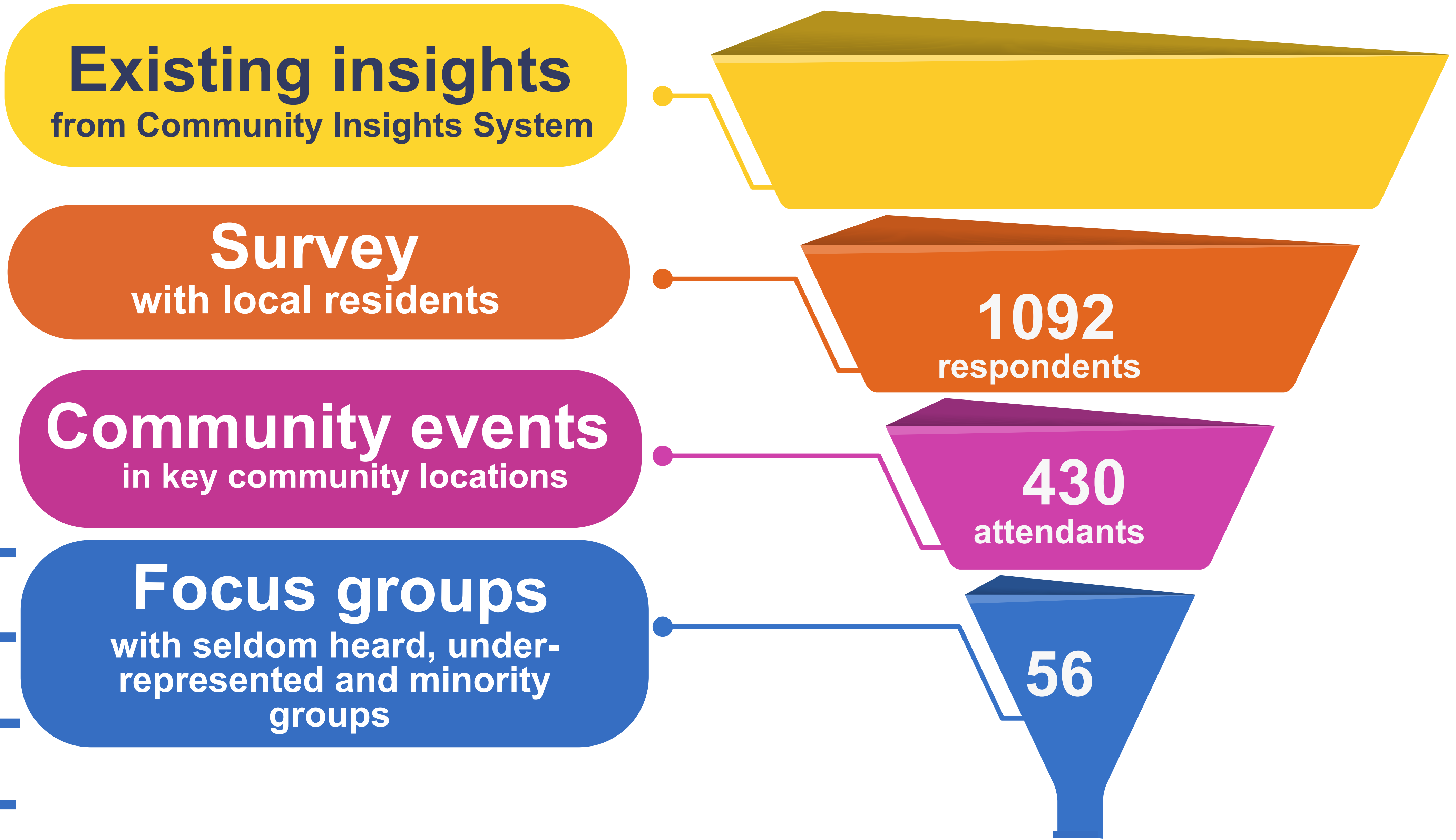
North East London
Health & Care
Partnership

NHS
North East London

Big Conversation

Big Conversation



Existing insights
from Community Insights System

Survey
with local residents

1092
respondents

Community events
in key community locations

430
attendants

Focus groups
with seldom heard, under-represented and minority groups

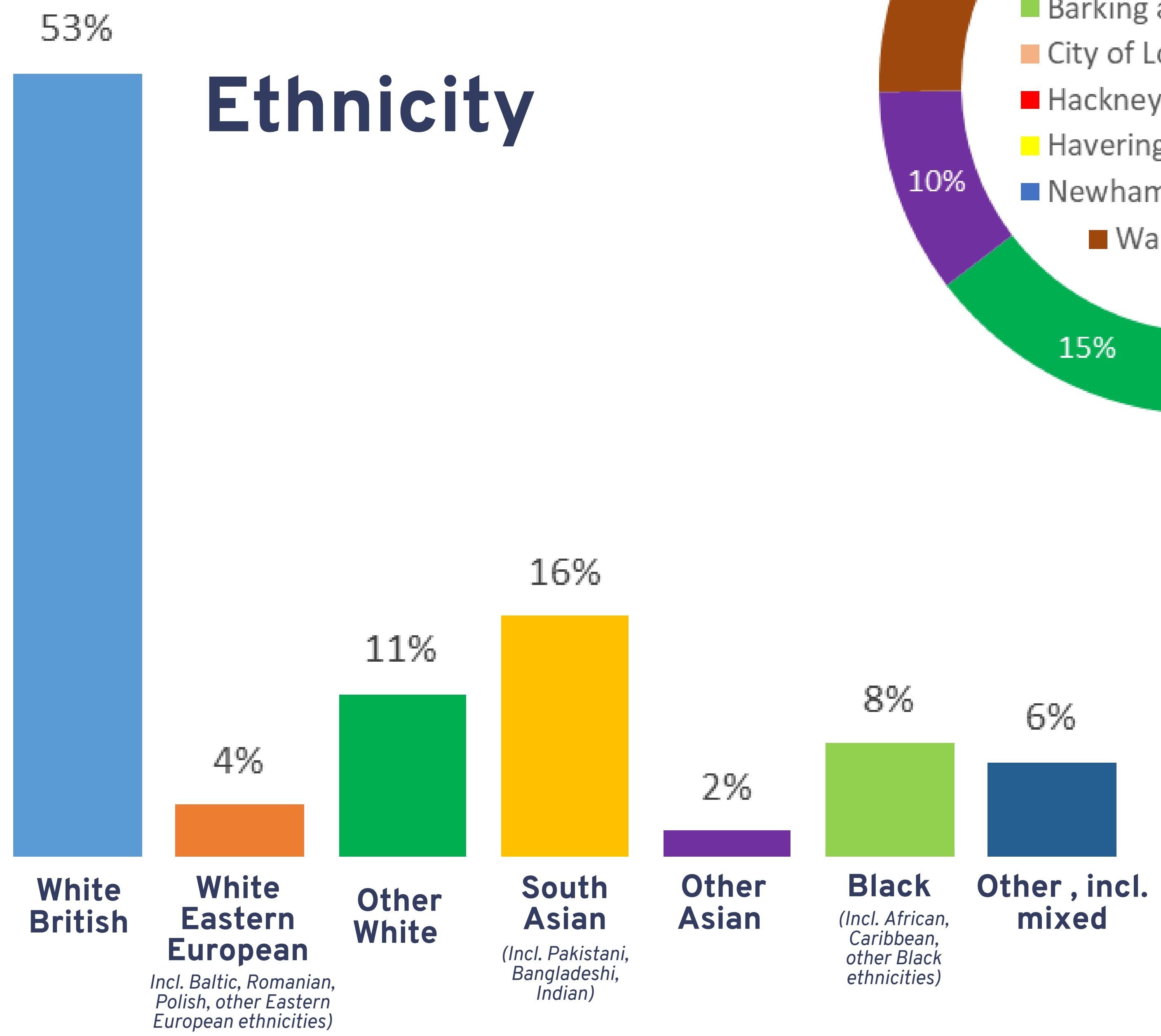
56

- **Turkish** mothers in Hackney
- **South Asian men** in Newham/Tower Hamlets
- **Older people** in the City of London
- **Black African & Caribbean men** in Hackney
- Patients living with **Long Covid** in Hackney
- **Young people** in Barking and Dagenham
- **Men** in Barking and Dagenham
- **Deaf BSL users** in Redbridge
- **Pakistani women** in Waltham Forest

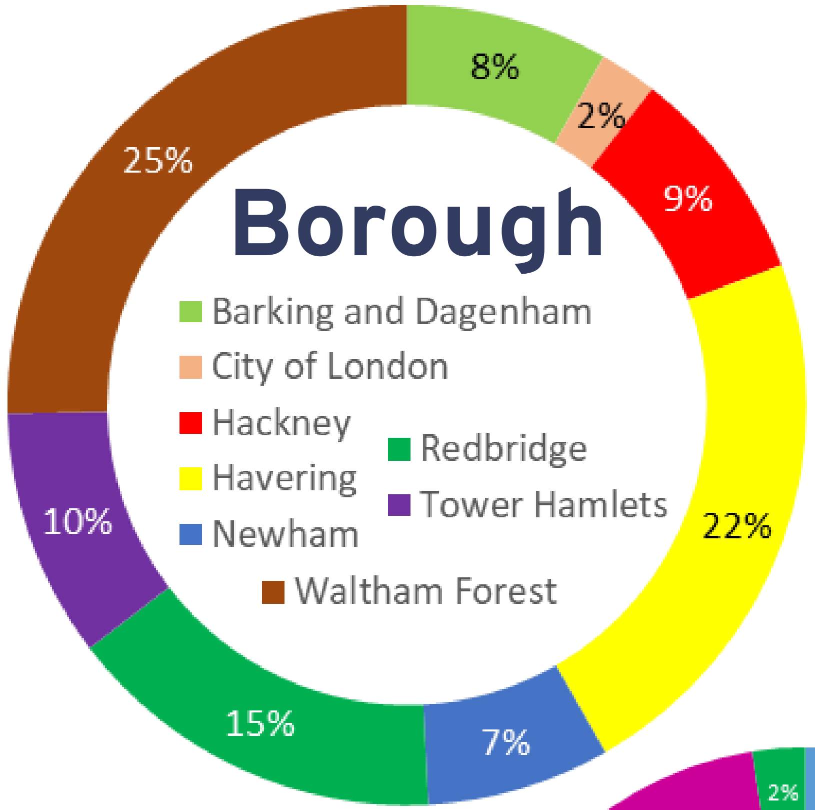
Demographics

survey respondents only

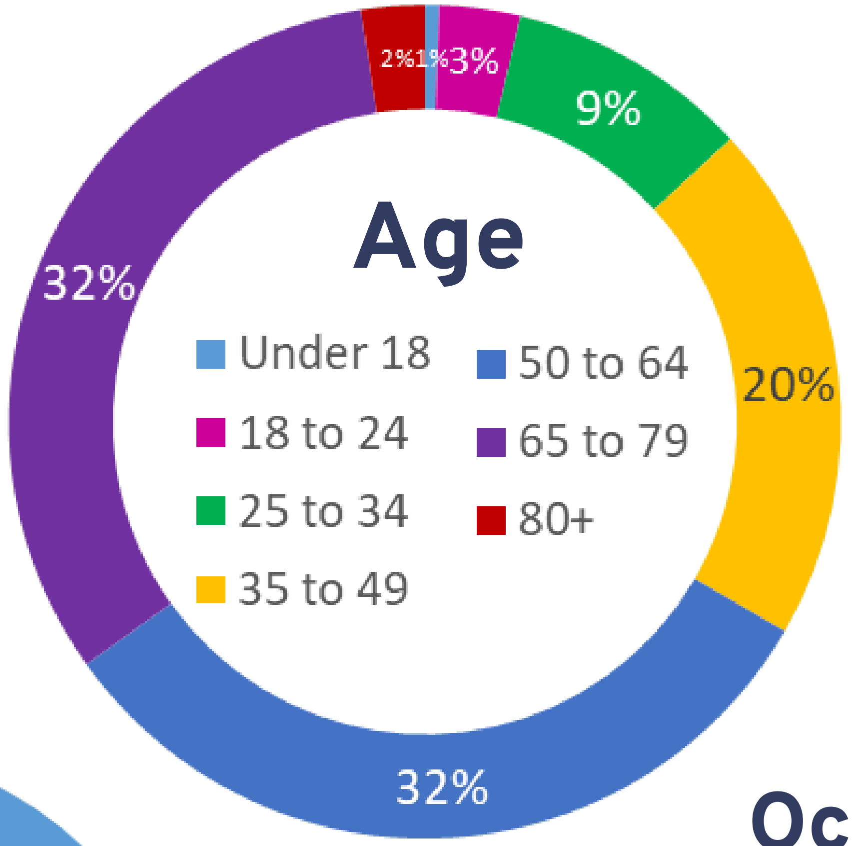
Ethnicity



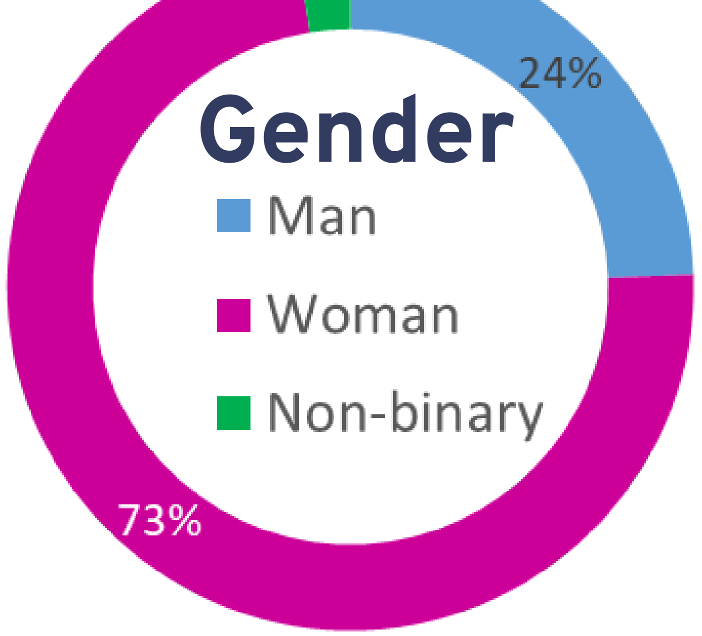
Borough



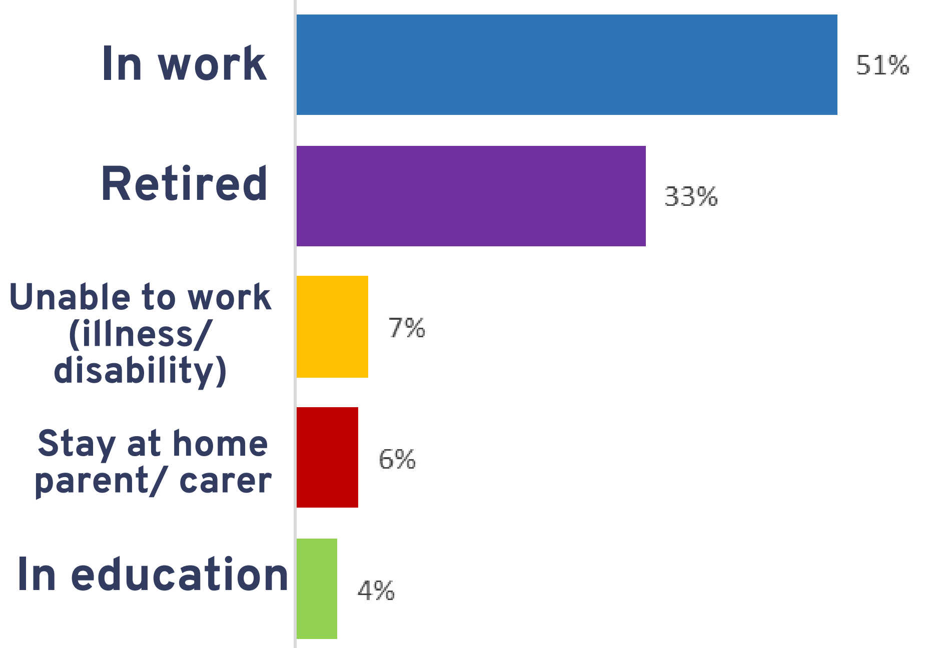
Age



Gender



Occupational status



98% were registered with a GP

93% had used health or care services in the last 12 months

7% were parents of a child/ children aged under 18

7% were carers for an adult loved one or family member

23% were digitally excluded

6% were disabled

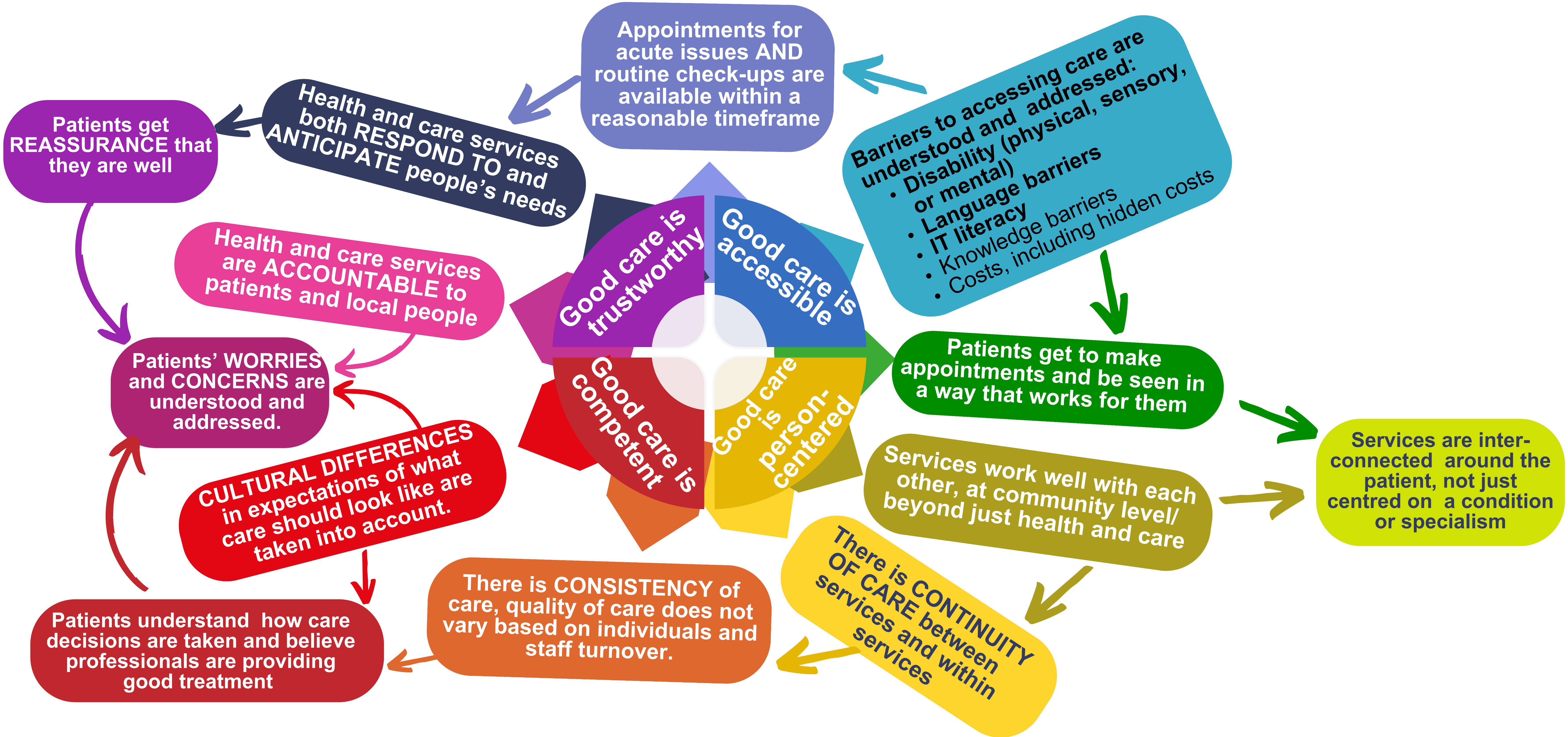
3% were neuro-divergent

41% had a long-term condition

3% were LGBT

32% were struggling financially or just getting by

What does good care look like?



Good care is trustworthy

Good care is accessible

Good care is competent

Good care is person-centered

Appointments for acute issues AND routine check-ups are available within a reasonable timeframe

Barriers to accessing care are understood and addressed:

- Disability (physical, sensory, or mental)
- Language barriers
- IT literacy
- Knowledge barriers
- Costs, including hidden costs

Patients get to make appointments and be seen in a way that works for them

Services are inter-connected around the patient, not just centred on a condition or specialism

Services work well with each other, at community level/ beyond just health and care

There is CONTINUITY OF CARE between services and within services

There is CONSISTENCY of care, quality of care does not vary based on individuals and staff turnover.

Patients understand how care decisions are taken and believe professionals are providing good treatment

CULTURAL DIFFERENCES in expectations of what care should look like are taken into account.

Patients' WORRIES and CONCERNS are understood and addressed.

Health and care services are ACCOUNTABLE to patients and local people

Patients get REASSURANCE that they are well

Health and care services both RESPOND TO and ANTICIPATE people's needs

Services mentioned by local people when thinking about care improvement

GP
413 mentions

Hospital
113 mentions

Dentist
55 mentions

Mental health
49 mentions

Community services
27 mentions

Social care
23 mentions

Good care is: accessible

807 mentions from 522 respondents

Improved booking systems
59 mentions

Availability of appointments
236 mentions

Adequate staffing
28 mentions

Accessibility- disabled patient
24 mentions

Affordable care
23 mentions

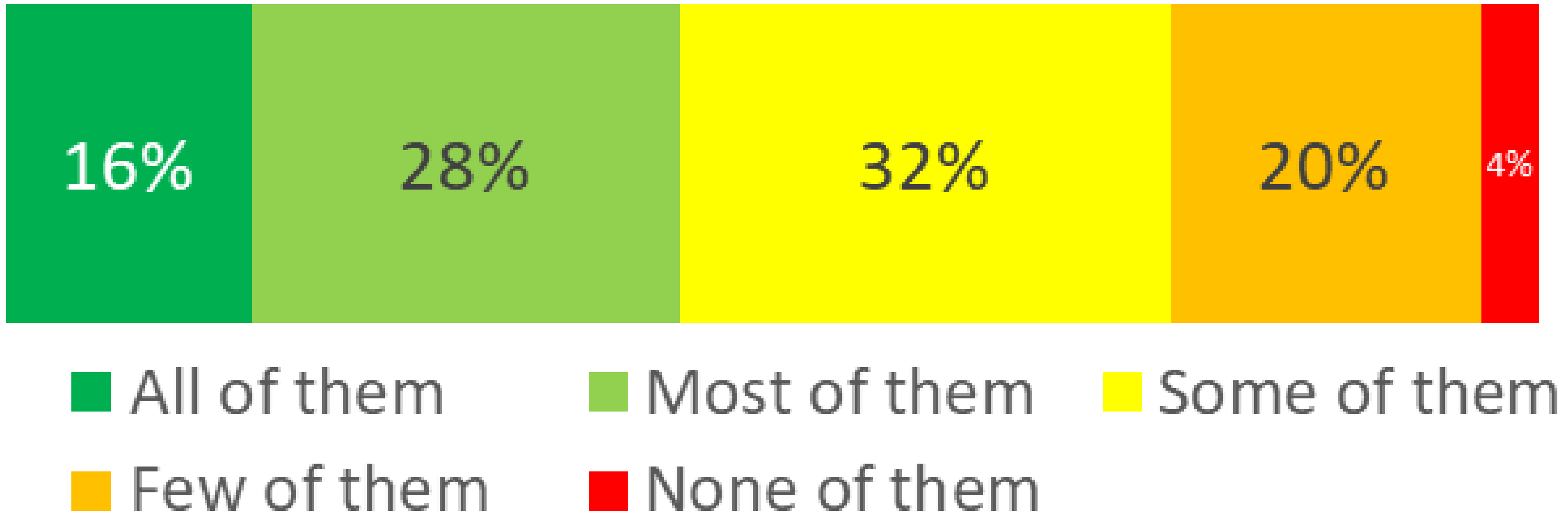
Convenient locations
21 mentions

Convenient opening times
10 mentions

Good care is: accessible

How important is it for you: Getting the care you need when you need it?

Professionals looking after me: Are available to provide the care I need when I need it



More likely to find professionals are available:

- Parents of children under 18
- Retired people
- Muslim religion

Less likely to find professionals are available:

- Patients with a long-term condition
- In very poor health
- Disabled people and their carers
- Neurodivergent
- LGBT
- Struggling financially

Good care is: accessible

What would indicate accessible care?

- Patients can reliably access both routine and urgent care within a reasonable time frame, commensurate with their clinical urgency.
- There are multiple equally reliable ways of booking appointments, taking into account both the needs of those who are most comfortable using online services and of those who are digitally excluded.
- Services are available locally or within reasonably commuting distance; the needs of patients who don't drive are taken into account.
- Services are available at different times, to meet the needs of patients who work full-time, as well as those who work irregular shifts/ non-standard hours and those with caring responsibilities.

What would NOT happen

- Patients going to A&E for issues that could have been dealt with by a GP or primary care walk-in centre.
- Over-stretched telephone lines, associated with attempts to implement a one size fits all booking system.

> *Getting a doctor's appointment when needed, not 4-6 weeks later.*
>
> *Better access to GP appointments, nothing more stressful than being on re-dial just to get into a queue. Plus on line appointments get taken so quickly.*
>
> *The services at King George Hospital to be extended, the travel to Queens is very stressful .*

Good care is: accessible

Solution for increasing accessibility: walk-in primary care, no appointments

25 respondents brought up a desire for urgent primary care to be available on a non-appointment basis, for example in urgent care centres,walk-in centres or even an online live chat facility.

Out of hours service is good but even they don't always have appointments. Appointments do need to be available in the evening to and we need to get referrals.

Have a 24/7 drop in local NHS live discussion web site with a couple of professionals (i.e. MDs, psychologists, nurses, etc.) Obviously it would be made clear it is not for treatment or emergency information.

More GP surgeries and services and walk in centres to take the pressure of A&E.

I can remember over 50 years ago when you just waited in the surgery to be seen by the doctor, they even had magazines to read to pass the time. Nowadays it's all "Call us at 8am " and hope you get a call back.

Better access to GPs and healthcare facilities, walk in hubs that people can access which run 24/7 so less pressure on A&E and less serious illnesses can be seen/sorted quicker. This will of course require more staff who need to be paid fair wages

Senior citizen local NHS hubs for "minor" ailments like hearing and foot problems. Mole checks and dermatitis, blood tests and fitness aids. You seem to have forgotten us.

Scrap appointments at the GP and have a golden hour where if you are in the surgery by a certain time you will be seen. This used to work and now you can not get appointments for over 3 weeks.

To have a nearby 7/7 medical drop-in centre open long hours with short waits to see either highly qualified nurses or doctors.

Good care is: accessible

What would indicate accessible care?

- All health and care services that patients need are free or affordable; no one has to go without necessary care because of the cost.
- Hidden costs of care are taken into account and minimised (for example: the cost of transport to healthcare facilities or of accessibility equipment)
- Services understand and accommodate the needs of disabled patients; including awareness of mental health-related disability, and of complex needs arising from multiple forms of disability.
- Services understand any other forms of barriers to accessing care (language barrier, digital exclusion, general literacy, knowledge of the system, cultural issues, domestic violence) and take steps to mitigate them.

What would NOT happen

- Patients paying for private healthcare they struggle to afford, because NHS care is too difficult to access.
- Patients going without the care they need (dental treatments, domiciliary care, etc.) because they cannot afford it.
- Patients going without the care they need because they struggle with the process of accessing it.

> *Can't access social care because the council charges for it (all of PIP and part of my ESA) leaving almost nothing to live on.*
>
> *I need more support to access healthcare, as my mental health prevents it.*

Focus on: Deaf BSL users

A focus group conducted by Healthwatch Redbridge with BSL users provides examples of how services can fail to be accessible.

One participant expressed they had requested an interpreter for an appointment (Whipps Cross) but has had to wait a very long time for reply.

A participant experienced issues with interpreters in A&E (Whipps Cross). Sensory Specialists had to talk to triage about Deaf awareness. They eventually got a video BSL interpreter.

A GP practice told a participant there were no BSL interpreters or entitlement to them. There was also information for BSL access. The participant explained there was a poster in the practice about BSL, but the GP got defensive and said they didn't know.

A participant said they received two letters for a hospital appointment (Whipps Cross) that didn't explain the nature of the appointment. There were no instructions on how to make contact in an accessible way. Sensory Specialists had to make contact to find out what it was about, and the appointment date kept getting pushed back and no interpreter confirmed.

A participant had a child recently. (King George and Queens hospitals) didn't have an interpreter for any maternity appointments, despite telling them she needed one. All communication had to happen on paper; her written English is basic to conversational.

They're not asking deaf people if they're getting what they need. It's frustrating accessing services. (Whipps Cross) is awful for pregnancy and childbirth (maternity services), specifically, there's an individual in that team who is horrible. She needs to be sacked because she is so discriminatory… Antenatal clinic is not accessible and will only offer appointments with interpreters during weekdays, but others can access evenings and weekends. I think it's because they don't want to pay more for interpreter out of hours.

Solution for increasing accessibility: health advocacy/ support in the community

I personally want someone to come over for home visits for support like giving advice on mental health and depression problems for the people from aged 30-40, years after giving birth to a child. Because I have seen many people in my communities that they're not really able to go out and not allowed to seek help from outside because of the family they're living with. For example- for a mum living with her mother and father in laws and a big family. There's many times I have heard that the family is giving the mum mental headache, forcing her to do all the work at home. In this case a mum needs some sort of help from GP or other clinics services. So it would really help people to access the services from home maybe if any professional could come over for home visit and do any fun activities with mum and dad.

Bangladeshi woman, aged 18 to 24

They should explain everything that I need to know, and offer support if I don't know how to do certain things - such as filling out forms. A lot of people are illiterate and can't do that - the system should help you proactively As it is, people have to pay private services or ask friends and family for help with that.

Romanian woman, aged 50 to 64

We need to be proactive in targeting at-risk communities in relation to access to health and care services. Not being reactive but be strategic to help these communities

Men's focus group, Barking and Dagenham

Health and care services could also be offered in faith settings.

African & Caribbean focus group, Barking and Dagenham

A Deaf mother had a good experience with a specific midwife, who listened and took on board that she was Deaf. The midwife booked lots of appointments for her and they were proactive in making sure there was always an interpreter for appointments. She took it on responsibility for her care directly and gave the participant a direct text number.

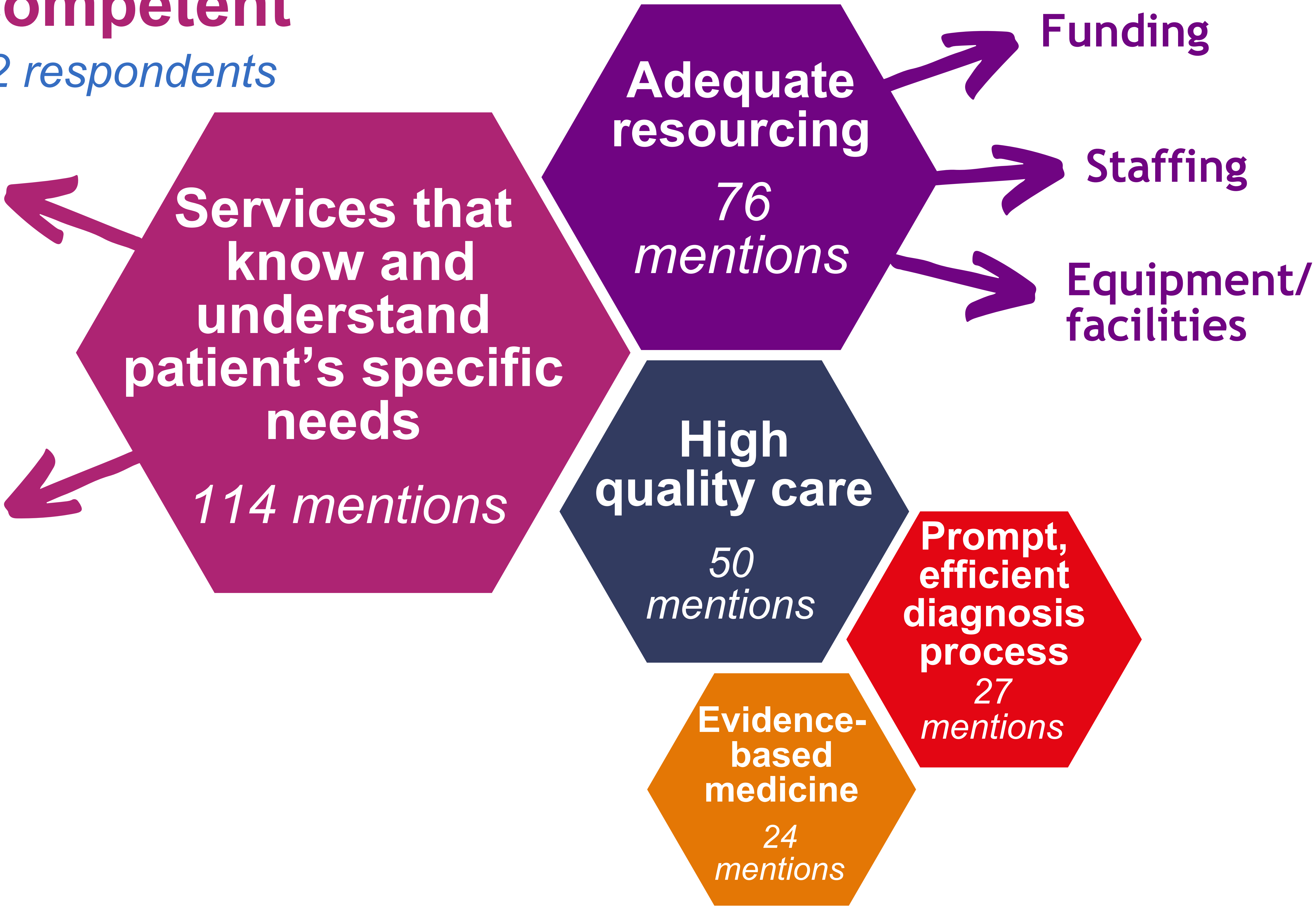
BSL users focus group, Redbridge

There's organizations or smaller organizations that are out there that are offering free counselling, they just don't know about them. The information about what's offered is supposed to be trickled down, filtered down the lines of connection to the residents that need it. But is it really happening? As much as we think it should, because it's still not reaching certain people, or certain people don't know that the services are available.

African & Caribbean men's focus group, Hackney

Good care is: competent

337 mentions from 262 respondents



Services that know and understand patient's specific needs

114 mentions

Medical needs - specific conditions

Cultural and social needs- how personal circumstances impact care

Adequate resourcing

76 mentions

Funding

Staffing

Equipment/ facilities

High quality care

50 mentions

Prompt, efficient diagnosis process

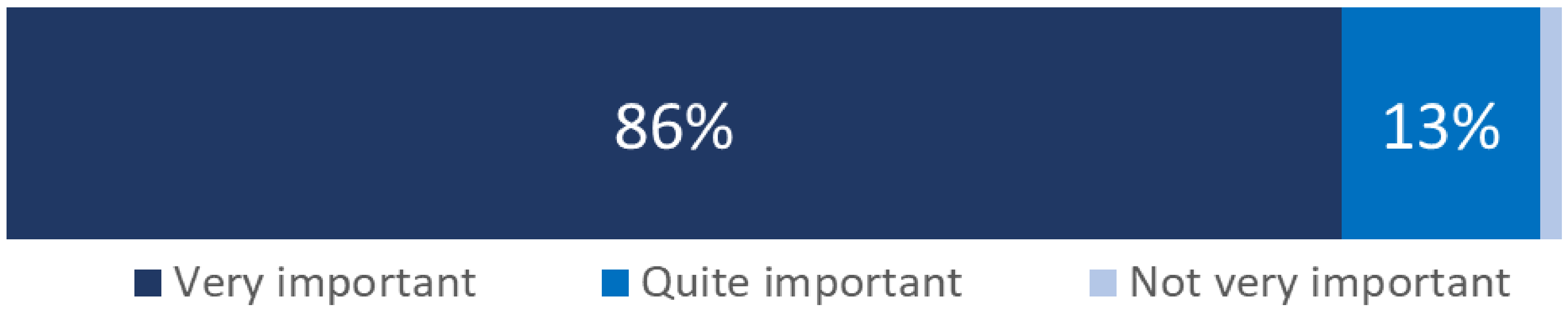
27 mentions

Evidence-based medicine

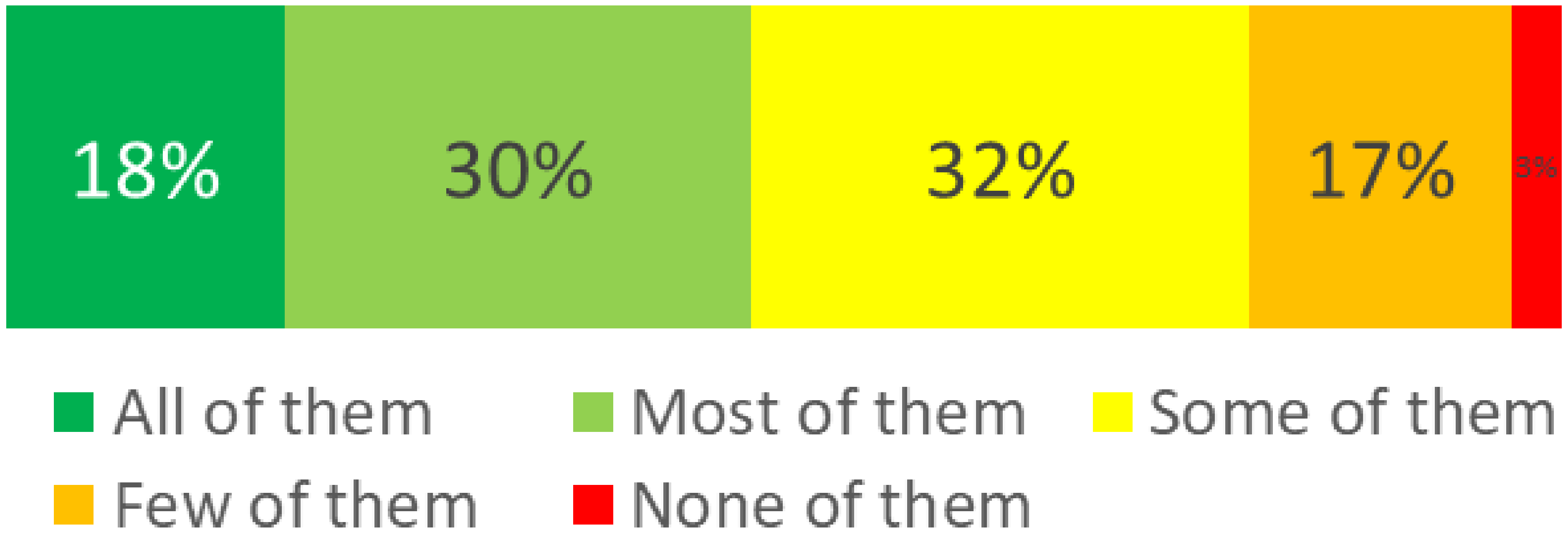
24 mentions

Good care is: competent

How important is it for you:
Being cared for by people who understand my specific needs



Professionals looking after me:
Understand my specific needs



More likely to find professionals understand their needs

- Aged under 25
- South Asian ethnicities
- Very comfortable financially

Less likely to find professionals understand their needs

- Patients with a long-term condition, especially those with mental health issues.
- Disabled, especially those with learning, sensory or mental health-related disabilities.
- Neurodivergent
- Eastern European ethnicities
- Digitally excluded

Good care is: competent

What would indicate competent care?

Professionals providing health and care services have up-to-date, in-depth knowledge of the conditions they are treating.

Professionals providing health and care services have a good working knowledge of patients' conditions, even outside their area of specialty, to the extent they impact patients' access to care, care needs and general wellbeing.

Professionals providing health and care services have a good working knowledge of health inequalities, social inequalities and cultural issues that may influence patients' access to care.

> *As a woman, I think there is an awful lot more that can be done to support women with pain and mental health issues. More information about menopause and fertility issues - don't just fob us off without exploring what can help us!*

Specific areas of training identified as needed/ important

- Mental health and mental health-related disability.
- Neurodiversity, particularly autism.
- Sensory disabilities.
- Women's health, particularly around menopause, endometriosis and severe period pain.
- The "younger older people" cohort- age 50 to 64.
- LGBT health and culture.

Go on a course about LGBT people and take it to heart. Don't make assumptions about what queer people look like.

Understand autism and make adjustments. Staff currently don't!

Better deaf awareness eg lowering face mask, facing me when speaking Better understanding of the physical effort of attending appointments Better understanding that a patient may have multiple different needs eg someone under psychiatric care may also have hearing loss etc - being sensitive to multiple needs at once

Good care is: competent

What would indicate competent care?

- Patients being diagnosed accurately and within a reasonable timeframe.
- Availability of necessary investigations for ensuring accuracy of the diagnosis process.
- Patients receiving treatment informed by the NICE guidelines, and by the latest evidence-based developments in medical science.

> *You need expert information to be understood. You need to know what you're talking about. It's knowing where you are in the system, how long it will take and what's appropriate to do while you wait. Provide services according to NICE guidance. It seems they can't do that at the moment because of money, staff or lack of knowledge.*
>
> *Healthcare professionals need to have an understanding that negative test results don't mean that symptoms are not life changing.*

What would NOT happen

- Excessively long waiting times for diagnosis/ investigations.
- Admin issues affecting the diagnosis process, such as lost test results.
- Misdiagnosis as a result of superficial consultations or lack of knowledge.
- Lack of support with symptoms during an ongoing/ potentially long diagnosis process.
- Clinical decisions being taken based on factors such as budget constraints or professional's own cultural biases, rather than clinical need and scientific evidence.

> *"Some health professionals' culture and religion comes first, rather then what the young people are telling you, if you are asking for contraception they look at you like you should not ask for it, as its obviously against their religion to have sex before marriage.*

Focus on: women‘s health

No one gives a stuff about women's health. It's under researched and under valued. Not sure why frontline staff should model good behaviour on this when powers that be don't.

The GP or Health Professional actually listening and looking; being able to see a professional face to face; better knowledge of women's health i.e. menopause, and vulval conditions, as well as heart health.

I have found that male doctors often don't appreciate challenges faced by women regarding female health care. Eg one doctor didn't provide any pre warning when inserting a speculum, didn't offer a modesty blanket or a tissue to wipe down afterwards which I don't believe would ever happen with a female. However I have also had positive experiences with male gynaecologists.

IAs a post menopausal woman I want better services tailored to support my specific needs, not to get the standard treatment. I also think there needs to be much better personalised advice about food - e.g. like Dr Tim Spector and the Zoe programme.

Focus on: LGBT health

I have never understood why various healthcare professionals, especially prior to operations, ask me "are you sexually active?". What is actually being asked, because as a gay woman who's never had sex with a man, do you really need to know if I have sex with my female partner, or even masturbate? Or this is actually about possible pregnancy, which is a different question? I feel that this is a question that could be rephrased to better support LGBT patients. When I was a First Aider, I was taught to ask, "is there any possibility you might be pregnant?" which is much clearer, much more relevant and more inclusive of gay women.

Talk to each other, have dedicated female care specialists that you don't have to travel excessively or pay private to use and the ability to understand my lifestyle as an LGBT member of society that isn't a gay man who has multiple partners

Educate themselves about Lesbian, Gay, Bisexual and Trans issues. Learn about racism in a realistic way. Learn the definition of Intersectionality - that some people are Black AND queer AND old AND disabled at the same time.

Good care is: person-centered

294 mentions from 394 respondents

Collaboration beyond health and care
14 mentions

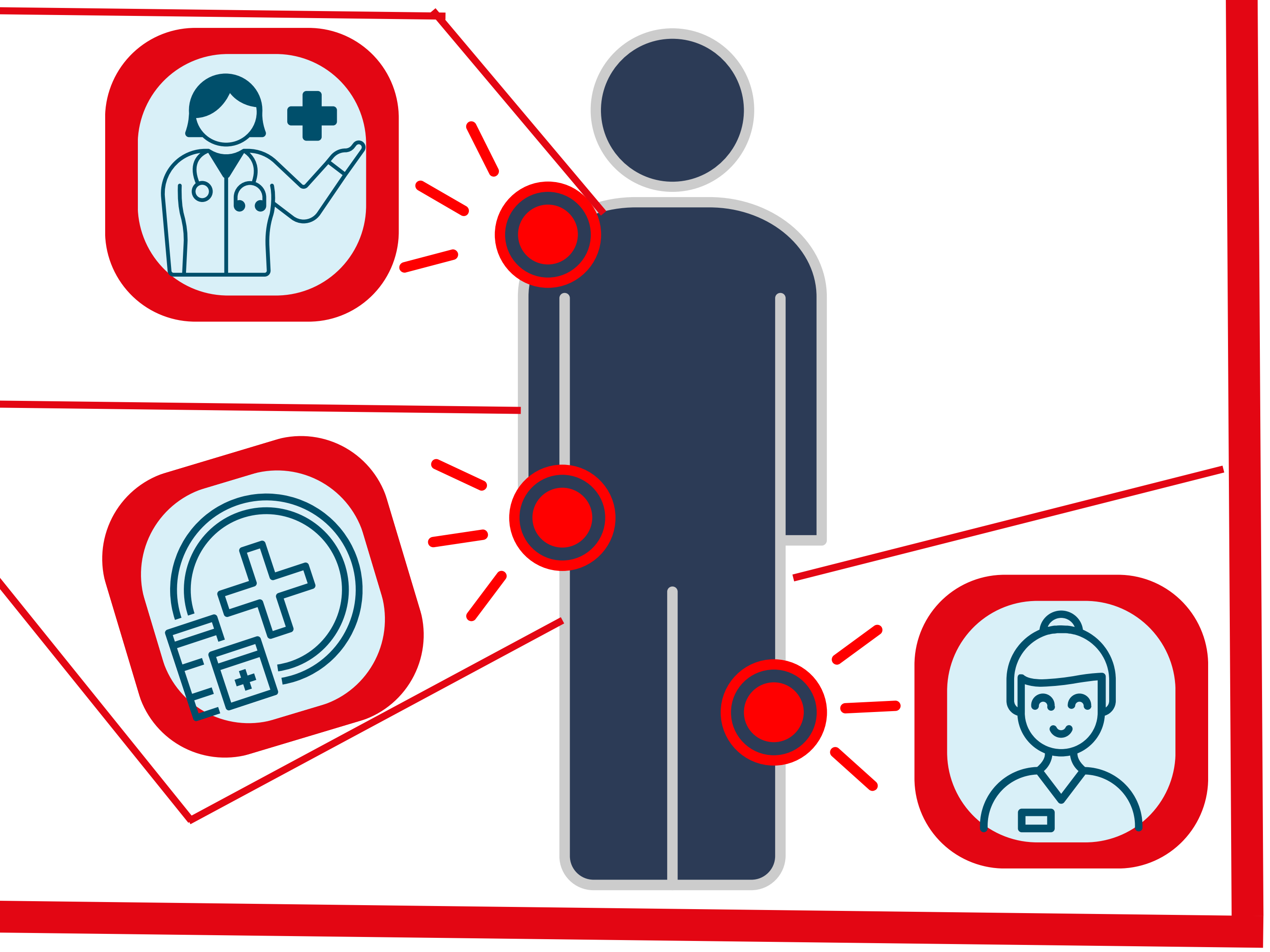
Continuity of care
74 mentions

Health and care services working with each other
125 mentions

Holistic approach to care
37 mentions

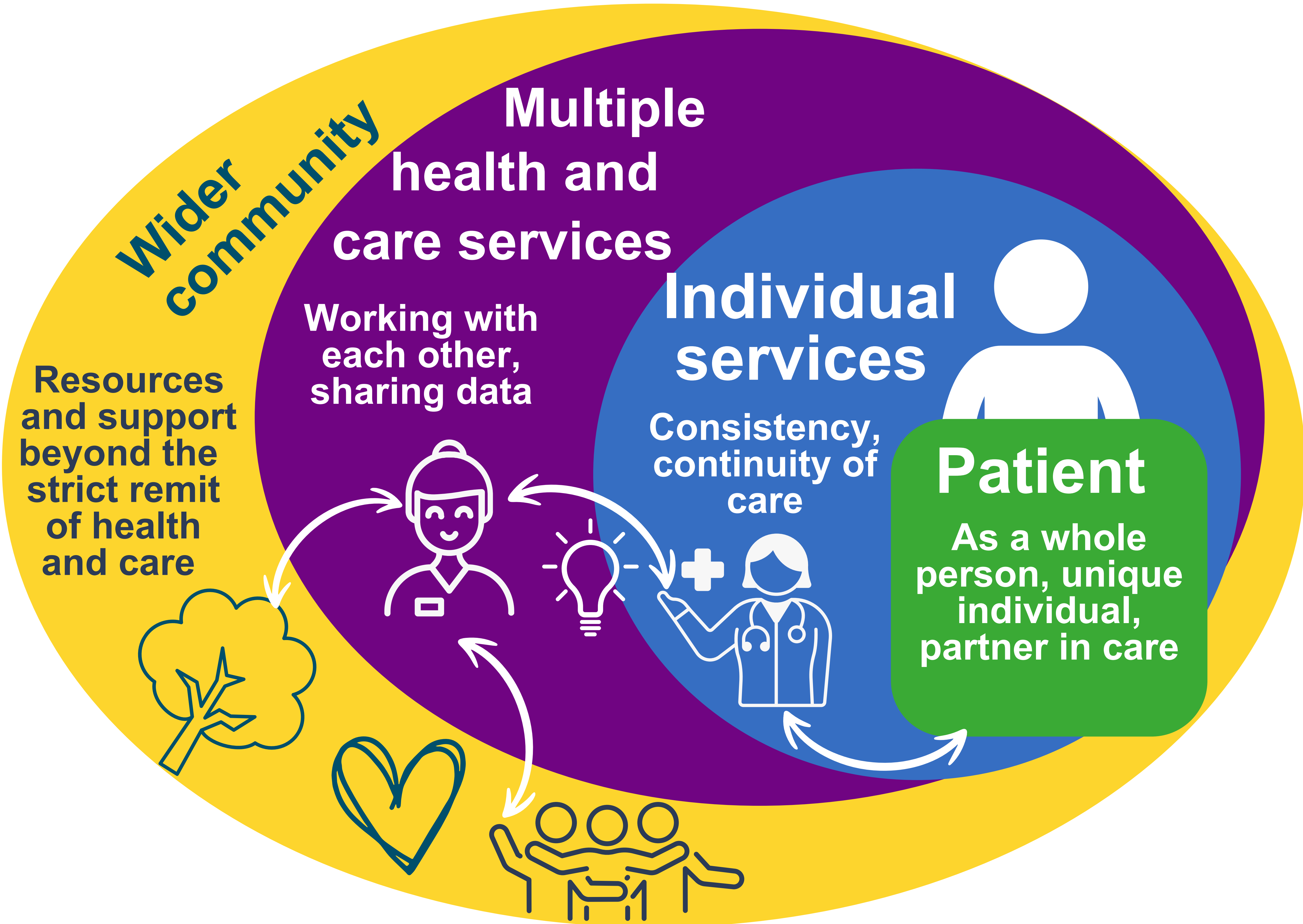
Patient involvement in treatment options
58 mentions

Condition-centered care



Treat me as a patient, not a disease.

Person-centered care



Wider community

Resources and support beyond the strict remit of health and care

Multiple health and care services

Working with each other, sharing data

Individual services

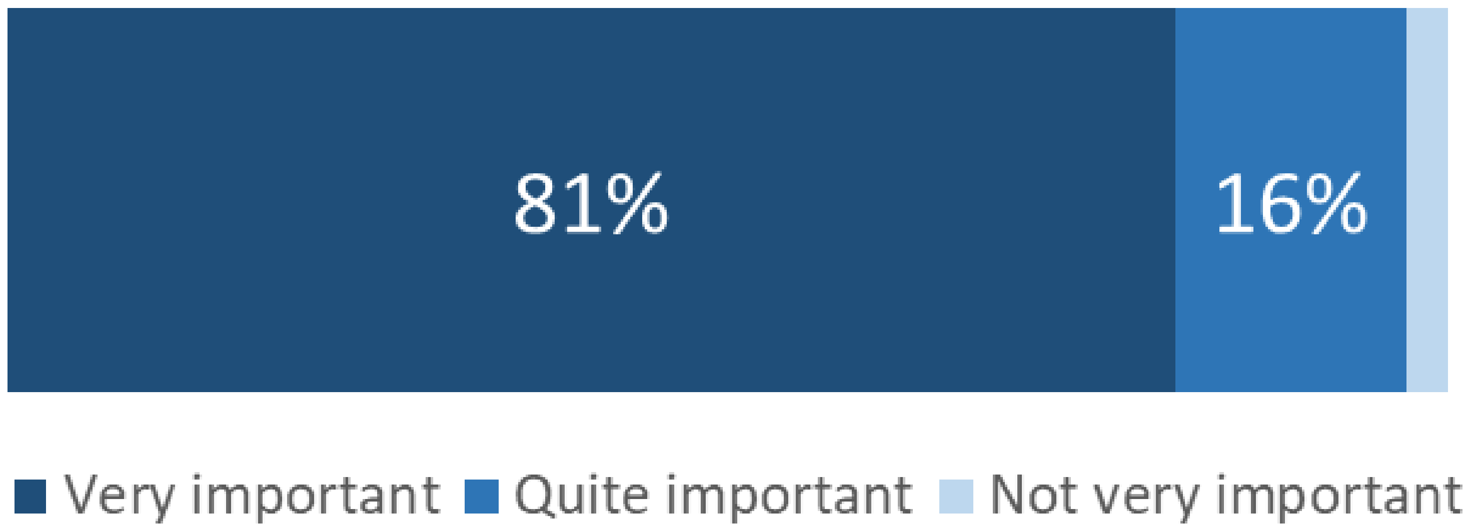
Consistency, continuity of care

Patient

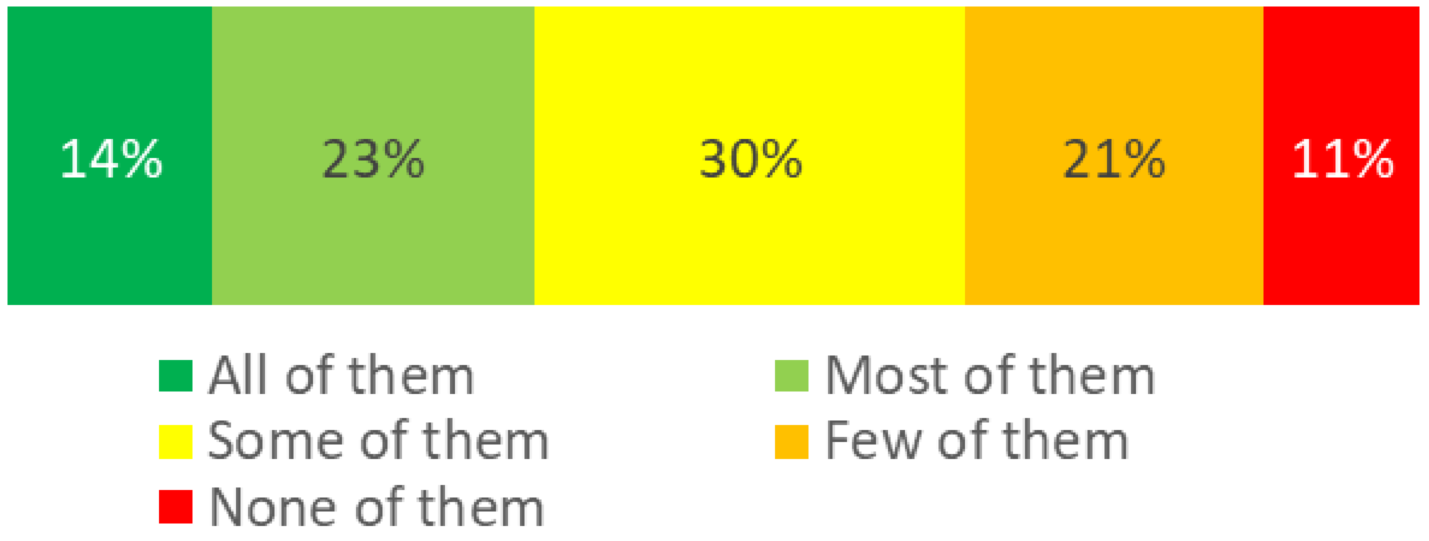
As a whole person, unique individual, partner in care

Good care is: person-centered

How important is it for you: Knowing that different services supporting you work well together



Professionals looking after me: Work well together



More likely to find professionals work well together

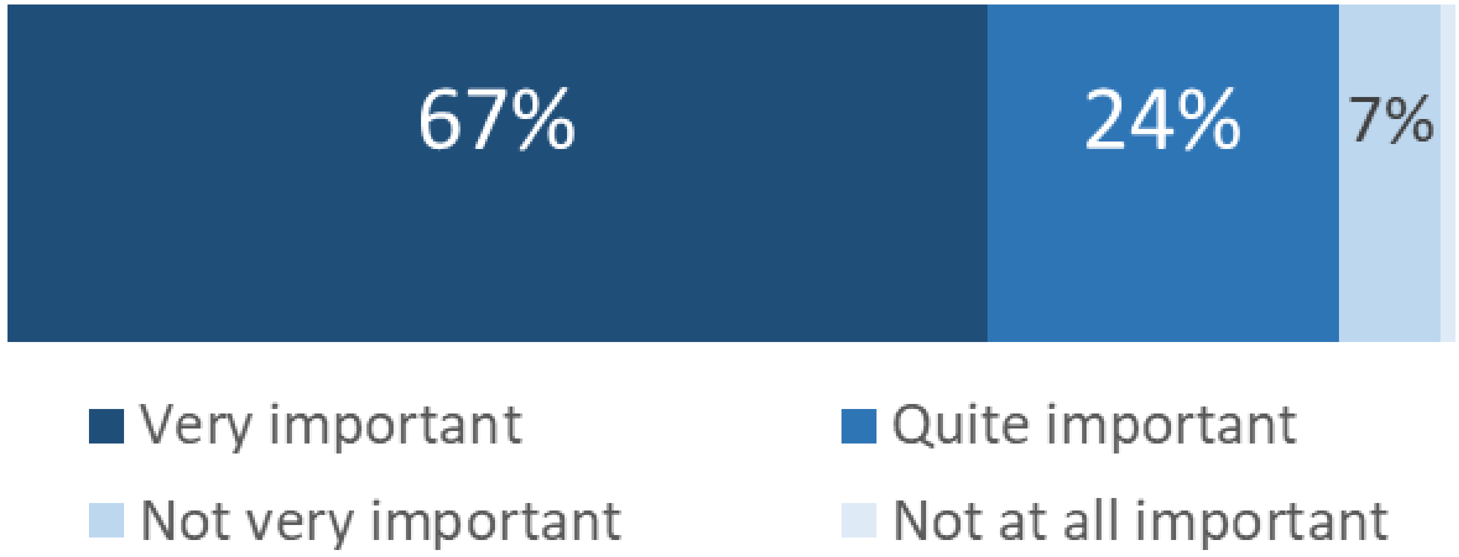
- Aged 65+
- South Asian ethnicities

Less likely to find professionals work well together

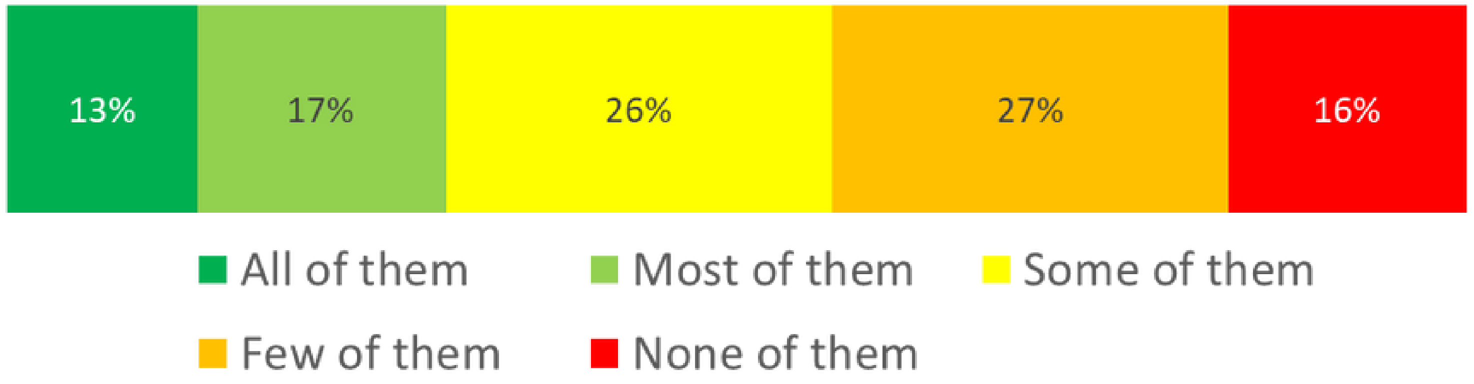
- Patients with a long-term condition, especially those with mental health issues.
- In poor health
- Disabled patients and their carers
- Neurodivergent
- Aged 25 to 49
- LGBT
- Struggling financially

Good care is: person-centered

How important is it for you:
Not having to tell your story or explain the same issue lots of times to lots of different people.



Professionals looking after me:
Communicate with each other, so that I don't have to repeat myself



More likely to find they can avoid repeating themselves

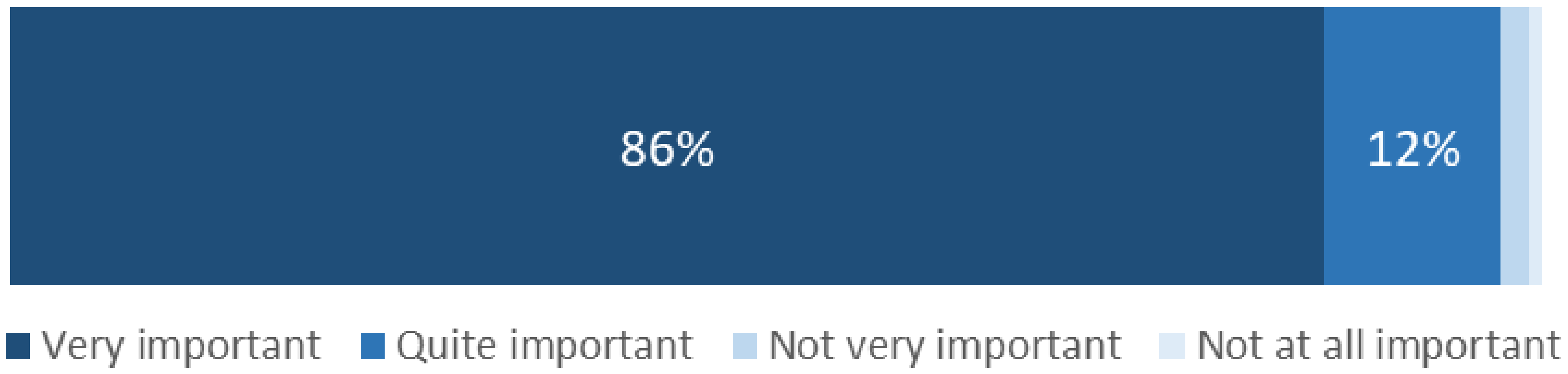
- Aged under 25
- South Asian ethnicities

Less likely to find they can avoid repeating themselves

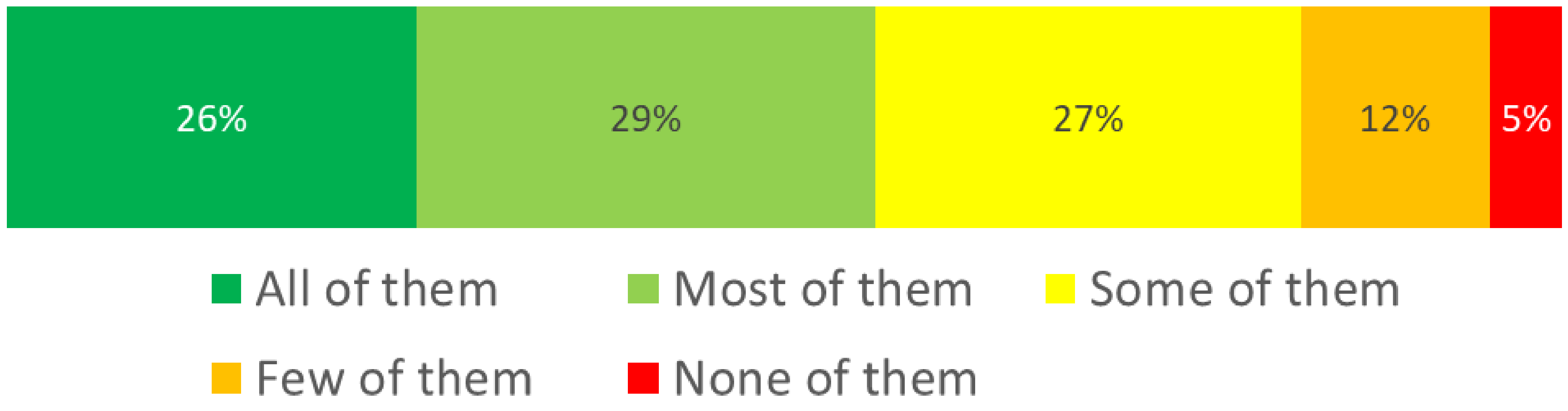
- Mental health condition
- In poor health
- Disabled patients and their carers
- Neurodivergent
- Eastern European ethnicities
- LGBT
- Just getting by or struggling financially

Good care is: person-centered

How important is it for you: Being involved in decisions about your own care



Professionals looking after me: Involve me in decisions about my own care



More likely to feel they are involved in their own care

- South Asian ethnicities
- Financially comfortable

Less likely to feel they are involved in their own care

- Living with a long-term condition
- In poor health
- Black Caribbean ethnicity
- Digitally excluded

Good care is: person-centered

What would indicate person-centred care?

- Patients get to see a the same medical professional consistently (for example the same doctor or midwife), as much as it is practical.
- When patients see different medical professionals within the same service or there is a staff turnover, notes and patient records are passed down and read. Quality of care remains constant regardless of who is delivering the care.
- Referrals between different services are issued as needed and processed promptly; services share medical records and information seamlessly.
- Health and care services actively working with the wider community to promote holistic patient health - social prescribers, the voluntary sector etc.

What would NOT happen

- Patients receiving contradictory information from medical professionals.
- Patients feeling like the level of care they receive is dependent on whom they get to see on any given day.
- Patients having to repeat information that should be in their medical records or notes already.
- Patients feeling like they are passed around between services with no actual help.

> *Often health care providers give contradictory information which is frustratingly vague and confusing*

Good care is: person-centered

What would indicate person-centred care?

- Patients feeling that thy are treated as a partner in their own care; and that medical professionals are interested in their own desired health outcomes.
- Health and care professionals giving patients clear options for treatment or care, pesented objectively with pros and cons; empowering them to make informed decisions.
- Health and care professionals taking a holistic approach to patients' health rather than examining conditions and symptoms in isolation.
- Patients get a choice about where and how they access care (using online services, having remote consultations or doing everything in person)

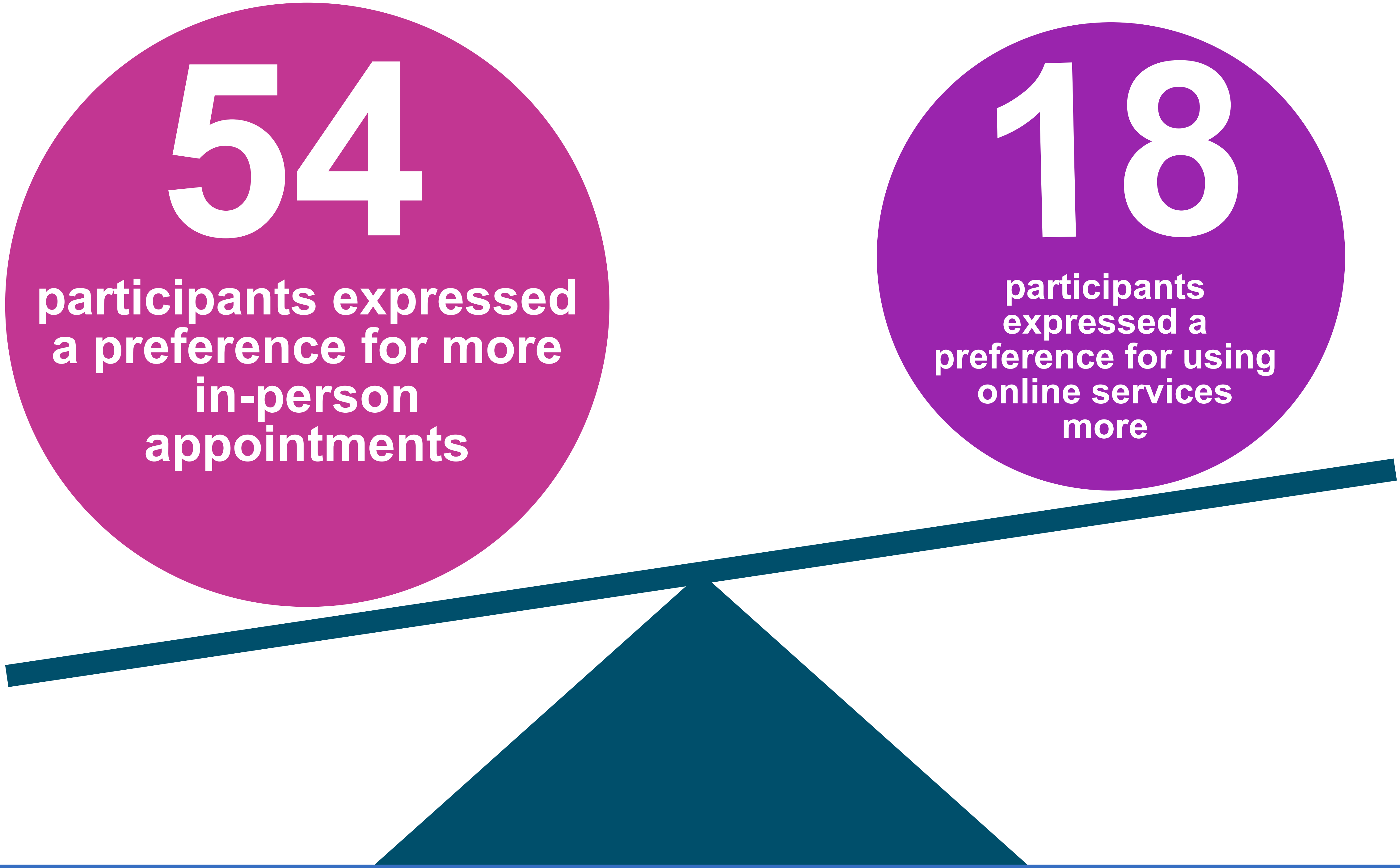
What would NOT happen

- Patients feeling like they don't have sufficient information to make informed decisions about their care.
- Patients only being allowed to discuss one symptom or condition per appointment.

> *Involve me in everything about me and make communication easier and transparent .*
>
> *I need to know that I am listened to, and have more choices than just 'box-ticking' options like CBT when it isn't suitable.*

Good care is: person-centered

Giving patients more choice over where and how they have appointments could be key to improving accessibility of care.



54

participants expressed a preference for more in-person appointments

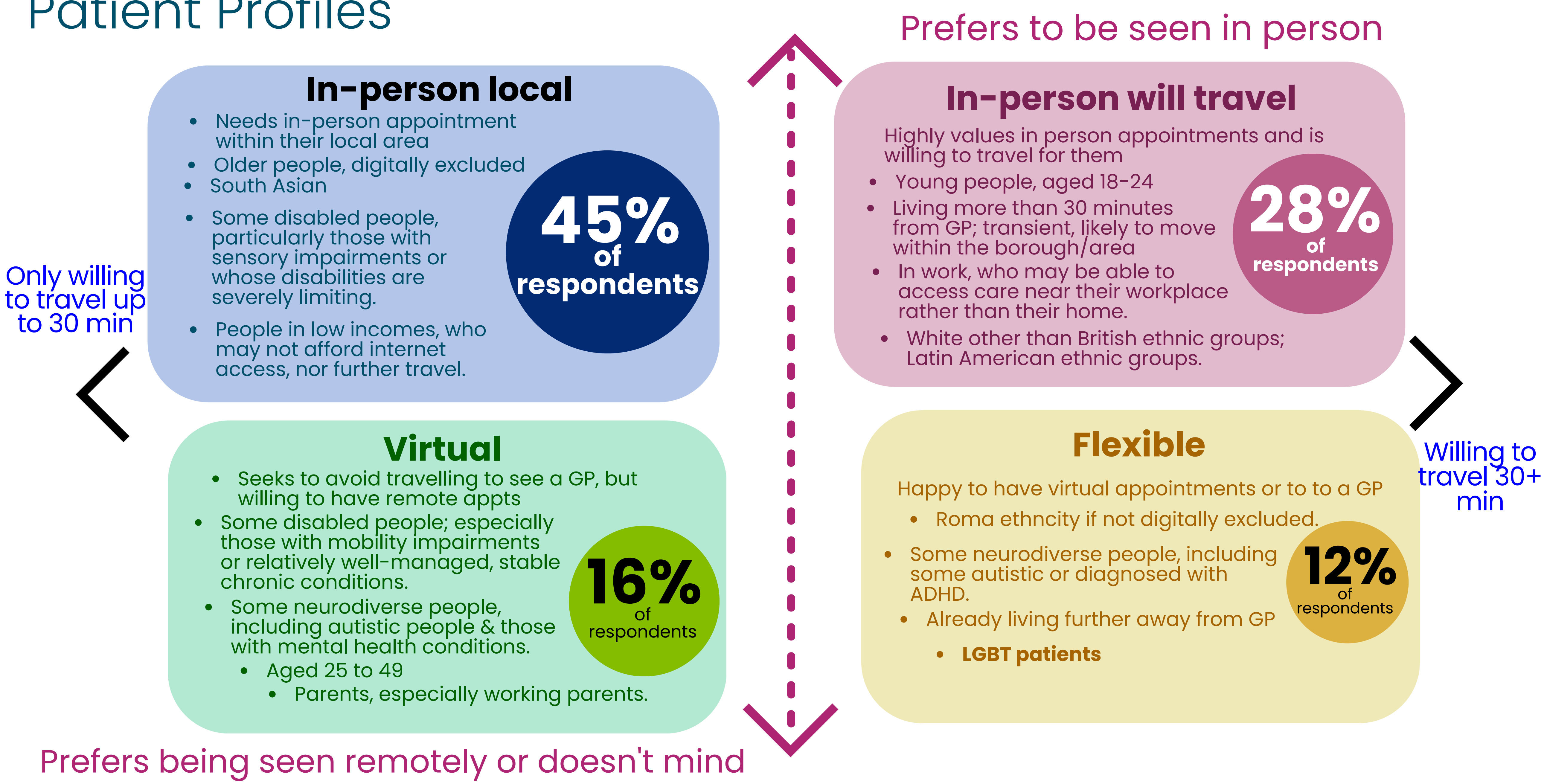
18

participants expressed a preference for using online services more

Good care is: person-centered

We have previously analysed data on where and how patients want to access GP appointments. Findings are consistent with the findings of this survey.

Patient Profiles



Prefers to be seen in person

Prefers being seen remotely or doesn't mind

Only willing to travel up to 30 min

Willing to travel 30+ min

In-person local

- Needs in-person appointment within their local area
- Older people, digitally excluded
- South Asian
- Some disabled people, particularly those with sensory impairments or whose disabilities are severely limiting.
- People in low incomes, who may not afford internet access, nor further travel.

45% of respondents

In-person will travel

Highly values in person appointments and is willing to travel for them

- Young people, aged 18-24
- Living more than 30 minutes from GP; transient, likely to move within the borough/area
- In work, who may be able to access care near their workplace rather than their home.
- White other than British ethnic groups; Latin American ethnic groups.

28% of respondents

Virtual

- Seeks to avoid travelling to see a GP, but willing to have remote appts
- Some disabled people; especially those with mobility impairments or relatively well-managed, stable chronic conditions.
- Some neurodiverse people, including autistic people & those with mental health conditions.
- Aged 25 to 49
- Parents, especially working parents.

16% of respondents

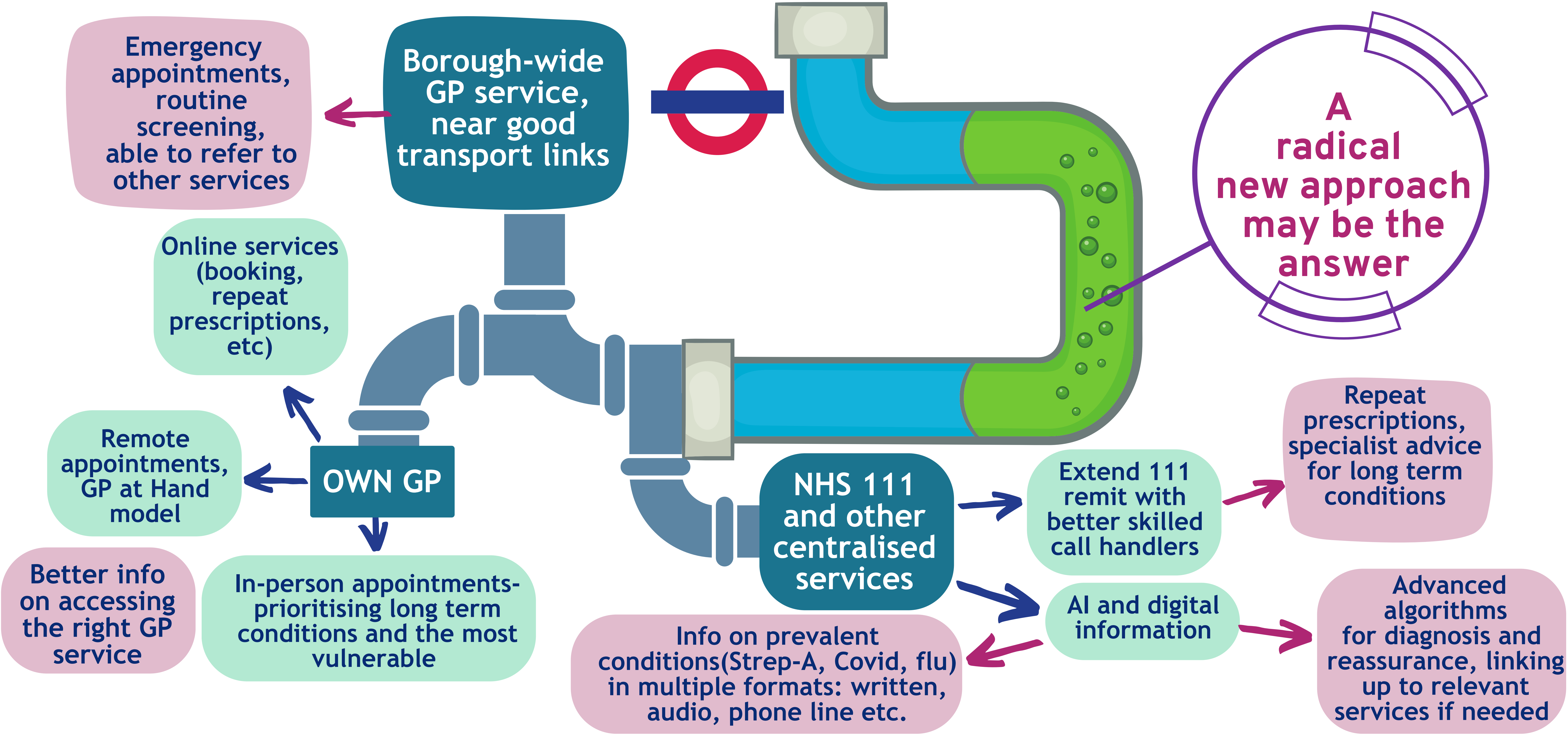
Flexible

Happy to have virtual appointments or to to a GP

- Roma ethncity if not digitally excluded.
- Some neurodiverse people, including some autistic or diagnosed with ADHD.
- Already living further away from GP
- **LGBT patients**

12% of respondents

Unblocking the pipeline



Emergency appointments, routine screening, able to refer to other services

Borough-wide GP service, near good transport links

Online services (booking, repeat prescriptions, etc)

Remote appointments, GP at Hand model

OWN GP

Better info on accessing the right GP service

In-person appointments- prioritising long term conditions and the most vulnerable

NHS 111 and other centralised services

Extend 111 remit with better skilled call handlers

Repeat prescriptions, specialist advice for long term conditions

AI and digital information

Info on prevalent conditions(Strep-A, Covid, flu) in multiple formats: written, audio, phone line etc.

Advanced algorithms for diagnosis and reassurance, linking up to relevant services if needed

A radical new approach may be the answer

Good care is: trustworthy

765 mentions from 445 respondents

Listening to patients, honest and empathetic care
494 mentions

Communication
110 mentions

Anticipative, not just reactive care
35 mentions

No gatekeeping
29 mentions

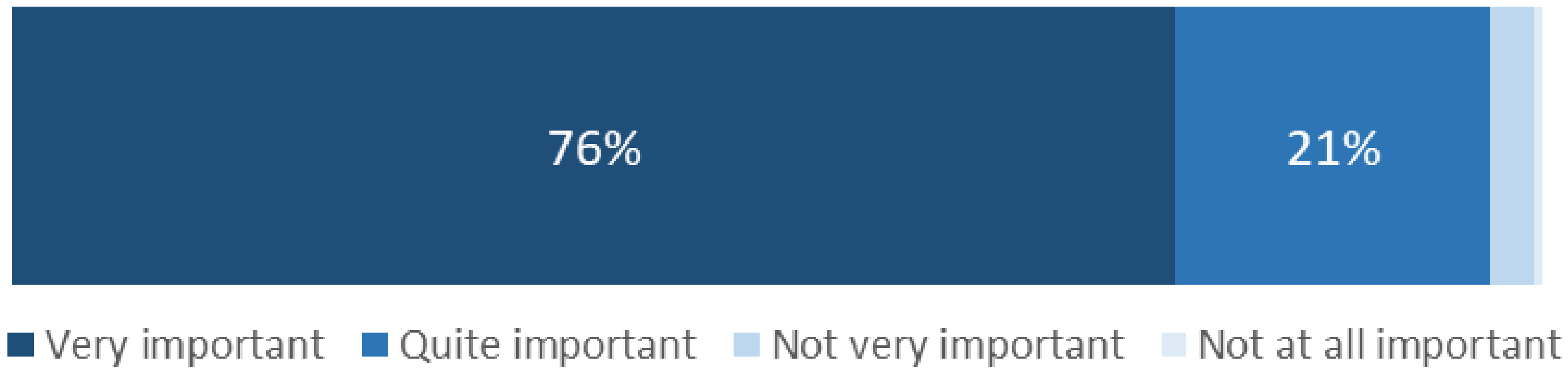
Reassurance, supported self-care
20 mentions

Follow-on, ongoing support
19 mentions

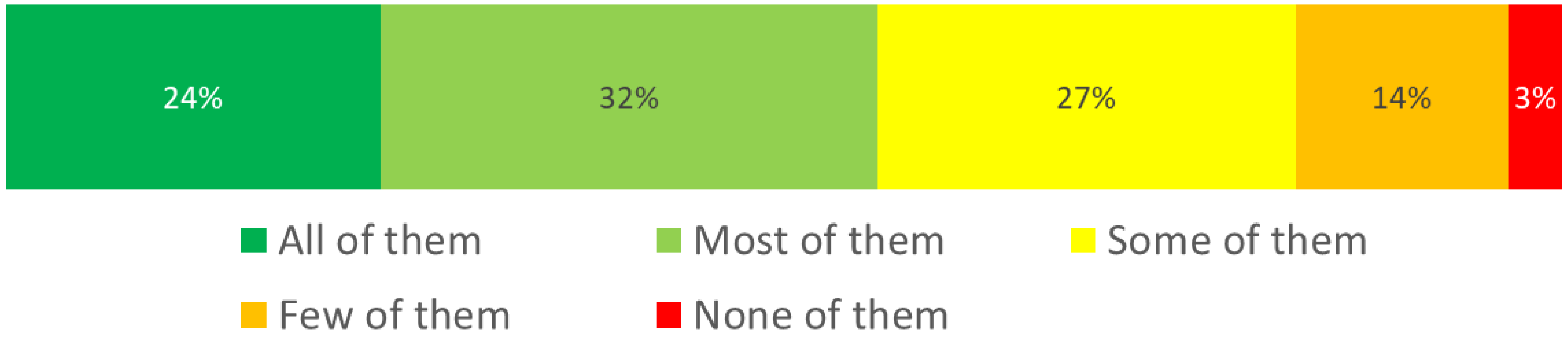
Accountable care
13 mentions

Good care is: trustworthy

How important is it for you: Receiving information in a way that's easy to understand



Professionals looking after me: give me information that's easy to understand



More likely to feel they receive good information

- Aged under 24
- Financially very comfortable

Less likely to feel they receive good information

- Mental health condition
- Disabled
- Neurodivergent
- Digitally excluded

Good care is: trustworthy

What would indicate trustworthy care

- Patients feeling listened to and reassured that their problems are taken seriously by care professionals; being given adequate time .
- Health and care services proactively engaging with patients and asking about what is important to them.
- Patients having someone they can turn to for competent advice, reassurance and prevention.
- Patients communicating with professionals about their care, in a honest, straightforward manner; understanding why they are offered a certain curse of action.
- A simple, straightforward and transparent process for accessing care.
- Services demonstrating accountability and acting upon feedback received from patients.

What would NOT happen

- Patients feeling like they are fobbed off or their concerns are dismissed.
- Patients feeling that they are treated like a burden; feeling discouraged from seeking care or asking questions.
- Consultations feeling more like a tick-box exercise than like a consultation.

> *I want someone who will look at me and listen to what I need. Not stare at a computer screen. They used to have time to do that.*
>
> *Generally people are helpful, however what tends to be missing in hospital consultations is explanation: what might be wrong; what tests are being done and why; what the tests can tell you; and what the pathway then is.*

Good care is: trustworthy

Focus on trust, communication and avoiding gatekeeping

Imagine this situation: You contact your GP, believing that you may need antinbiotics or further investigation for new, acute symptoms you are experiencing. Your GP offers ou a same-day telephone consultation; then they advise you to take paracetamol and keep monitoring your symptoms, and to let them know if they persist or get worse.

How would this outcome make you feel? Would you be reassured and relieved that you don’t need antibiotics after all, or would you feel fobbed off and ignored? The answers likely depends on how trustworthy the care you receive from your GP usually is.

→ **Do you understand why you received the advice/ course of treatment that you did?**

→ **Do you feel like this advice came after you were adequately listened to and understood?**

→ **Do you feel confident that if your symptoms don’t improve you will be able to get back in touch, and get an alternative solution within a reasonable time frame?**

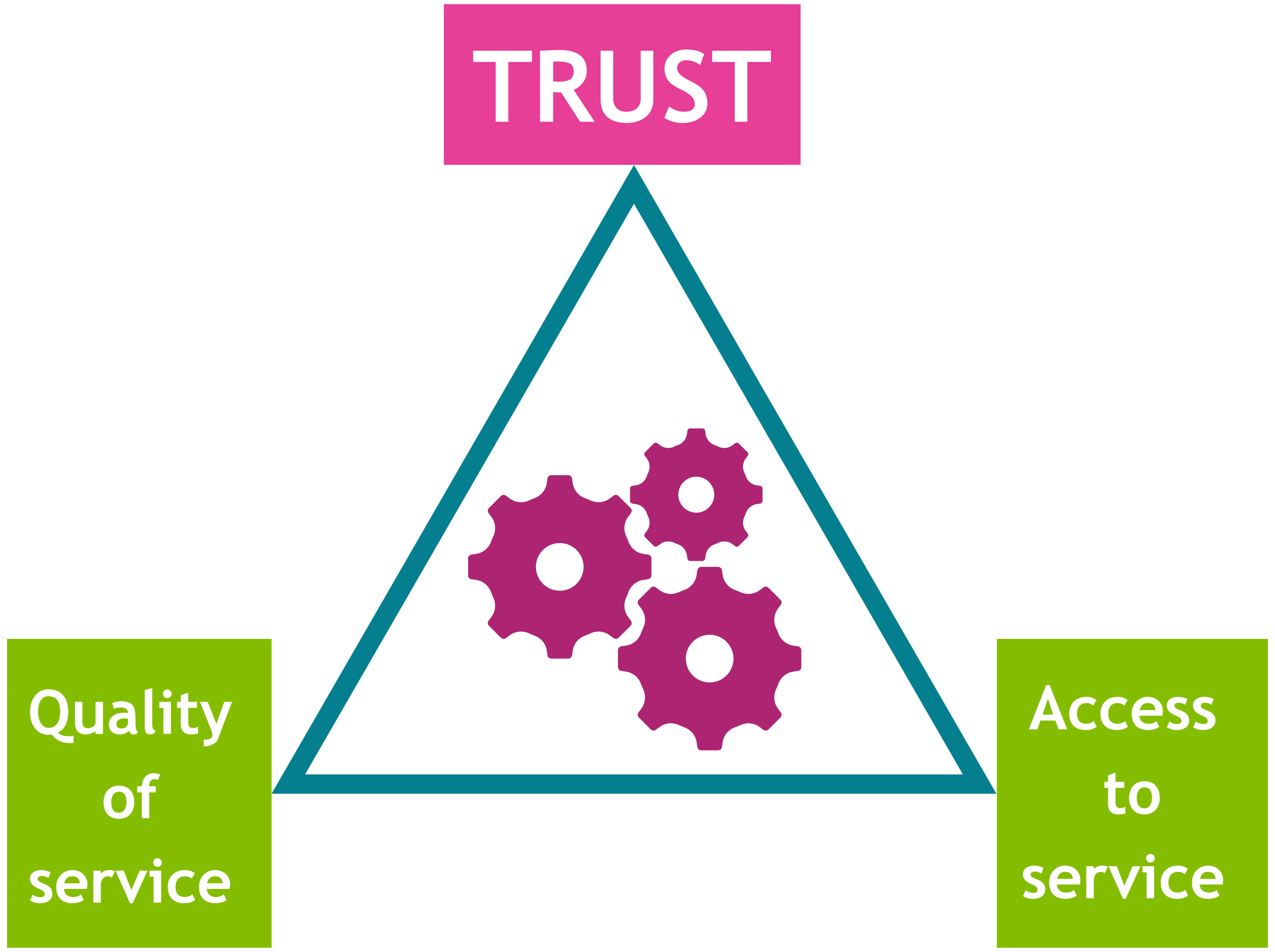
Make sure the 'patient'/client becomes the focus not trying to fob them off to save money. Listen to their needs not ignore the phone.

Good care means consistent contact with health services, open and honest communication and a holistic approach to health and care.

All the new information they know as doctors - they should share it with the public. Give you options for what you can do to manage your health - sometimes I feel like they are holding back information.

Good care is: trustworthy

Focus on trust, communication and avoiding gatekeeping



Doctors are good but the ones I have problems getting through are the receptionists at my GP. They lie, and are a law on their own.

Good care means not just being sent texts or asked to fill in lengthy forms for triage before you are even considered for an appointment.

Experience of access to services impacts the level of trust people feel they can have; which, in turn, impacts perception of the quality of care.

At worst, when trust is eroded, patients may feel like services don't want to provide the best care they can, but just the minimum they can get away with, and the processes through which care is accessed start to feel like gatekeeping.

Most notably:

→ **Admin staff in GP surgeries triaging patients on the phone.**

→ **Long and complex e-consult forms.**

Good care is: trustworthy

Focus on reassurance and anticipative care

Patients, especially parents of small children, people living with long-term illness and the elderly, may not feel certain about how to tell whether they are well, or whether they are experiencing worrying changes in their health.

Anticipative and trustworthy care can provide them with reassurance and confidence. This could entail:

→ **Providing reassurance (what’s normal, what’s not) and educating on self-care**

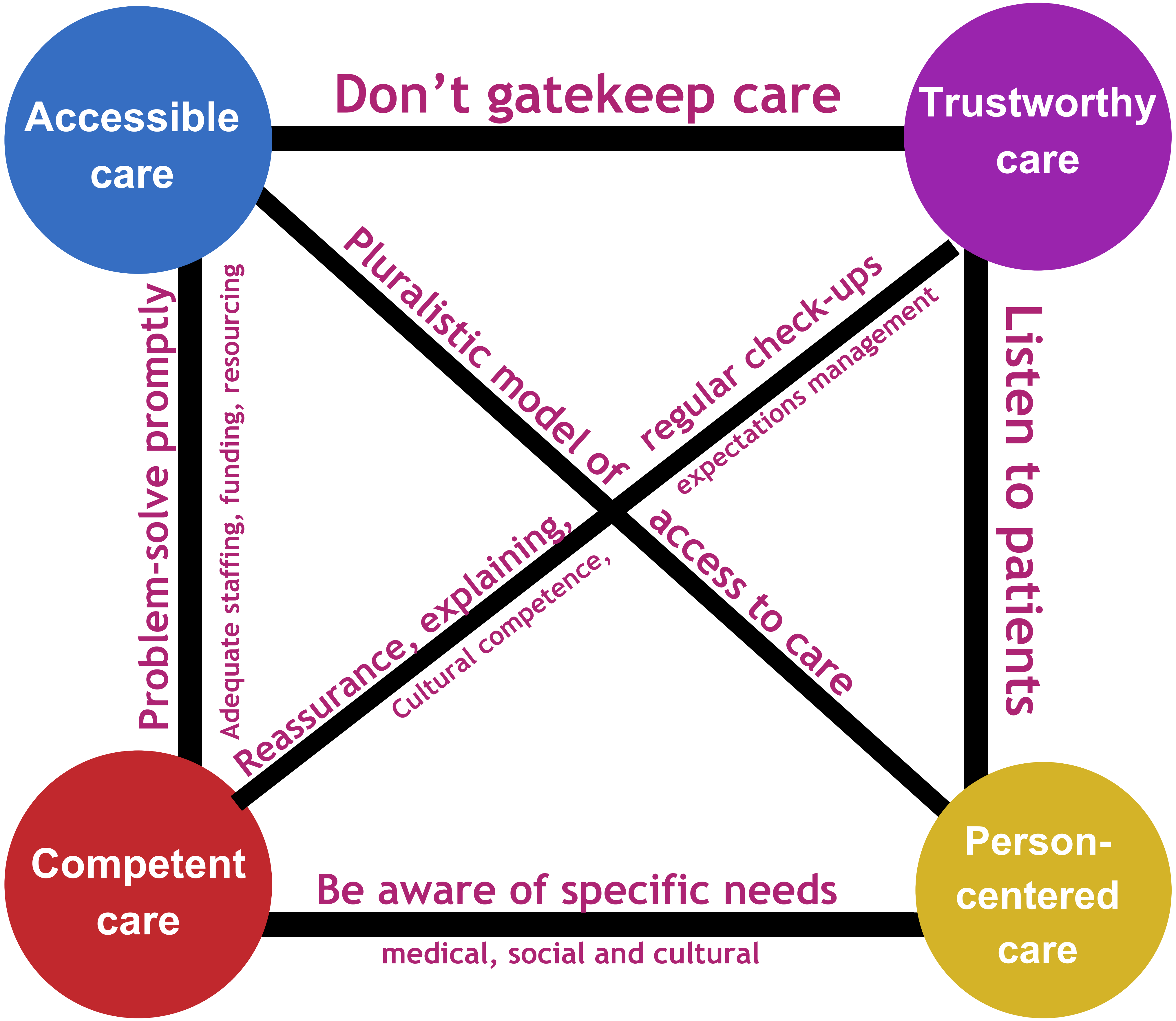
→ **Prioritising prevention over reactive care; proactively offering check-ups, routine investigations or other forms of care and support.**

38 respondents brought up a desire for routine health-check-ups relevant to the state of their health, to be administered by their GP or other primary care practitioner on a routine, “health MOT” basis.

I was called for a routine mammogram and this was carried out fine but I feel the opportunity could have been used for basic checking of weight and blood pressure etc., same when I visited my doctor for smear test I had the test no problem but why weren't basic health checks carried out.

Access to healthcare professionals at the time of need, as well as invitations for regular preventative / advisory check ups.

What does good care look like?



Accessible care

Trustworthy care

Competent care

Person-centered care

Don’t gatekeep care

Problem-solve promptly

Adequate staffing, funding, resourcing

Listen to patients

Be aware of specific needs

medical, social and cultural

Pluralistic model of access to care

regular check-ups

expectations management

Reassurance, explaining,

Cultural competence,

What about cultural competence?

A note on engaging with local people on their beliefs and values.

When asked “What do you think health and care staff who support you could do to consider your beliefs and values?” some people felt confused by the question, felt it did not apply to them or that beliefs and values have no place in care. In some cases, they associated the concept of “beliefs and values” specifically with ethnicity and religious belief.

I do not know or care if my medics understand my culture . I did not ask them and they did not ask me . The hospital is like the United Nations , staff and patients from all over.
I hope we are all treated the same .

As a middle class white woman, I am privileged and my beliefs and values tend to reflect those of the dominant groups, so I don't have much experience in this.

For me as a white person this generally isn't an issue.

Beliefs and values should not be in the NHS as this inevitably always leads to some form of discrimination. All should be treated the same and no pandering to religious groups as religion does not belong in the care system and ends up creating an expensive mess.

I am white British so I'm not sure this applies. Previously I've had to ask questions about sexual health and explain I am gay (I'm female), which seemed to be not a values issue but a knowledge one.

Good healthcare should be standard regardless of your beliefs and values.

I don't know that I have any beliefs or values that would bump up against the health and care system really.

I don't think they need to do that, my beliefs are my own business.

I have no specific beliefs.

Not really sure this would ever be an issue but understand it could be necessary in some cultures. not much experience on this

What about cultural competence?

A note on engaging with local people on their beliefs and values.

While respondents may not define it that way, our beliefs and values can shape our understanding of and experience with the health and care system. For example:

Immigrants/ expats who experienced different healthcare systems may compare their experience in the UK with the experience they had in their country of origin. (For example: they may be used to self-referring to specialist care rather than going through their GP; they may be used to having certain investigations -such as routine bloodwork- carried out on a routine check-up basis; or to certain procedures such as cervical screenings being carried out by a specialist in a clinic rather than a GP practice nurse). In turn, especially in the absence of communication, this may lead some patients to distrust the NHS or view it as less competent than other medical systems. However, they may not think of it as a “culture“ issue rather than an access or competence one.

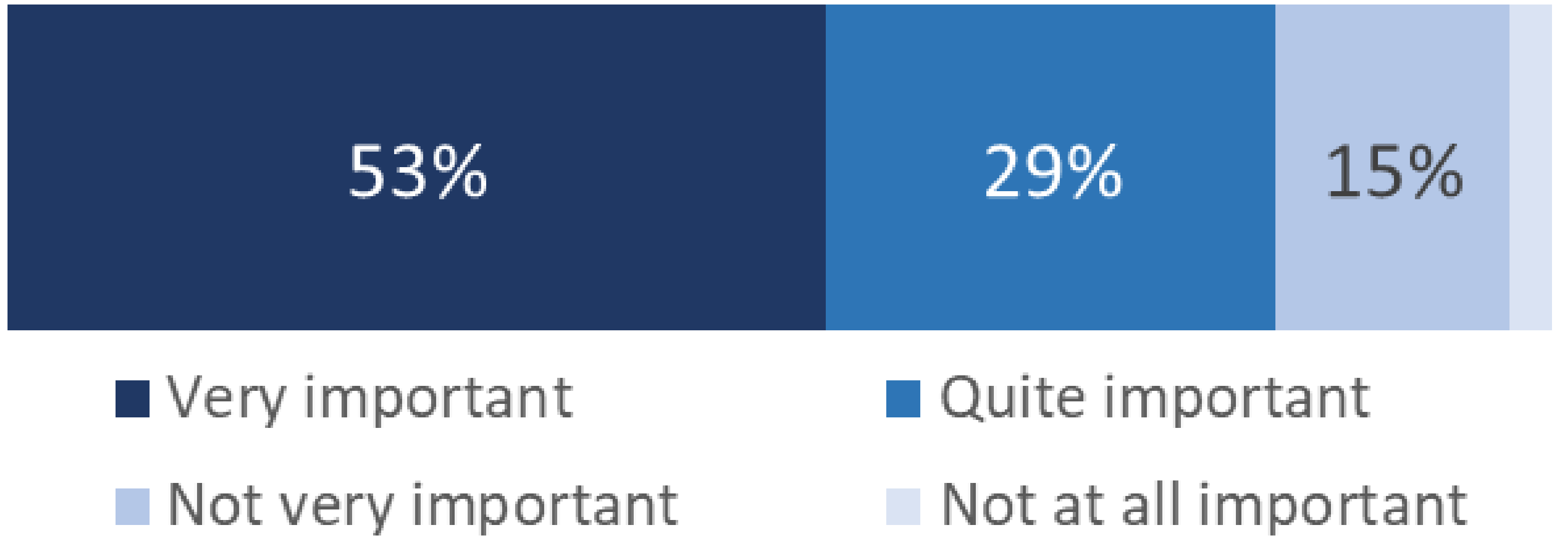
> *They should be more involved in caring for patients - not like "There's nothing I can do, here's some paracetamol. Don't look at your phone while talking to patients - I just don't think doctors here are as smart and wise as the ones in Romania.*

A patients’ political opinions may influence whether they believe that private care is better (more customer-focused, more efficient, more accountable) or , on the contrary, less good than public/ socialised health and care services (oriented towards profit rather than the greater good, less trustworthy). In turn, consciously or not, knowledge about who provides the care and on what basis may influence patients’ perception of the quality of care.

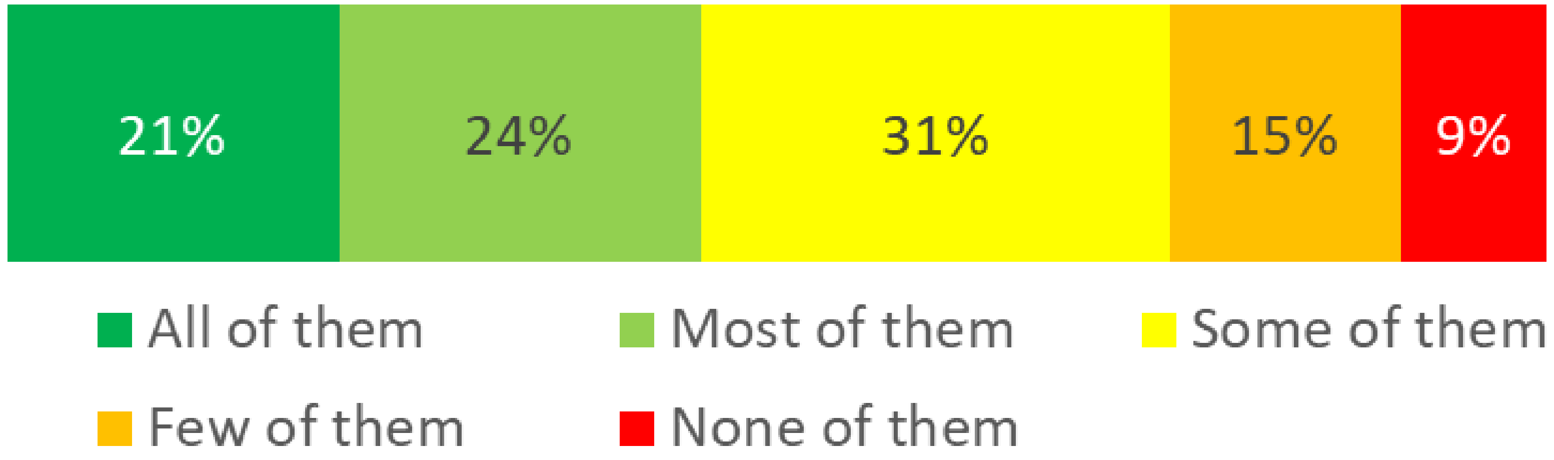
> *Health and care professionals are great. You need to pay them more. A happy workforce is one that is appreciated. I want to see private profiteers out of the NHS and for it to be returned to us - renationalise the NHS.*

What about cultural competence?
A note on engaging with local people on their beliefs and values.

How important is it for you: Being looked after by people who understand your beliefs and values.



Professionals looking after me: understand my beliefs and values



More likely to feel they are cared by people who understand their beliefs and values

- South Asian ethnicities, especially Pakistani
- Aged under 25

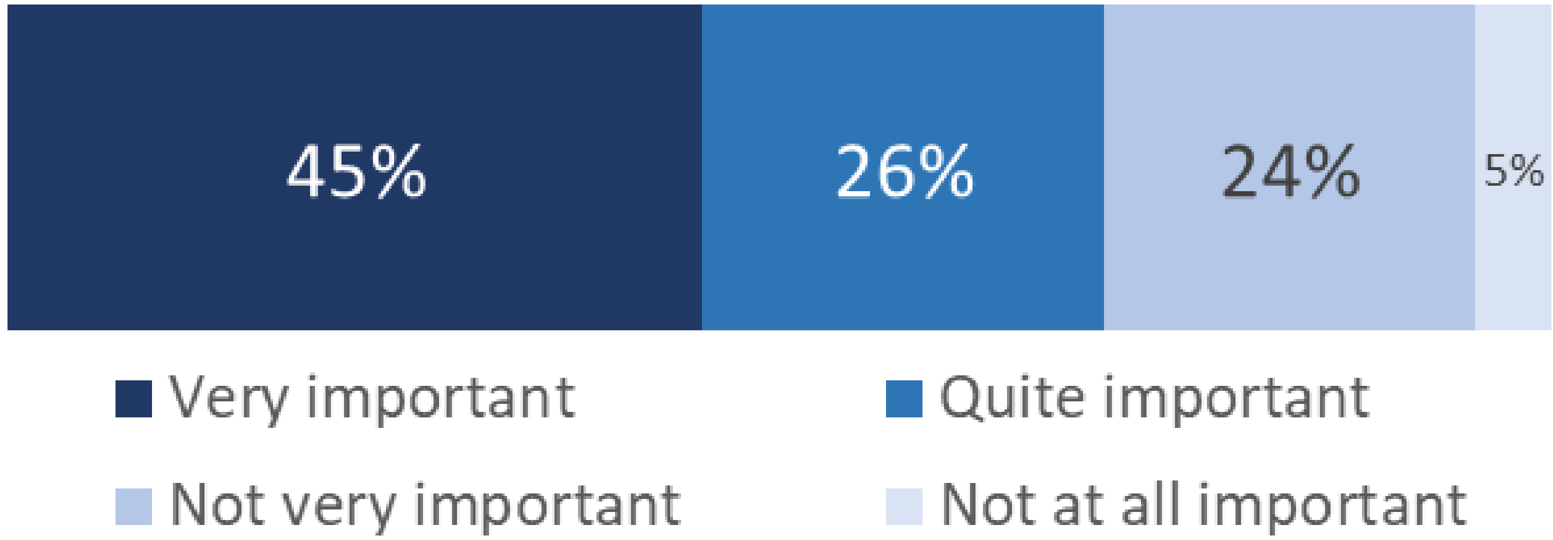
Less likely to feel they are cared by people who understand their beliefs and values

- Mental health condition
- Disabled
- Neurodivergent
- Black ethnicities
- Eastern European
- Digitally excluded

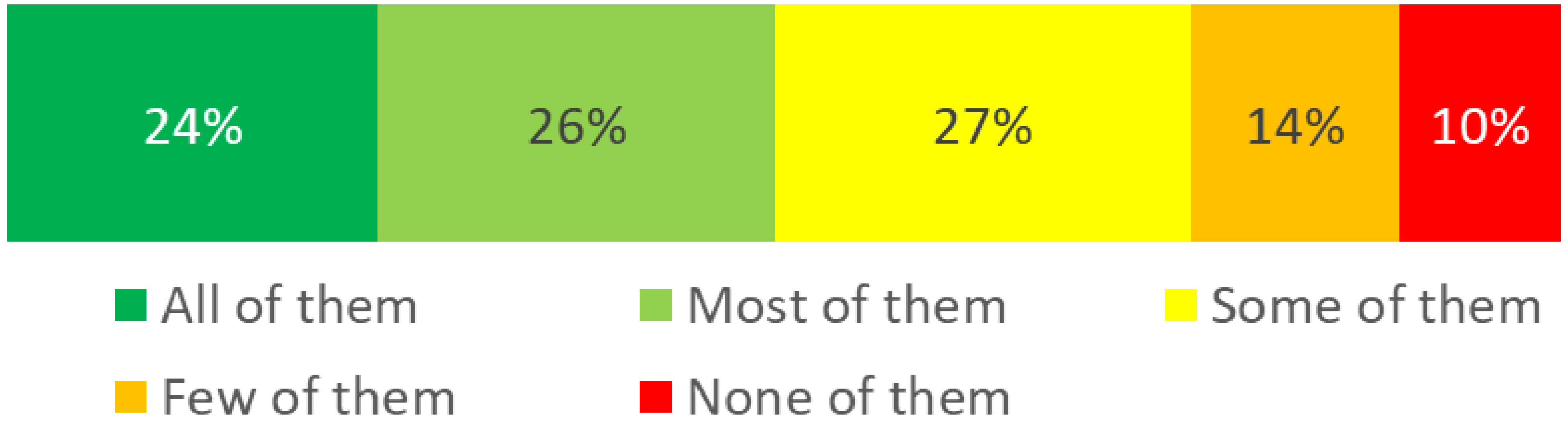
What about cultural competence?

A note on engaging with local people on their beliefs and values.

How important is it for you: Being looked after by people who understand your culture.



Professionals looking after me: understand my culture



More likely to feel they are cared by people who understand their culture

- Indian, Pakistani or Black African ethnicity
- Hindu or Muslim faith
- Aged under 25
- Financially comfortable

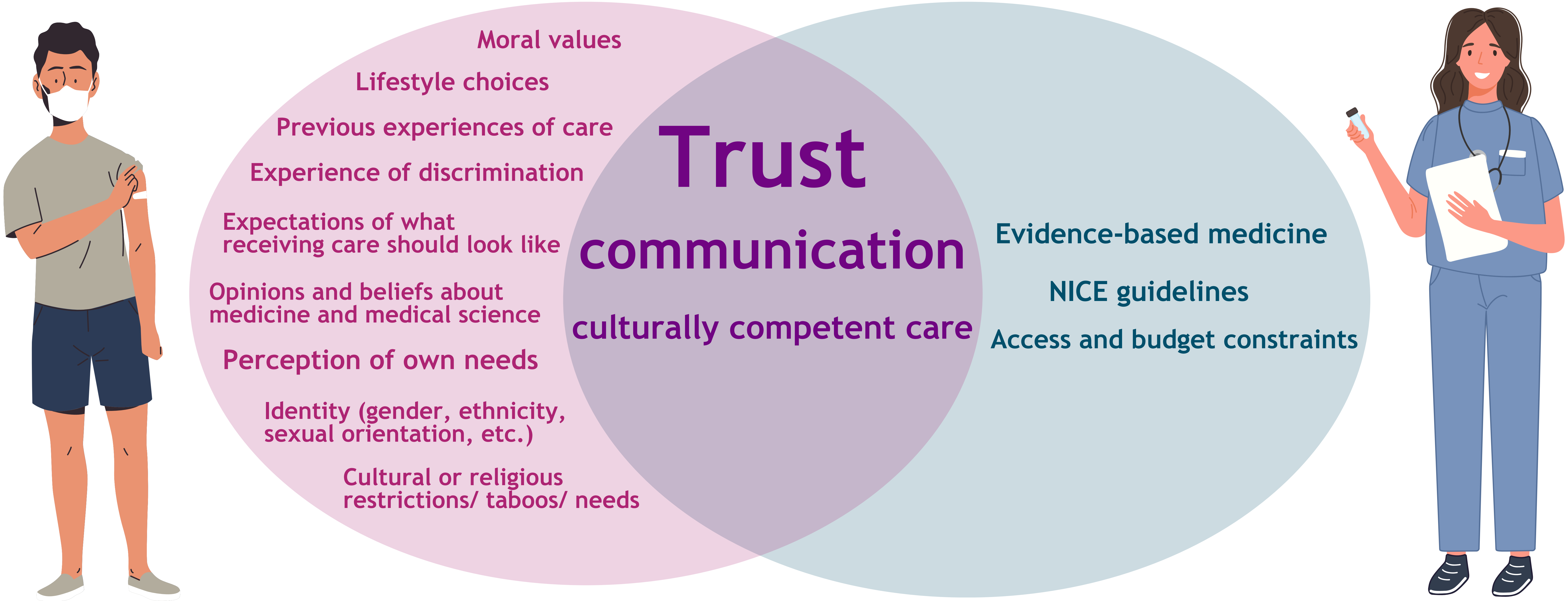
Less likely to feel they are cared by people who understand their culture

- Disabled
- Neurodivergent
- Aged 50 to 64
- Black Carribean ethnicity
- Eastern European
- Digitally excluded

What about cultural competence?

A note on engaging with local people on their beliefs and values.

In some situations, rather than asking local people about their culture, beliefs and values in relation to health and care services, an alternative way of framing the question would be to address their expectations in relation to the care they receive. This could in turn inform culturally competent care.



- Moral values
- Lifestyle choices
- Previous experiences of care
- Experience of discrimination
- Expectations of what receiving care should look like
- Opinions and beliefs about medicine and medical science
- Perception of own needs
- Identity (gender, ethnicity, sexual orientation, etc.)
- Cultural or religious restrictions/ taboos/ needs

Trust

communication

culturally competent care

- Evidence-based medicine
- NICE guidelines
- Access and budget constraints

Cultural competence in health and care- *what local people are saying*

One nurse who gave me my b12 injection told me I must eat meat, and wouldn't accept it when I told her that I didn't want to. The only other person in my family who needed b12 injections was my granddad, who ate meat more than once a day.

Health and care services need to understand the culture of how gay sex works.

There is not always time to be aware of everything about everyone's beliefs and values but you can learn the basics and if you ask the right questions you can pretty soon get the answers you need in order to understand someone. This isn't just about values and beliefs for example. Autism awareness is necessary and communication is so important.

At times just having a conversation about one's beliefs and values can be very helpful. If the health and care staff is skilful in communication he/she may want to help the user/patient consider if the values and beliefs are getting in his/her way.

Example: patients with different perspectives

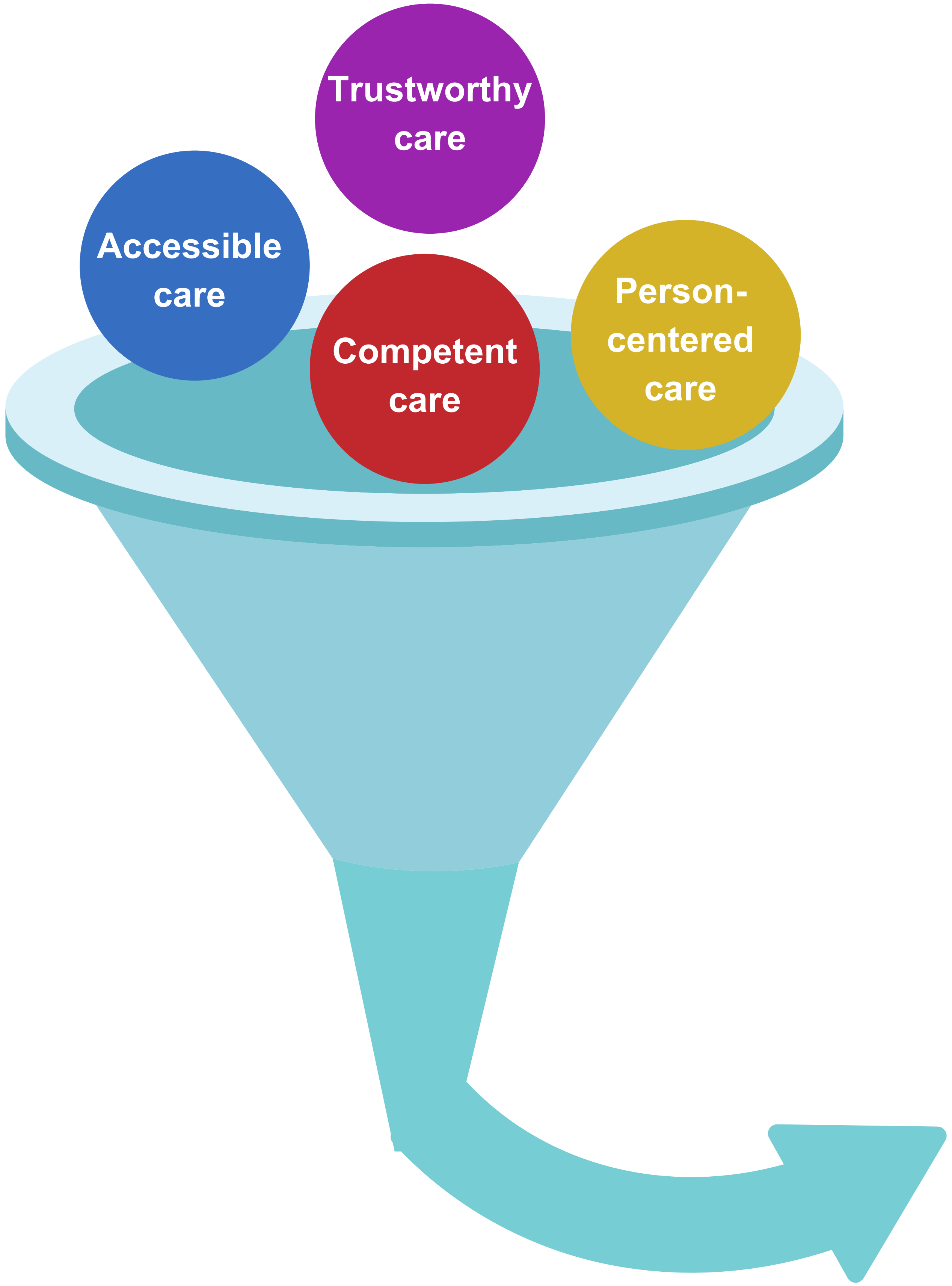
These two patients have different views about the issue of weight management.

I would stop any informations or campaigns that focus on people changing the shape of their body as a marker of health. Heathly lifestyles should be encouraged without a body shape being connected - be weight neutral. So many behaviours can change a body shape and some are very unhealthy. People are constantly told having fat on a body is unhealthy - it's no always true. People can be fat and healthy. Encourage healthy life choices and let people's bodies be what they will be as a result of a healthy life. We can assume that because someone is bigger they are unhealthy.

I would love the opportunity to speak and help people realise how important keeping your weight at a healthy weight is so important. I feel the health service is being restricted on what they can say. I speak from experience. A Consultant wanted to put me on blood pressure tablets , when it was clearly weight gain causing the raised BP. I felt he should have encouraged the weight loss first instead of the tablets. I lost the weight and maintained it, which in turn lowered my BP.

- **Competent care is informed by scientific evidence on the relation between weight and health.**
- **Person-centred care recognises that different patients may have different goals/ seek different outcomes.**
- **Trustworthy care empowers patients and professionals to discuss it honestly and non-judgementally.**

What does good care look like?
Good care has good consequences



Trustworthy care

Accessible care

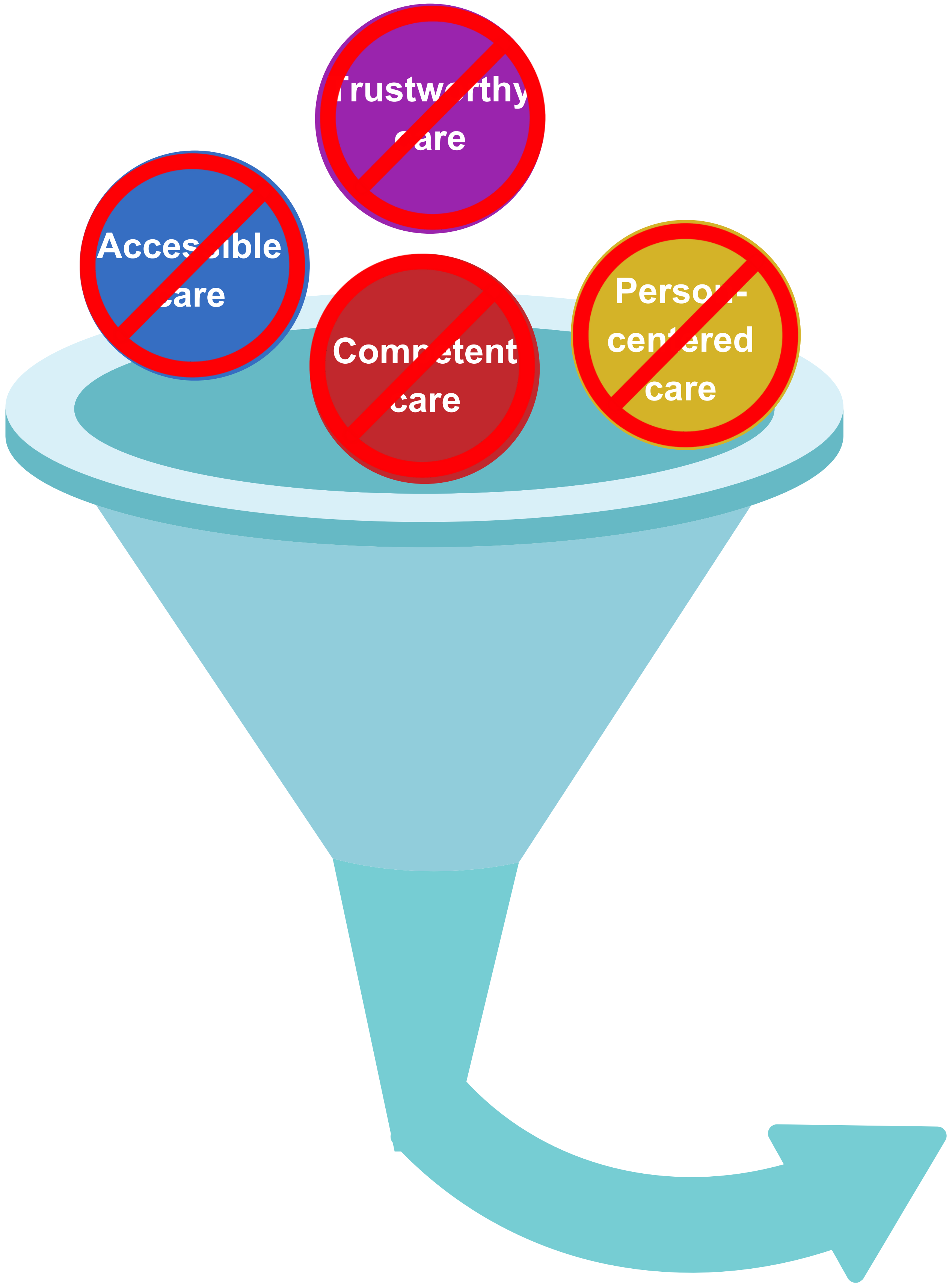
Competent care

Person-centered care

- Local people feel empowered to live full healthy lives, to look after themselves and families. They feel heard and reassured. They worry less about their own health.
- Children and young people have a good start in life.
- People with long-term conditions manage them well. They are able to work and/or contribute to society in other ways. They are able to engage with others and do things they enjoy.
- Older people stay healthy and active for longer. They maintain a goo level of independence.

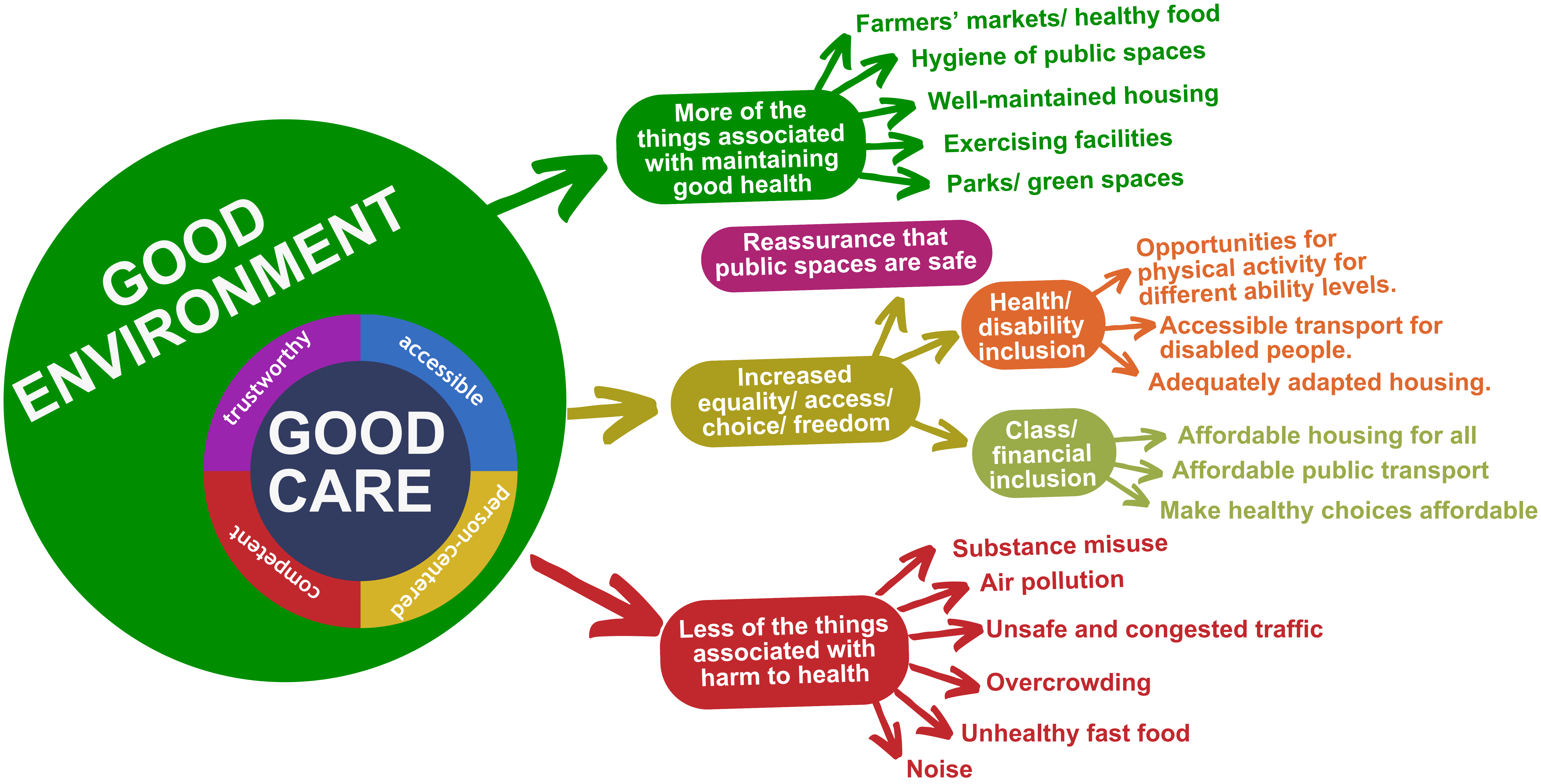
What does good care look like?

Bad care has bad consequences



- People worry about their health, as they don‘t have the knowledge to assess their own level of health or deal with specific symptoms; and they don;t have a reliable source of advice.
- People distrust doctors and the treatments they prescribe; they may see the health and care system as defined by gatekeeping and doing the bare minimum. As a result, they may turn to alternative sources of care and/or reassurance, including those which may be pseudoscientific or harmful.
- Conditions that would have been more easily treated or controlled at an early stage worsen.
- People with long-term conditions, especially as they age, leave the workforce earlier and experience highter risks of social isolation.

What does a healthy community look like?



GOOD ENVIRONMENT

GOOD CARE

trustworthy

accessible

person-centered

competent

More of the things associated with maintaining good health
- Farmers' markets/ healthy food
- Hygiene of public spaces
- Well-maintained housing
- Exercising facilities
- Parks/ green spaces

Increased equality/ access/ choice/ freedom
- Reassurance that public spaces are safe
- Health/ disability inclusion
  - Opportunities for physical activity for different ability levels.
  - Accessible transport for disabled people.
  - Adequately adapted housing.
- Class/ financial inclusion
  - Affordable housing for all
  - Affordable public transport
  - Make healthy choices affordable

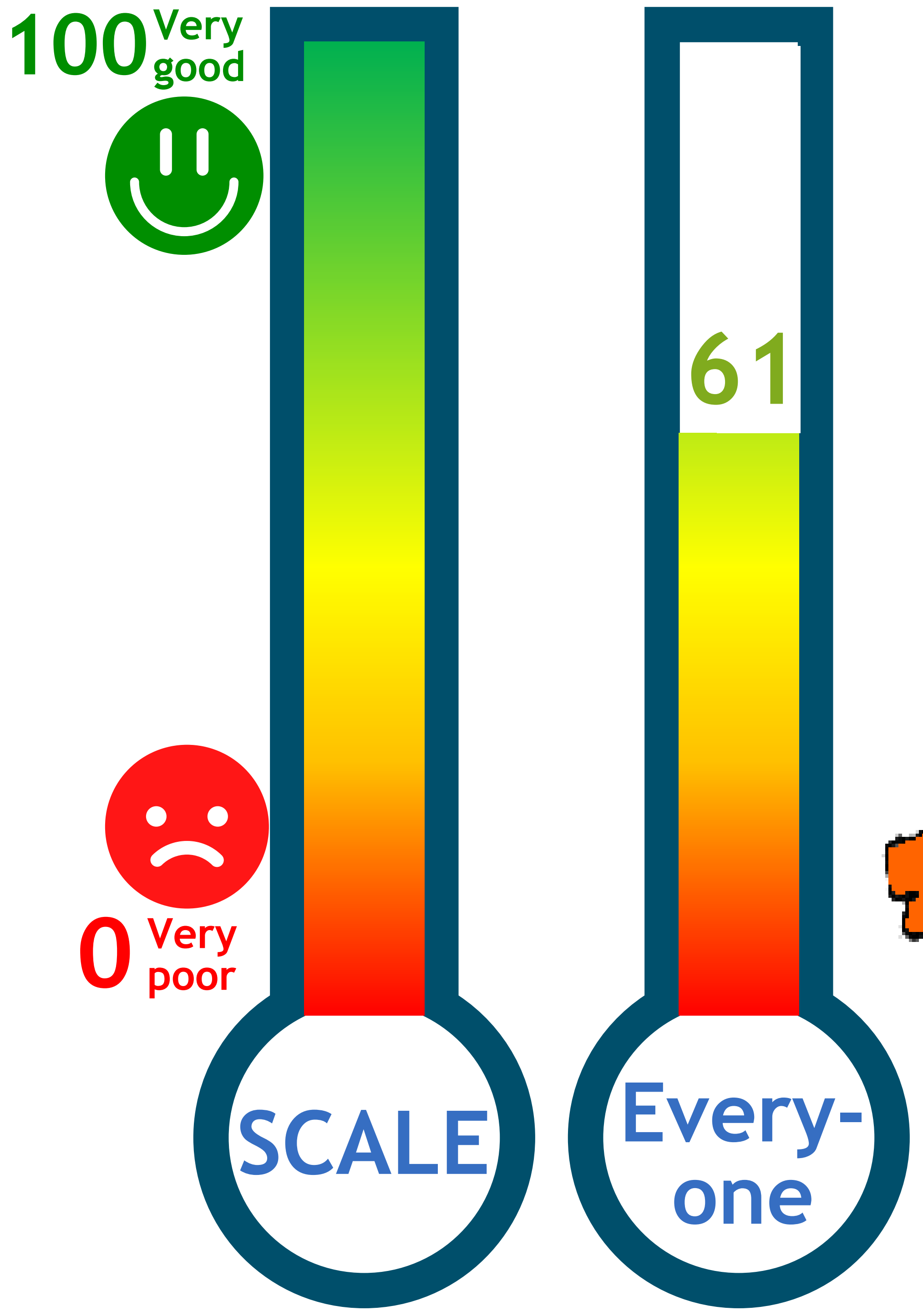
Less of the things associated with harm to health
- Substance misuse
- Air pollution
- Unsafe and congested traffic
- Overcrowding
- Unhealthy fast food
- Noise

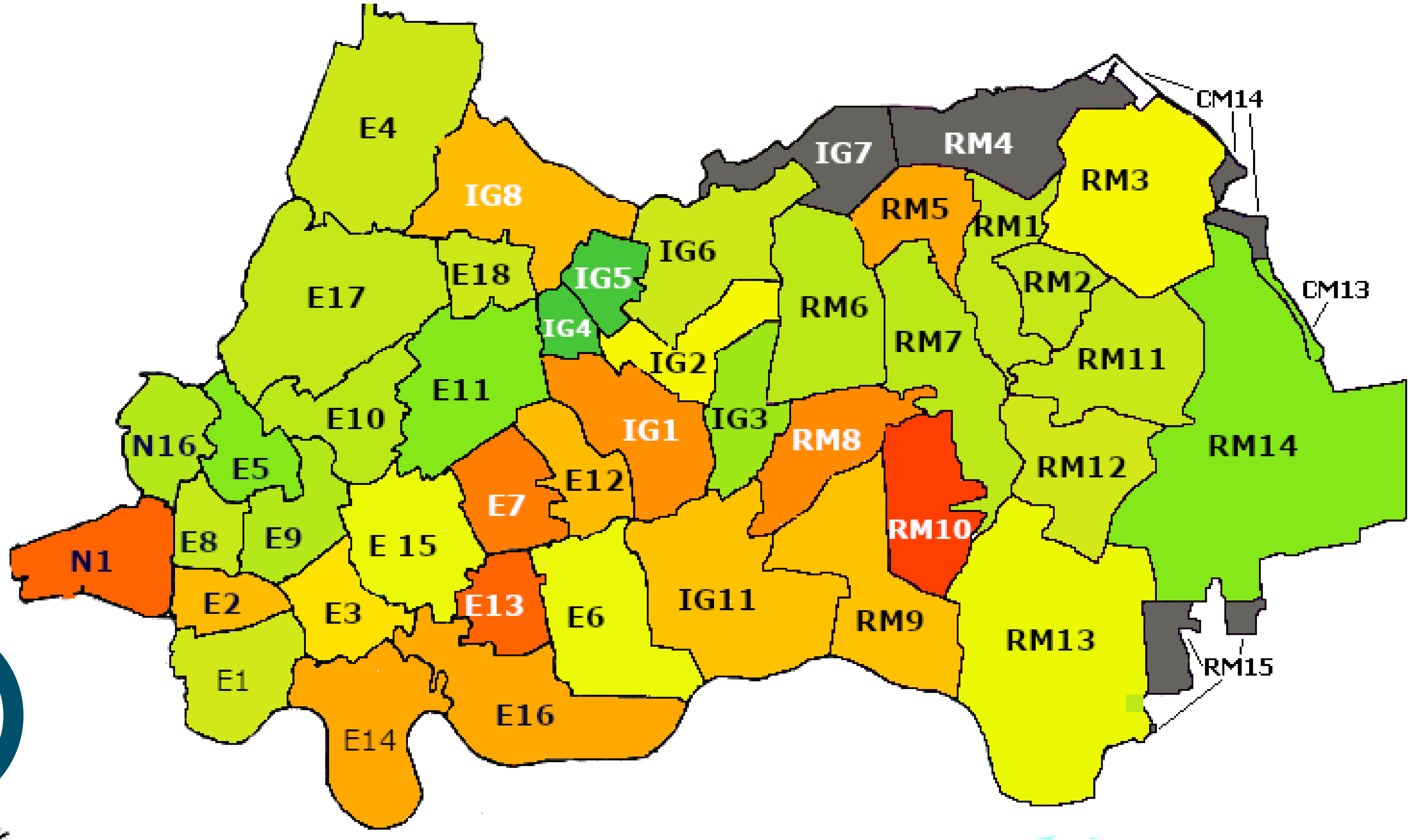
How to measure the health of the wider community based on what matters to local people

Success looks like...

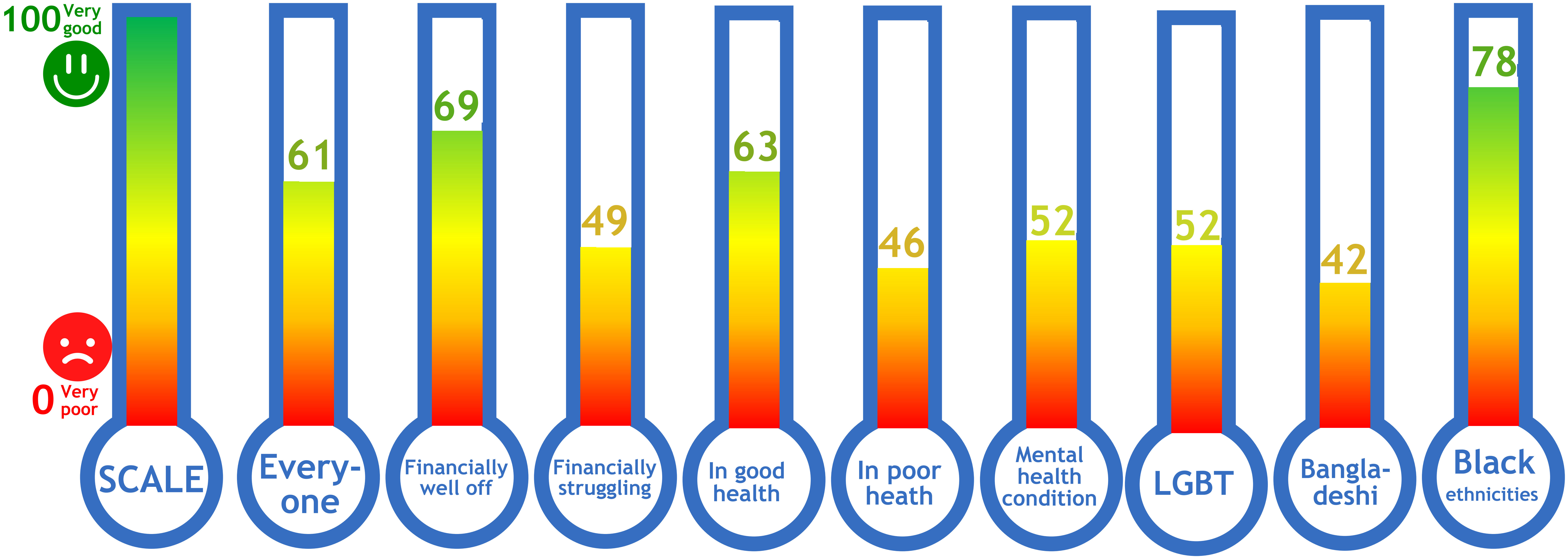
- Improved affordability of public transport
- Improved accessibility of public transport
- Reduction in traffic congestion
- Safer roads for pedestrians and cyclists
- Improvement in air quality
- Increased availability of inclusive exercising classes for all abilitiesat times suitable for all
- Increased availability of inclusive exercising classes for all abilities
- Increased availability of free or affordable exercising facilities
- Increased % of local residents who are physically active
- Decrease of amount of rubbish in public spaces/ green spaces
- Improved diet for residents on low incomes
- Decrease of substance misuse

My neighbourhood is a place where I can live a healthy life- *survey respondents*

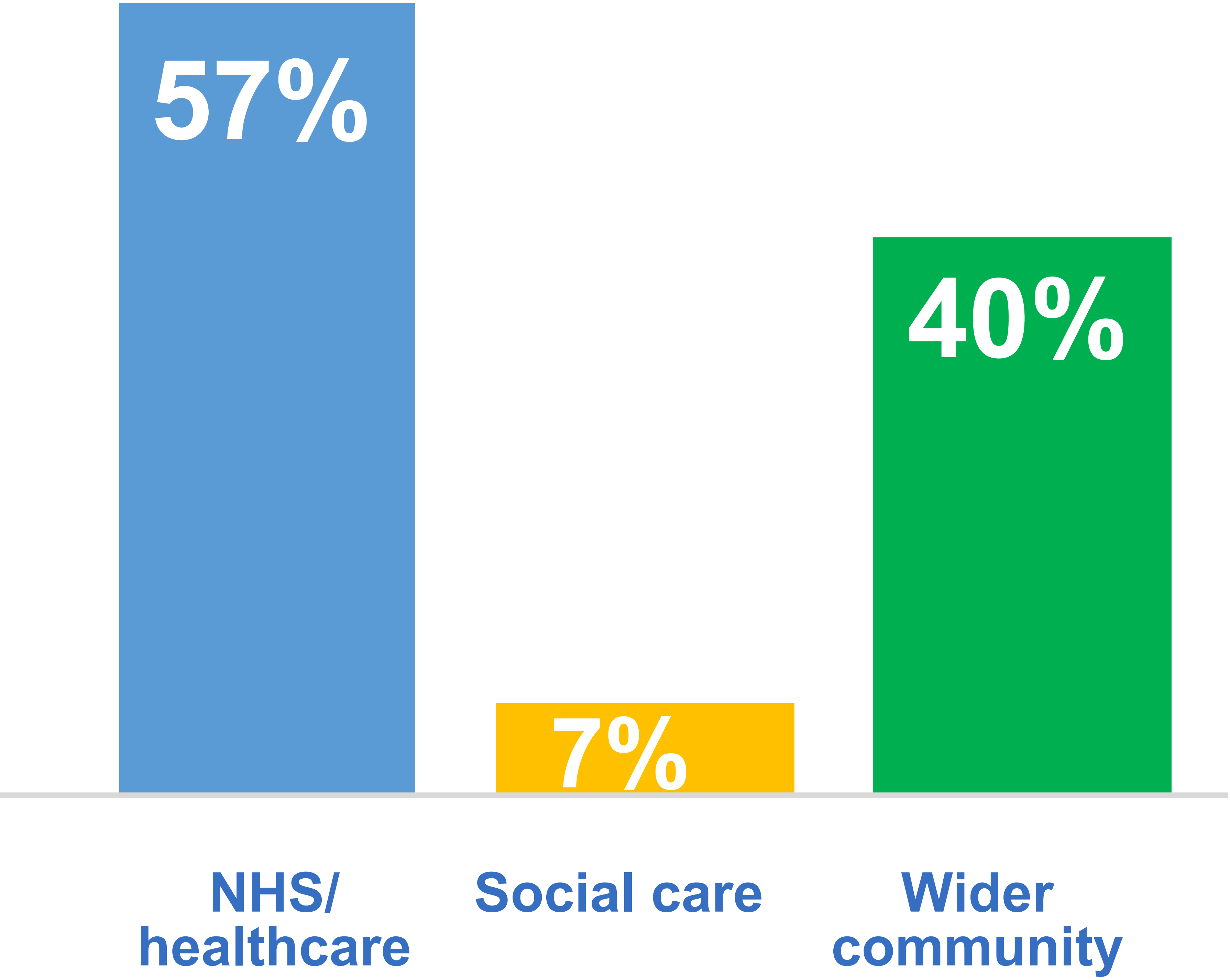




My neighbourhood is a place where I can live a healthy life- *survey respondents*



What changes would make an immediate positive difference to people's lives?



Most mentioned healthcare change: improve access to primary care, especially to GP appointments.

What changes would make an immediate positive difference to people's lives?

GOOD CARE

→ **Improve availability of primary care**

- More flexible, less complicated ways of booking GP appointments- reduce telephone morning queues and "gatekeeping" aspects of the booking process.
- Urgent non-emergency care available on a walk-in/ hub basis
- Routine regular health checks for some groups (children, elderly, chronic illness)

→ **Improve record-sharing/ information flow between NHS, social and community services, especially between GPs and all others**

GOOD ENVIRONMENT

→ **Improve road traffic**

- Tackle congestion through targeted local measures to make traffic flow more efficient.
- Improve road safety for cyclists and pedestrians, including improving pavements

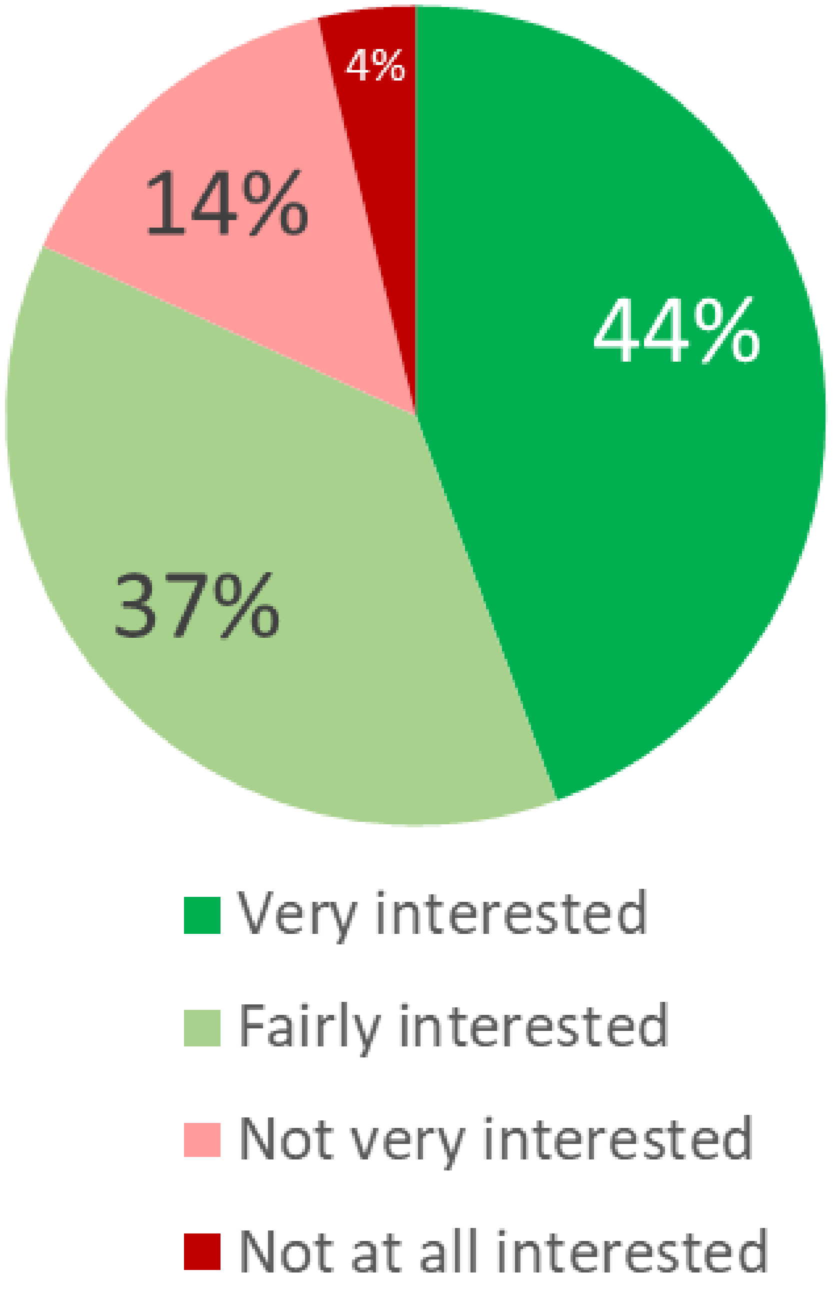
→ **Improve access to healthy food for families on low incomes, taking into account the practical barriers they face.**

→ **Improve access to exercising facilities and dedicated classes for those who would currently struggle to access them.**

- Those with limited ability to exercise strenuously (older people, disabled)
- Those who work full-time/ busy or unpredictible schedules

→ **Improve cleanliness of public spaces, especially of green spaces.**

How interested would you be about having information available where you live about living a healthy life? - *survey respondents*



More interested

- Retired
- Receiving benefits
- Struggling financially
- Black or South Asian ethnicities
- Jewish, Muslim or Hindu faith

Less interested

- Romanian
- LGBT
- In poor health

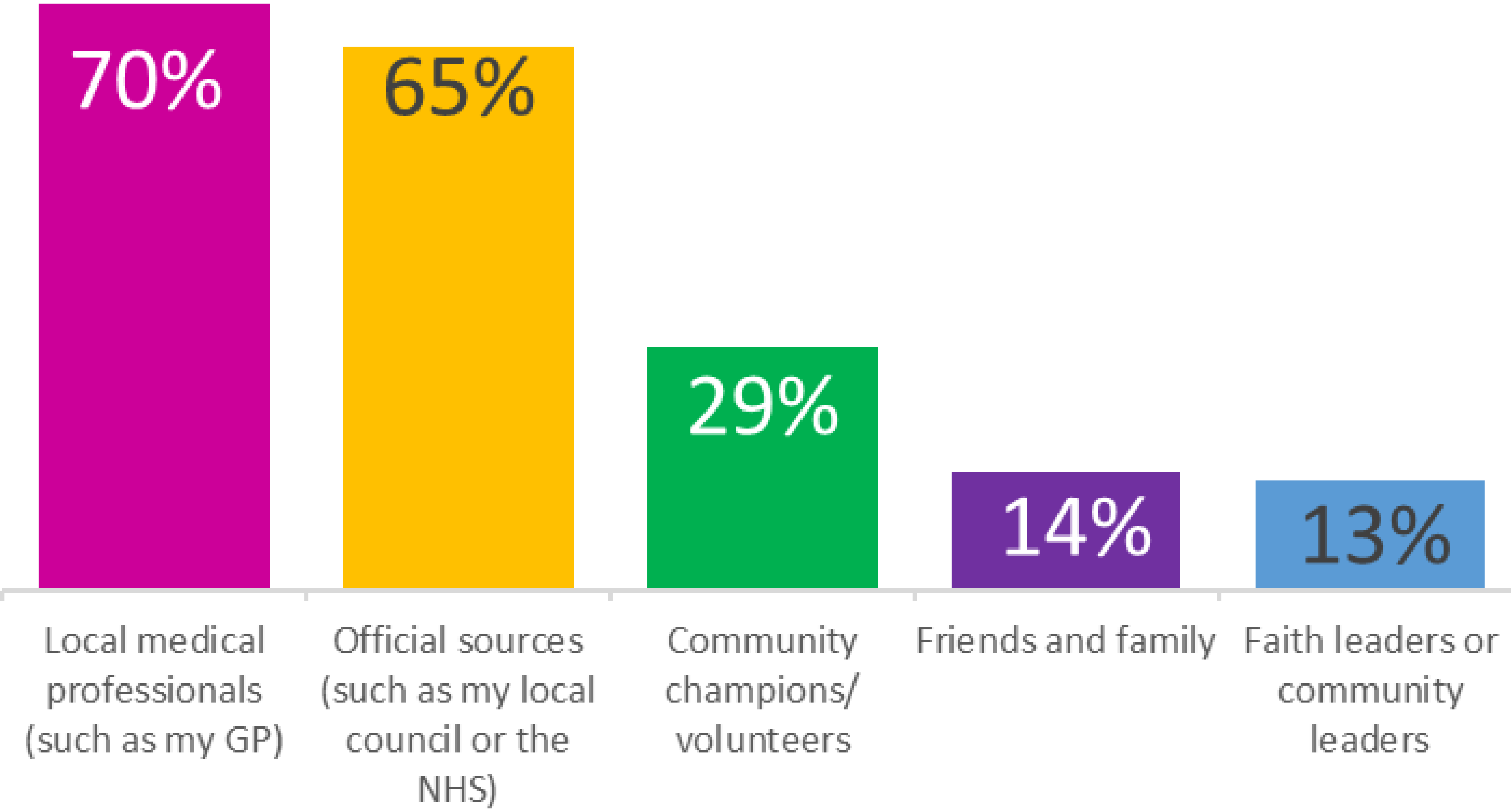
65%
of those not interested said they already had enough information.

29%
of those not interested said the obstacles they face to living a healthier life cannot be tackled with just information.

How interested would you be in having information available where you live about living a healthy life? - *survey respondents*

Whom information should come from

according to those who would like to receive info



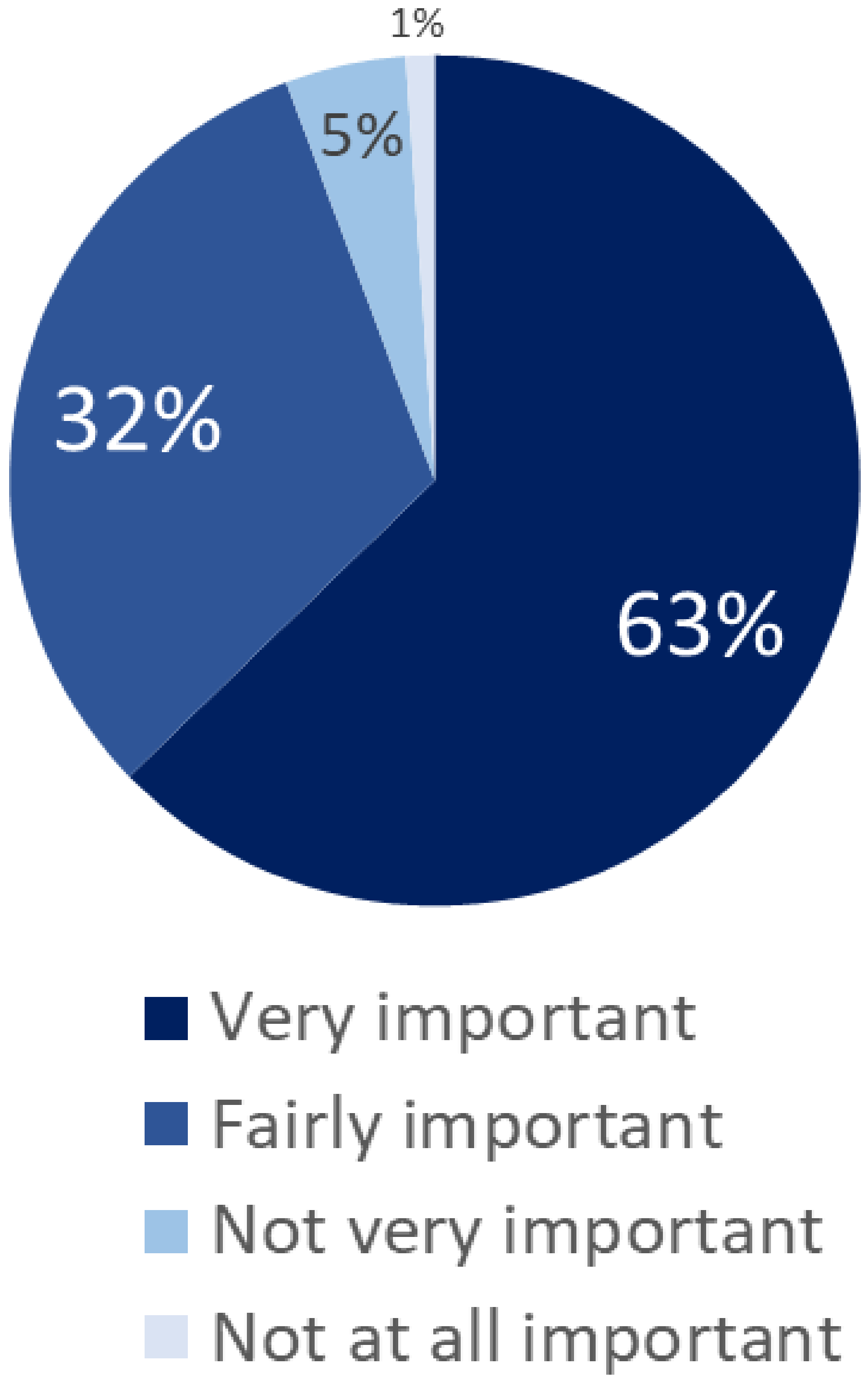
More likely to say info should come from friends and family:

- Living with learning or sensory disabilities
- Men
- Aged under 50
- Struggling financially
- South Asian ethnicities, especially Bangladeshi
- Black ethnicities, especially Caribbean
- Hindu or Muslim faith

More likely to say info should come from faith leaders or community leaders:

- Just getting by or struggling financially
- Not native speaker of English
- Muslim
- South Asian ethnicities, especially Bangladeshi
- Black ethnicities, especially Caribbean
- Parents
- Aged under 35

How important is it for you to have a say about how local health and social care services are run? - *survey respondents*



Respondents who placed the most importance in having a say were more likely to:

- Be aged 50+
- Be of Black African, Indian or Pakistani ethnicity
- Report having a mental health condition
- Identify as disabled
- Say that they are in very poor health
- Just get by financially
- Have used health or care services in the last 12 months

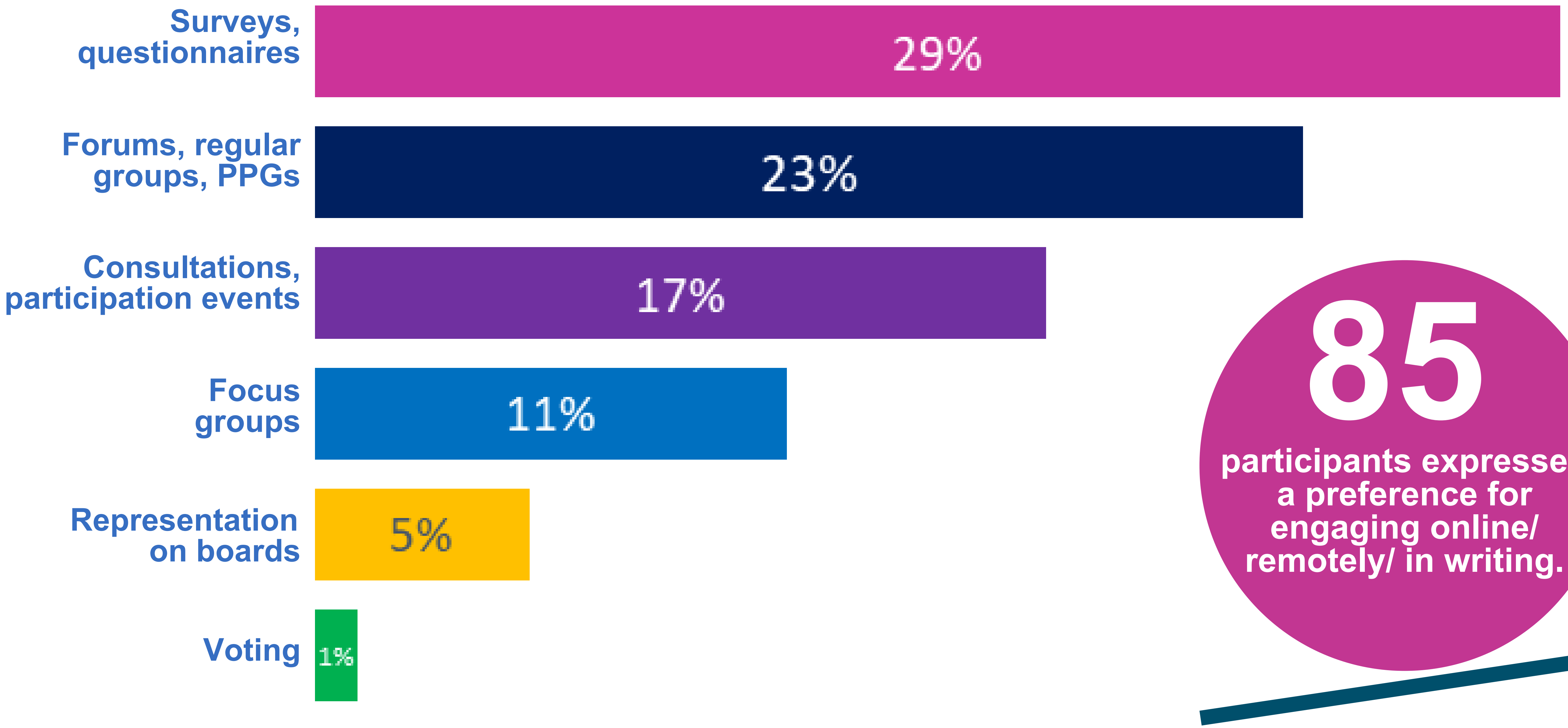
They were less likely to:

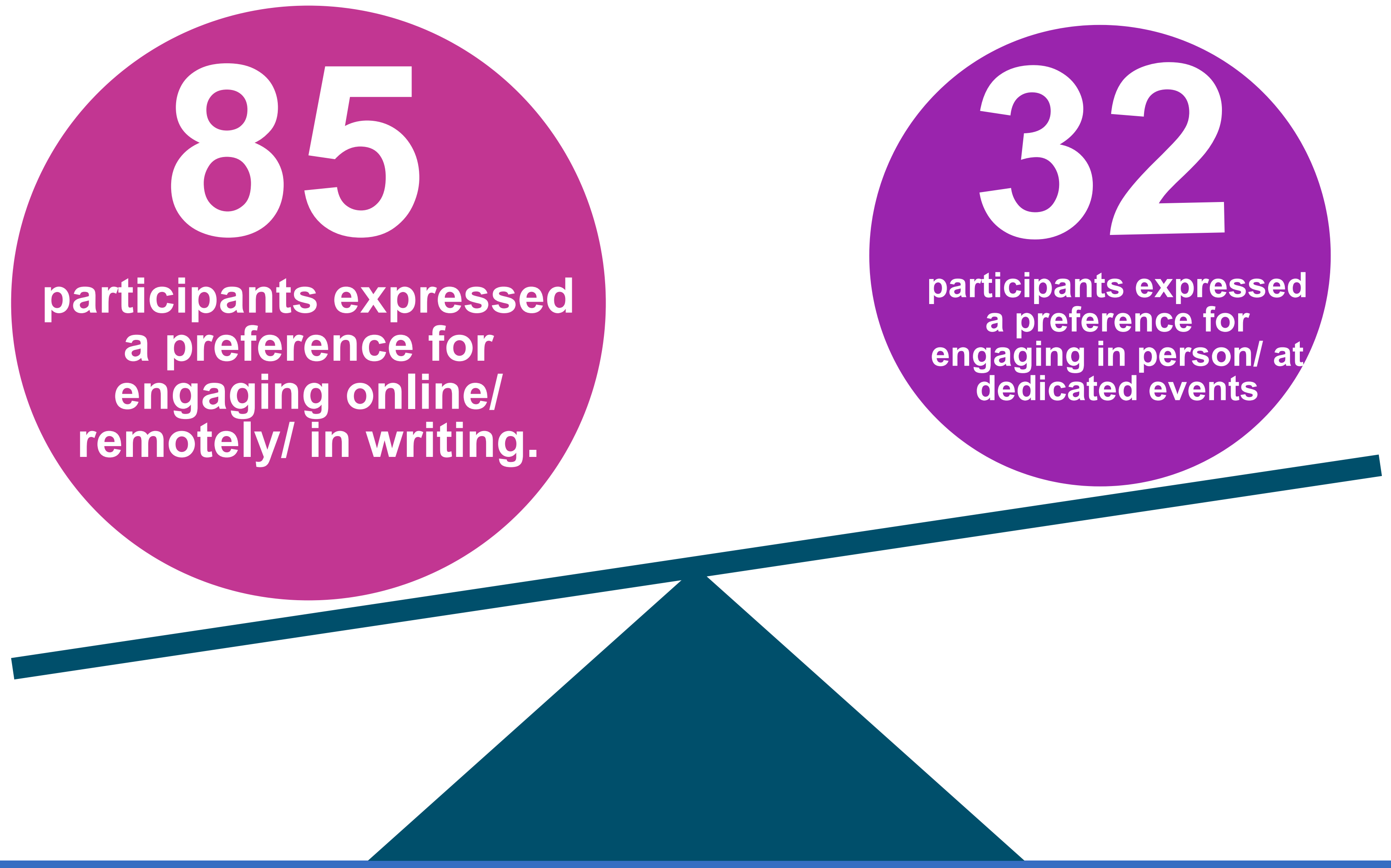
- Believe their local area is a place where they can live a healthy life
- Have children aged under 18

Accross all demographic categories, a majority of respondents said it is important to have a say

Becoming more involved in shaping local services- how to do it

395 survey respondents gave feedback about specific ways they could take part in shaping local services





85

participants expressed a preference for engaging online/ remotely/ in writing.

32

participants expressed a preference for engaging in person/ at dedicated events

Becoming more involved in shaping local services- what would help

Inform local people about involvement opportunities

Be flexible in terms of dates/time and medium; consider accessibility

Accommodate those who prefer to take part in meetings and those who prefer to give feedback in writing; those who are digitally excluded and those who prefer online communication; those who work full-time and those with limited ability to travel.

Consider the specific expertise individuals can bring

Professional experience, lived experience, transferrable skills.

Consider financial incentives/ paying for expertise

Show local people how their involvement is making a difference

Offer clarity on how their data will be used; demonstrate accountability; publicise "You Said/We Did" results

Becoming more involved in shaping local services- a pluralistic approach

Different people have different skills, different levels of knowledge about how health and care systems work,; different levels of time availability/ commitment and face different obstacles to getting involved. Those who are likely to participate in multiple co-designing events and workshops are likely to be demographically different from those in seldom heard groups.

It is therefore crucial to engage with people in different ways and at different levels.

Gather ideas from patients and staff and marry them up, no use asking patients' views on stuff they don't understand.

Put info in public domain - honest reflections on current issues and how people can help.

Being a busy professional I wouldn't have time to attend face to face events. It would help if I can choose areas of interest/relevancy and feedback online.

It's important to me that engagement with the local community is inclusive, ensuring a wide range of views, thoughts and opinions, but I'm not currently aware of any ways I can get involved locally.

Would need to understand processes and why they work like they do. My experience is in delivering IT systems and in lean working and business systems.

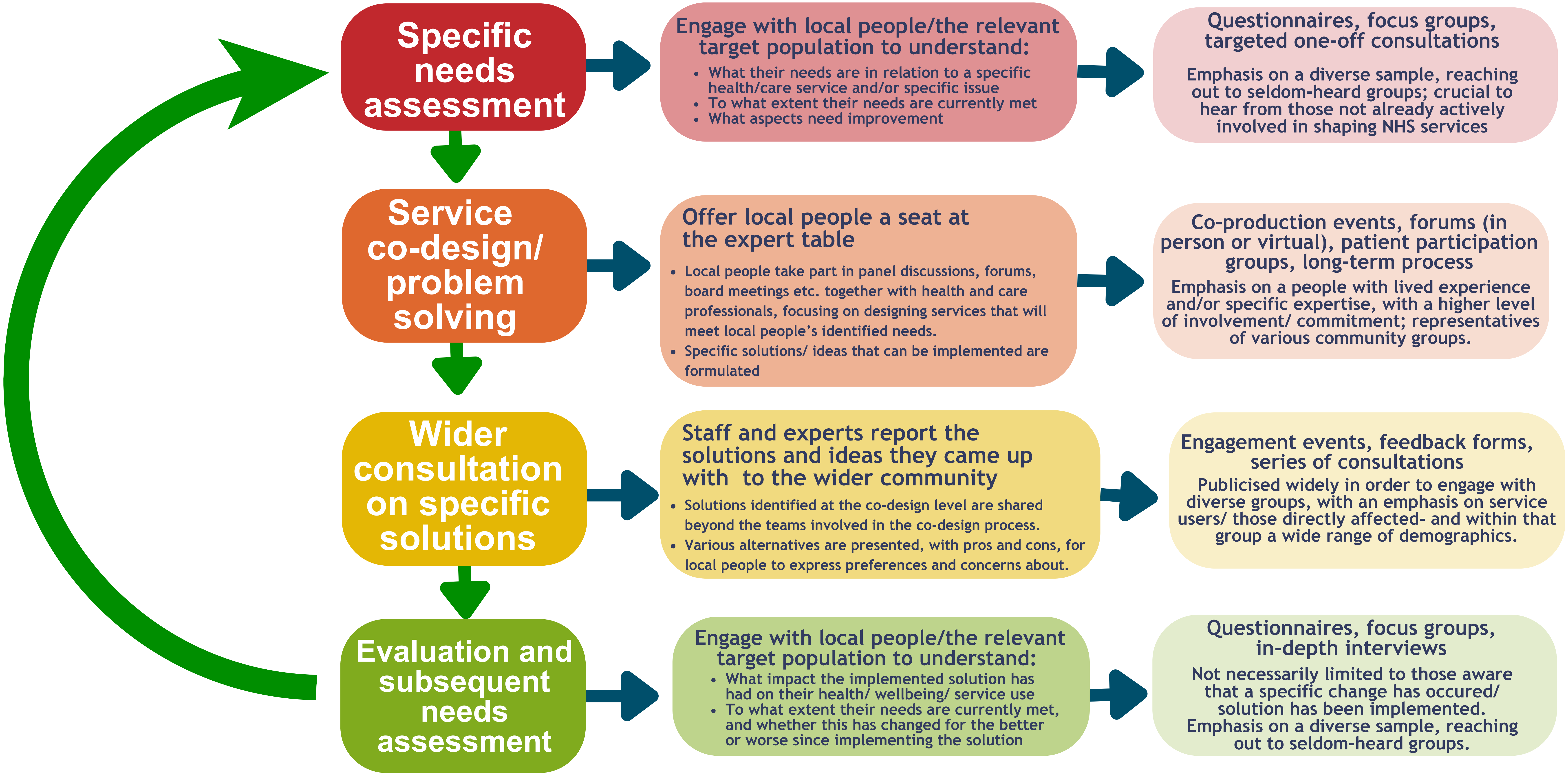
Be more people focussed, less clinical in the jargon, friendlier, not dismissive or defensive - listen and joined up contact.

I would like to be able to show those who commission front line health services the reality of everyday interactions and attempting to access care.

I was a local councillor involved in Health and Social Services scrutiny, so I can bring a lot of local experience, my active and dedicated participation. I am currently Chair of my local survey's Patient Participation Group.

Invite normal people to participate to get a real view from the ground!

A pluralistic approach shaping local services- a possible model



Specific needs assessment

Engage with local people/the relevant target population to understand:

- What their needs are in relation to a specific health/care service and/or specific issue
- To what extent their needs are currently met
- What aspects need improvement

Questionnaires, focus groups, targeted one-off consultations

Emphasis on a diverse sample, reaching out to seldom-heard groups; crucial to hear from those not already actively involved in shaping NHS services

Service co-design/ problem solving

Offer local people a seat at the expert table

- Local people take part in panel discussions, forums, board meetings etc. together with health and care professionals, focusing on designing services that will meet local people's identified needs.
- Specific solutions/ ideas that can be implemented are formulated

Co-production events, forums (in person or virtual), patient participation groups, long-term process

Emphasis on a people with lived experience and/or specific expertise, with a higher level of involvement/ commitment; representatives of various community groups.

Wider consultation on specific solutions

Staff and experts report the solutions and ideas they came up with to the wider community

- Solutions identified at the co-design level are shared beyond the teams involved in the co-design process.
- Various alternatives are presented, with pros and cons, for local people to express preferences and concerns about.

Engagement events, feedback forms, series of consultations

Publicised widely in order to engage with diverse groups, with an emphasis on service users/ those directly affected- and within that group a wide range of demographics.

Evaluation and subsequent needs assessment

Engage with local people/the relevant target population to understand:

- What impact the implemented solution has had on their health/ wellbeing/ service use
- To what extent their needs are currently met, and whether this has changed for the better or worse since implementing the solution

Questionnaires, focus groups, in-depth interviews

Not necessarily limited to those aware that a specific change has occured/ solution has been implemented. Emphasis on a diverse sample, reaching out to seldom-heard groups.

Becoming more involved in shaping local services- avoiding tokenism

91 survey respondents expressed concerns about consultations about health and social care being tokenistic or failing to make a difference.

Accountability and impact reporting are crucial to meaningfully engage with local people; people will be less willing to get involved with shaping health and care services if they believe that their feedback will not be meaningfully used and that decisions are taken without them.

Avoiding tokenism, or the appearance thereof, requires demonstrable efforts to meaningfully engage with a variety of groups, anticipating and addressing obstacles to participation; and feeding back to local people how their feedback is making a difference.

Events, talks, Q&A sessions would lead for some problem solving. There are lot of talks and promises, however nobody knows/ sees any real life action.

We need less exclusionary Integrated care network and more time for our local gps to work with the patient groups.

I would first of all need to feel that the health provider really did value my opinion and experiences.

I once volunteered with Healthwatch for over 3 years. I'm not totally convinced the work and involvement of volunteers there actually makes any difference to users of health /care services in the medium to longer term. They don't take on individual cases.

I think the health and council and social care need to work in partnership; this does not happen. At a local carers event adult services didn't show up; this is not good why weren't they there???

Listen to what the people at the sharp end are telling you. So many services talk a good story but do little if anything. I would happily join any way possible to help if your organisation really and truly listen to the people and action their issues but I'm not willing to work with a organisation that is only paying lip service to complete your tick-box if we consulted and will now ignore anything they have told us. As is my experience.