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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 at involvement@diabetes.org.uk

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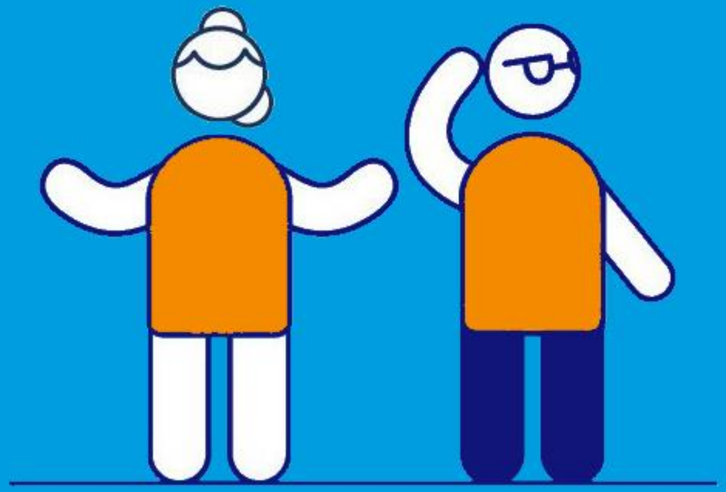
WHERE TO START



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INVOLVEMENT 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 can’t do something say so and why.

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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? Use existing evidence to inform and shape your work. Use our Involvement Insight Tracker which holds existing internal insights.

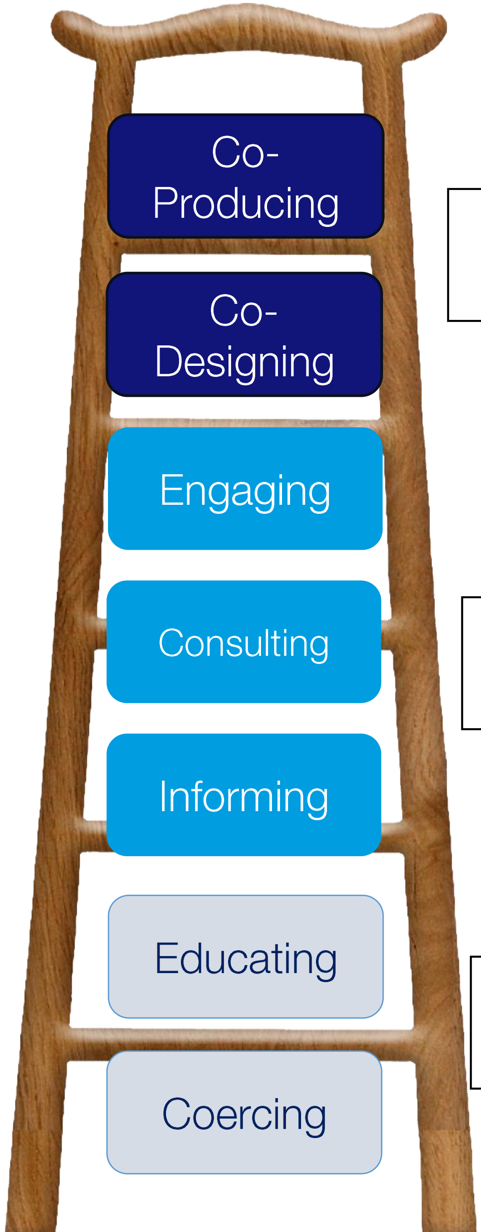
TARGET AUDIENCE

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



		EXPLANATION	EXAMPLE
DOING WITH	Co-Producing	You work with service users and other organisations from design to delivery. You share all, or almost all, decisions and they support with co-delivery.	"We are thinking about making some changes to the service – would you like to help us design them?" Involvement on a steering group/planning group. Partnership working. Plus Co-delivery.
	Co-Designing	You involve services users and other organisations in designing your service. They influence decisions but aren't involved in co-delivery.	Involvement on a steering group Partnership working. Power sharing "We are thinking about making some changes to the programme – would you like to help us design them?"
DOING FOR	Engaging	You give service users regular opportunities to express their views in a variety of ways. They can influence some decisions.	Power shifting towards the service user: "We are planning to make some changes to the programme. What would you like to see? What do you think needs to change?"
	Consulting	You invite service users to fill in surveys or attend meetings to say which proposal they prefer or what they think about an issue or service.	"We are **planning** to make some changes to the programme – **what do you think about these suggested changes?**"
	Informing	You inform people about your services and explain how they work. Sometimes you tell people what decisions you've made and why.	Use insight gathering for feedback to improve "We are going to make some changes to the programme, this is what it is going to look like. Do you have any feedback?"
DOING TO	Educating	You educate people on the benefits and rationale of your services. You may try to convince them to act differently.	Changes are made to the programme or service – changes may be explained but no meaningful service user input beforehand.
	Coercing	You require people to use your service or do some things without understanding their true wants and needs.	Changes are made to the programme or service and the new version starts. No service user input.

THE INVOLVEMENT LADDER

- 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 no right or wrong place to be on the ladder – it is what's appropriate, useful and achievable for your activity.
- Different involvement activities within the same project will be at different points on the ladder.

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

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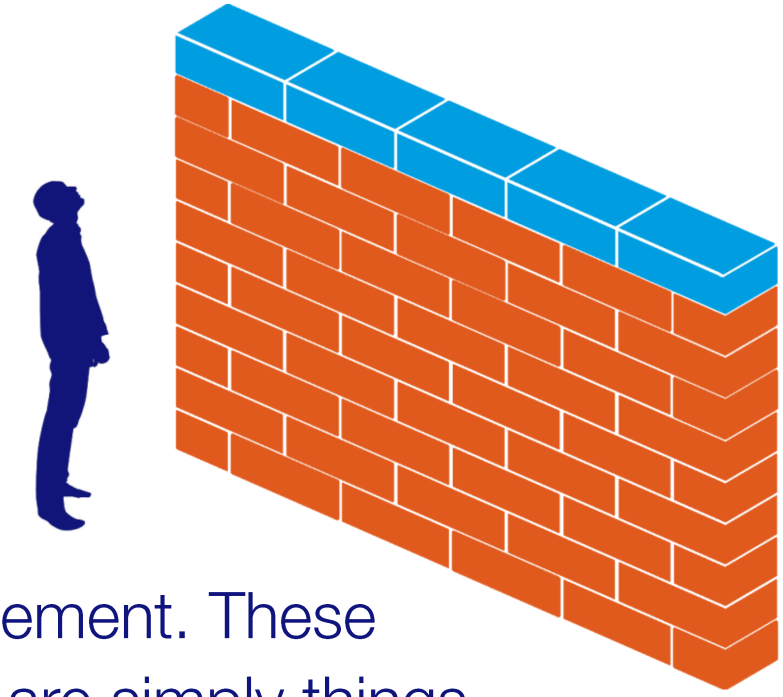
BARRIERS AND SOLUTIONS

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 from 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.
RECRUITMENT	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 + Social Media Listening

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

Volunteers/Health watch

Artwork/prose/poetry

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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

Use SmartSurvey for internal surveys as it is GDPR compliant. However, always consult Infogov when collecting personal data and ensure you are using up-to-date consents.

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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: TOP TIPS

Surveys vs 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

Be clear on who, why, what and where:

- Who you want to involve
- Why you want to involve them
- What you want to ask them
- Where you want hold the focus group. Online or face to face.
- Consider your timelines remembering to allow for recruitment, selection and preparation.

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FOCUS GROUP: TOP TIPS

Preparing for a focus group:

- Prepare a discussion guide
- Organise 2-3 facilitators
- Recruit participants that are representative of your target population
- Organise Incentives
- Create a short brief for advertising the group and collect relevant information

Managing conversations

- Actively calling on people who are quiet
- It’s ok to interrupt people
- Summarize points and ask for other opinions
- Provide option of follow-up 1-1s
- Utilize group agreement if conflicts arise
- Remain neutral and focus on shared goals
- Have a wellbeing physical space or activities for break away

Running a focus group:

- If in person: arrive early, prepare the space with refreshments, signposting resources, recording devices and consent forms
- Explain RRR (Rules, Respect and Running of a session)
- Use introductory questions to start the conversation
- Close by asking for final comments and let people know the next steps

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ANALYSING FOCUS GROUPS

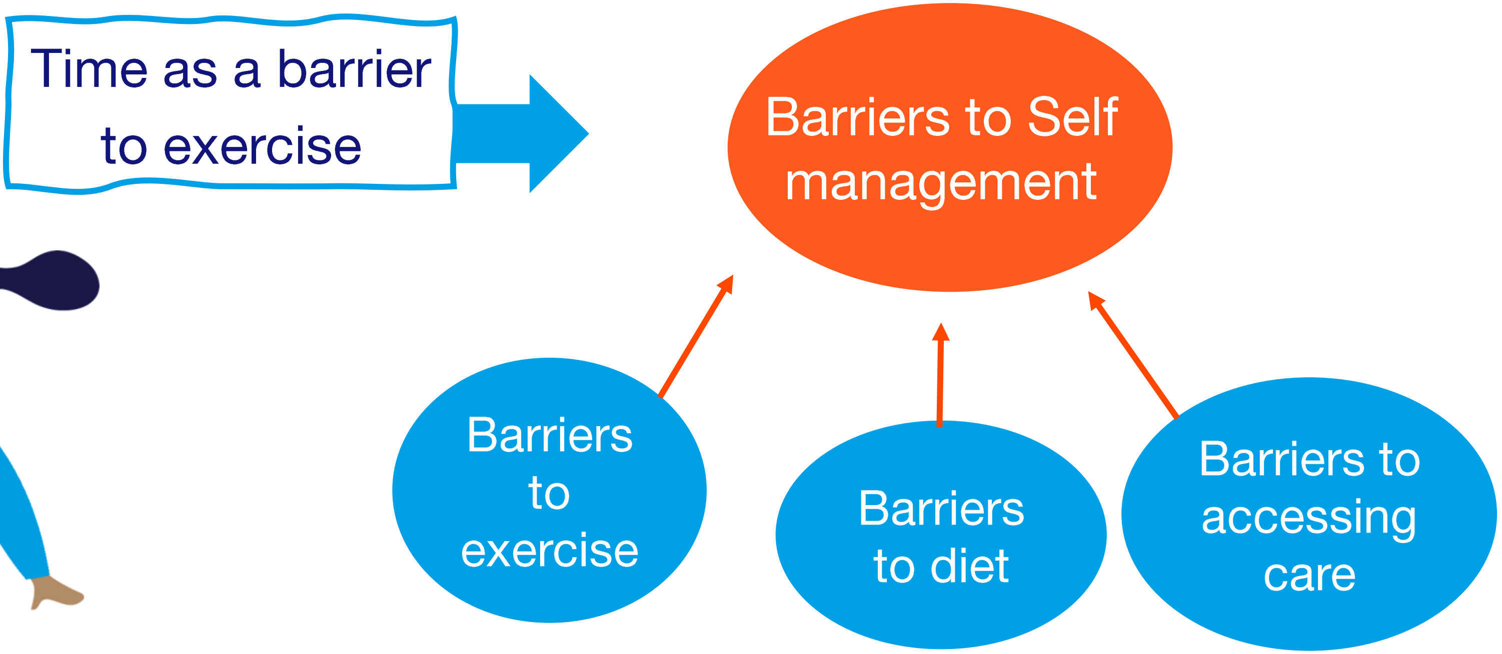
1. Familiarise yourself with the data: review notes, listen to recordings, review transcript

2. Highlight key quotes and create codes

"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"

3. Codes can then be built into themes



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

Finding participants and recruiting them to an involvement activity takes time and consideration but is achievable.

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
- geographical location

Checkout our top tips for diversity in involvement!

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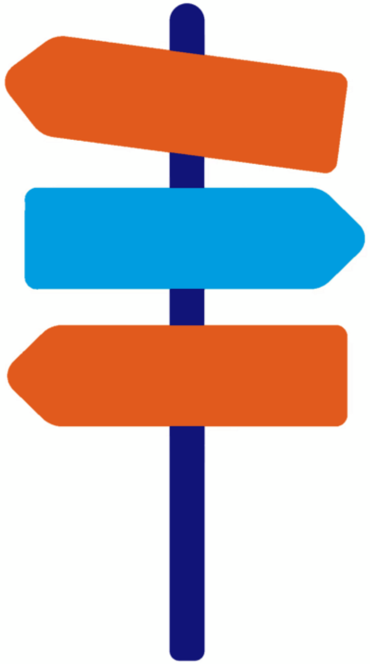
FINDING PARTICIPANTS CHECKLIST

Don't do it alone!

How to find respondents:

- 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

From the Engaging Communities Officers Network / Tackling inequalities Commission

Farhana Darwich / Aoife Slattery

WHY IS IT IMPORTANT

There is a disproportionately higher number of people living with diabetes and at risk of developing it from ethnically diverse communities and those in deprivation.

People of Asian (including Indian, Pakistani, Bangladeshi) Chinese, Black African and Black Caribbean ethnicities have been found to be two to four times more likely to have diabetes than White populations.

Poverty – JRF

In 2020/21, around one in five people in the UK (20%) were in poverty – 13.4 million people. Of these, 7.9 million were working-age adults, 3.9 million were children and 1.7 million were pensioners. Therefore, one in four children in the UK are living in poverty (27%)

2023 census – population England and Wales

- Asian, Asian British or Asian Welsh 9.3%
- Black, Black British, Black Welsh, Caribbean or African 4%
- Mixed or Multiple ethnic groups 2.9%

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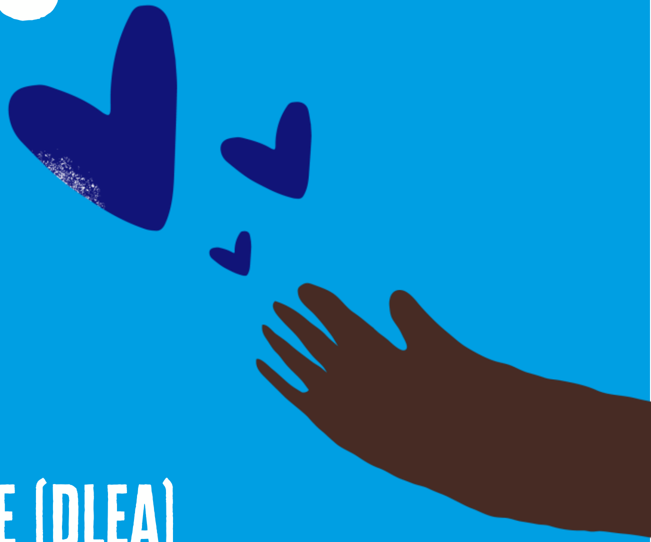
TOP TIPS FOR DIVERSITY IN INVOLVEMENT

1. BE CLEAR & KEEP IT SIMPLE
2. DO YOUR HOMEWORK
3. BE SPECIFIC
4. IMAGINE SUCCESS
5. BE CONFIDENT
6. BUILD IN TIME & BUDGET INVOLVEMENT
7. WHERE WILL YOU ENGAGE
8. ALWAYS PROVIDE FEEDBACK

ENGAGING WITH PEOPLE IMPACTED BY DIABETES

- ENGAGING IN PERSON
- WE CAN HELP AND WE REPRESENT YOU
- REGIONAL AND NATIONAL CONTACT DETAILS
- DIABETES LIVED EXPERIENCE ADVISORY COMMITTEE (DLEA)
- DIABETES VOICES NETWORK (DVN)



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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. We CAN help and we REPresent.
- **Be honest and open:** explain your role and what you know and why you want to talk to them
- **It's okay if you don't know it all!** Signpost to further resources and connect them with relevant teams/colleagues if you can't help
- **Medical advice:** clarify you cannot offer medical advice, recommend they speak with their GP 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.

Checklist for the day:

- Diabetes UK T-shirt
- Diabetes UK lanyard
- Noticeable sign or balloons
- Diabetes UK Pens
- Photo consent form
- Diabetes information resources
- Diabetes Voices Network leaflets

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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 have funded 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

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

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.
- DLEA meetings provide a safe space for our colleagues to have honest and open conversations with people who are passionate about representing everyone within the diabetes community, to ensure all voices are considered from our earliest stages of planning
- We are recruiting more members and focusing on improving diversity: starting with young adults, people with type 2 diabetes and people from Black Caribbean, Black African and South Asian Backgrounds.

HOW TO GET INVOLVED

Anyone in the UK, impacted by diabetes and over the age of 18 can apply to be a member of the Diabetes Lived Experience Advisory Committee.

Applicants can fill out this form or email involvement@diabetes.org.uk with either a video or up to one page of A4 explaining why they are interested in this role and what experiences they 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."

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DIABETES VOICES NETWORK

YOUR EXPERIENCES
YOUR EXPERTISE
WORKIN TOGETHER FOR CHANGE

Diabetes Voices Network is a vibrant community network of individuals affected by or at risk of diabetes.

AIM: to connect Diabetes UK and our partners with people personally impacted by diabetes to shape the work and decisions of the charity.

We're on a mission to empower all diabetes-affected communities to take action and make a difference.

Here, the unique insights, knowledge, and experiences of people affected by diabetes takes centre stage to drive positive change.

Previous Involvement:

- Discovering Leadership Panel
- Supported the creation of our new podcast
- Shared experience at All-party parliamentary group meeting
- Survey testing
- Stigma research

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Diabetes Voices Network | Diabetes UK

WHAT WILL YOU BE DOING?

- Using your experiences to inform and influence our work.
- Discovering and exploring a range of opportunities to get involved in those that align with your interests and expertise.
- Choosing your level of involvement as you have the flexibility to decide how involved you want to be and what activities you want to participate in.
- Connect with others by engaging with us, healthcare professionals and other people affected by or at risk of diabetes.

HOW WE'LL STAY IN TOUCH WITH YOU:

- Quarterly involvement newsletter with updates on the impact of Diabetes Communities in Action.
- Regular monthly round ups on news, available roles, material reviews, fresh ideas, and surveys.

KAYLEIGH, DIABETES VOICES MEMBER

"I enjoy being involved with Diabetes Voices Network as I feel like I make a difference to others with diabetes.

The way DVN is set up is great, I can find opportunities through the regular email updates or through the Assemble app that fit around my busy lifestyle of working full time and studying for a masters.

I would recommend joining DVN if you live with diabetes, or support someone who does. It's so important that everyone with or affected by diabetes is represented and being a Diabetes Voices member is the perfect way to do that."

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HOW TO JOIN

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Join Diabetes Voices Network to get involved anc
share your opinions, views and experiences.

VISIT: WWW.DIABETES.ORG.UK//SUPPORT-US/VOLUNTEER/DIABETES-VOICES-NETWORK

EMAIL: INVOLVEMENT@DIABETES.ORG.UK

Scan me

INVOLVEMENT REQUEST PROCESS

All involvement requests to be sent to:

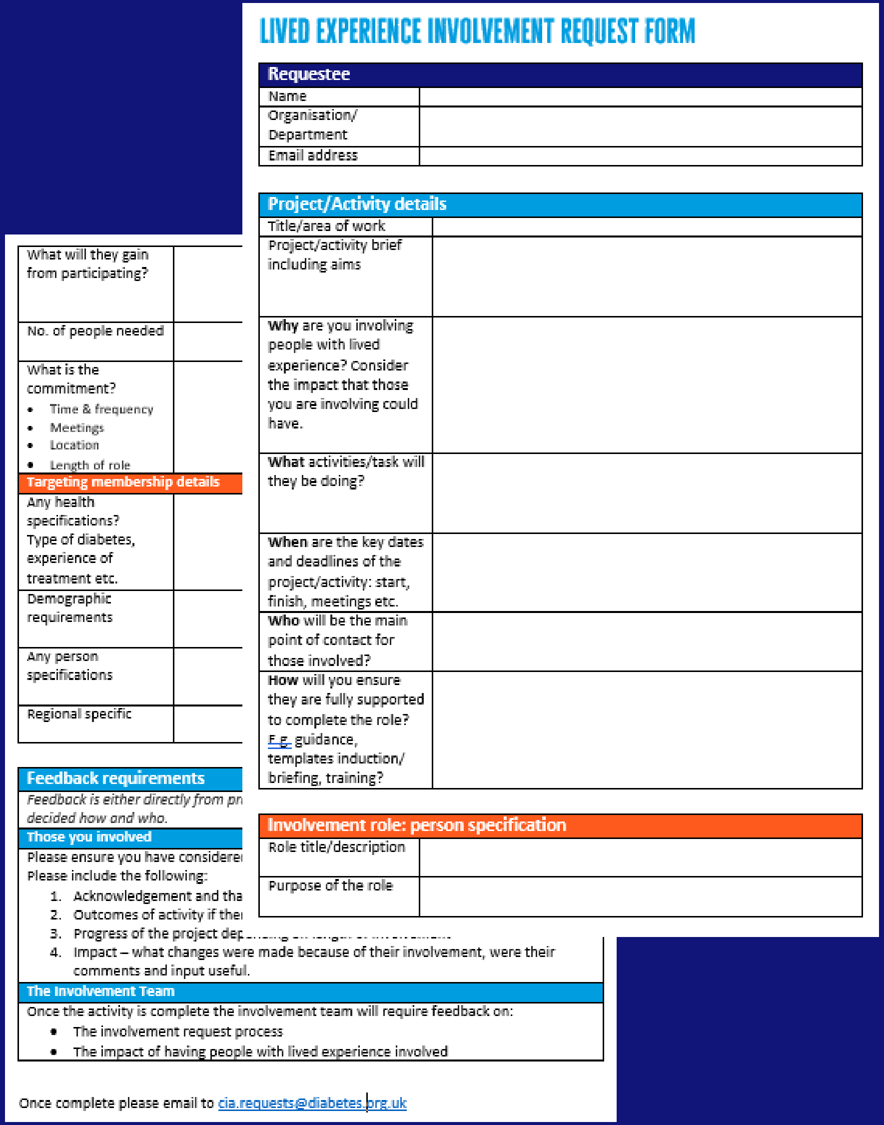
involvement@diabetes.org.uk

Automated email containing LIVED EXPERIENCE REQUEST FORM sent, 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 the Diabetes Voices Network and/or DLEA to find interested individuals who meet any required specifications.

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

Minimum 3 weeks' notice required.



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 Voices Network

GDPR GUIDANCE

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The involvement team can provide guidance and templates based on our best practice examples. However it is your responsibility if you are collecting any personal data that you check you are following Diabetes UK data protection processes and using the correct wording for consent.

USEFUL LINKS

- How we support data protection at Diabetes UK (sharepoint.com)
- Privacy Policy | About Us | Diabetes UK
- Special category data – what should I do? (sharepoint.com)
- infogov@diabetes.org.uk

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 VOICES 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 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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WANT TO KNOW MORE OR REQUEST FURTHER SUPPORT?

CONTACT US AT: INVOLVEMENT@DIABETES.ORG.UK

Bespoke requested information

How to go out and engage with people in person
How to write a survey
How to plan, run and analyse a focus group
How to recruit participants
Top tips on recruiting from ethnically diverse communities
Finding participants - checklist
Feedback: why it's important and what to feedback on
Consent & GDPR
Guidance to incentives

Templates

Involvement Activity template
Focus group discussion guide
Focus group email templates
Focus group consent forms
Focus group Participation information sheet
Recruitment template
Survey demographics data template