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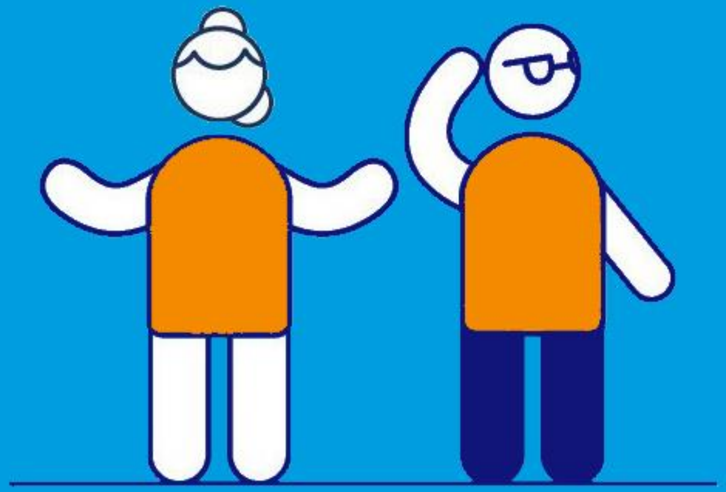
PUTTING INVOLVEMENT INTO PRACTICE

TOP TIPS AND TOOLS TO GET STARTED

CONTENTS

In this document we have collated our top line guidance on how to do involvement successfully. For more detail on any particular area please contact us involvement@diabetes.org.uk

WHERE TO START



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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.

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.

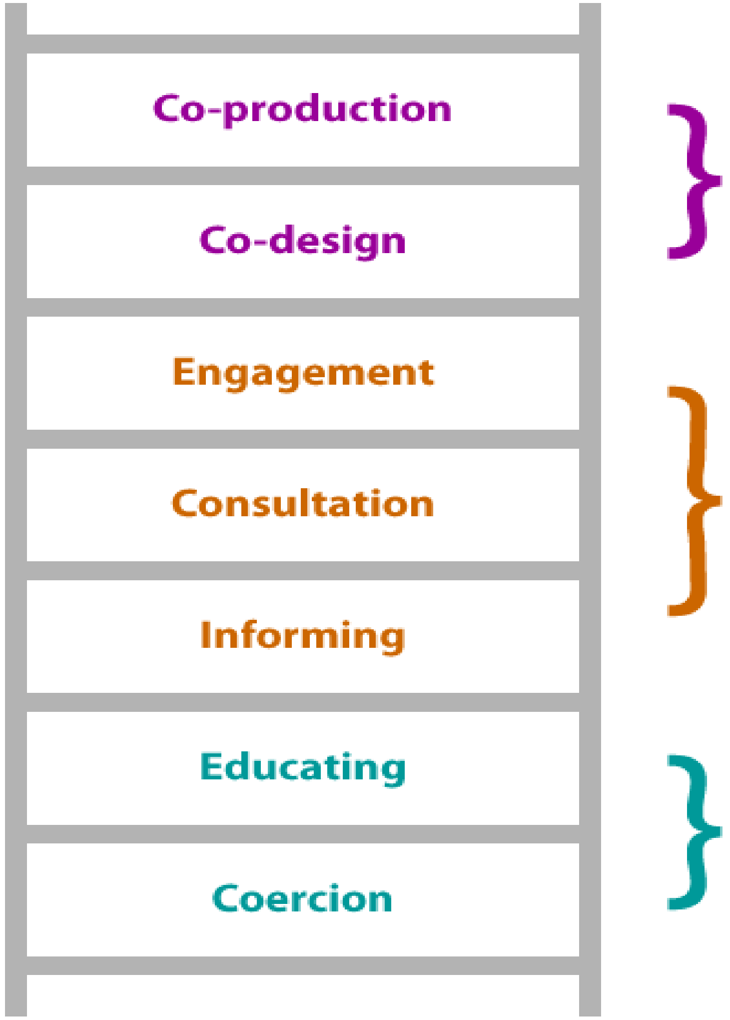
TARGET AUDIENCE

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.

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

The ladder shows the different levels of involvement and how the power shifts towards the patient as you move up the ladder reaching equal partners at the top.

There is not right or wrong place to be on the ladder – it is what is appropriate, useful and achievable for your activity.

Different involvement activities within the same project will be at different points on the ladder.

- 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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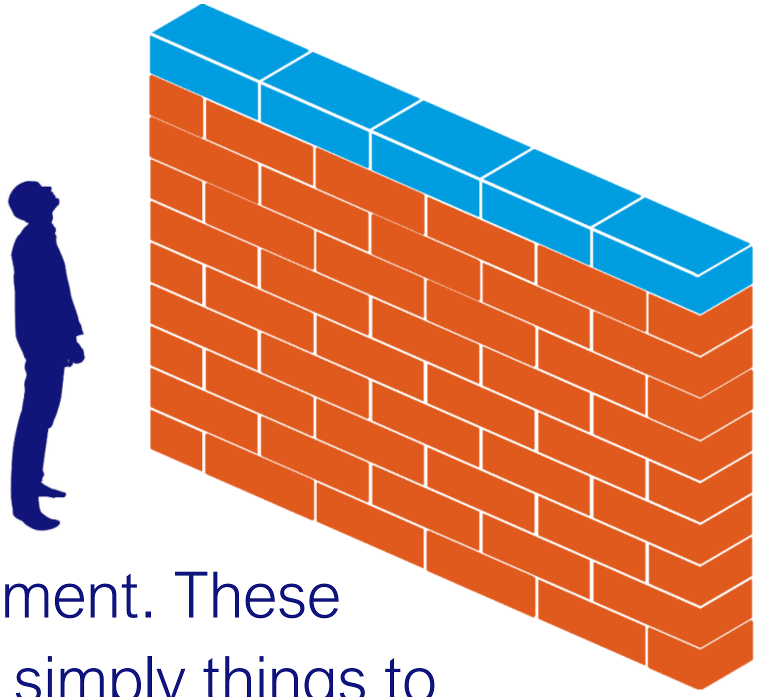
BARRIERS AND SOLUTIONS

What are the barriers to involvement and how are they overcome



There are many barriers that we all face when doing involvement. These barriers should not stop you for doing involvement, they are simply things to work around and overcome. There is no dodging these barriers and they need to be faced head on. Consider what barriers you might face and the best ways to deal with them.

We have shared some solutions for common considerations to involvement on the next page, contact us for a more comprehensive look at barriers and solutions.

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BARRIERS AND SOLUTIONS

BARRIER	NOTES	SOLUTIONS
TIME	Of the people we involve DUK staff time - logistics, planning Deadlines and time constraints	• Time pressures will always need careful management which is why **planning** involvement from the **start** is vital. Be clear on deadlines and consider the best methods of involvement to use within your timeline. • Consider not only the time needed to organise and complete the involvement activity but also the time needed for promotion and recruitment to the activity and, time allowance for feedback and consolidation of insights.
COSTS	Incentives Travel and accommodation Childcare Work schedules Venue Materials	• Cost does not need to be a barrier to involvement. Consider your budget from the start: **how much do you have and how do you want use it?** • This will guide what methods of involvement you decide to choose. For example, if you have a very limited budget opting to do involvement online removes the costs of venue and travel etc. • Try to **consider all possible costs** including incentives, costs of materials and promotion of the opportunity. • Don't forget to use your **imagination**. For example, incentives do not always need to be monetary based. It could be a unique experience, the opportunity to go on a lab visit, hear from a researcher, see the impact they will have and connecting with peers.
RECRUTIMENT	How and where to reach out to people so not just getting the same people	• Know who your target audience is and explore different ways of connecting with them. See our **Finding participants resource** for suggestions and consider contacting our existing groups **Diabetes Lived Experience Advisory Committee** and **Diabetes Communities in Action**.
ACCESSIBILITY	Access to technology if online Timing of meetings/discussions considering work schedules and childcare	• It is the responsibility of the activity owners to ensure it is accessible to as many people as possible. Consider what accessible means for **what you want to achieve and who you need to include.** • The best way to ensure accessibility is to **use different methods of engaging** with people and different methods of involving them. By trying multiple approaches you will be able to include more people and **provide different options of how people can get involved** based on their needs.

KNOW YOUR INVOLVEMENT TOOLS

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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

Phone calls

Presentations sharing lived experience

Photo journey

Surveys

Meetings/Focus Groups

Artwork/prose/poetry

Zoom/Teams Interviews

Volunteers/Health watch

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SURVEY DESIGN

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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

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SURVEY DESIGN QUESTIONS:

Quality questions lead to quality data and quality improvements :

MAKE THEM ACTIONABLE TO LEAD TO IMPROVEMENT BASED ON THEIR EXPERIENCES

Ensure you are asking for feedback that you can use and will shape actionable change.

OPEN VS CLOSED QUESTIONS

- Open-end questions: respondents provide a response in their own words
- Closed questions: respondents choose from a pre-determined list of answers

KEEP IT SHORT AND SIMPLE

Keep respondents attention by following a logical order, use clear and direct language and don't make it too long.

USE RESPONSE SCALES WHERE POSSIBLE

This helps to capture the direction and intensity of attitudes giving richer data.

SPEAK THEIR LANGUAGE

Make it easy to understand and accessible. Avoid jargon and phrase questions neutrally.

FOCUS GROUPS

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FOCUS GROUPS

- Surveys can give insights on the ‘what’ whilst focus groups can give in-depth understanding of the ‘why’
- Surveys can also be used to feed into what is asked within a focus group or focus groups can support the development of higher quality surveys

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PREPARING FOCUS GROUPS

- Prepare a discussion guide (contact the team for our template)
- Organise 2-3 facilitators
- Recruit participants that are representative of your target population (at least 3 weeks in advance)
- Decide on size, length and location of focus group (if online, ensure an accessible platform).
- Oversubscribe to factor in non-attendance. E.g. If aiming for 8 attendees recruit 10-12 people.
- Create a short brief for advertising the group and collect relevant information
- Organise Incentives

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RUNNING FOCUS GROUPS

- If in person: arrive early and prepare the space with refreshments, signposting resources, recording devices and consent forms
- Explain RRR (Rules, Respect and Running of a session) and collect consent
- Create a welcoming environment; use introductory questions to start the conversation
- Tips for managing group discussion: actively bring in those who haven't spoken much, thank and summarise if you need to move on to the next question (it's okay to step in when needed!)
- Close by asking for final comments and let people know the next steps

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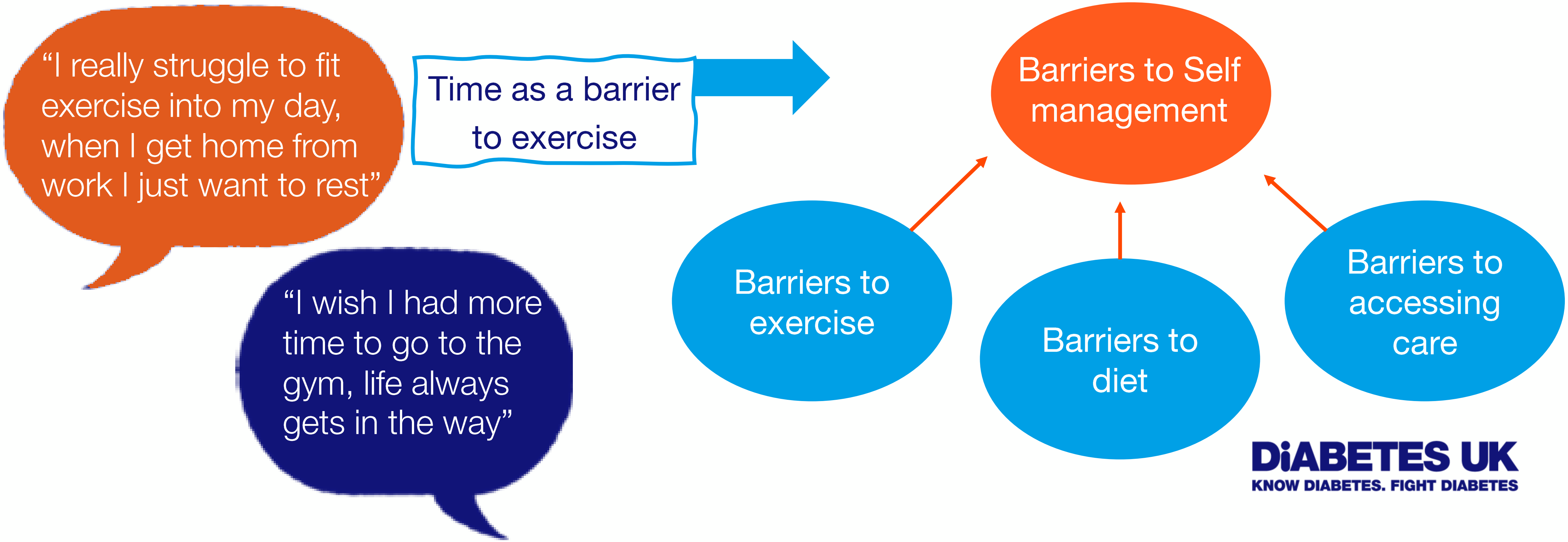
ANALYSING FOCUS GROUPS

1. Familiarise yourself with the data: review notes, listen to recordings, review transcript

2. Highlight key quotes and create codes

3. Codes can then be built into themes



"I really struggle to fit exercise into my day, when I get home from work I just want to rest"

"I wish I had more time to go to the gym, life always gets in the way"

Time as a barrier to exercise

Barriers to Self management

Barriers to exercise

Barriers to diet

Barriers to accessing care

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FINDING PARTICIPANTS

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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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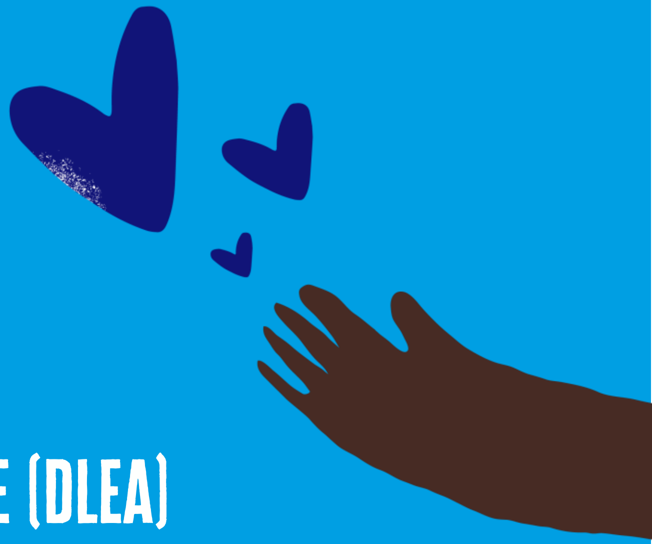
ENGAGING WITH PEOPLE IMPACTED BY DIABETES

- TIPS FOR ENGAGING IN PERSON
- WHAT DIABETES UK OFFER: WE CAN HELP AND WE REPRESENT YOU
- REGIONAL AND NATIONAL CONTACT DETAILS
- DIABETES LIVED EXPERIENCE ADVISORY COMMITTEE (DLEA)
- DIABETES COMMUNITIES IN ACTION (CIA)



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ENGAGING WITH PEOPLE IMPACTED BY DIABETES IN PERSON

Building relationships and interacting:

- **Sharing what we do at Diabetes UK:** check out the next slide for tips on what you can talk about and the support and information you can offer through Diabetes UK. We CAN help and we REPresent. Our online shop has a variety of leaflets and resources you can download and order to share.
- **Be honest and open:** explain your role and why you want to talk to them
- **It's okay if you don't know it all:** Signpost to further resources and direct them to contact Diabetes UK through the regional and national teams

- **Medical advice:** clarify you cannot offer medical advice to them even if you are a medical professional, recommend they speak with their GP/Diabetes Team for medical advice and share any resources you think they might find helpful
- **Discussing experiences can be an emotional conversation:** allow space for the person to share. You don't need to find solutions or provide advice, listening is just as valuable.
- **Share information about the Lived Experience Groups they can join:** Diabetes Communities in Action and Diabetes Lived Experience Advisory Committee.

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CAN DIABETES UK HELP ME? WE CAN

CALL US

Talk to our specially trained advisors to get advice and support from Monday to Friday, 9am to 6pm. Interpreters are available. Call 0345 123 2399 or email helpline@diabetes.org.uk

ADVICE ONLINE

Our website offers information for all types of diabetes including everything from recipes to advice on driving or going on holiday. You can even do some learning zone modules to help you get to grips with your diabetes when it suits you.

NEAR ME

The regional teams each have Facebook pages where they share details of local events and groups – get to know yours!

WHY SHOULD I SUPPORT DIABETES UK? WE REPRESENT

RESEARCH

Over the last 80 years we funding research which:

- Changed the management of type 2 diabetes worldwide
- Developed the 1st insulin pen
- Developed the 1st foot clinics halving the number of amputations needed

EDUCATION AND ADVOCACY

- We create training for everyone working in diabetes and support them to give the best care
- We advocate for people living diabetes at every level from calling for government action down to helping support local health systems

PEOPLE

We support everyone living with diabetes with: Recipes, Guides, Events and support groups and our Care line

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REGIONAL TEAMS

SOUTHWEST AND SOUTH CENTRAL

Get in touch
email: **south.west@diabetes.org.uk**
call: **01823 448260**

NORTH OF ENGLAND

Get in touch
email: **north@diabetes.org.uk**
call: **019925 653281**

MIDLANDS AND EAST OF ENGLAND

Get in touch
email: **midlands@diabetes.org.uk** or
eastern@diabetes.org.uk
call: **01902 916444**

SOUTHEAST COAST AND LONDON

Get in touch
email: **SECoastAndLondon@diabetes.org.uk**
Call: **01372 720 148**

NATIONAL TEAMS

DIABETES UK SCOTLAND

Get in touch
email: **scotland@diabetes.org.uk**
call**: 0141 245 6380**

DIABETES UK CYMRU

Get in touch
email: **wales@diabetes.org.uk**
call**: 029 2066 8276**

DIABETES UK NORTHERN IRELAND

Get in touch
email: **n.ireland@diabetes.org.uk**
call**: 028 9066 6646**

USEFUL RESOURCES

0345 123 2399
@DiabetesUK
/diabetesuk
www.diabetes.org.uk
Helpline@diabetes.org.uk

DIABETES LIVED EXPERIENCE ADVISORY COMMITTEE (DLEA)

Bringing the collective voice of people living with diabetes to the heart of our plans and work, through regular consultation and involvement

Linking with their local community to represent a wider voice

Diabetes Lived Experience Advisory Committee | Diabetes UK

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ABOUT DLEA

- DLEA is a voluntary group of people affected by diabetes who represent the wider voice of lived experience and feed this into our long-term strategic plans.
- Each member can volunteer for 2 terms (3 years each).
- Each year we hold 4 meetings, alternating between online and in person.
- Meetings are attended by our CEO, Executive Team and Involvement Team as well as other members of the charity.
- We are improving diversity: starting with young adults, people with type 2 diabetes and people from Black Caribbean, Black African and South Asian Backgrounds.
- Also looking to reach LGBTQI+ communities, those at risk of diabetes, other types of diabetes, neurodivergent people and many more!
- Improving the volunteer experience with training, peer support & more opportunities for involvement

HOW TO GET INVOLVED

If you would like to put yourself forward to be a member of the Diabetes Lived Experience Advisory Committee, please fill out this form or email involvement@diabetes.org.uk with either a video or up to one page of A4 explaining why you are interested in this role and what experiences you could bring to the group.

QUOTE FROM A MEMBER OF DLEA

> "THIS IS A GREAT OPPORTUNITY TO EMPOWER OTHERS, TO SHARE KNOWLEDGE AND PROVIDE COURAGE FOR PEOPLE WITHIN THE DIABETES COMMUNITY. I WANTED TO HELP OTHERS LIVE A BETTER LIFE, I BECAME A MEMBER SO I COULD MAKE A DIFFERENCE."

DIABETES
COMMUNITIES
IN ACTION

YOUR EXPERIENCES.
YOUR EXPERTISE.
WORKING TOGETHER FOR CHANGE.

WHAT IS IT?

Diabetes Communities in Action is bringing together people affected by and at risk of diabetes to influence the work and decision making of Diabetes UK. This group will empower all communities affected by diabetes to act and get involved.

AIMS OF THE GROUP

- Be involved with activities across Diabetes UK
- Influence change
- Share in decision making
- Be representative of all communities affected by diabetes

WHY ARE WE DOING THIS?

The experiences and knowledge of people affected by and at risk of diabetes has to be at the centre of all we do. We believe this new community will help us achieve that. We will ensure anyone can join and enable all levels of involvement.

[Diabetes Communities in Action | Diabetes UK]

KEEPING IN TOUCH & ASSEMBLE

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IMPACT NEWSLETTER

We will share the Involvement Newsletter with you 4 times a year. The newsletter will feature activities members have taken part in and the impact that the group is having across the charity. We want your input in the newsletter and will ask you to contribute to it.

ASSEMBLE

Assemble is a great resource for information and training opportunities. To find out more about Assemble and how it works check out these video guides:
Our new Volunteering System: Assemble | Diabetes UK

DROP-IN SESSIONS

At least twice a year we will hold drop in sessions (online for now) to hear from you, highlight great activity and workshop improvements to the group.

TARGETED EMAIL REQUESTS

For specific requests such as experiences of Type 1, we will spend a email to those registered with that particular experience to make requests relevant to you.

MONTHLY ROUND UP EMAIL

We will email each month to share updates on news, roles you can apply for, asks to review materials, thoughts on new ideas and surveys to complete.

HOW PEOPLE JOIN

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JOIN
DIABETES
COMMUNITIES
IN ACTION

Do you have experience of diabetes and want to influence our work and decision making?

What will you be doing?

- Using your experiences to inform our work.
- Finding out about the different opportunities to take part in.
- Have the choice of how involved you want to be.

Scan me

POSTER & LEAFLETS TO SHARE

> “IT'S BEEN GOOD FUN AND MADE ME FEEL INVOLVED AND WANTED.”

SIGN UP ONLINE:

DIABETES COMMUNITIES IN ACTION | DIABETES UK

Scan me

INVOLVEMENT REQUEST PROCESS

Would you like to connect with our Lived Experience groups? All involvement requests to be sent to:

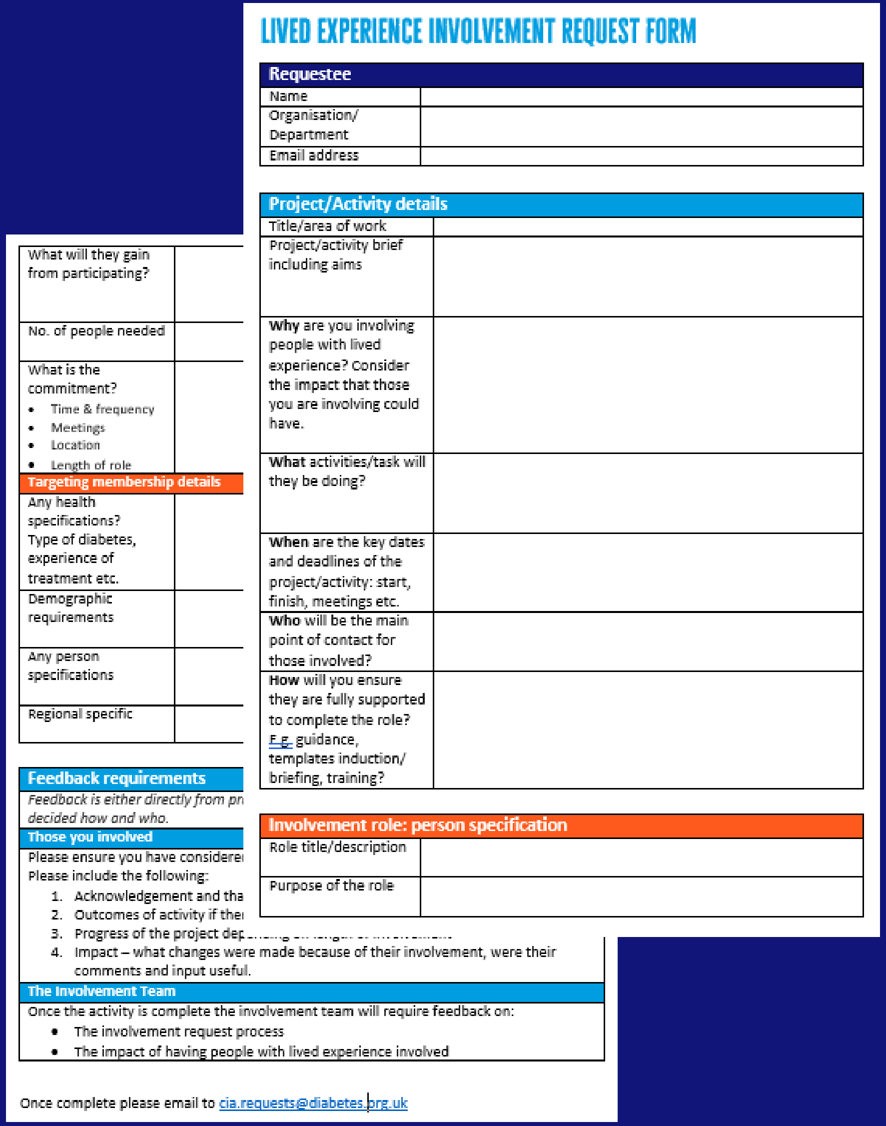
cia.requests@diabetes.org.uk

Automated email containing LIVED EXPERIENCE REQUEST FORM, to be completed and returned.

The Involvement team will be in touch to discuss activity, what support is needed and the best way to contact Diabetes CiA and or DLEA to find interested individuals who meet any required specifications.

Each requestee is responsible for completion of their own involvement activity.

We would prefer a minimum 4 weeks notice.



LIVED EXPERIENCE INVOLVEMENT REQUEST FORM

Requestee	
Name	
Organisation/ Department	
Email address	

Project/Activity details	
Title/area of work	
Project/activity brief including aims	
Why are you involving people with lived experience? Consider the impact that those you are involving could have.	
What activities/task will they be doing?	
When are the key dates and deadlines of the project/activity: start, finish, meetings etc.	
Who will be the main point of contact for those involved?	
How will you ensure they are fully supported to complete the role? E.g. guidance, templates induction/ briefing, training?	

Involvement role: person specification	
Role title/description	
Purpose of the role	

What will they gain from participating?	
No. of people needed	
What is the commitment? • Time & frequency • Meetings • Location • Length of role	
Targeting membership details	
Any health specifications? Type of diabetes, experience of treatment etc.	
Demographic requirements	
Any person specifications	
Regional specific	

Feedback requirements

Feedback is either directly from pr

decided how and who.

Those you involved

Please ensure you have considere

Please include the following:

1. Acknowledgement and tha
2. Outcomes of activity if the
3. Progress of the project dep
4. Impact – what changes were made because of their involvement, were their comments and input useful.

The Involvement Team

Once the activity is complete the involvement team will require feedback on:

- The involvement request process
- The impact of having people with lived experience involved

Once complete please email to cia.requests@diabetes.org.uk

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INCENTIVES

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

How much to pay?

- Diabetes UK doesn’t have formal guidance on providing incentives.
- Budget in incentives at the beginning stages of a project.
- Offer clear information about incentives.
- Consider the needs of those you are involving e.g. the conditions those in receipt of state benefits must follow.
- Offering vouchers can be a less complicated option.
- We offer £25 vouchers for shorter involvement e.g. survey testing and £35 for more in depth involvement e.g. focus groups.
- Research agencies tend to offer between £40 - £50

Other ways to incentivise

- Always thank people for their contributions.
- Reimburse people for their travel and/or accommodation or book and pay on their behalf.
- Opportunities for people impacted by diabetes to connect with each other can provide great value.
- Keep those actively involved updated about the progress of your research/project, including how their contributions have made a difference.
- Offer further opportunities for involvement and participation in similar projects.
- Encourage participants to join our Diabetes Communities in Action group

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.

> "CLOSING THE LOOP IS REALLY IMPORTANT. IF YOU ARE INVOLVED IN A FOCUS GROUP, COMPLETE A SURVEY, OR TAKE PART IN ANYWAY, YOU WANT TO KNOW THE OUTPUTS, OUTCOMES AND IMPACT OF WHAT YOU HAVE CONTRIBUTED TO." DIABETES CIA MEMBER

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?

THANK YOU

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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 not 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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CONTACT US

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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INVOLVEMENT@DIABETES.ORG.UK

CIA.REQUESTS@DIABETES.ORG.UK

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