

# Big Conversation

**What does good care look like to local people?**

**27 November 2023**

# Big Conversation

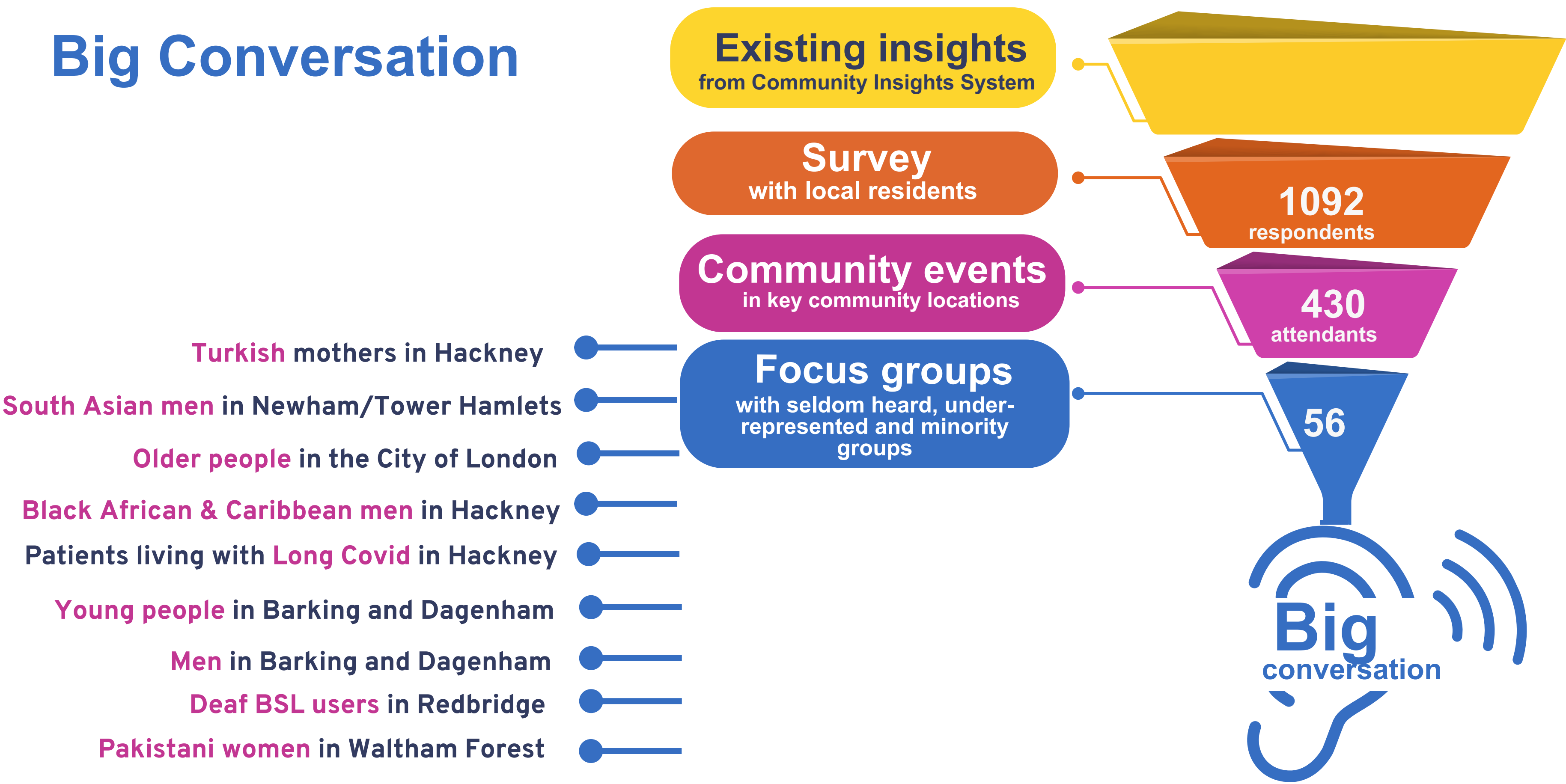
## What you will find in this report

- Methodology and demographics -----➤ Slides 3-5
- What local people have told us -----➤ Slides 6-58  
The four pillars of good care
- Focus on the four priorities -----➤ Slides 59-92  
Measuring succes with the four pillars

*Please see slide 7 for a detailed map/contents table of the framework.*

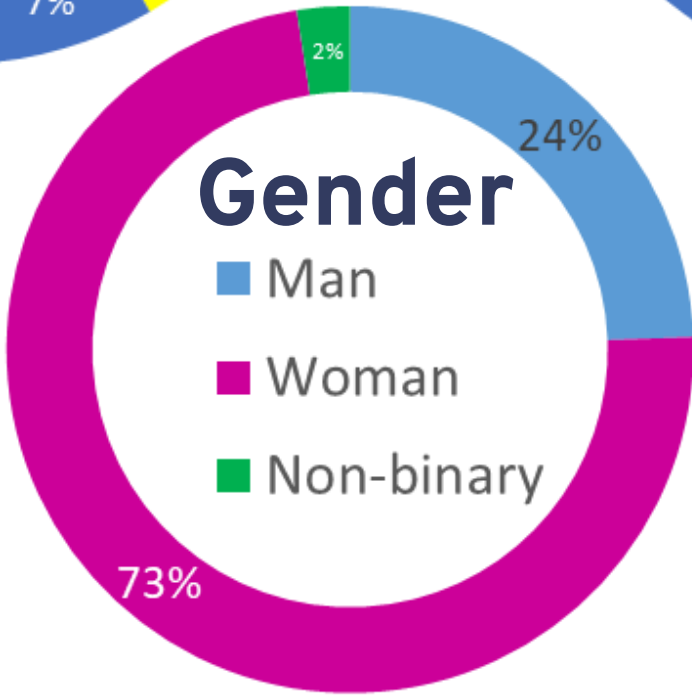
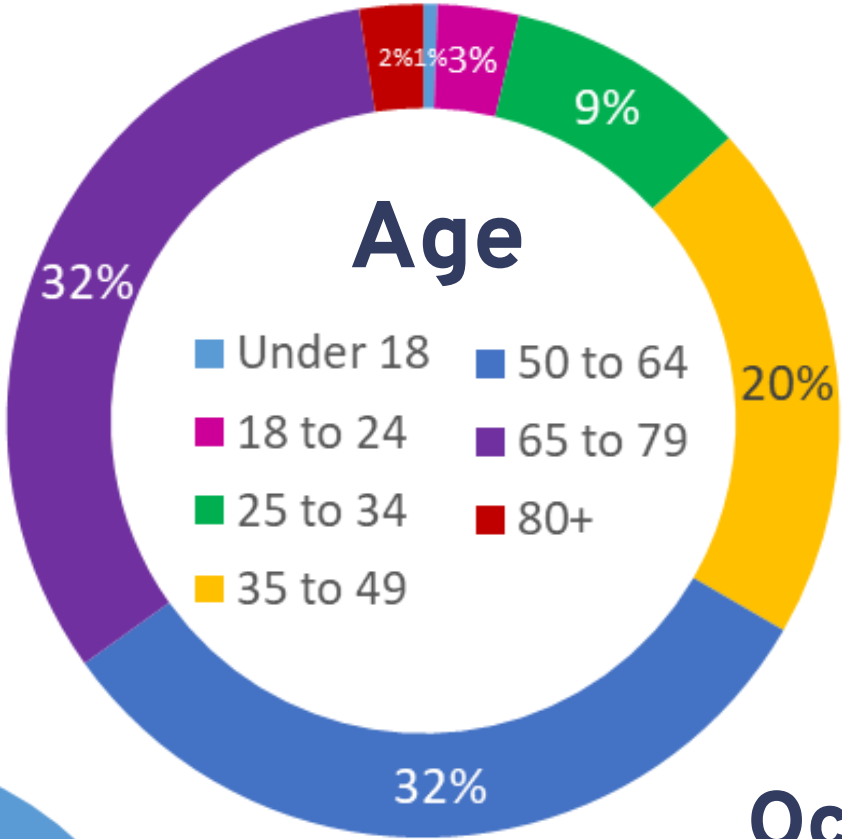
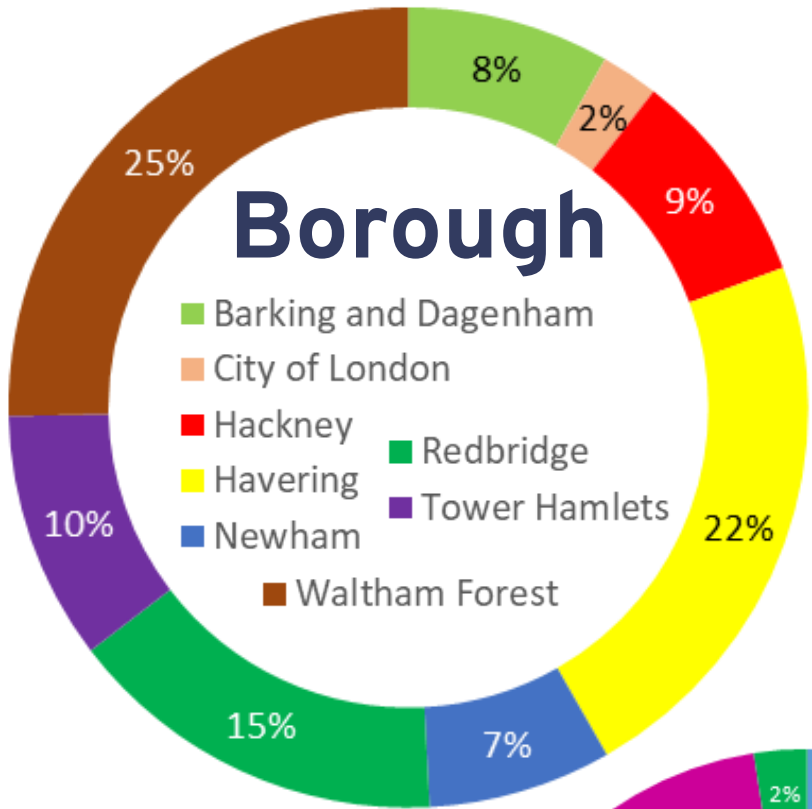
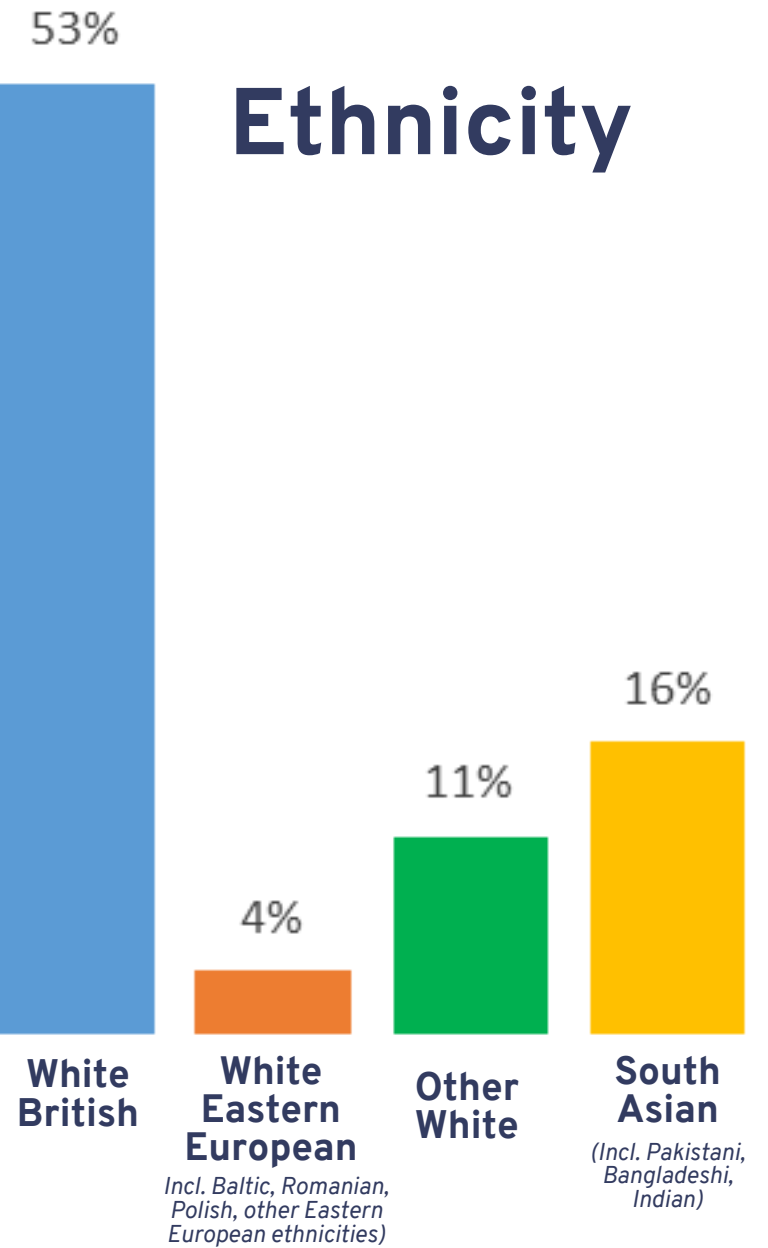
This report is an adaptable document; different sections of it can be used either separately, in conjunction with each other or alongside your own data. Health and care stakeholders are encouraged to use it as a framework for developing their own success measures and quality improvement aims. The deep dive into the four priorities offers a potential example for how to do that.

# Big Conversation

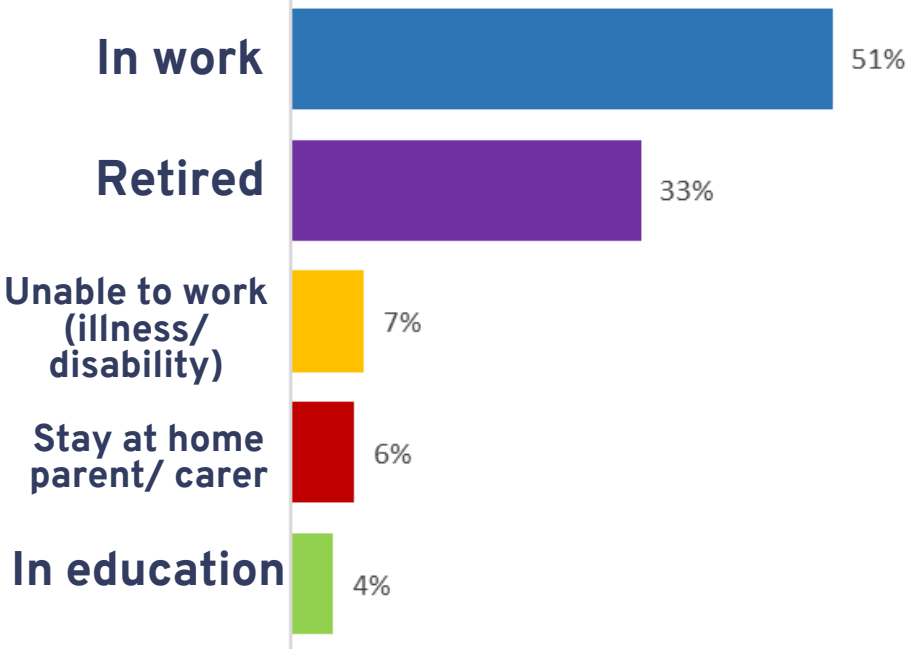


# Demographics

survey respondents only



### 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

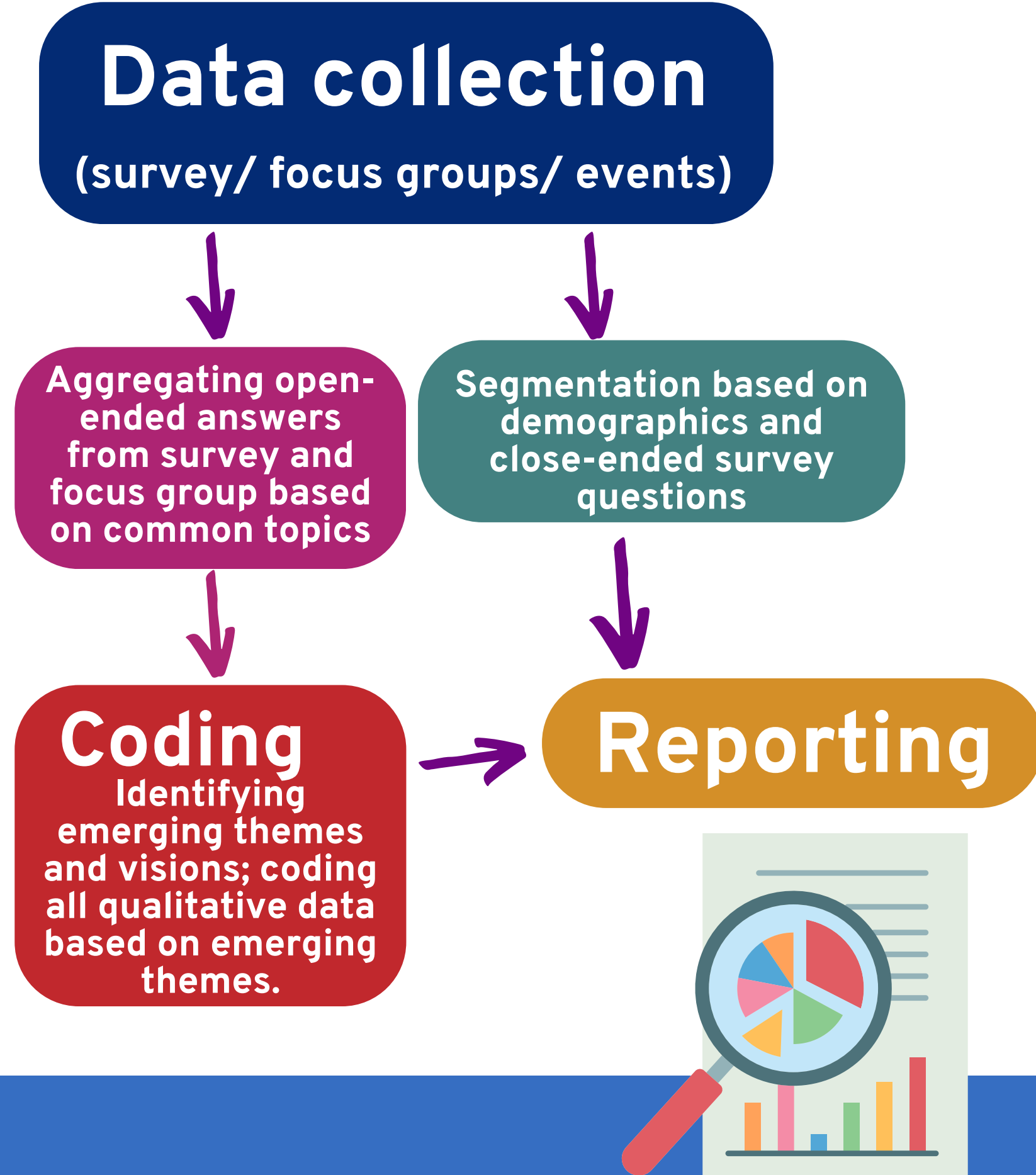
41% had a long-term condition

3% were LGBT

32% were struggling financially or just getting by



# Data analysis methodology



Qualitative data analysis is the process of examining and interpreting qualitative data (open ended questions) to understand what it represents.

Coding is the systematic process of categorising and organising qualitative data into distinct themes, identifying connections and relationships between them. It entails assigning labels to words or phrases that represent important (and recurring) themes in each response.

All answers submitted by participants have been read and systematically coded; the coding has been done as a team effort by Local Voice researchers.

All findings in this report are directly derived from the data- quantitative and qualitative.

# The good care framework

## What does good care look like?

A diagram illustrating the Good Care Framework. It features a dark teal triangle at the top with the text "Everybody can THRIVE" in white. Below the triangle are four vertical pillars of different colors: blue, red, yellow, and purple. Each pillar has a label written vertically in white text: "Accessible", "Competent", "Person-centred", and "Trustworthy".

Everybody  
can THRIVE

Accessible

Competent

Person-centred

Trustworthy

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

We asked 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, can be used by stakeholders to develop their own success measures and evaluation tools. We have used it to examine in depth four priorities, chosen by local people in previous consultations.

# Introduction to the framework

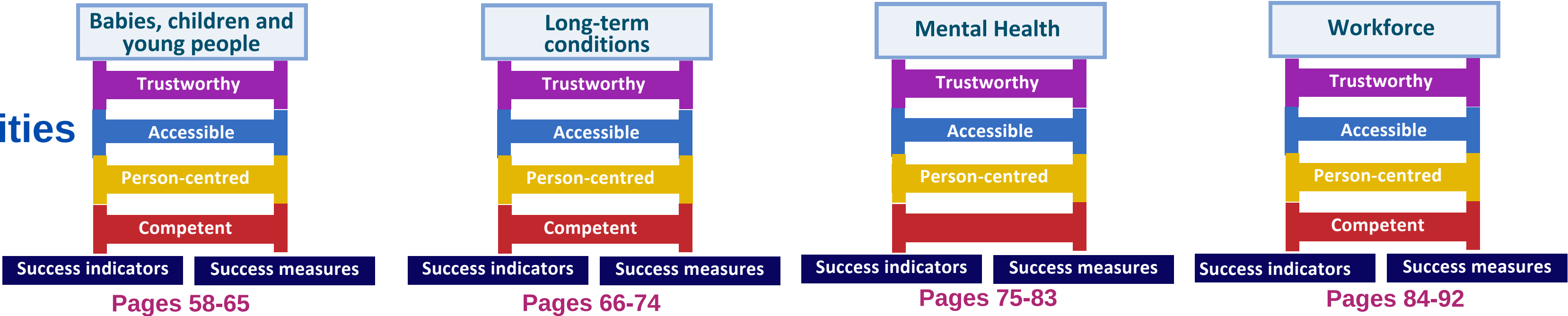
What does good care look like?  
Pages 8-16



What people told us

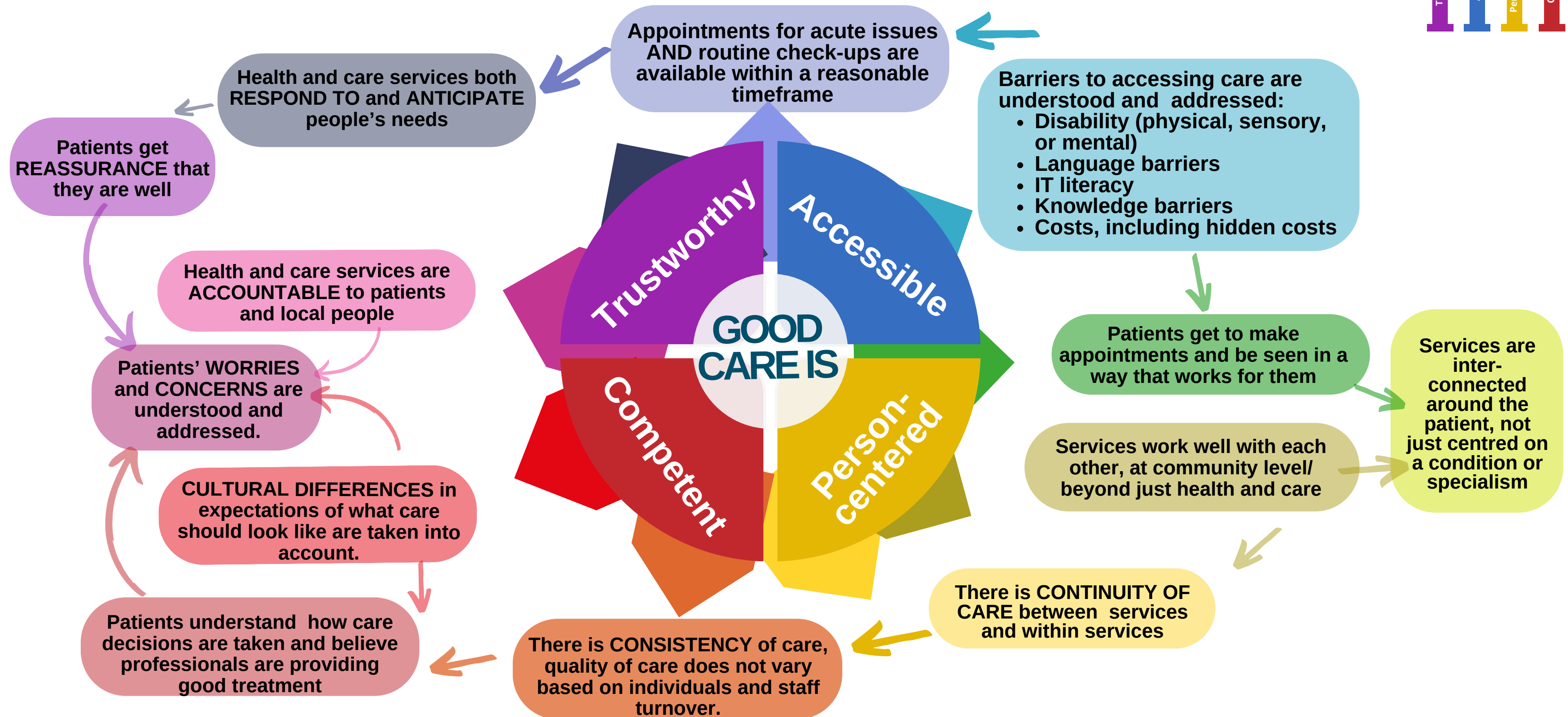


Priorities



We hope to make this report and the dataset as adaptable as possible; different sections of it can be used either separately, in conjunction with each other or with additional data. The aim is to use it as a framework from which people led success indicators and measures can be developed. There is still a lot of work to do.

# What does good care look like?





# What does good care look like?



## Good care is: trustworthy



## Good care is: accessible



## Good care is: person-centred



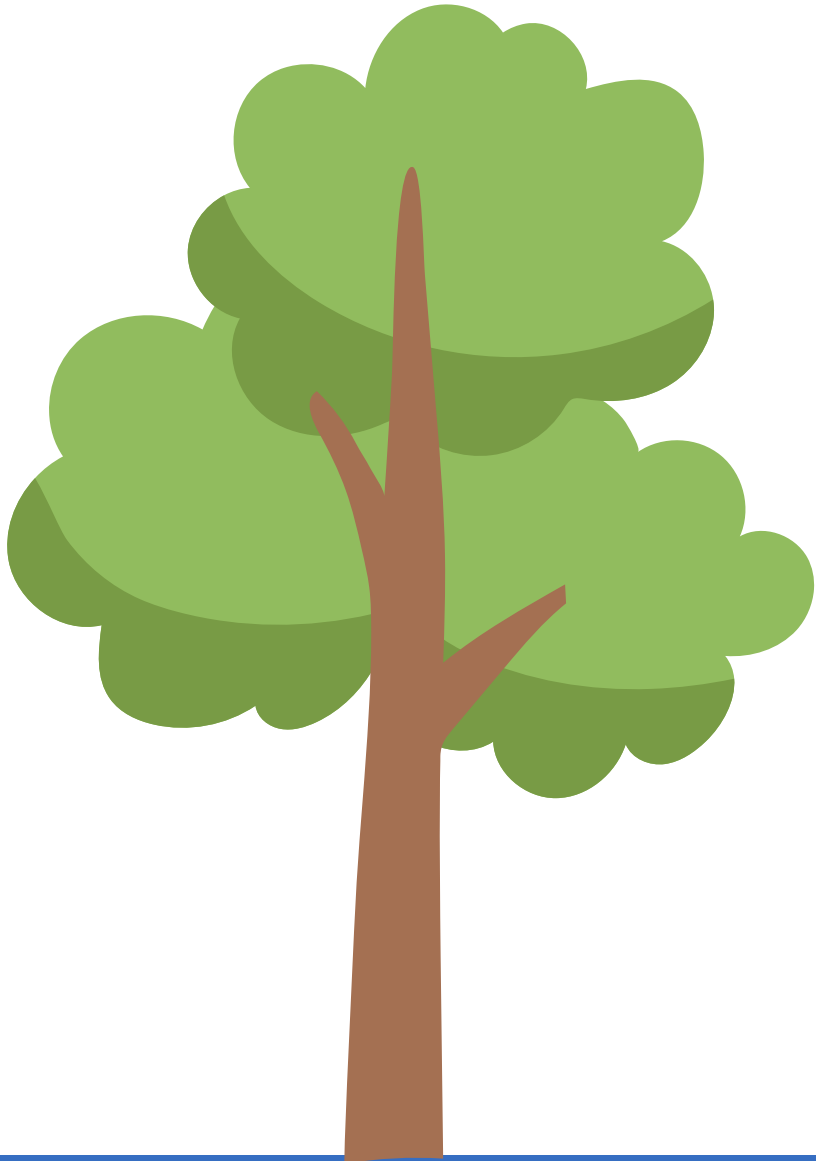
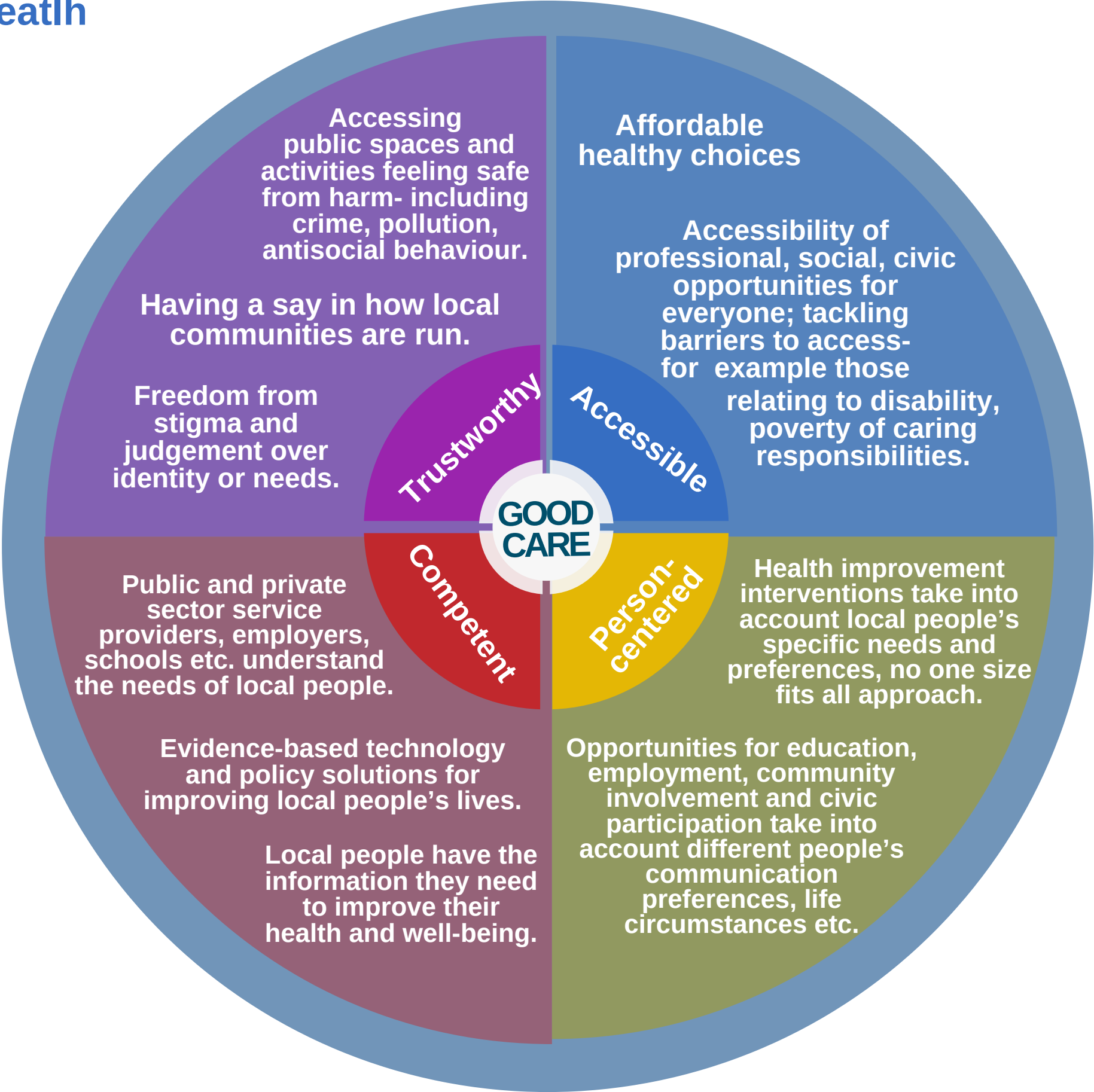
## Good care is: competent



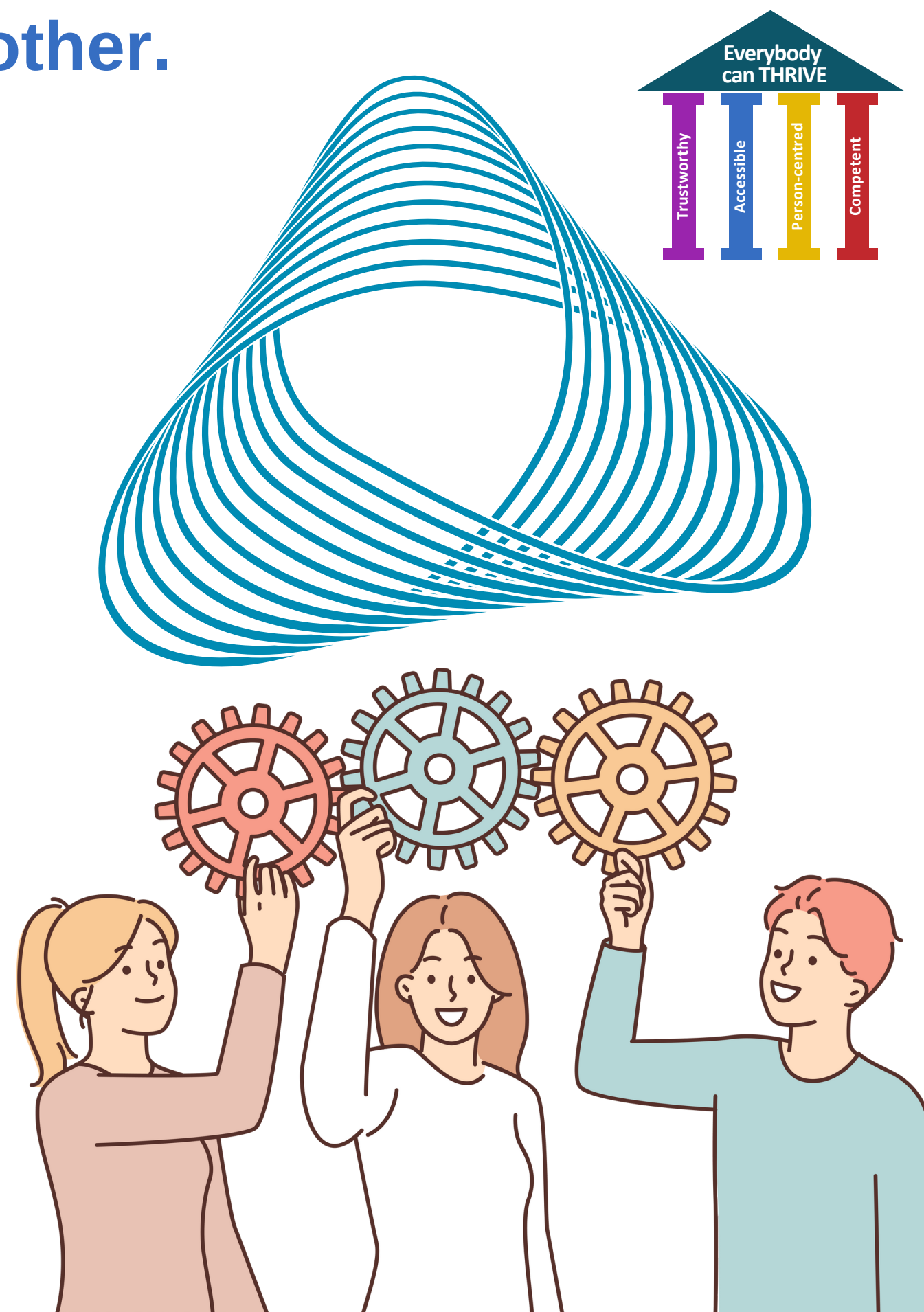
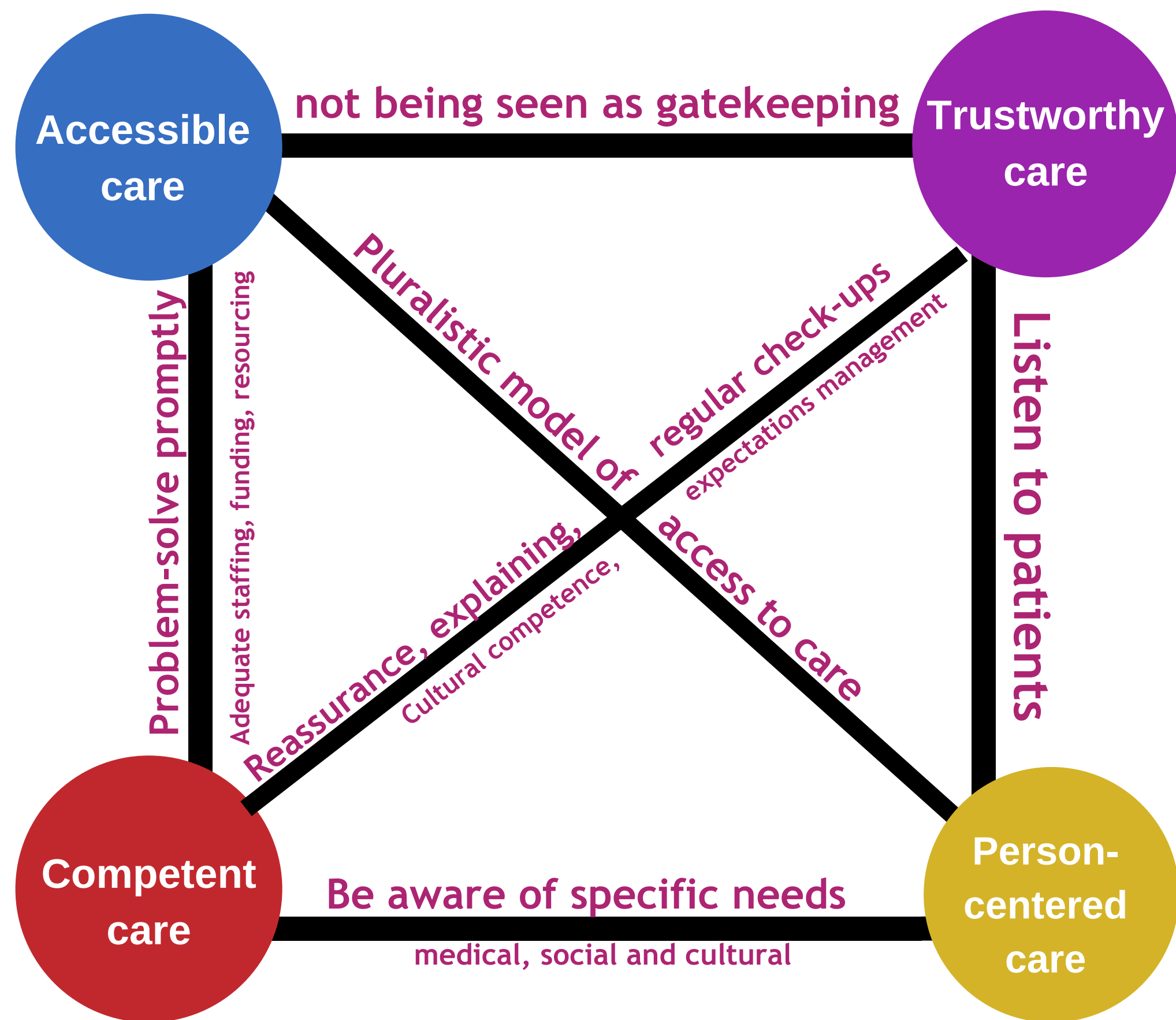
# What does enabling everyone to thrive look like?

The wider determinants of health

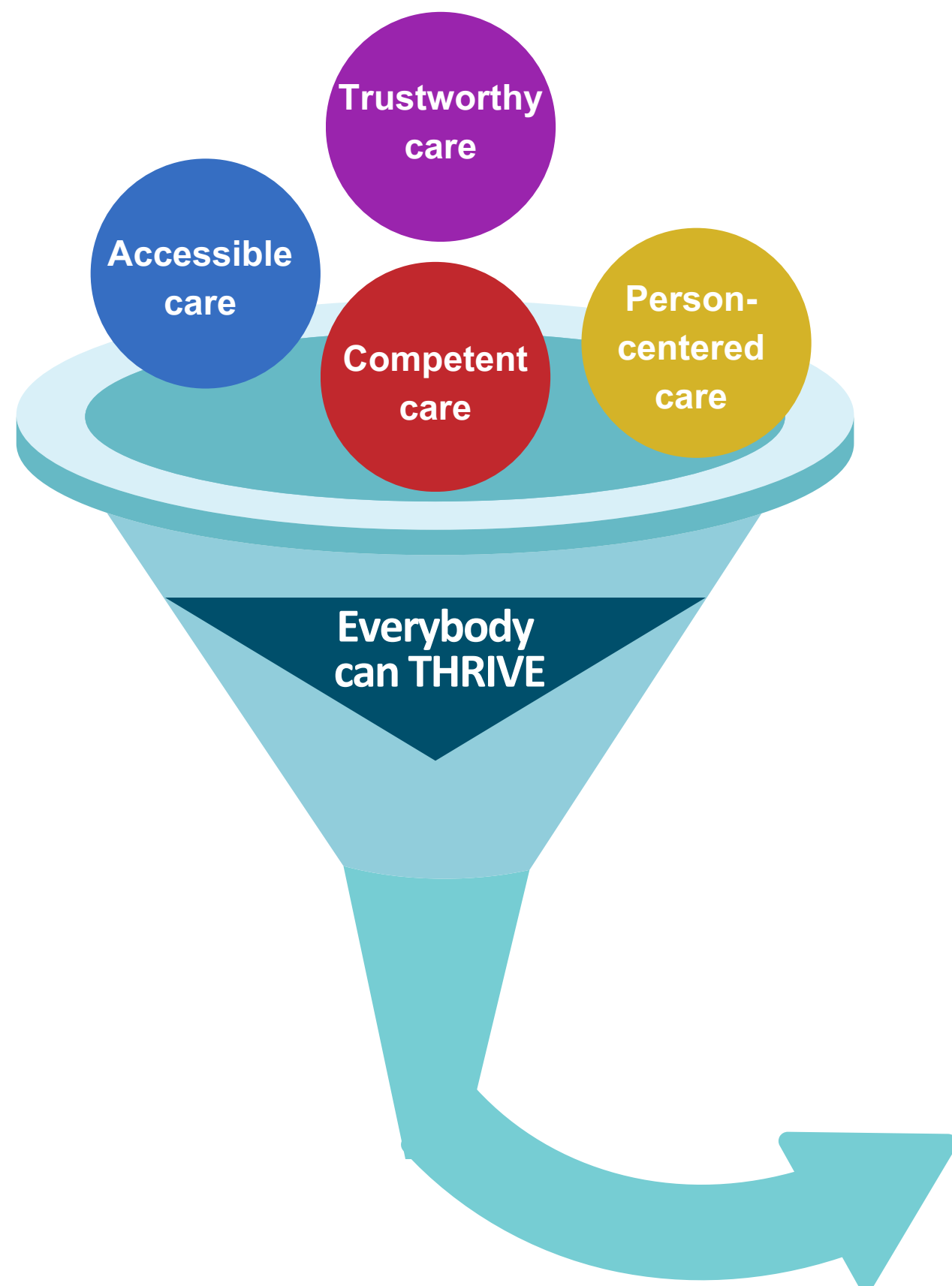
Everybody  
can THRIVE



# The four pillars interconnect and impact each other.







## What does good care look like?

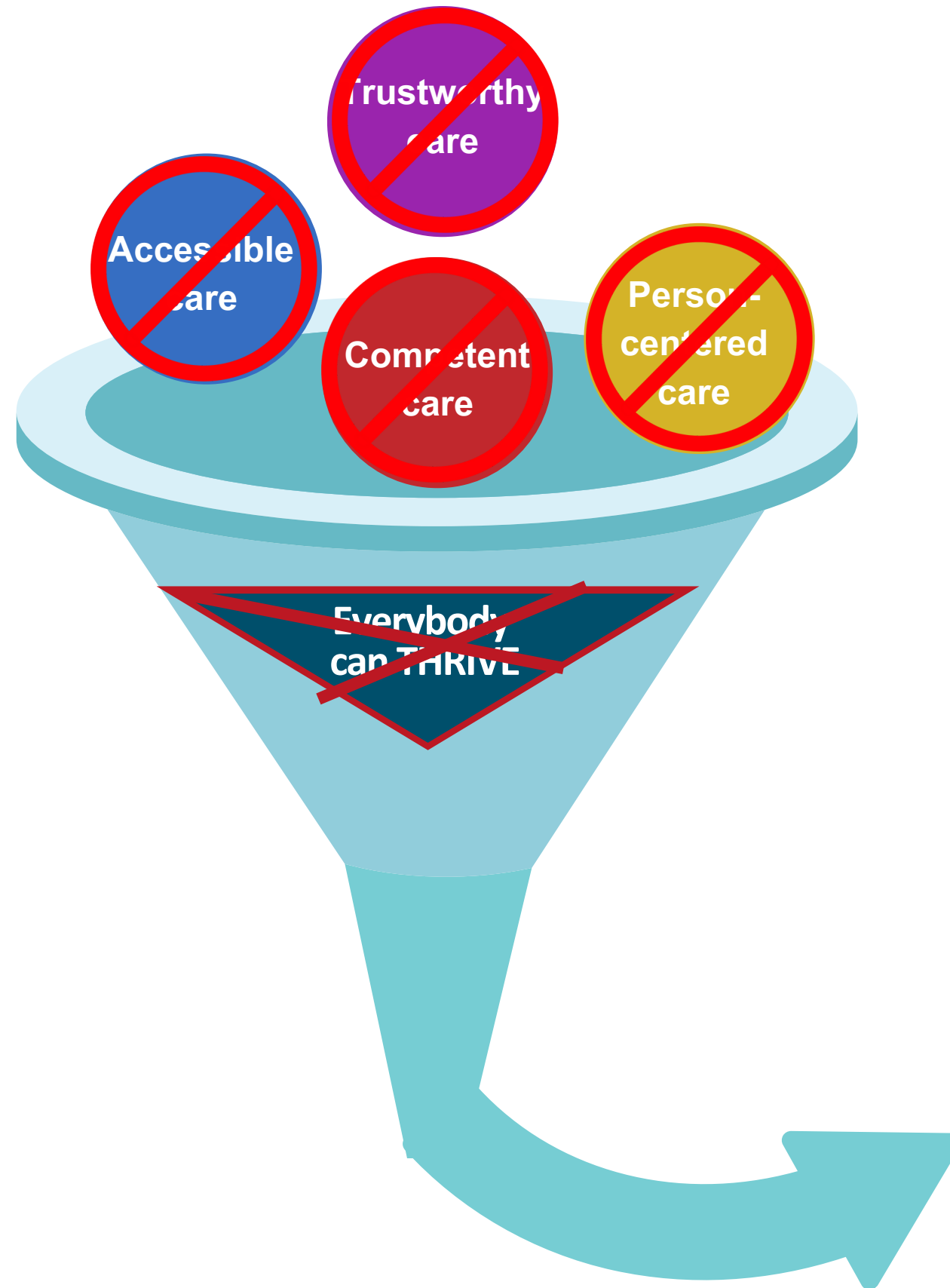
### Good care has good consequences



- 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 good 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 higher risks of social isolation.

# Services mentioned by local people when thinking about care improvement

**GP**  
**413 mentions**

**Hospital**  
**113 mentions**

**Dentist**  
**55 mentions**

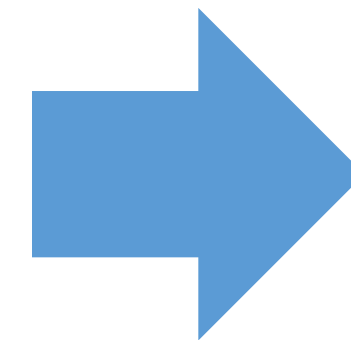
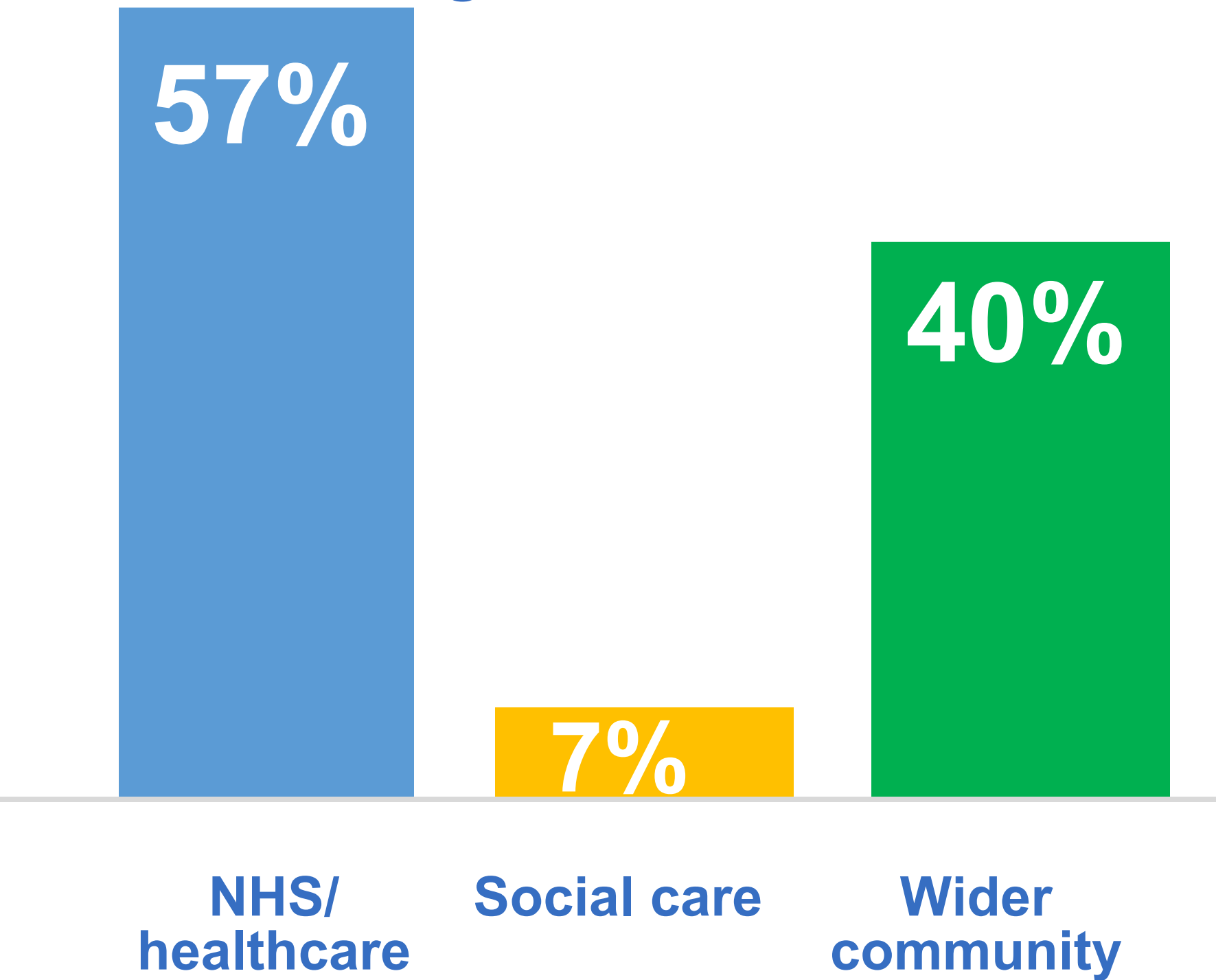
**Mental health**  
**49 mentions**

**Community services**  
**27 mentions**

**Social care**  
**23 mentions**



## 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 unpredictable schedules
- **Improve cleanliness of public spaces, especially of green spaces.**

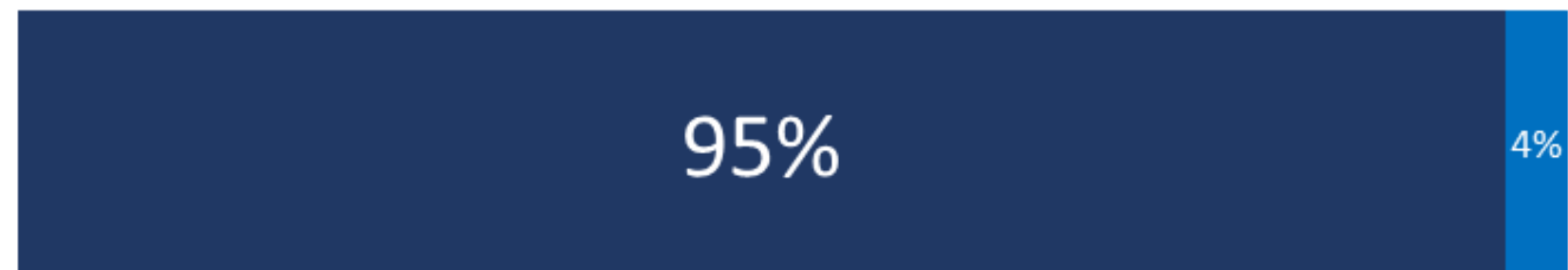


# Accessible



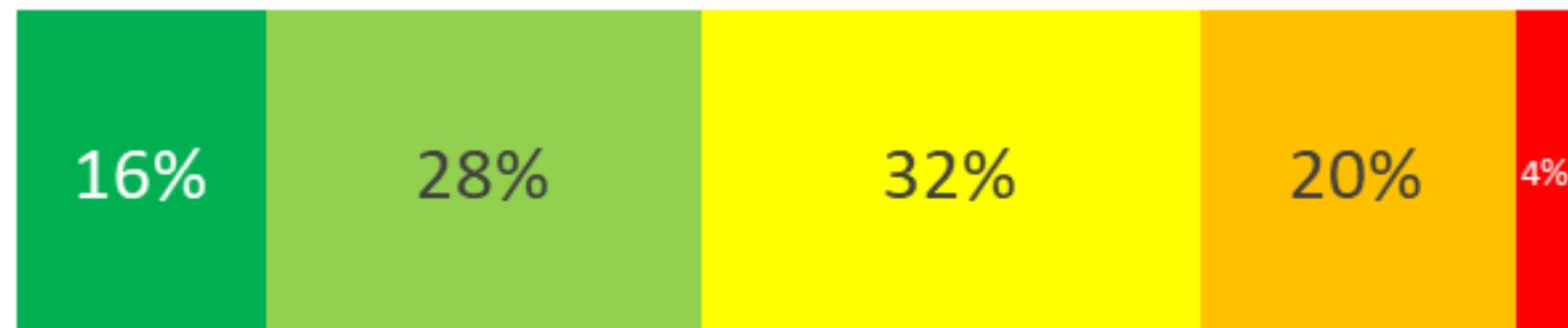
## Accessible

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



■ Very important ■ Quite important ■ Not very important

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



■ All of them ■ Most of them ■ Some of them  
■ Few of them ■ None of them

**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



# 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; and 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.

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; as well as understanding and taking steps to mitigate any other forms of barriers to accessing care (language barrier, digital exclusion, general literacy, knowledge of the system, cultural issues, domestic violence).

Making healthy lifestyle choices is realistic for all; for example, people on low incomes and those who cannot cook for themselves still can have a healthy diet; exercise classes are available for those with limited mobility who can only handle gentle physical activity etc.

Accessible

*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.*

## What would NOT happen?

Patients going to A&E for issues that could have been dealt with by a GP or walk-in centre.

Over-stretched telephone lines, associated with a one size fits all booking system.

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, or because they struggle with the process of accessing it.

People feeling that their personal circumstances (income, daily schedule, working conditions, physical limitations) force them to make unhealthy choices instead of healthier ones (for example making unhealthy diet choices because they can't afford healthier ones).

# Focus on: Deaf BSL users

## Accessible

*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 no 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 Queen's 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: **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.*



## 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**

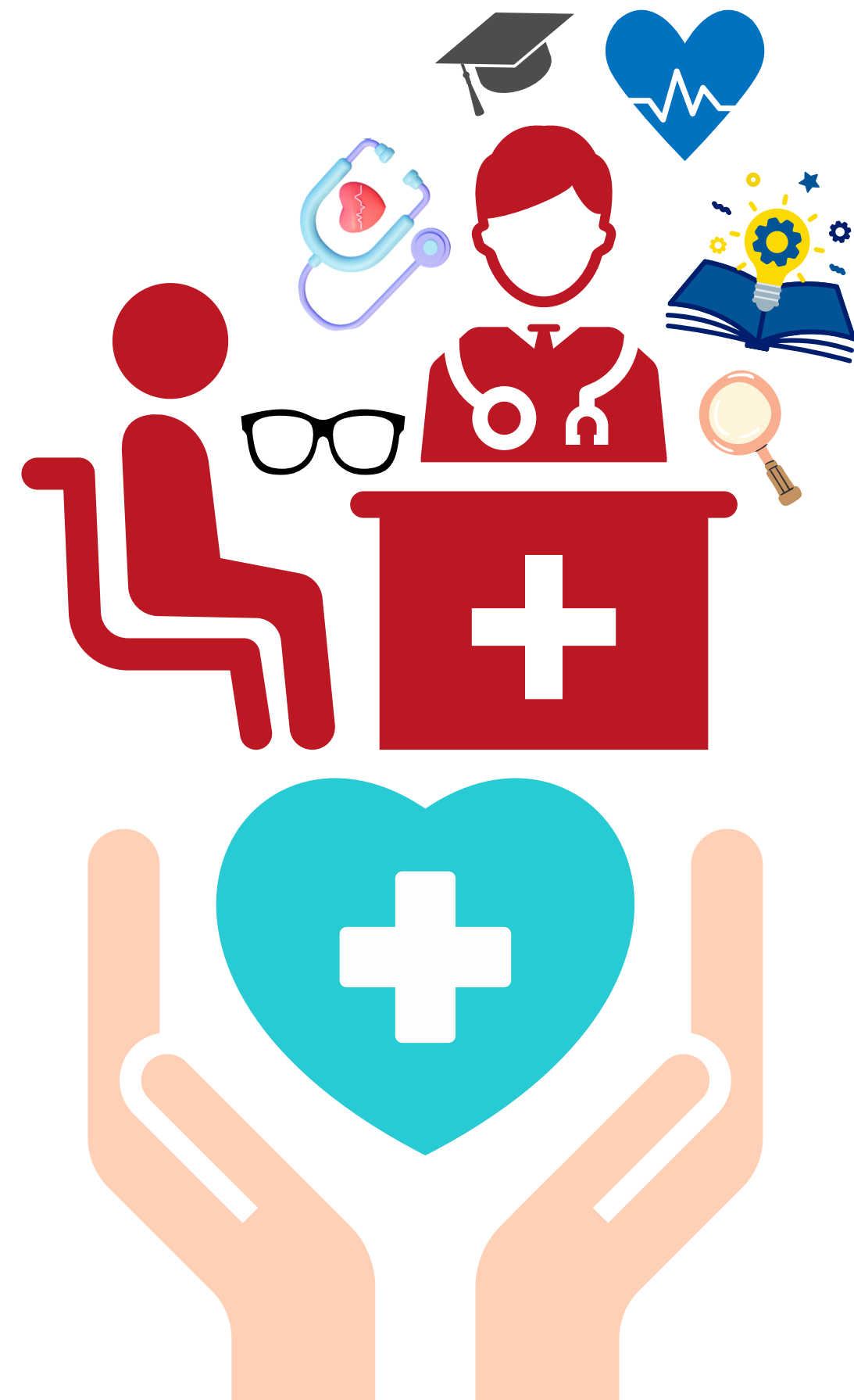
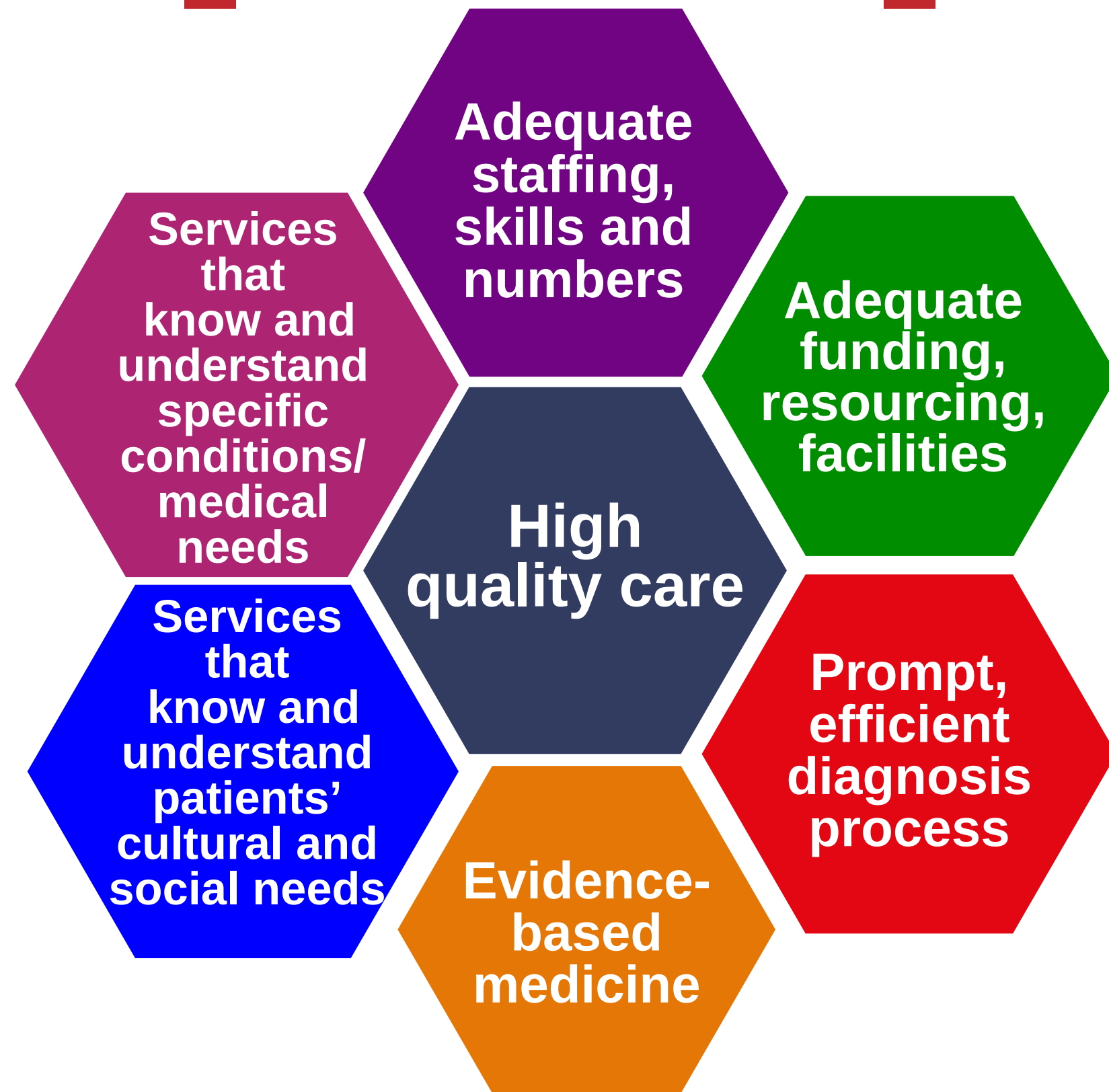
*A Deaf mother had a good experience with a specific midwife, who listened and took on board that she was Deaf. The midwife booked lots of appointments for her and they were proactive in making sure there was always an interpreter for appointments. She took it on responsibility for her care directly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

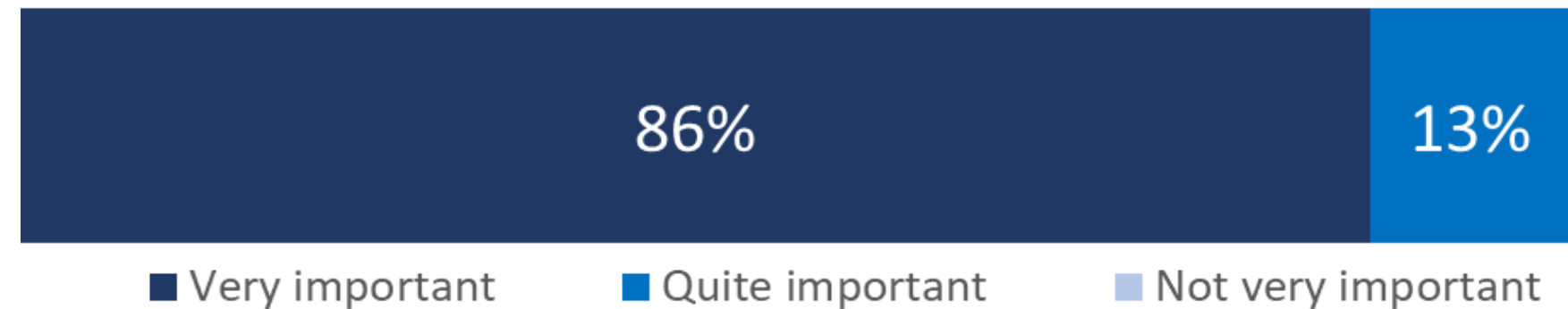
**African & Caribbean men's focus group, Hackney**

# Competent

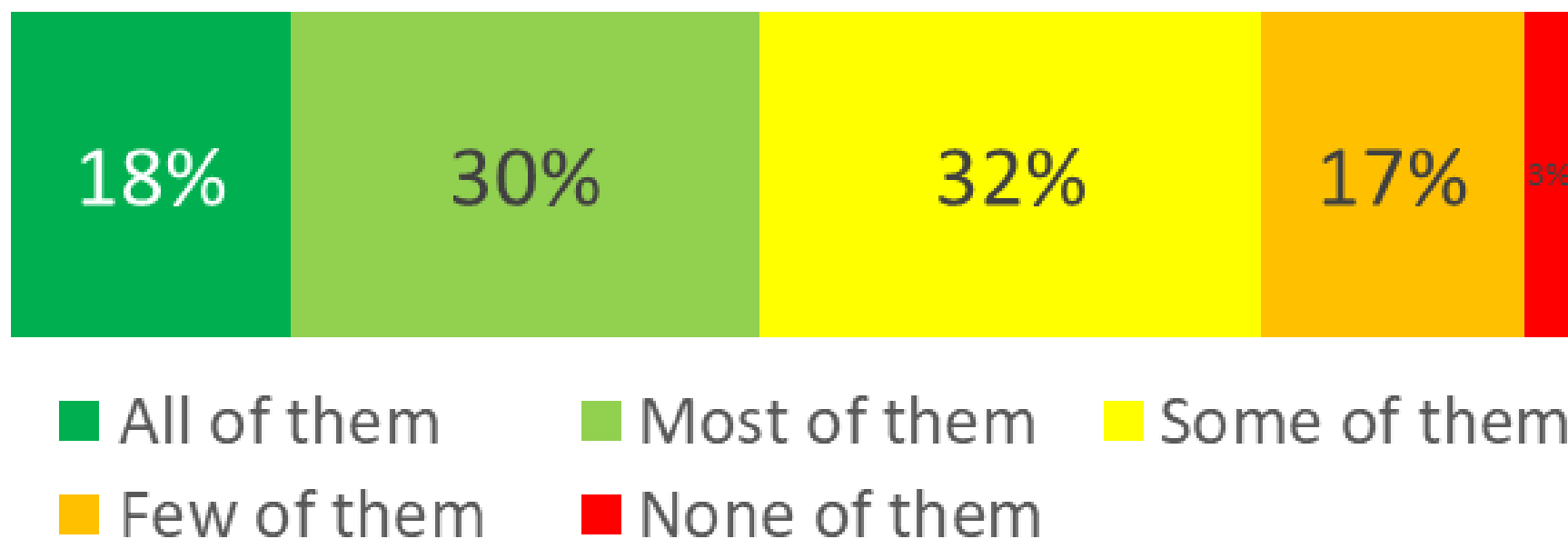


## Competent

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

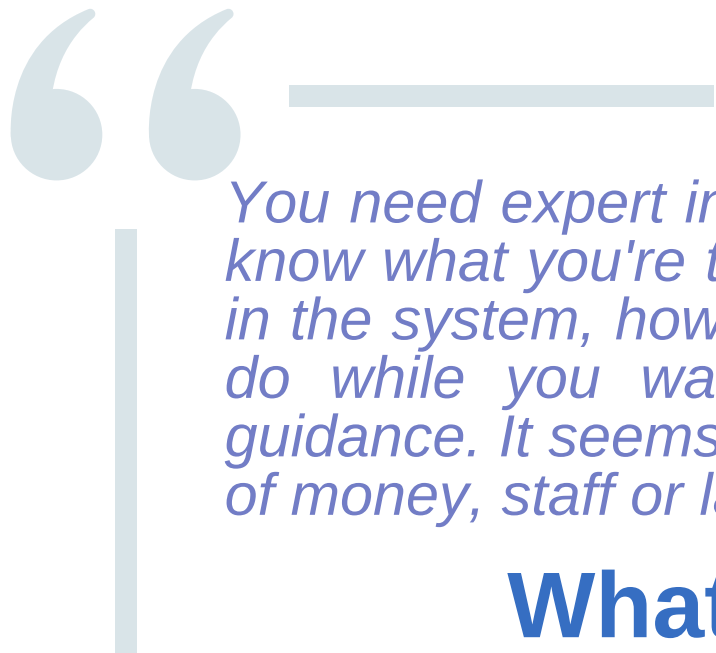
**Less likely to find professionals understand their needs**

- 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

# 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.
- Patients are diagnosed accurately and within a reasonable timeframe; necessary investigations are available to ensure the accuracy of the diagnosis process.
- Patients receiving treatment informed by the NICE guidelines, and by the latest evidence-based developments in medical science.
- Local people having a good level of knowledge about keeping themselves healthy and well.
- Employers, schools, public services and local businesses knowing how to ensure they provide a healthy environment.



*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.*

## What would NOT happen?

- Excessively long waiting times for diagnosis/ investigations.
- Admin issues affecting the diagnosis process, e.g.: lost test results.
- Misdiagnosis as a result of superficial consultations/ poor 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 professionals' own cultural biases, rather than clinical need and scientific evidence.
- Ineffective public health/ prevention interventions at a wider social level.
- Local people making decisions about their own health based on incorrect information or pseudoscience.



# Specific areas of training identified as needed/ important

Competent

- 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.

## 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.*

*As 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.*

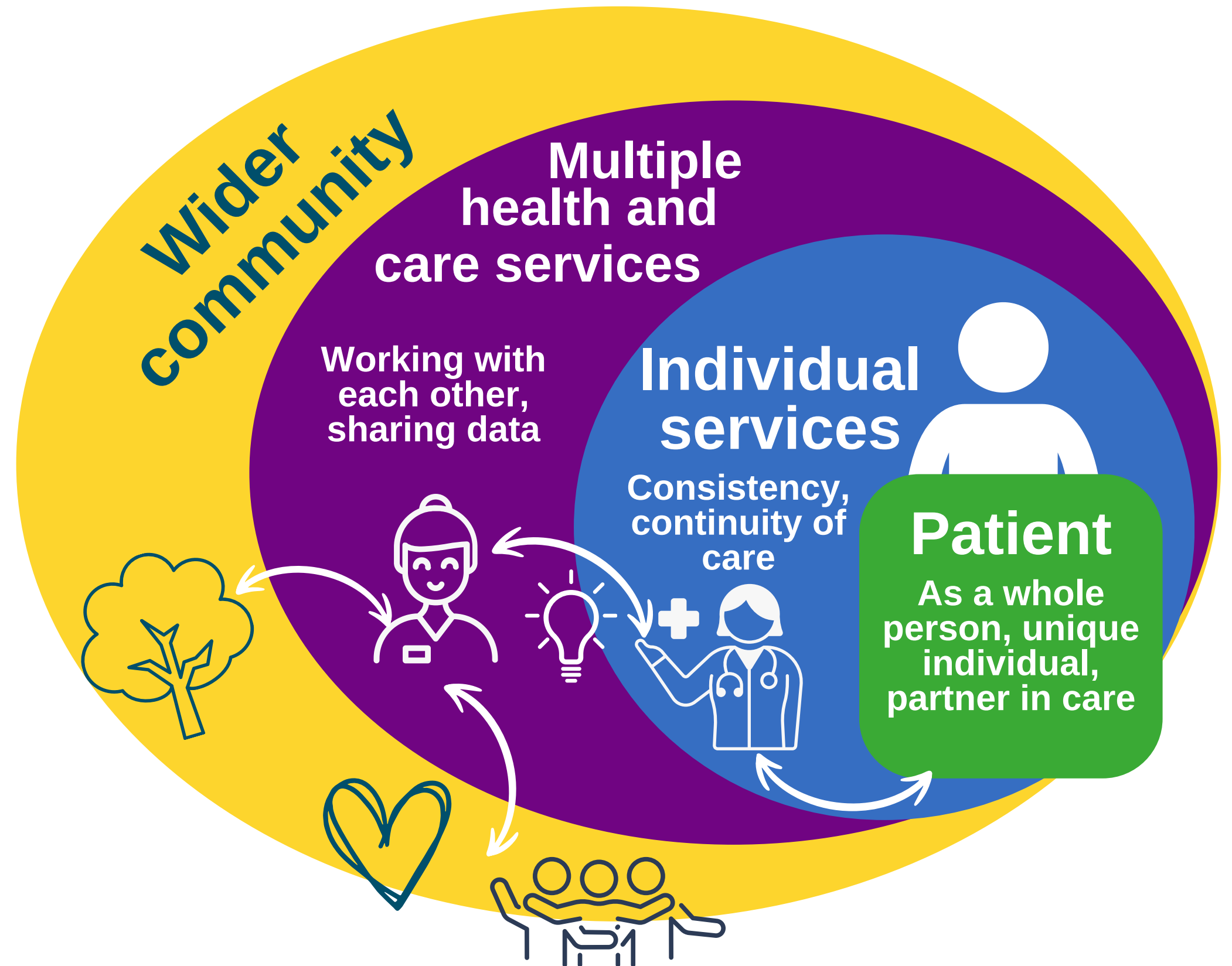
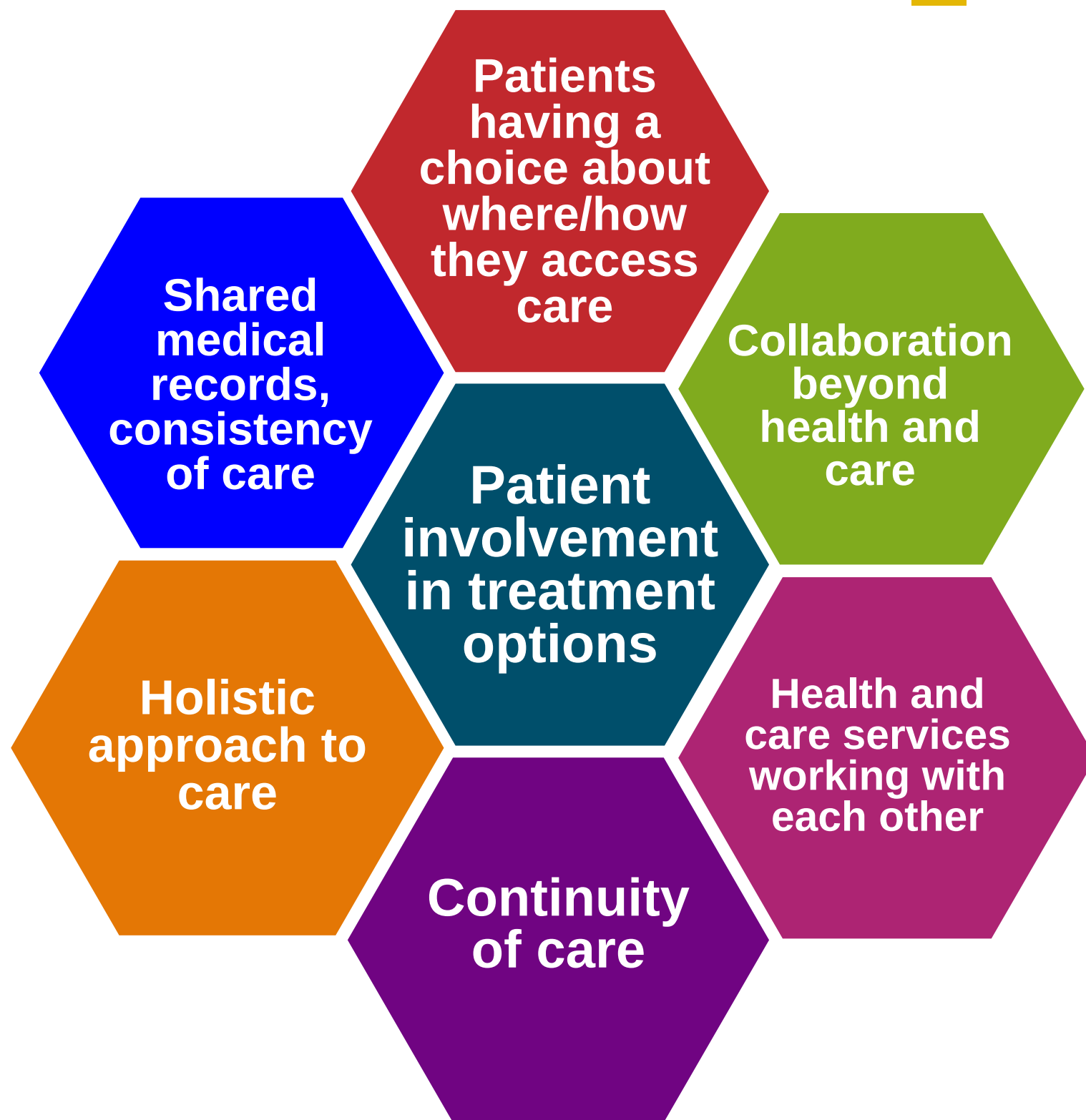
## Focus on: LGBT health

*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*

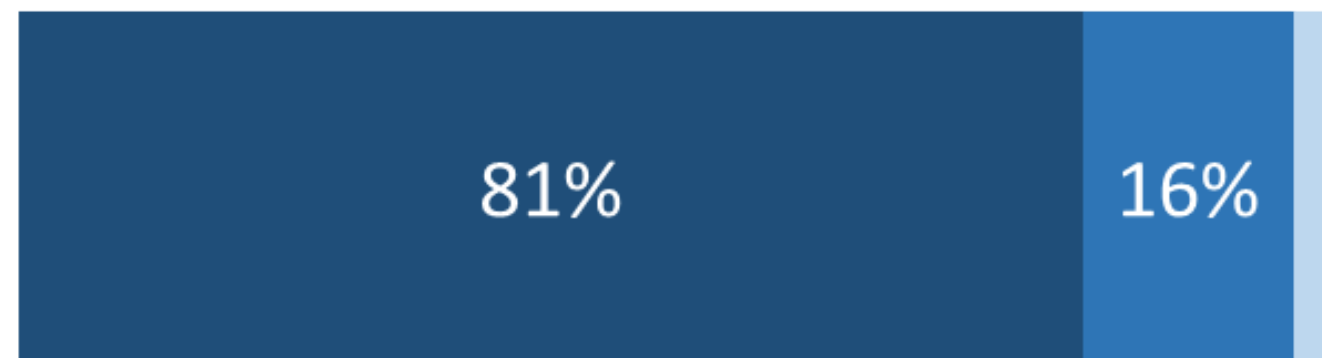
*Educate themselves about Lesbian, Gay, Bisexual and Trans issues. Learn about racism in a realistic way. Learn the definition of Intersectionality - that some people are Black AND queer AND old AND disabled at the same time.*

# Person-centred



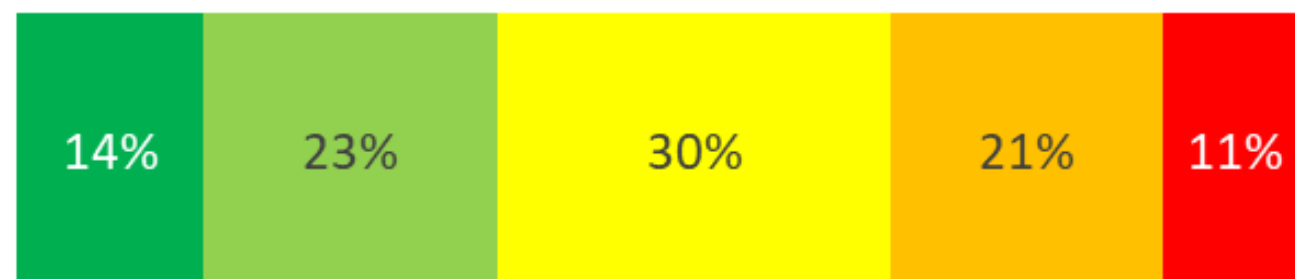
## Person-centred

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



■ Very important ■ Quite important ■ Not very important

Professionals looking after me:  
Work well together



■ All of them ■ Most of them  
■ Some of them ■ Few of them  
■ None of them

More likely to find professionals  
work well together

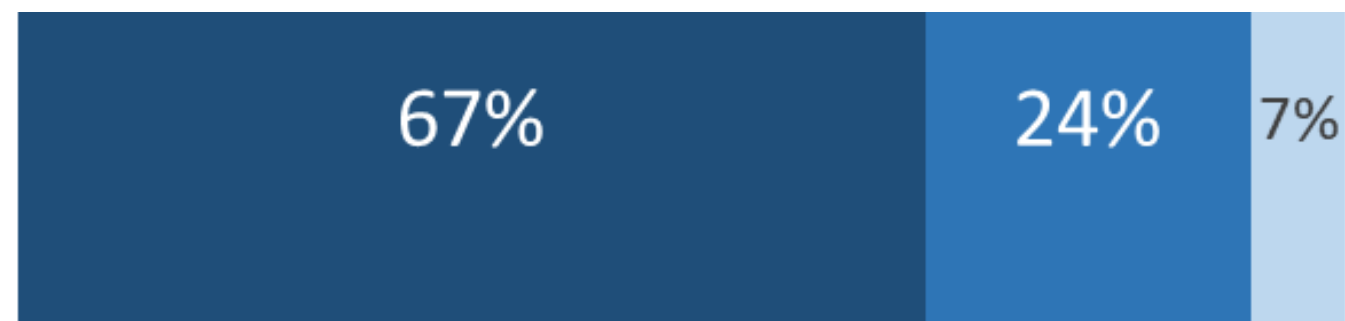
- Aged 65+
- South Asian ethnicities

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

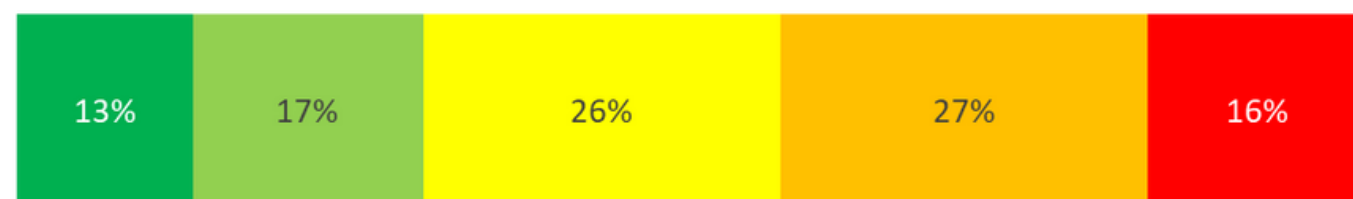
## Person-centred

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.



■ Very important      ■ Quite important  
■ Not very important      ■ Not at all important

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



■ All of them      ■ Most of them      ■ Some of them  
■ Few of them      ■ None of them

More likely to find they can avoid  
repeating themselves

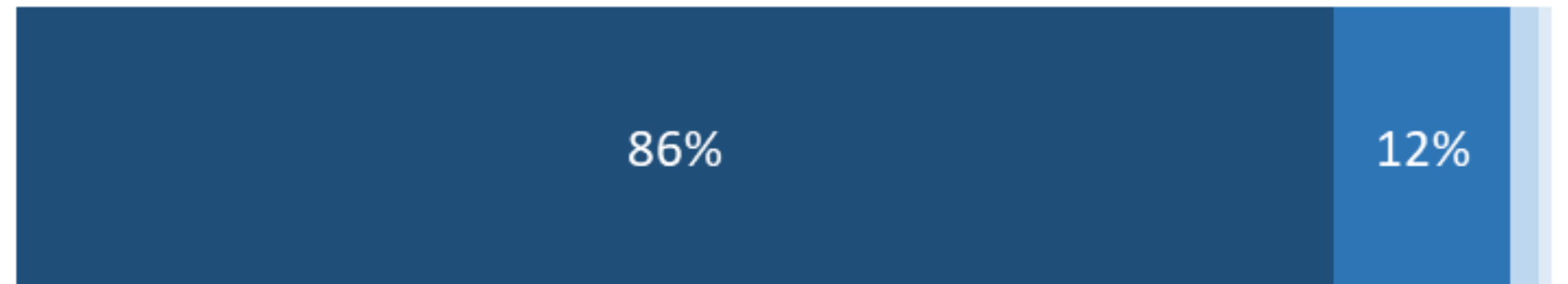
- Aged under 25
- South Asian ethnicities

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

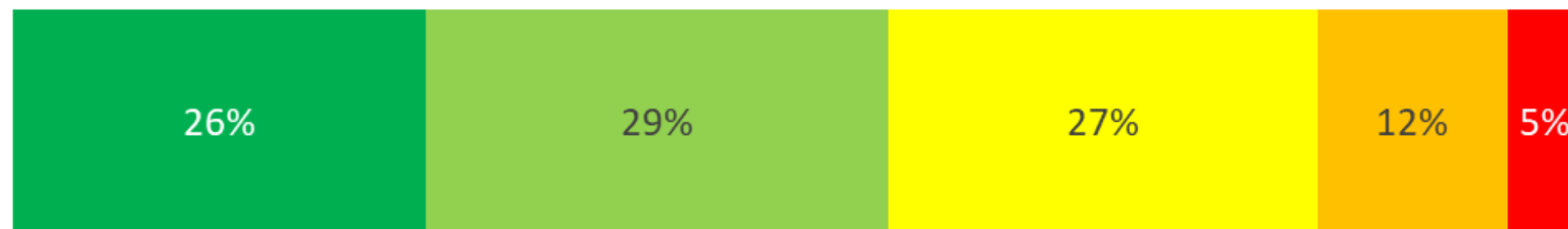
## Person-centred

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



■ Very important ■ Quite important ■ Not very important ■ Not at all important

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



■ All of them ■ Most of them ■ Some of them  
■ Few of them ■ None of them

**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



# What would indicate **person-centred** care?

Patients get to see the same medical professional consistently (for example the same doctor or midwife), as much as it is practical. Otherwise, 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 are actively working with the wider community to promote holistic patient health - social prescribers, the voluntary sector etc.

Health and care professionals give patients clear options for treatment or care, presented objectively with pros and cons; empowering them to make informed decisions. Patients feel treated as a partners in their own care; and like medical professionals are interested in their own desired health outcomes.

Health and care professionals take 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 or public services (using online services, having remote consultations or doing everything in person).

Information is available in a variety of formats and outreach channels

Employers, recruiters and schools consider work-life balance and fitting around workers' and students lives; processes for workforce recruitment and career development look at the worker holistically.

Person-centred

“

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

## 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.

Patients only being allowed to discuss one symptom or condition per appointment.

## Person-centred

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

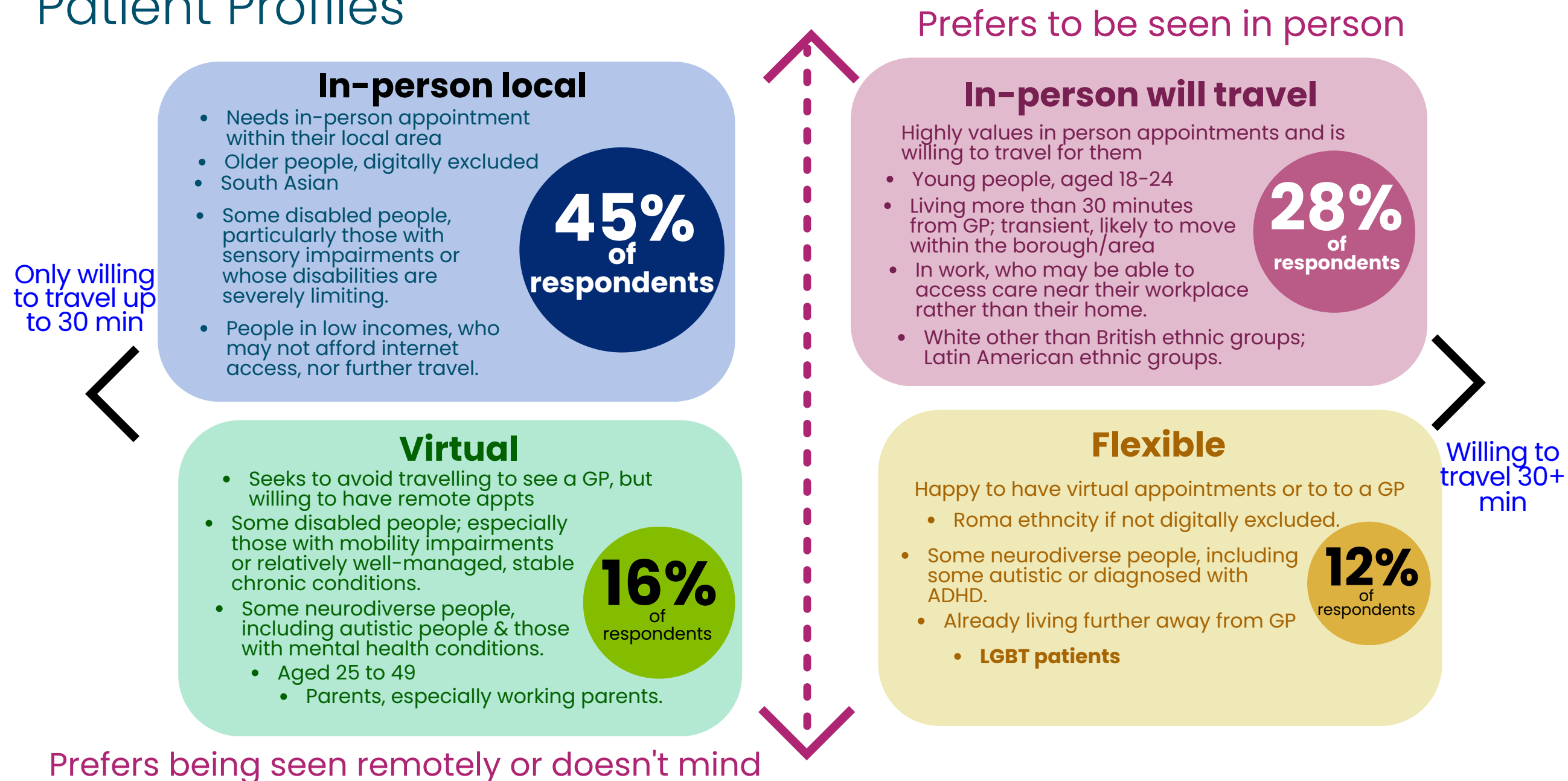




# Person-centred

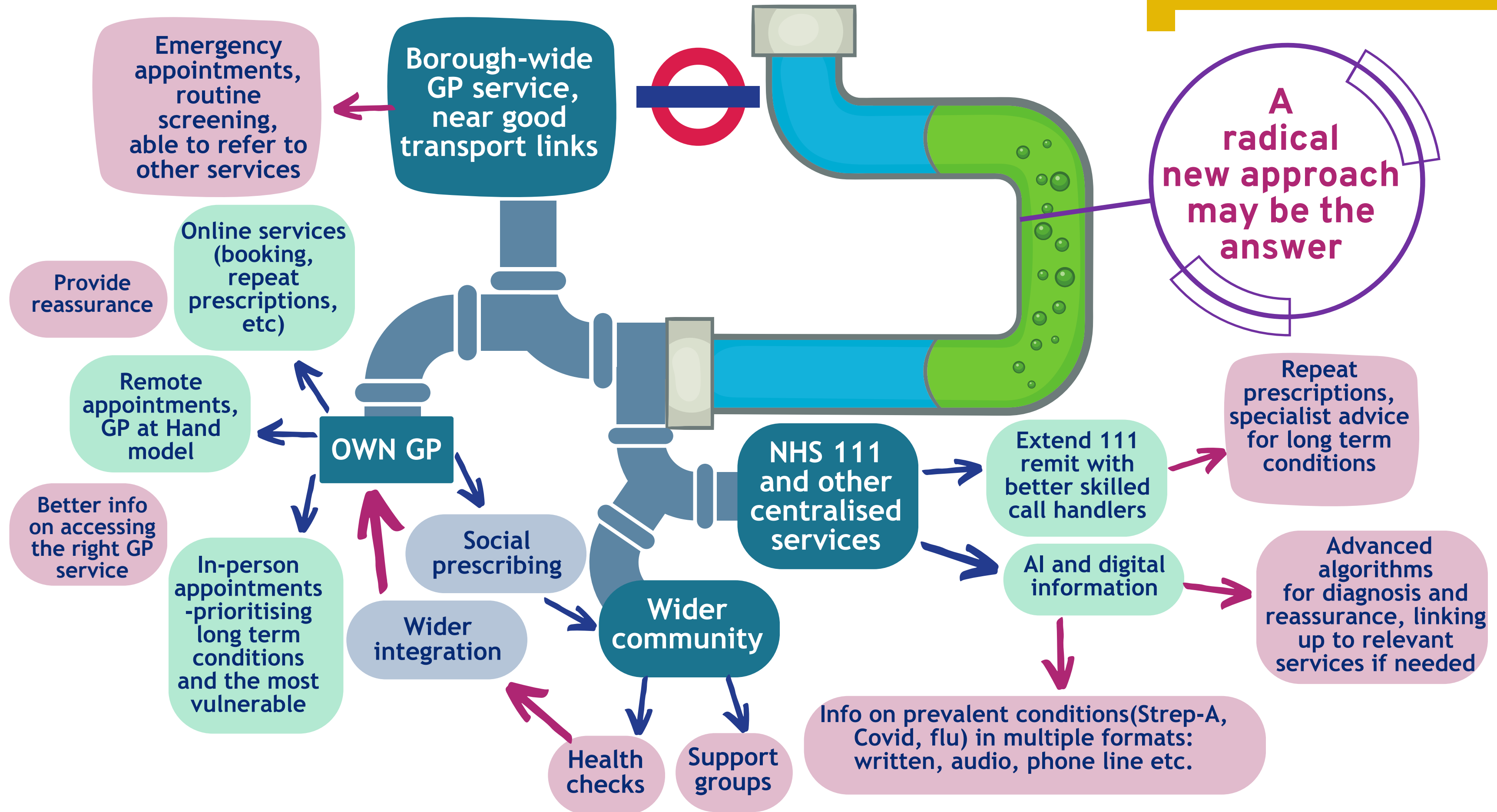
We have previously analysed data on where and how patients want to access GP appointments. Findings are consistent with the findings of this survey.

## Patient Profiles



# Unblocking the pipeline

Person-centred

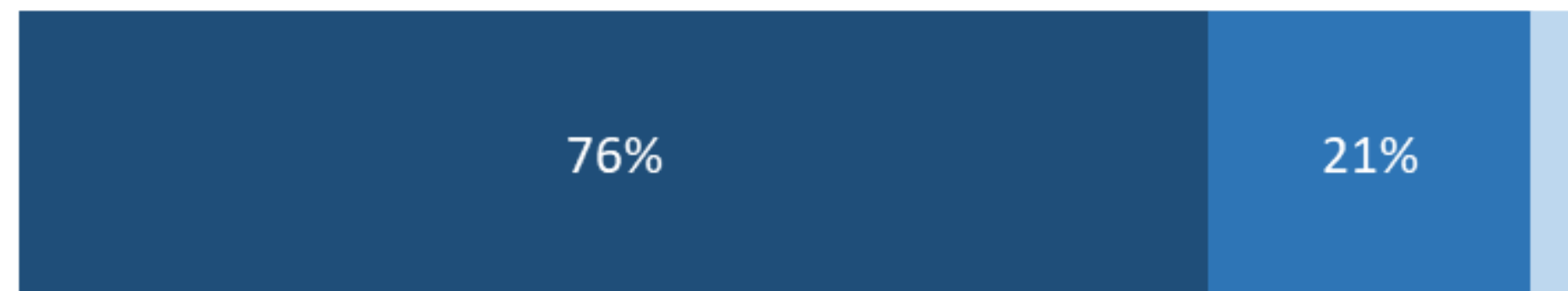


# Trustworthy



## Trustworthy

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



■ Very important ■ Quite important ■ Not very important ■ Not at all important

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



■ All of them ■ Most of them ■ Some of them  
■ Few of them ■ None of them

**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



# What would indicate trustworthy care?

- Patients feel listened to and reassured that their problems are taken seriously by care professionals; they feel that they are given adequate time .
- Health and care services proactively engage with patients and ask about what is important to them.
- Patients communicate with professionals about their care, in a honest, straightforward manner; understanding why they are offered a certain course of action.
- Patients have someone they can turn to for competent advice, reassurance and prevention; they know whom they can turn to if they are worried about specific aspects of their health.
- There is a straightforward and transparent process for accessing care.
- Patients have access to routine check-ups in order to feel fully reassured that their health is good.
- Services demonstrate accountability and act upon feedback received from patients.
- In the family, workplace and community, local people feel comfortable talking about their health needs with no fear of judgement or stigma.
- Local people feel safe from harm in their local community; they are comfortable using local amenities/facilities and engaging with their neighbours.

## Trustworthy

“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.

# 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 a consultation.
- Patients perceiving admin staff as gatekeepers or relating to them in an adversarial way.
- Workers feeling reluctant to ask for sick leave or necessary adaptations at work, fearing discrimination or judgement.

## Focus on trust, communication and avoiding gatekeeping

Trustworthy

Imagine this situation: You contact your GP, believing that you may need antibiotics or further investigation for new, acute symptoms you are experiencing. Your GP offers you 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?

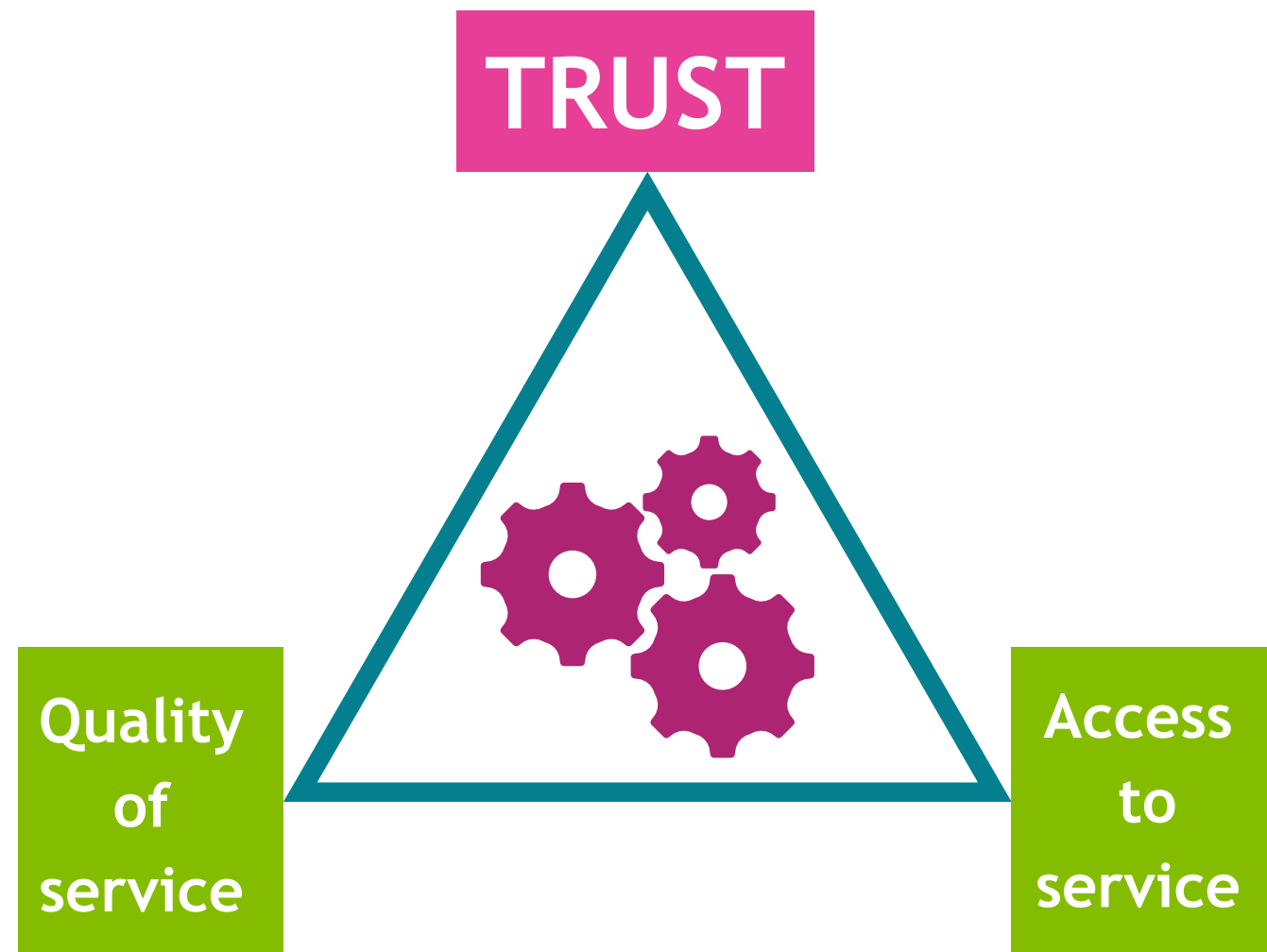
*Make sure the 'patient'/client becomes the focus not trying to fob them off to save money. Listen to their needs not ignore the phone.*

*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.*

## Focus on trust, communication and avoiding gatekeeping

Trustworthy



*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.**

## Focus on reassurance and anticipative care

Trustworthy

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 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*

## 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.**

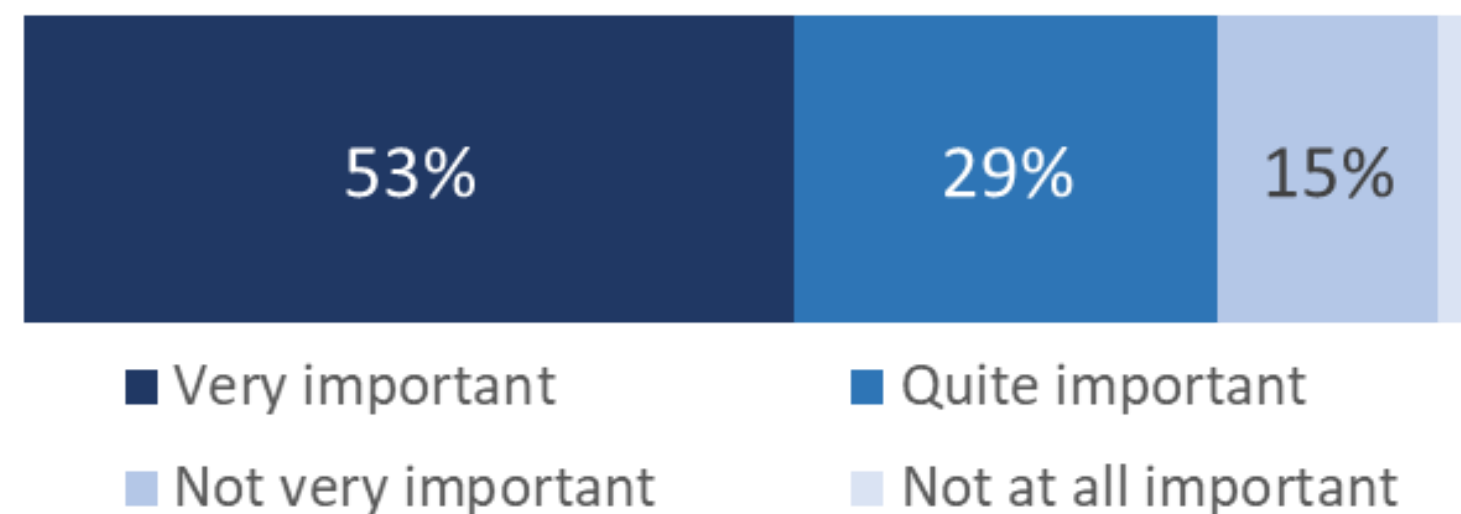
➡ A patient's political opinions may influence whether they believe that private care is better (more customer-focused, more efficient, more accountable) or , on the contrary, less good than public/ socialised health and care services (oriented towards profit rather than the greater good, less trustworthy).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

*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.*

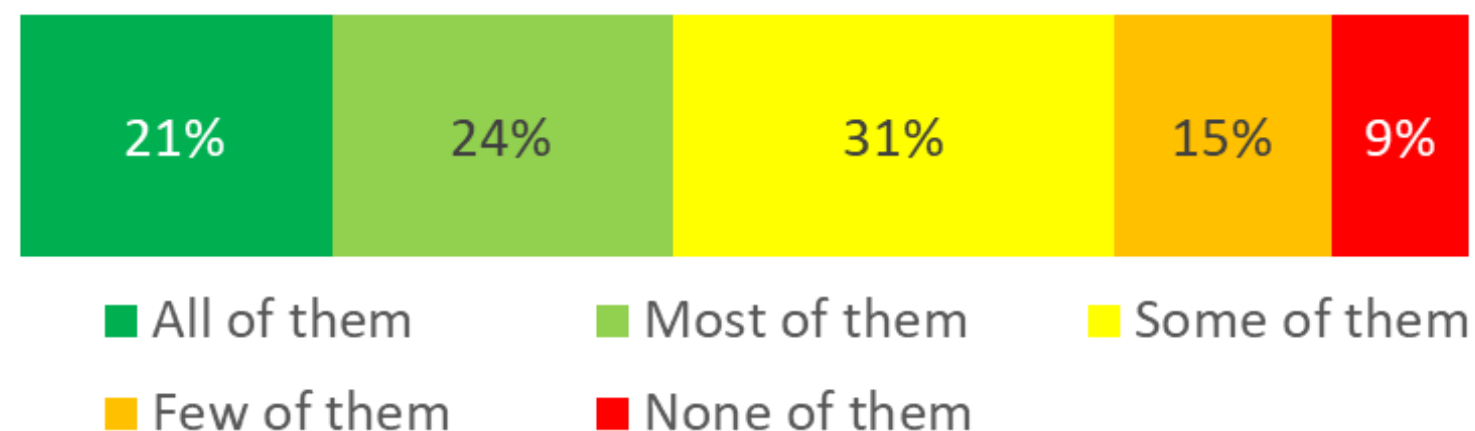
*Health and care professionals are great. You need to pay them more. A happy workforce is one that is appreciated. I want to see private profiteers out of the NHS and for it to be returned to us - renationalise the NHS.*

## 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

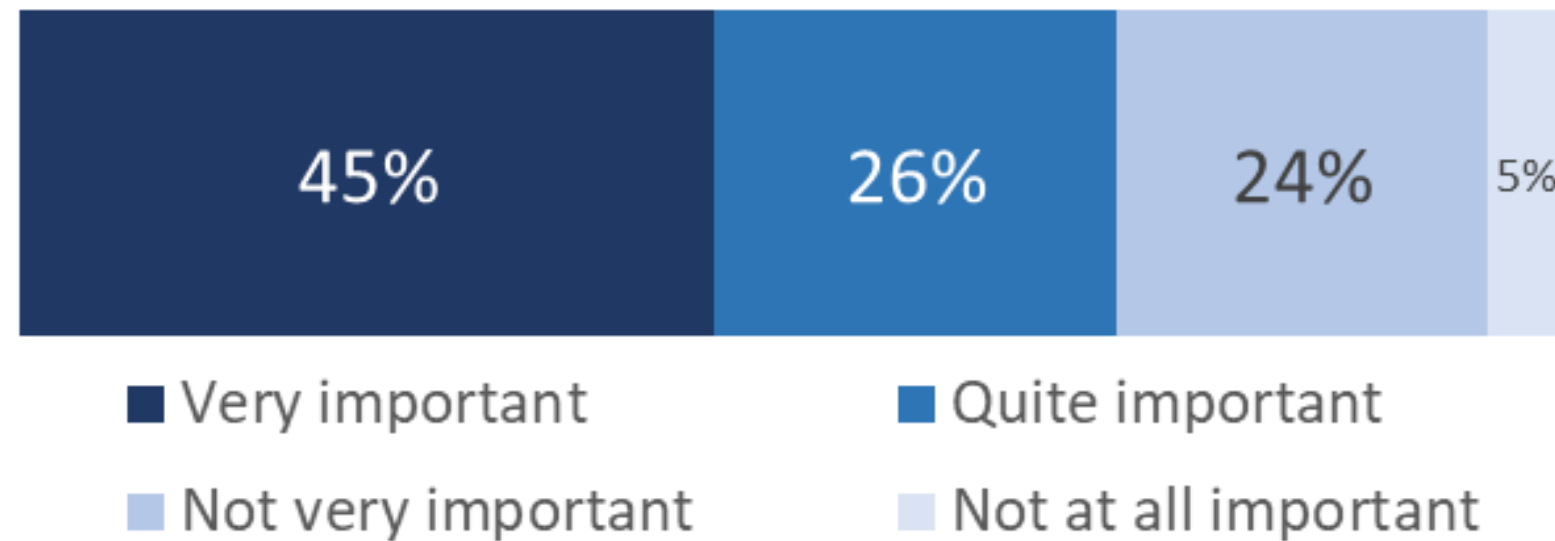
**Less likely to feel they are cared by people who understand their beliefs and values**

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

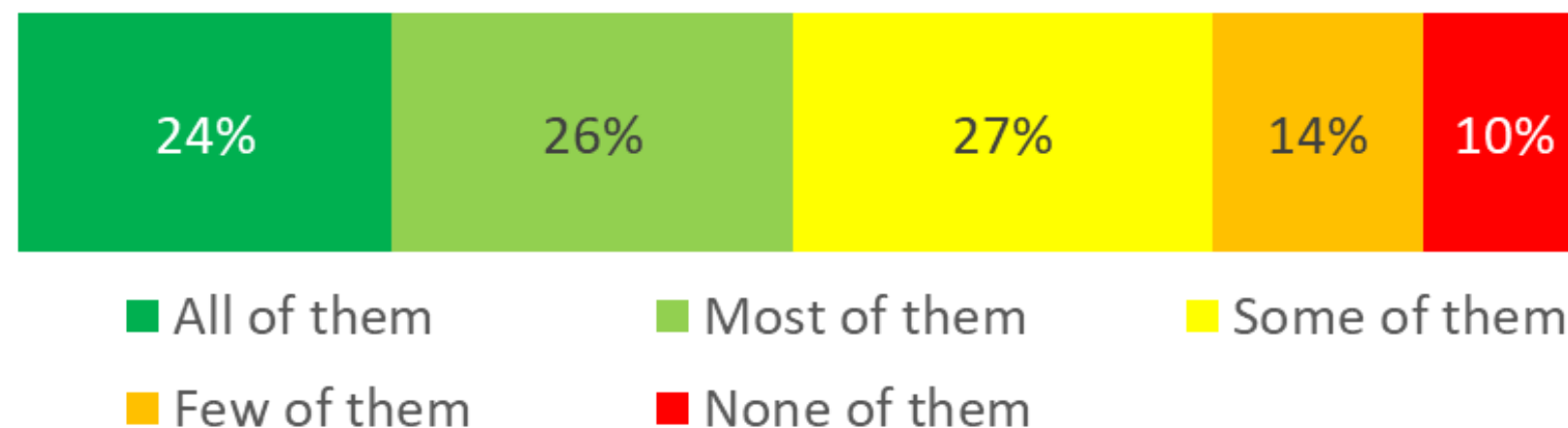
# What about cultural competence?

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**

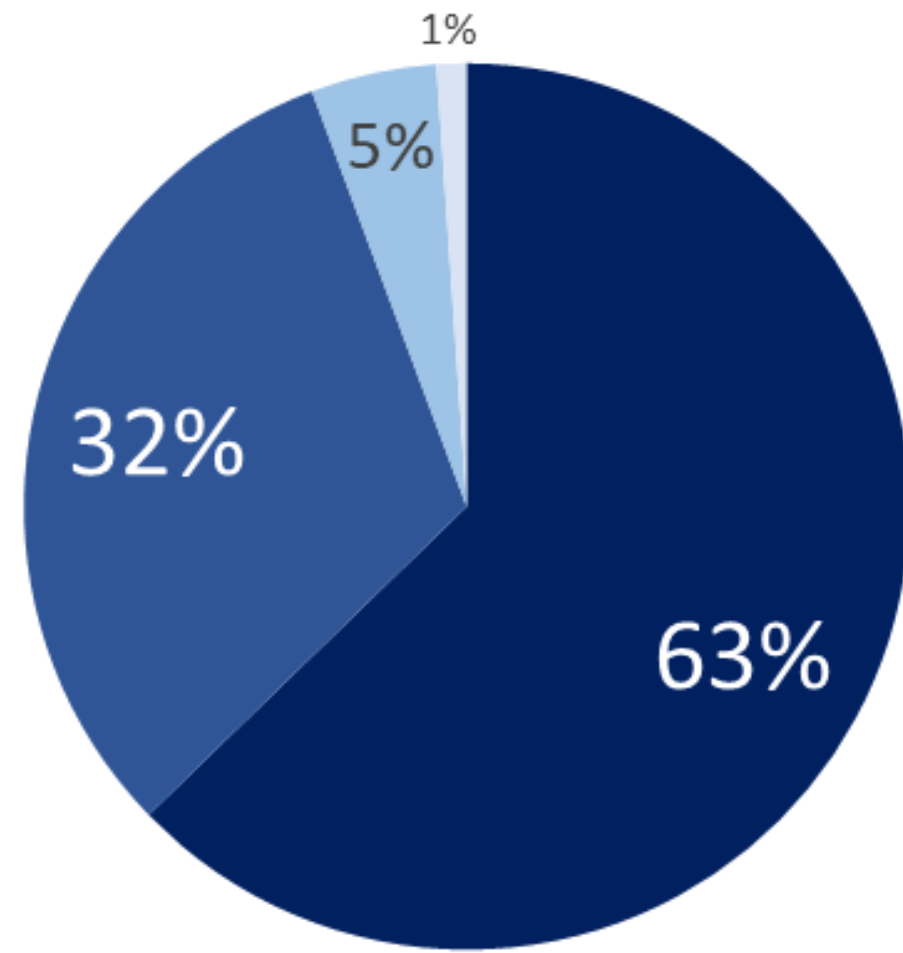
- Indian, Pakistani or Black African ethnicity
- Hindu or Muslim faith
- Aged under 25
- Financially comfortable

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

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



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



- Very important
- Fairly important
- Not very important
- Not at all important

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:

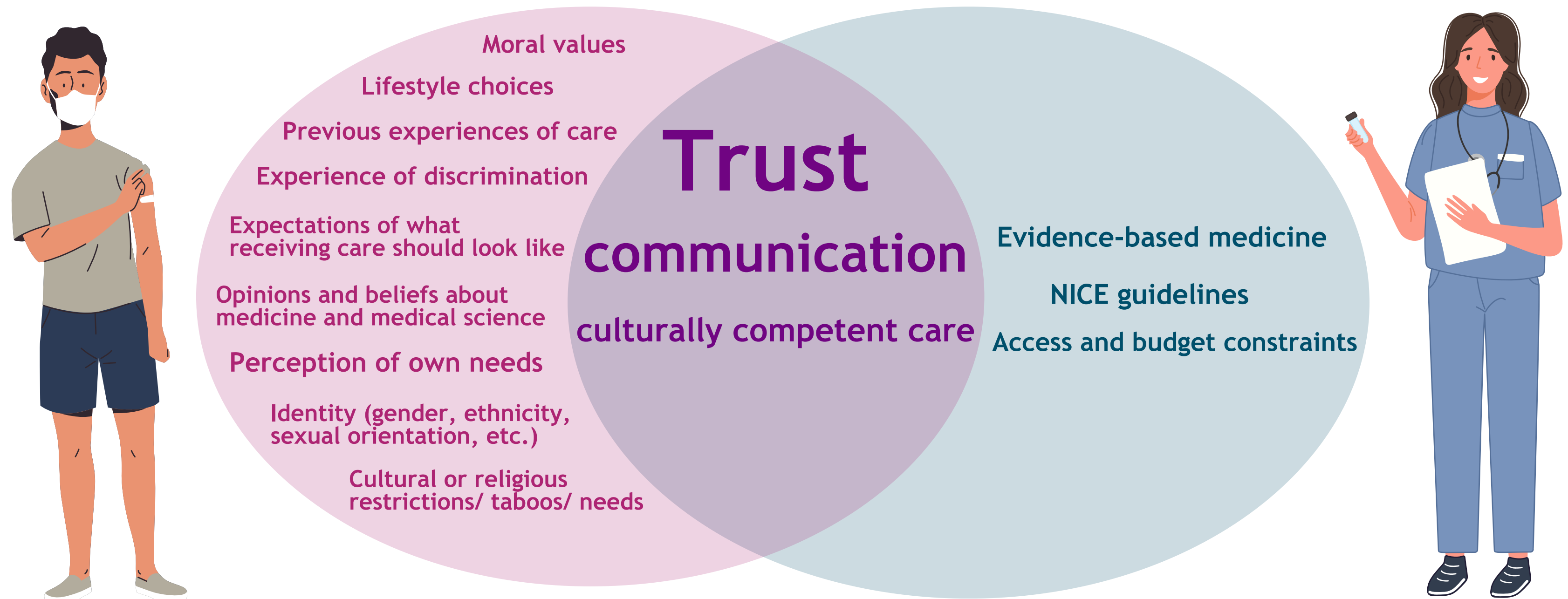
- ▶ Believe their local area is a place where they can live a healthy life
- ▶ Have children aged under 18

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

# 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.



## 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

Trustworthy

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 not 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 [shouldn't] 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 [level] 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.*

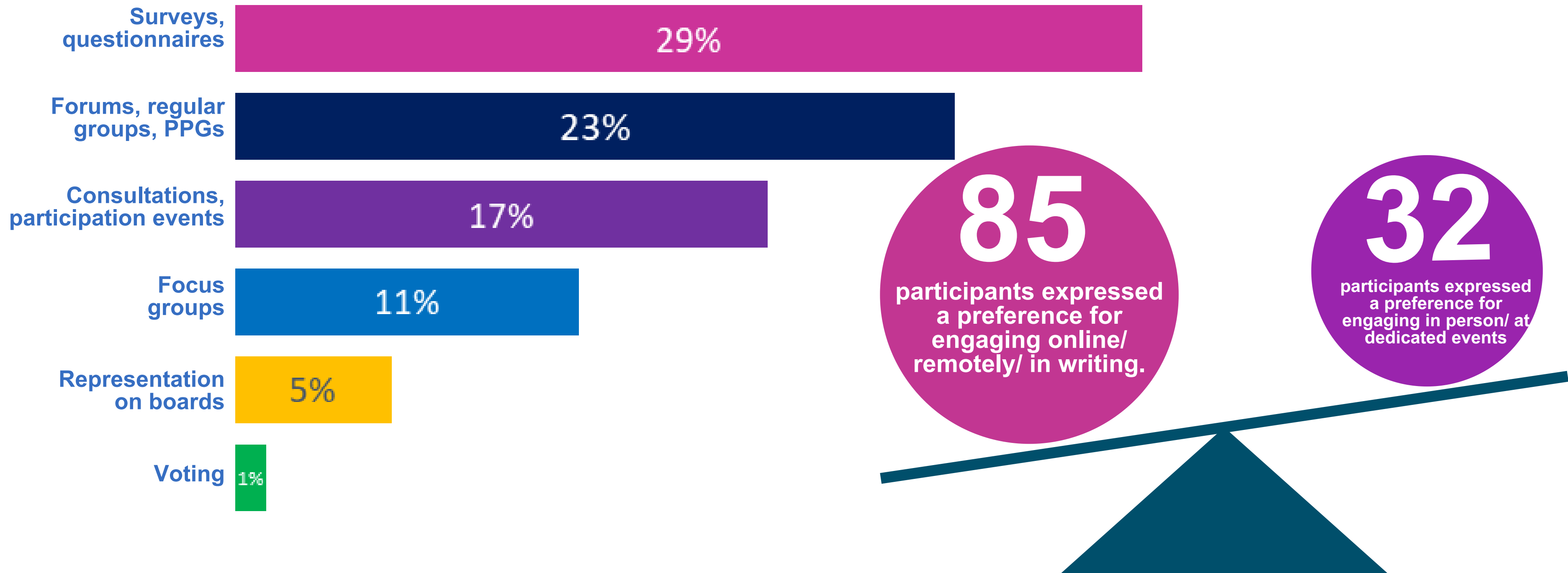
- ➔ **Competent care** is informed by scientific evidence on the relation between weight and health.
- ➔ **Person-centred care** recognises that different patients may have different goals/ seek different outcomes.
- ➔ **Trustworthy care** empowers patients and professionals to discuss it honestly and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



Trustworthy

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

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



## 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.*

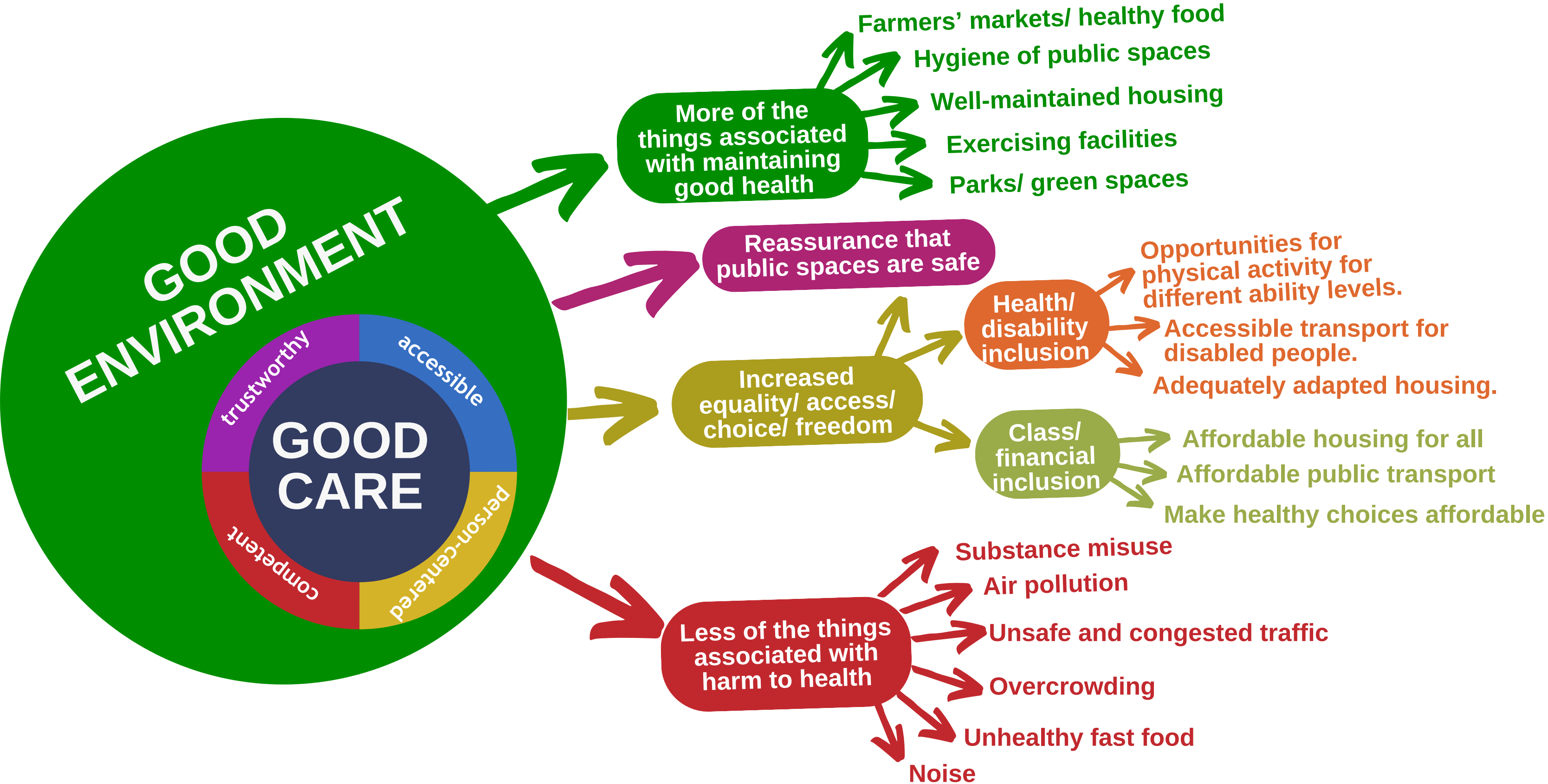
*I would like to be able to show those who commission front line health services the reality of everyday interactions and attempting to access care.*

*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!*

# What does a healthy community where everyone can thrive look like?

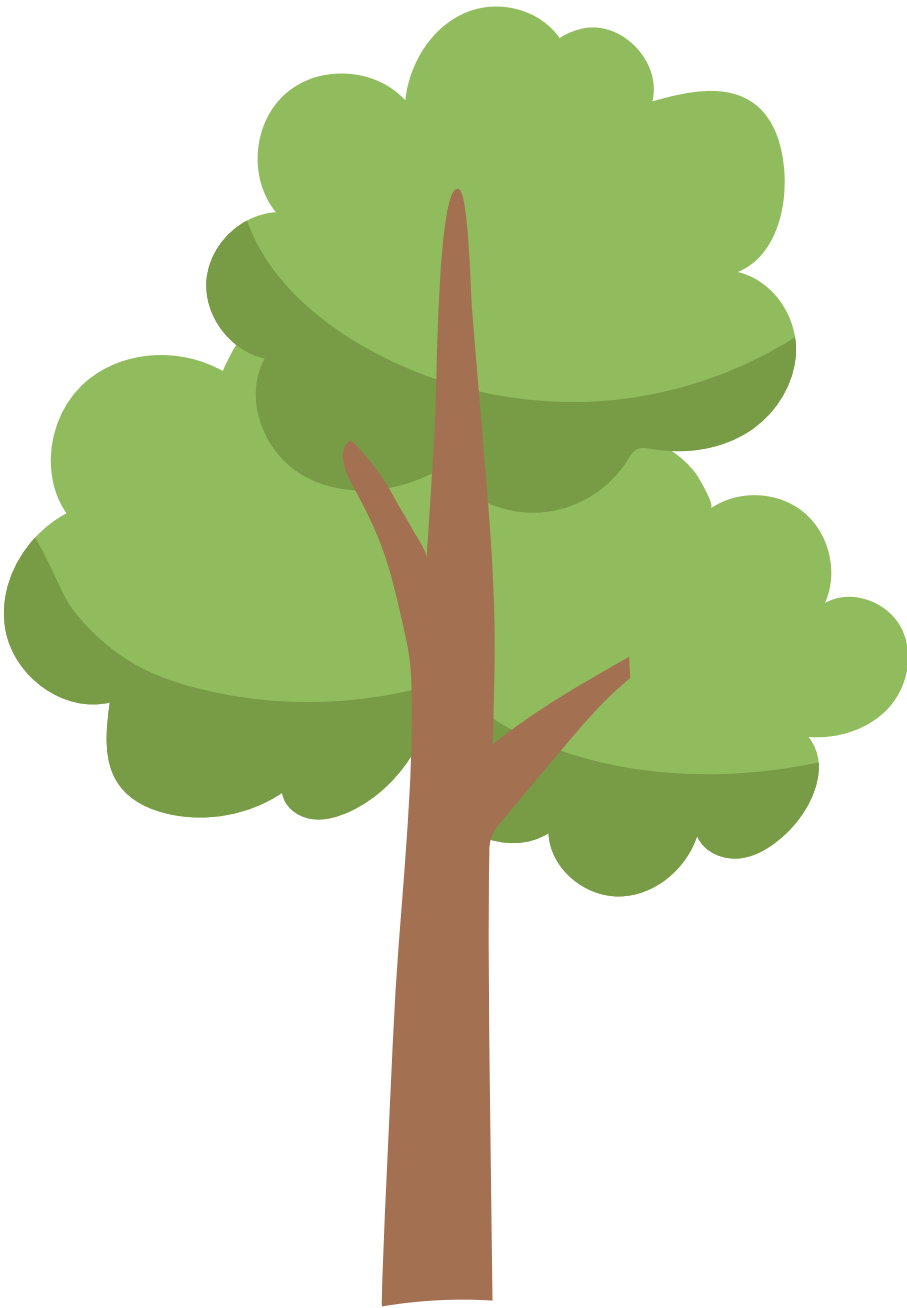
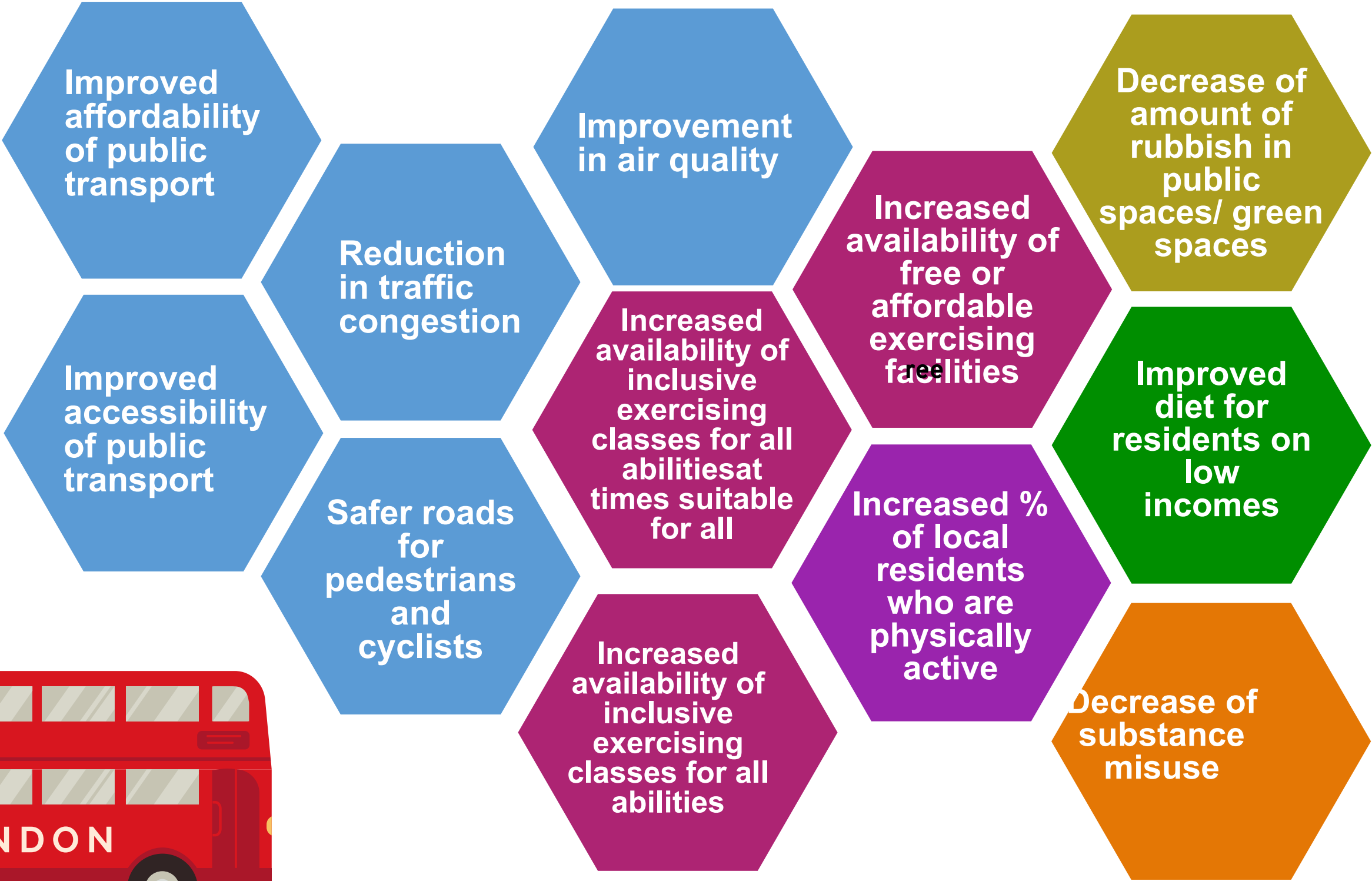
Everybody  
can THRIVE



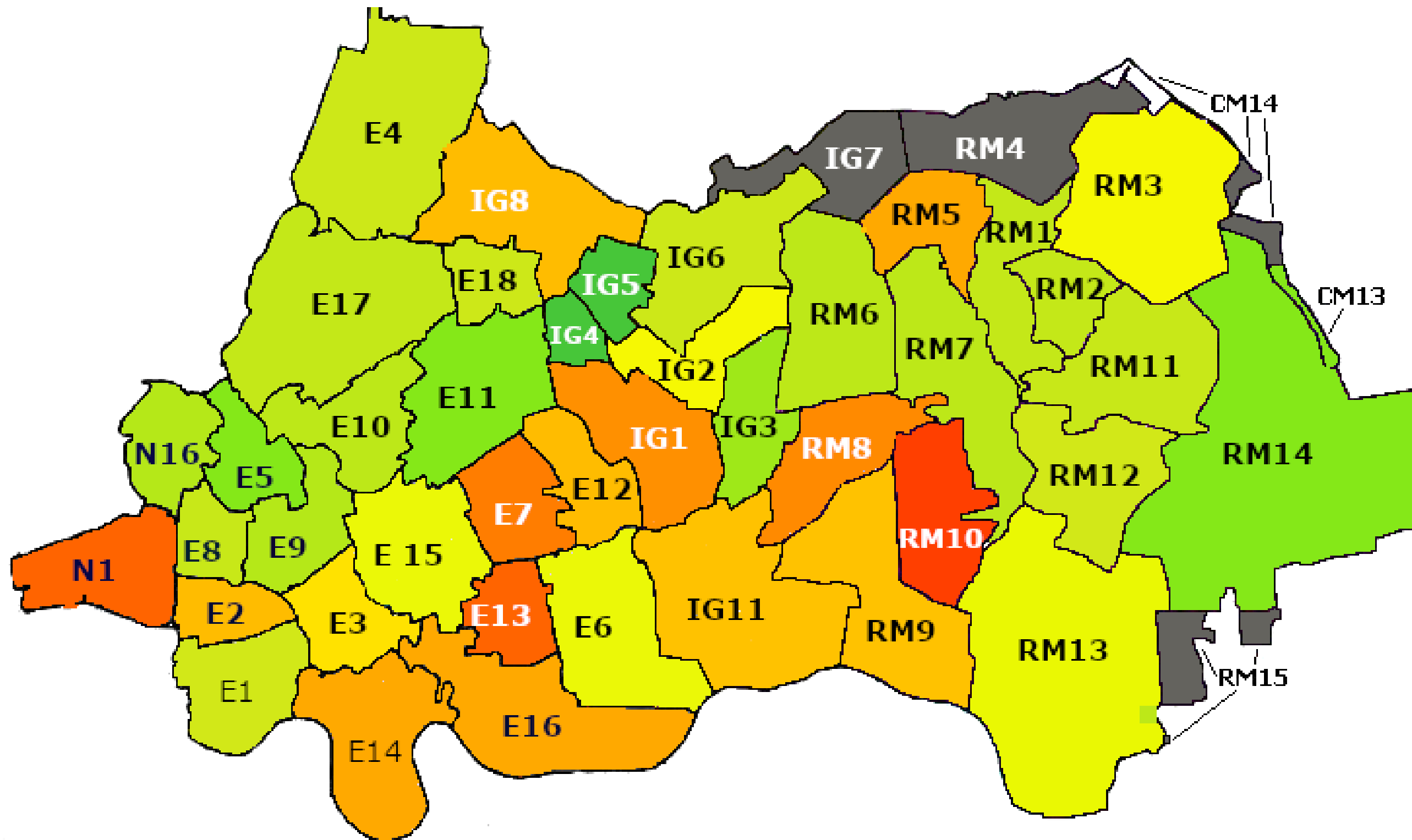
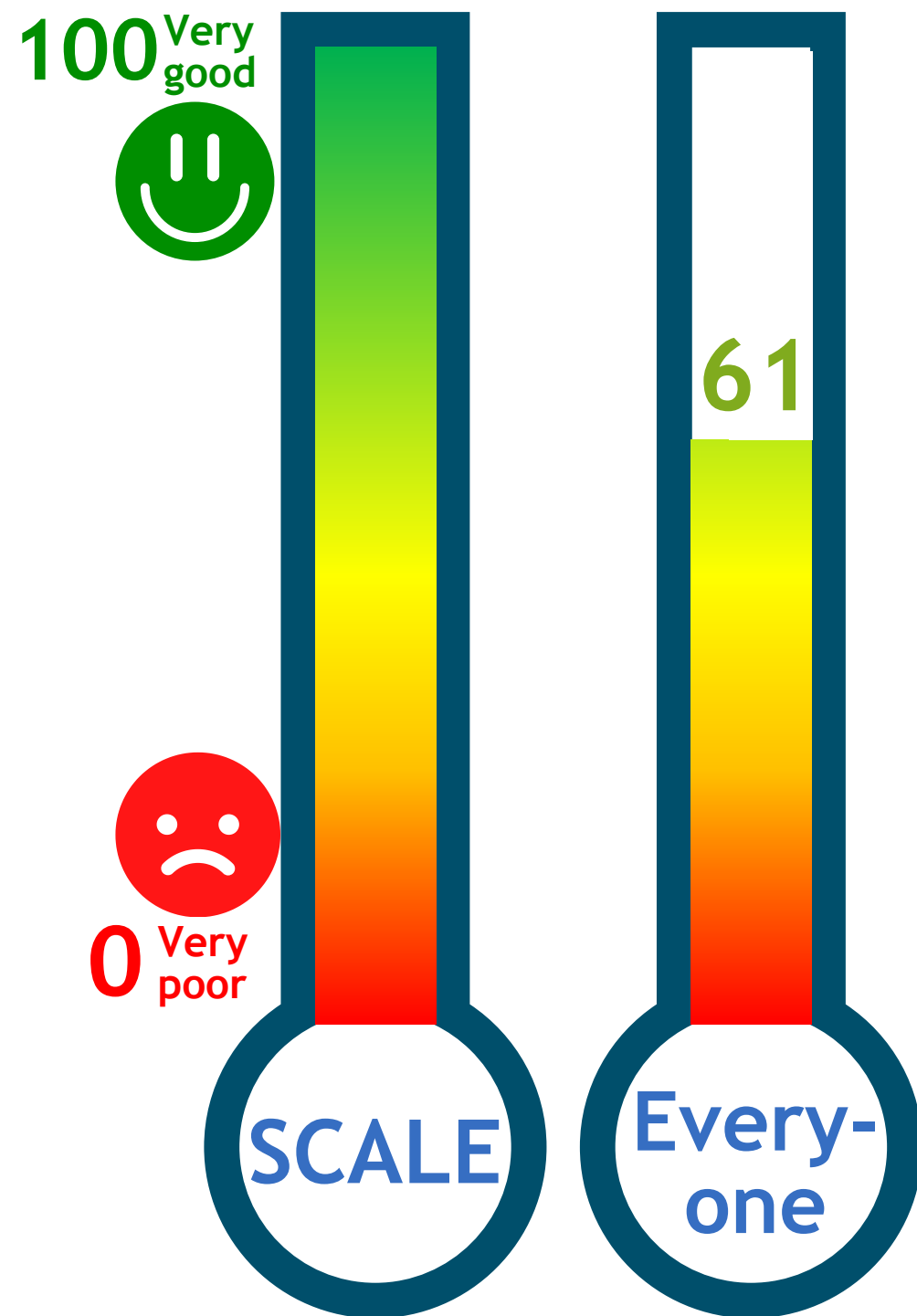


# How to measure the health of the wider community based on what matters to local people

Success looks like...

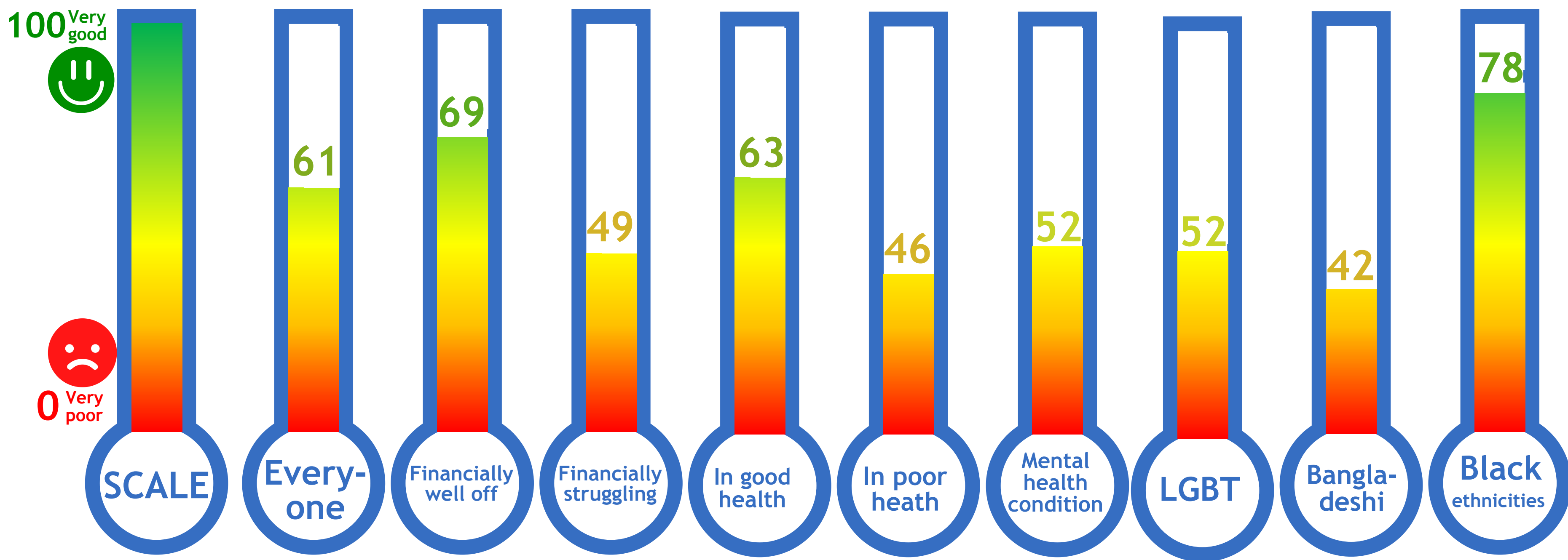


## My neighbourhood is a place where I can live a healthy life- *survey respondents*



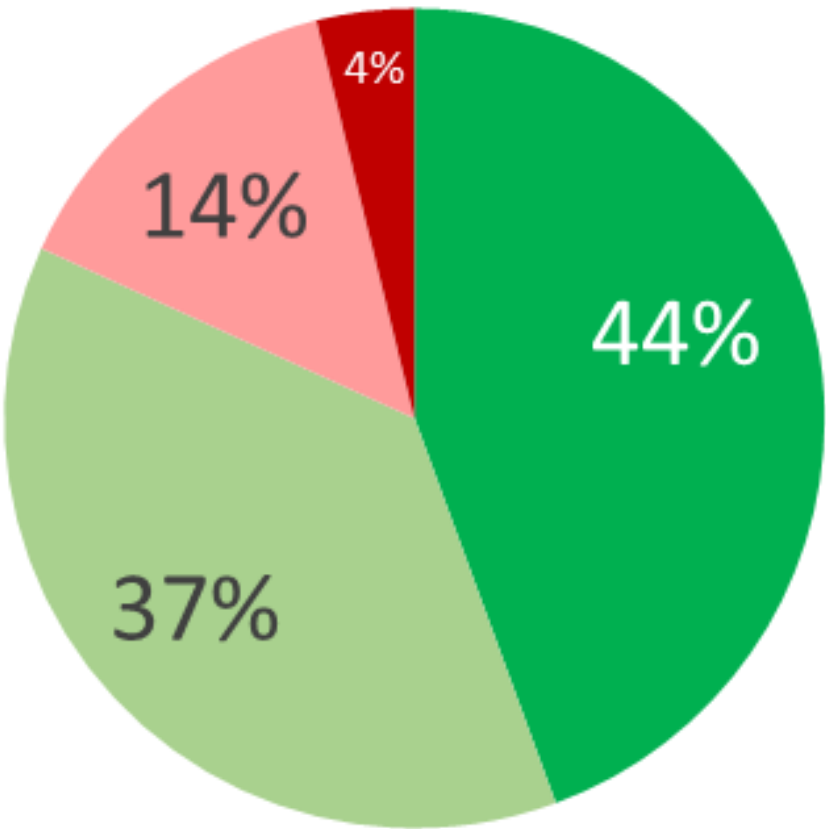
Everybody  
can THRIVE

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



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

Everybody  
can THRIVE



- Very interested
- Fairly interested
- Not very interested
- Not at all interested

## 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.

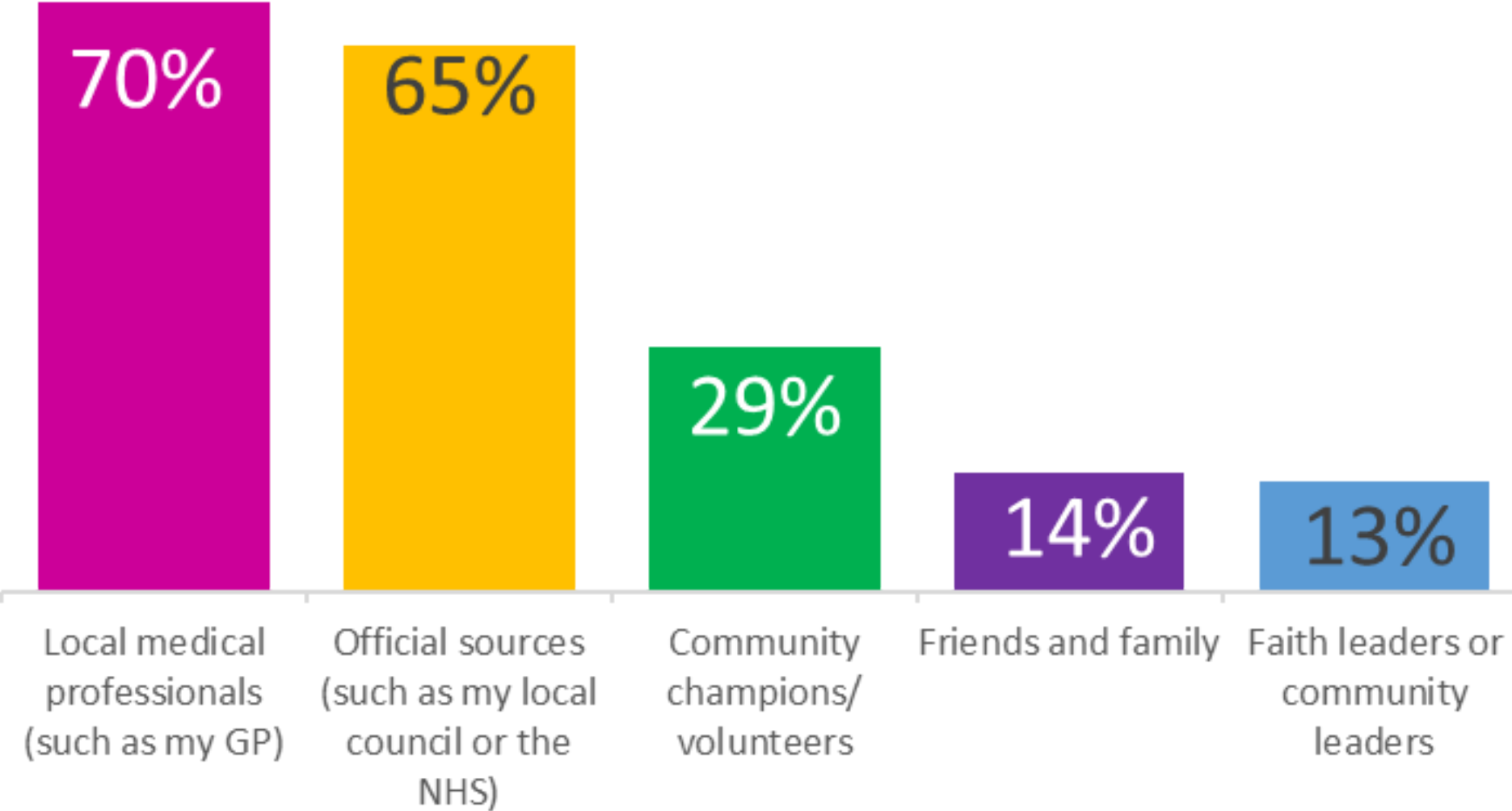




# How interested would you be in having information available where you live about living a healthy life? - *survey respondents*



## Whom information should come from according to those who would like to receive info



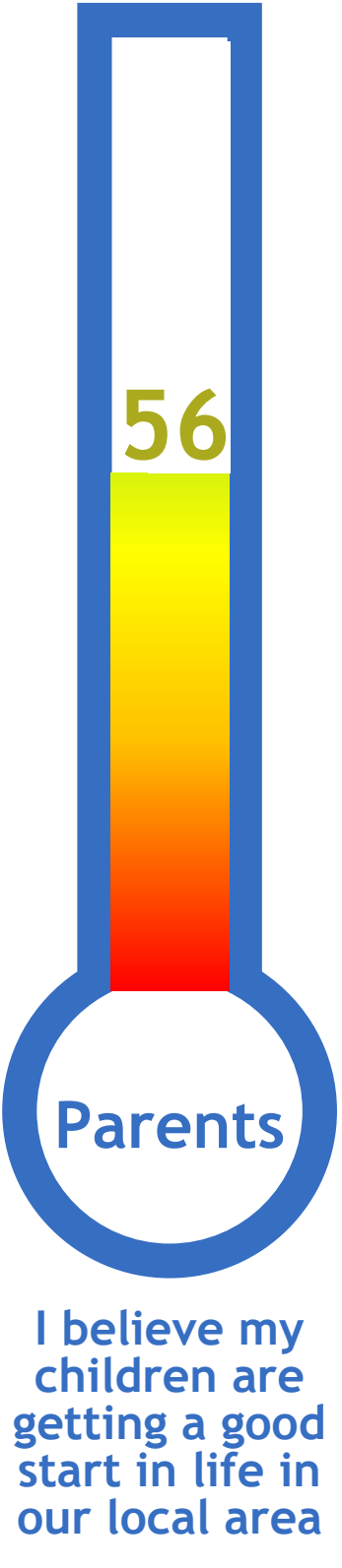
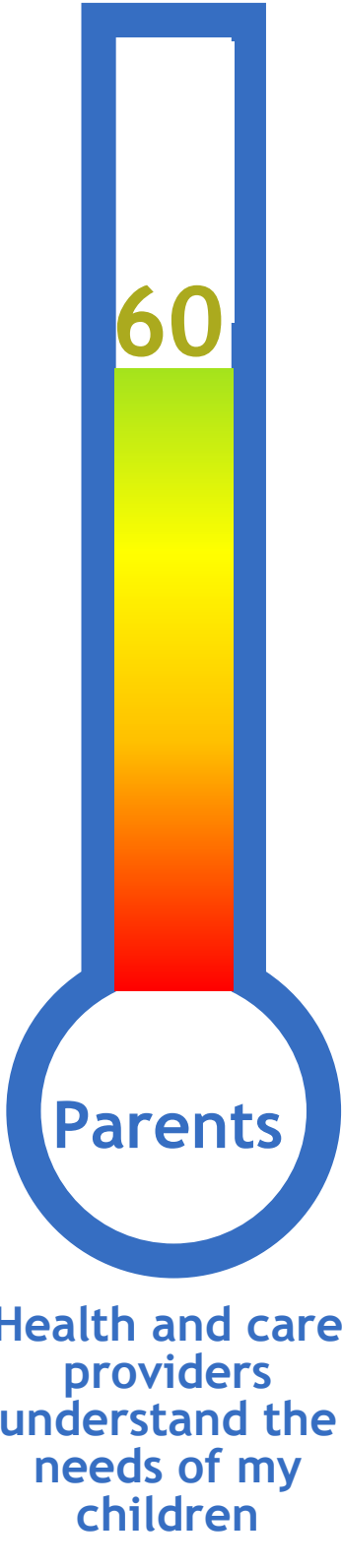
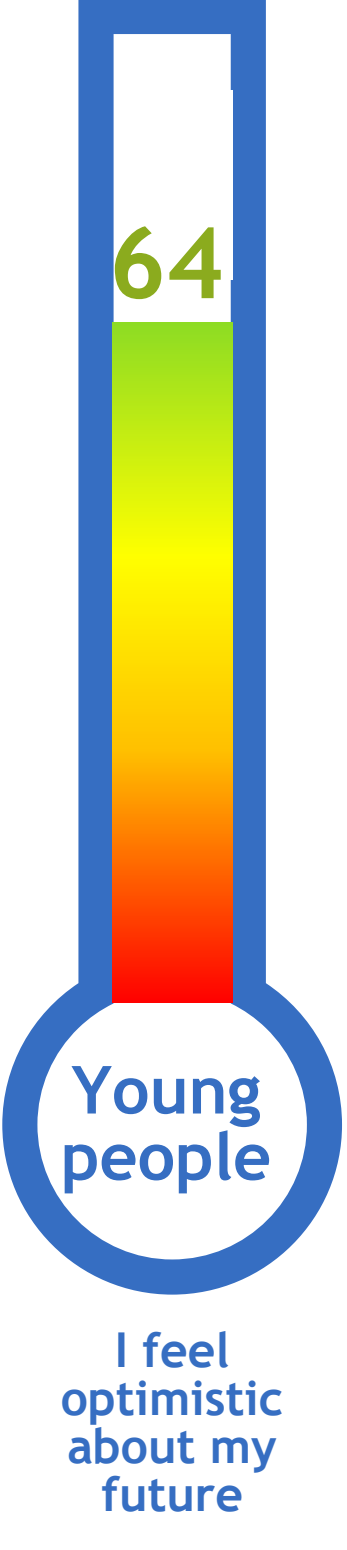
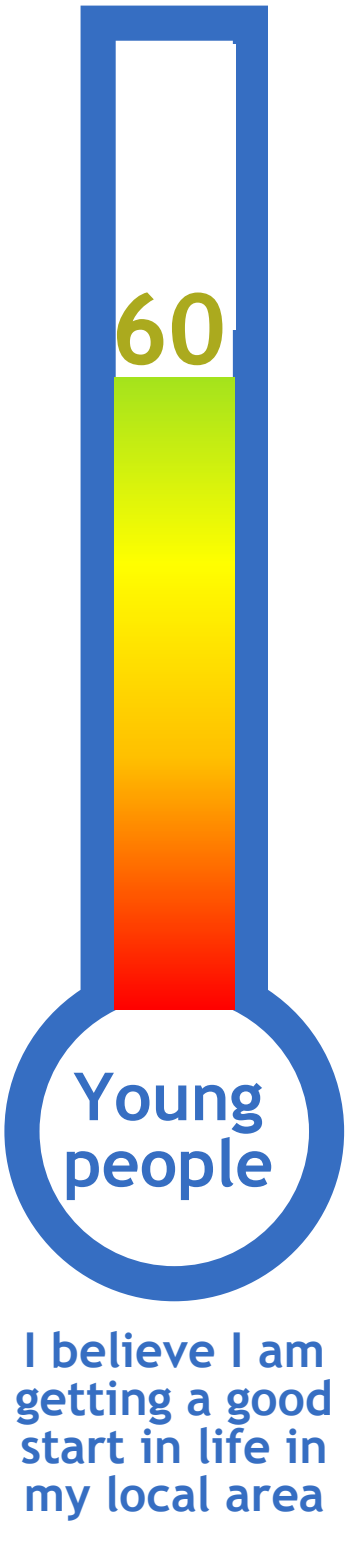
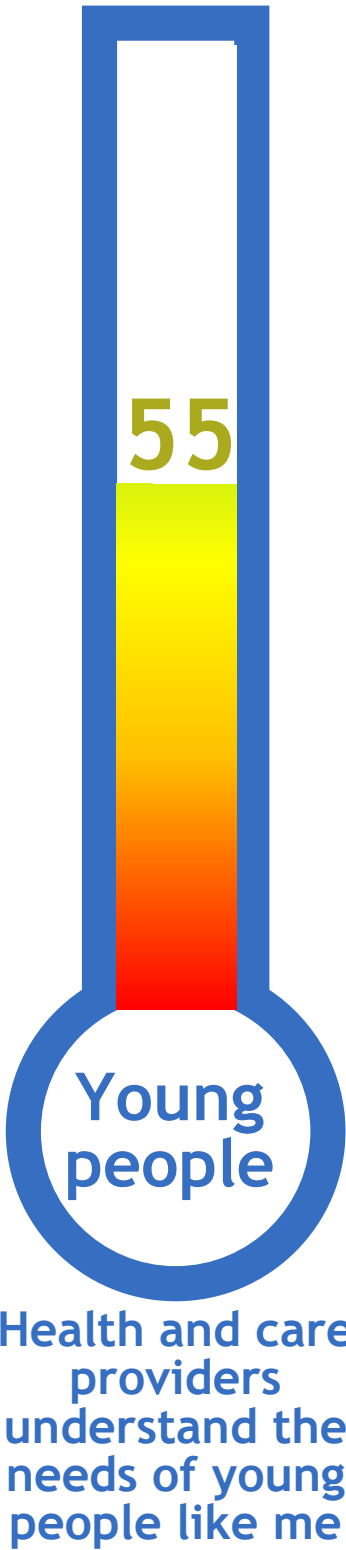
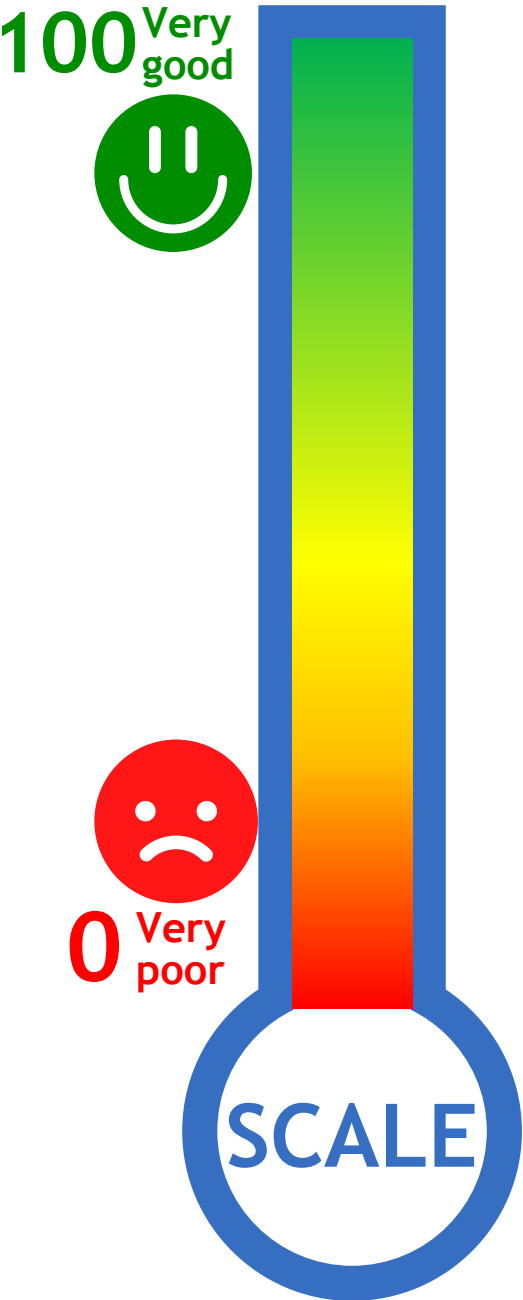
### More likely to say info should come from friends and family:

- ▶ 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

Priority: babies, children and young people



# Priority: babies, children and young people

## The good care model



### Accessible

Babies and children can get same-day GP appointments or be seen on a walk-in basis.

There is a single point of access for children's health services.

Health and care services for children and young people take into account school schedules when offering appointments.

Children's centres, family hubs and youth clubs are in every neighbourhood.

Mental health support and interventions/activities to improve mental well-being are available in a school and community setting.

Parenting classes, activities for children, families and young people are free or affordable.

Healthy food options are convenient and affordable including for those who can't cook (children at school, students living in halls etc.)

### Competent

Young people and new parents have access to impartial, evidence-based advice on living a healthy lifestyle.

All services working with new parents, babies, children and young people, including schools, nurseries, health and social care services, have a good awareness of mental health in the context of parenthood, childhood and youth; as well as of learning disabilities and neurodivergence.

Professionals don't assume young people's symptoms are less serious or that they can't have chronic conditions.

### Person-centred

Transition between child and adult services is straightforward and happens without disrupting access to care for young adults; patients are not required to undergo complex bureaucratic processes or tell their story from the beginning all over.

Health services, social care, schools and community organisations work together and signpost to each other. Support for special needs/ vulnerable families (poverty, domestic violence etc.) is holistic and inter-connected.

Schools, universities and training providers work with employers to build skills and recruit young workers.

Teaching in schools is holistic/ interdisciplinary.

### Trustworthy

Routine health checks for babies and children are available in hubs, children's centres or GP surgeries, providing reassurance to parents.

Young people get to access care and speak about their concerns to professionals that take them seriously, respect their dignity and their confidentiality; they get to ask about sensitive topics such as mental health or sexual health without fear of being judged.

Young people's health concerns are taken seriously, not dismissed.

Younger social workers and friendly spaces put vulnerable children at ease.

Children, young people and parents feel safe from harm in their local area and at school.

Community offers safe spaces for self-expression.

# Priority: babies, children and young people

## What young people want from health and care services



- ➔ Trustworthy sources of information about healthy lifestyles
- ➔ Routine check-ups/ screenings/ blood tests
- ➔ Mental health and wellbeing support; faster access to mental health services; holistic mental health support
- ➔ Awareness of mental health-related disability; signposting and integration.
- ➔ Services that are easy to use (streamlined admin), with reasonable waiting lists; simplified access/paperwork
- ➔ Non-judgemental, empathetic professionals you can be open with; communicating sensitively.
- ➔ Younger social workers and friendly space them can put them at ease
- ➔ Medical professionals that speak to them in an age appropriate way from as early as possible, not just to their parents
- ➔ Respect for their confidentiality and privacy
- ➔ Health professionals that do not dismiss young people's concerns and symptoms, especially those that make them stressed or self-conscious; not having their concerns dismissed because of age.
- ➔ Social prescribing; working within the community.
- ➔ Continuity and integration of care when transitioning from child/adolescent to adult health services; without a need for restarting the referral process.
- ➔ They place a high importance on health and care workers being fairly paid and having a good work environment



# Priority: babies, children and young people

## What young people want from schools



- ➔ Holistic/ interdisciplinary teaching
- ➔ Better security/ protection/ safe environment.
- ➔ School-based mental health support.
- ➔ Opportunities to learn about different career paths, including for those who are not academic over-achievers.
- ➔ Work experience. opportunities to build employable skills.

## What young people want from their local communities

- ➔ A strategy to address poverty, especially food poverty and housing poverty/homelessness;
- ➔ Better awareness of the different types of abuse and support for abuse victims.
- ➔ More after-school clubs particularly aimed at young men, as a violence prevention strategy.
- ➔ Work experience. opportunities to build employable skills.
- ➔ Better promotion of community organisations/ charities offering relevant services.
- ➔ Safety from bullying, harassment, robberies and gangs.
- ➔ Connection, motivational community; encouragement to pursue dreams
- ➔ Open green spaces, spaces for physical activity and sports
- ➔ Disability inclusion

# Priority: babies, children and young people

## What young people want from health and care services



In meetings with health or social care professionals, **5 out of 10 young people reported feeling judged, which made them uncomfortable.**

*Young people focus group, Barking and Dagenham*

*I cried and left the dentist's office because I detested needles. I was treated kindly by the dentist, who welcomed me back to talk about how to have a better experience and suggested getting an anaesthetic. I felt understood and that the adult was trying to make me feel at ease.*

*I went to the dentist because I had trouble cleaning my teeth and was feeling judged since my teeth weren't being taken care of. The dentist's opinion was stated in a tone that made me feel humiliated.*

*I had an appointment at CAMHS, and the doctor asked many questions in the presence of her mum. His eyes were on me, and I felt kind of guilty for having issues.*

*My orthopaedic surgeon was good; I would need to visit him every 6 months since I was 3 years and as I grew older, he always listened and spoke to me and didn't just ask my mum questions. He was very attentive and never made me feel like I had to rush. He set a very good example as to how a health expert should be with kids and young people.*

*My physiotherapist was always on point and adjusting exercises and equipment to what I needed, I felt seen and heard. She was really good. I have experienced quite a few and she was the one who gave me a set of exercises that were able to do at school easily which meant I didn't always have to miss my breaks or lunch with my school friends.*

*"A social worker forced me to answer questions in an interrogative manner, making me feel uncomfortable. I think that having better listening skills and maintaining the privacy of my information would have made me feel less anxious."*

*I had eczema but was not given the necessary treatments to cure it and was ignored by the doctor, who felt that it was just part of growing up and having to deal with things. During the cold season, my skin would become extremely red and itchy, which would make me feel extremely self-conscious*

*I went to the doctor to talk about my period discomfort but felt pushed away and told to deal with it on my own.*

# Priority: babies, children and young people

## What parents want from health and care services



- ➔ Easily accessible/ availability of appointments
- ➔ Quick access to urgent primary care (same day or walk-in); a dedicated helpline for paediatrics advice/
- ➔ Single point of access for children's services
- ➔ Local children's hub providing health checks; for older ages (from primary school onwards) continue to provide routine health checks and health information in a regular basis, possibly in a different setting.
- ➔ Better continuity/ consistency of care in the provision of postnatal health visitors, especially for vulnerable families and those with mental health issues; better non-judgemental breastfeeding support; continuity of care/ support from birth to school age. Extend Home Start to older ages
- ➔ Nutrition, mental health and family education for parents and children; access to antenatal/ parenting classes, including for those on low incomes.
- ➔ Multicultural staff reflecting the diversity of local areas
- ➔ Signposting service connecting to community resources
- ➔ Holistic/ community-connected support for families with special needs or vulnerabilities.
- ➔ Better support for children with special educational needs in schools.
- ➔ Better, more accessible child and adolescent mental health services
- ➔ Mental health support and health education in schools.



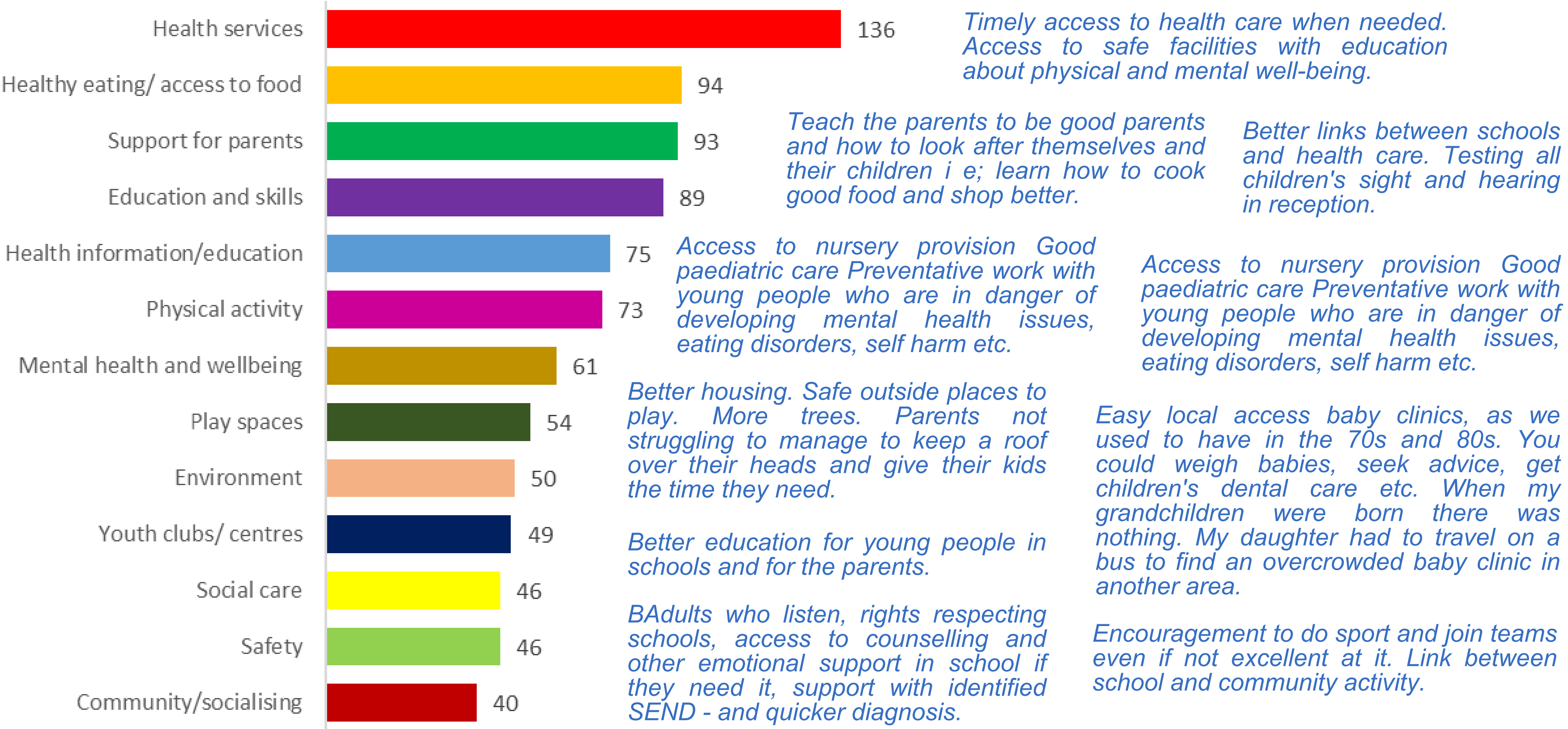
# 57%

of parents didn't have anyone to turn to for advice on supporting their children to grow healthy and well.

For most of those who DID have someone, it would be a family member.



# What would make a positive difference for babies, children and young people? according to survey respondents



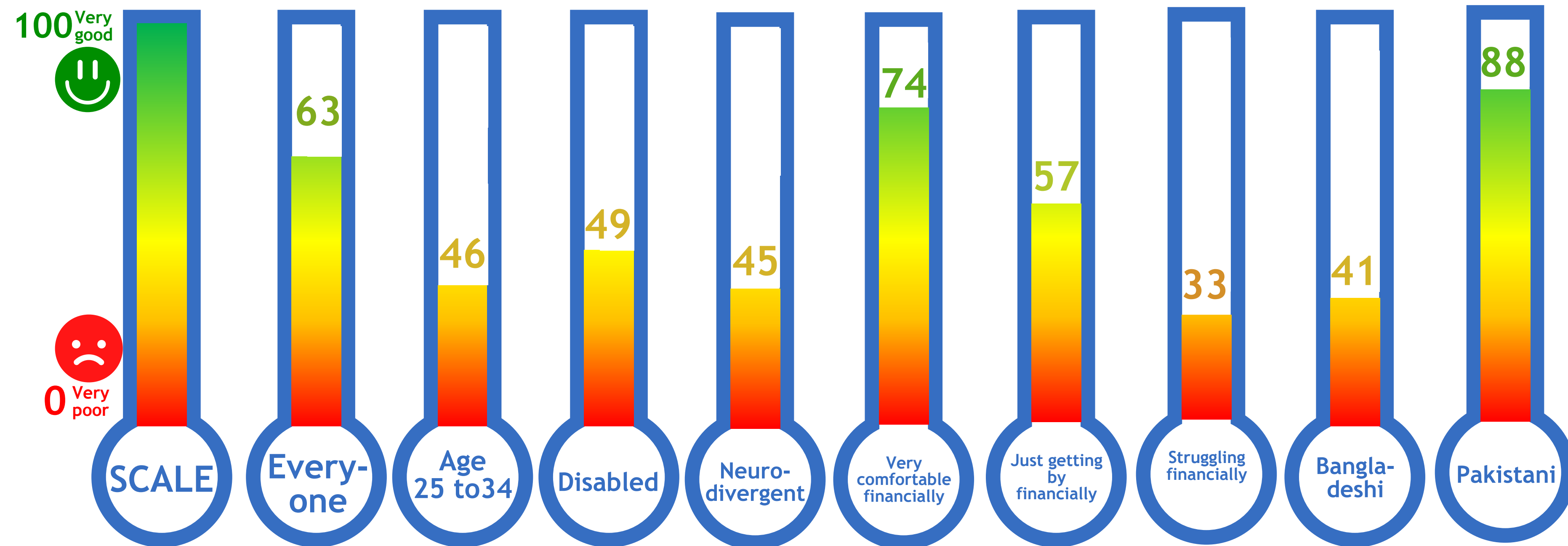


# How to measure success for babies, children and young people based on what matters to local people



Pillar	Success indicator	How it could be measured
Accessible	<p>Decrease in waiting times for GP appointments for babies and young children.</p> <p>Decrease in waiting times for children and young people accessing mental health/ neurodivergence services.</p> <p>Improved ease of accessing health services for children and young people- in terms of booking processes and flexibility.</p> <p>Improved provision of resources for promoting physical and mental health in schools and the wider community.</p> <p>Improved access to community resources for children and families on low incomes</p> <p>Improved access to affordable healthy food in schools; improved affordability of healthy food options that don't require cooking at home. Decrease in demand for food banks.</p> <p>Improved access to jobs with a career progression for young people, including for those from working class backgrounds and those who are not high academic achievers.</p>	<p>Data generated by health and social services providers: waiting times for appointments by age; % of patients who unsuccessfully try to make appointments by age; mapping booking and referral processes.</p> <p>Engaging with parents and young people on how easy or hard they find accessing services.</p> <p>Engaging with young people on their lifestyles and the incentives/ obstacles the experience for healthy or unhealthy behaviour; taking into account physical and mental health.</p> <p>% of parents on low incomes accessing parenting classes</p> <p>% of children and young people on low incomes taking part in extracurricular activities and youth clubs.</p>
Competent	<p>Improved knowledge of health lifestyles among parents, children and young people.</p> <p>Improved knowledge of mental health and of neurodivergence among health professionals working with children and young people, including those not specialised in neurodivergence or mental health.</p> <p>Improved knowledge of the wider determinants of health among professionals working with children; decrease in poverty-related preventable illness in children and young people.</p> <p>Presence of evidence-based, effective interventions and initiatives on public health (smoking/vaping cessation, healthy eating, physical activity, reduction of substance misuse) and wider determinants (crime reduction, violence prevention)</p>	<p>Monitoring and evaluation- success rate of public health and related initiatives (for example % of young people who give up smoking, reduction in of young people who take up vaping, reduction in violent crime locally, reduction in substance misuse)</p> <p>Measures of general well-being among children and young people.</p> <p>Engaging with young people on their lifestyles and knowledge levels, including ability to identify impartial vs biased advice, and evidence-based vs pseudoscientific</p> <p>Engaging with health and care professionals about their knowledge of mental health/ neurodivergence in young people/ wider dererminants of health and their training needs</p> <p>Engaging with young people who are experiencing mental health issues and/or are nurodivergent on the extent the feel understood,</p>
Person-centred	<p>Improved continuity of care for young people with long-term conditions (including mental health conditions) aging out of children's services</p> <p>Simplified/ single point of access health, care and social services for babies/ new parents/ vulnerable families</p> <p>Improved links between schools/ universities/ training providers and employers; including for those who are not high academic achievers.</p>	<p>Mapping referral and transition processes for young people with long-term conditions (for example, between CAMHS and a CMHT); engaging with patients to understand their experience.</p> <p>Mapping journeys of new parents or vulnerable families accessing care, with a focus on points of access/ how often do they have to tell their stories.</p> <p>Mapping journeys of young people into employment, in combination with anaysing statistics about education and employment (for example: what % of graduates have a job within a year/ within five years? Are the jobs they are getting in the field they trained for? Do they have career progression? How do they find out about jobs/ how are they recruited?</p>
Trustworthy	<p>Increased availability of health checks for young children; parents receiving reassurance and learning how to tell whether their children are well; decrease in rates of unnecessary children's A&amp;E visits</p> <p>Young people feeling comfortable talking about mental health with health professionals; at school; and in community settings.</p> <p>Young people feeling safe at school and in communities.</p>	<p>% of children attending A&amp;E not receiving treatment; % of children receiving health checks; mapping patient journeys.</p> <p>In-depth interviews with young people about worries, trust and emotions in various contexts.</p>

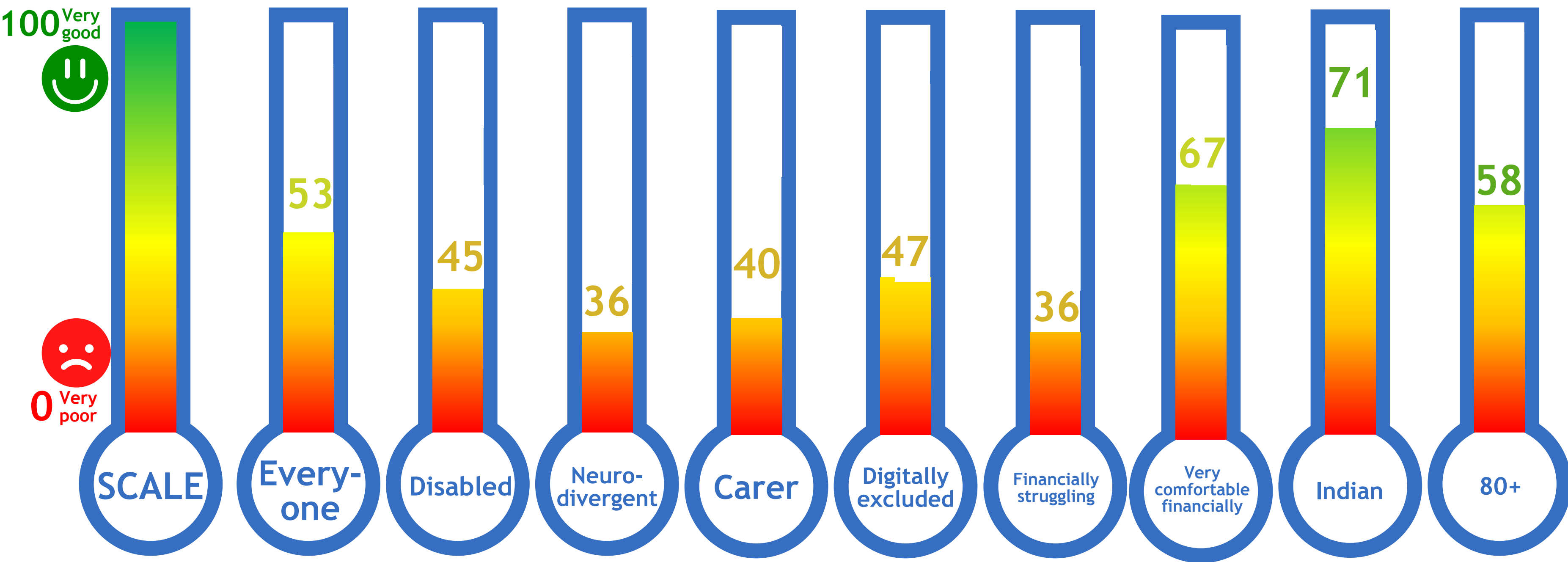
**Priority: long-term conditions**  
**I am able to manage my long-term condition well**  
*Survey respondents with long-term conditions*



Priority: long-term conditions



I am receiving good care for my long-term condition  
*Survey respondents with long-term conditions*



# Priority: long-term conditions

## The good care model



### Accessible

GP routine appointments are scheduled ahead of time and available.

Practical help/solutions to empower people with long-term conditions to manage their lives and live well are available, including to those on low incomes.

People with long-term conditions have a reliable way of getting specialist advice when needed (for example: a helpline dedicated to their specific condition)

Exercising classes and physical activity are accessible for all levels, including those who need gentle exercise.

Workers with long-term conditions have the flexibility and accommodations the need to stay in work.

### Competent

Health and care providers understand long-term conditions; including how different conditions and co-morbidities may impact each other.

Impartial, evidence-based advice on self-care and managing long-term conditions is available in the community.

Patients experiencing new symptoms are diagnosed promptly and reliably.

### Person-centred

Primary care, specialist health services and wider community support are connected with each other.

Patient records are shared between services; referrals are processed smoothly and efficiently.

There is a single point of access for patients with a long-term condition (could be GP surgery, care navigator or community hub).

Patients are treated holistically, not each condition in isolation (especially for those with multiple conditions)

### Trustworthy

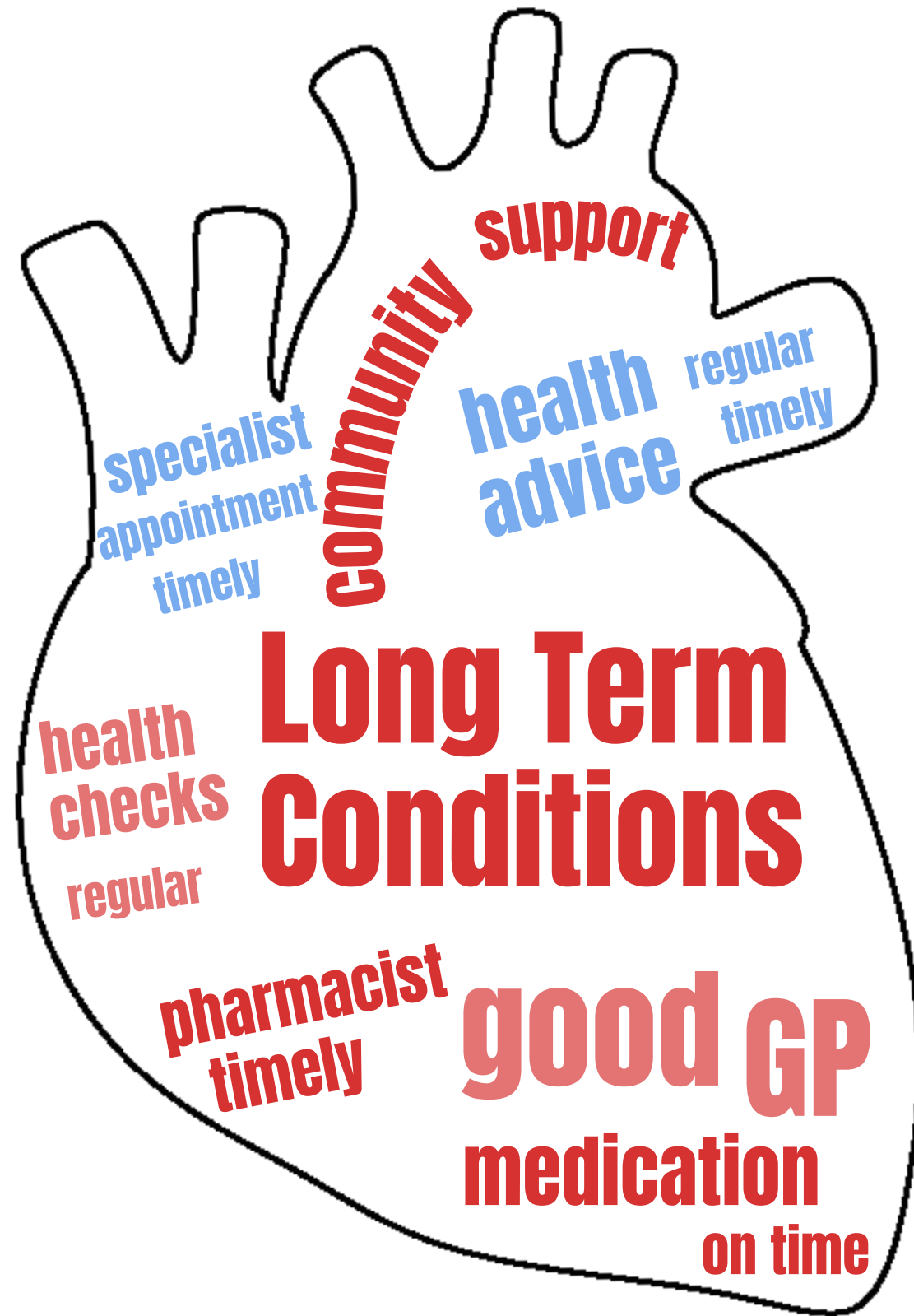
Patients have access to routine check-ups and reviews, in order to understand the progress of their condition, make sure they are well and improve self-care ability.

Patients in the process of being diagnosed or those experiencing new symptoms are taken seriously, listened to and supported to manage in the meantime.

Workers feel safe disclosing their condition at work, taking sick leave or asking for accommodations.



## Priority: long-term conditions



Appropriate levels  
of care advice and  
support

Easy access to  
information and GP  
nurse

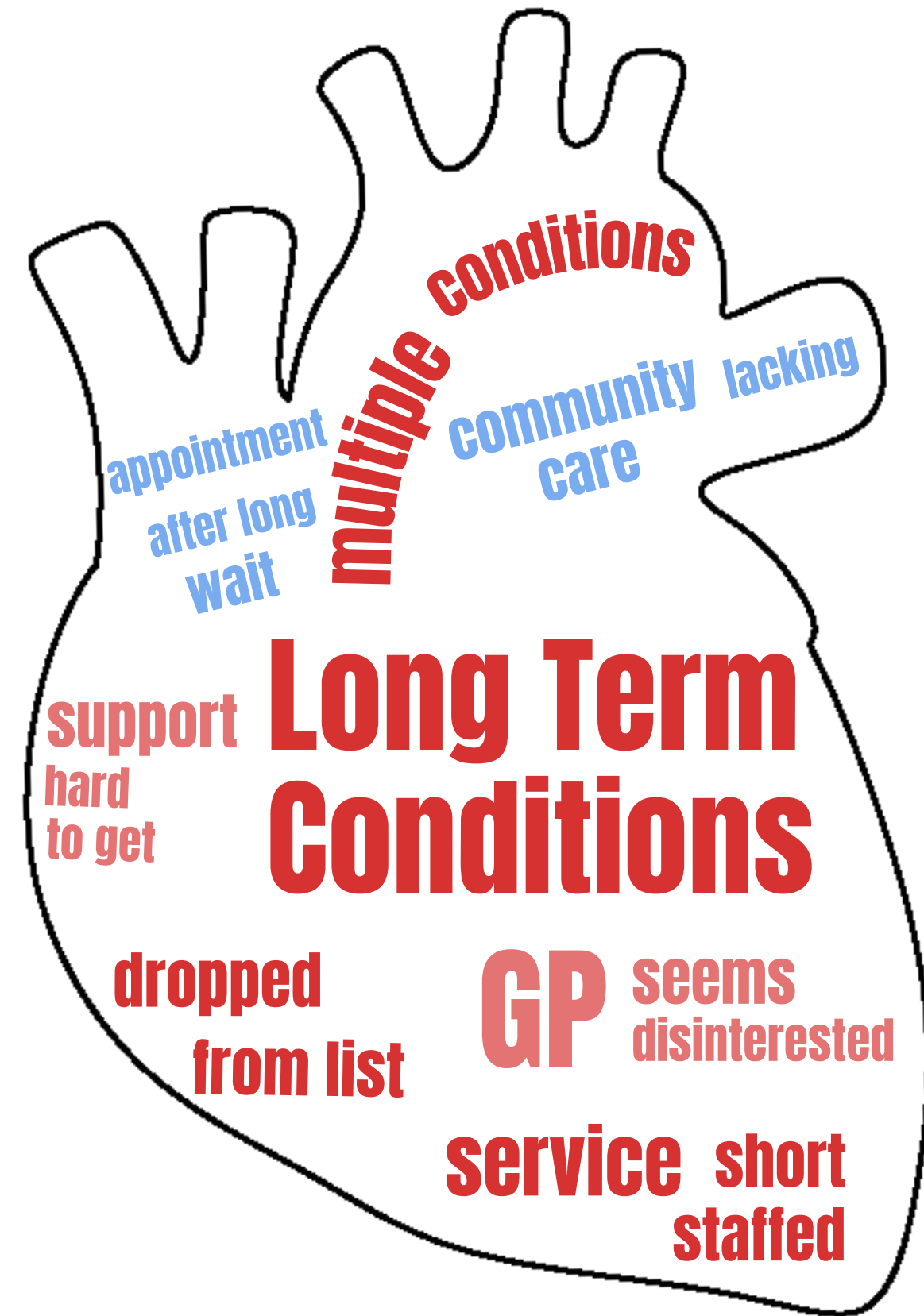
Have a check once a year  
and if it's not good they  
will monitor it

### What happens when care is good

The survey responses indicate that many people with long-term conditions appreciate the care they receive from their healthcare providers, particularly when they are listened to, receive regular check-ups, and can access specialised services.



## Priority: long-term conditions



Gps are not very interested

Given strategies for coping with it

Lack of resources, poor investment in community care

# What happens when care is so-so

The responses indicate that individuals with long-term conditions often find their care to be inconsistent, with many feeling they are left to manage their conditions on their own.

## Priority: long-term conditions



No follow ups

I am stuck on a waiting list with no idea when I will receive treatment

No support, no treatment, no help.  
Nothing

# What happens when care is poor

The given responses portray a picture of dissatisfaction, frustration, and neglect from healthcare providers. Numerous individuals feel they are not being heard, taken seriously, or given adequate care for their long-term conditions.

# Priority: long-term conditions

What makes the difference between those who manage their long-term condition well and those who manage them badly?



*I'd like to be regularly assessed with the doctors to review my health condition and offer more support with other lifestyle choices that could help me better manage my health condition.*

*I have arthritis in both knees and have essentially been fobbed off. I've been on the same medication for anxiety for 10 years with no review or discussion, or even regular blood pressure tests as required by the type of meds I'm on*

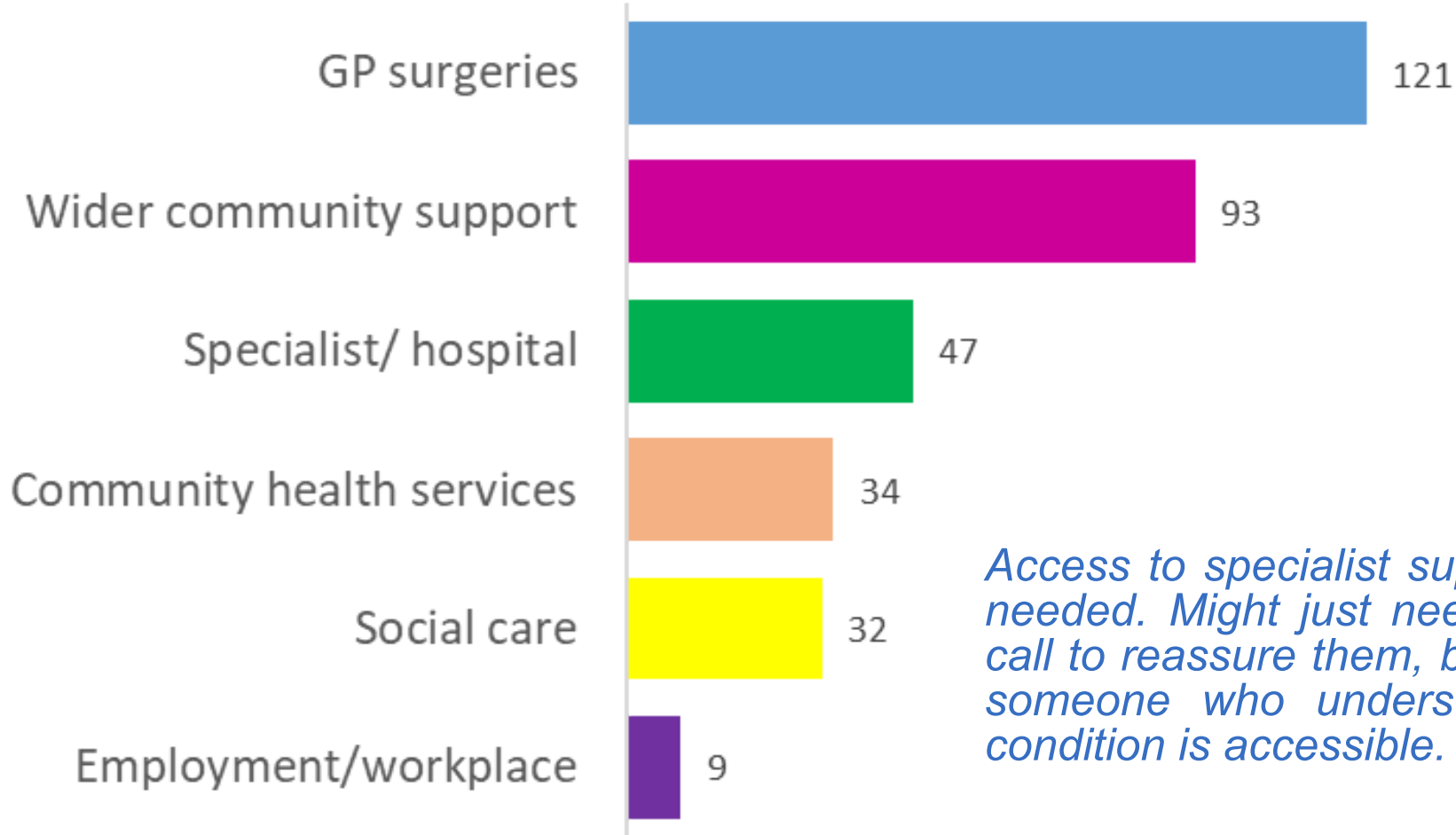
*My condition is being monitored well; I know how to get in touch with my team if I need to, and I've been informed about future treatment options, and my opinions were listened to. The only criticism I have is the amount of time it took to have my thyroid tested. It took seeing a locum to be sent for thyroid blood tests-previous doctors hadn't picked up on it, even though I had many obvious symptoms.*

*It's a constant battle to get appointments, to ask for services, to be proactive in remembering the need for next steps in diagnosis and treatment.*

# What would make a positive difference for people with long-term conditions?



Care partners/ stakeholders



*GP's being able to set up 'follow up' appointments at every say 6 weeks is hugely helpful for patients and ultimately time-saving for GP's and pressure on Primary care.*

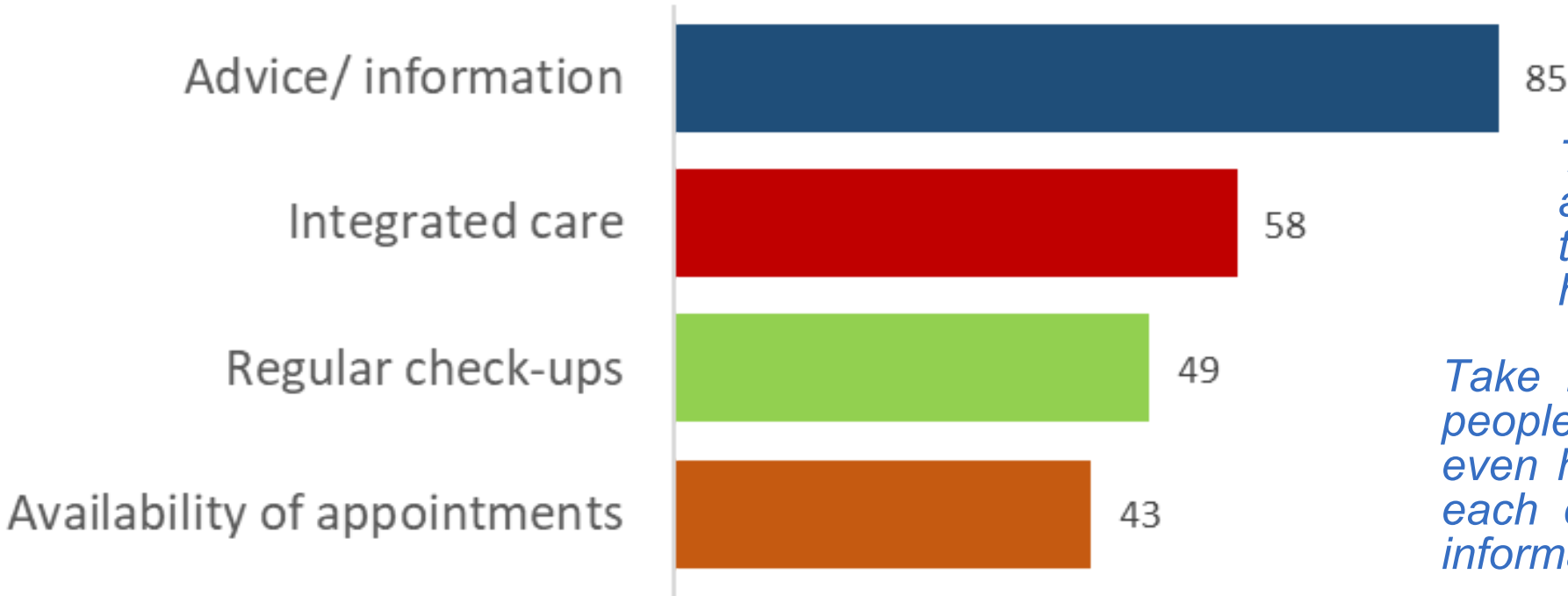
*Regular access to the mental health team - how is managing a condition giving someone anti depressants and leaving them to take them for the rest of their life? Is that treating the condition or managing an individual by making them go away and continue to 'get by' whilst living an unhappy and unfulfilled life. Life should not be about 'managing' or getting by. Why should people be unhappy their whole life.*

*Access to specialist support when needed. Might just need a phone call to reassure them, but knowing someone who understands their condition is accessible.*

*Cost of living makes accessing paid resources a challenge and as a part- time worker I cannot afford it.*

*I am unable to get a referral to the service I need because my GP lost my test results twice and I'm waiting another month for another appointment.*

Actions



*Being informed about the services available, but importantly who to contact to find out more. Offering information on peer groups and support groups when at the GP or points of care.*

*The focus around asthma is management rather than improvement. There are options including lifestyle etc that would help improve my condition. I fear that for certain conditions the pharmaceutical industry determines the healthcare provided rather than the doctor.*

*Take long term care clinics out of surgeries into commuunity spaces where people can not only speak to the specialists but also to other patients and maybe even have specialists come to give talks and advice. For example get chefs to each diabetic friendly cooking in a community kitchen. Stop giving reams of information on paper - but install practical stuff.*



# How to measure success for people with long-term conditions based on what matters to local people



Pillar	Success indicator	How it could be measured
Accessible	<p>Increased availability of on-demand specialist advice for managing long-term conditions.</p> <p>Increased availability of routine check-ups for managing long-term conditions.</p> <p>Decrease in number of people accessing private services because of NHS waiting lists.</p> <p>Decrease in number of people leaving the workforce or limiting their career prospects because of long-term conditions.</p> <p>Decrease in number of people limiting their social lives because of long-term conditions.</p> <p>Increased uptake of physical activity among people with long-term conditions.</p>	<p>Audit of available resources (medical, patient and community) and mapping patient journeys in terms of accessing them.</p> <p>Engaging with patients about where they turn to for advice and care; and what obstacles they experience.</p> <p>Analysis of statistics about the employment status of people diagnosed with long-term conditions, in terms of type of jobs held, numbers of hours worked, career progression, rates of leaving the workforce before retirement age.</p> <p>In-depth interviews both with professionally successful people living with long-term conditions; and with people who have left jobs/ left the workforce entirely because of their long-term condition</p>
Competent	<p>Decrease in the amount of time it takes to get a diagnosis and receive appropriate treatment.</p> <p>Increased knowledge of co-morbidities and of how different long-term conditions impact each other among health and care professionals.</p>	<p>Mapping patients journeys; time passed from first symptoms to diagnosis and treatment.</p> <p>Engaging with health and care professionals about their knowledge of long-term conditions and their training needs.</p>
Person-centred	<p>Availability of specialist advice for managing long-term conditions in a variety of formats and settings (for example: phone helplines, online resources, community-based peer support groups etc.</p> <p>Decrease in the amount of time it takes to get a referral.</p> <p>Improvement in the sharing of data and records between services.</p>	<p>Mapping patients journeys; referral rate, time passed from first GP appointment to first specialist appointment, sharing of patients record and data</p> <p>Engaging with patients on whom they turn to for advice and their experience doing so.</p>
Trustworthy	<p>Increased availability of health checks; people with long-term conditions receiving reassurance and learning how to tell when they are well and when they need to be seen; decrease in rates of unnecessary A&amp;E visits</p> <p>Workers feeling comfortable disclosing their long-term condition as work; asking for sick leave or adaptations as needed, with no fear of discrimination.</p>	<p>Audit of available resources in terms of routine checks and patient education.</p> <p>Monitoring of A&amp;E attendance by patients with long-term conditions.</p>

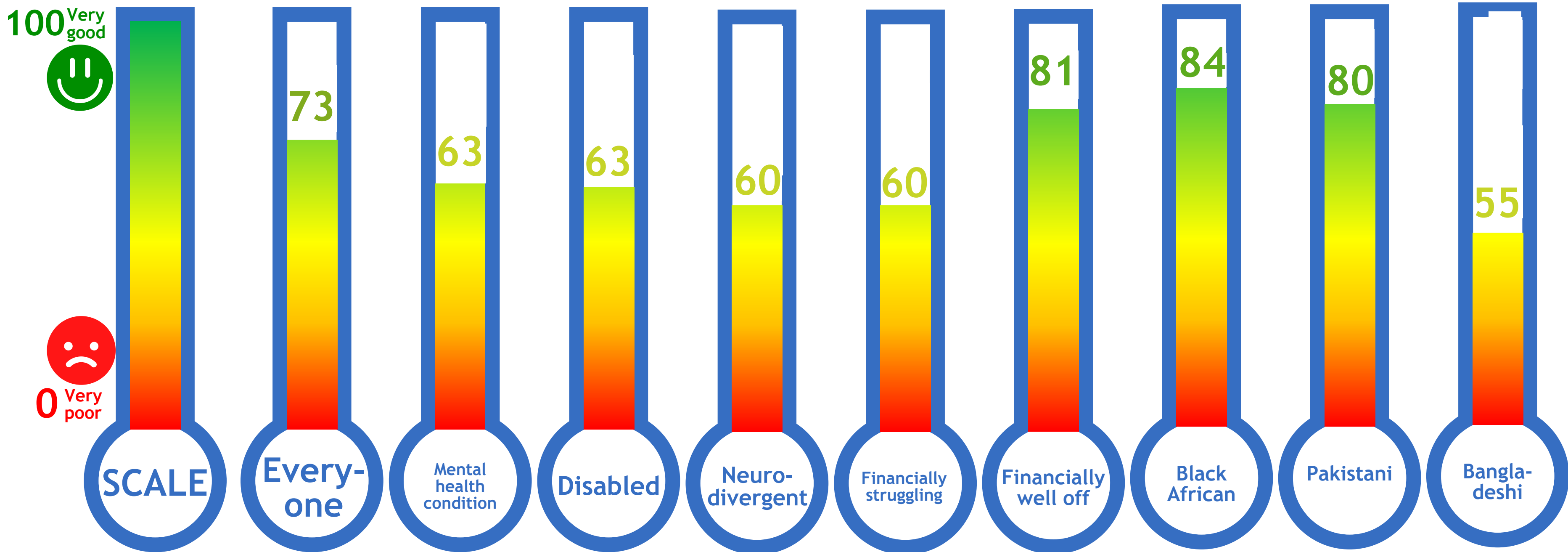


Priority: mental health and well-being

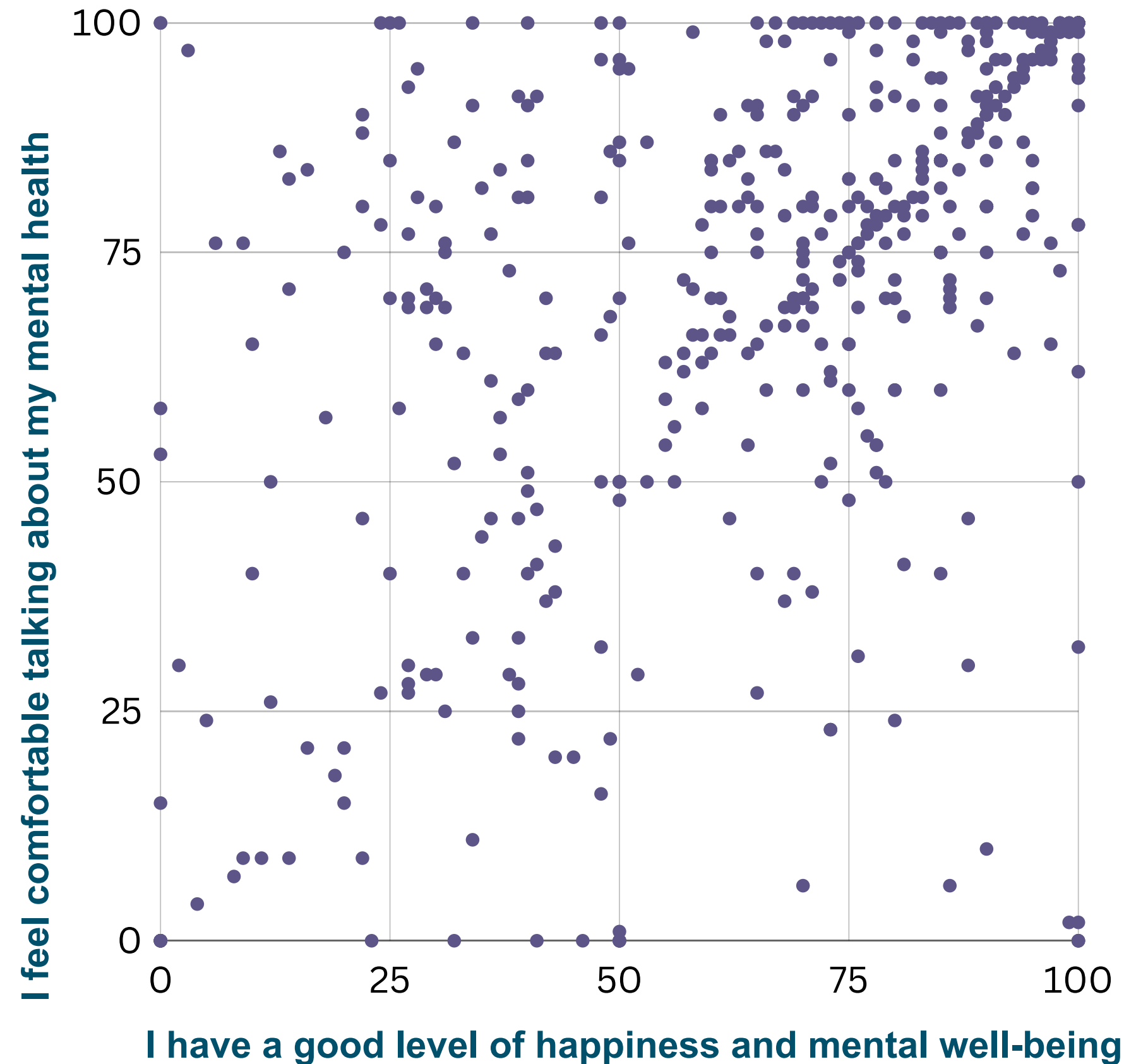


I feel comfortable talking about my mental health

Survey respondents

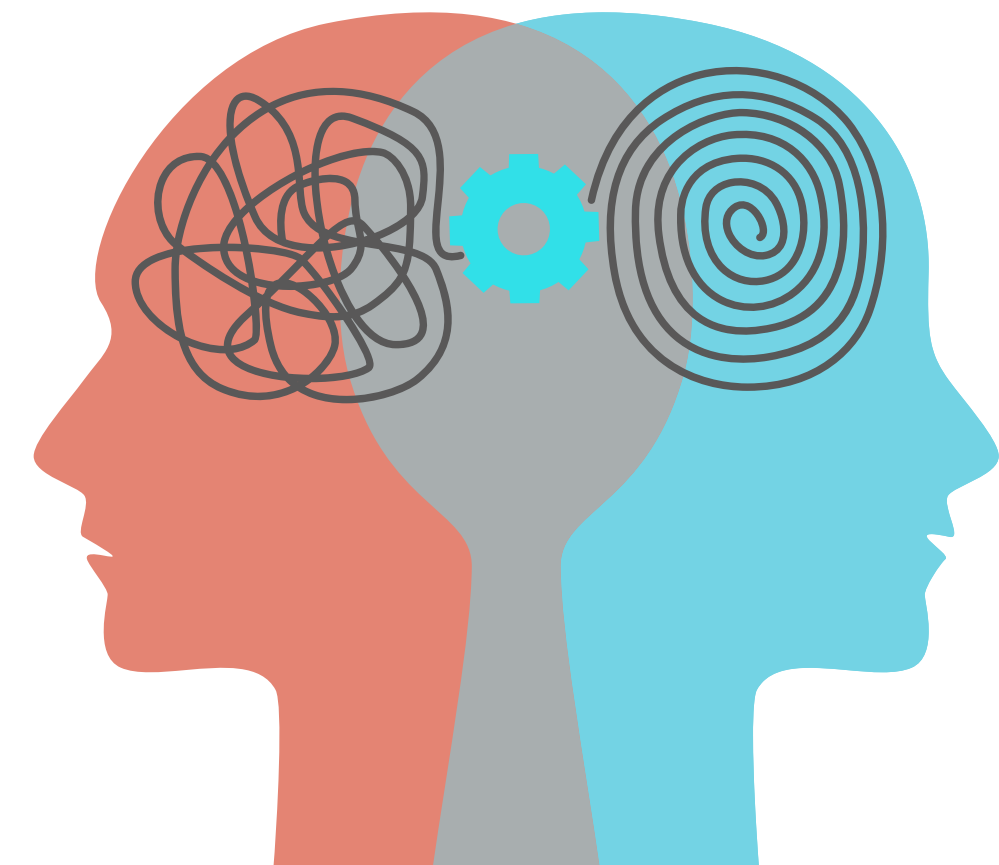


## Priority: mental health and well-being



**There is a strong correlation between higher levels of mental well-being and feeling comfortable talking about mental health.**

**Those with the lowest levels of mental well-being are the least willing to talk about it.**

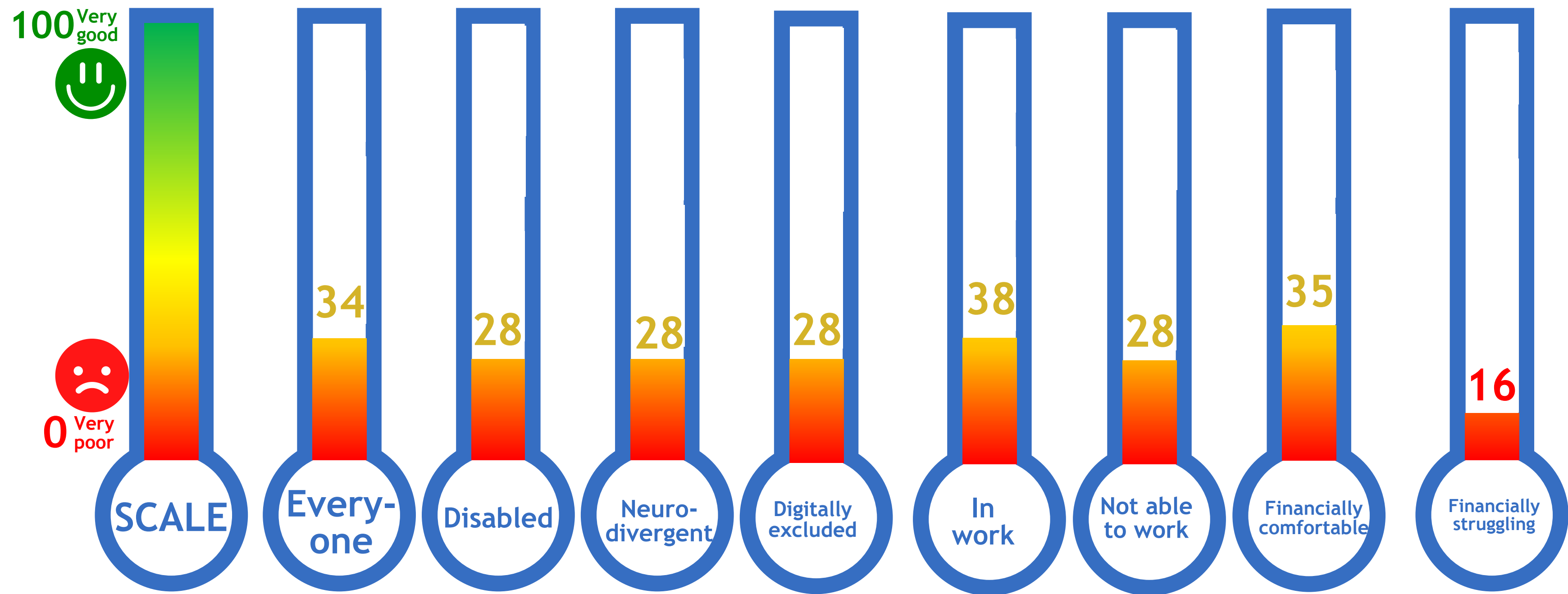


Priority: mental health and well-being



I am receiving good care for my mental health condition

Survey respondents with a mental health condition



# Priority: mental health and well-being

## The good care model



### Accessible

People can access therapy, specialist services (such as an ADHD diagnosis) or other forms of support (such as emotional support groups for mothers or grief counselling) within a reasonable time frame.

Health and care services understand stigma around mental health and difficulties some people may have in seeking help.

Therapy and counselling are available in a variety of community languages.

Mental health-related disability is taken into account when considering accessibility in healthcare, social care, community and workplace settings.

### Competent

Health and care providers, including those not working directly in mental health, understand various mental health conditions and how they can impact access to care.

Health and care providers understand the link between physical and mental health.

Employers, school and community stakeholders have knowledge of how to promote well-being for all at a wider social level.

### Person-centred

A variety of evidence-based treatment options are available (for example: multiple types of therapy rather than just CBT)

Health and care services work closely with the wider community to tackle issues such as poverty and social isolation, both for people experiencing mental health issues and for the wider community, as a prevention strategy.

Mental health is understood in a wider social context, not only from a strictly clinical point of view.

### Trustworthy

Patients accessing services for mental health are supported long-term in a proactive way; follow-on support is available and routinely offered.

Patients can talk to health and care professionals about their mental health needs without fear of stigma or being dismissed.

Routine health check-ups (for example: for new parents, for people with long-term conditions, for the elderly) include questions on mental health and well-being.

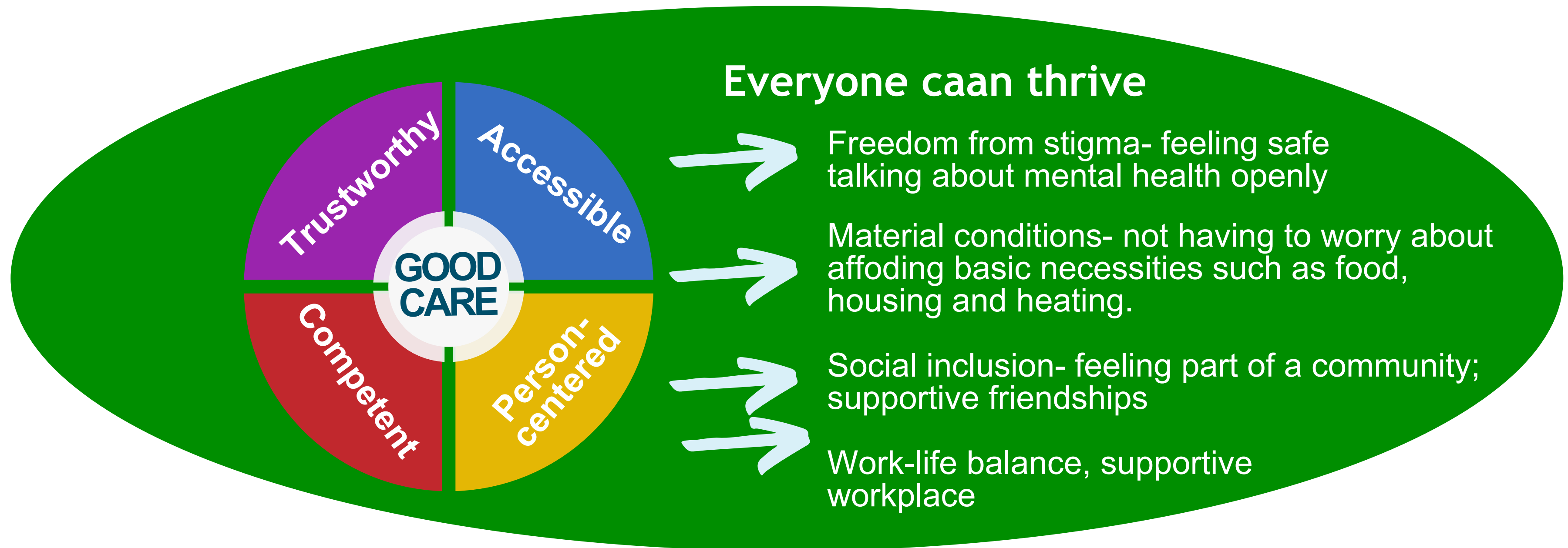


# Priority: mental health and well-being

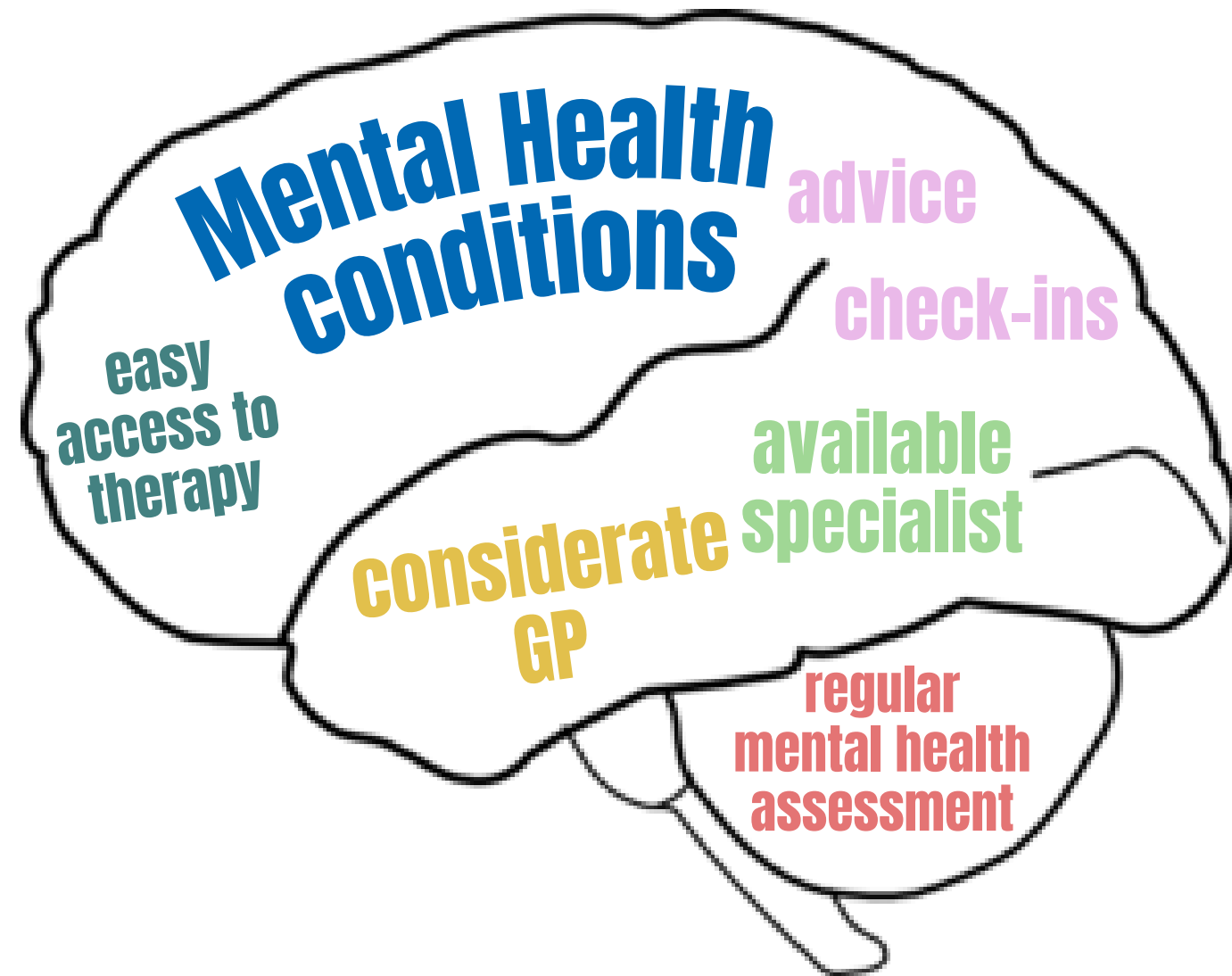
## How do we measure success?



Mental well-being depends on multiple factors. For those in need or receiving care (medical or social) either specifically for their mental health or physical health issues with an impact on general well-being, the care they receive is a highly important factor. At a wider social level, mental well-being is impacted by social and cultural factors. A model of success must, therefore, take into account health and care services as well as the wider society.



## Priority: mental health and well-being



Have had a good GP that was a Mental Health specialist

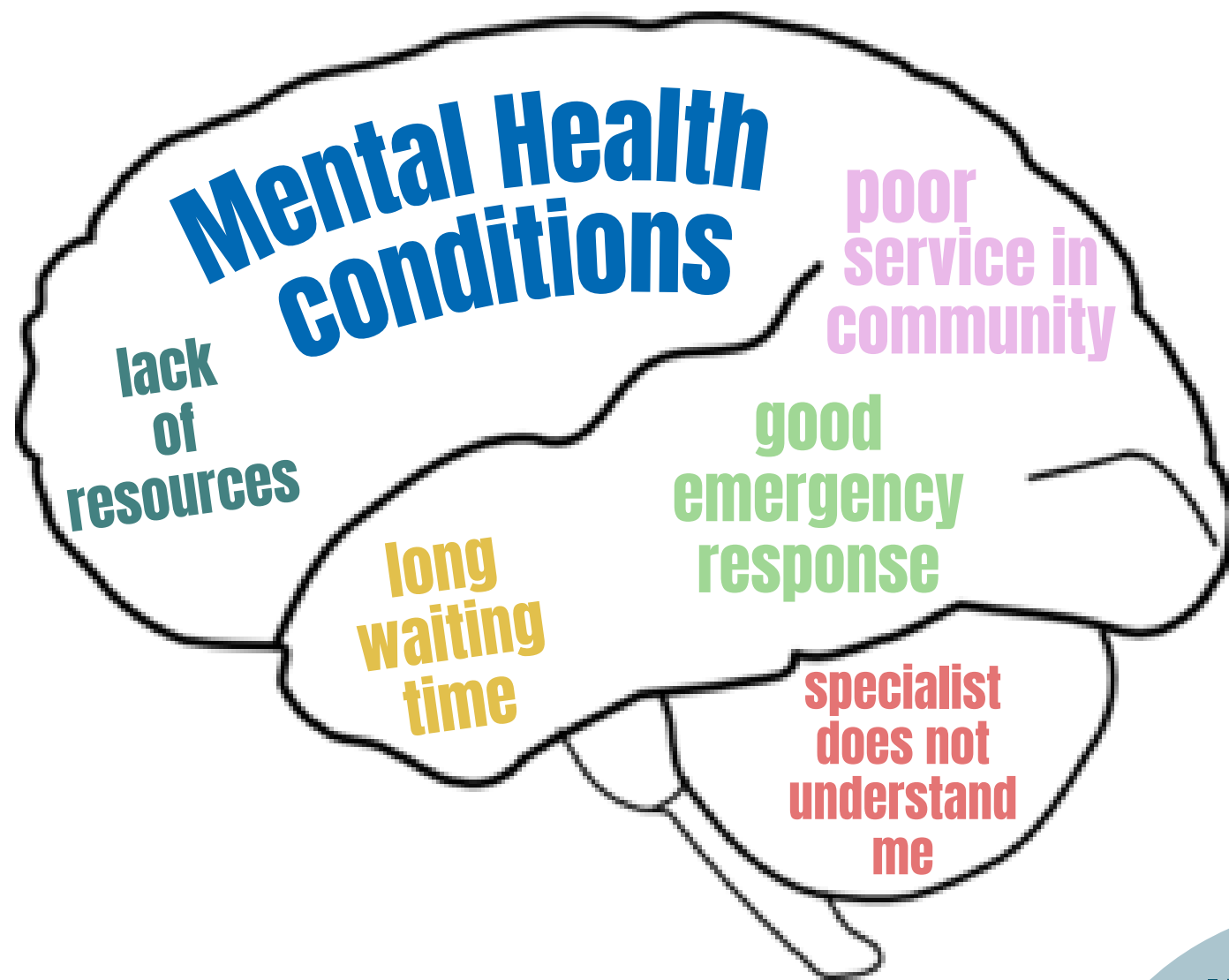
I have a good counsellor

Good advice from staff. Follow ups from staff

# What happens when care is good

The responses highlight the importance of good mental health support and the difference it can make in individuals' lives. Positive themes emerge from these comments, emphasizing the value of access to therapy, the quality of care provided by specific professionals, and the overall impact of mental health support on well-being.

## Priority: mental health and well-being



Would like more frequent medical reviews and discussions about mental health that includes long term plans etc

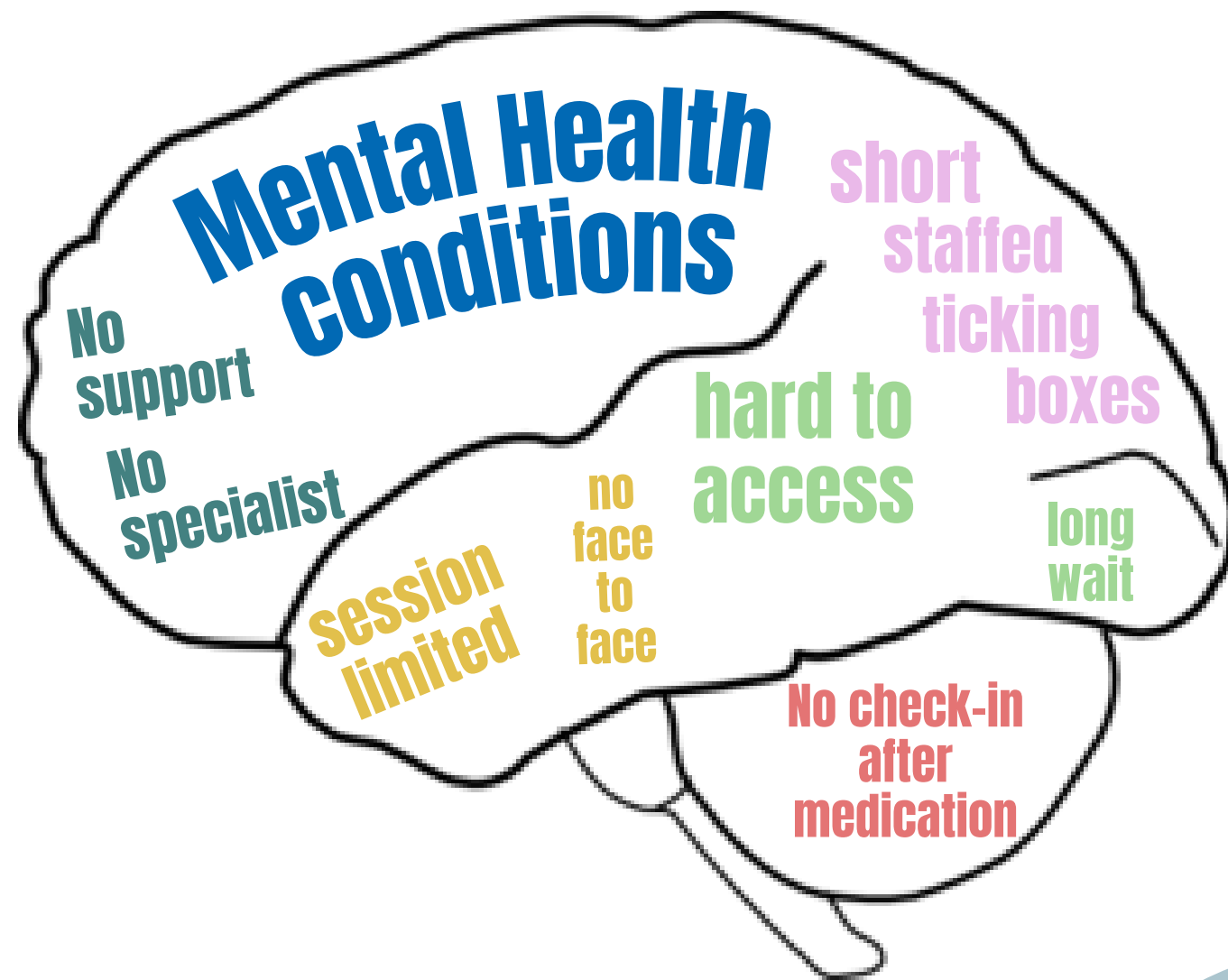
# What happens when care is so-so

I have the wrong psychiatrist who does not understand me

I'm still grappling alone with a myriad of things

These responses touch on the middle ground of healthcare experiences. Individuals who find their care to be "so-so" or average are often caught in a place where they recognize some effort or quality in their care, but it's not meeting all their needs or expectations.

## Priority: mental health and well-being



I've been on a waiting list for a referral for over a year

No treatment only medication

No follow up. An annual review of medication but not follow up

# What happens when care is poor

These responses highlight various issues, including prolonged waiting times for appointments and therapy, lack of follow-ups, and an over-reliance on medication rather than addressing the underlying issues and offering holistic treatment.



# How to measure success for mental health and well-being support based on what matters to local people



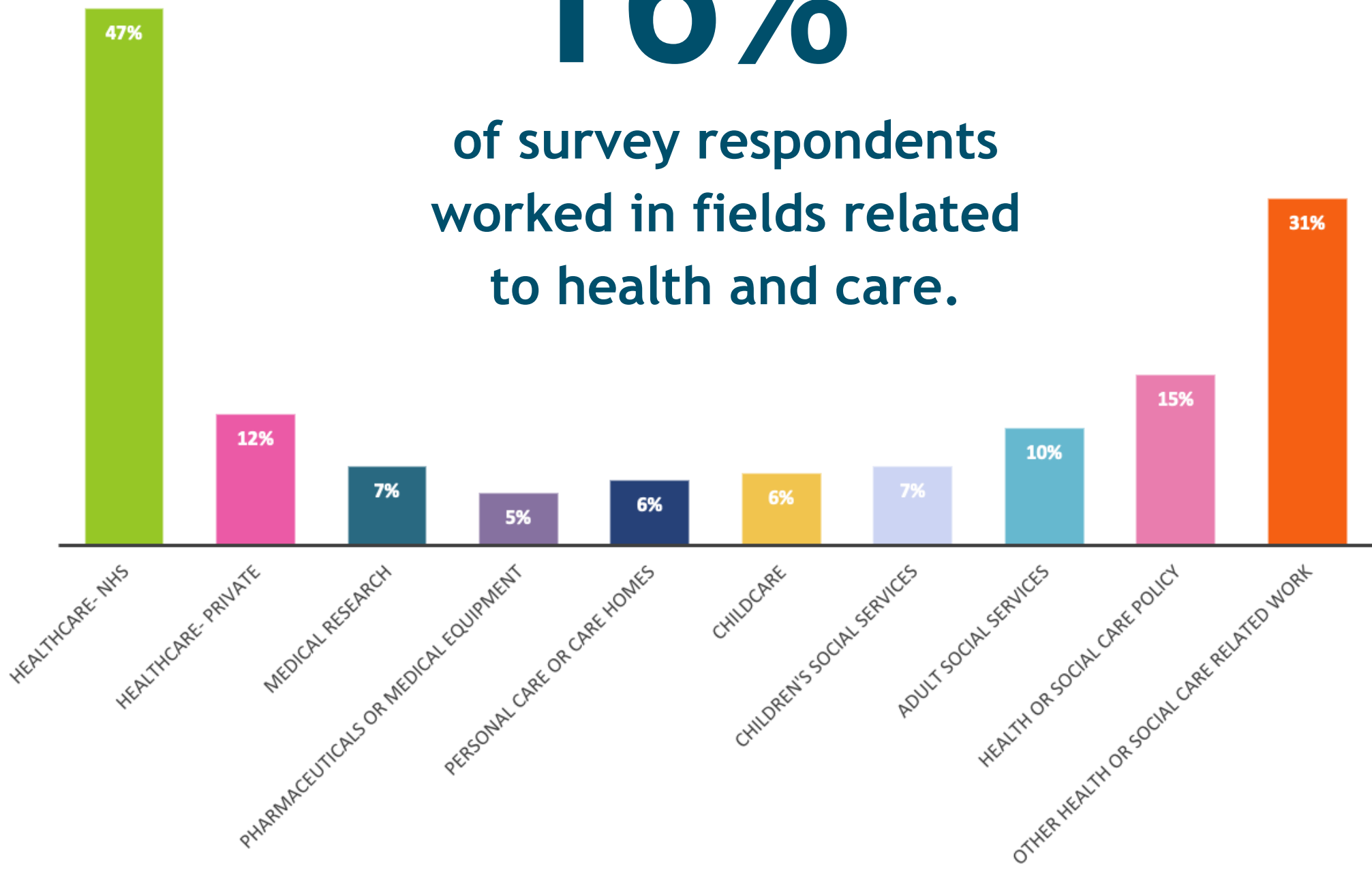
Pillar	Success indicator	How it could be measured
Accessible	<p>Decrease in waiting times for services such as IAPT, CMHT, CAMHS, autism/ADHD assessments etc.</p> <p>Simplification of the process by which people access care for their mental health- improvement in user experience</p> <p>Decrease in social isolation among people living with mental health issues</p>	<p>Data generated by services- “hard data” on waiting times.</p> <p>Engagement with service users; specific questions about user experience when trying to access care, and to take part in the life of their community.</p>
Competent	<p>Improved understanding, among health and care professionals, of the link between physical and mental health; improved understanding on mental health among professionals not specialised in mental health (such as GPs or occupational therapists).</p> <p>Improved understanding among managers of HR professionals of how to support health and wellbeing in the workplace, and how to accommodate workers experiencing poor mental health. Increase in number of people who report having a good work-life balance.</p>	<p>Engagement with professionals; data on training available and undertaken.</p> <p>Engagement with service users to assess the extent the feel professionals treating them are aware of mental health issues.</p> <p>Engagement with workers on their experience of mental wellbeing at work.</p>
Person-centred	<p>Increased integration between primary care, specialist mental health services, social care services and the voluntary/ community service,</p> <p>Increased availability and awareness of community services supporting local people, including but not limited to those affected by mental health issues, with topics such as access to benefits, employment rights/ employability, tackling social isolation etc.</p>	<p>Data generated by services- mapping of referral systems and patient journeys.</p> <p>Audit/ stock-take of available community resources.</p> <p>Engagement with service users on their experience.</p> <p>Engagement with local people who may need support but are currently not accessing it</p>
Trustworthy	<p>Increased availability of follow-on appointments and routine check-ups for patients receiving mental health care.</p> <p>Patients feeling comfortable talking t about their mental health- to health and care professionals; to friends and family; in the workplace.</p> <p>Decrease in number of people who report feeling worried about issues such as poverty, housing or safety locally.</p>	<p>Data generated by services- availability and uptake of follow-on.</p> <p>Engagement with local people on their experience of communicating about mental health in various situations</p> <p>Hard data/ statistics: relation between mental health diagnosis and poverty/ deprivation; elation between mental health diagnosis and unemployment and/or leaving the workforce before retirement age</p>



Priority: workforce and employment

16%

of survey respondents  
worked in fields related  
to health and care.



In five years, would you see yourself working in the same field?

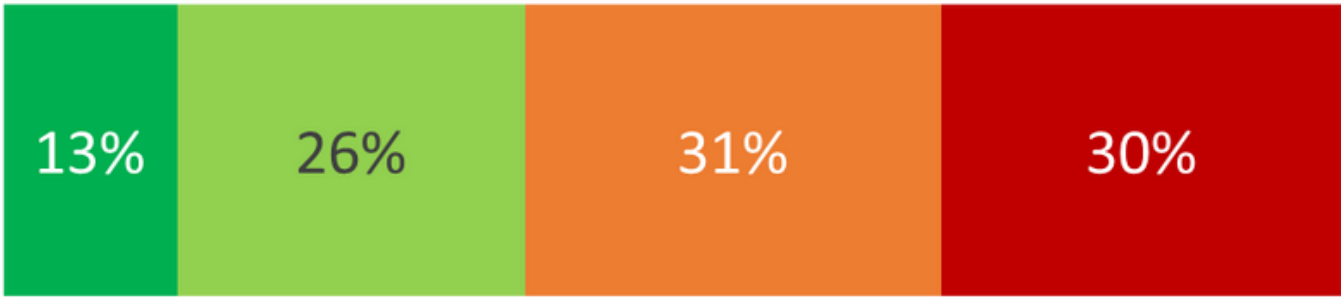
- respondents currently working in health and care-



- Yes, I would happily work in the same field
- No, I would like to do work relating to a different aspect of health or social care
- No, I would like to do work unrelated to health or social care instead
- No, I would like to leave the workforce (for example, to retire or become a stay at home parent)
- Not sure/ undecided

Would you consider a career in health and care in the future?

- respondents NOT currently working in health and care-



- Definitely
- Probably
- Probably not
- Definitely not

# Priority: workforce

## The good care model



### Accessible

People can train/qualify professionally and earn at the same time; entry-level jobs pay a living wage.

Workplaces offer flexibility and adaptations for those who need it (disabled, parents, carers etc.); including those with mental health related disabilities.

ESOL classes are available for those with employable skills from abroad.

The job advertisement and recruitment process is designed with diversity in mind, tackling obstacles faced by under-represented groups.

### Competent

Understanding of health inequalities/holistic approaches to health is built into training for all health and care professionals.

Health and care professionals feel supported and empowered to do their jobs to the highest possible standard of quality.

Knowledge is shared through mentoring and shadowing; ; support in matching existing or transferrable skills with job opportunities.

There are comprehensive guidelines about how to qualify for specific professions.

### Person-centred

There is a good level of flexibility and work-life balance, to the full extent of what the nature of the job allows.

Schools, universities and training providers work together with employers to train local people in the right skills and connect skilled workers with relevant jobs.

Career advice in schools doesn't focus exclusively on academic high achievers.

Workplaces establish connections with the local community (shops, community centres, faith groups) for advertising jobs, training opportunities and mentoring; jobs are advertised where the community is rather than expecting jobseekers to know where jobs are.

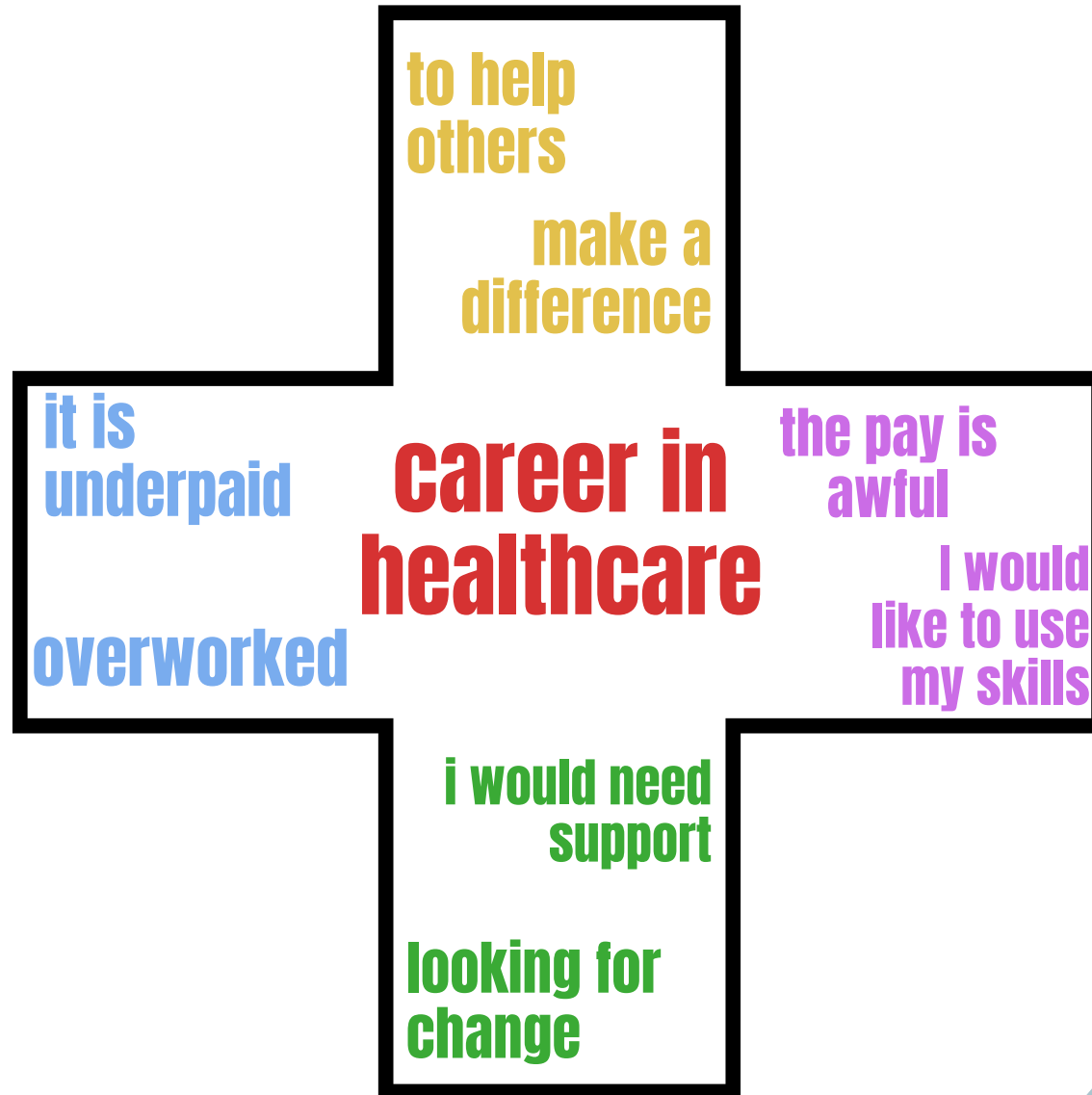
### Trustworthy

Workers have a good level of job stability.

There is a clear and realistic career progression path.

People can talk about their needs in the workplace, including their mental health needs, and ask for flexibility or adaptations without fear of discrimination or judgement.

Workers feel appreciated and believe they are making a difference



I work in homelessness. Trauma-informed approach and there are a lot of transferrable skills that can be linked to health and social care.

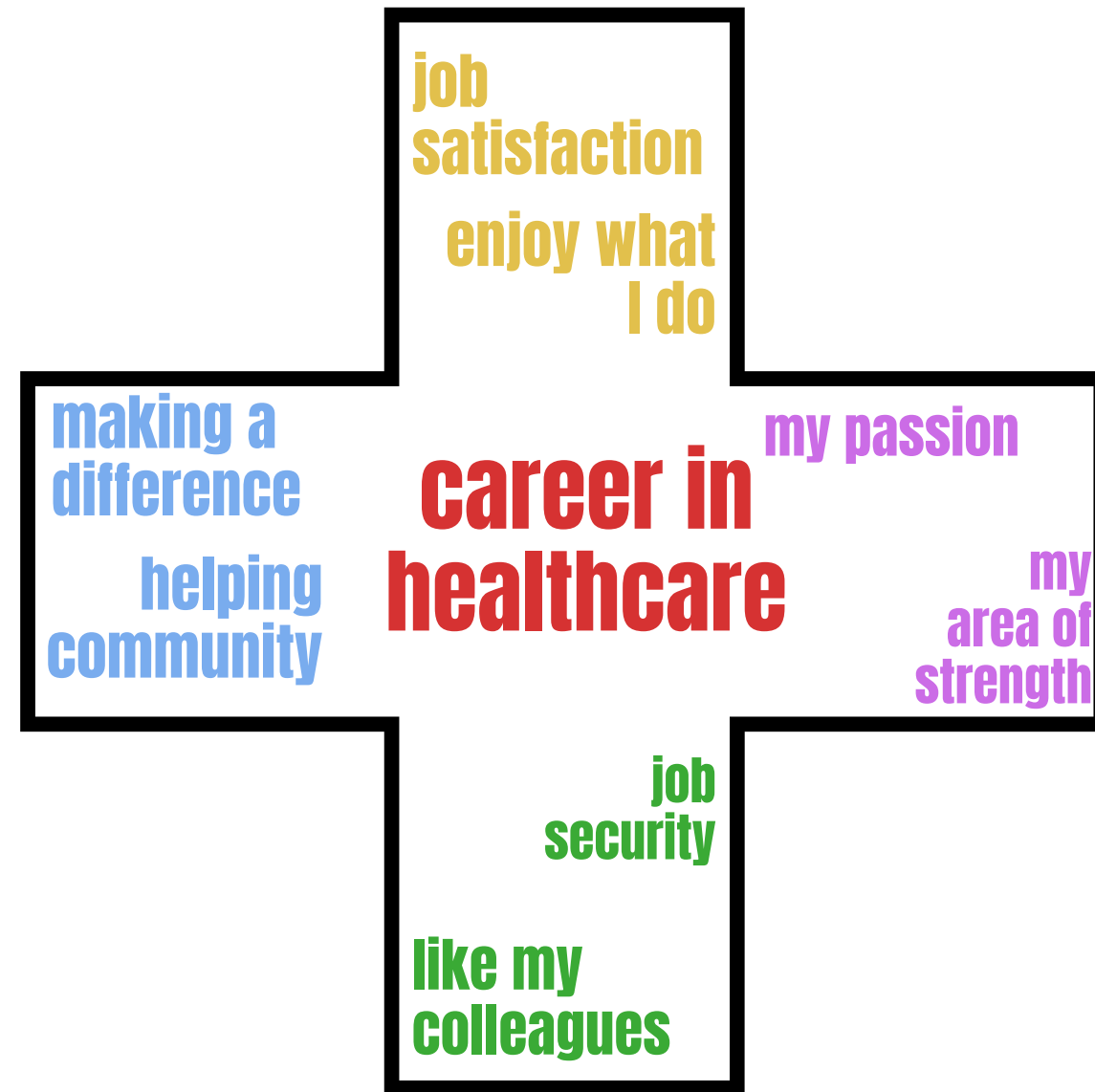
## We engaged with:

People NOT currently working in health and care, but who would consider a career change towards it.

The respondents interested in a health and care career in the future expressed a desire to change their career to healthcare due to their passion for helping others, personal experiences with healthcare, and the ability to make a positive impact in the community. They see value in contributing to society meaningfully.

I like to help people

I'm passionate about health



I enjoy doing work that can make a difference for others

## We engaged with:

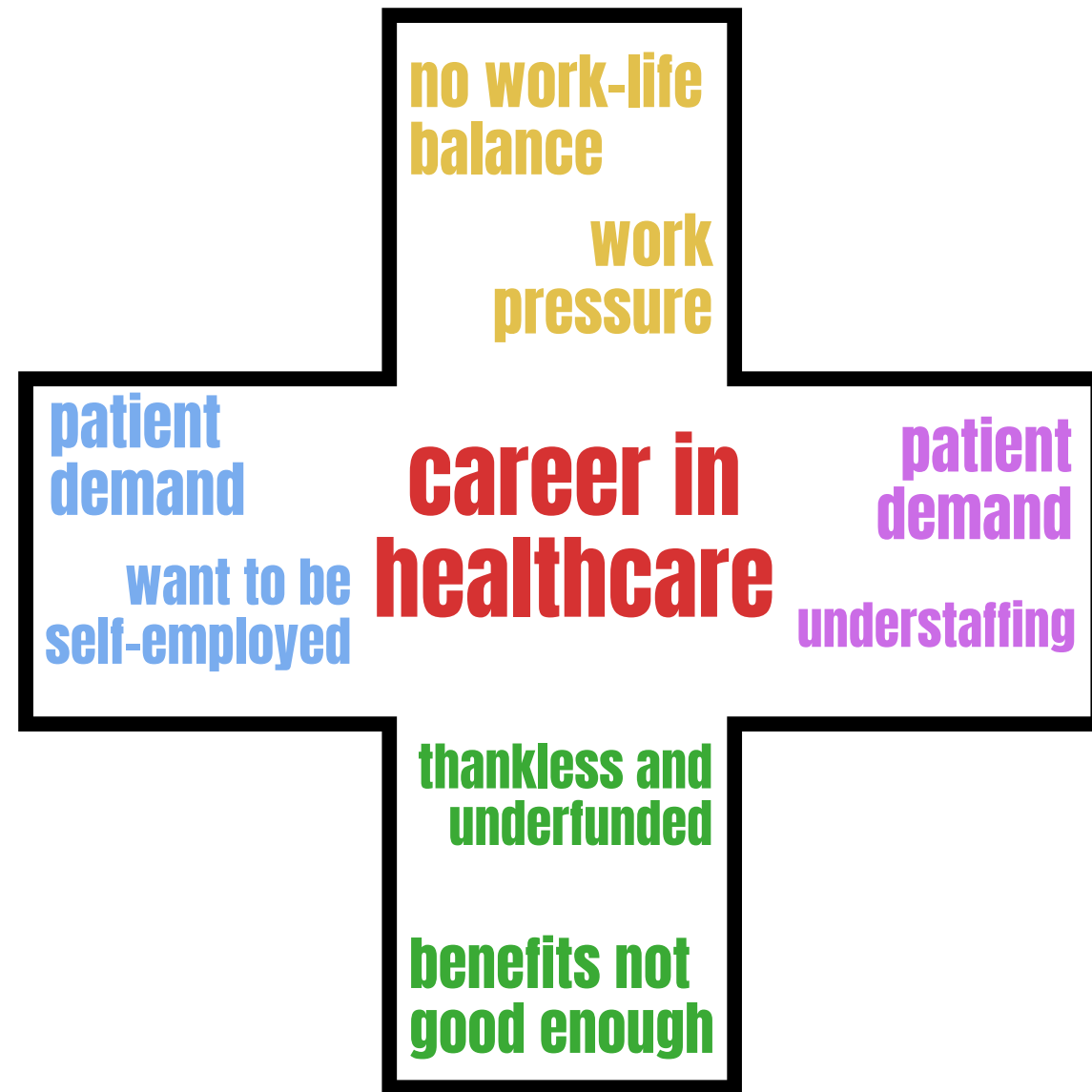
People currently working in health and care who would be willing to commit to the field in the long run.

It's my area of strength

I like my job, I have good job satisfaction, I like my colleagues and partners

The respondents already working in health and care who wanted to continue doing so express strong feelings of job satisfaction, a passion for helping others, and a belief in the importance of their work. They find their roles rewarding.





I don't believe in working for a healthcare system that doesn't treat my own healthcare problems

## We engaged with:

People currently working in health and care, who were considering leaving the field.

The respondents wanting to leave the health and care fields expressed frustration with the healthcare system, highlighting systemic issues such as lack of resources, poor pay, high work stress, and low morale.

NHS pressure is untenable

Not sure if I can maintain work life balance

## Priority: workforce and employment



### What kind of support would people need for a health or social care career?

- ➔ Pathways to training while getting paid (such as apprenticeships); availability of free training; less reliance on volunteering/ unpaid work for gaining experience.
- ➔ Mentoring and shadowing opportunities from people with experience in the field; information on qualifications needed for specific jobs; support in matching existing or transferrable skills with job opportunities. Job cafes and open days.
- ➔ Work experience in partnership with schools; career advice in schools not exclusively focused on high academic achievers.
- ➔ A clear and realistic career progression path; a living wage at entry level.
- ➔ Workers having a say in how their workplace is run/' management accountability to workers.
- ➔ Better connections with the local community (shops, community centres, faith groups) for advertising jobs, training opportunities and mentoring.
- ➔ ESOL training for immigrants with health and care experience in their countries of origin.
- ➔ Disability-friendly workplaces, including for those with mental health related disabilities.
- ➔ Accommodations for working parents and carers, especially single parents.

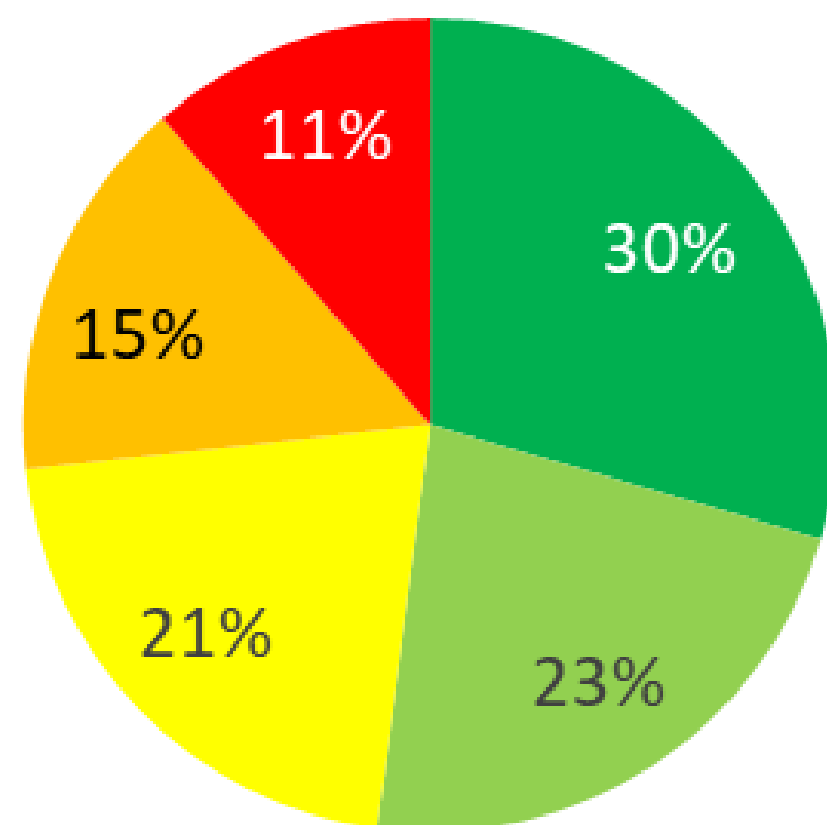
# Priority: workforce and employment

## Volunteering

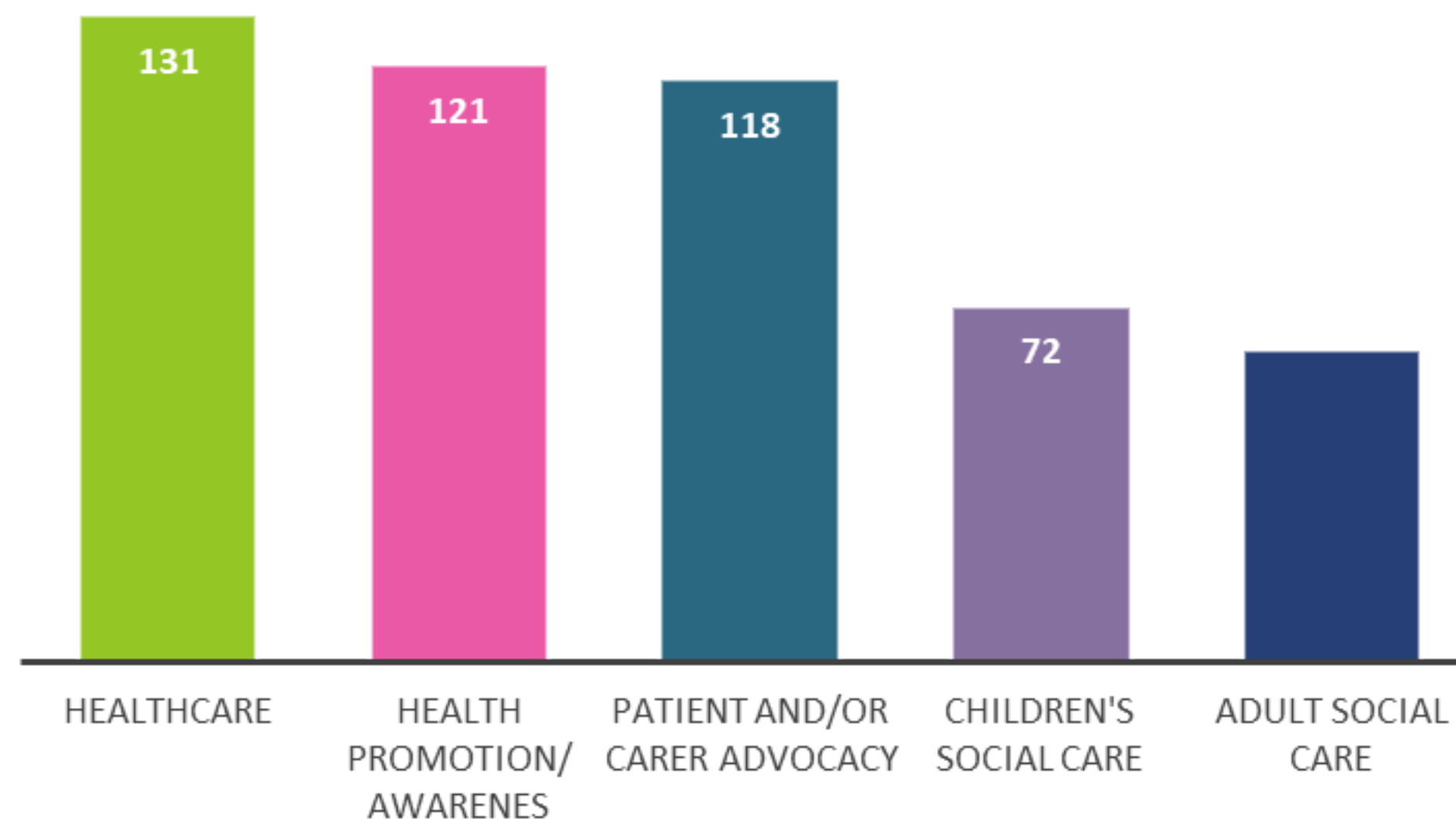


More than half of survey respondents would potentially be interested in volunteering locally.

**72%** of those interested in volunteering would be interested in health and care volunteer work.



- Definitely yes
- Probably yes
- Maybe/ not sure
- Probably not
- Definitely not



# Priority: workforce and employment

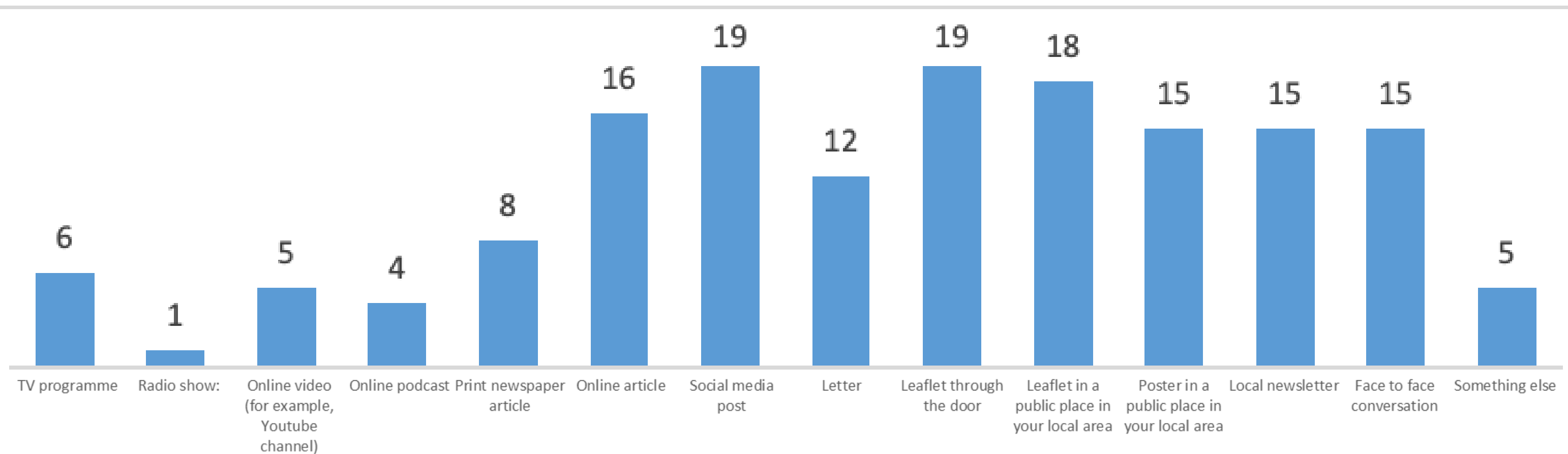
## Volunteering



**16%** of those interested in health and social care volunteering said they knew nothing at all about local volunteering opportunities.

**10%** only knew a little bit.

### How they would like to receive information about volunteering





# How to measure success for work force development based on what matters to local people



Pillar	Success indicator	How it could be measured
Accessible	<p>Increase in opportunities to access health and care jobs among groups who would otherwise struggle to access this career path.</p> <p>Increase in workplace flexibility</p>	<p>% of workers who are from disadvantaged backgrounds/ have caring responsibilities/ are from any other under-represented groups, in junior and senior positions.</p> <p>Engagement with jobseekers and workers, to understand their career progression and experience.</p>
Competent	<p>Improved knowledge of issues such as health/ social inequalities and mental health among health and care professionals; and among managers in various fields.</p> <p>Increased number of professionals who feel confident and empowered to do their jobs well.</p>	<p>Engagement with health and care professionals; data on training available and undertaken.</p> <p>Assessment of training needs, monitoring of how they are being met.</p> <p>In-depth interviews on mentoing and knowledge-sharing.</p>
Person-centred	<p>Improved collaboration/ continuity between education/training and work; improved collaboration between workplaces and key community stakeholders.</p> <p>Culture of workplace flexibility, in which workers can have work-life balance and align their career goals with other aspects of their lives.</p>	<p>Mapping career journeys.</p> <p>Audit/ stock-take of available community resources in terms of education, training and employability advice.</p> <p>Engagement with workers on carreer rprogression and work-life balance.</p>
Trustworthy	<p>Increased rate of success/ positive outcomes for working requesting flexibility or adaptations in the workplace (for example, as new parents or to accommodate a disability).</p> <p>Workers feeling comfortable talking about their mental health and well-being at work.</p> <p>Workers feeling optimistic about their career progression and job stability.</p>	<p>% of new parents, people with long-term conditions etc. continuing to work vs. leaving the workforce;</p> <p>Mapping/ monitoring career progression, including for groups such as parents and people with long-term conditions.</p> <p>Engagement with workers on communication and trust in the workplace.</p>