

# PATIENT PERSPECTIVES PEOPLE ON PROBATION



**CORE20 PLUS5**



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# BACKGROUND



The purpose of this engagement was to enable people serving a community sentence to share their views around health themes relating to NHS England's Core20PLUS5 improvement approach to reducing health inequalities.

EP: IC engaged with people on probation through surveys. These surveys were co-produced with partners such as NHS England Health & Justice and HMPPS, and were sense-checked by individuals with lived experience of probation.

The EP: IC team encapsulates both the lived and learned experience of criminal justice and exists to centre the lived experience within justice-based research and consultations. Our work involves direct engagement with those experiencing a system, a service or a process and seeks to present learning in a way that informs organisations, with the overall aim of promoting co-production and improving outcomes for the people and communities they serve.

Given the extent of the dataset, this report has been organised as follows.

Part 1	Lifestyle and healthcare needs
Part 2	GP services
Part 3	Medication, access to services and mental health
Part 4	Understanding and learning about health conditions
Part 5	Bowel cancer screening
Part 6	Prostate cancer screening
Part 7	Cervical and breast cancer screening

Opportunities to be involved were advertised in the following ways:

- In participating probation areas
- In community services
- Through people with lived experience of prison and probation.
- Via social media.
- In women's centres.
- Through EP: IC's networks, including other criminal justice services.

To ensure accessibility to as many people as possible, people were able to contact us in a range of ways, including:

- Email
- Text
- Freephone number
- Freepost address

A blended approach was taken in terms of survey completion to support a range of communication needs, allowing participants to choose how to take part. Choices included:

- Independent completion (online or paper-based).
- Telephone interview with our lived-experience team.
- Face to face interview with our lived experience team.
- With the aid of a support worker within a particular accessed service.

**In total, 177 people on probation engaged with this consultation.**

The learning from this engagement forms part of a wider consultation relating to Core20Plus5 priorities for people connected to the criminal justice system. Simultaneously, we also engaged with the following groups:

- Women with maternity needs (in prison or on probation).
- People residing in Approved Premises.
- Prison leavers.
- People in prison

This report outlines the key learning attained from all engagement. It is broken down into sections and all key learning is highlighted at the beginning of each section.



# PARTICIPANTS

## Gender

Just over three quarters of participants were male, at 76%. Women made up 23% of the overall total and the remaining 2% preferred not to state their gender.

When asked whether they identified with the gender registered at their birth, 2% of participants stated that they did not.

The following table provides a quick overview of participants across all parts of the survey. Individuals were asked to complete parts 5, 6 and 7 of the survey based on the gender with which they identify.

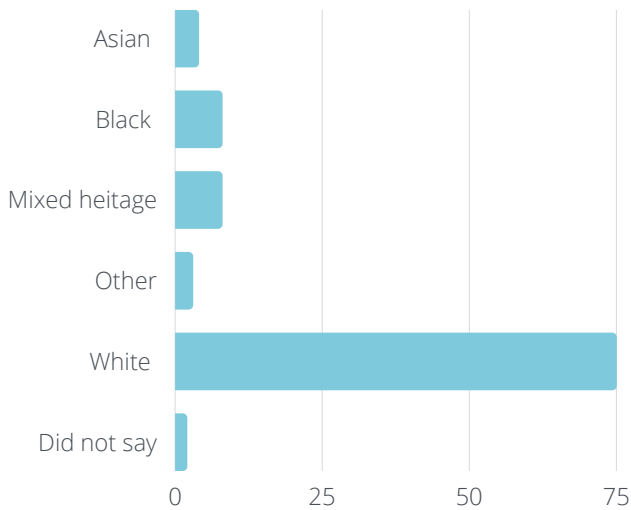
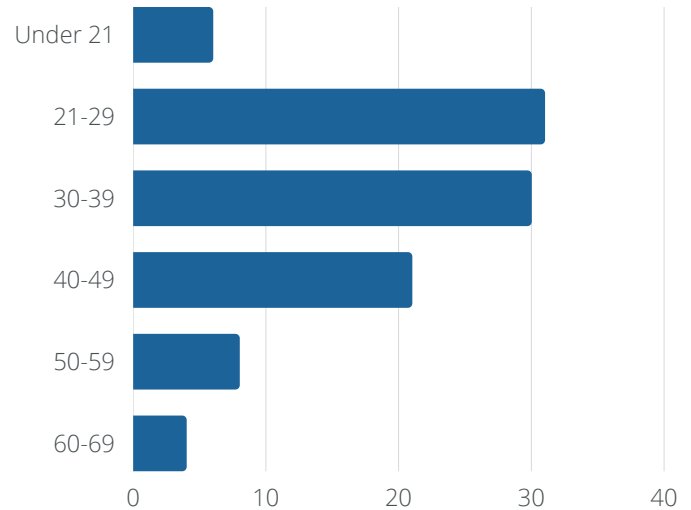
	Part 1 - 4	Part 5	Part 6	Part 7
Male	135	108	101	0
Female	40	34	0	53
Did not say	2	2	0	0
Total	177	144	101	53



## Age

A broad range of ages participated in parts 1-4 of the survey. The largest age group, when banded by age, was the 21-29 year category (31%), followed closely by those aged 31-39 years, who made up 30% of all respondents.

A further fifth (21%) were 40-49 years old while those aged 50-59 years made up under a tenth, at 8%. Just 6% were under 21 years old and the smallest group comprised older adults aged 60-69 years (4%).



## Ethnicity

By far the most common ethnic identity of respondents to parts 1-4 of the survey was white, at 75%. Just under a tenth of respondents were black at 8% and a further 8% identified as mixed heritage. Some 4% of responses were from Asian people while 3% were of an 'other' ethnicity. A small number (2%) preferred not to state their ethnicity.

In total, those from ethnic minorities formed just under a quarter of all respondents, at 23%.



# KEY FINDINGS

## LIFESTYLE AND HEALTHCARE NEEDS

- Mean BMI was recorded as 26.9 for men and 23.1 for women (calculated from those who knew their height and weight).
- 5% drink alcohol daily.
- 49% were smokers.
- 14% had never smoked but vaped.

- 30% had undertaken in excess of 30 minutes of exercise for more than five days during the previous week, while the same percentage had taken no exercise.
- Cost was seen as the greatest barrier to increasing exercise, with time and confidence being seen as additional challenges.
- Some people recognised that physical activity positively impacted on their wellbeing.
- 43% were reducing the amount they smoked or vaped.
- 62% were choosing healthier meals.
- 47% were consuming less alcohol.
- 55% were choosing healthier snacks.
- 50% were aiming for a healthy body weight.
- 57% stated that all pharmacy needs were fully met, meaning that their medication needs were satisfied.
- 42% reported that their healthcare needs provided by GP services were fully met.
- 33% said that their mental health needs were fully met.
- 38% reported that their drug and alcohol services needs were fully met.
- 39% stated that their hospital healthcare needs were fully met.
- 33% said that their social care needs were fully met.



## LEARNING LIFESTYLE

Over two thirds of individuals knew their height.

Less than two thirds knew their weight, as shown in the tables.

	Do you know your height?
Yes	70 %
No	30%

	Do you know your weight?
Yes	61%
No	39%

From those who knew their height and weight, the following mean BMIs were calculated:

- **Male - 26.9**
- **Female - 23.1**

Individuals were questioned about their use of alcohol. Most people use alcohol sometimes, though around a fifth reported being a former drinker. 4% stated they use alcohol daily, Full results are shown below, though;

- A third (33%) of daily drinkers were female; the remainder were male.
- All participants who drank alcohol daily were white, apart from one Asian participant.
- Equal numbers of individuals aged 21-49 years used alcohol daily, with the exception of one person who was 60-69 years old.

### Which statement best describes your use of alcohol?

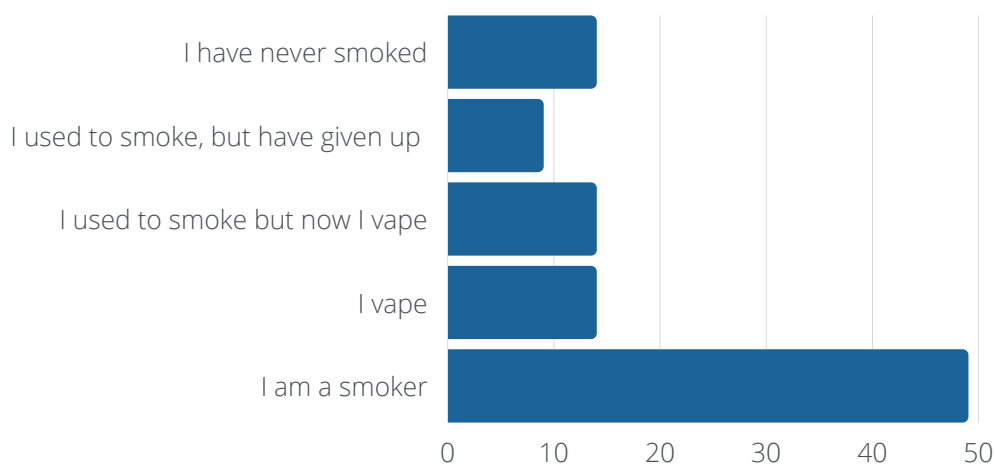


Nearly half of all participants were current smokers:

- 84% were male and the remaining 16% were female.
- Most were white, at 80%.
- In terms of age, the greatest proportion of smokers (over a third, at 35%) were aged 30-39 while the smallest group were under 21 years old.

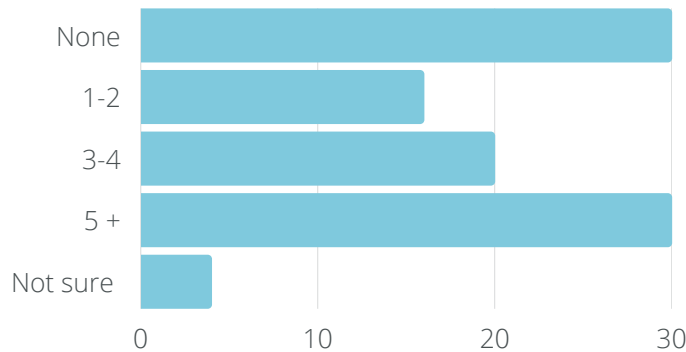
Less than a fifth, 14% of people on probation within this consultation explained that they were former smokers but now vaped. The same proportion (14%) had never smoked but now vaped; a third of these were under 30 years old and 75% were women.

### Which statement best describes your history of smoking?



In regard to exercise taken during the previous week, nearly a third had undertaken no physical activity at all. A similar number, at 29%, had participated in exercise on at least five days during the previous week.

### How many days last week did you take part in exercise for more than 30 minutes?



From the comments provided concerning exercise, it is clear that some individuals were able to link their physical activity to feeling better.

**“Walking loads and it’s the only way I can relax. I walk 10 hours a day to get myself out of trouble and look at the trees and sun.”**

**“Walk and cycle a lot – this helps my mental health. When I’m indoors I get bogged down and think too much.”**

**“Walk for an hour every day – I go to the gym 3 times a week – this really helps me stabilise my mental health. I do it more for my mental health more than anything.”**

When considering increasing exercise levels, cost was seen as a barrier for most.

Over half of participants (53%) cited insufficient money as preventing them from increasing their physical activity. It was regularly noted that gym memberships were desirable but unaffordable.

**“I walk every day. If I could afford a gym membership I would go all the time.”**

**“Support with going to a gym. I asked probation for help with gym membership but they said no even though they’ve done it for others.”**

**“Finances being better would help with better access to gyms or sport groups.”**

15% of individuals felt that they needed additional encouragement or support to increase their time exercising.

**“Learning a team sport and being involved in a team sport or coaching but worried about DBS.”**

**“Community meet ups for gym or work out sessions in the park or community centres where you can get help in how to work out.”**

**“Someone to support me and make me feel more confident.”**

Around a fifth (19%) commented on having insufficient time.

**“I’m working, I’m a plasterer and have no spare time.”**

**“Kids, work between that and everything else there’s not time to exercise.”**

15% of participants felt they lacked confidence when considering exercise.

**“Someone to support me and make me feel more confident.”**

**“Help to get motivated and help with my self-esteem.”**

**“If I feel more confident, I would like to know about keeping fit.”**

Just over a tenth (12%) spoke of physical and mental health preventing them from exercising.

**“I had a stroke so exercise is just moving at the moment, lol.”**

**“With my anxiety, I struggle to leave the house.”**

**“I walk only but I’ve got a broken heel and being in better head space.”**

Participants were asked if they were currently making any lifestyle change

	Yes	No	Unsure	Not needed
Reduce vaping/smoking	65	63	23	21
Choosing healthier meals	99	43	18	16
Drinking less alcohol	66	53	19	37
Increasing exercise	89	40	26	20
Choosing healthier snacks	87	45	26	17
Aiming for a healthy body weight	89	41	22	23

Similar numbers reported that they were reducing how much they vaped or smoked (43%), compared to those who were not (42%) (this excludes those who reported not needing to make any changes).

Nearly two thirds (62%) were choosing healthier meal options, compared to 29% who were not. A tenth felt that no dietary changes were required.

Just under half (47%) of respondents were consuming less alcohol, compared to 38% who were not. Meanwhile, 21% of participants felt no need to change their alcohol intake.

Over half (57%) were exercising more, compared to a quarter who were not. Just over a tenth (11%) reported not needing to change their level of engagement of physical activity.

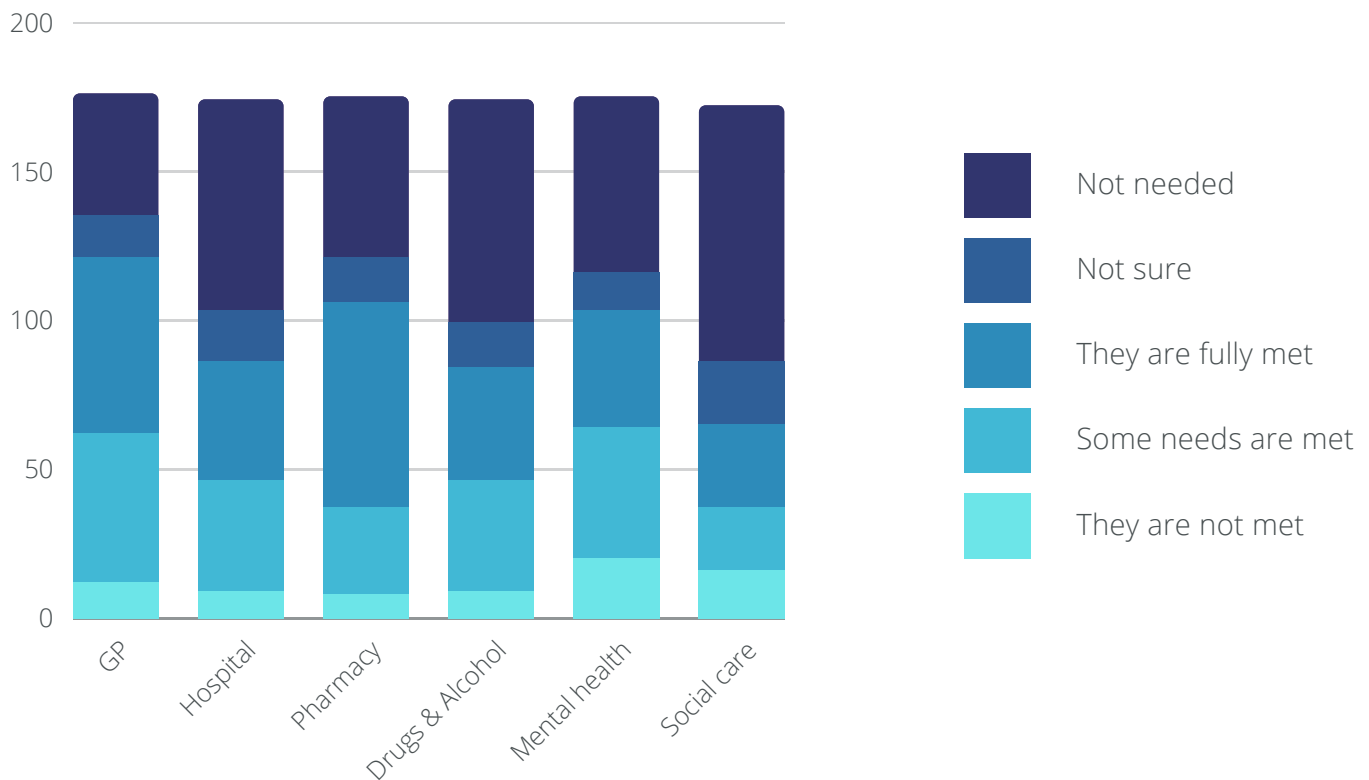
Fifty-five percent were choosing healthier snacks, compared to 16% who were not, while a tenth (9%) reported not needing to change their snacking habits.

Fifty-nine percent were aiming for a healthy body weight, compared to 14% who were not. A similar number (13%) stated that aiming for a healthy body weight was not necessary.

## HEALTHCARE NEEDS

When we look at met or unmet healthcare needs people on probation highlight that the community services least required were social care, drug and alcohol services, and hospitals while those most needed were GPs, pharmacies and mental health services.

### How well are your current health needs being met?



More often than not most needs were met though there were some disparities in experience.

- Of those who had a GP need 81% of needs were partially or fully met.
- Of those who had a hospital related need 75% were partially or fully met.
- Of those who had a pharmacy need 75% were partially or fully met.
- Of those who had a drugs or alcohol need 53% were partially or fully met.
- Of those who had a mental health need 45% were partially or fully met.
- Of those who had a social care need 57% were partially or fully met.

When looking at unmet needs;

- Of those who had a GP need 9% report these not being met.
- Of those who had a hospital related need 9% report these not being met.
- Of those who had a pharmacy need 7% report these not being met.
- Of those who had a drugs or alcohol need 9% report these not being met.
- Of those who had a mental health need 17% report these not being met.
- Of those who had a social care need 19% report these not being met.



## SECTION SUMMARY

While we acknowledge that BMI is an imperfect measure of health, the mean BMIs of the men and women on probation who participated in this consultation were 28.9 and 23.1 respectively, suggesting that women on probation were closer to attaining a healthy BMI than men on probation.

Whilst lifestyles varied greatly, it was found that that a small number of people used alcohol daily and almost two thirds were either smokers or vaped.

Around the same proportion of individuals had participated in more than 30 minutes of physical activity on at least five days during the previous week compared to those who did not exercise at all. For some time restraints, cost and confidence were all cited as barriers to increasing exercise.

Most people were attempting to make healthier choices, with many selecting healthy meals and snacks, and almost half of all participants reducing their alcohol intake. Around the same number were trying to maintain a healthy body weight, indicating an appetite for many to strive for a healthy lifestyle.

When exploring a range of healthcare needs, we discovered that people viewed GP needs, hospital and pharmacy needs were mostly met, with drug and alcohol, mental health and social care needs with the most unmet needs.



## KEY FINDINGS

### GP SERVICES

- 9% needed help registering with a GP since being on probation.
- 45% had seen a GP in the previous six months.
- Whilst most needed to call their surgery to see a GP, getting through could be difficult.
- 6% had to use an online form to request an appointment.
- 6% had tried to make an appointment, but were unsuccessful .
- 17% told nobody about a new symptom (in the under 21 years category, this rose to 40%).
- 12% told their GP about a new symptom when they had the time.

- 22% told their GP about a new symptom within a week.
- 4% told their GP about a new symptom within two weeks.
- 4% told their GP about a new symptom within a month.
- 6% told their GP about a new symptom within three months.
- 7% told their GP about a new symptom within six months.
- 51% were unsure how long to wait before consulting a GP about a new symptom.
- 53% felt confident returning to a GP for the same health problem if it persisted.
- 49% felt confident returning to a GP with the same health problem following a test result suggesting that there was nothing to worry about.
- 43% were discouraged to consult with a GP by the difficulty of obtaining or travelling to an appointment.
- 31% were discouraged to consult with a GP out of embarrassment about a symptom.
- Some were hesitant to consult with a GP for fear of not being taken seriously due to a protected factor.
- 21% were concerned that they would not be taken seriously due to being on probation.
- The most common reasons for consulting with a doctor were painful symptoms, encouragement from a friend or family member, or the sense that something was not right.



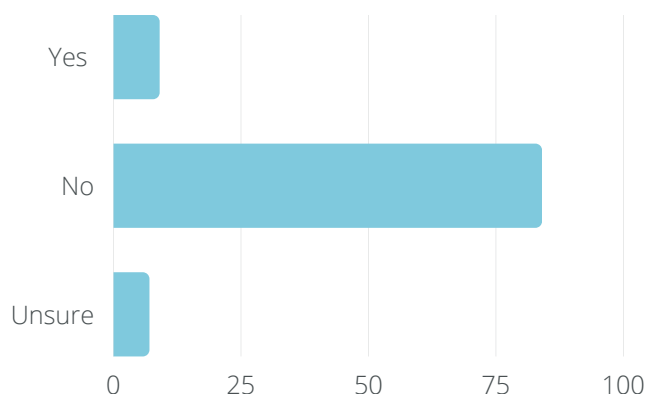
## LEARNING GP SERVICES

We asked participants about their access to healthcare services whilst on probation.

Most required no help registering with a GP (84%). Just under a tenth (9%) needed help with this task and the remaining 7% were unsure.

The responses indicate that a tenth of men needed support to register with a GP, compared to just 3% of women.

Did you need help registering with a GP since being on probation?



When broken down by age, it is evident that, of those requiring help registering with a GP, those aged 50-59 years represented the greatest proportion needing help, followed by those aged 21-29 years. Interestingly, older participants were the most unsure.

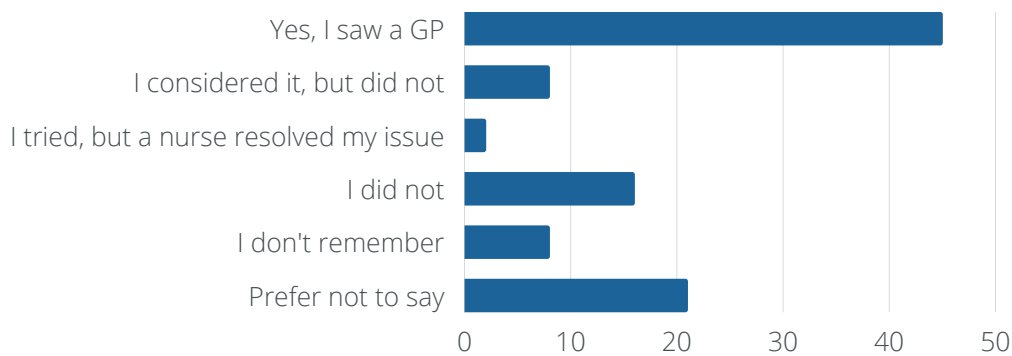
In terms of ethnicity, only participants from the black and white ethnic groups reported needing help registering with a GP. Those from an 'other' ethnicity were the least sure whether they had required help.

Where an individual indicated the need for support to register with a GP, we queried whether such support was offered; over a tenth (12%) had received none. One person explained that, not only did they not know how to register with a GP, they had never consulted with a GP in their adult life.

### **"I'm not sure how to access doctors – not been [to] doctors since a child."**

During the previous six months, 45% of participants had seen a GP while 2% had attempted to but another healthcare professional had resolved their health issue. Some 8% had considered consulting with a GP but had not.

### **In the last 6 months have you tried to see a GP about any concern?**



For those who had seen a GP, most obtained their appointment after telephoning the surgery (38%), although we heard how this could be difficult.

### **"Not realistic appointments, and they never answer [the] phone, [in] my opinion they take money for nothing, they are totally useless."**

### **"It would help if they picked up that actual phone – impossible to get through."**

A tenth of people selected 'other' when reflecting on their experience trying to see a GP, and these individuals mostly received a remote appointment by phone.

### **"I got a telephone consultation."**

### **"I spoke to doc [on] the phone and he got me some medication."**

Despite attempts, 6% were unable to obtain an appointment.

### **"Nightmare to get through even to reception, let alone get an appointment."**

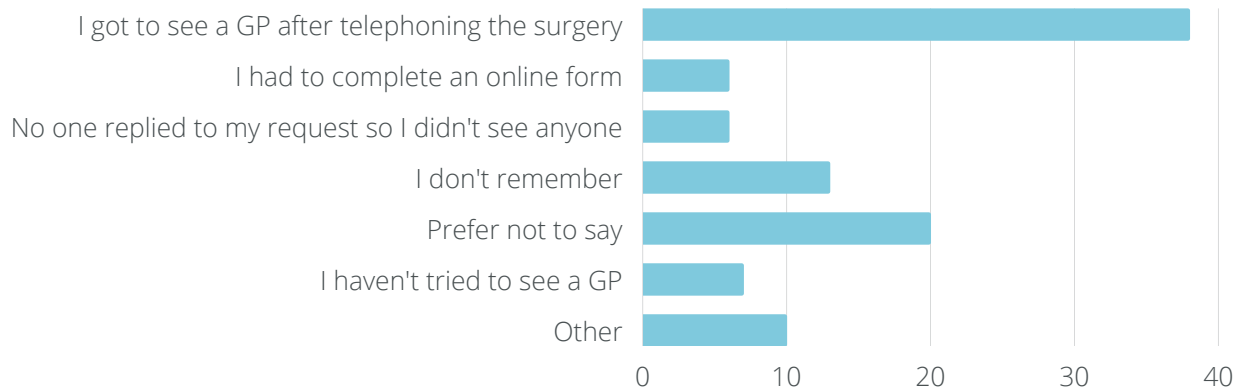
### **"I tried, but couldn't get through so gave in."**

One person had called the surgery and arranged an appointment but failed to attend. Another stated that they had not bothered and instead had attempted to help themselves prior to seeking treatment from a GP.

### **"I phoned but didn't go to my appointment."**

## “I try and wait until I understand why I can’t get rid of the problem before calling them.”

### If you tried to see a GP in the last 6 months for any reason, what happened?

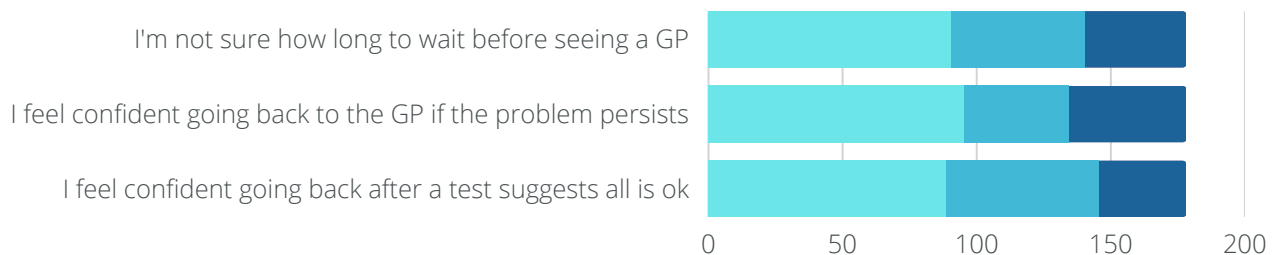


Looking at the length of time individuals waited after noticing a new symptom before consulting with a GP, we found that:

- 17% told nobody about a new symptom (this rose to 40% for those aged under 21 years)
- 12% told a GP when they had the time.
- 22% alerted a GP within a week.
- 4% told a GP within two weeks.
- 1% told a GP within three weeks.
- 4% told a GP within a month.
- 6% told a GP within three months.
- 7% told a GP within six months.

Overall, over half of all participants were unsure how long to wait before contacting a GP following a change to their health.

### How much do you agree with the following statements?



Mostly, it was people from ethnic minorities that were either the most unsure, or did not know how long to wait, before contacting a GP.

- Asian – 85%
- Black – 85%
- Mixed Heritage – 93%
- Other – 60%
- White – 67%

Women appeared less confident and more unsure when considering when to contact a GP about a change to their health, compared to men.

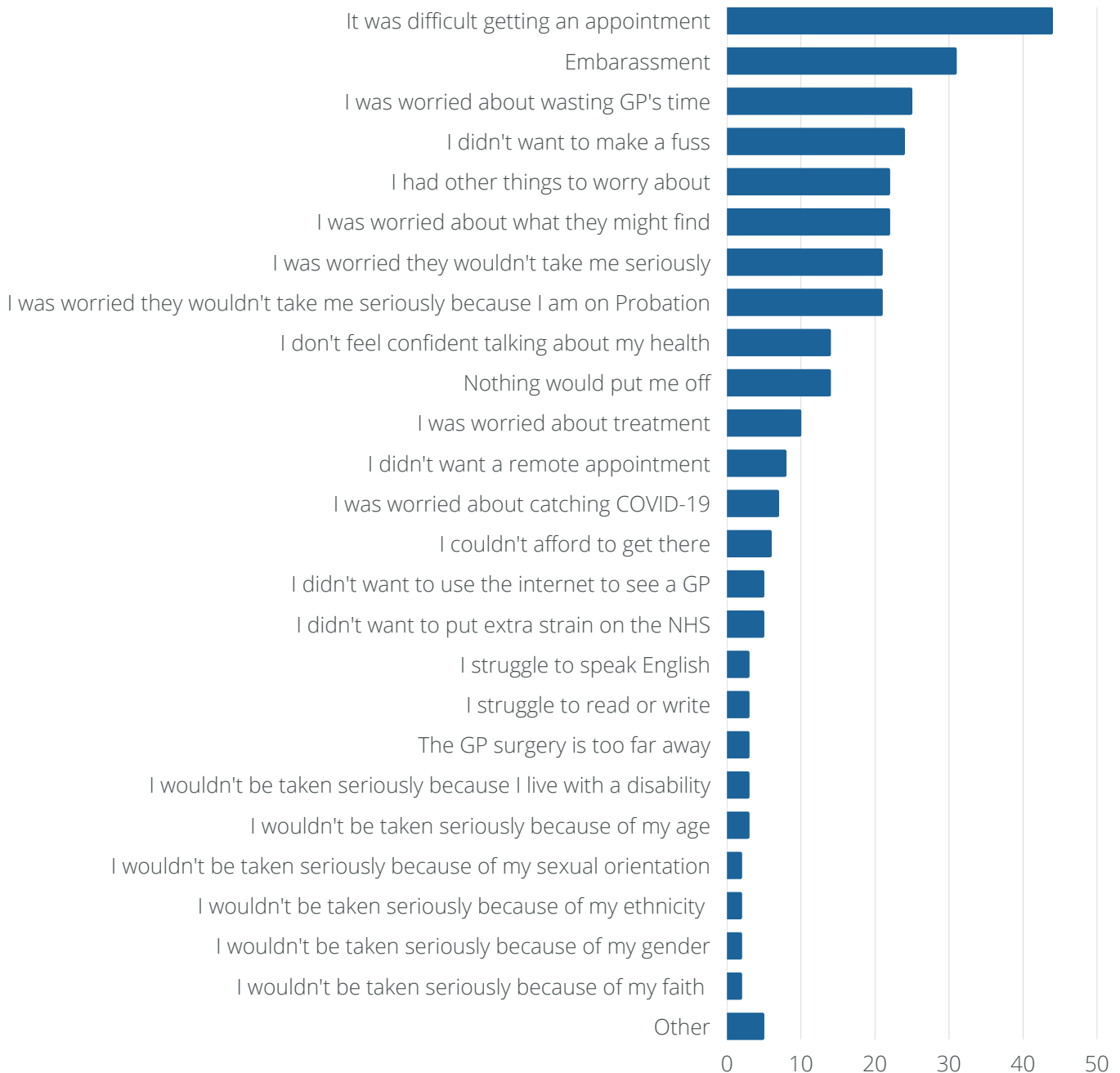
- Women – 86%
- Men – 69%

Around half of participants (53%) felt able to return to a GP with the same health issue if it persisted or worsened.

Similar numbers, feel able to return to the GP with the same health problem, when a blood test result suggests nothing of concern.

Exploring hesitancy, numerous situations can discourage an individual from consulting with a doctor. In this survey, more than one reason could be selected, and the results are shown in the graph below.

### Thinking about the last time you considered seeing a GP, did any of the following put you off or delay you?



At 43%, many respondents were discouraged from consulting with a GP for reasons of access (difficulty obtaining an appointment or getting to an appointment).

This was followed by feeling embarrassed about their symptoms (31%) and concerns that they might be wasting the GP's time (27%).

Importantly, over a fifth (21%) were concerned that they would not be taken seriously because they were on probation.

A small number were put off due to language barriers and literacy levels (3%) and, although in a minority, some were discouraged by the feeling that they would not be taken seriously due to the protected factors of gender, sexual orientation, faith and disability.

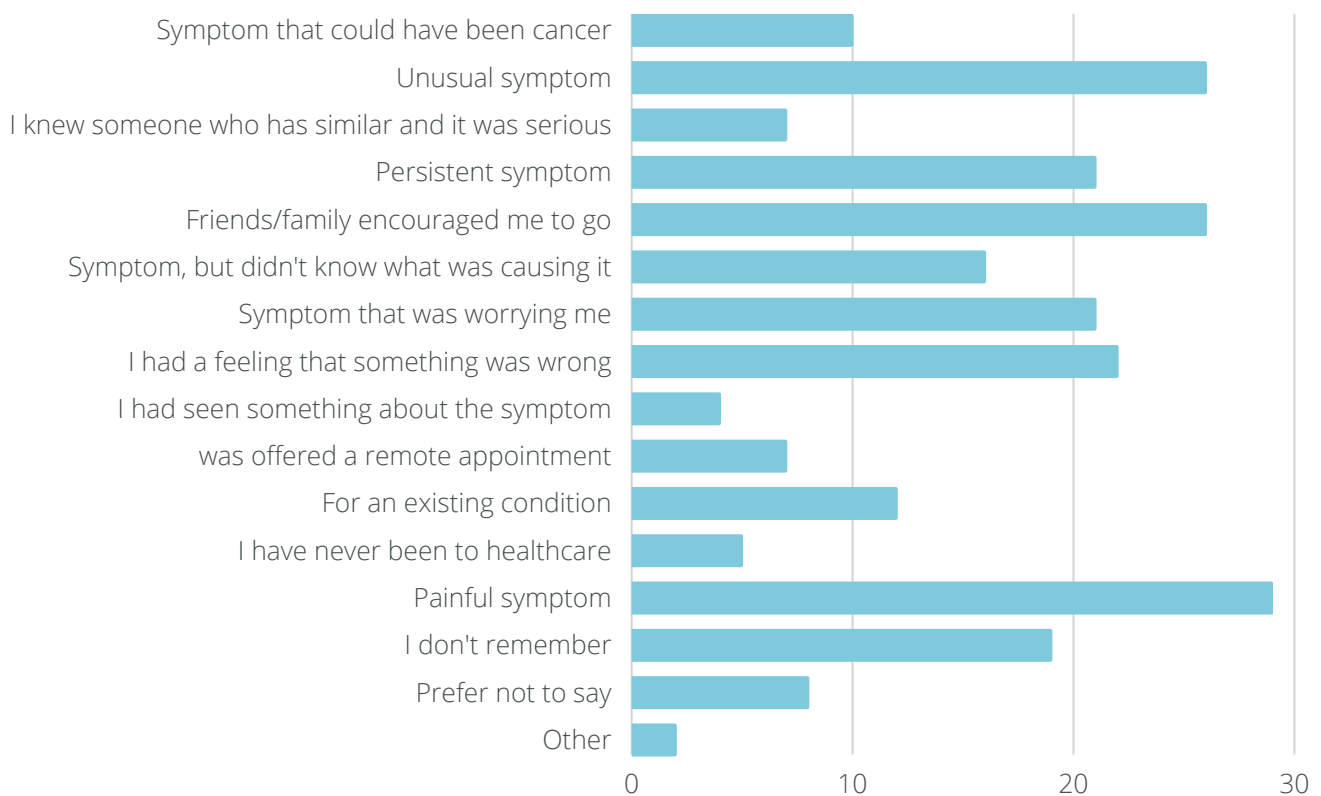
Two percent were not registered with a GP.

Considering participants' last consultation with a healthcare professional, the most common reason for the appointment was a painful symptom (29%).

Over a quarter were encouraged to obtain an appointment by a friend or family member (26%), while a further 26% experienced an unusual symptom.

A fifth (22%) consulted with a healthcare professional for a symptom that did not feel right or in response to a sense that something was wrong.

### Which of the following statements were true when you last thought about seeing a healthcare professional?



## SECTION SUMMARY

Less than 10% of people on probation who we consulted needed help registering with a GP and less than half had needed to see a GP in the previous six months. Very few had experience using an online form to access their GP, and at times this was off putting, alongside being offered a remote appointment.

Most needed to call their local surgery to book an appointment, though this could be



problematic. Many found it difficult to get through to the surgery, with 43% failing to persist or contact their GP.

Despite feeling the need to consult with a GP, 6% had been unsuccessful in obtaining an appointment.

Younger patients were the least likely to tell anyone if they recognised a change in their health, but most participants tended to contact their GP within a week of noticing any such changes.

Importantly, over half of participants were unsure when to contact a GP about their health and nearly a third were reluctant due to feeling embarrassment about a symptom.

Interestingly people were conscious about wasting a GP's time or putting extra strain on the NHS, with only 14% of participants letting nothing stop them from reaching out, if needed.

Notably some people perceived stigma and felt they may not be taken seriously by a GP because of a protected characteristic, and over a fifth felt that being on probation could impact on how they will be received by a GP.

The majority of people accessing a GP did so, mostly, when seeking help to manage a painful or unusual symptom; or after being encouraged to do so by a family member or friend.

Interestingly, another common reason for seeing a GP came from a sense that something was not right, even though the exact health concern could not be pinpointed.



## KEY FINDINGS

### MEDICATION, ACCESS TO SERVICES & MENTAL HEALTH

- 40% of people were able to access their required medication.
- 82% had received support to get medication.
- Access to a GP was seen as integral to obtaining the correct medication.
- Easier access to medication was desired, such as online ordering and increased delivery services.
- Cost was a factor in some obtaining their medication.
- Some did not understand why they were taking certain medication.
- Easier access to medication was desired, such as online ordering.

- Increasing opportunities to receive medication deliveries were seen to be beneficial.
- 23% needed help accessing other community healthcare services (outside of GPs and medication).
- 45% found probation helpful when accessing community healthcare services.
- Some were uncertain what community healthcare service were available to them locally.
- Probation was viewed as a good opportunity to learn more about services.
- Homelessness was seen as an additional barrier in accessing services.
- Out-of-region moves were seen to disrupt continuity of care.
- 33% stated that their mental health had declined since being on probation.
- 10% felt it was sometimes difficult to cope with daily life.
- 21% coped with daily life (all the time).



## LEARNING

### MEDICATION, ACCESS TO SERVICES & MENTAL HEALTH

When asked whether they could access their required medication, of the participants who reported needing medication;

- 40% reported receiving it.
- 51% stated that they had not received it.
- 9% were unsure whether they had received it.
- 84% reported being supported to access medication, (if support was required).

Exploring the responses of those who said they had not received the medication they needed, only 6% of women reported being unable to obtain medication, compared to the remaining 94% being men. Unsurprisingly, the youngest participants (under 21 years old) were least likely to require medication with just 4% reporting this.

People aged 30-39 year olds were most likely to need medication, and were also the highest proportion reporting an inability to obtain the correct medication.

When exploring ethnicity:

- 100% of Asian participants reported a medication need
- 85% of white participants reported a medication need
- 80% of those identifying as an 'other' ethnicity reported a medication need
- 79% of mixed heritage participants reported a medication need
- 71% of black participants reported a medication need

Participants of mixed heritage represented the highest proportion of medication need being met, at 50%.

Participants shared suggestions as to how they could more easily obtain the correct medications. Most responses referenced access issues while others were directly linked to access to pharmacy.

**“A reliable delivery service that delivers consistently on the same day each week/month.”**

**“Order online so it’s easy and then get it delivered. It’s hard to get if you’ve got work and kids etc.”**

Consulting with a GP in order to obtain a prescription in the first instance was linked to more easily obtaining medication, as was the need for earlier assessments and diagnoses – made more challenging for those with complex health needs.

**“I need a medication review as I haven’t had my meds since March. I have PTSD, a personality disorder, paranoia and depression but can’t get to see a GP.”**

**“I don’t know, not on it anymore. I need to be, but waiting for the Dr to see me.”**

**“Quicker turn around especially for those people [with] ADHD.”**

**“I watched my friend get killed and that was so stressful, I’m frightened to be seen on the street so getting to appointments is horrible as I can’t always afford a taxi.”**

We again saw the impact of cost to individuals obtaining required medications, perhaps impeded more substantially by the current cost of living increases seen in everyday spends.

**“Free prescriptions, I work and so it depends on if I have the money.”**

**“Not always have enough in the bank to pick up my prescriptions, so depends. I get no help cos I work.”**

We heard how the reliability of pharmacy services could impact on people’s access to medication.

**“The chemist actually having the prescription on the day they said they would have it.”**

**“You need to sort it out. I can go to the chemist and he doesn’t always have it.”**

Notably, some respondents felt that probation could play a role in helping people obtain their required medication while others believed that improving probation staff’s understanding of medications could strengthen the relationship between those workers and individuals on probation.

**“More awareness from probation understanding the side effects of medication impacting on a person.”**

**“It could be a lot better if probation could give you a chemist [who] will work with you and probation to make sure you get what you need, especially for depression etc.”**

Importantly, some people needed help understanding the medication they were taking or support in being prompted to get repeat medications.

**“I need help to understand what it is, what it does, I can’t pronounce [it] and don’t know what it does.”**

**“Delivery would be good and some reminders for repeat prescriptions, as I can forget them sometimes.”**

A significant number of participants experienced no issues obtaining their required medication and, where they commented, they often spoke of accessible, efficient services.

**“It’s quite easy to get. On meth and get it once a week from CGL.”**

**“Antidepressants. Yes, doctor is good and pharmacy is in walking distance of where I live. about 20 minutes.”**

**“Repeats are very easy and I use a direct delivery service.”**

## ACCESS TO COMMUNITY HEALTHCARE SERVICES

We asked whether people on probation needed help accessing other healthcare services in the community and almost a quarter of participants (23%) did require such help.

Have you needed to access any other healthcare services while on probation?	
Yes	23%
No	64%
Unsure	9%

Nearly a third, 31% of those needing help with other healthcare services were female, with the remaining being male.

Over a quarter, 27% were of a minority ethnicity, while 40-49 year olds represented the greatest proportion of people (banded by age) needing help, at 28%.

Older adults accounted for 16% of responses to this question, while 21-29 year olds made up a fifth of respondents. Nobody under 21 years old required support.

Participants were offered the opportunity to share with us, who had been most helpful to them when trying to access healthcare services whilst on their community sentence.

Interestingly, when probation workers were informed about local services, they were seen as the most helpful in aiding access to community healthcare services, demonstrating how wider services can act as effective enablers for this patient group:

- Just under half of participants found probation helpful when accessing healthcare services.

**“Unpaid work helped massively as they knew where I could go for help.”**

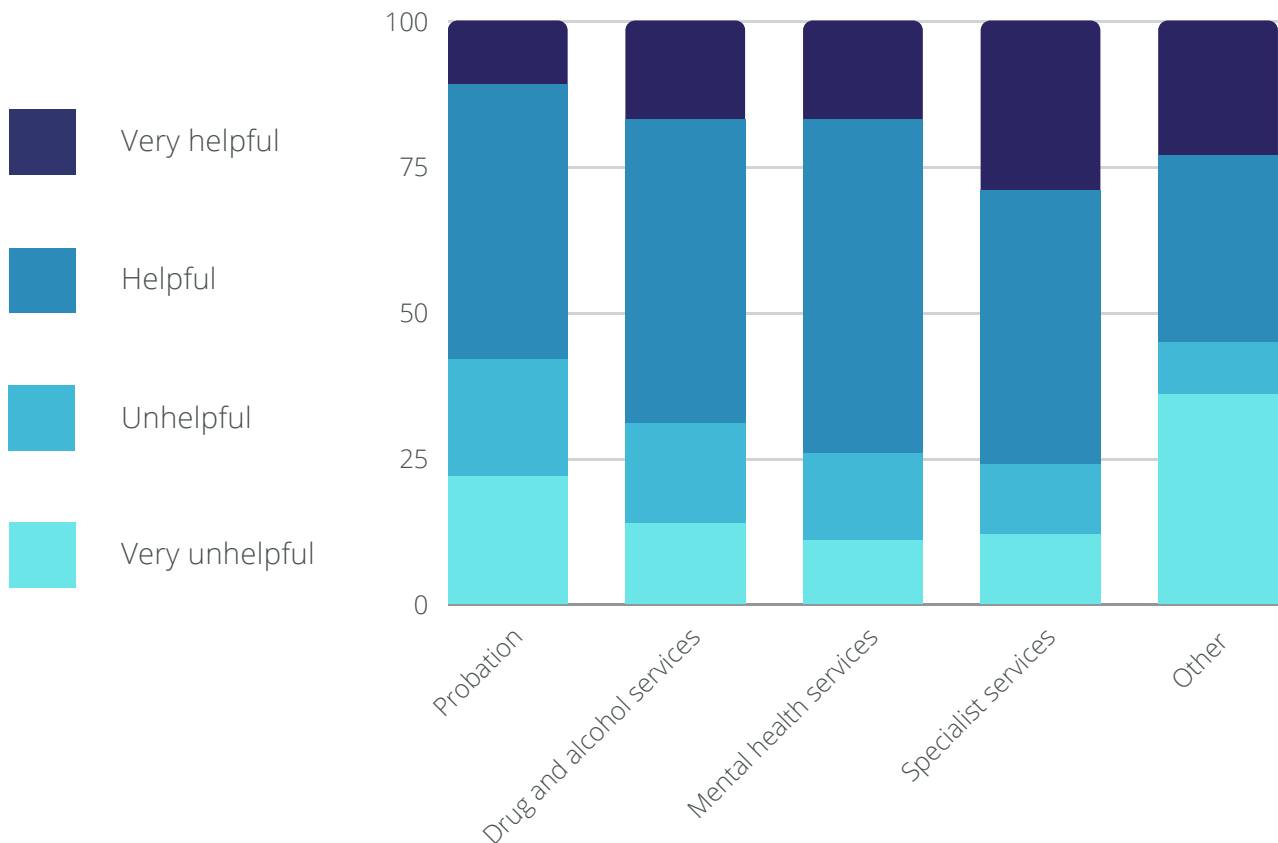
When people on probation were engaged in other community services, these were also seen as helpful to different degrees.

- Over two thirds of those engaged in drug and alcohol services found them helpful when accessing healthcare services.

- Nearly three quarters of those engaged in mental health services found them helpful when accessing healthcare services.
- A similar number (76%) found specialist services and charities helpful accessing healthcare services.

**“My family and Inner City Life really helped me to understand the way things work.”**

**In terms of getting health services, how helpful were the following groups?**



It was also evident that other factors were positive contributors to the health of individuals on probation; support from family members, faith groups and self-determination all helped.

**“My family are amazing, they helped me get help.”**

**“My church group rallied around me when I needed support.”**

Nevertheless, some situations arose in which relationships impacted on a person’s health detrimentally.

**“I started using Spice in 2016, and [it] was the only drug that I ever used. I met a boy who smoked it and was very controlling and [I] used spice because he did it and was very controlling. Spice is a very big thing in Margate. But I found I helped myself more than any agency.”**

**“When all your friends do it [use drugs] and even when you think you're gonna have a sensible night, have a bit of dinner and a few drinks; and the missus say, 'shall we call it in?' and suddenly you're out, out, and it's 3 o'clock in the morning and your buzzing, know what I mean?”**

When asked how an understanding of, and access to, community healthcare services could be improved

, participants provided a range of responses which can be broken down into the following themes;

- **44% mentioned improved awareness and understanding of community healthcare services**

Many participants spoke of the need for improved communication about healthcare services, reporting a difficulty or lack of understanding of the healthcare services that are available to them in their local community.

**“More information needs to be provided as I feel probation don’t care or want to help. Information isn’t easy to get hold of, so make it easier and give us a more friendly approach to the help they [community healthcare services] can provide.”**

Responses indicated that many people on probation spoke about struggling to find out about needed services.

**“More awareness of what’s available. Being given more knowledge of what is there to help me. I haven’t got a clue and need help with my mental health.”**

Participants suggested a range of ways in which individuals can be better informed about local healthcare services. Alongside more traditional methods of leaflets and posters in probation offices, people were keen to see the application of digital, audio or visual methods of health messaging. This was particularly important for those with limited literacy skills, which was seen as a potential barrier in terms of feeling informed about healthcare services.

**“A lot of people on probation can't read or write so if [there] was a vocal message on a service that would help.”**

**“We could be given online resources to look up, like when the doctor shares a link about a health issue, that’s really useful.”**

**“They could do some videos couldn’t they, put things up on YouTube.”**

- **16% highlighted improved probation input**

Linked, and frequently overlapping with improving awareness, it was apparent that people on a community sentence saw probation workers as a means to being more informed. Several suggestions were made that health should be discussed in meetings with probation, especially as health and wellbeing was seen to impact on sentence compliance.

**“More time in a meeting should be given to explain the help available as health can make a difference to reporting – and officers should know this about you.”**

**“To understand people have anxiety and for probation to understand it's a struggle to go out doors at times and see probation.”**

Some people felt that, if probation officers were fully informed about local healthcare services, this would result in more people being able to access the services they needed.

**“I don’t think they [probation] know because when I asked about counselling, they said to google it, but I haven’t always got data, so that’s hard work. But if they knew, they could help.”**

Others felt that probation could act as a healthcare hub for community services, where people could learn about services or, indeed, access them.

**“Having some information hub of what support is available with visiting services.”**



Some suggested offering information courses in probation offices to help those who might need it.

**“In depth courses on what you can get in the local community.”**

It was clear from some responses that probation workers were seen as trusted professionals and so the ability to access health information from the service would be helpful.

**“I think just to feel easier to approach when it comes to getting help around things out of the criminal justice system as my probation officer is nice, but hasn’t done much with me about this.”**

- **13% wanted easier access to healthcare services**

Several people spoke of the challenges accessing healthcare services in the community, ranging from difficulties seeing a GP to frustration caused by limited services such as mental health and substance misuse.

**“I needed more help getting support for drugs and alcohol. It’s hard to get in. I waited ages but thankful to have it now and it’s helping me.”**

**“Hard to say as it's difficult getting an appointment or even getting through to them.”**

Being homeless was deemed an additional barrier to accessing healthcare services.

**“Being able to get help when you’re homeless is much harder, you don’t always know where you’re going to be and so physically getting somewhere can be difficult. There are some outreach services, but you need to be in the right place at the right time.”**

Again, probation was perceived as a good setting from which individuals could access healthcare services.

**“Possibly have a representative from the NHS to come to probation and meet you, do like a health check.”**

This was particularly important for those who had to attend offices, and the cost of travelling to healthcare services determined attendance.

**“I don’t always have the funds to get the bus to places so to have it [healthcare] at probation would be good.”**

Additionally, we heard how moving out of an area can disrupt care and treatment, and leave people feeling unsure about the next steps they can take to stay healthy.

One person described his experience in an interview.



**I didn’t have much support living in the first area where I was on probation. I had to move to another area for a fresh start after being told by my friend I couldn’t stay with him anymore, so I was homeless. I was on the waiting list for a mental health assessment in the first area but when I asked about this I was told the case was closed because I moved and probation didn’t know anything about it.**

**I don’t know how to get support or what support is even in this area. Probation have been in contact with me once since I moved out of area and that was 10 weeks ago even though I am a MAPPA. It would be good to have one person to help me as this might help me get my mental health sorted.”**



- **8% mentioned access to specialist support**

Nearly a tenth of patients disclosed needing specialist health services but not being able to access them. This included services for issues in relation to mental health, substance misuse, neurodiversity, disability and trauma.

**“I really, really needed help with PIP, being diagnosed with ADHD.”**

**“I need help with my mental health and anger issues.”**

**“I need help as I’m not able to see a doctor to explain what the problems are in my life and how to be diagnosed in order to get a life and move on in life. I don’t understand how I became so low as to become a criminal.”**

**“A single point of contact would help to co-ordinate all healthcare services and to act as an advocate in my best interest.”**

- **5% wanted improved partnership working between probation and community healthcare services**

Participants were keen for probation to work more closely with local healthcare services, to help them stay informed about services and to support access. Notably, some recognised the importance of accommodation and how this can impact on improved health.

**“Probation could work more closely with [the] council to help [with] accommodation for the homeless as it’s hard to get anywhere when you’re on the streets.”**

**“If I had somewhere to live [I] would [have] better mental health and physical health – so housing initiatives would be good.”**

## WELLBEING AND MENTAL HEALTH

Looking at the impact of probation on individuals who completed the survey:

- 33% said their mental health had declined
- 49% stated their mental health had remained the same
- 18% reported improved mental health

In terms of gender, men on probation see the most significant improvement to their mental health, at 21%, compared to just 8% of women on probation.

Our youngest participants (under 21 years old) see the greatest improvement to mental health, with 33% reporting feeling better whilst on probation. Our oldest adults saw the next largest positive shift, at 21%, although they also reported the least change, meaning that they correspondingly reported the greatest decline, at 57%.

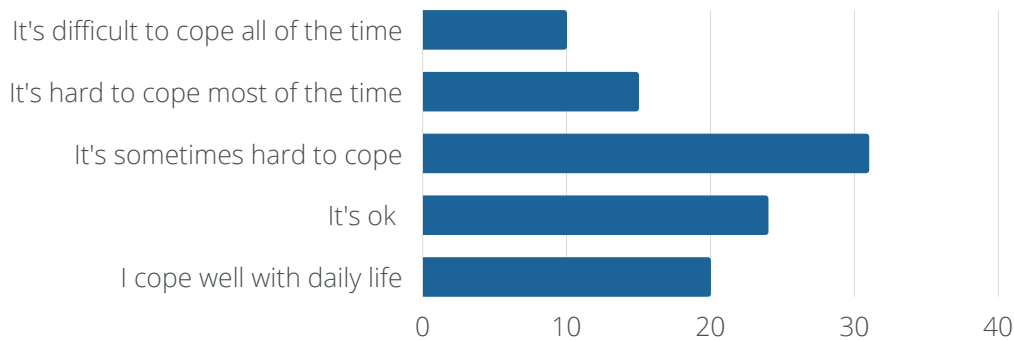
Those from an ‘other’ ethnicity reported the highest proportion of improved mental health (40%), compared to Asian and people of a mixed heritage, who saw the least improvement (14% and 14% respectively).

Moreover, all ethnic minorities reported declining mental health in higher proportions than their white counterparts. Overall, white participants saw the least change to how they were feeling, at 55%.

The survey explored how well people coped with daily life and a range of responses were collected. Just under half of respondents (44%) felt that they could manage with daily life, while;

- 10% found it difficult to cope every day.
- 15% found it hard to cope most of the time.
- 31% sometimes found it hard to cope.

### How well are you coping with daily life?



When asked what would help them cope, the following dominant themes arose:

- **Access to healthcare and specialist services**

Numerous responses were received from people with co-morbidities or complex needs, where access to specialist help was currently problematic. Mostly, it was felt that increased mental health services and talking therapies would help individuals manage their daily lives.

**“To get more MH support and support with drugs and alcohol. Struggling with drug issues. It’s hard to find people who don’t do drugs. 3 months clean now from drugs but finding it hard [because of] the people I’m hanging around with. That there were not such long waiting lists as I am waiting to see a counsellor.”**

**“More therapy, and not long waiting lists. People need more support with life events and trauma as well as normal health stuff.”**

**“More spaces in rehab and funded places for rehab and detox. National health, you wait too long and stress makes you drink more.”**

**“Lack of support in general, the doctor said anger management and psychologists would call, but no. No ADHD test either, I’ve been waiting since August and has not mentioned it since.”**

Holistic health and wellbeing assessments, signposted in the relevant services, were suggested.

**“Holistic needs assessments for those with mental health to help provide more care.”**

**“More support! The right referrals to the right agencies.”**

- **Increasing social capital**

Several comments suggested loneliness amongst people on probation. A notable number of people suggested that simply having someone to talk to would better able them to cope with daily life.

**“Just talking to someone who kind of has an understanding or experience.”**

On occasion, this view overlapped with people wanting to become involved in community projects.

**“Having a “go to” centre or place for support or just a friendly chat.”**

**“More community projects and events to help out with and go to. More things to do.”**

**“Have some support hub where you can get advice and speak to someone as a friend or more openly.”**

Others suggested that more proactive support networks, such as buddying or mentoring schemes, would be beneficial.

**“Need a support worker that can hold your hand through worse times and give advice.”**

**“Have a Mentor of some sort.”**

**“Have a buddy support person.”**

- **Financial wellbeing and accommodation**

Some participants wished to more easily access employment or be supported into education or training to help them become more work-ready.

**“Guaranteed work, and help with applying and the shame and embarrassment of telling employers about your record.”**

**“Money, is a big worry. Something to eat and no gas at home either all makes you feel bad.”**

**“I’d like to retrain to help with employment.”**

Being placed in suitable and safe accommodation impacted on how people managed with daily life.

**“Being homeless means you really can’t do anything else, so having a home would be a good start.”**

**“People need help with housing, without that – everything is stressful.”**

**“Having a key worker/helper. When I was discharged from the hostel for the homeless and supported living and returned to independent living, all of my care stopped.”**

- **Probation**

It was apparent some participants wanted to improve their relationship with probation and felt that probation workers did not always understand them or the challenges they faced.

**“Certain days if I had probation appointment, no leeway was given, physical health was allowed but not mental health.”**

**“More time to talk with my officer, a better relationship with probation, less stress and anxiety, less loneliness.”**

**“Better understanding [of] issues and less pressure from the probation service.”**

Some spoke of a positive experience with probation and how this helped them cope with daily life.

**“My probation officer has been excellent, not judging.”**

**“My officer is good, has helped me loads with my mental health.”**

A few people felt that their community sentence had not accounted for their healthcare needs and this made coping with life more difficult.

**"The unpaid work supervisor was not helpful. Unpaid work is not set up for people with my sentence but also health issues."**

**"I have MS and found the heavy outside work very hard at times but there were no alternatives at all."**

**"They [Probation] don't understand about my depression and how it can stop me doing things."**

## SECTION SUMMARY

Less than half of those on probation who we consulted reported that they could access their required medication, despite almost all respondents saying that they had accessed support to acquire these.

It was recognised that initial access to a GP could be fundamental to ensuring people could obtain their medications, but there were also different levels of medication needs noted across ethnicities which was notable when exploring responses.

In addition, we heard how, for those who paid for their prescriptions, affordability was a factor in whether someone got their medications or not. Other barriers included homelessness as was moving out of a particular community which seemed to disrupt continuity of care.

Nearly half of participants found probation helpful when accessing community health services, and saw it as a potential enabler in helping people connect to service, though we heard that not all probation workers understood people's health and this could impact on complying with a community order.

To varying degrees all services were seen to be helpful to people when trying to connect to wider community healthcare services, suggesting that if a person is engaged in one service, this can be used as conduit for others.

There was evident appetite for people on probation to gain further insight into services within the local community to help them stay healthy.

A third of people within the consultation highlighted a decline in their mental health since being on probation, with disparities noticed for older adults, women and some ethnicities either reporting a greater decline to mental health or the least improved since being on probation.

Strikingly, only a fifth of participants stated that they coped well with daily life.



# KEY FINDINGS

## UNDERSTANDING AND LEARNING ABOUT HEALTH

- Poor diet, smoking and high blood pressure were considered the most significant risks to heart health.
- Chest pain, heart palpitations and breathing difficulties were the most frequently understood symptoms of poor heart health.
- GP surgeries, TV and conversations with friends, family or neighbours were the most common circumstances in which people had heard or seen information concerning heart health.
- Smoking, air pollution and genetics were seen as the greatest risks to lung health.
- Breathing difficulties, coughing and chest pains were the most frequently understood symptoms of poor lung health.
- GP surgeries, cigarette packets and TV were the most common circumstances in which individuals had heard or seen information concerning lung health.
- Harmful drinking, drug use and a poor diet were considered the greatest risks to liver health.
- Jaundice, abdominal or back pain and yellowing of the eyes were the most commonly understood symptoms of poor liver health.
- GP surgeries, conversations with friends/family and attendance at specialist health services were the most common circumstances in which participants had heard or seen information about heart health.
- Stress, alcohol/drug use and past experiences were considered to pose the most significant risks to mental health.
- Over half of participants reported a mental health need.
- TV, GP surgeries, the internet and social media were the most common circumstances in which people had heard or seen information about mental health.
- Of all the health conditions, more people wanted to gain additional knowledge about mental health than any other condition, with the exception of younger people who preferred to learn about physical health conditions.
- Social media, leaflets, TV and radio were viewed as the most effective way of sharing health messages.





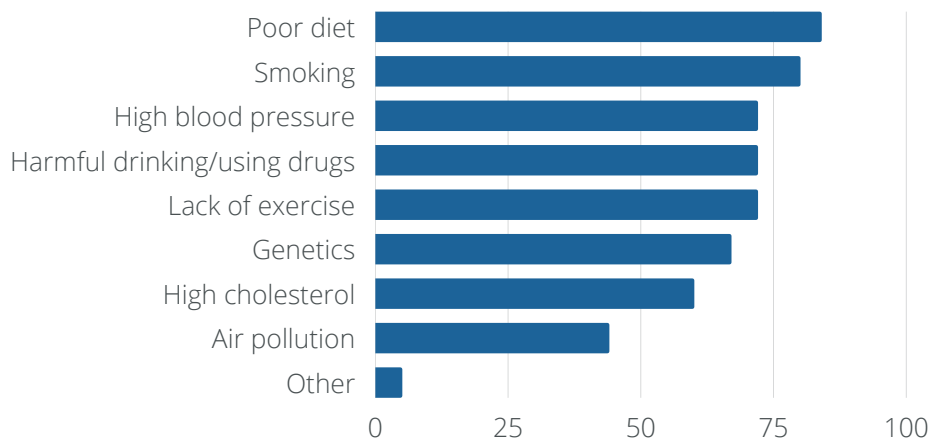
# LEARNING

## UNDERSTANDING & LEARNING ABOUT HEALTH

### Heart health

When asked about the causes of developing poor heart health, the respondents cited the contributors shown in the table below; participants could check more than one box. Poor diet, smoking and high blood pressure were seen to pose the greatest risks to heart health. In the free text section, relationships, family, stress and the COVID-19 vaccine were seen as contributors to poor heart health.

#### What do think can cause people to develop poor heart health?



Respondents were asked to list all the warning signs and symptoms of poor heart health they could think of; the responses are listed below:

- 31% related to chest pain.
- 29% stated heart palpitations.
- 23% noted breathing difficulties.
- 7% reported a change in blood pressure.
- 7% stated fatigue or lethargy.
- 4% noted a change in behaviour.
- 4% highlighted being overweight or obese.
- 3% stated coughing.
- 2% reported pins and needles or tingling.
- 2% reported general poor health.
- 1% suggested confusion.

10% reported having needed treatment for heart health. When asked what helped them feel better, most people responded that medical treatment had been beneficial.

**“My heart was beating irregularly and the top of my heart was not syncing with the bottom of my heart. I think the drips and the medication helped me and the care of the hospital nurses and doctors.”**

**“Had Kawasaki disease but was treated.”**

#### Have you ever needed treatment, care or support for heart health?

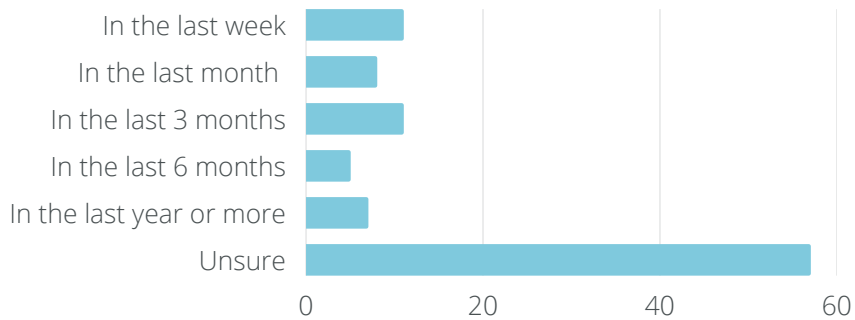
Yes	10%
No	84%
Unsure	6%

However, not everyone followed up with their treatment provider.

**“I had chest pains recently but they think it’s a blood clot, but don’t want to get it checked out as feel fine at the moment.”**

Most people were unsure when they had last seen or heard any information relating to heart health. Those who were able to recall when this had last occurred offered a range of responses. The highest proportion of people believed they had seen or heard information about heart health during the previous three months, followed by the last week.

**When was the last time you saw or heard something about heart health?**



When asked where individuals had last heard or seen information concerning heart health, those who responded cited the following:

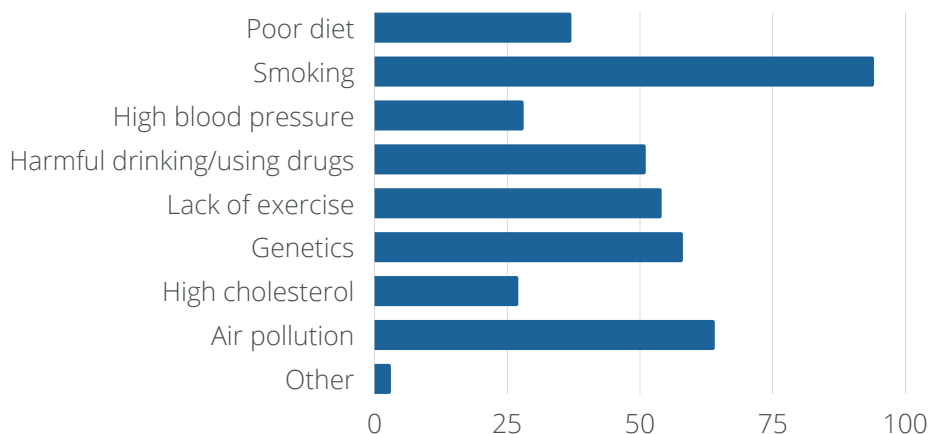
**Lung health**

Almost everyone on probation (94%) could correctly identify smoking as a contributor to poor lung health. The next most common answers provided were air pollution at 64% and genetics at 58%.

- 24% while seeing the GP or at the GP surgery.
- 21% on TV.
- 16% from family, friends or a neighbour.
- 11% at their place of employment.
- 5% in a shopping centre, newspaper or specialist charity.
- 2% at an education setting.
- 5% had never seen or heard anything relating to heart health.

In the free text box, dusty or poor working conditions and anxiety were considered to impact on lung health.

**What do you think can cause people to develop poor lung health?**



Respondents could list as many warning signs and symptoms of poor lung health as they could think of and their responses are set out below:

- 88% related to breathing difficulties or wheezing.
- 38% related to coughing.
- 18% reported chest pains.
- 14% spoke of an existing diagnosis (asthma, COPD, TB and cancer).
- Around a tenth stated coughing up blood.
- 4% said struggling to walk a long distance.
- 3% noted a change of appearance to a person’s skin.

Several individuals mentioned being prescribed an antibiotic or receiving hospital treatment.

**“Being on a drip (steroids, antibiotics and others) when I was in hospital.”**

A small number of people described how lifestyle changes had helped them stay healthy and improve their lung health.

**“I’ve stopped smoking cannabis and feel better.”**

**“I’ve upped my exercise more now and things are good.”**

Have you ever needed treatment, care or support for lung health?	
Yes	13%
No	84%
Unsure	5%

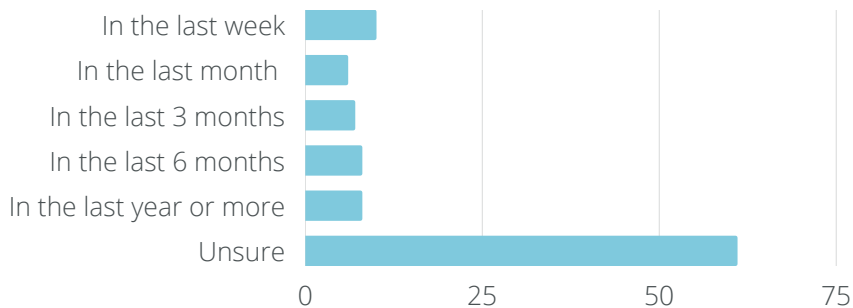
Some 13% of participants reported that they had undergone treatment for lung health – slightly greater than the number requiring treatment for heart health.

Again, most stated that medical intervention had improved their lung health; most commonly, the use of an inhaler to help them breathe.

**“I’m asthmatic so Ventolin and Fostair inhalers work with my breathing.”**

Again, the majority of participants were unsure of the last time they had heard or seen any information relating to lung health, though there was a range of responses from those who could recall.

**When was the last time you saw or heard something about lung health?**



There was little difference in numbers between those who had seen or heard information during the previous week (9%) or in the last year or more (8%). Exploring where health messaging was seen or heard, people told us:

- 35% when attending their GP.
- 14% on cigarette packets.
- 14% on TV.
- 14% in a hospital.

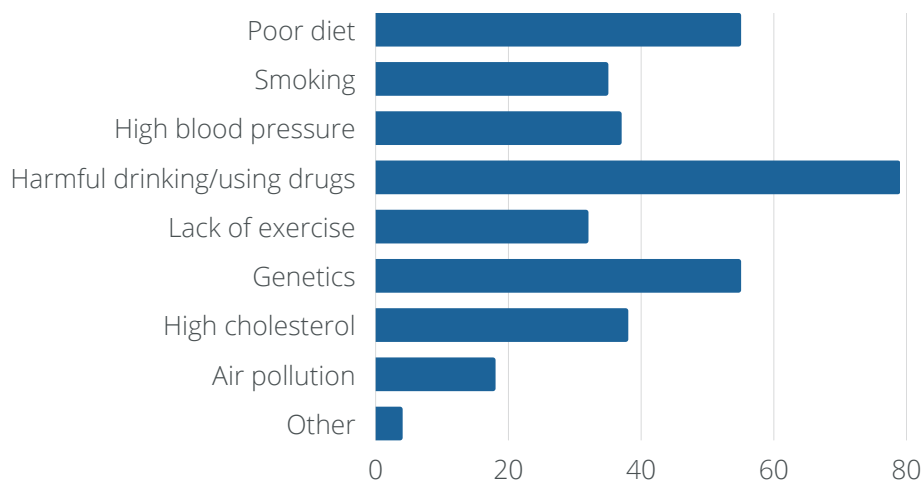
- 8% from family, friends or neighbours.
- 5% in a newspaper.
- 3% in an education setting.
- 3% in their place of employment.
- 3% during a previous prison sentence.

## Liver health

Looking at views on what can cause people to develop poor liver health, the most common reason identified was harmful drinking or drug use, highlighted by 79% of participants, followed by consuming a poor diet or unhealthy food (55%) and then genetics (55%).

In the free text box, participants cited that injuries sustained to the body, the COVID-19 vaccine and contracting a blood-borne virus were additional potential contributors to poor liver health.

### What do you think can cause people to develop poor liver health?



When asked about the warning signs and symptoms associated with poor liver health, participants listed the following:

- 36% mentioned yellowing of the skin or jaundice.
- 32% spoke of abdominal or back pain.
- 10% mentioned yellowing of the eyes.
- 6% said changes to urination.
- 5% said a change to heart rate.
- 5% mentioned fatigue or tiredness.
- 3% reported a loss of appetite.
- 3% linked high blood pressure.
- 2% stated a swollen abdomen.
- 2% said itchy skin, and the same number reported nausea.

### Have you ever needed treatment, care or support for liver health?

Yes	7%
No	87%
Unsure	4%

Less than a tenth (7%) of respondents had required treatment for liver health – less than the number needing treatment for heart or lung health.

Most were relieved of their symptoms by medical treatment, including treatment for Hepatitis C.

**“I had Hep C meds.”**

### "Getting treatment for Hep C means it's all good now."

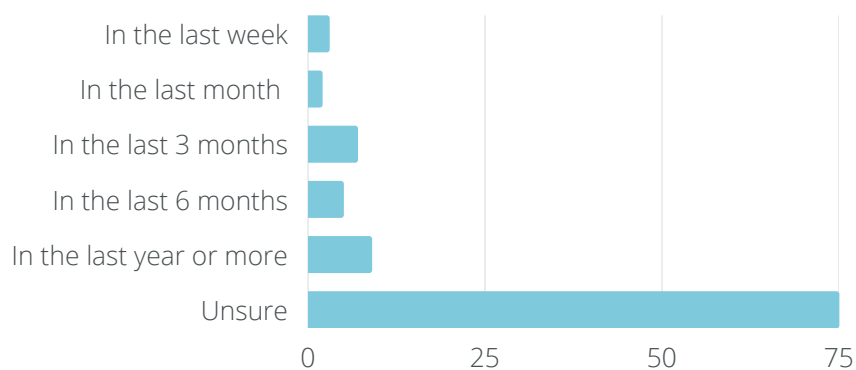
Others received support from substance misuse services and made lifestyle changes.

**"I abuse alcohol so liver not great, but I've reduced it now, as getting help and nowhere near as bad as I was."**

**"I had cirrhosis due to alcohol abuse in younger years but it's cleared up now, healthier lifestyle."**

Mostly people were unsure when they had seen or heard something about liver health, with three quarters of respondents choosing this option. Outside of this the most common answer was within the last year or more at 9%.

### When was the last time you saw or heard something about liver health?



During the previous year, fewer people had seen or heard information about liver health (26%), compared to heart health (42%) or lung health (39%), albeit a greater number were unsure when they had last seen or heard any such information.

Far fewer responses were received in relation to liver health messaging than the other health conditions covered in this consultation, but information had been observed in the following locations:

- 28% when seeing a GP or at their GP surgery.
- 19% from family or a friend.
- 11% from a specialist service (Hep C Trust or substance misuse service).
- 11% in a hospital.
- 5% on TV.
- 3% in their place of employment or education.
- 3% online or on the radio.

### Mental health

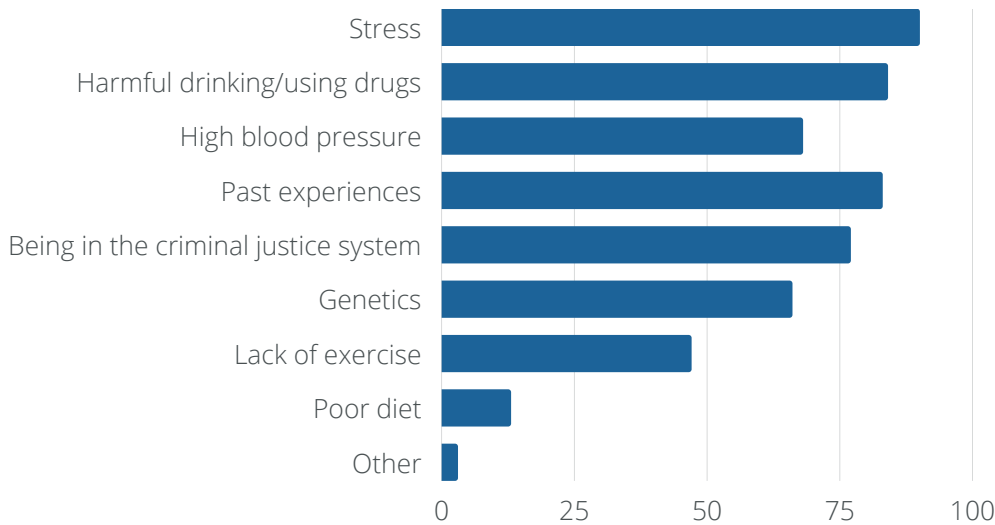
Participants were asked about the causes of poor mental health and full responses are shown below; more than one box could be selected on the survey.

The biggest contributors were stress noted by 90% of respondents, drug and alcohol abuse, 84%, and past experiences 83%. Though another significant contributor highlighted by over three quarters of participants (77%) was 'being in the criminal justice system'.

In the free text box, social isolation, abuse and trauma, bereavement, homelessness, family issues (including managing legal proceedings around children), finances and hunger were all mentioned as contributors to poor mental health.

**"It's very stressful trying to manage it all, trying to pay the bills, keep up with the cost of living, make sure the kids have what they need. It gets you down, never ends."**

## What do you think can cause people to develop poor mental health?



### Have you ever needed treatment, care or support for mental health?

Yes	53%
No	38%
Unsure	9%

Over half of all participants spoke of needing treatment, care or support for mental health.

**"I have always had low moods, but now they think I have bi-polar."**

**"I'm on happy pills for depression. Be lost without them. Feel ok at the moment."**

**"I have a number of mental disorders."**

The following range of interventions had helped people manage their mental health, the most common being prescribed medication. This was not always limited to mental health symptoms; being prescribed medication for pain and neurodiverse conditions was also mentioned as helpful in improving mental health.

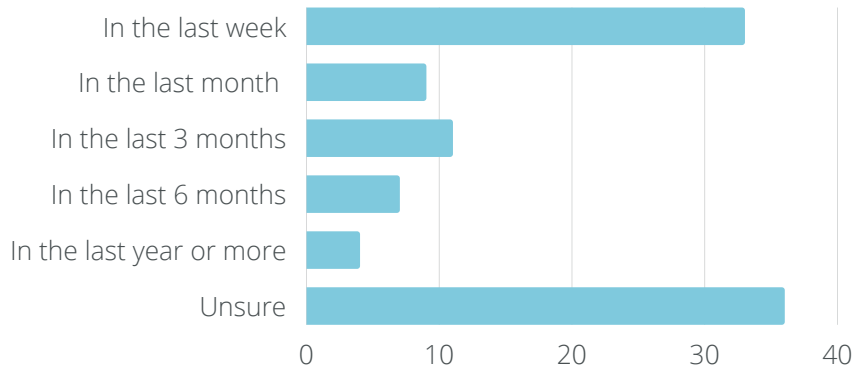
- 22% reported medication (in isolation of any other intervention).
- 12% said taking medication whilst engaging in talking therapies.
- 9% said taking medications in combination with exercise.
- 9% mentioned talking (in general).
- 5% mentioned that talking therapies had helped (although many reported being unable to access this).
- 5% said just knowing that support was available and someone would listen.
- 4% stated that the community mental health team were beneficial (although, again, many seemed unable to access this).
- 4% benefitted from support groups.
- 4% said specialist services.
- 2% reported keeping busy or being around others.
- 2% were supported by Crisis teams or had received care in a mental health in-patient service.
- 2% had benefitted from exercise alone.
- 1% had received effective support from their GP.
- 1% reported accessing effective support from a mental health worker at a police station following arrest.

Alongside the above, 15% stated receiving no support for their mental health.

More people than not had seen or heard something about mental health during the previous year while a third (33%) had encountered information within the previous week and further 9% in the last month.

A greater number had seen or heard something about mental health during the previous year, compared to heart, lung and liver health.

### When was the last time you saw or heard something about mental health?



Where individuals had heard or seen information in relation to mental health are listed below:

- 26% on TV (adverts or programmes).
- 18% when seeing a GP or at their GP surgery.
- 14% on the internet or social media (Instagram and TikTok were specifically mentioned).
- 9% at probation.
- 9% from friends or family.
- 6% on the radio.
- 4% whilst accessing mental health services.
- 4% in hospital.
- 1% at their place of employment, their work setting, in a newspaper or on the underground.

When people on probation were asked which health conditions they would like to learn more about, the responses received were as follows:

- 45% wanted to learn more about heart health.
- 40% wanted to learn more about lung health.
- 39% wanted to learn more about liver health.
- 87% wanted to learn more about mental health.

Similar proportions of men and women were keen to learn about the physical health conditions, with slightly more interest being evident in relation to heart health.

Most men and women were also keen to learn about mental health; indeed, almost every woman was keen to enhance their knowledge.

Interestingly, younger participants wished to learn more about the physical health conditions than mental health while a greater number of older people were more keen to learn about mental health than physical health.

Participants from ethnic minorities were more interested in learning about physical health than their white counterparts, although there was little distinction in interest in learning about mental health.

Participants shared their views on which aspects of health it would be most helpful for them to know. Most wished to be more informed about preventative measures and how to stay healthy or improve health, as noted by over a third (37%).

**“How to deal with situations differently in mental health and how not to damage my liver in future.”**

**“Anything to improve my health, how to keep a healthy mind.”**

This was followed by 23% who wanted to increase their understanding of the signs and symptoms of each of the noted health conditions, and 6% of who wished to learn more about risk factors.

**“How to notice if you or someone else is suffering from any of these issues.”**

**“You need awareness of signs and symptoms so you can look out for things.”**

Fifteen percent were keen to learn more about where relevant local services and treatment, help or support can be sought.

**“More services that are available to me in my town.”**

**“Where I can go locally for this, that’s actually accessible?”**

A tenth of individuals wished for a greater level of general information about the noted health conditions, with 3% interested in treatment options.

**“Anything to improve my health and what the choices are.”**

**“I think anything would help really as I don’t know enough.”**

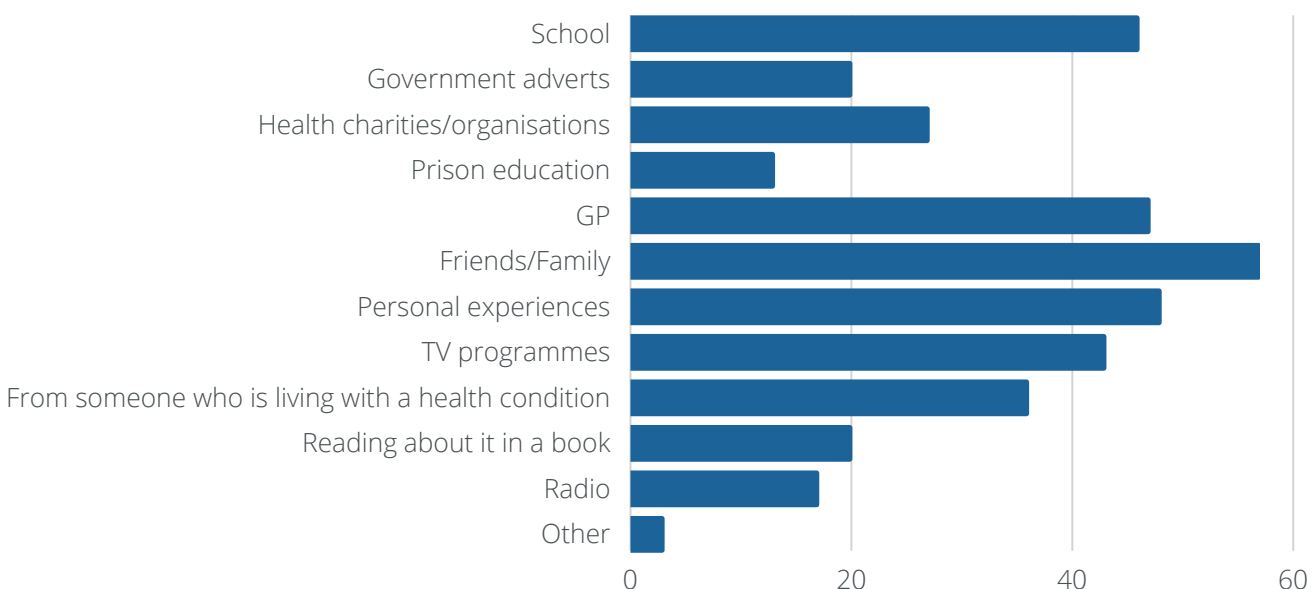
A lower number (2%) wanted additional information concerning how to live with mental ill-health.

**“Ways to improve it please.”**

**“Ways to cure being depressed.”**

### **Where did people on probation learn the most about health?**

It was evident that people learnt the most about their health from talking to family and friends, followed by learning gained through their own experiences and by way of their GP

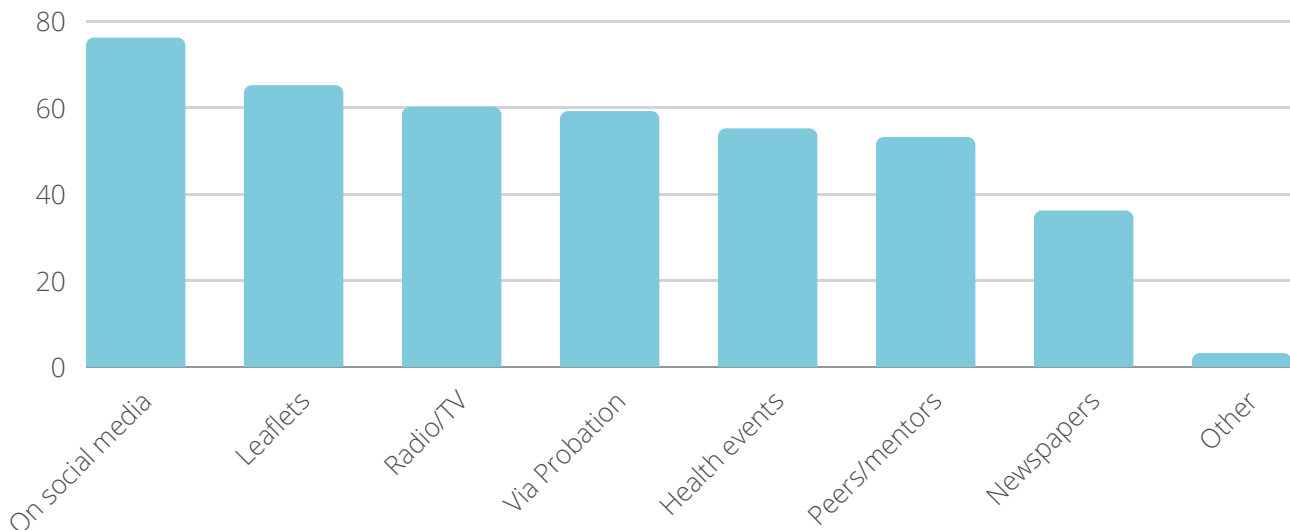




In the free text box provided on the survey we heard people also learnt about health through their own research, on the internet, from leaflets available in healthcare settings, TV adverts, discussions with prison officers, attending prison-based courses and from newspapers.

### How can we best inform people on probation about health?

The range of responses indicate that individuals would like to be informed in a variety of ways, although social media (76%), leaflets (65%), TV and radio (59%) were considered the most effective means of sharing health messages.



**“Everyone is on social media; I mostly watch things on Insta[gram] and YouTube.”**

## SECTION SUMMARY

When asked about heart health, people on probation were able to recognise a range of risk factors and symptoms related to the heart, lungs and liver, as well as to mental health and cancer more generally.

Looking at where people had seen or heard information relating to each health condition, GP surgeries, conversations with others and television were frequently noted. In the case of mental health, the internet and social media were more frequently highlighted.

Over half of people had personal experience of mental ill-health, compared to much lower instances of heart, lung or liver ill-health. A number of interventions – medical, therapeutic and social – were highlighted as being able to make individuals feel better. It was noticeable in some instances how feelings of social isolation and loneliness impacted on wellbeing.

A distinct appetite to learn more about all health conditions was evident, although a clear indication existed that a greater number of older people wished to learn about mental health compared to physical health conditions and more people from ethnic minorities wanted to learn about physical health more than mental health.

Different types of media were viewed as effective means by which health messages could be shared, moving forward.



## KEY FINDINGS

### CANCER SCREENING

- Individuals were able to identify a range of cancer symptoms; unexplained swelling, changes to a mole and coughing up blood were the most easily recognisable.
- Smoking, sunburn, obesity and genetics were viewed as the greatest contributing factors to developing cancer.
- 
- More than two thirds of people did not know how health services screen for bowel cancer.
- 4% had completed a bowel screening kit test when last provided with one (fitting with those who are eligible by age).
- If provided with a bowel screening test, most (62%) said they would complete it.
- Of those who were reluctant (20%), a tenth were aged 60-69 years.
- An absence of bowel cancer symptoms appeared to be the greatest barrier to completing a bowel screening kit test.
- 12% understood the age criteria for prostate screening and 11% knew how health services screen the prostate for cancer.
- 10% had attended a prostate screening appointment, although 9% of eligible men explained that they had never received an invite.
- Half of men who responded stated that they would attend a prostate screening appointment if offered one; of those who would not, a third were of an ethnic minority.
- The most common barriers to attending a prostate screening appointment included experiencing no symptoms and embarrassment.
- Less than 10% felt that nothing would put them off attending.
- 43% of women understood the age criteria for cervical screening and 53% had attended their last cervical screening.
- 53% said that they were likely to attend their next cervical screening, with 17% saying they were not.

- Women were put off mostly by feeling that cervical screening would be painful, although 15% said that nothing would put them off attending their next appointment.
- 83% of women were not aware of when they were eligible for breast screening, though 54% of women said they were likely to attend a breast screening appointment when invited, with 77% of those who were unsure being of an ethnic minority.
- Embarrassment, fear of pain and not having experienced a breast cancer screening were the most common reasons not to attend a screening appointment.
- Less than half of women knew how to check their breasts for lumps.

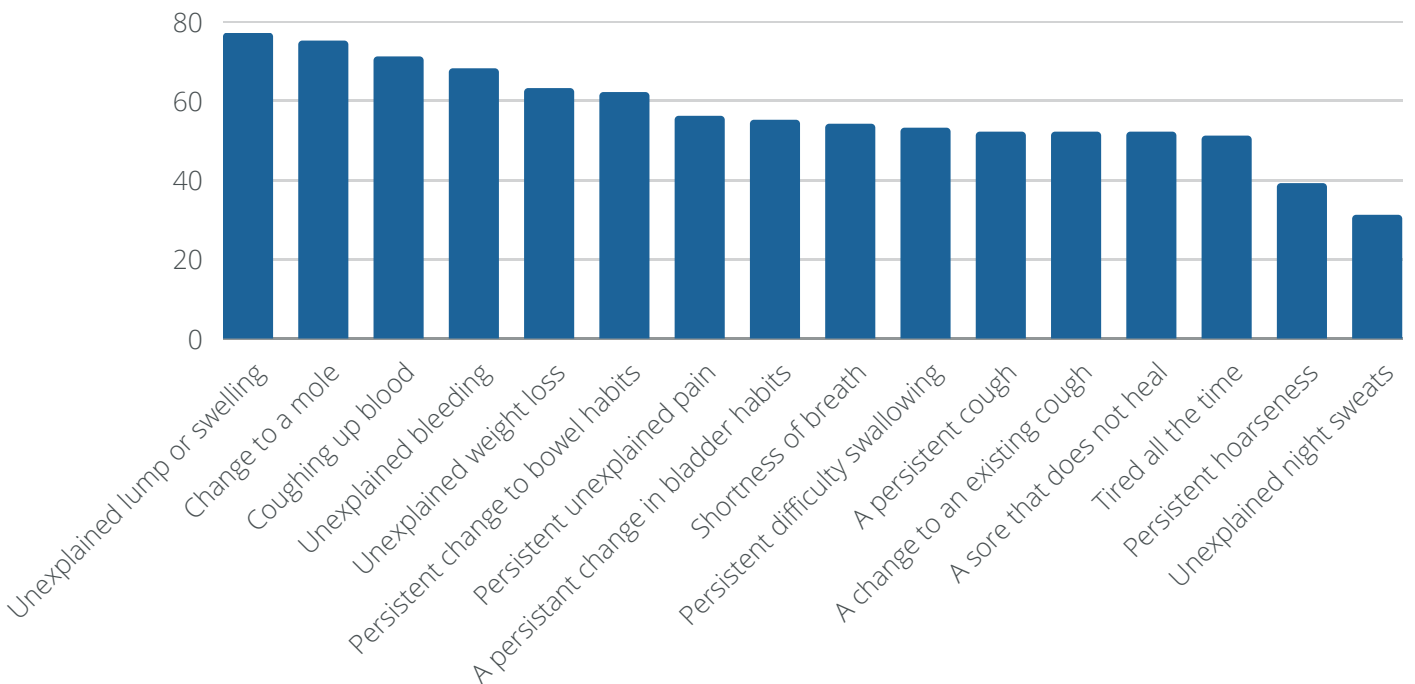


# LEARNING CANCER

## Warning signs and symptoms of cancer

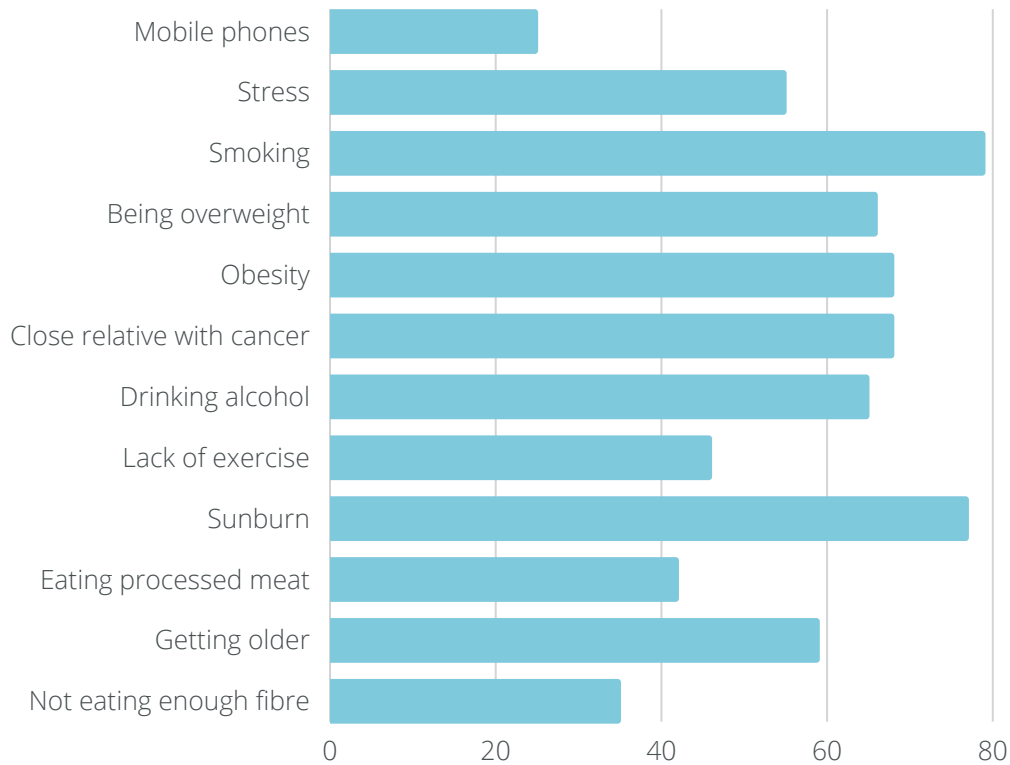
People on probation were able to identify a range of signs and symptoms of cancer; here, they were able to select more than one box. The symptom most highlighted by participants was an unexplained lump or swelling, noted by 77% of participants. A change in the appearance of a mole and coughing up blood were the next most understood warning signs, at 75% and 71% respectively.

Unexplained night sweats, a persistent hoarseness and feeling tired all the time were less likely to be viewed as warning signs of cancer, at 31%, 39% and 51% respectively. In the free text box, stress, anxiety, confusion and a lack of concentration were further symptoms highlighted by respondents.



People were asked to consider what could increase a person's chance of developing cancer, in response to which smoking, sunburn, obesity and genetics proved the most easily identified factors. Notably, 25% felt that using a mobile phone could increase a person's chance of developing cancer.

### Which of the following do you think could increase a person's chance of developing cancer?



### Bowel Screening

A total of 144 people responded to questions about bowel screening.

All participants were asked about their views on bowel screening test kits. Fewer than a tenth knew when they were eligible for bowel screening.

#### Do you know when people are eligible for a bowel screening test kit?

<b>Yes</b>	7%
<b>No</b>	62%
<b>Unsure</b>	31%

#### Do you know how health services screen your bowel?

<b>Yes</b>	7%
<b>No</b>	68%
<b>Unsure</b>	25%

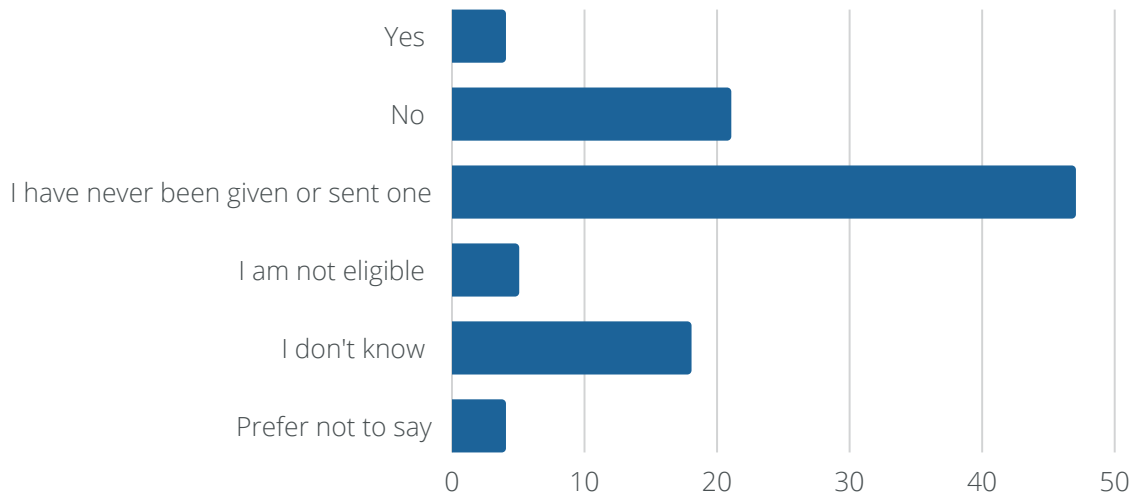
Over two-thirds of those who responded to this question knew how health services screen for bowel cancer.

Only 7% were confident they understood the process while a quarter were unsure.

When asked if they had completed a bowel cancer stool test kit the last time they were given or sent one, only 4% of respondents had.

This correlates with the proportion of participants who would be eligible for bowel screening by age alone.

### Did you complete a test kit last time you were sent or given one?

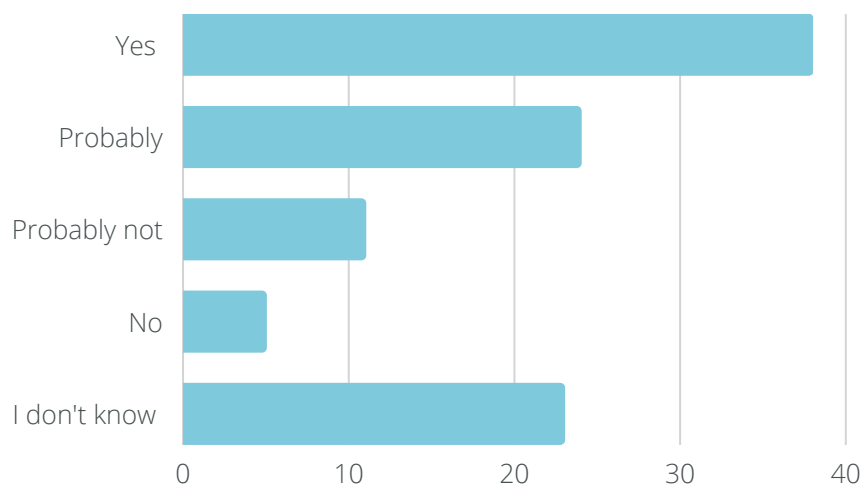


Thinking about the future, over a third of participants, 38%, said they would complete a bowel screening test the next time they are sent or given one, and 24% stated they probably would. A further 11% reported they probably would not complete a screening test while 5% said they would not.

Of those expressing reluctance, 4% were men and the remainder were women. Nearly everyone was white, at 91%, with the remainder being of another ethnicity.

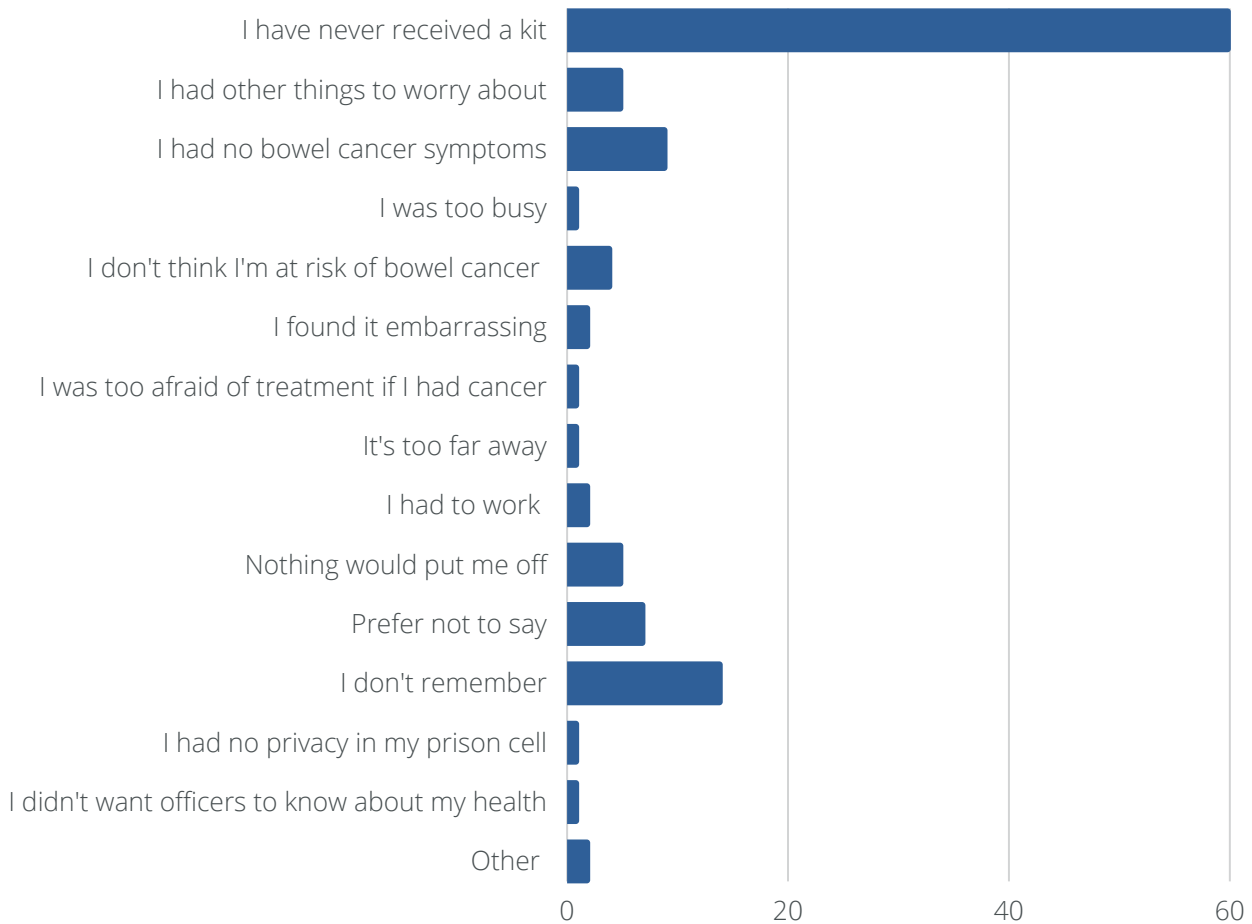
Over a quarter of those expressing hesitancy or who would decline a screening kit were under 30 years old (27%), a fifth were aged 30-39 years and a tenth were 50-59 and 60-69 years old.

### Will you complete a kit next time you are sent or given one?



When asked what had previously discouraged them from completing a bowel screening test kit, most were reluctant as they had no symptoms. Others felt that more important things could get in the way of completing a screening kit or that they had other things to worry about.

## Thinking about the last time you received a bowel cancer stool test kit, did any of the following put you off completing it?



## Prostate cancer screening

Those identifying as men were asked to complete the following questions relating to prostate screening and 101 men took part.

We initially asked if they knew when men were eligible for prostate screening. Only 12% responded that they knew the answer to this.

### Do you know when people are eligible for prostate screening?

<b>Yes</b>	12%
<b>No</b>	81%
<b>Unsure</b>	7%

### Do you know how health services screen your prostate?

<b>Yes</b>	11%
<b>No</b>	62%
<b>Unsure</b>	27%

A similar proportion (11%) of respondents were confident they knew how health services complete prostate screening.

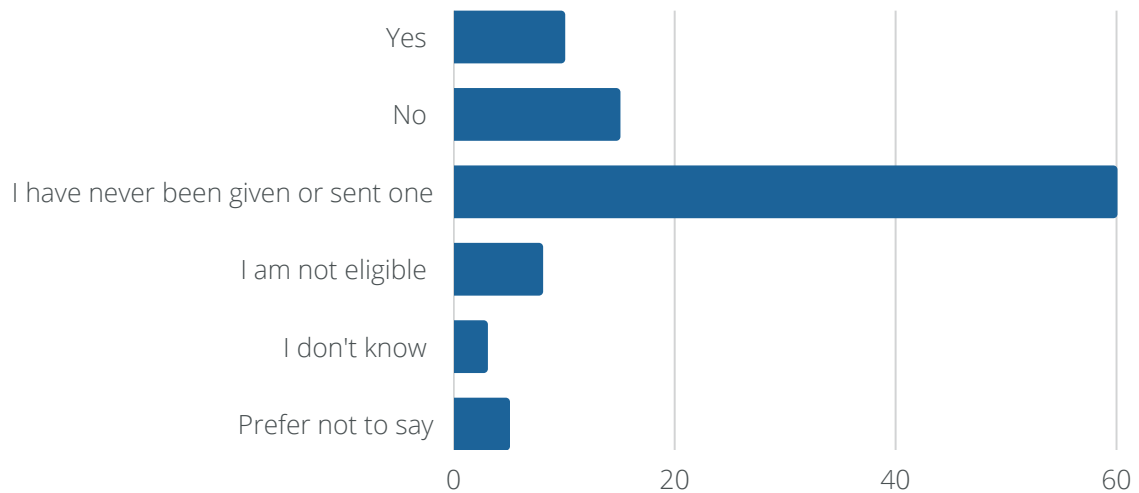
Nearly two thirds (62%) did not know and almost a quarter were unsure.

A tenth of participants explained they had attended prostate screening when it was last offered, with 15% stating that they had not.

Most had not been invited and, looking at the ages of respondents, this fits with the age criteria in England.

However, just under a tenth (9%) were aged 50 years or older (and can access prostate specific antigen (PSA) testing).

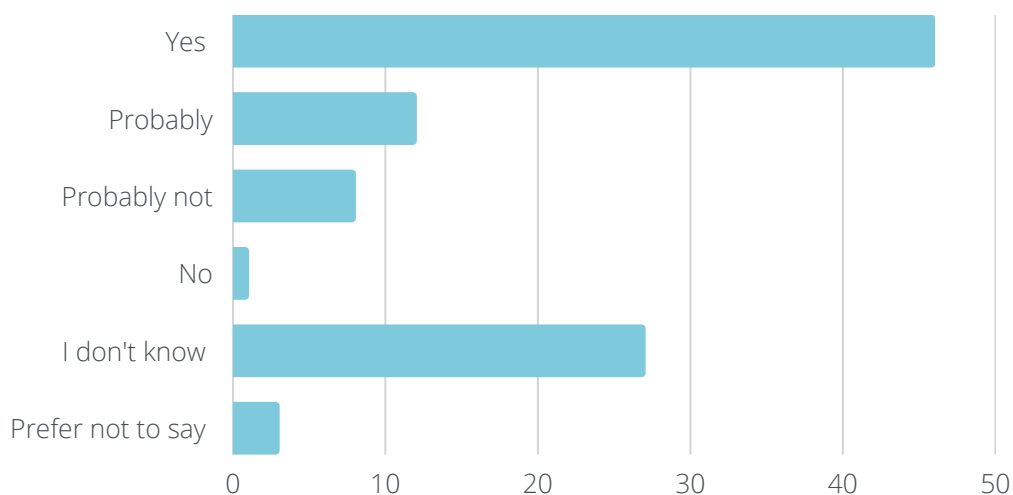
### Did you accept a prostate screening last time you were offered one?



Encouragingly, nearly 50% said they would accept prostate screening next time it was offered.

Of those who would decline a test, a third were of an ethnic minority and 8% were aged 60 years or above. Most who would decline a screening were younger (aged 30 or under).

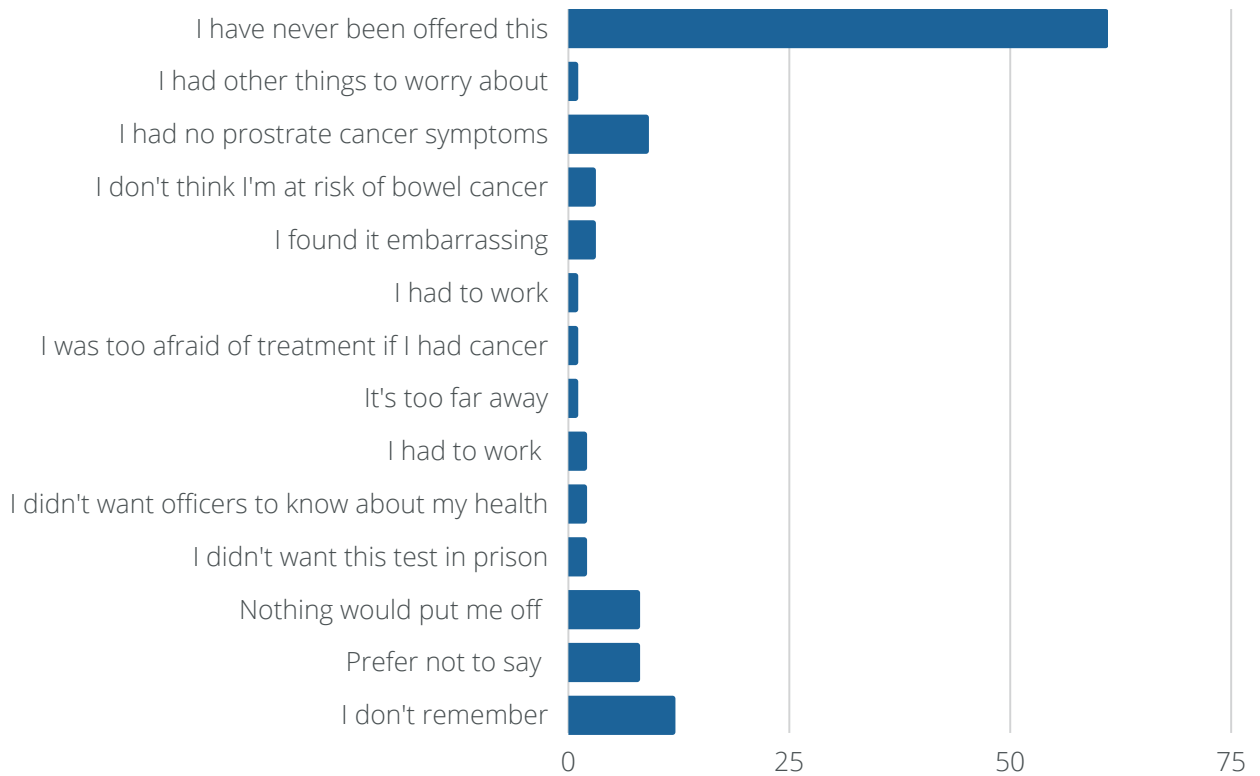
### Will you accept a prostate screening next time you are offered one?



Exploring the reasons why someone might not attend a screening, and excluding those who are ineligible due to age, the most common reasons include experiencing no prostate cancer symptoms, embarrassment and not feeling at risk of prostate cancer.

Only 8% said nothing would discourage them from attending the next offered screening appointment.

**Thinking about the last time you were invited for prostate screening, did any of the following put you off completing it?**



**Cervical screening**

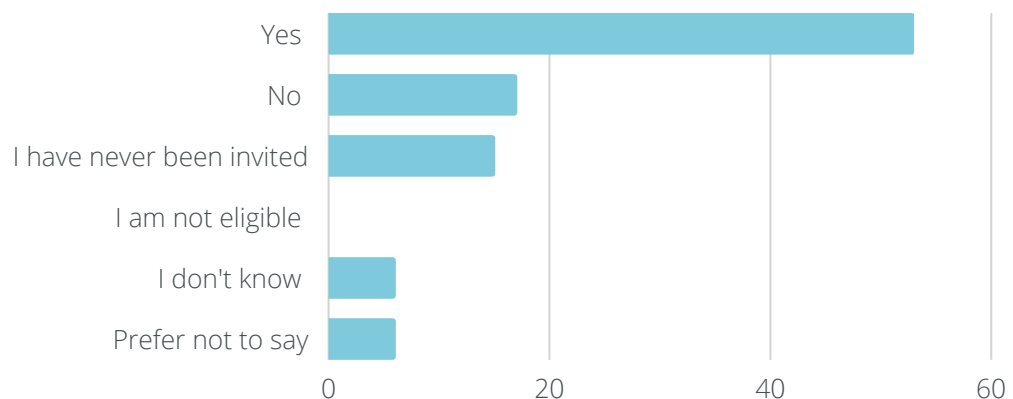
People identifying as women were asked about their views on cervical and breast screening appointments, and 53 women took part.

The responses show that fewer than half of the women (43%) who participated understood when they would be eligible for cervical screening.

Over half (51%) did not know and 6% were unsure.

Do you know when women are eligible for a cervical screening?	
Yes	43%
No	51%
Unsure	6%

**Did you attend cervical screening the last time you were invited?**

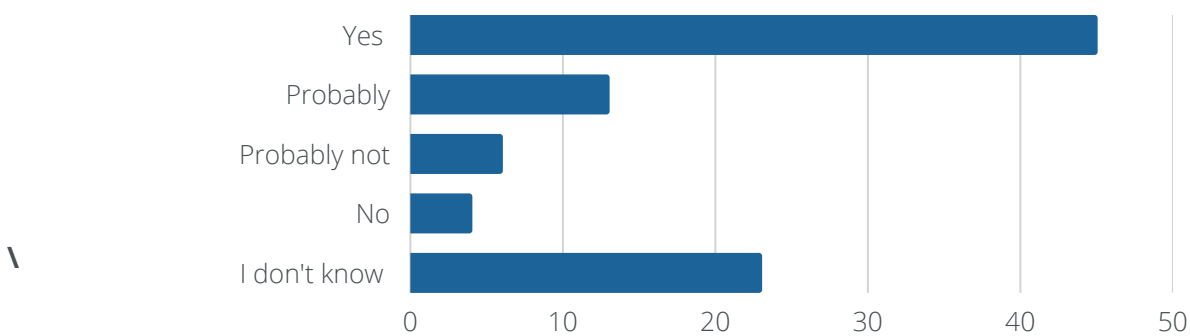




Over half of the women said they had attended their last cervical screening, with less than a fifth having not attended; this encompassed women aged 21-59 years. A small number of women were unsure if they had attended, while 15% had never been invited to attend cervical screening.

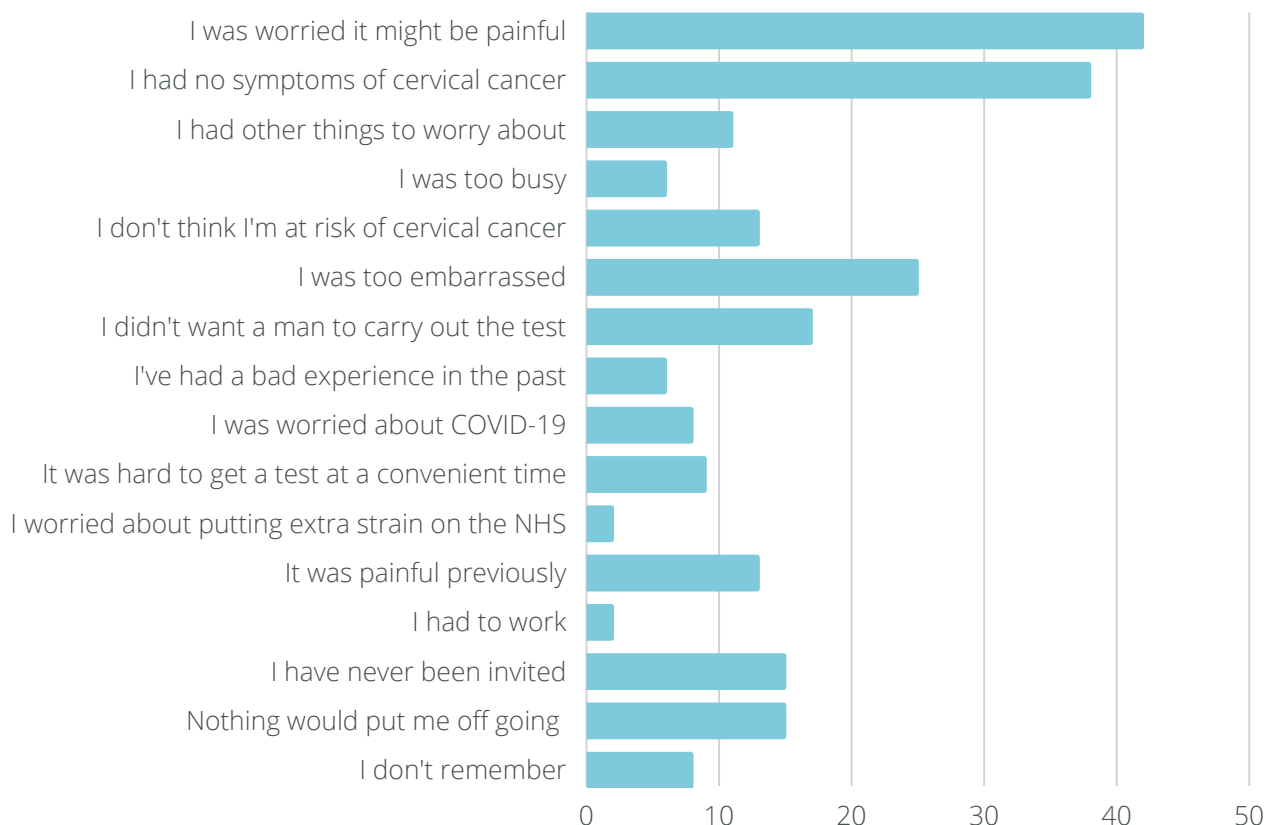
Thinking about the next time they are invited to attend cervical screening, 45% said they would attend an appointment with a further 13% explaining they probably would attend. Only 4% stated they would not attend, with a further 6% stating they would probably not. Most of these women were aged 30-49 years and almost half were Asian (48%); 39% were white and the remainder were of mixed heritage (13%). Nearly a quarter (23%) demonstrated hesitancy, reporting they were unsure whether they would attend future cervical screening.

### Will you go for cervical screening next time you are invited?



It was evident that the most common discouraging factor to attending cervical screening appointments related to concerns that the screening would be painful. Not experiencing any cervical cancer symptoms was also seen to significantly increase hesitancy, followed by embarrassment. However, nothing would discourage 15% of women from taking up their next cervical screening invitation.

### Thinking about the last time you were invited for cervical screening, did any of the following put you off going?



We also asked women to reflect on their experience of their last cervical screening.

A third of women found the screening a little uncomfortable but not painful (33%) and around a quarter (24%) reported it to be painful. Less than a tenth reported the screening as not being painful with no discomfort and 15% reported never having received a screening invitation.

### Which of the following statements best describes how it felt when a nurse/health professional collected a sample from your cervix last time you went?



### Breast screening

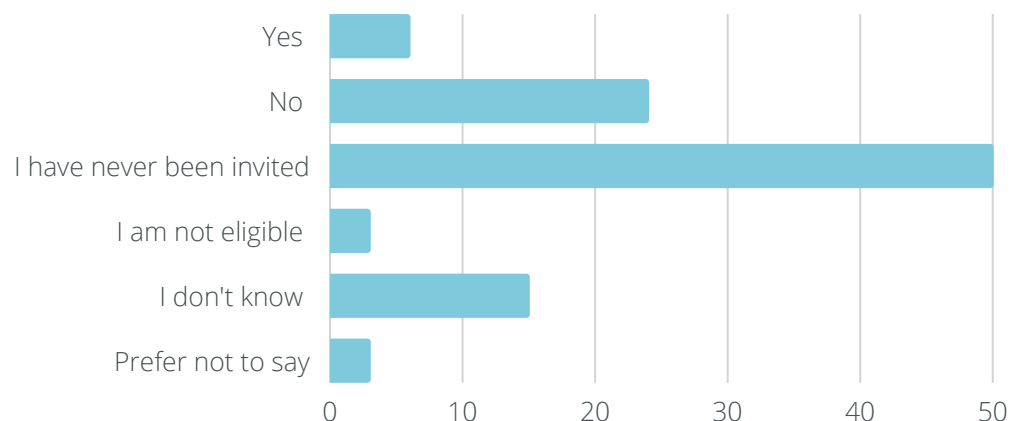
Do you know when women are eligible for a breast screening?	
Yes	17%
No	83%
Unsure	0%

In relation to breast screening, we found that nearly all women on probation, 83%, did not know when they would become eligible for this type of screening.

The remaining 17% did know when they would be eligible.

Half of women had never attended a breast screening appointment but, as all of those consulted were aged under 50 years, they are unlikely to have been invited to a routine breast screening appointment in England. Of those who did not attend their last screening, 50% were within the eligible screening age (50-69 years).

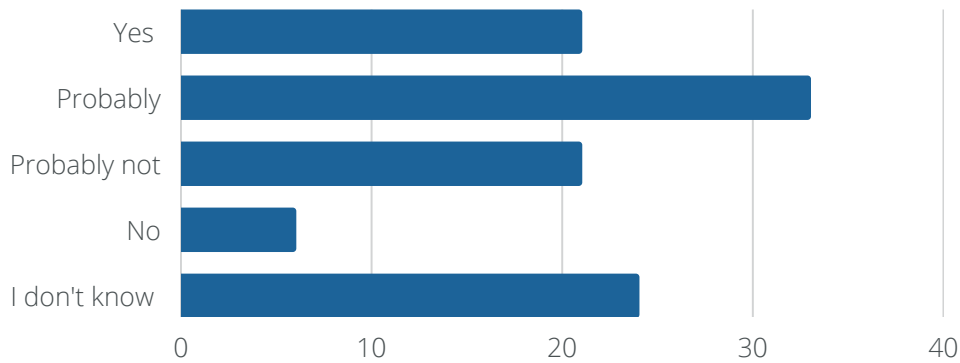
### Did you attend a breast screening appointment last time you were invited?



Thinking about next time they are invited to attend a breast screening appointment, over half (54%) of the women said they probably would attend. Of those who would decline or probably not attend, 50% were 50 years or older and most (88%) were white. Of those who were unsure whether they would attend, over three quarters (77%) were of an ethnic minority.

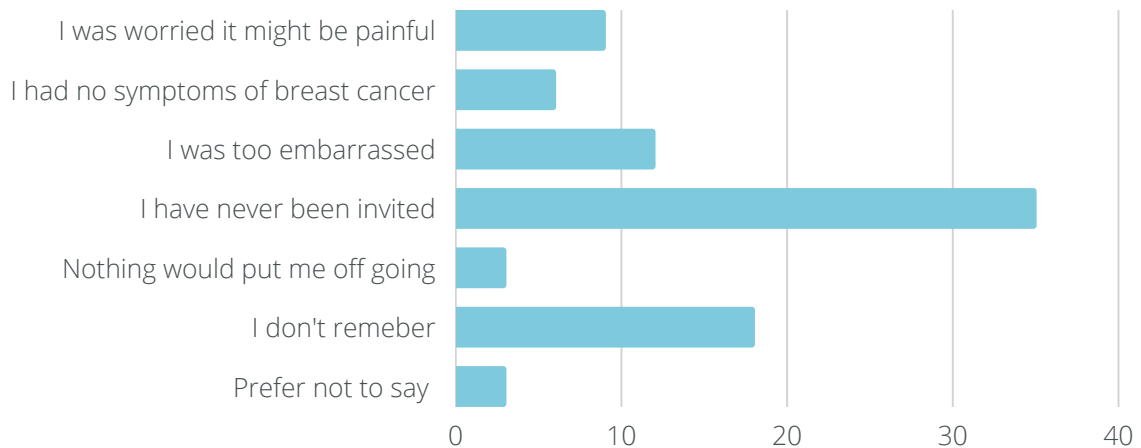
All women who said they would attend their next breast screening appointment were under 40 years old.

### Will you go for breast screening next time you are invited?



When considering factors that can discourage women from attending breast screening, those who had previously attended such an appointment reported embarrassment, concerns around pain and the fact they may not be experiencing symptoms as all potentially being off-putting.

### Thinking about the last time you were invited for breast screening, did any of the following put you off going?



Our final question queried whether women knew how to check their breasts for lumps, to which 41% responded that they did know.

A further 41% were unsure and 14% did not know.

### Do you know how to check your breasts for lumps or changes?

**Yes**

41%

**No**

14%

**Unsure**

41%

## SECTION SUMMARY

More than two thirds of those on probation did not know how bowel cancer screening was carried out, evidencing a need to increase knowledge around this. Only a small number had undertaken bowel screening, aligning with eligibility by age for the group.

Encouragingly, most would complete a screening kit when next provided with one; 10% of those who would not complete the test were of an age where risk increases (60 years and older).

Only 12% of men understood when they would become eligible for prostate screening, again indicating that health promotion relating to screening would be beneficial in increasing awareness.

With only 11% being certain about how health services screen for prostate cancer, and with embarrassment creating a barrier to completing such screening, this may indicate a lack of awareness around PSA testing.

Just under 10% of eligible men (by age) spoke of never having been invited to a prostate screening appointment although, positively, 50% would attend an appointment if invited and a further tenth stated that nothing would put them off attending a screening.

Less than half of women participants knew when women became eligible for cervical screening, but over half had attended their last appointment.

Perceived pain during the screening was seen as the biggest contributor to increasing reluctance to attend cervical screening, and just under a fifth of the women said that they would not attend a screening in the future.

Far less women (83%) were unaware of when women were eligible for breast screening. Overall, whilst 53% would likely attend their next breast screening appointment, of those who would not, 77% were from ethnic minorities. This suggests that relatable health promotion aimed at women from diverse communities might be helpful in reducing reluctance and increasing attendance.

Again, embarrassment presented as a common barrier to women taking up breast screening invitations, meaning that additional work is necessary across the discouraging cancer screening themes to enable people to feel more comfortable in appointments.

It was striking that less than half of women on probation were confident in checking their breasts for lumps, highlighting the need for enhanced health promotion around this, especially considering the importance of early detection of cancer symptoms to improve health outcomes.



# ACKNOWLEDGEMENTS



Our thanks, as always, to;

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NHS England and Improvement and HMPPS who continually create space for people to be heard.