



North East London

NIHR | National Institute for Health and Care Research



North East London Integrated Care System Research Engagement Network

April 2024



How we engaged local people

3

community events

300

event participants

433

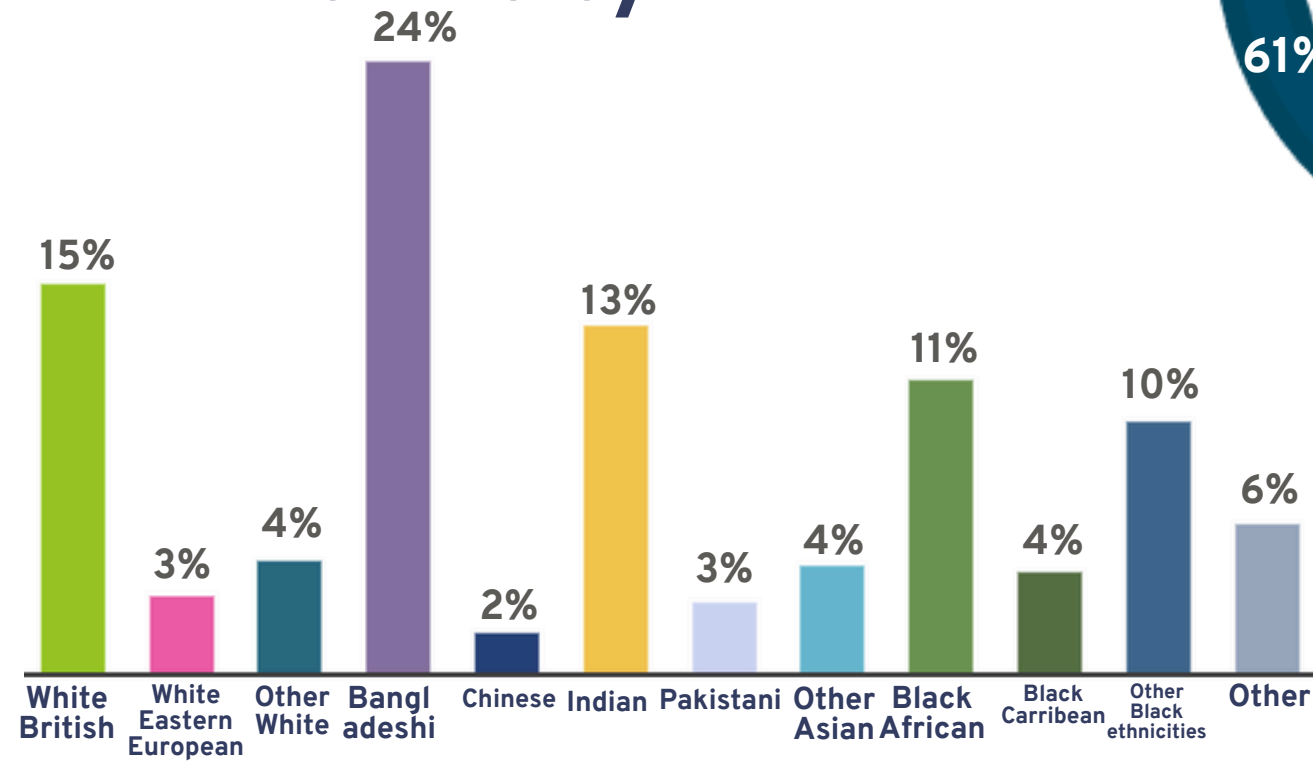
survey respondents

We have drawn on the feedback from over a thousand residents who recently engaged in the North East London Big Conversation.

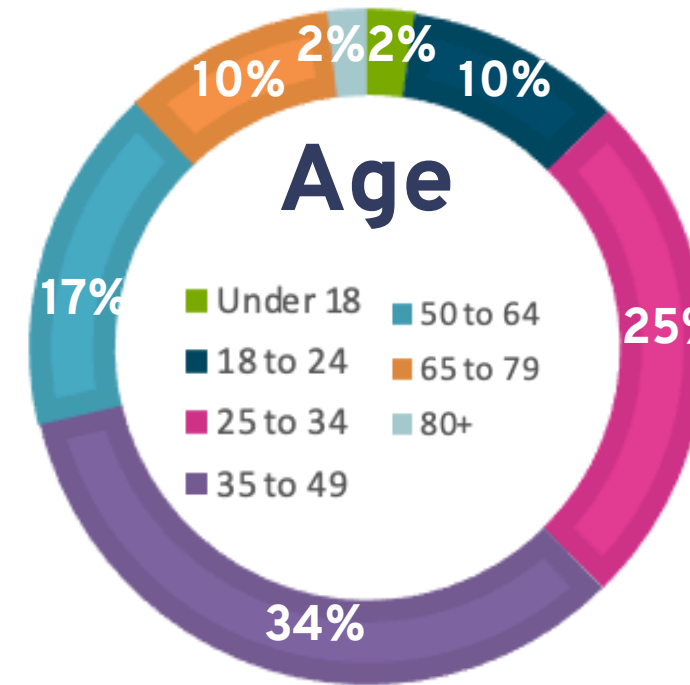
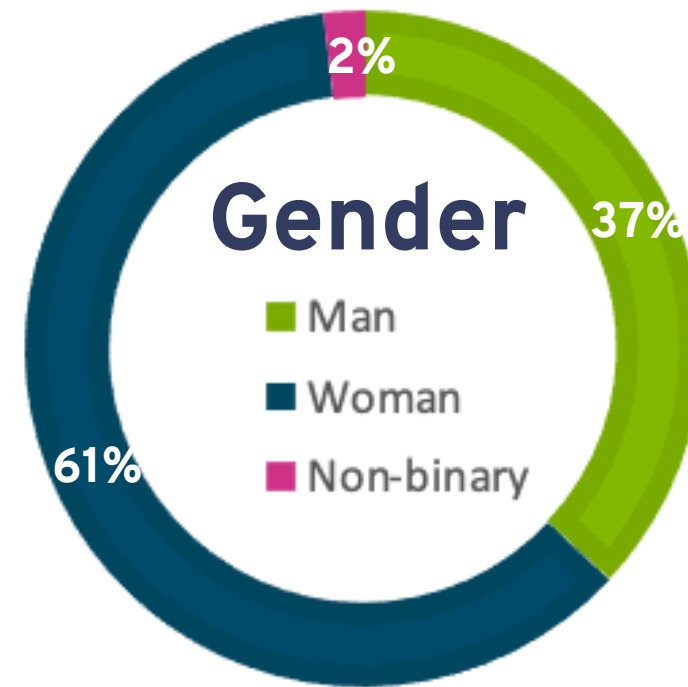
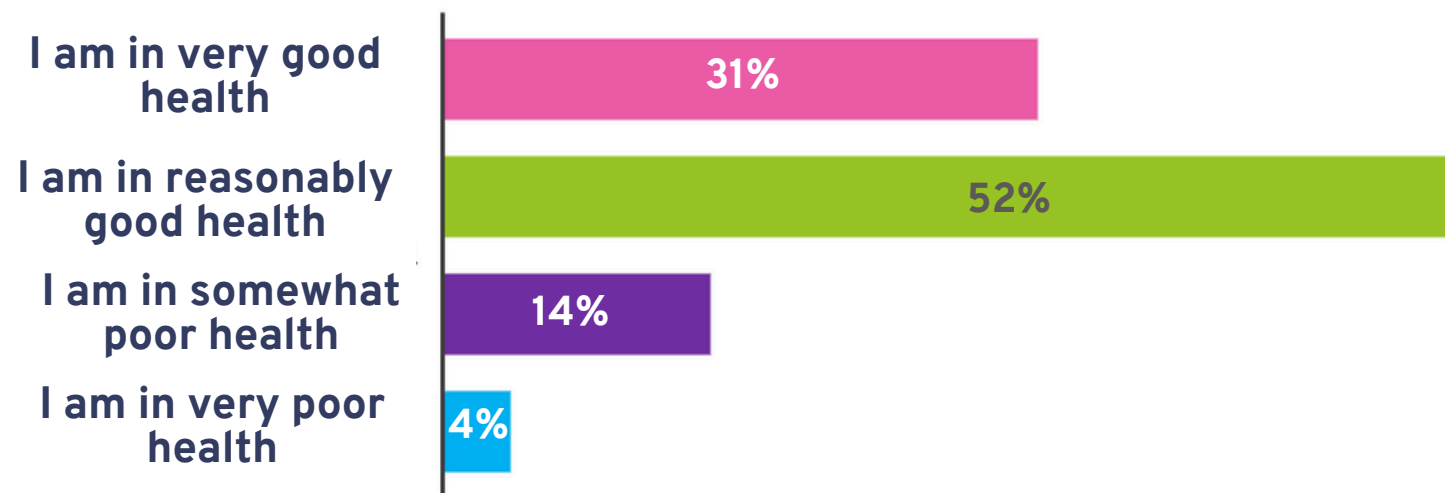


Demographics

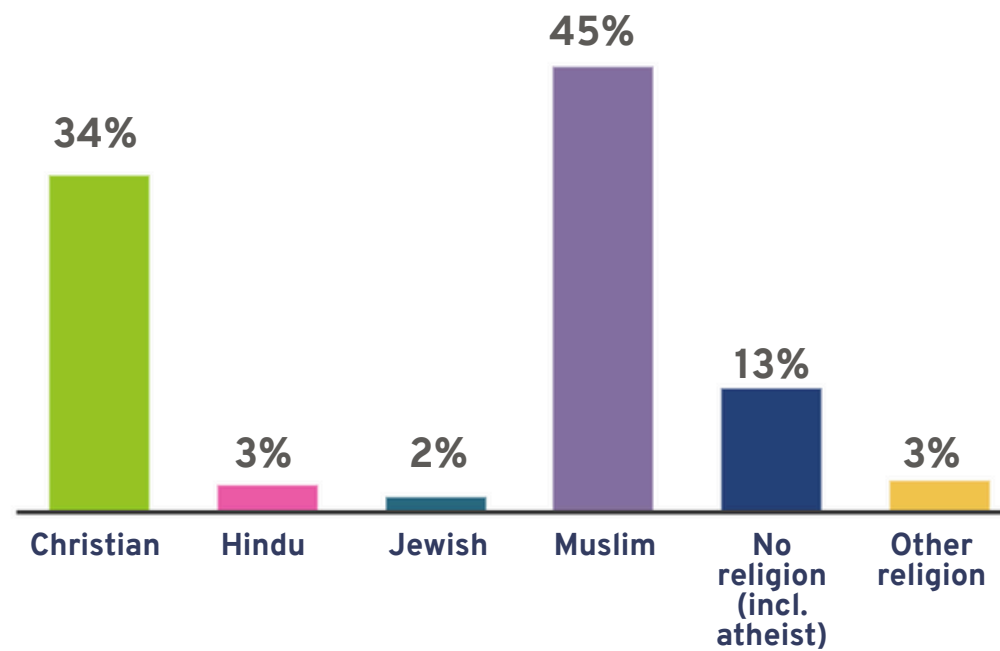
Ethnicity



Health status



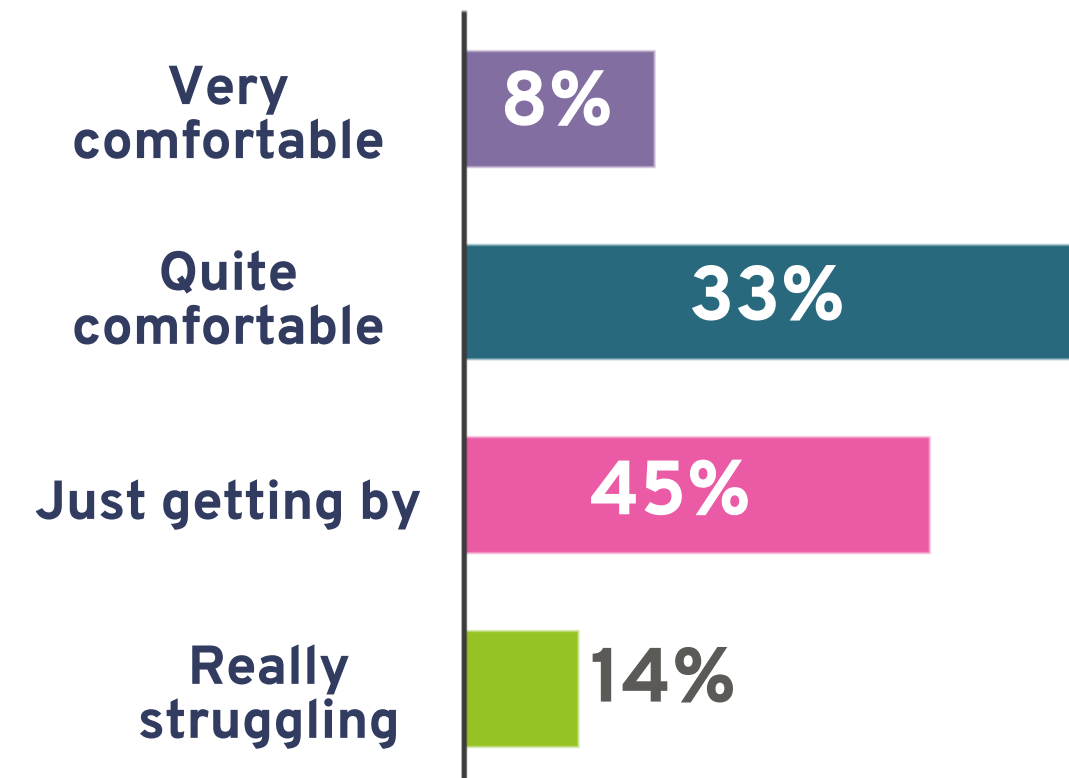
Religion



Estimated social class

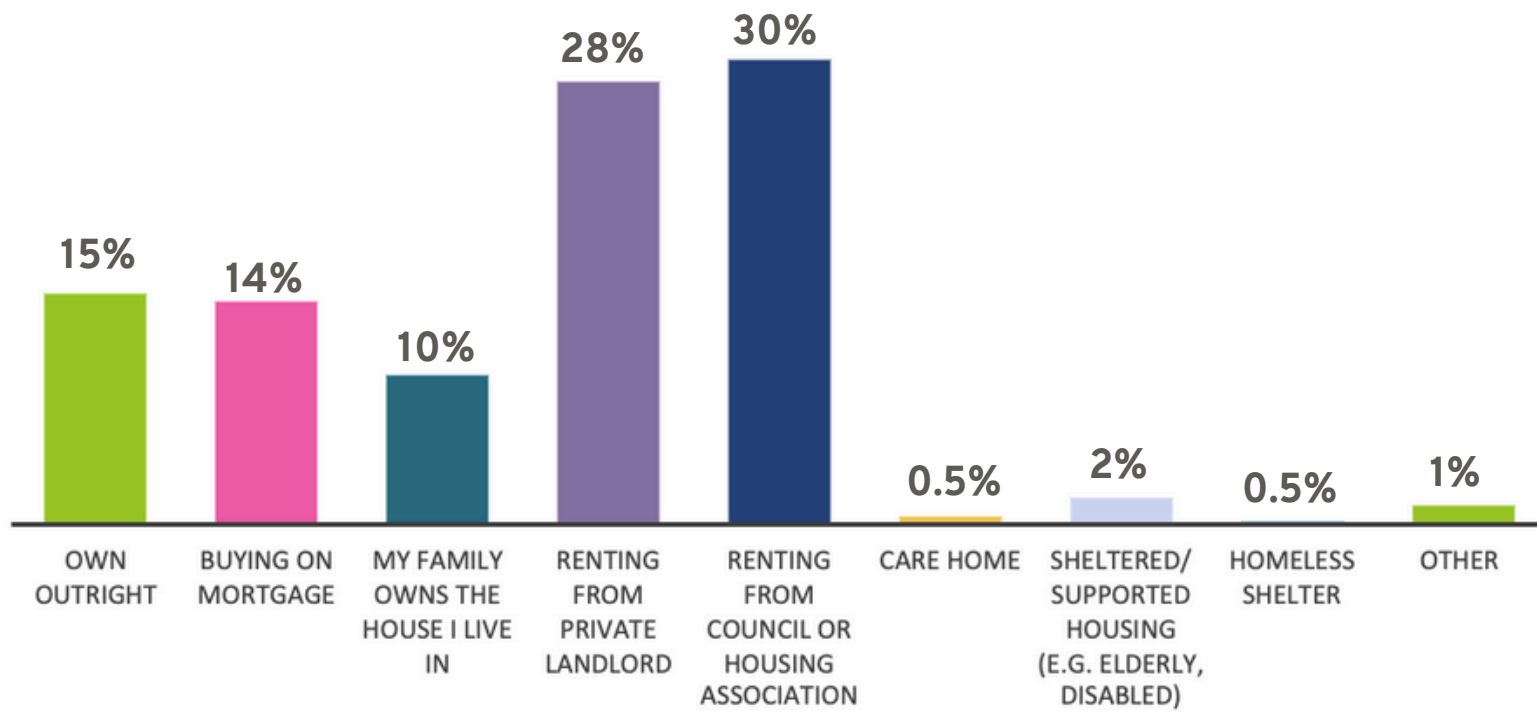


Financial situation

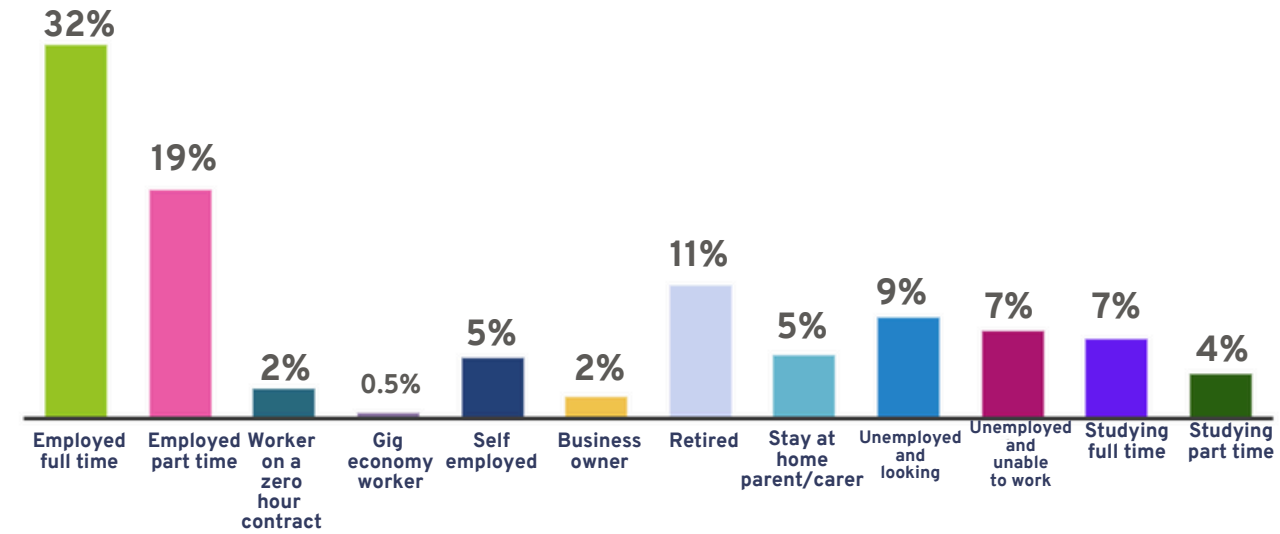


Demographics

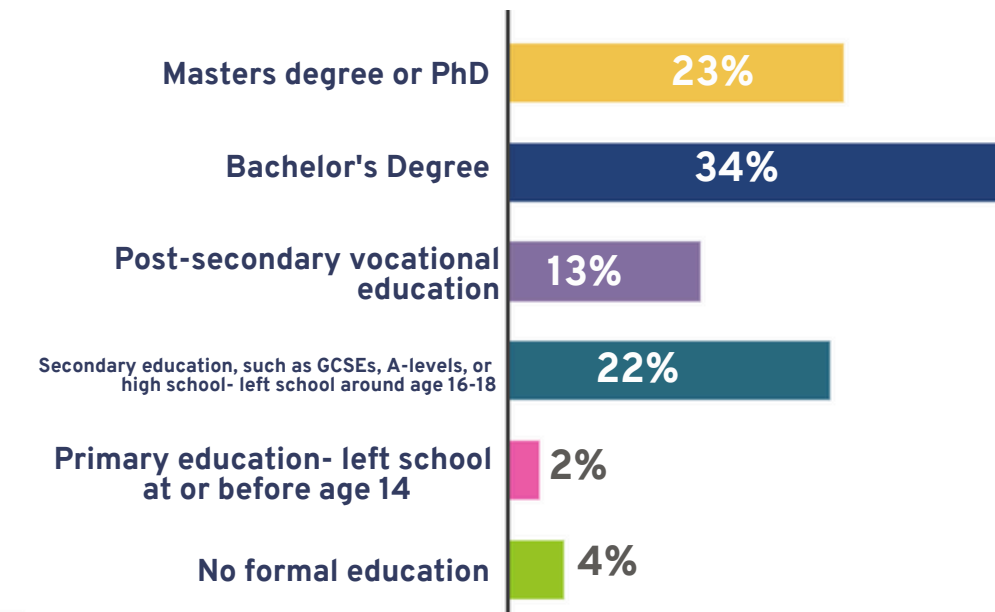
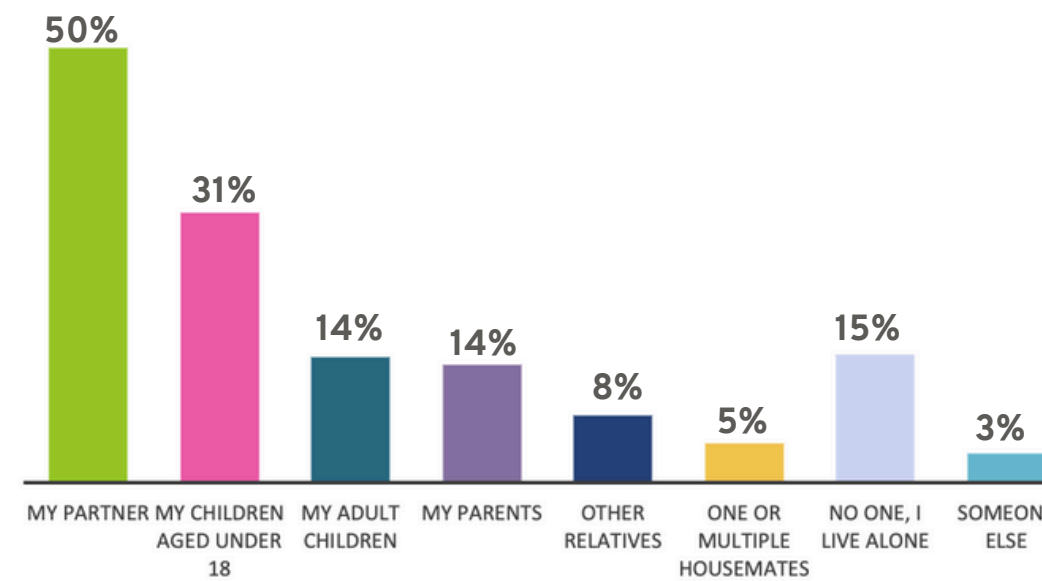
Housing situation



Employment situation



Who you live with



19%
were disabled

9%
were neurodivergent

28%
had a long term condition affecting their physical health

15%
had a long term condition affecting their mental health

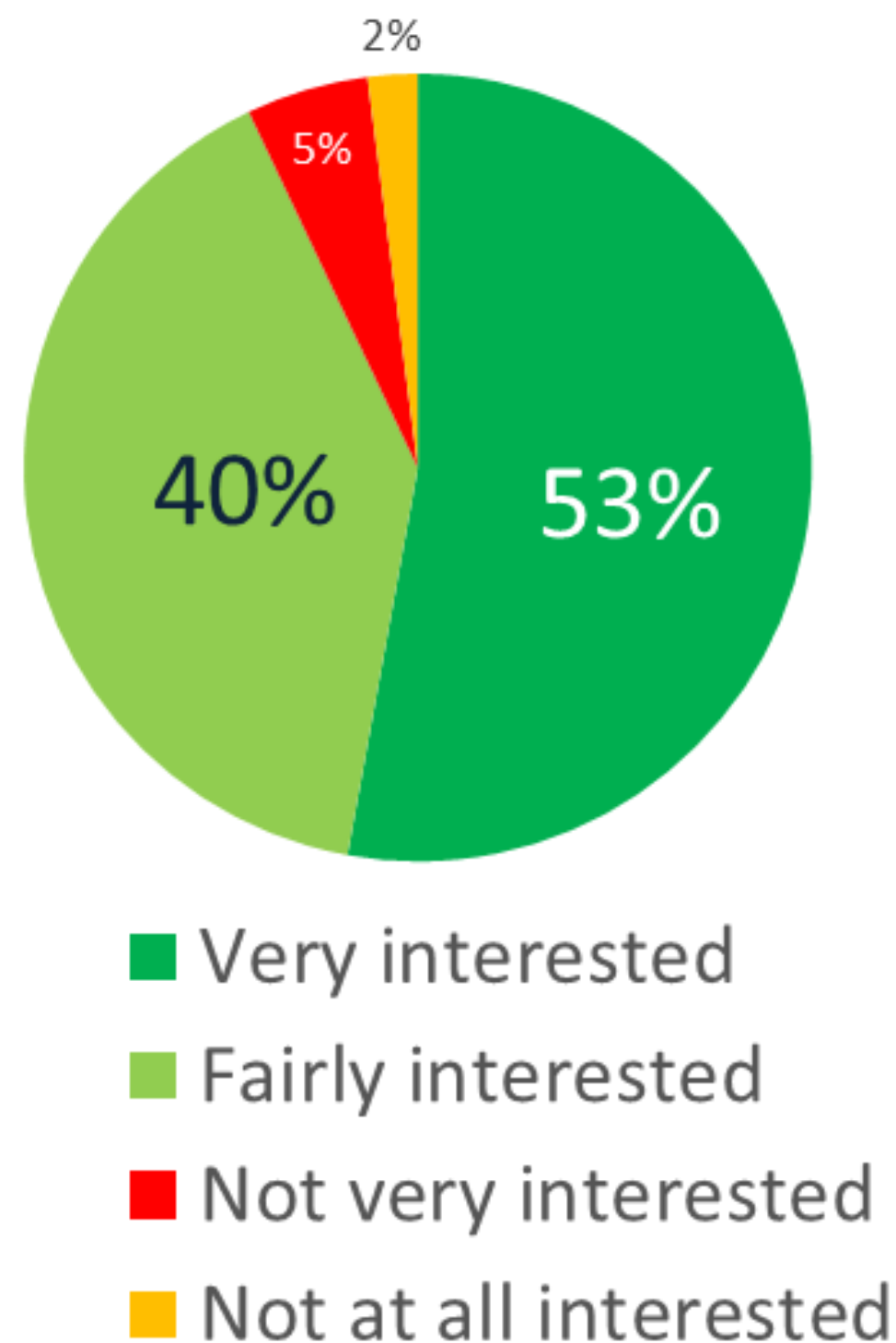
8%
were LGBT

37%
were digitally excluded

16%
were parents to a child aged under 5

30%
were parents to a child aged 5 to 18

Participants showed high levels of interest in taking part in research.



More interested

- Event participants
- Black Caribbean
- Chinese or South East Asian
- Aged 65+
- Disabled
- In very poor health
- With a mental health condition
- LGBTQ+
- In part-time/ casual work or retired
- Students

Less interested

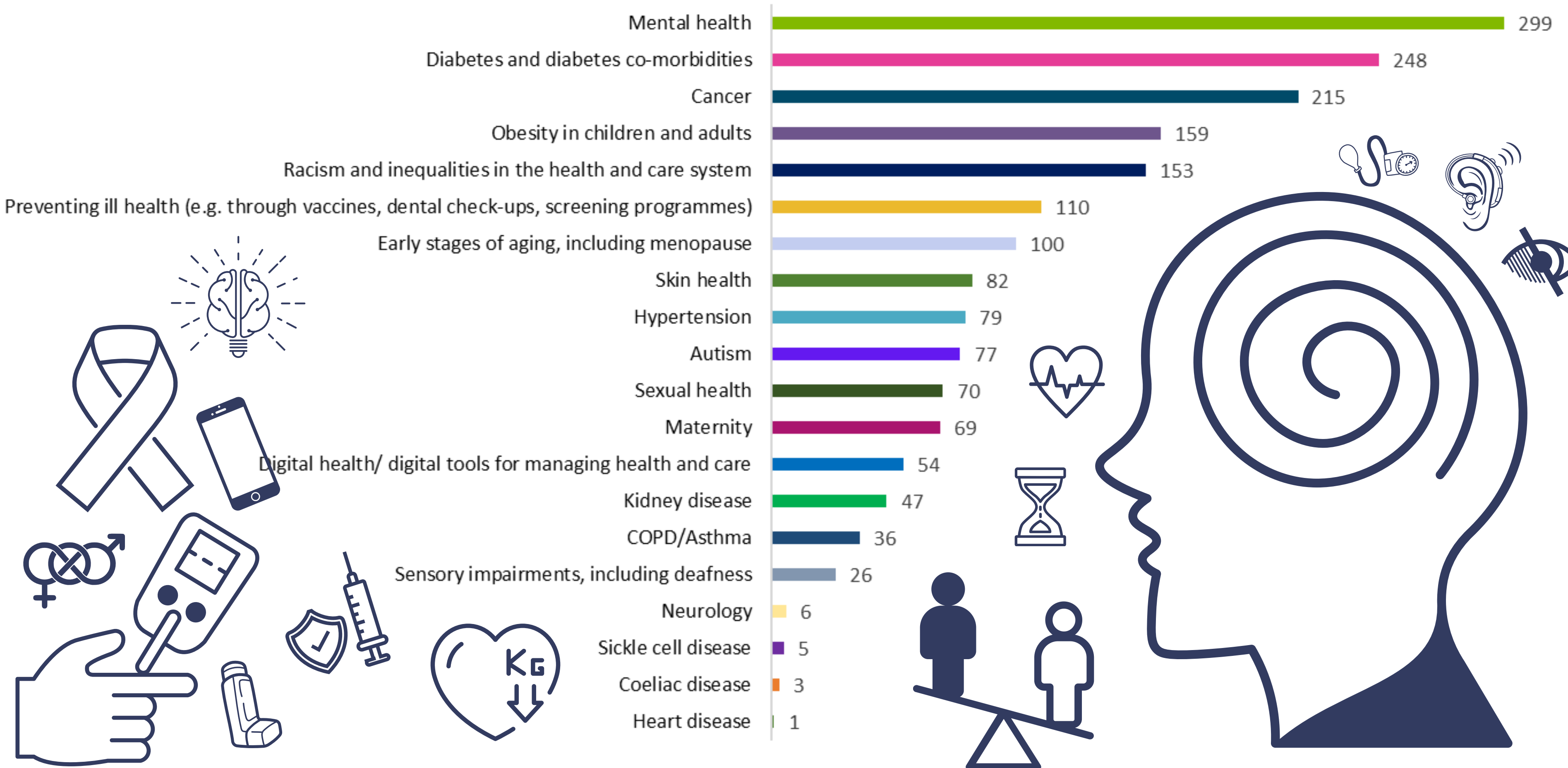
- Eastern European
- Pakistani
- Non-religious
- In full-time work

96%

of workshop participants who had previously attended other REN workshops said those influenced their level of interest in taking part in research.

People with more complex medical needs were more interested in being research participants. Factors such as gender, family situation and social class made little difference to levels of interest.

Research topics participants were most interested in:



Biggest takeaways from engagement:

→ Engage with diverse populations; reach out to seldom heard communities wherever they are and communicate about existing projects.

72%

→ Continue participants' involvement in the research project after they take part in research activities; communicate about results and impact, take feedback on board for quality improvement.







54%

→ Build trust through honest dialogue; demonstrate transparency in communication.

53%

Only 5% of participants brought up compensation or incentives.

More takeaways from engagement:

-  **Create research that's relevant to the concerns of local people and diverse groups; improve cultural competence to gain a better understanding of what matters to them and the perspectives they come from.**
-  **Provide a balanced view of the potential positive impact of taking part in research and the potential risks.**
-  **Engage in a variety of community languages; support participants to overcome the language barrier.**
-  **Make research convenient to engage in; consider barriers around accessibility, communication, time and poverty.**
-  **Provide information and reassurance on how participants' data is being used and protected; have strict policies and procedures in place for safeguarding.**
-  **Past research participants can be highly valuable as community champions in their own communities, by sharing their own experiences and encouraging others to participate.**

The main reasons people were NOT interested in being research participants:

- ➔ **Concern about effects on their health or disruptions to their treatments. 8 mentions**
- ➔ **Lack of time. 7 mentions**

Scared of catching side effects and NHS will not help. I don't trust the NHS anymore after what happened to my last pregnancy.

Scared of testing new drugs on my body, and any negative effects it may have on me.

I'm not a Guinea pig.

I don't like the risk of side effects and don't have time.

I work full time and have two children, I'm very busy.



The good care framework

What does good care look like?



Everybody
can THRIVE

Accessible

Competent

Person-centred

Trustworthy

The good care framework has been developed based directly on what local people have told us.

In our recent NEL ICB Big Conversation we asked over a thousand local people open-ended questions about what good health and care means to them. At community events and in focus groups we helped local people to draw out what their own vision of good care would look like, using Liberating Structures and Participative Appraisal tools.

We took what they told us and started to use qualitative data coding to identify themes, these themes eventually developed into the good care framework and our four pillars of good care, or four aspects of what makes the difference between good care and inadequate care. We also looked at the wider issues that impact good care at a society level.

The resulting framework, informed by what local people said, is now being used by partner's to develop success measures and evaluation tools.

The good care framework

What does it mean for research?



Accessible

- Participants can engage in a way that works for them (for example, over the phone, online or in person); and in different languages.
- Demands on participants' time are reasonable, including travel-time for in-person activities; they get to participate on a flexible schedule.
- Accessibility needs are taken into account and accommodated; not just for physical and sensory disabilities but also for neurodivergence and mental health-related disability. Participants are proactively engaged with on their accessibility needs.
- Participants are compensated for their out-of pocket expenses and their time. Obstacles to participation related to poverty (such as struggling to afford travel costs upfront even if compensated later) are addressed.
- Seldom heard groups are engaged with and are aware of opportunities to take part in research.

The good care framework

What does it mean for research?



Competent



Researchers have carefully considered the benefits and risk of research, and can confidently have honest conversations with participants about them.



Researchers have a good knowledge of the seldom heard groups they are engaging with, their challenges and differences in culture and perspective.



There are rigorous policies, protocols and procedure in place to ensure safety and dignity for participants, as well as for data governance and data protection.



Reputable institutions and scientists are involved in the research process.

The good care framework

What does it mean for research?



Person-centred

Research is relevant and interesting to the participants engaged with, including to seldom-heard groups.

Patients receive personalised feedback after the research process; they get to learn specific things about their own health whenever possible.

Different viewpoints and perspectives from different cultures are valued and encouraged.

Research teams are diverse; patients get to engage with researchers and community champions from their own communities.

Patients feel seen, understood and treated as individuals.

The good care framework

What does it mean for research?



Trustworthy

→ Participants are engaged in honest, informative conversations about the benefits and risks of participating in research, and they feel empowered to make their own decisions.

→ Effort is put into building rapport; participants can understand researchers' motivations.

→ Communication is a two-way street, patients get to ask questions and raise concerns.

→ Participants understand what the next steps are after their involvement ends; they receive relevant updates.

→ Participants' feedback is taken on board and helps shape future research.

→ Research is a non-judgemental space; all participants are treated with kindness, dignity and respect.

→ Participants understand how their data is being used and kept safe.

Respondents of Black ethnicities

- ➔ Could be engaged with support from community champions who were research participants themselves; and who could speak about their experience and the positive impact they made.
- ➔ Community events, promoted via schools and faith groups, could raise awareness and boost involvement.

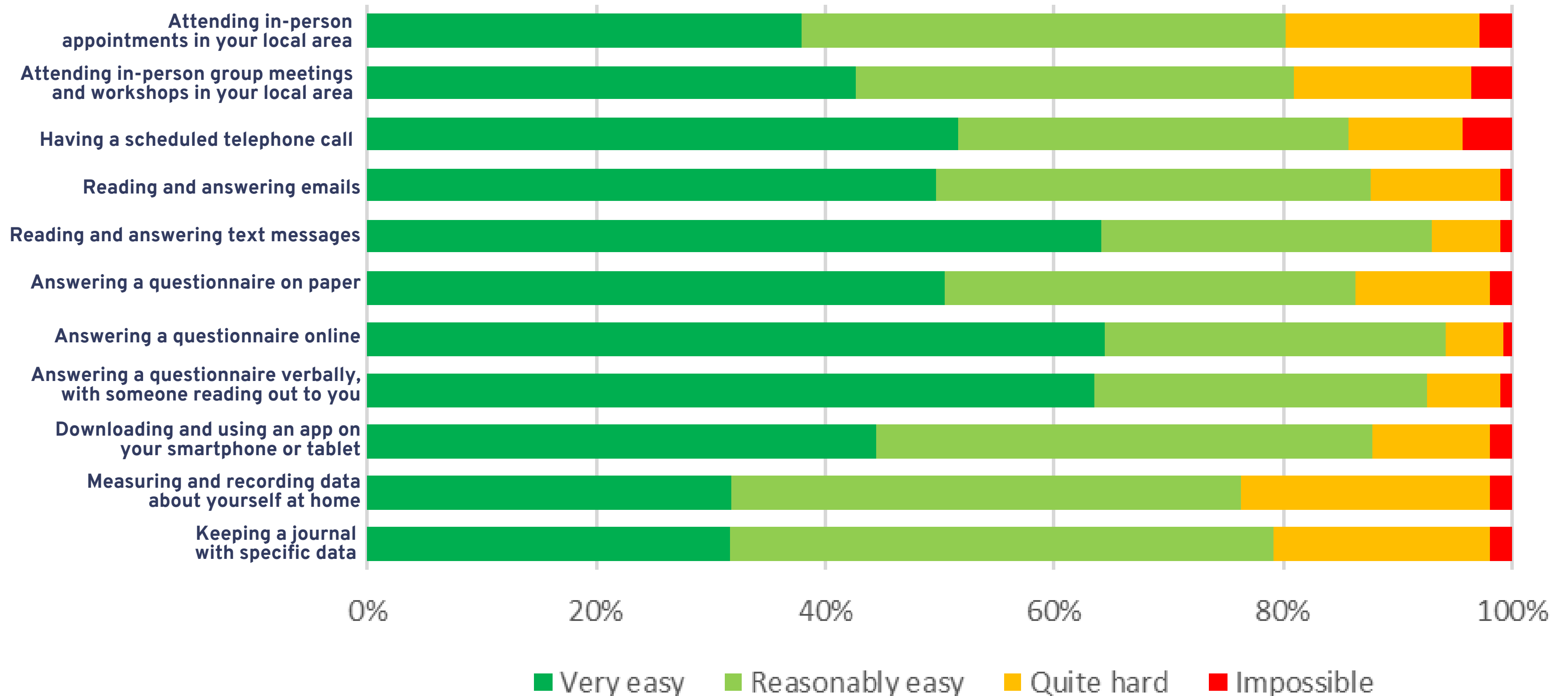


Respondents of Bangladeshi and Pakistani ethnicities

- ➔ Place a high level of importance on building trust through honest dialogue and having ongoing involvement and updates after taking part in research
- ➔ Being able to engage in Urdu or Bengali makes research more accessible for them.
- ➔ Mosques can be valuable engagement partners.



Making research participation easier: What do respondents feel confident doing?

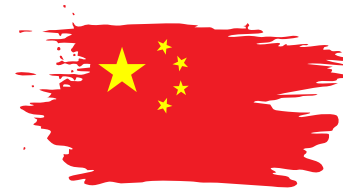


Making research participation easier: What do respondents feel confident doing?

These groups were more likely to find most research-related tasks difficult:

- ➔ Black African
- ➔ Disabled or in very poor health
- ➔ Digitally excluded

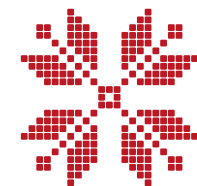
Digitally excluded respondents were also more likely to find it difficult to do tasks not directly related to digital access, such as attending appointments (but not group meetings) in person, having a scheduled phone call or answering questionnaires on paper/ verbally.



Chinese respondents were more likely to find research-related tasks difficult; except for in-person appointments/ group meetings and measuring data at home.



Pakistani respondents were more likely to find in-person appointments and questionnaires difficult.



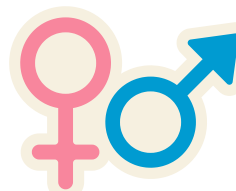
Eastern European respondents were more likely to find it difficult to have an in-person appointment (but not a group meeting), to be interviewed for a questionnaire and to measure



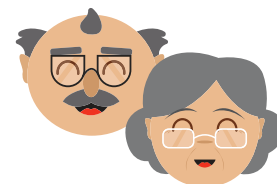
People in traditionally working class occupations were more likely to find it difficult to have scheduled phone calls and answer emails; but not to answer text messages.



In-person appointments and group meetings were harder for parents of children under 5, respondents who worked full-time and those who were financially struggling.



Scheduled phone calls and keeping a journal of specific info were harder for **men**; answering emails, paper questionnaires and downloading an app was harder for **women**.

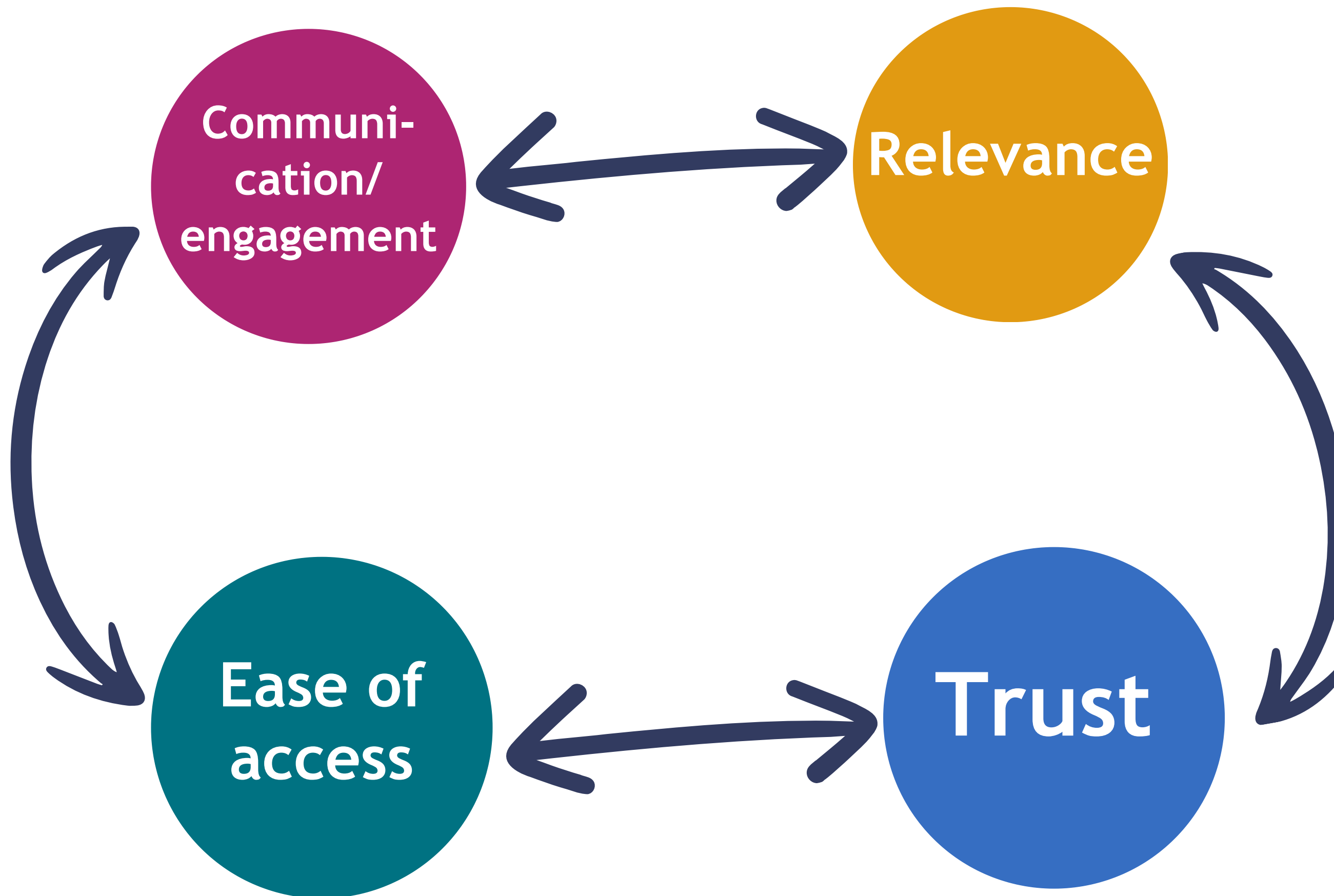


Answering emails or texts was harder for people aged **65+**. Downloading and using an app was harder for people aged **50+**



Young people aged under 25 found it harder to take part in group meetings in-person or to have scheduled phone calls

What would make research easier and more accessible?



6%

of participants said they would need to take part in research in a language other than English. The most mentioned languages were Bengali and Chinese.

What would make research easier to take part in?

Make it easily accessible (in terms of location, convenience, information format)

117 mentions

Make it engaging and interesting

65 mentions

Communicate about existing research. invite participants

97 mentions

Reinburse costs, provide rewards

44 mentions

Flexible, convenient times

33 mentions

Explain risks and benefits

44 mentions

Personalised feedback

18 mentions

What would make research easier to take part in?

What local people are saying:

Give more information and allow mothers to go with children as sometimes they find difficult to leave with to childcare providers.

Flexibility would be great for those who work.

Easy, not too time consuming and led by friendly straightforward staff.

More invites like this one I got from my local church; which targets me from a race, gender and age angle.

Information, transparency, accessibility; research questions easy to read and understand.

First I would like to know about new research and its impact.

Information about available events being easily accessible.

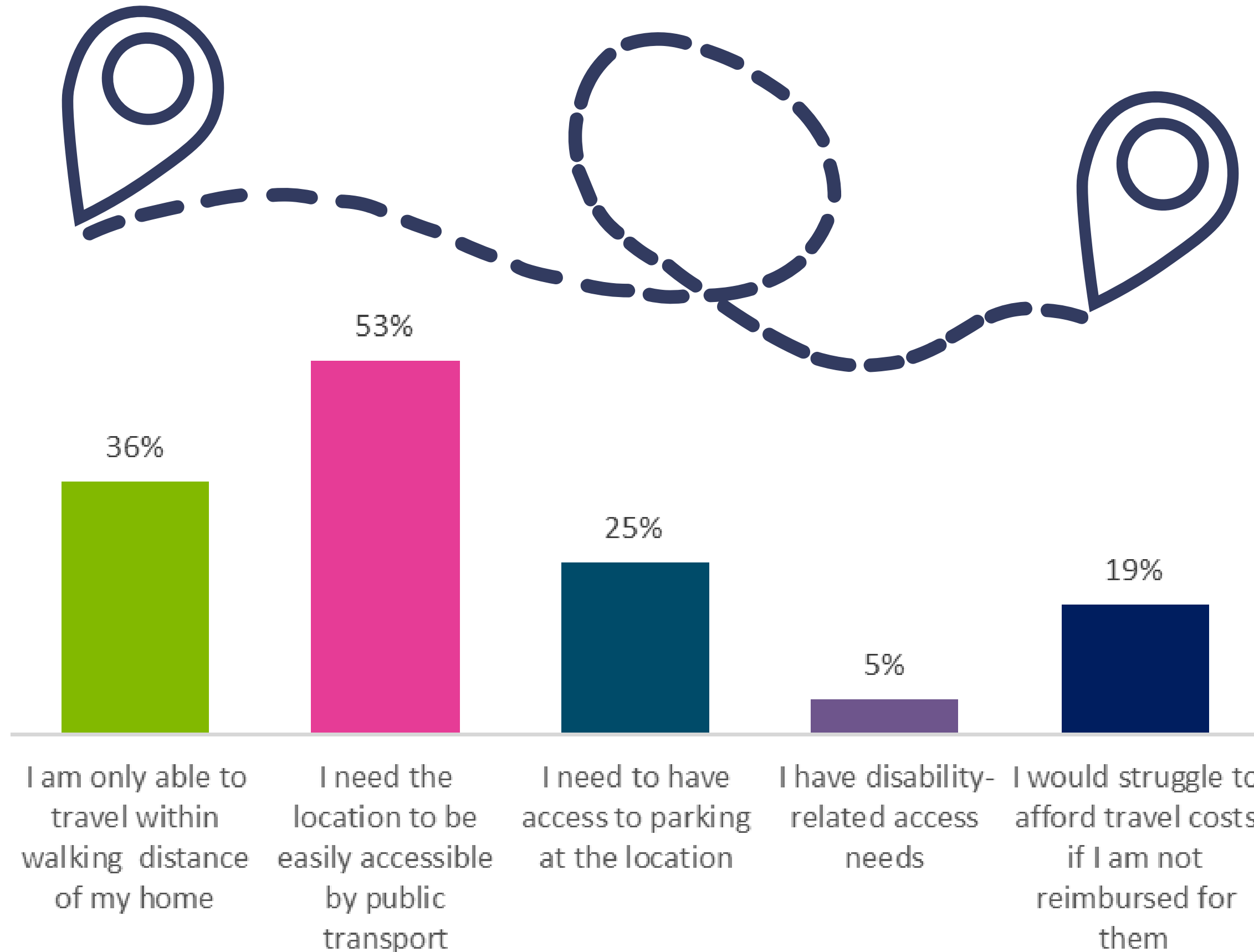
Training, opportunity, meeting someone already involved who can tell you about what it involved.

Clear information around how outcomes are going to be communicated. Incentives

Explain clearly objectives and outcomes of research with KPIs. Not simply collecting data. Update regularly on changes

in most cases we depend on doctors so that we consult them and take the tablets. If we take part in this research we will get a knowledge how to control the situation at home before going to doctor.

What would make research easier to take part in?



Respondents of Asian ethnicities, especially Bangladeshi, and young people aged under 25 were more likely to say they would only be willing to travel within walking distance of home.

Women and Black Caribbean respondents were more likely to say they would need a location easily accessible by public transport.

People of White ethnicities or Black African were more likely to say they would need access to parking.



What would improve diversity in research?

Engage with diverse/
seldom heard groups; raise
awareness

134 mentions

Develop cultural
competences/ understand
different viewpoints

18 mentions

Diversity quotas/
representative
participant group

79 mentions

Address the
language barrier

42 mentions

What would improve diversity in research?

What local people are saying:

Share information within areas that there is a diversity of people. Go in to local communities, hand out flyers door to door in diverse areas. Speaking to people in heavily populated diverse areas eg a shopping centre.

Make information available in schools, churches, local communities etc.

Evening sessions and weekend sessions. Remote sessions, A lot of people from the BAME community do shift work

Raise awareness to debunk taboos and cultural misconceptions

Ensure there are diverse individuals leading sessions and workshops

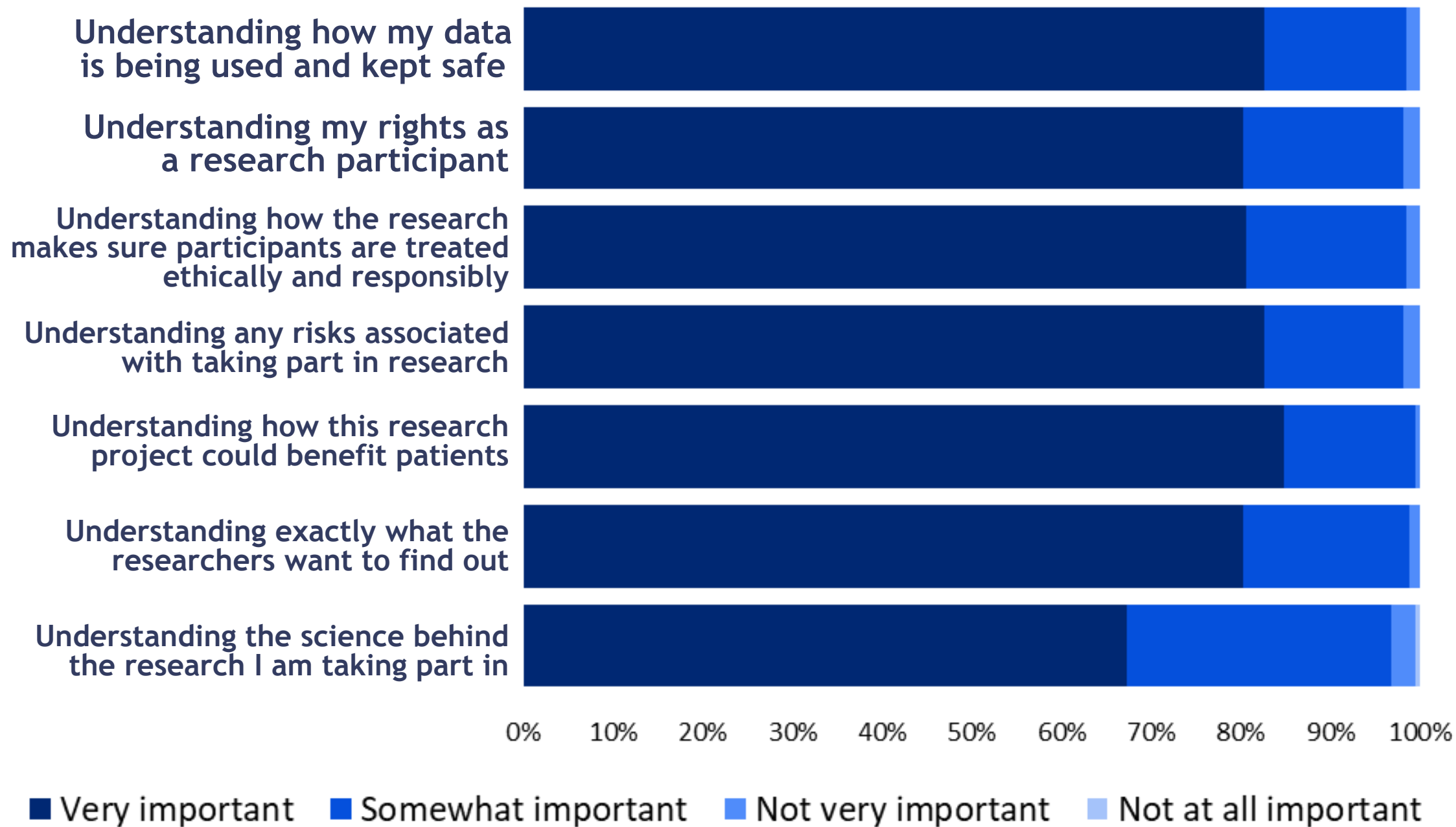
Offer research on different languages and make it more accessible during different hours. 9-5 does not suit a lot of people.

Have more community representatives that can relate to the relevant community

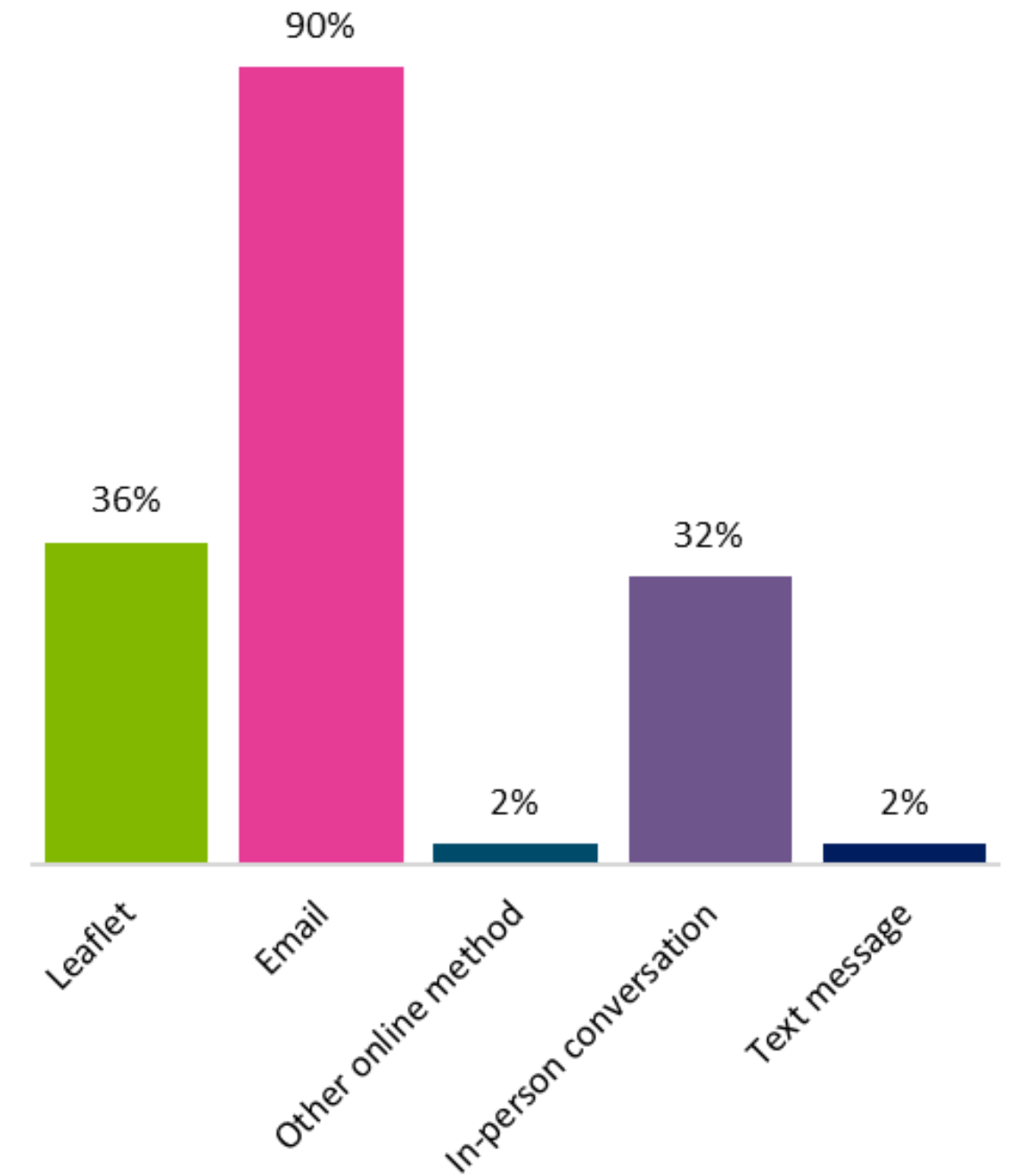
Understand the needs of the different demographics to participate

Personally, I think Religious centres and workplaces should be reached out to more.

How important are the following for you when taking part in research?



Best way to receive info about these



What helps establish trust?

Honest
communication/
transparency

91 mentions

Talk about positive
impacts of research

15 mentions

Non-judgemental space/
kindness and dignity

65 mentions

Feeling understood/ no
bias in data analysis

23 mentions

Confidentiality/
privacy/data
governance

89 mentions

Talk about
safety
concerns/ risks

8 mentions

Diverse team/
researchers who
liik like me

6 mentions

What helps establish trust?

What local people are saying:

Open and honest sharing of information regarding research, what is done with it and what the outcomes would mean for the individual taking part. Most people don't involve themselves because they probably can't see how it will affect them.

Keeping all info confidential of course and being completely transparent on research.

I took my role because my research participants can see first hand that their opinions & input is valued, respected & channelled directly into the system. This helps with them trusting me - it is a two way relationship.

Understanding that the researchers are working for their benefit and interest.

Being involved in all stages of research
Transparency of results
Seeing how research translates to action.

What this would mean for me is receiving feedback and it being carried along with outcomes or progress of the research I participate in.

Openness and accountability.

Data protection and confidentiality is very important.

Debunking the negative beliefs a lot of ethnic minorities have about research.

Clear understanding of the purpose of the research. Able to see my information. Seeing the outcomes of the research.

Knowing my data was being used in a secure manner. Not being cold called after taking part etc

What can reassure you that it's safe to take part in research?

Transparency/
clarity/having all
information

114 mentions

Authoritative/
reputable figures
being involved

50 mentions

Follow-on/
information about
results

16 mentions

Confidentiality/
privacy/ data
governance

73 mentions

Risk assessments/
openly communicating
about risk

72 mentions

Shared experiences
of past participants

12 mentions

Established protocols,
policies, regulations

18 mentions

Knowing you will
make a difference

27 mentions

What can reassure you that researchers are communicating honestly?

Transparency/
sufficient
information
116 mentions

Two-way
communication/ a
chance to ask questions
49 mentions

Updates/ regular
communication
39 mentions

Authoritative/
reputable figures
being involved
22 mentions

Effort to build trust and
rapport/ understanding
motivations
39 mentions

Info in
writing
22 mentions

Straightforward,
no jargon
13 mentions

Understanding
positive impact
13 mentions

Understanding
risks
16 mentions

What can reassure you that you are listened to and taken seriously?

Open, honest
conversations

111 mentions

Receiving
personalised
feedback

21 mentions

Continued
involvement in
next steps

27 mentions

Seeing feedback acted
upon/concerns taken on
board for further actions

81 mentions

Questions
answered with
adequate info

28 mentions

**What can make you feel that
your participation is making a difference?**

**Being informed of
the impact**

182 mentions

Feeling heard/
suggestions taken
into account

34 mentions

Continued involvement
in activities post-
research

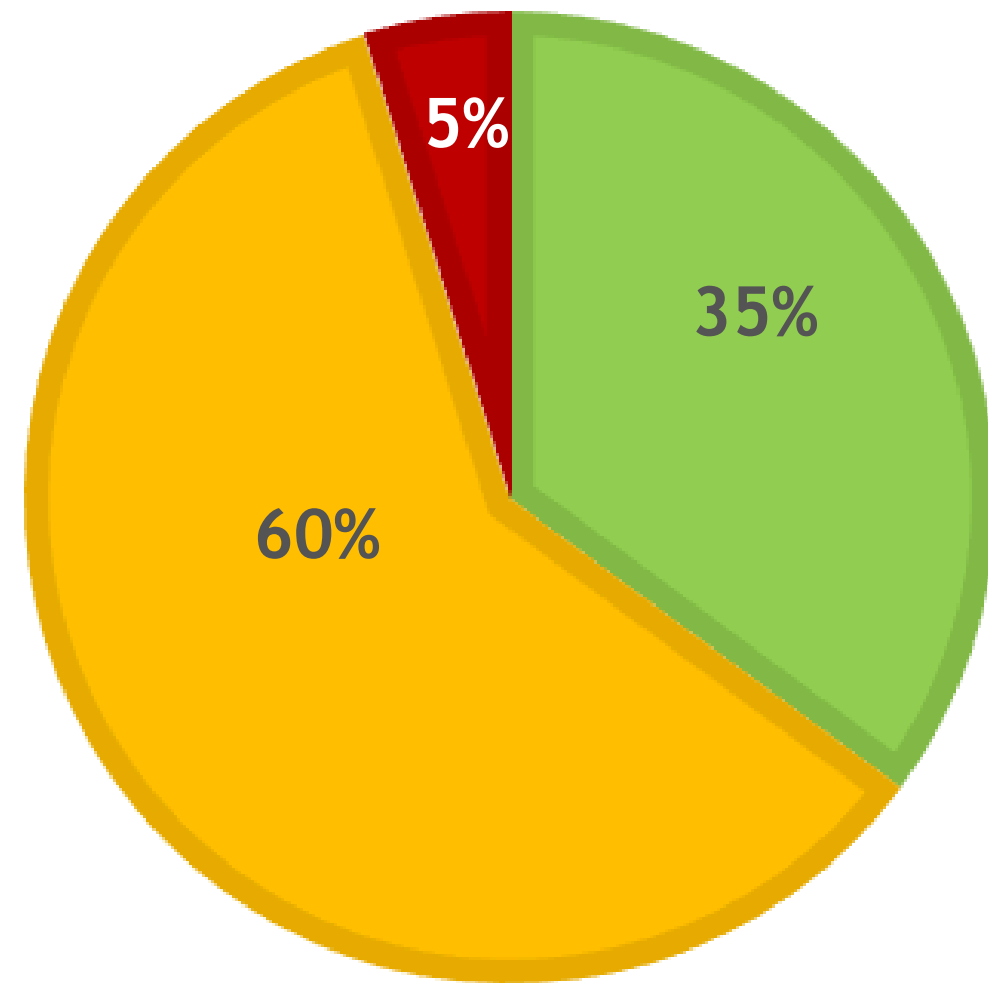
15 mentions

Understanding
the purpose of
the research

14 mentions

Be Part of Research App:

Have you joined the “Be Part of Research” app?



■ Yes ■ No, but I may join in the future
■ No, and I am not interested



Why not?



Never heard of it
40 mentions

Need to know more before joining
18 mentions

Don't have time
9 mentions

May join in the future
14 mentions

Don't have internet/
not good with technology
6 mentions

Don't speak English
2 mentions

Why haven't you joined the app?

What local people are saying:

I'll see in future if I can manage time then I'll take part

Need time to think

I like to think about things before signing up / also want to read up more on it

Haven't thought about joining to be honest

I am not aware of that

I still need to understand more and want particular research

Don't speak English

I wasn't aware of this app

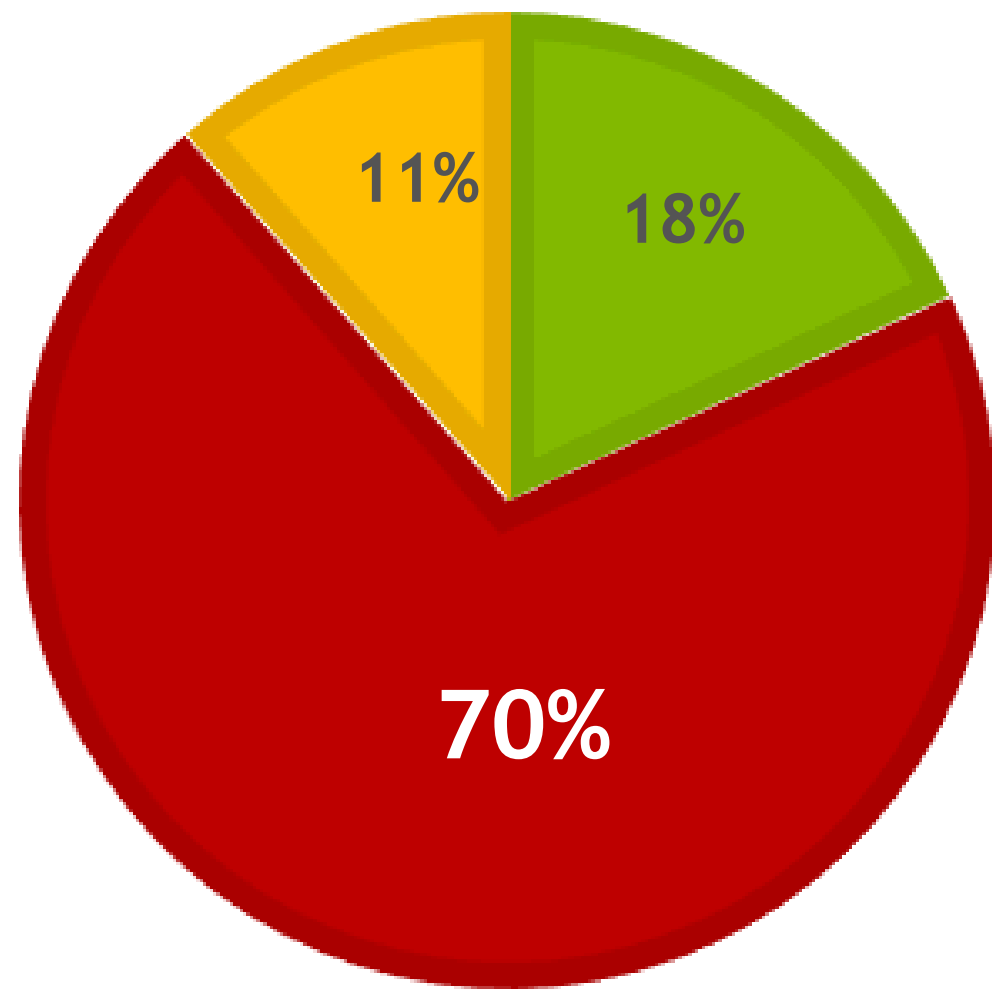
I am not savvy in technology

I want to find out as much as possible

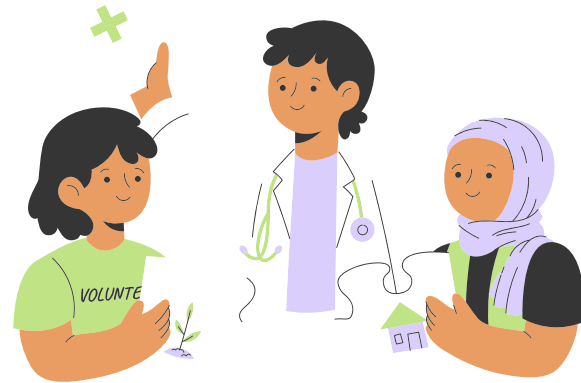
I need to think about it, because of my schedule

Community champions programme:

Have you ever heard about our Community Champions Programme?



■ Yes ■ No ■ Not sure/ can't remember



After having heard about our Community Champions programme, do you think it has the potential of making a positive difference in your community?



68% Yes, definitely



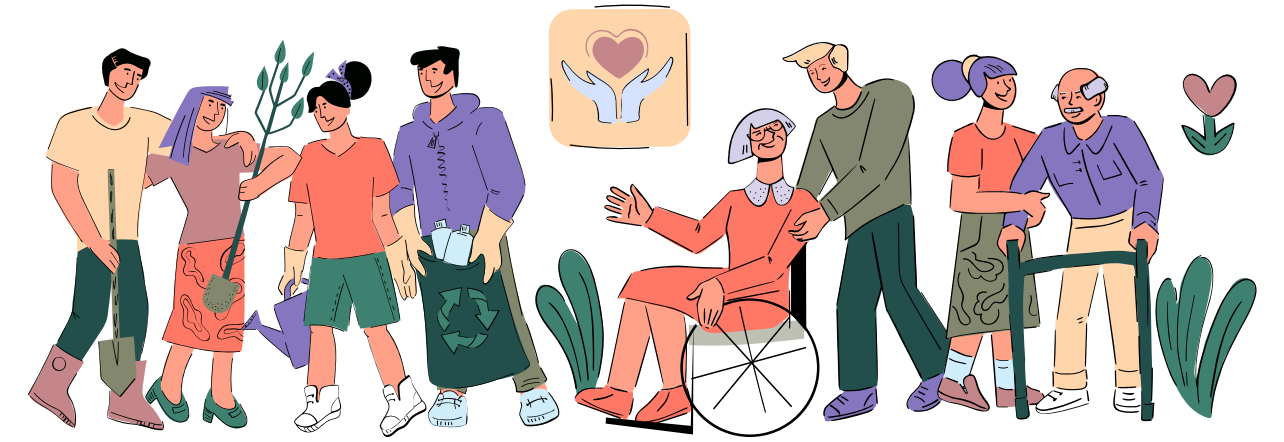
38% Yes, to some extent



4% No, not at all



Community champions programme:



Valuable for sharing
information/
engagement
38 mentions

Effort to build trust and
rapport/ understanding
motivations

24 mentions



Opportunity to share
experience/ important
things

6 mentions

Equality-focused/ for
everyone/ representation
for seldom-heard groups

32 mentions

Why do you think the **Community Champions programme** will make a difference?

It is very necessary for each and every individual. It is not just related to the professionals or clinical personnel

It will reach a much wider audience and access to minority groups

Building links with the community and celebrating local can really motivate others.

People are sharing their personal journey

Improve life of residents

Being part of community champions means the community has the chance to make a difference

Because they will get awareness

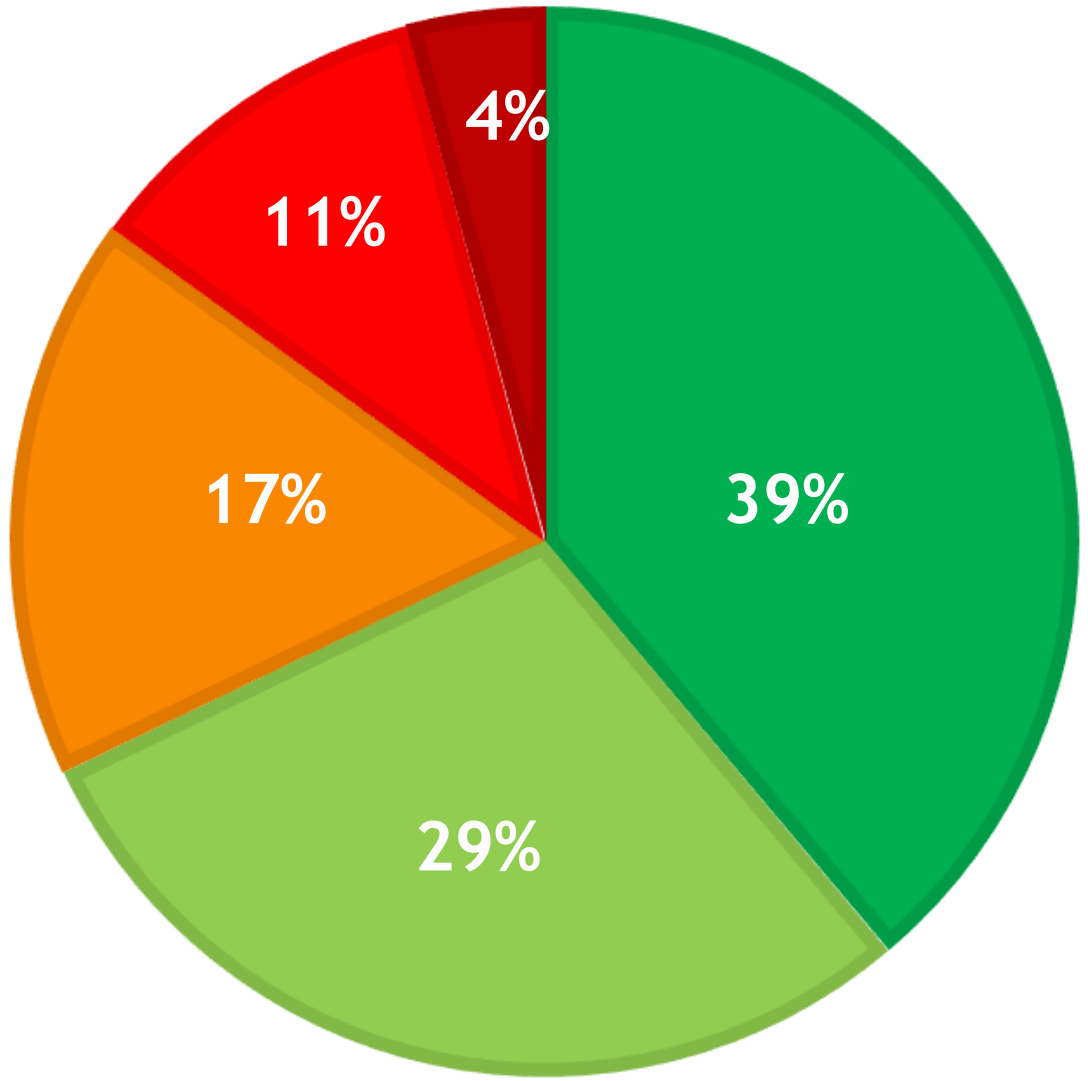
To reach hard to research communities

Gets information out to communities

For a healthy community in the world

Because people in the community know the community and are trusted

Would you be interested in becoming a **community champion**?



■ Definitely yes ■ Probably yes ■ Not sure/ haven't decided yet
■ Probably not ■ Definitely not

Why not?

Time limitations
14 mentions

Language barrier
3 mentions

Health issues
1 mention

Lack of interest/motivation
2 mentions



Why local people would not be interested in joining the **community champions programme**?

It involves a lot and I would not be able to commit completely

I am already very busy with my volunteering responsibilities

Language barrier

I don't have much time

Time commitments

I don't have time

Don't have time

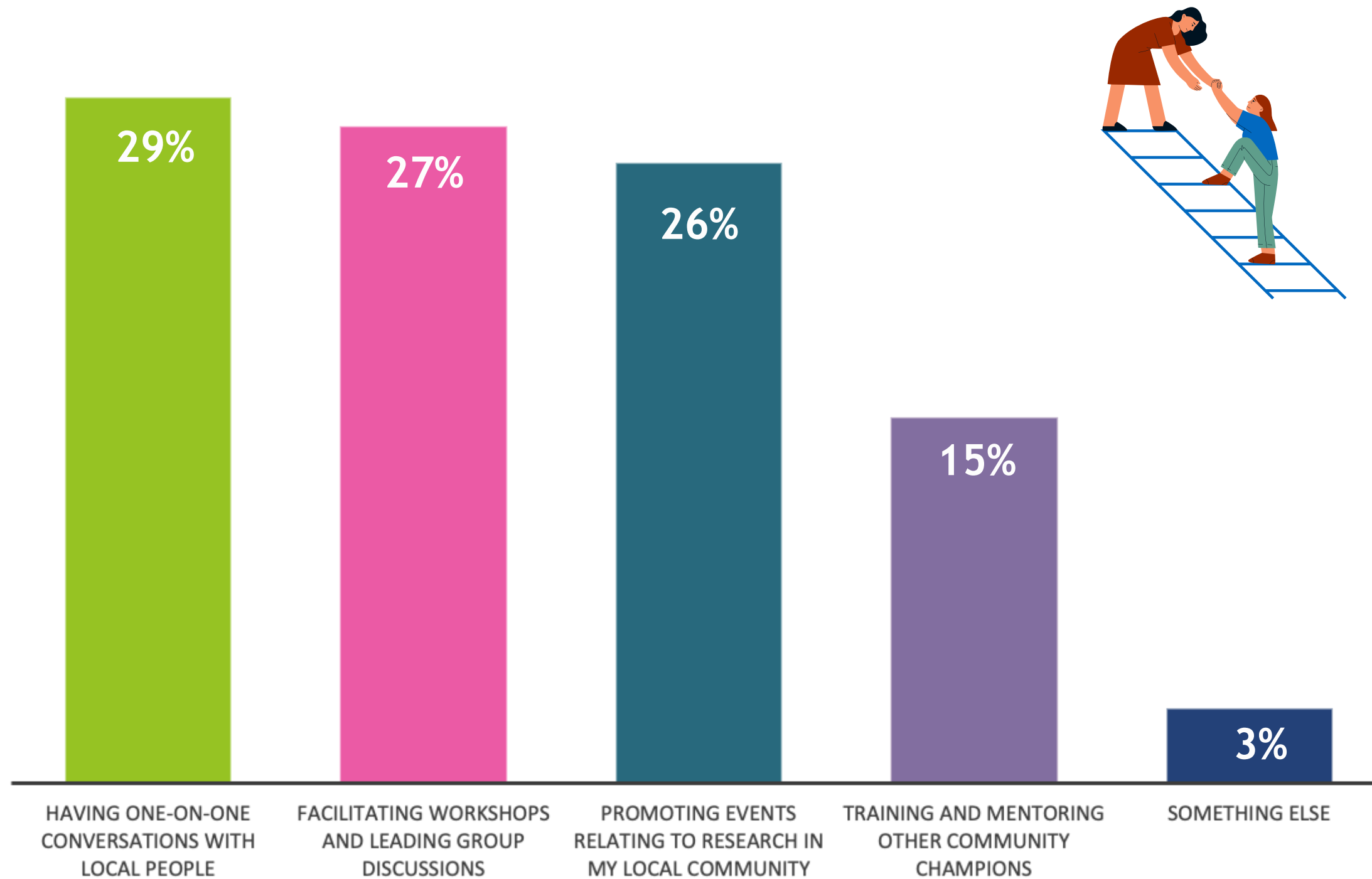
I don't speak english

Not interested at the moment

I'm unwell

Too busy, wouldn't be commitment. Post deserves commitment

If you were to become a **community champion**, what kind of work or activities would you be interested in taking part?



Something else:



Event participants only- how happy were you with the event today?



- Not at all satisfied
- So-so
- Vey satisfied
- Not very satisfied
- Quite satisfied

Suggestions for improving events

“Maybe some activities to make it more interactive.”

“One to one conversations to kick start people's availability for research.”

“Start at a later time- missed quite a bit as coming from work.”

“Have regular workshops to empower members of the public.”

