
DOING INVOLVEMENT – ‘THE HOW’

THE INVOLVEMENT LADDER



Co-production

Co-design

Engagement

Consultation

Informing

Educating

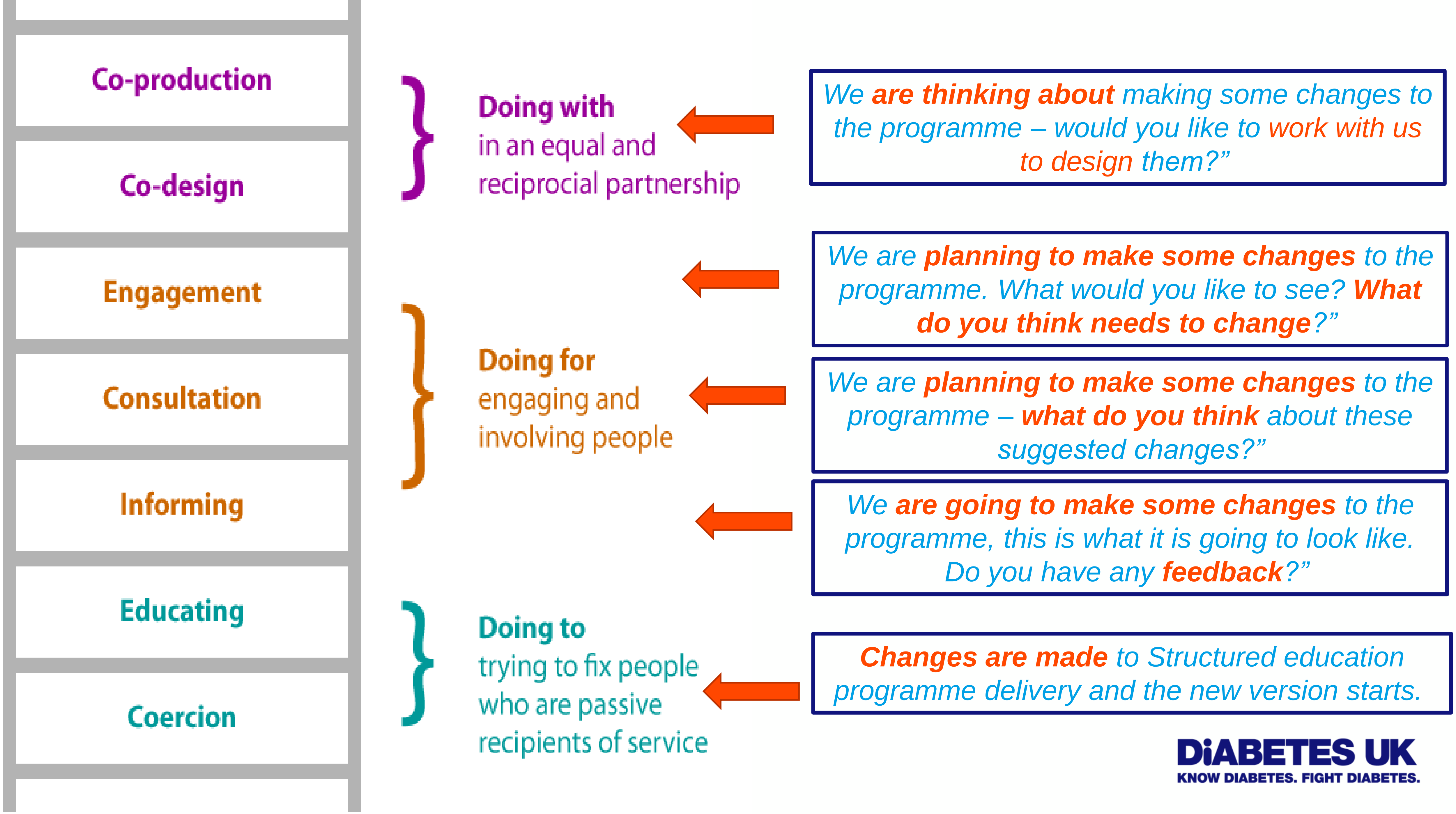
Coercion

Doing with
in an equal and
reciprocial partnership

Doing for
engaging and
involving people

Doing to
trying to fix people
who are passive
recipients of service

- Where is your project on the ladder?
- Where should it be? Where is it appropriate for it to be?
- What could you do to get to the next rung?



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*We **are thinking about** making some changes to the programme – would you like to work with us to design them?”*

*We are **planning to make some changes** to the programme. What would you like to see? **What do you think needs to change**?”*

*We are **planning to make some changes** to the programme – **what do you think** about these suggested changes?”*

*We **are going to make some changes** to the programme, this is what it is going to look like. Do you have any **feedback**?”*

***Changes are made** to Structured education programme delivery and the new version starts.*

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INVOLVEMENT METHODS

WHICH METHOD?

Need to consider:

- Existing evidence
  - What do you know already? Blank canvas?
- Qualitative or quantitative data (or both)?
- Sample size
  - What is available? What do you need? (stats or stories?)
  - Self-selecting sample vs targeted
- Target audience
  - Who are you trying to reach? Which method best meets the needs of that group?
- Timings/budget/resource

Just talk to them! Doesn't always have to be formal…

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INVOLVEMENT METHODS

Insight gathering

- Surveys (online or paper)
- Interviews
- Focus groups

Collaborative working

- Workshops
- Steering group representation
- Patient Advisory groups (PAGs)

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INVOLVEMENT METHODS

Surveys	In -depth interviews	Patient Reps	Focus Groups	Patient advisory group	Workshops
A set of questions designed to gather opinions and perspectives from many people to inform and shape your research project.	An in-depth conversation that allows you to gather rich information. Interviews can be conducted face to face or over the phone (or via Teams/zoom) and can be structured, semi-structured or informal.	A group of patients that provide feedback and new perspectives over a longer period. They receive training and an induction.	An event where you bring a group of people together to take part in well planned and facilitated discussions on a topic. You can use different activities and facilitation techniques to gather insights. These can also be run online.	Patients that sit on an existing project team or steering group alongside other experts. Ideally there should be at least 2 patient representatives. This provides another patient perspective and peer support. Patients will receive training and an induction.	An event where participants are invited to take part in activities and work together, sometimes with healthcare professionals too, to come up with solutions. These can range from 'blue sky thinking' to gaining feedback on a particular topic and talking through changes together. They usually take place over a period of a day or half day.
ADVANTAGES: • Large sample • Time efficient • Responses can be analysed with quantitative methods • Honest insights	**ADVANTAGES:** • Good for complex issues • Can clarify questions or answers • Rich qualitative information • Honest insights	**ADVANTAGES:** • Expertise increases with time • Keeps research focused on patient benefit • Act as critical friends • Ongoing feedback and discussion throughout your research project	**ADVANTAGES:** • Good for complex issues • In depth discussion • Group can bounce ideas off each other • Many techniques for gathering insights	**ADVANTAGES:** • Can build rapport • Range of skills and experiences • Expertise increases with time	**ADVANTAGES:** • Gather diverse views over a longer period of time • Hands on activities / stimulus
DISADVANTAGES: • Can't clarify questions or answers • Can't gather in depth insights • Limited on the type and number of questions	**DISADVANTAGES:** • Small sample size • Time consuming (interviews, transcription and analysis)	**DISADVANTAGES:** • Patients can become experts (so are no longer 'lay') • Can require a lot of support • Limited number of perspectives • Higher expenses	**DISADVANTAGES:** • People can be influenced by others' opinions • Time consuming • Higher expenses • Not always accessible to some groups	**DISADVANTAGES:** • Require a lot of support • Friendships can change group dynamic • Patients can become experts (so are no longer 'lay') • Higher expenses	**DISADVANTAGES:** • Labour intensive • Recruitment, staffing on day, and a lot of time commitment for plwd

INVOLVEMENT TOOLS: WAYS TO GATHER FEEDBACK

Video diary/Vlog

Peer to peer interviews

Comments box + online version

Journaling/Blogging

Online chat forum e.g. Whatsapp/ Facebook groups

Anecdotal feedback

Informal chats

Photo journey

Phone calls

Presentations sharing lived experience

Surveys

Zoom/Teams Interviews

Meetings/Focus Groups

Artwork/prose/poetry

Volunteers/Health watch

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RESOURCES

USER INVOLVEMENT GUIDELINES

INVOLVING PEOPLE IN THEIR CARE

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

Working in partnership with

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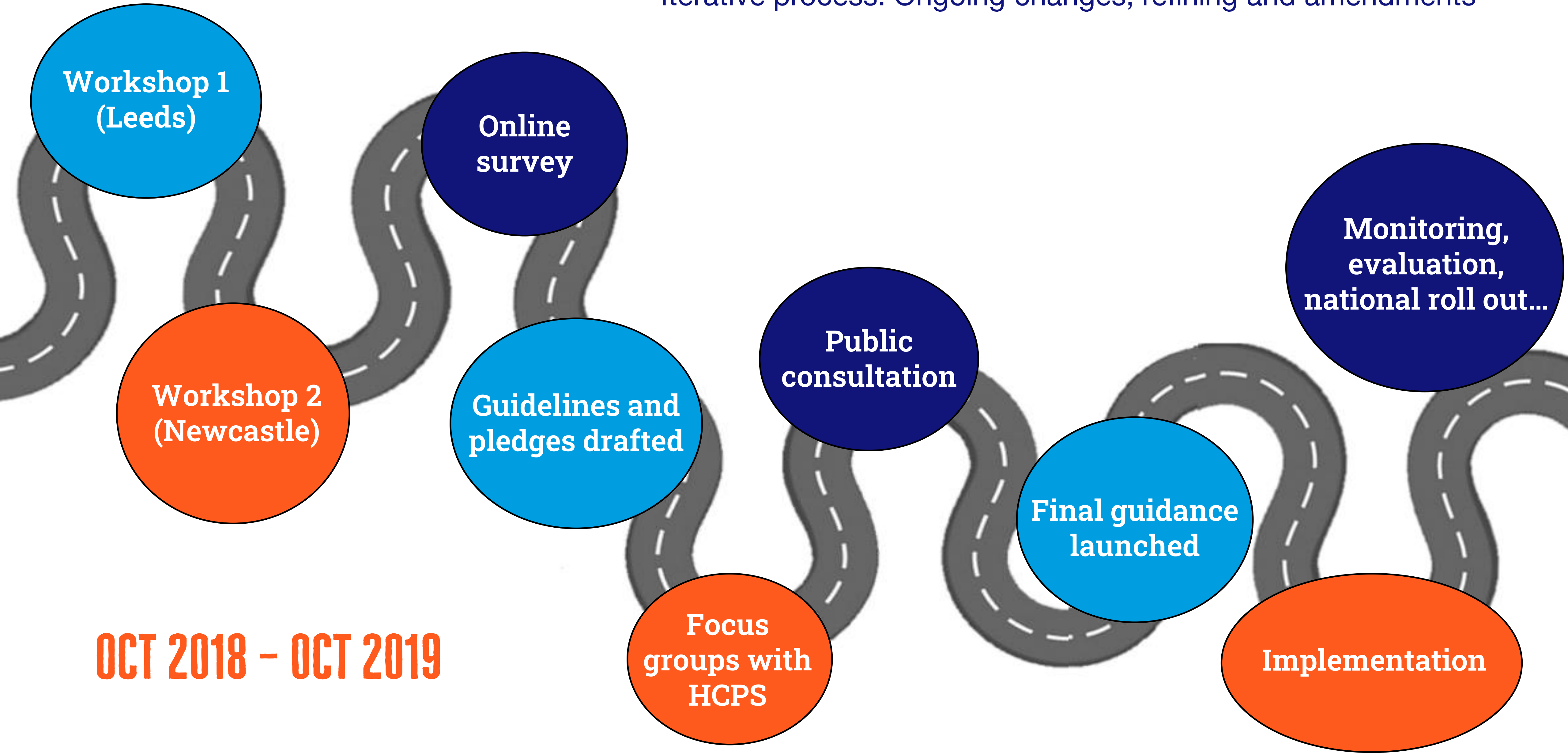
USER INVOLVEMENT GUIDELINES

- Developed, piloted and launched in Northern region
- Co-produced with people affected by diabetes, commissioners, healthcare professionals and Diabetes UK
- Workshops, focus groups, interviews, on-line survey
- Supporting five projects in the Northern region to use these guidelines on ‘live’ projects
- National launch planned – lots of generic themes

DEVELOPMENT JOURNEY

Involvement and consultation with NHSE, HCPs, PLWD throughout

Iterative process. Ongoing changes, refining and amendments



Workshop 1 (Leeds)

Workshop 2 (Newcastle)

Online survey

Guidelines and pledges drafted

Focus groups with HCPS

Public consultation

Final guidance launched

Implementation

Monitoring, evaluation, national roll out...

OCT 2018 – OCT 2019

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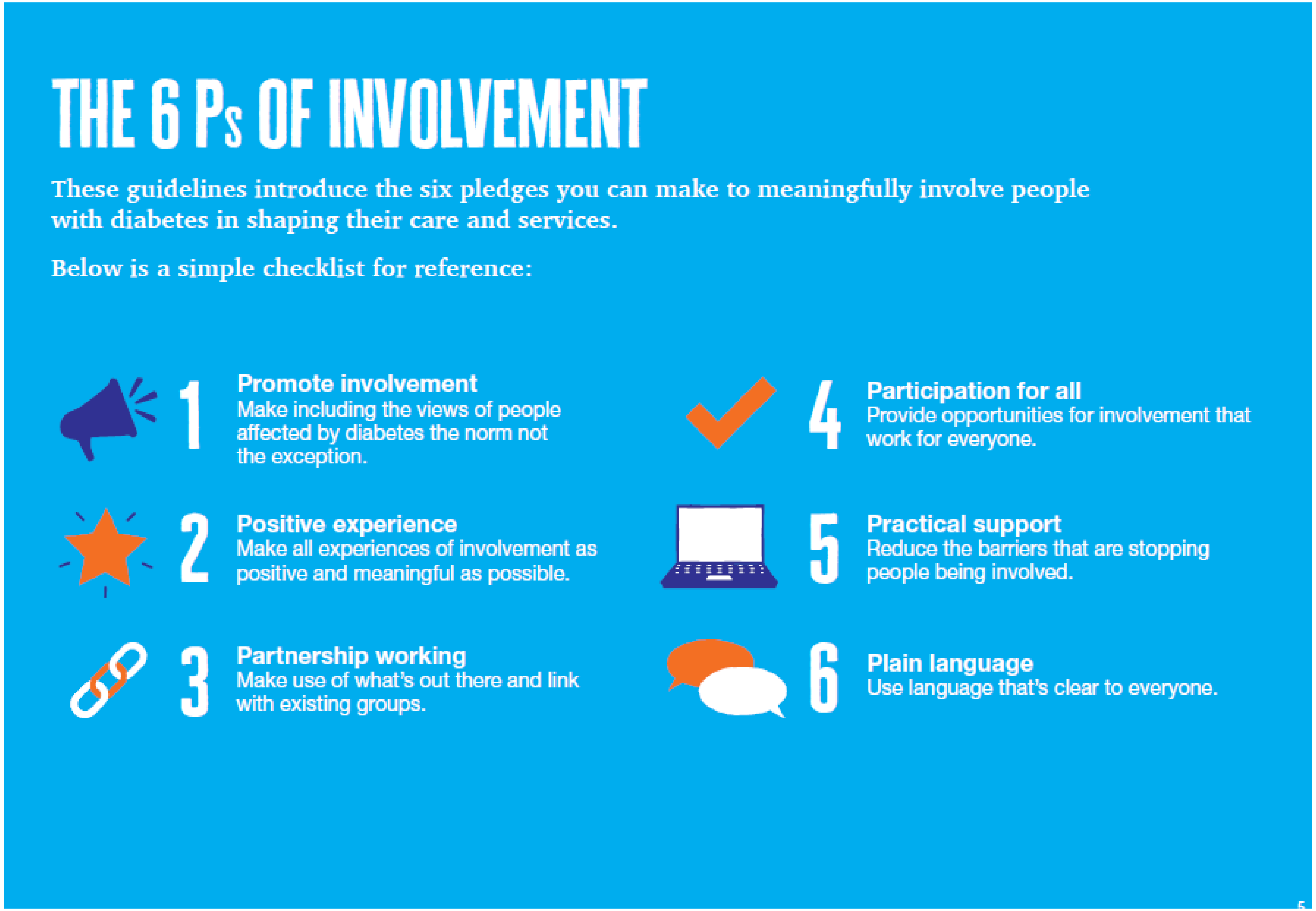

THE 6 Ps OF INVOLVEMENT

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.

3 **Partnership working**
Make use of what's out there and link with existing groups.

4 **Participation for all**
Provide opportunities for involvement that work for everyone.

5 **Practical support**
Reduce the barriers that are stopping people being involved.

6 **Plain language**
Use language that's clear to everyone.

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.

FEEDBACK

“PLEASED THAT WE WERE LISTENED TO, OUR POINTS WERE ACTUALLY TAKEN ON BOARD , AND IT WAS NOT A TOKENIST EXERCISE”

“ARGUABLY THIS DOCUMENT IS THE BEST I HAVE RECEIVED FROM THE JOINT PARTNERSHIP AS IT IS A COLLABORATIVE PIECE OF WORK WHICH RECOGNISES THAT PEOPLE WITH DIABETES ARE DIFFERENT, THEIR IN-LIFE EXPERIENCES CAN CONTRIBUTE TO HOW THEIR DIABETES IS MANAGED AND IT RECOGNISES CARERS”

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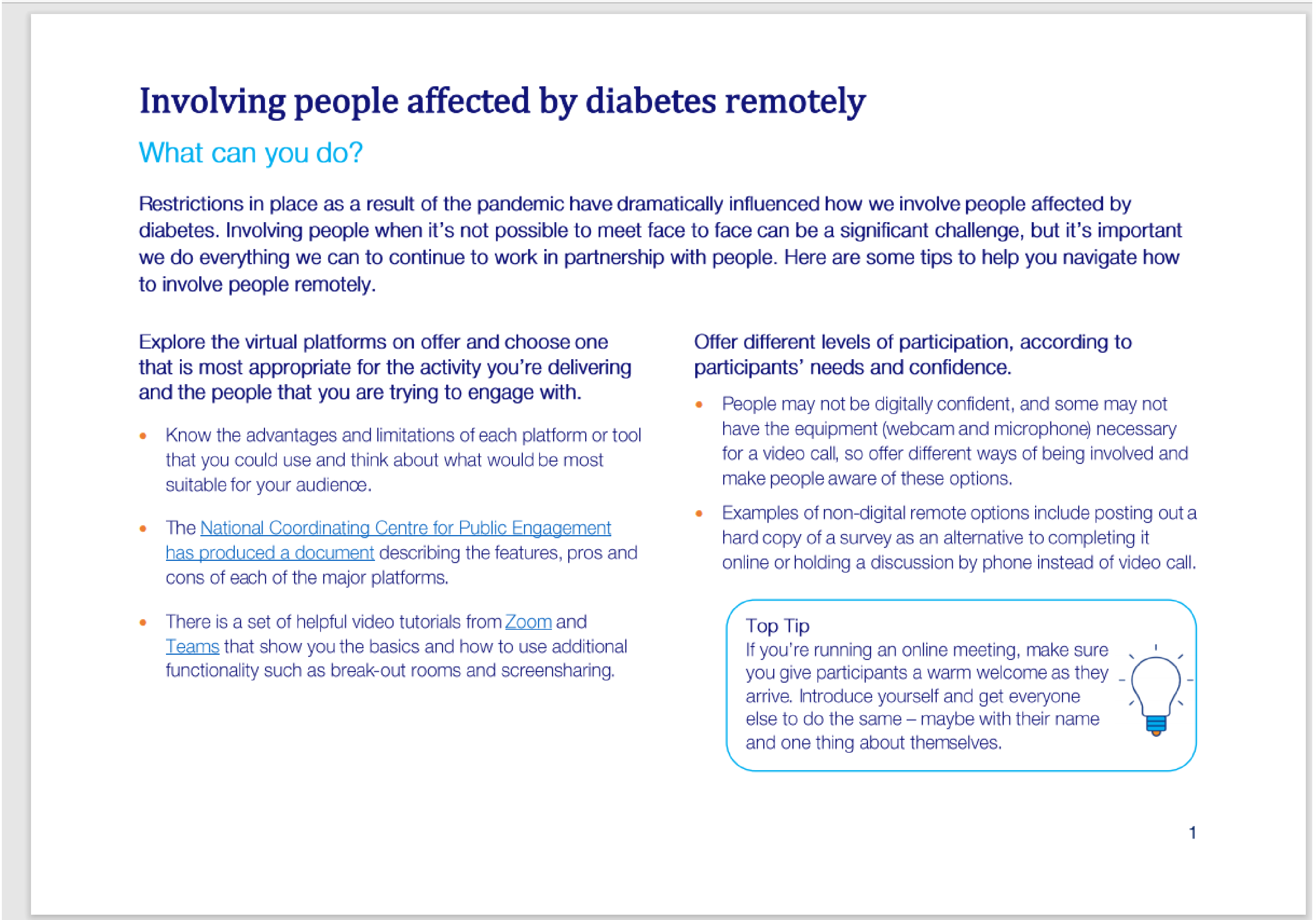
REMOTE GUIDELINES

NEW:
Remote appendix

[Involving people affected by diabetes remotely_Jan20.pdf (amazonaws.com)]()



Involving people affected by diabetes remotely

What can you do?

Restrictions in place as a result of the pandemic have dramatically influenced how we involve people affected by diabetes. Involving people when it's not possible to meet face to face can be a significant challenge, but it's important we do everything we can to continue to work in partnership with people. Here are some tips to help you navigate how to involve people remotely.

Explore the virtual platforms on offer and choose one that is most appropriate for the activity you're delivering and the people that you are trying to engage with.

- Know the advantages and limitations of each platform or tool that you could use and think about what would be most suitable for your audience.
- The [National Coordinating Centre for Public Engagement has produced a document]() describing the features, pros and cons of each of the major platforms.
- There is a set of helpful video tutorials from [Zoom]() and [Teams]() that show you the basics and how to use additional functionality such as break-out rooms and screensharing.

Offer different levels of participation, according to participants' needs and confidence.

- People may not be digitally confident, and some may not have the equipment (webcam and microphone) necessary for a video call, so offer different ways of being involved and make people aware of these options.
- Examples of non-digital remote options include posting out a hard copy of a survey as an alternative to completing it online or holding a discussion by phone instead of video call.

Top Tip
If you're running an online meeting, make sure you give participants a warm welcome as they arrive. Introduce yourself and get everyone else to do the same – maybe with their name and one thing about themselves.

1

LEARNINGS

Need time and space to do it properly

- whole process took nearly 18 months

Need to ‘practice what we preach’ in terms of representation

More work needed on engagement with HCPs

- needs to happen earlier
- fit working patterns better

Challenges of working in partnership with commissioners

Board buy-in and support is essential from the outset

People affected by diabetes appreciate being involved (and need to be)

TOP TIPS

1. Plan involvement from the start.

It needs to be embedded not an afterthought.

2. Doesn’t have to be perfect.

Try different methods and choose the right level for your project. There is no right way.

3. Be ready to share control.

Involvement can be unpredictable, embrace it and allow the power shift.

4. Share impact and ask them for feedback.

Respectful to acknowledge contributions and share results. Feedback is an opportunity to learn.

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TOP TIPS

5. Choose the right methodology

- For the project
- For the participant(s) and their needs

There is no one way to do involvement. Try different things and offer choice and flexibility.

6. Think about diversity and representation

Partnership working and community engagement is key. One size doesn't fit all: know your audience and let that guide how you engage them.

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THANK YOU AND ENJOY THE REST OF YOUR EVENING!

BRIDGET, SARAH AND HOPE

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INVOLVING PEOPLE AFFECTED BY DIABETES IN SERVICE DESIGN AND IMPROVEMENT: PART 2

13th July 2023

Bridget Hopwood, Jenni Mohammadi & Amy Hodgkinson – Diabetes UK

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INVOLVEMENT CONFIDENCE

HOW CONFIDENT DO YOU FEEL ABOUT INVOLVING PATIENTS IN SERVICE DESIGN AND IMPROVEMENT? (SCALE OF 1-10)

WHAT DID YOU LEARN IN PART 1?

‘CHATBOMB’:
USE THE CHAT FUNCTION TO TELL US WHAT RESONATED THE MOST FROM THE FIRST INVOLVEMENT SESSION

INVOLVEMENT ELECTIVE - AGENDA

- **Objectives:**
  - An understanding of why involvement is important
  - Understand the different involvement tools and methods
  - Learn tips for putting together an involvement plan
  - Increased confidence in involving people
- **Recap: Involvement Learning from Part 1**
- **Doing Involvement:**
  - Tools for involvement
  - Finding Participants / Diversity
- **Putting learning into practice: Group Work**
- **Resource review**

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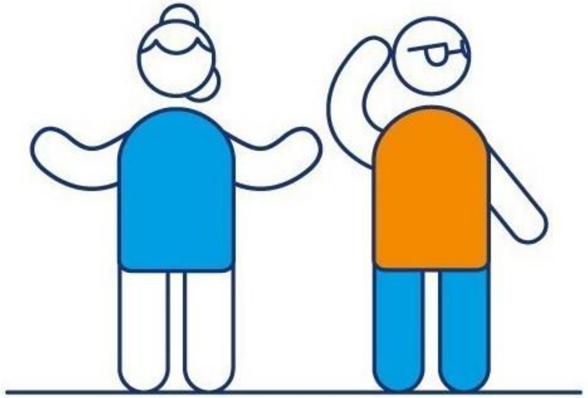
PART 1 RECAP



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INVOLVEMENT METHODS

INVOLVEMENT METHODS

Insight gathering

- Surveys (online or paper)
- Interviews
- Focus groups

Collaborative working

- Workshops
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INVOLVEMENT METHODS

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FINDING PARTICIPANTS

FINDING PARTICIPANTS CHECKLIST

Think about the barriers

Identify the barriers to people being involved and what you can do to mitigate those.
e.g. Working full time: provide options for involvement that take place during the day, evening, and weekend.

Define who is your target group:

- demographics
- type of diabetes
- specific treatment experiences
- experience of complications
- a specific user group e.g. DPP participants
- use of services

Consider representation and diversity:

- age
- gender
- ethnicity
- disability
- social and economic status

Checkout our top tips for diversity in involvement!

How to find respondents: don't do it alone

- Think about your target group: you need to go to them: what form of contact will they respond to?
- Employ an agency
- Use existing connections, partnerships and relationships
- Use existing communication routes e.g. Balance
- Share with our lived experience groups:
  - Diabetes Lived Experience Advisory Committee
  - Diabetes Communities in Action
- Reach out to community groups, faith groups
- Utilise social media
- Work with other charities/organisations and tap into their networks
- Advertise in areas such as community buildings, GP centres, outpatient departments
- Media adverts in local newspapers, local radio

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TOP TIPS FOR DIVERSITY IN INVOLVEMENT

1 MAKE YOUR GOALS CLEAR

2 USE EXISTING EVIDENCE

3 BE SPECIFIC

4 IMAGINE SUCCESS

5 BE CONFIDENT

6 BUILD IN TIME & BUDGET FOR INVOLVEMENT

7 WHERE WILL YOU ENGAGE

8 ALWAYS PROVIDE FEEDBACK

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GROUP WORK: INVOLVEMENT SCENARIOS

SCENARIOS

Scenario 1:

You are developing a research project understanding the impact of an intervention on control of blood glucose levels. How would you incorporate the patient voice?

Scenario 2:

You are investigating the impact of diabetes on young adults and what their experience of diabetes care is. How would you find out about their experiences?

SCENARIOS

Scenario 3:

You want to make some changes to the way the outpatients clinic is designed to make it more functional – how would you go about doing this to ensure that the new design is as patient friendly as possible?

Scenario 4:

You have been asked to get feedback from patients about the way the service will run in the future – and gather their opinions on remote consultations? How would you go about ensuring you hear from as many people as possible?

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SCENARIOS

To think about for each scenario:

- What does **good involvement** look like in this scenario?
- What **level of involvement** on the ladder is appropriate?
- Who is your target audience and how would you find them?
- What methods would you choose and why?
- What challenges might you face?

Please nominate 1 speaker to feedback the key points to main room.

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FEEDBACK

Please nominate a speaker from each group – and stick to a few key points

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RESOURCES

PUTTING INVOLVEMENT INTO PRACTICE

TOP TIPS AND TOOLS TO GET STARTED

FOCUS GROUPS

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INCENTIVES

People impacted by diabetes are experts by experience and deserve to have that expertise acknowledged.

DIABETES
COMMUNITIES
IN ACTION

WHERE TO START:

Begin thinking about these key things:

WHY DO YOU WANT TO INVOLVE PEOPLE WITH LIVED EXPERIENCE?

Consider what you want to learn from them, what impact could they have on your work and be prepared to share power and decision making.

TIMINGS/BUDGET/RESOURCE

Planning involvement from the start is vital.
Be clear on deadlines, consider time needed to organise, complete the activity, promote/recruit and consolidate insights.
Consider your budget from the start: how much do you have and how do you want use it? Be inventive.

EXISTING EVIDENCE

What do you know already? Blank canvas? Existing projects/research? Use existing evidence to inform and shape your work.

TARGET AUDIENCE

Who do you need to reach? Which methods should you use to reach them and engage with them?
Consider their needs and let that shape your methods.

SAMPLE SIZE AND DATA CAPTURE:

What do you need?
Stats or stories or a combination?
Self-selecting sample vs targeted
Insight gathering or collaborative?
These answers will inform your chosen methods.

SURVEY DESIGN: KEY PRINCIPLES

1. **Define the purpose of the survey**
2. **Involve people with lived experience in the survey design process**
3. **Define your target audience**
4. **Choose most appropriate methodology**
5. **Test with the target audience**
6. **Ask good questions**

YOUR EXPERIENCES.
YOUR EXPERTISE.
WORKING TOGETHER FOR CHANGE.

DON'T FORGET TO FEEDBACK!

Feedback is important for you, for the people you involve and for the wider charity (including the involvement team!)

Feedback provides motivation, fulfilment and learnings.

What feedback should you provide participants?

Acknowledgement and thank you: is the minimum to acknowledge the time and effort participants have given, often sharing difficult experiences.

Outcomes: Whatever the outcomes share them. If you aren't able to action participant contributions, then be honest about this and say why. Participants want to know what happens next.

Progress of project: Some projects are ongoing rather than a one off activity so plan in progress updates.

Impact: This might take longer share. What changes were made as a result of their contributions? Were their comments useful? Did their involvement lead to change or not?

“CLOSING T
YOU ARE IN
COMPLETE
ANYWAY, Y
OUTCOMES
CONTRIBUT

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GROUP DISCUSSION

- Would this resource be useful for the involvement work you would like to undertake?
- Is there anything missing from the resource?
- Are there any changes you would like to see?

INVOLVEMENT CHECKLIST

- ☐ **What level** of involvement will we need?
  - ☐ Consider timelines/budget
- ☐ **Who** do we need to engage in this work?
- ☐ **When** is it appropriate to engage them?
- ☐ **Where/how** can we find them?
- ☐ **What method** of involvement will we use? (may need multiple approaches/choice)
- ☐ **Incentives**?
- ☐ **How** will we feed back to them about how their involvement helped?

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THANK YOU AND ENJOY THE REST OF YOUR EVENING!

BRIDGET, JENNI, AMY AND FLORA

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" IF YOU ALWAYS DO WHAT
YOU'VE ALWAYS DONE,
YOU'LL ALWAYS GET WHAT
YOU'VE ALWAYS GOT'
HENRY FORD

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