

PATIENT PERSPECTIVES PRISON LEAVERS



CORE20 PLUS5



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BACKGROUND



The purpose of this engagement was to enable people who have left prison within the last year to share their views around health themes relating to NHS England's Core20PLUS5 improvement approach to reducing health inequalities.

EP: IC engaged with prison leavers through surveys and interviews. 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 and prisons.
- 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, 135 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.
- People serving a community probation sentence.
- 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 63%. Women made up 37% of the overall total. When asked whether they identified with the gender registered at their birth, one person 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.

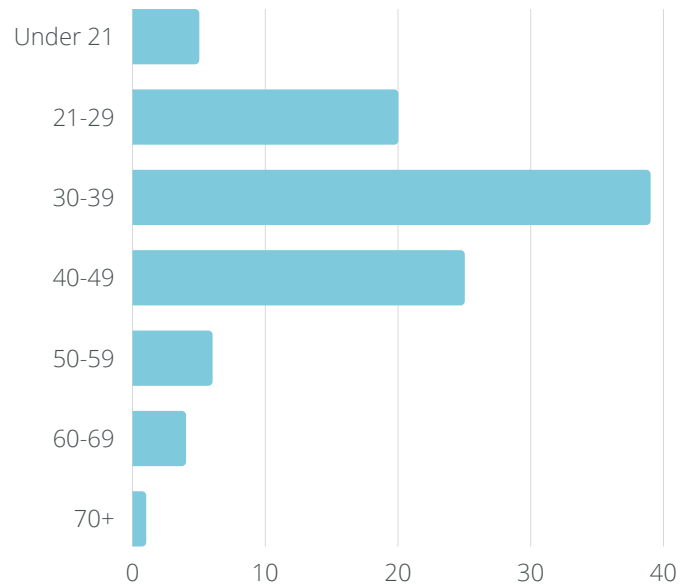
	Part 1 - 4	Part 5	Part 6	Part 7
Male	86	51	86	0
Female	49	33	0	42
Did not say	0	0	0	0
Total	135	84	86	42

Age

Individuals from a range of ages participated in parts 1-4 of the survey. The largest age group was that of 30-39 year olds, making up 39% of all respondents. This was followed by the 40-49 year old group, at 25%.

A further fifth (20%) were aged 21-29 years, with smaller numbers making up older adults.

Six percent were aged 50-59 years, four percent were aged 60-69 years and 1% were aged 70 years or older. The youngest participants were aged 18-21 years, comprising 5% of participants.

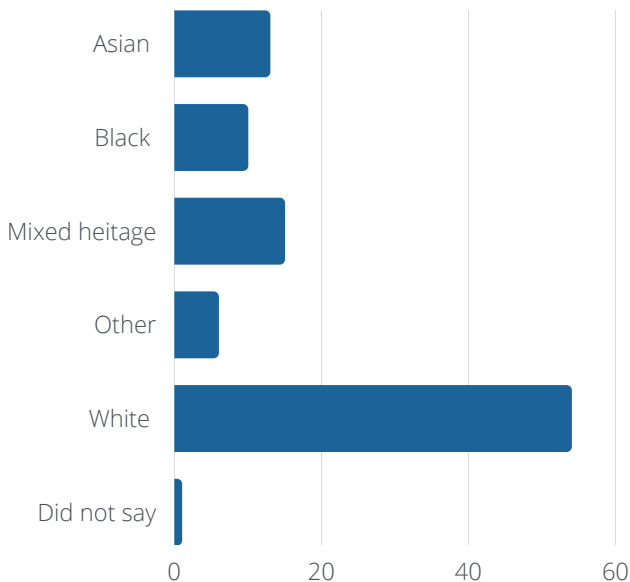


Ethnicity

Just over half of participants were white, at 54%, while 15% were of mixed heritage and 13% were Asian. A tenth were black and 6% were of an 'other' ethnicity.

A small number (1%) preferred not to state their ethnicity.

In total, those from ethnic minorities formed 44% of the overall sample.



Prison locations

Individuals were asked the prison where they had most recently served a sentence and this provided some indication of the range of experiences.

Some 46 prisons were mentioned, one of which was Scottish, although this person had resettled in England.

How long have participants been released?

- 14% had been released within the previous month.
- 21% had been released between one and three months previously.
- 27% had been released between three and six months previously.
- 47% had been released between six months and one year previously.



KEY FINDINGS

LIFESTYLE AND HEALTHCARE NEEDS

- Mean BMI for males was recorded as 27.2 and for females as 27.3 (calculated from those who knew their height and weight).
- 5% drank alcohol daily.
- 36% were smokers.
- 10% had never smoked but vaped.
- 27% had undertaken in excess of 30 minutes of exercise for more than five days during the previous week, while 31% had taken no exercise.
- Depression and negative feelings about self were seen as the most significant barriers to increasing exercise, although access to gyms, cost and physical health were also factors.
- 34% were reducing the amount they smoked or vaped.
- 46% were choosing healthier meals.
- 43% were consuming less alcohol.
- 41% were choosing healthier snacks.
- 48% were aiming for a healthy body weight.
- 79% reported physical health needs upon leaving prison, with 17% of such needs being fully met one month following release.
- 60% reported a substance misuse need after prison, with 26% of such needs being fully met one month after release.
- 80% reported a mental health need upon leaving prison, 18% of which were being fully met one month after release.
- 27% reported a social care need, with 17% of such needs being fully met one month after release.



LEARNING

LIFESTYLE AND HEALTHCARE NEEDS

The survey looked to ask participants about themselves and the first question looked at height and weight.

Almost all participants knew their height, at 86%, and nearly three quarters knew their weight, at 71%.

Do you know your height?	
Yes	86 %
No	14%

Do you know your weight?	
Yes	71%
No	29%

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

- **Male - 27.2**
- **Female - 27.3**

Participants were asked about their use of alcohol, from which it was determined that most drank sometimes, at 45%, and 5% used alcohol every day.

- A third (33%) of daily drinkers were female; the remainder were male (similar to the proportions of those on probation).
- All participants who used alcohol daily were white.
- 17% were under 21 years old, and 50% were over 50 years old.

Which statement best describes your use of alcohol?

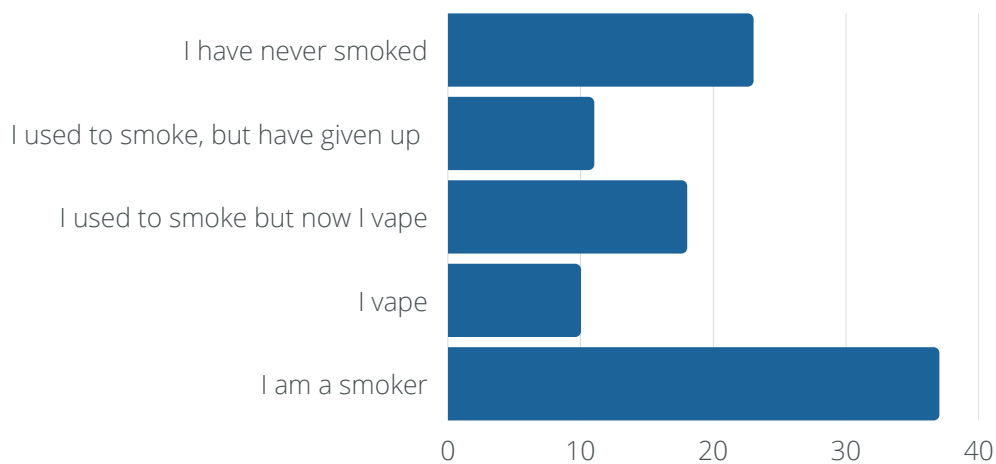


Over a third (36%) of participants were current smokers. Considering that prisons are smoke-free environments, this suggests they began smoking again on release, following a break in prison. Of current smokers:

- 61% were male and the remainder (39%) were female.
- Over two thirds (67%) were white, 13% were of mixed heritage, 9% were black and 4% were Asian.
- The greatest proportion of smokers (almost half, at 48%) were aged 30-39 years.
- The smallest group was that of the under 21 year olds, which aligns similarly to people on probation.

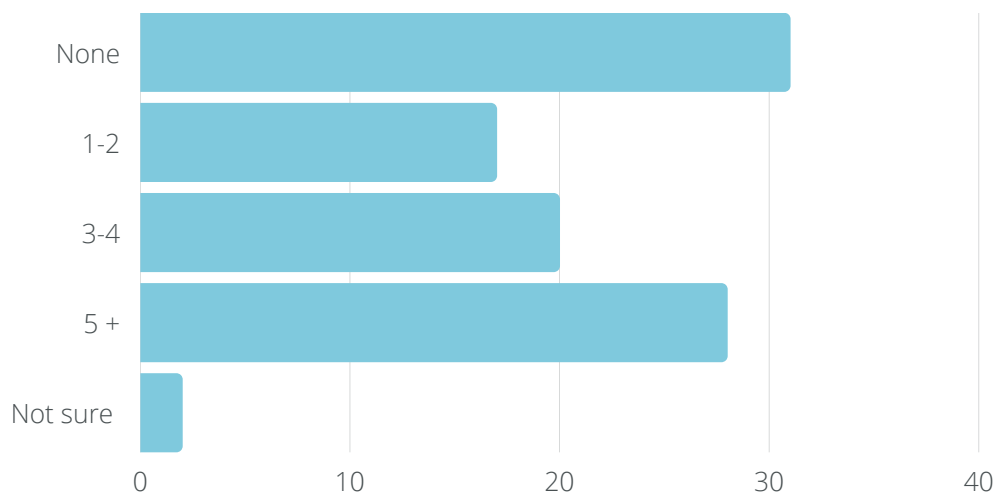
Nearly a fifth, at 18%, were former smokers but had switched to vaping. A tenth, had never smoked but now vaped, of which 92% were women. Of these, 30% were under 21 years old and the remainder were under 40 years old.

Which statement best describes your history of smoking?



When examining the amount of exercise in which participants had engaged within the previous week, around a third had undertaken no physical activity at all (31%) . A similar proportion (27%) 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?



Of the 94 comments provided around what would motivate individuals to increase their exercise levels, 38% spoke of mental ill-health or negative views of self preventing them becoming more involved in physical activity. It appeared that low mood or having a self-deprecating view impacted on the likelihood of some people exercising more.

“I’d like to exercise everyday cos it’s good for my head, and no electric where living. A free gym pass, probation appointments at the gym would be good and feeling less down about myself would help me.”

“I need to feel good and settled inside myself to work out, I need to feel good inside first to want to exercise, a clear mind.”

“When I feel in happy place I will. I know it’s good for my body and mind, but need to be feeling happier in myself and how I look.”

Importantly, some individuals were able to acknowledge the potential for exercise to improve how people feel, as evidenced within several responses.

"I do 5 training sessions a week of CrossFit at the centre and I ride a bike everywhere I go. I love it! I work hard and feel great."

"Motivated by mental health – improves my wellbeing massively. I discovered the joy of running – I found this in prison and it's the one benefit I can take away from prison. I have continued running and lifting weights."

"Going to the gym in prison kept me sane and I have kept it up since leaving. I don't need any more motivation, thanks."

Some 28% of participants would like easier access to a gym or fitness classes.

"Cheaper leisure centre passes. My friend goes swimming and finds this helps her mental health, but I can't afford it. I haven't been swimming since before prison so nearly 10 years ago."

"Probation should provide gym passes to people who are trying to change."

"I walk everywhere – if I had the money I'd go to the gym, but I'm skint, lol. One of the good things about prison is free gym. I loved prison. I was living my best life in there."

Walking was a notable feature within comments, mentioned by 12% of participants. This participant group spoke of engaging in lots of walking due to its low cost; not being able to afford public transport or the running costs of a car. However, some simply found it enjoyable and walked regularly.

"I walk everywhere because I can't afford the bus and don't want to do any more, thanks."

"I walk my dog every day, and am looking into a charity that walks dogs for elderly or disabled people and thinking about doing that."

"I don't like exercise but I have no transport because everything is so expensive, so I walk all the time."

Interestingly, affordability and cost arose as a barrier for 7% of respondents.

"I haven't got money for exercise; I can barely afford to eat and heat my flat."

"I have no money, so more money would help as there's a nice gym down the road from me."

Importantly, a tenth (10%) of respondents recognised that they needed the support or encouragement of another person to help them increase their physical activity. Isolation and/or loneliness and a lack of confidence appeared to feature as a barrier for people to exercise. One person spoke of the stigma of previously being in prison.

"Having someone with me. I love exercising and understand the benefits. When I was inside, I would exercise non-stop and now I don't as much and certainly would love to more, but I don't want people to find out I've been in prison."

"I appreciate that I need to but I don't know what to do. Family and friends would help but I don't have them, meeting more people like me would be good."

"A training partner. Some help to get out and do it."

Under a tenth (7%) spoke of their physical health impacting on their ability to exercise more.

"I've bad arthritis so it's hard to move around. If I had better health to cope with pain, I would increase my movement. So, when I'm past the running out of breath and aching part, I'll go for a run!!"

“I have Rheumatoid Arthritis now, so want to be pain free, that would help me.”

“Maybe after the baby arrives [I’ll exercise].”

The remaining participants mentioned other challenges to increasing exercise. For instance, some women wanted access to single sex exercise spaces, while others felt that they lacked time, and some felt that they would exercise more once the weather improved. Additional comments centred around a lack of internet access and having other priorities (such as parenting, working or having insufficient time to exercise).

“I need to have more time which I don’t with everything else to sort out like work, house and kids.”

“When there’s less stress and worries. I need help with sorting the basics in life.”

When respondents were asked whether they were currently making any lifestyle changes, it was noted that:

- 34% were looking to reduce the amount they smoked or vaped compared to 52% who were not. A fifth (20%) felt that no changes were necessary.
- Just under a half (46%) were choosing healthier meal options, compared to 35% who were not. A further 14% felt that no dietary changes were required.
- Some 43% were consuming less alcohol, compared to 24% who were not. Meanwhile, 25% of participants felt no need to change their alcohol intake.
- 42% were exercising more, compared to 24% who were not. Just under a tenth (8%) reported not needing to change their level of engagement with physical activity.
- 41% were choosing healthier snacks, compared to a quarter (25%) who were not, while a tenth (10%) reported not needing to change their snacking habits.
- Just under a half (48%) were aiming for a healthy body weight, compared to 26% who were not. Around a tenth (13%) stated that aiming for a healthy body weight was not necessary.

Are you currently trying to make any of the following lifestyle changes?

	Yes	No	Unsure	Not needed
Reduce vaping/smoking	34	51	14.	25
Choosing healthier meals	51	39	20	15
Drinking less alcohol	40	30	23	31
Increasing exercise	47	38	27	11
Choosing healthier snacks	46	39	28	11
Aiming for a healthy body weight	51	28	28	16

HEALTHCARE NEEDS

In this section we refer to the first month following the release from prison as time point 1 (TP1) and the date of completion of the the survey as time point 2 (TP2). The duration between TP1 and TP2 will be different for each participant. We also have to consider that for 14% of respondents who left prison in the previous month, there is less time to experience any changes to healthcare needs.

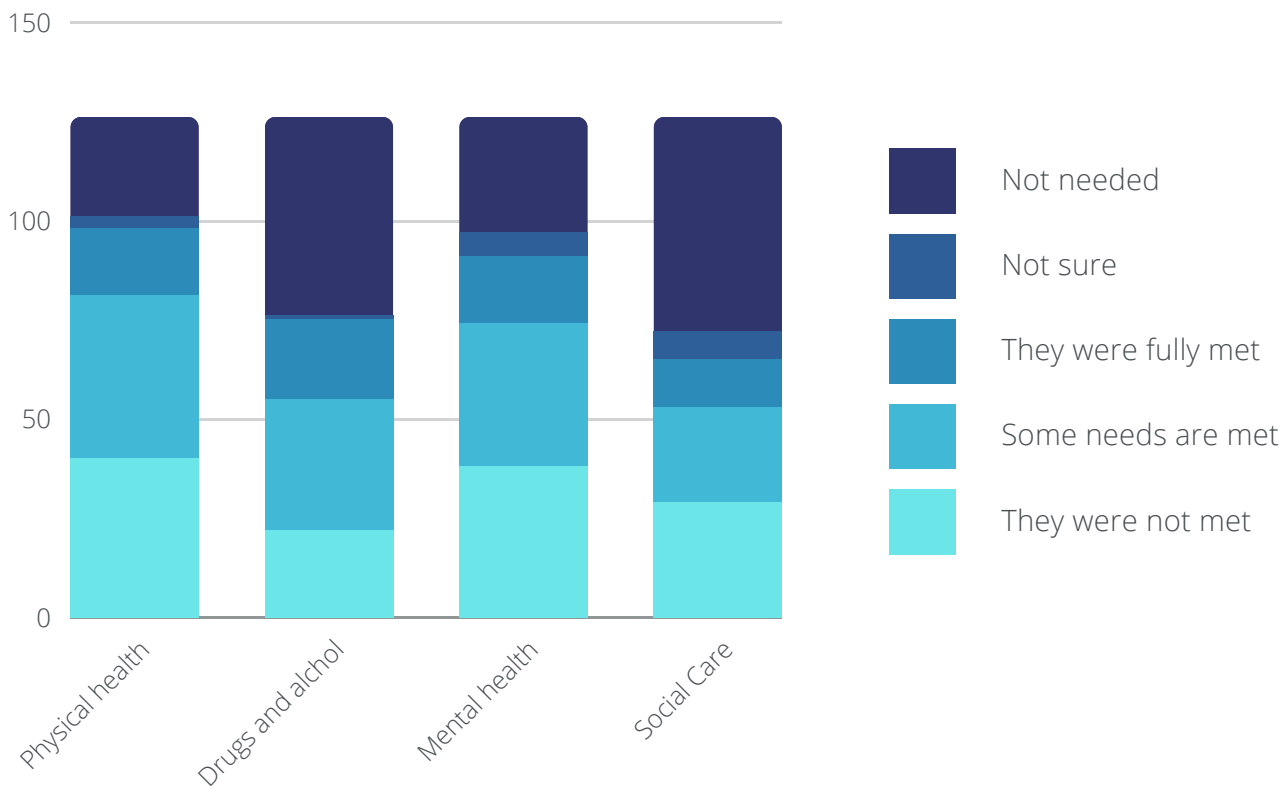
However, looking at the reported needs during time TP1 it is notable that 79% of people reported a physical health need. Of this patient group, 17% reported their needs as being fully met and 40% as not being met at all. It was striking that no one over the age of 50 years believed their physical health needs were fully met in TP1.

Over half of respondents, 60%, disclosed a substance misuse need, of which over a quarter (26%) reported their needs to have been fully met at TP1. Again, it was in the older adult cohort that the least met need was found (with just 25% reporting their needs to have been fully met).

Over three quarters of participants (80%) reported a mental health need, with under a fifth (18%) of those reporting their mental health needs as being fully met. For 40%, none of their mental health needs were met and the most unmet needs were experienced by those under 40 years old.

Further, 27% highlighted a need for social care support, with just 17% reporting these needs as being fully met, and, similar to those experiencing mental ill-health, 40% reported that their social care needs remained unmet in TP1.

How well were your healthcare needs met in the first month after leaving prison (TP1)?



Reflecting on the healthcare needs of participants at TP2, it is evident there has been some changes in terms of met or reducing healthcare needs.

Around a third (30%) of people reported their physical health needs as being fully met at the time of the survey, compared to 17% during the first month after prison.

A slight increase in fully met substance misuse needs was identified, moving from 26% in TP1 to 29% at TP2.

A notable decrease in the number of people reporting unmet substance misuse was also noted, from 26% reported in TP1 to 17% at TP2.

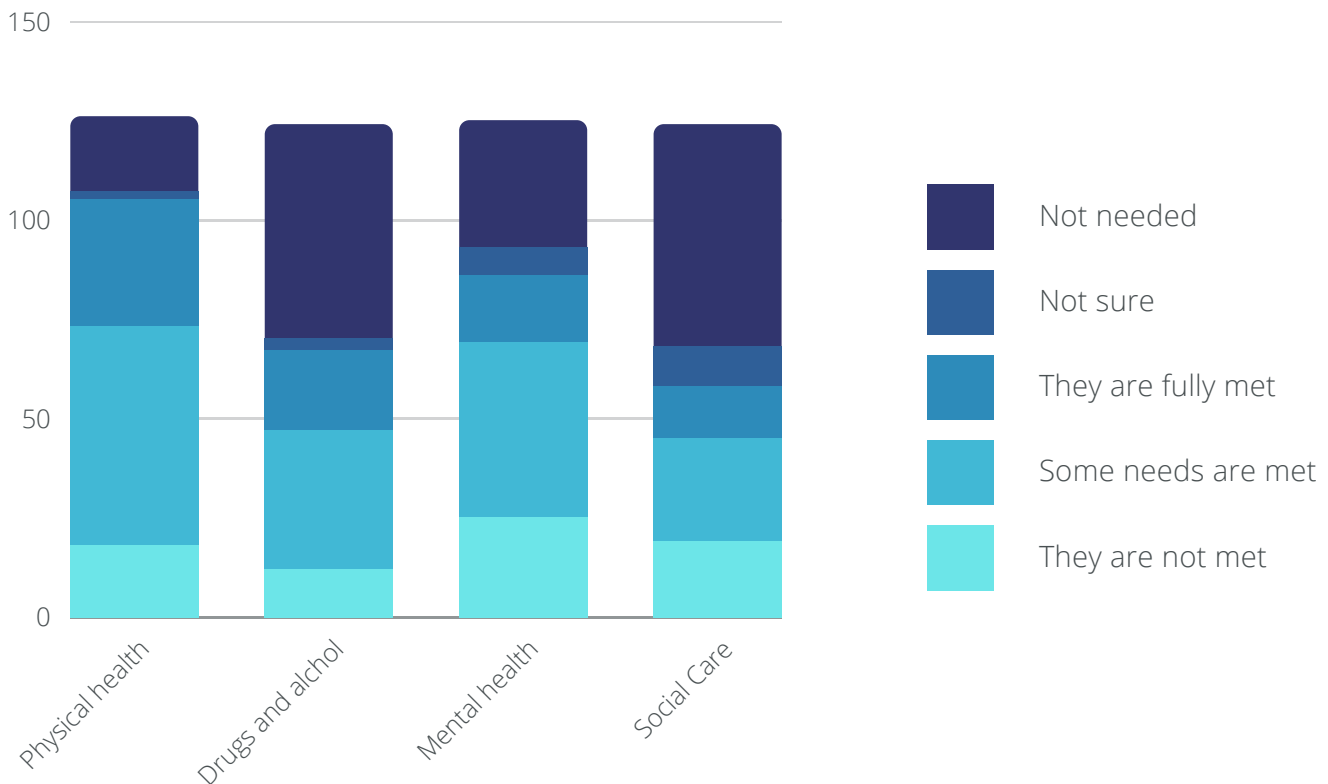
There was a marginal decline in people reporting fully met mental health needs, with a slight fall from 18% of people reporting needs met in TP1 to 17% at TP2.

Overall there was a 6% reduction in people reporting a mental health need in TP2.

Further, fewer individuals reported unmet mental health needs in TP2, with a shift from 39% in TP1 to 27%, suggesting a higher number of people can experience an immediate mental health need in those early days following release of prison, which then reduced over time.

Looking at social care, again we see fewer people needing this kind of support, but with a slight increase in unmet needs (40% - 41%) and a slight increase in fully met needs (17% in TP1 -19% in TP2).

How well are your healthcare needs met now? (TP2)?



SECTION SUMMARY

The consultation provides a broad indication of the BMIs of participants, albeit BMI is recognised as an imperfect indication of the overall health of an individual. The mean BMIs of men and women slightly exceed what is deemed healthy.

Looking across responses allows us to build a broader picture of people's lifestyle choices and

priorities. A small number of individuals used alcohol daily, all of whom were white and over a third of whom were women. Nearly half of all participants were actively trying to reduce their alcohol intake.

As all participants had been released from prison within the previous year, it was surprising to realise the number of smokers (36%) within the sample, given that prisons are smoke-free environments and it is likely that smokers would have had access to smoking cessation services in prison and/or vaped. This means that, despite this health intervention, at least some people began smoking again following the break enforced on them while in prison. Encouragingly, around a third of smokers did show some appetite to reduce their smoking and this group can hopefully be reintroduced to smoking cessation services in the community.

Similar numbers were either very engaged in exercise or not exercising at all. It was apparent that many individuals engaged in walking, and we also saw a benefit whereby accessing the gym in prison then transferred into people's daily routine in the community. The most significant highlighted barrier to participants engaging in increased exercise related to mental ill-health or negative feelings about self. However, in contrast, others were able to recognise how involvement in regular physical activity helped individuals to feel better and benefit from a boost in mood. Nearly half were aiming for a healthy body weight, and a similar number were trying to exercise more, showing positive intent around healthier lifestyles.

The health needs of people leaving prison presented as complex, with almost all participants reporting a physical health, mental health and substance misuse need, and few reporting that these needs were fully met one month post-release. In some instances, older adults reported the least needs being met, although this situation changes across services. Over time, needs seem to reduce, even if marginally at times, and there was some movement in terms of people reporting needs being met.



KEY FINDINGS

GP SERVICES

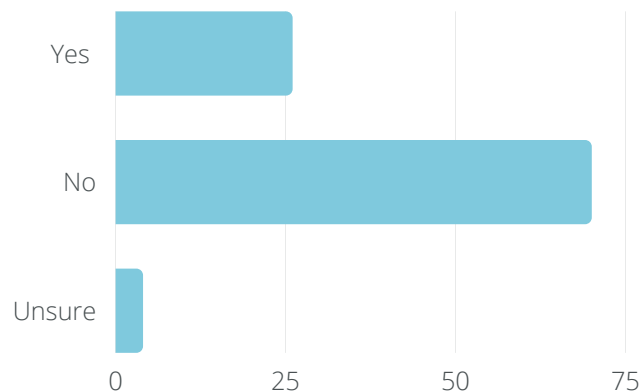
- 26% needed help registering with a GP after leaving prison; around two thirds of these were of an ethnic minority and twice as many were men than women.
- Some people leaving prison were unsure whether they were still registered with their previous GP, although returning to the same GP after prison could feel embarrassing.
- Through the Gate support helped individuals access a GP.
- 52% had tried to see a GP in the previous six months.
- Most needed to call their surgery to see a GP, less than a tenth of whom used digital access methods.

- Over a tenth had attempted to make an appointment, but were unsuccessful.
- 15% told nobody about a new symptom (mostly Asian women).
- 21% told their GP about a new symptom when they had the time.
- 27% told their GP about a new symptom within a week.
- 3% told their GP about a new symptom within two weeks.
- 3% told their GP about a new symptom within three weeks.
- 7% told their GP about a new symptom within a month.
- 6% told their GP about a new symptom within three months.
- 4% told their GP about a new symptom within six months.
- 47% were unsure how long to wait before consulting a GP about a new symptom.
- 48% felt confident returning to a GP for the same health problem if it persisted.
- 43% felt confident returning to a GP with the same health problem following a test result suggesting that there was nothing to worry about.
- More individuals from ethnic backgrounds were unsure when to see a GP, compared to white individuals.
- Whilst individuals might not see a GP for multiple reasons, the most common was the belief that they would not be taken seriously because of their prison history – as mentioned by 49%.
- 37% were discouraged by difficulties accessing a GP.
- Some were hesitant to consult with a GP for fear of not being taken seriously due to a protected characteristic.
- A tenth could not afford to travel to a GP practice.
- One person did not want to see their GP due to their illicit drug use.
- The most common reasons for consulting with a doctor were a symptom that caused concern, a feeling that something was not right and pain.



Considering the support required for individuals to access healthcare services in the community post-release, just over a quarter acknowledged needing help to register with a GP, with double the proportion of men needing assistance compared to women.

Did you need support to register with a GP when leaving prison?



Of those needing help to register with a GP, 40% were aged 60 or older. Nearly a third were 30-39 years old and a similar proportion were 40-49 years old. Lesser numbers of younger adults needed help.

Interestingly, when viewing the ethnicity of those requiring support to register with a GP, around two thirds (68%) were of an ethnic minority (23% were black, 21% were mixed heritage, 12% were Asian and 12% were of an other ethnicity) – the remainder were white (34%).

People were able to comment on their experiences registering with a GP. Several were unsure how to go about this upon leaving prison, and some were reluctant to disclose their time in prison to their doctor.

“I wasn't sure if I had been deregistered when I was in prison and therefore, I wasn't sure if I needed to go back to the doctor I had before prison and no one explained that to me and no one at probation ever mentioned it to me either. I was embarrassed to go to the doctor because I didn't want to have to explain that I was in prison and I didn't have any ID either.”

“I didn't want to go back to my GP because of my crime and being in prison – so had to go to another.”

Only one person mentioned being supported to register whilst still in prison, although several spoke of being supported by probation on release. However, most commonly, specialist services were highlighted as helping people gain access to a GP and this included faith based, substance misuse and care leaver services.

“I got the support to register with a GP through the Muslim women in prison project.”

“I was met at the gate by a recovery based housing team. Got a lot of support leaving prison.”

“My leaving care worker helped me loads.”

“Yes, residential rehab got [me] sorted with the local GP.”

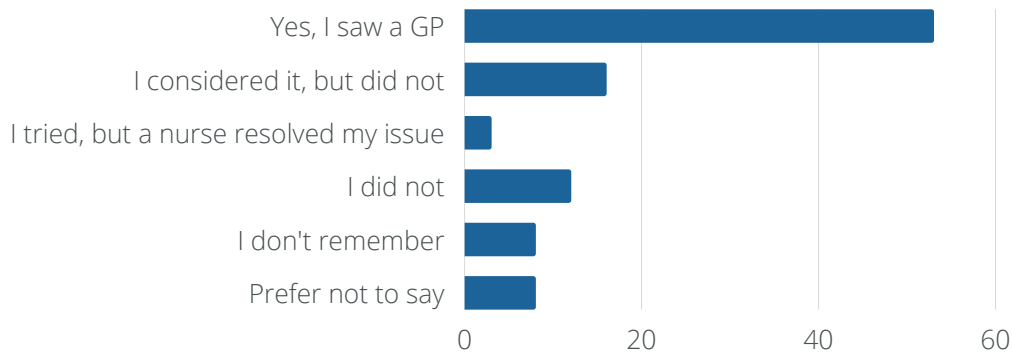
During the six months prior to the survey, 52% of participants had attempted to see a GP while 3% had attempted to but another healthcare professional had resolved their health issue.

“I saw [a] nurse instead, and [she] sorted my issues.”

“I went to GUM clinic as it was easier to book in with them.”

15% of people had thought about seeing a GP, but had not.

In the last six months have you tried to see a GP?

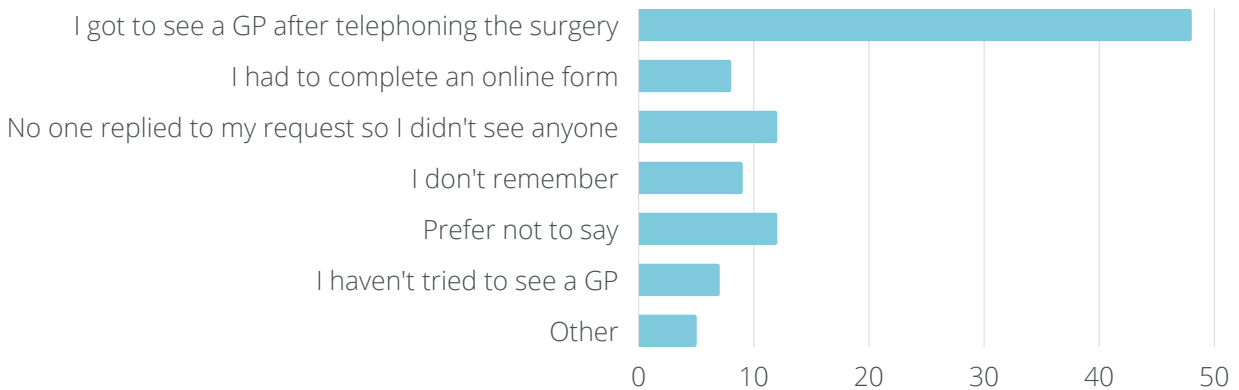


For those who had seen a GP, most obtained their appointment after telephoning the surgery (48%), although this was difficult for some. Less than a tenth used digital means, such as eConsult or the Patient Access app, to access a GP.

Over a tenth were unable to see a GP, despite trying, resulting in disengagement for some.

“I find it very hard to get to a dr. I try multiple times and I give up as I get nowhere.”

If you tried to see a GP in the community, what happened?



Most respondents highlighted the challenge of getting through to a surgery to book an appointment, aligning strongly with the experiences of people on probation.

“No one picks up the phone – it’s bloody useless.”

“If you’ve got a spare hour to wait, you might get through if you’re lucky!”

Others spoke of the time it took to see a GP, despite being able to book an appointment.

“Such a long wait for an appointment but I eventually got a call back cos of my bad health condition.”

“It took weeks, is that normal.”

Some found that being a prison leaver disrupted their healthcare.

“I didn't have a doctor when leaving prison so had to delay my healthcare until I could register with another.”

“I moved to Blackpool and had to register there, so was a bit of a wait, pain, really.”

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

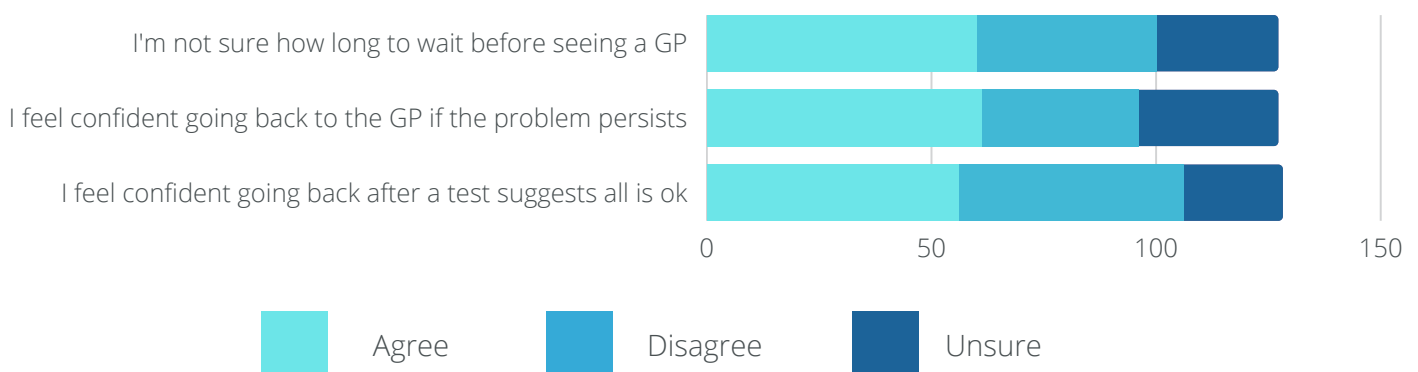
- 15% told nobody (mostly Asian women who were under 30 years old).
- 21% told a GP when they had the time.
- 27% alerted a GP within a week.
- 3% told a GP within two weeks.
- 3% told a GP within three weeks.
- 7% told a GP within a month.
- 6% told a GP within three months.
- 4% told a GP within six months.

How long after noticing a new symptom would you leave it before you tell a GP?



Overall, just under half (47%) of all participants were unsure how long to wait before contacting a GP following a change in their health.

How much do you agree with the following statements?



Mostly, people from ethnic minorities were either the most unsure or did not know how long to wait after noticing a change in their health, before contacting a GP.

- Asian – 69%
- Black – 85%
- Mixed heritage – 90%
- Other – 85%
- White – 59%

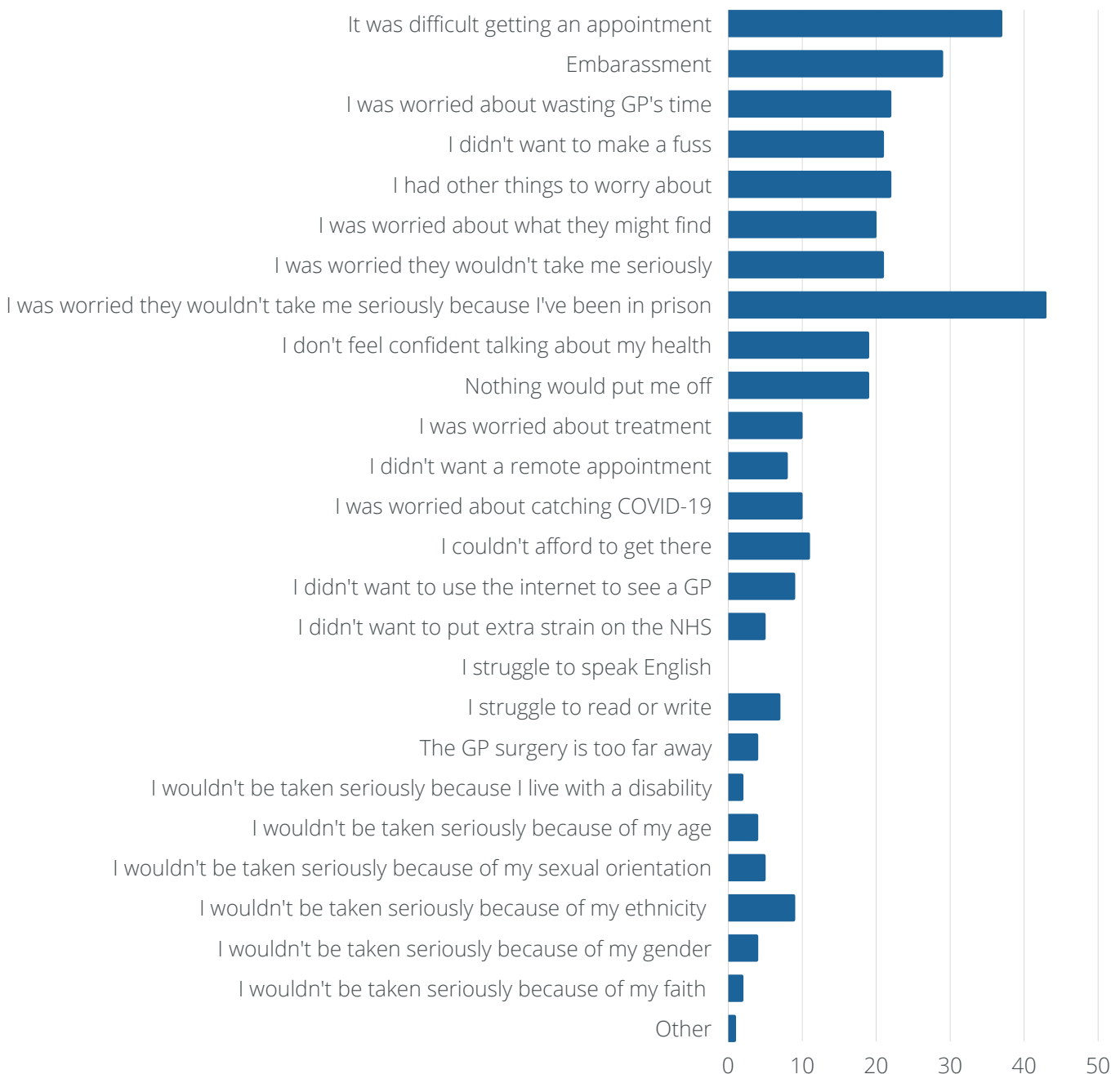
Women appeared less confident when considering how long to wait before contacting a GP about a change in their health, compared to men.

- Women – 78%
- Men – 63%

Around half of participants (48%) felt able to return to a GP with the same health issue if it persisted or worsened. A similar number (43%) felt able to return to the GP with the same health problem, when a test result suggested nothing of concern.

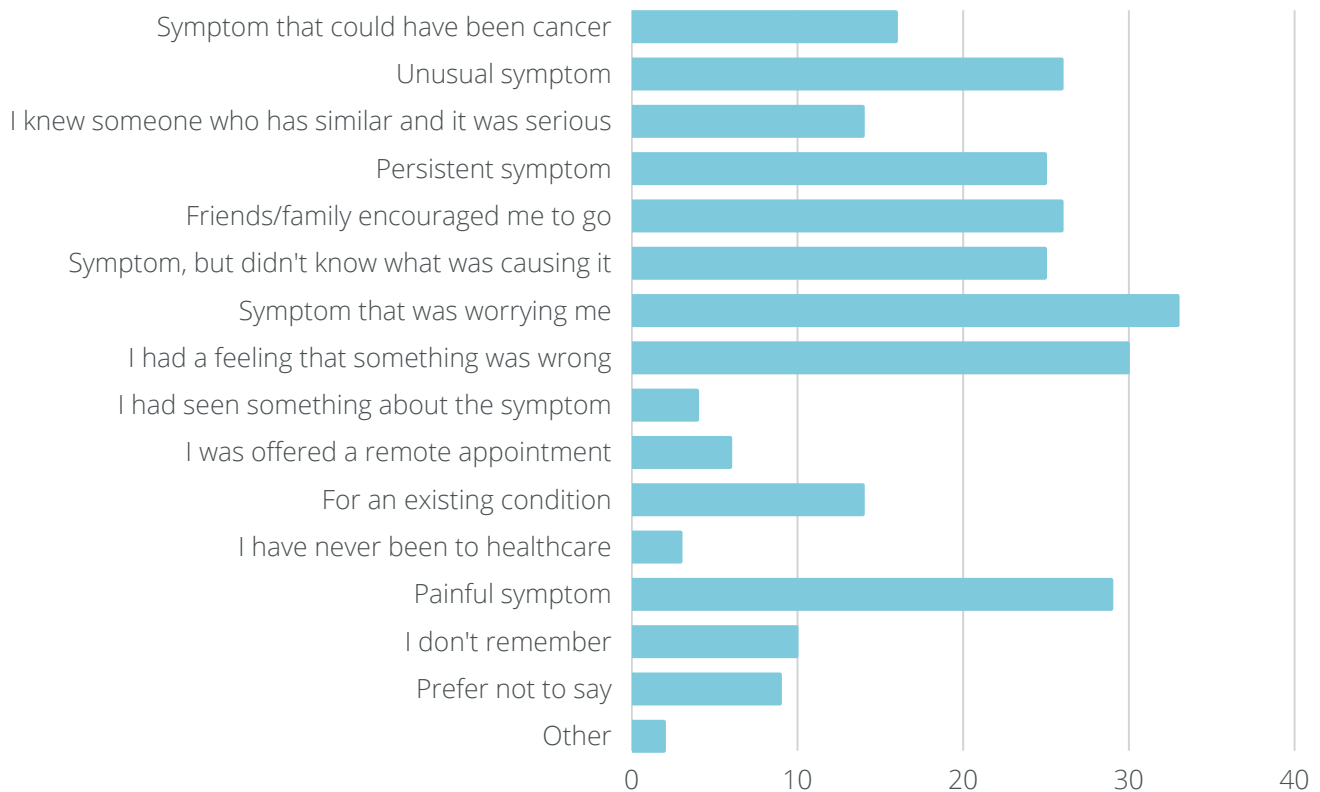
When looking at what can discourage people from seeing a GP, multiple reasons contributed to hesitancy or delayed treatment. Participants could check more than one response to this question.

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



Exploring the reasons why people had most recently considered consulting with a GP, a multitude of reasons arose. The most common reason related to a symptom that caused concern, as highlighted by 33%. The next most common reasons related to a feeling that something was not right (30%), pain (29%) or an unusual symptom (27%).

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



SECTION SUMMARY

Over a quarter of prison leavers needed help registering with a GP, with two-thirds of these being of an ethnic minority. A degree of uncertainty was evident for some as to whether their GP registration prior to prison had been retained, indicating that more could be done to inform patients about their GP status before release to avoid confusion.

Providing information to prison leavers on finding an alternative GP (if a person felt too embarrassed to return to a previous surgery because of their incarceration) would also be helpful for some. It was evident that, where Through the Gate services existed, valuable support was on offer.

The most common reasons to see a doctor included worrying symptoms, a feeling that something was not right and pain. Over half of all respondents had considered consulting with a GP during the six months previous to the survey and most reported needing to call their surgery to book an appointment. Accessing the GP in this way was sometimes seen as problematic, however, due to the length of time it could take to connect with the surgery, resulting in a tenth of participants not seeing a GP, despite their attempts. Very few participants had used digital methods to see a GP.

Most people alerted their GP about a change in their health within one week, although 15% shared new symptoms with nobody (mostly Asian women).

Nearly half were unsure as to how long to wait before contacting a GP about a health change, and again those from ethnic minorities were less sure than others. Similar numbers (around half) felt confident about returning to a GP where a symptom persisted.

Individuals were discouraged from reaching out to a GP in numerous ways, but it was striking that 49% were concerned that they would not be taken seriously by a healthcare professional because of their prison history. Building on perceptions of stigma, those with protected characteristics were also seen to feel that they would not be taken seriously, especially in terms of ethnicity.

On occasion, even where a need to consult with a GP existed, cost of travel and distance could be prohibitive.



KEY FINDINGS

MEDICATION, ACCESS TO SERVICES & MENTAL HEALTH

- Over half of participants (56%) needing medication on release reported being provided with this – the proportion rising for ethnic minorities.
- Embedding healthcare more consistently into release planning was seen as valuable, in order to reduce breaks in medication.
- Easier access to medication was desired, such as embedding healthcare more consistently into release planning, leaving with a list of medications and leaving with a month's worth of medication.
- 43% needed help accessing other community healthcare services.
- GP and pharmacy services were seen as the greatest needs, and it was clear that a range of services were required.
- 40% of people who used probation found them helpful when accessing community healthcare services.
- 43% of people who used substance misuse services found them helpful when accessing community healthcare services.
- 53% found mental health services helpful when accessing community healthcare services.
- 54% of those who used specialist charities found them helpful when accessing community healthcare services.

- Family and friends were also seen to help individuals access community services.
- 56% reported a decline in their mental health upon leaving prison, 28% reported improved mental health and 16% reported no change.
- Women appeared to be more impacted by leaving prison than men, as were those of an ethnic minority.
- Overall, 14% of people found they could cope well with daily life.
- Assistance with their integration into the community, everyday tasks, accommodation, sex-based services and trauma support, as well as increased social opportunities, were all seen to help individuals manage.



LEARNING

MEDICATION, ACCESS TO SERVICES & MENTAL HEALTH

Positively, of those requiring medication on release, over half (56%) were provided with that medication, 36% reported not getting medication they needed. Less than a fifth (17%) required no medication.

No discernible differences were evident between the gender or ages of those not receiving their required medication, although some differences were noticeable when the ethnicities of this patient group were examined.

Of those needing medication on release but not receiving it, 30% were white and 70% were of an ethnic minority, suggesting a disparity in experiences.

Upon exploring the experiences of individuals relating to their medication needs upon leaving prison, and what could be done to ease access to medication, a notable breadth of experiences arose. Some left prison with a month's supply of medication and this was often seen as good practise due to the time it could take to register with or see a GP and other healthcare services upon release.

“I was OK. I was given a month's worth of antidepressants and a prescription for methadone which meant I had time to see a dr and not have any breaks in my meds.”

“More medication to stop panic of 4 weeks to give more time to sort outside GP etc.”

Most respondents appeared to be issued with a week's worth of medication, but this could be problematic for those disconnected from healthcare services in a new resettlement area.

“Give them 2 weeks of medication in advance at least. One week is not enough with all the things you have to [do]. If they have an adequate supply and on time, it would be better.”

“I got one week's worth of prescription and a doctor's appointment is usually about a 3 week wait.”

Some participants were provided with no medication upon leaving prison.

“They should be [giving] a prescription but they didn’t. They took all my medication off me. I was left with nothing and needed antidepressants. They wouldn’t give me a prescription.”

“Didn’t get none. The drs told me the prison didn’t let them [know] I needed meds and I needed meds for my alcohol addiction.”

“They didn’t give me a prescription. I needed my bipolar meds and still haven’t got them (been out [of] them 7 days).”

It was interesting that people also wanted to be more informed about the medication they were taking. Some struggled to talk to a community GP about their health and explain how certain medications helped them feel well.

“I was in with the doctor and couldn’t tell them why I was taking some of my medications, and that caused problems because she changed them and things still aren’t right, so more info and a list to go to the dr [with] would have been good.”

“People should have an understanding of their meds, what they do and the importance of taking them. That way they can make sure healthcare give them the right prescriptions, for a long enough period, before release and they can talk to their GP.”

Making time to discuss medication and ensure medications form part of release planning was seen as a priority for people leaving prison. This includes ensuring sufficient medication is provided to see individuals through until they can consult with a community GP, registering with a GP prior to release where possible and ensuring medication is ready for those leaving prison. It also includes situations where there is a release from court, which at times was seen to ‘catch services out’.

“Be ready for when people are released from court and don’t go back to prison.”

“You need to make sure medications are not delayed for people leaving prison.”

“No prescription was ready for me so it took ages but I’ve got it now. I need sertraline cos if I have gaps it messes my head up.”

Often, we heard that improved dialogue between prison healthcare services and community services would ease the process of obtaining medication for individuals leaving prison. An earlier consideration of medications and transfer of medical information were suggested to reduce delays in obtaining medication.

“Would be better for GP to be sent the medication information before release so there’s not a delay.”

“Prison healthcare teams need to transfer medical record to local GP (once user is registered with local GP). Improve data sharing between prison and community teams.”

“Staff prepare things earlier to make sure all there for release and also to give a longer period to help with any delays. Prison Dr needs to tell that person’s Dr out of prison.”

Others suggested that a linkage between prison healthcare departments and community pharmacists would be helpful and, for those with limited transport links or limited mobility, pharmacy deliveries were also viewed as helpful.

“Dispensary deals with your local pharmacy while waiting to register with GP. I’ve heard people leave without a prescription and then suffer.”

“Get it delivered, especially as I have health problems that mean I can’t walk far.”

ACCESS TO COMMUNITY HEALTHCARE SERVICES

When asked, 43% of respondents stated that they needed to access healthcare services in the community.

Of those needing support, 61% were male and 39% were female, 66% were white and 33% were of an ethnic minority. Across this group was a range of ages, although no one under 21 years old reported requiring access to a community healthcare service.

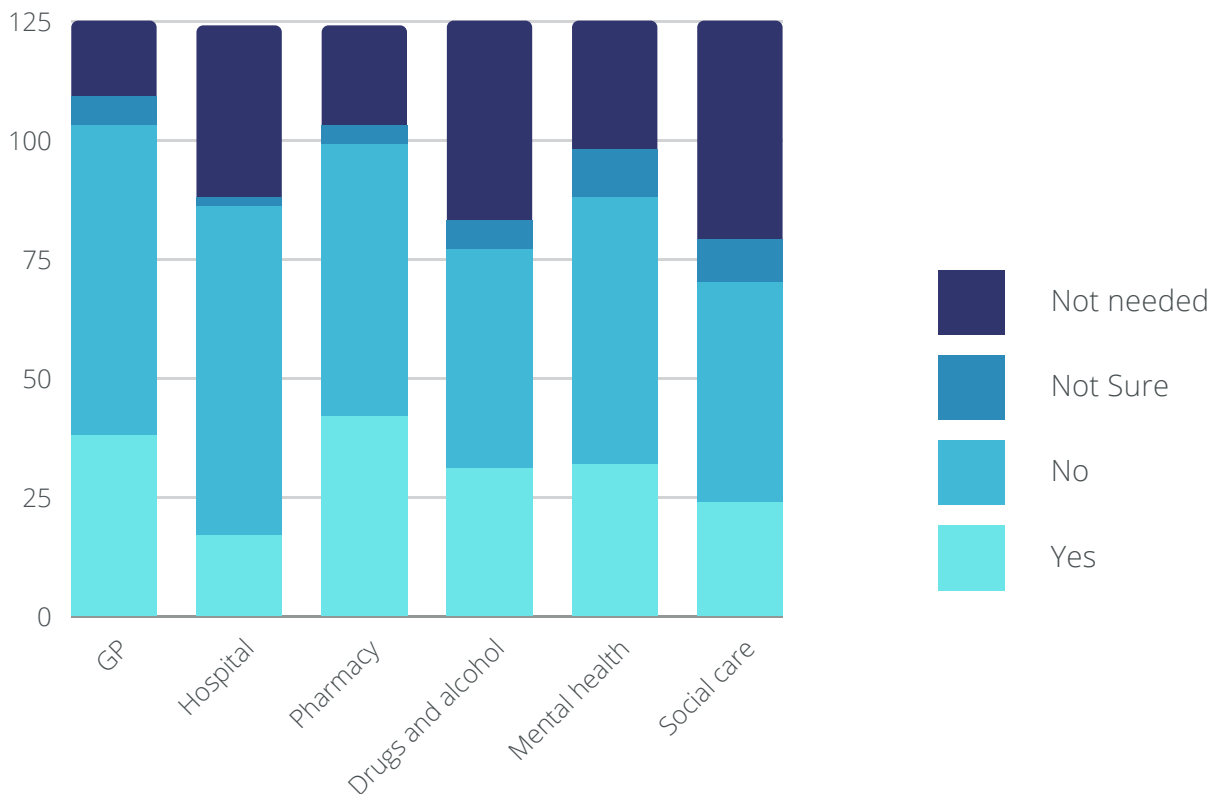
Did you need to access any other healthcare services when leaving prison?

Yes	43%
No	51%
Unsure	6%

Exploring the services with which individuals needed help with access to healthcare services after release, the greatest need to emerge related to GP and pharmacy services while the lowest need related to hospital treatment and social care. Full responses showing where help with access was required are shown below.

- 30% accessing a GP.
- 14% accessing hospital treatment.
- 34% accessing a pharmacy.
- 25% accessing substance misuse services.
- 26% accessing mental health services.
- 19% accessing social care.

Have you been helped to access any of the following health services since leaving prison?



Participants were given the opportunity to comment on any healthcare services needed after leaving prison. Of those who responded, the number of people citing multiple needs was notable and the range of services mentioned is broadly shown below by theme.

- 26% mentioned substance misuse services

"I was on a methadone script when I left prison – and have been on this since 1999. I used to be a heroin user – and then they introduced methadone. I have done a few detoxes but always end up maintaining on 70 mls. I pick up twice a week. The prison SMS made an appointment for me before I left. I was given an appointment on the day I left. I had to go to probation the day I left too, and then had to go and pick up my prescription. There was too much to do when I first got out."

"I needed to get housing and drugs and alcohol but they weren't readily available. Also setting up benefits was an uphill struggle."

- 24% highlighted a need to see a dentist

"I wanted to go to the dentist, but was waiting for benefit to prove I was entitled to free dental treatment so that was difficult because I was in pain and hadn't seen a dentist all the time I was in the prison."

- 20% reported a mental health need

"I went to NA meetings but needed to see a psychiatrist. I got support from probation for this."

- 12% needed to see an optician

"I need to see an Optician as never got seen in prison and still waiting for dentist."

- 8% disclosed poor liver health and a need to see a dedicated service

"Liver problems, liver specialist but I did it off own bat."

- 4% spoke of a neurodiversity need

"I have ADHD and Mental health issues and I couldn't see anyone. I went 5 days without meds so went to [A&E] in Sidcup."

- 4% highlighted the need to access a specialist service

"I was having an investigation on lump found in breast, but thankfully was benign."

- 4% reported maternity needs

"I needed help with my pregnancy, needed to get scans and checks."

- 4% spoke of the need to access social care

"I needed help with my mobility, because I can't walk far without a stick."

Alongside this, participants were offered the opportunity to suggest what more could be done to help people understand and access community healthcare services. Overall, 153 comments were provided. The top five themes are set out below, although healthcare – being more central to release planning – and Through the Gate (TTG) services emerged as overwhelming priorities.

Healthcare addressed in release planning/Through The Gate: 52%

"In resettlement – there's a real gap talking about health – could do with a prison leaver health pack that provides relevant contact details for health services. Services should take time with patients to understand their needs prior to release to ensure there is a smooth transition."

"You need to register prison leavers prior to release so more needs to be done to know which location they are getting [released] to. People shouldn't be homeless after prison. You need to know what address you are going to else you will not know what doctor to register with. Not everyone goes to approved premises and even if they do, you don't know till the day you leave the precise location. So impossible to go to a dr and no wonder people can't get the help they need."

"Through the gate care plans in place. I left prison feeling unsupported, lost and alone with nobody to turn to and did not know what services to go to."

Signposting and improved information: 18%

"Giving us phone number to do so, with more signposting or a guide on how to access services in the community."

"Feed us lots of information, more help setting up outside help."

"Leaflets and explanations. More advice."

Improved access to community healthcare services: 10%

"I've had to wait nearly a year to see a psychiatrist online so it would be better if waiting times were better."

"It's hard to get GP appointments. They should make it easier as it's too hard."

"I found registering with a dr very hard! I had to ring 111 on 2 occasions to get an emergency prescription."

Dedicated mental health services: 7%

"Organise mental health help and support. Someone to talk to like a [counsellor] or psychiatrist. Mental help is needed. It's [a] different world when you come out."

"Community mental health services have been a nightmare to access - you need a phone - this is the first time I've ever had a phone - and they wanted to make a phone appointment for an assessment - and I struggle to remember passwords. It took me 6-7 weeks before I managed to understand the process and get through to someone. Sometimes I [also get] frustrated. I gave up and I'm trying to get help because I really need it."

"Mental state on release, part of probation that offers therapy or support for mental health."

Accommodation: 5%

"Housing is the biggest one. It took me ages to get somewhere and I was on the streets. It took about a year to find somewhere to live."

"I committed an offence cos I was on the streets. They should give you somewhere to live once you leave."

"Accommodation help so no one is homeless after a month out of prison."

Importantly, 5% of comments evidenced the positive experiences of some when leaving prison.

"Quite good, healthcare assessed me on leaving prison, set me up with a GP etc."

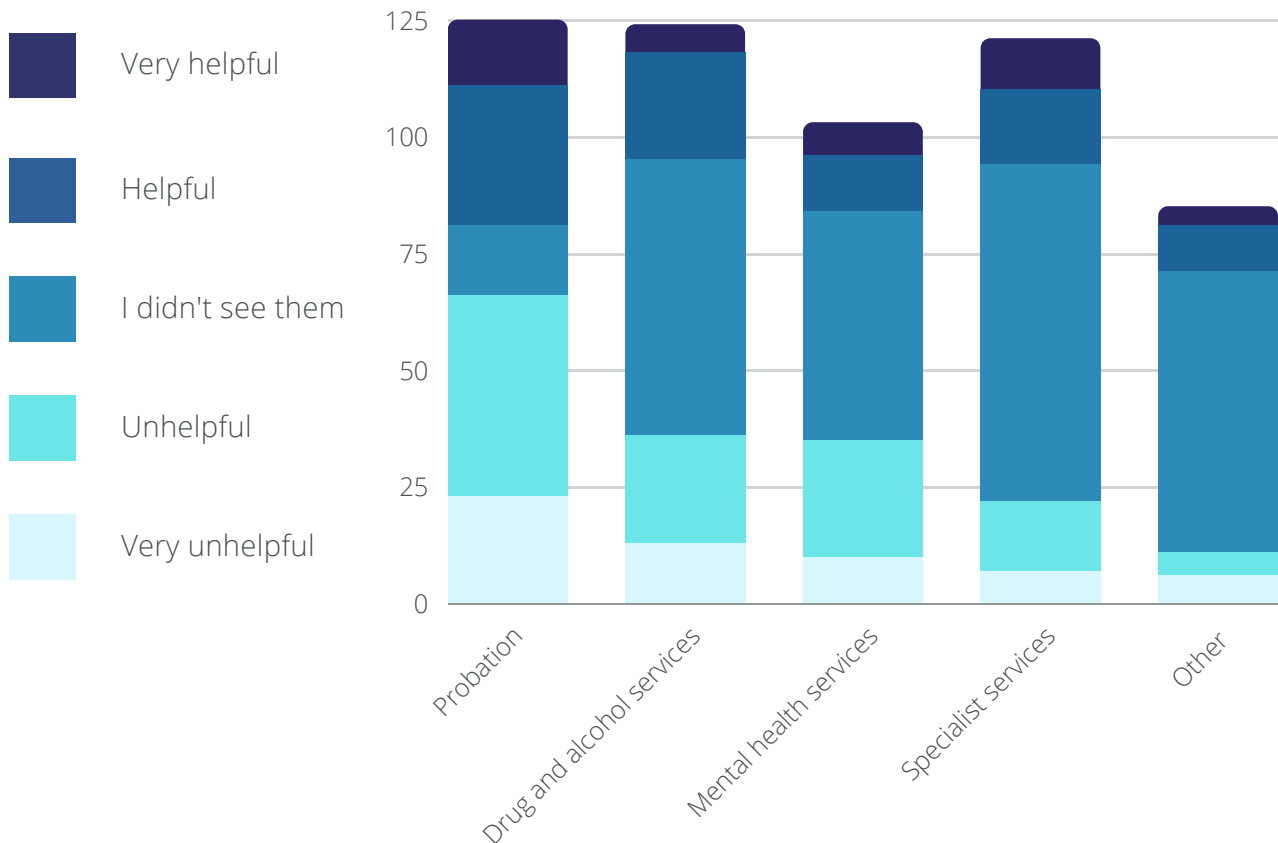
"I got sign posted to local services in my release area."

“Probation were helpful and directed me to the local community hub where I can get a hot breakfast, a shower, clean clothes 3 x a week. This has really helped me as I’m homeless.”

“I think people who leave prison get a good amount of support now. They set it all [up] before I left.”

The survey looked at the support available to prison leavers when accessing community healthcare services.

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



It was understood that not all prison leavers used services. Indeed, the survey results revealed that just over a tenth of individuals leaving prison did not use probation and less than half used substance misuse or mental health services. Even less used specialist services or charities although, for those who did use any of the services highlighted, those services were shown to be of some benefit in regard to accessing community healthcare services.

In terms of accessing healthcare services after leaving prison:

- probation were helpful for 44% of the people who used them.
- drug and alcohol services were helpful for 43% of those who used them.
- mental health services were helpful for 53% of those who used them.
- specialist services or charities were helpful for 54% of those who used them. Marginally, these services appeared to be the most enabling, albeit they were the least-used by people leaving prison.

“Gravesend hub is my therapy. This is pucker. It couldn’t be any better. I used to be the chef here but I’m living in a tent now and they help me with so much with everything including health.”

“The Muslim Women in Prison Project has been invaluable. I had lots of trauma to deal with and [they] linked me into local services.”

Another common response related to family and friends (who were sometimes former prisoners) enabling participants to access wider community services.

“My GP was very supportive but I also relied on my friends/colleagues who understood what I was going through and helped me get support.”

“My family helped me no end and I got the help I needed and they continue to help me. 8 weeks after release, I felt very traumatised, panic attacks, sirens were setting me off, loud noises and bangs. My family recommended therapy and so that was the best source of support, as well as help from former prisoners.”

It was also notable how self-determination acted as a motivator to accessing community healthcare services.

“It was lovely to access healthcare like a normal person. The whole system is designed to withhold treatment until crisis.”

“Probation did not ask me about my health. It was come in, sign these forms, tick [these] boxes - you're lucky if you get your appointment. The GP can be difficult to see in the community, but I have capacity to fight my corner. I don't think others have that. It took ages and it was long winded and frustrating. I did it myself.”

Despite the help and support available, in some instances individuals continued to face difficulties in accessing the service they needed.

“I did get help from housing, but the process was a nightmare. I almost backed off.”

“Yes, I got support from the drug and alcohol service but after a lot of chasing.”

WELLBEING AND MENTAL HEALTH

Exploring the impact of leaving prison on individuals:

- 56% said that their mental health had declined.
- 16% stated that their mental health had remained the same.
- 28% reported improved mental health.

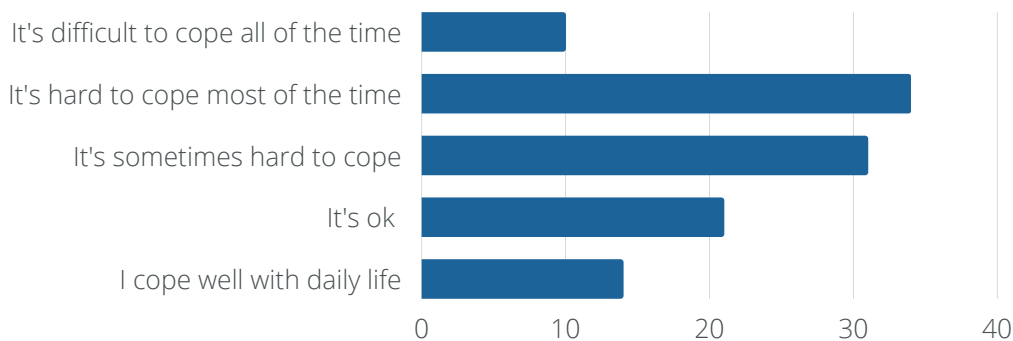
Looking at the different responses to this question by gender, significant changes are apparent. No marked differences were obvious when considering these experiences through the lens of age but ethnicity did present as a factor when considering the experience of release from prison in terms of impact on mental health.

People of mixed heritage reported the most negative impacts, with 78% highlighting a decline in their mental health, compared to 69% of black people, 50% of those identifying with as ‘other’ or Asian ethnicity, and 49% of white people.

In relation to the impact of leaving prison on mental health, most improved respondents were of an ‘other’ ethnicity, at 50%, followed by 32% of white respondents, 25% of Asian individuals, 23% of black people and just 5% of those of a mixed heritage.

- 10% found it difficult to cope every day.
- 34% 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, certain dominant themes arose. Overwhelmingly, people wanted more dedicated support for people who had been in prison to help them manage. There was a myriad of support needs mentioned – practical help such as support with form filling, managing a budget, obtaining ID, understanding and obtaining benefits, accessing education and gaining employment – as well as simple support such as navigating a new area. Some 53% of respondents noted that additional support related to leaving prison would help them cope.

“I needed support in accessing local services and to be made aware what services are available. I also needed help with finding jobs, how to cope with negative perceptions and how to get around the new town I had to move to.”

“Help with finances would have been a help, and running a house, normal things.”

Others wanted support from someone who could relate to them and their contact with the criminal justice system. Isolation and stigmatisation often developed as a result of imprisonment, and individuals felt they would have benefitted from peer-led interventions to help them cope with daily life.

“More time to talk and somebody who understands how difficult prison is and how leaving prison is anxiety-ridden. A peer mentor network would be good, nice people who care.”

“More support given outside and not just dropped in deep end. Make sure there is a support network setup to help do real work stuff, employment or basic shelter, reduce reoffending with income.”

“Some mentor service or somewhere you can actually speak to someone for advice and get actual support to get the help you need.”

The other notable theme relating to additional support was the need for a friendly person to talk to, which could help combat feelings of loneliness or isolation.

“Just someone to talk [to.] I have a supportive family but they don't really understand what I've been through, and so it would be nice for someone outside to have a chat with.”

“Someone to talk to who won't judge me. People look differently at you once they know you've been a prisoner.”

The next most prominent theme referenced support with reintegrating into the local community, joining community groups or activities with like-minded people, or just providing an opportunity to 'fill time', in order to reduce rumination on negative thoughts and worry. Many spoke of support managing the transition from prison to the community and how help navigating these changes would help them cope with daily life – a sense of purpose coincided with 'feeling part of something' after prison. Support reintegrating into the community made up nearly a fifth of all responses (17%).

“I think having the option to keep busy and have support there from people who understand. My family didn't get it and I was diagnosed with a long term illness when I was in prison with

no support or understanding of what was wrong with me. I think volunteering helped me but when I wasn't busy with that, boredom and bad thoughts could become a problem."

"A question of "what now?" hangs over me. I have a plan in my head, having been derailed by jail. Biggest problem was the press reports at the time. Nothing about the defence, just about the alleged offence. Overblown. It is really disruptive to my life and difficult to get back on track, get back involved in my local area."

"I wonder what's the point of [it] all? I'm at the age where I'm at the point where I think, "what was the point of my life?" I'm not suicidal - you just get to this age and you wonder about death. I remember being young and optimistic - useful. I think you get to this age and you think - what's the bloody point? What next? What's the purpose of it all? It's my age, I know, more opportunities, more social events. Just to be around people would be nice, that's why I liked prison so much, there was always someone to talk to, always something going on."

The final notable support related theme was gender/sex based support. This was highlighted by women wishing to access help in safe single-sex spaces. Previous trauma and sexual and domestic violence were referenced by some.

"Drop in centres for WOMEN ONLY, to help women feel at ease, to feel they are thought of. This will help self-esteem, self-confidence and wellbeing, and give them space, this is very important to me because of bad relationships."

"I could have done with some help with my ex - he was controlling, lots of women affected by this and need more help."

"Help to run my home. Dealing with the children, rebuilding stuff. Support with schools. Support with how to face people in community after leaving an abusive relationship. Support with how to change and move areas, a fresh start. Support with dealing with someone who has died when u come out of prison."

Safe and suitable accommodation was the next most common theme, where again it was notable that women did not always feel safe in the accommodation offered. Accommodation related issues made up 15% of responses.

"Women especially need the security of being released to a home of their own or with other women, not thrown in a hostel, HMO, support housing, or told to stay with family or friends who might be bad for them."

"I had been in for 5 and a half years but nothing had been put in place for my release and [psychologically] a secure, clean home is the best start possible."

"I was released to my ROTL address which was not the most suitable accommodation but it was better than being homeless as my homeless application was not being addressed."

Finally, despite the survey question centring on what can help individuals cope with everyday life, access to mental health services and (mental health) medications made up the fewest comments, albeit it remained a notable theme. Reduced waiting times, more visible community services, and improved access to medications and trauma therapy were all highlighted.

“People need to understand that prison is traumatic. I can't go to big towns. I am more secluded after prison as this is more manageable for me. I carry a lot of disturbance induced by my past. Prison adds to the trauma people already have.”

“We need mental health support. More support like therapy, making people aware of different coping methods, maybe community talking groups.”

“More recognition of [the] trauma we have and the feelings of being overwhelmed.”

“A lot of people leave prison with their heads messed up. Free counselling is crap but proper counselling normal people can't afford. That's why mental health is so bad. Therapy!!!! I left [with] heightened anxiety and paranoid; people knew I [had] been inside and [I had a] low mood.”

“Have medications ready and therapy for those who need it.”

SECTION SUMMARY

Notable disparities were present when considering the obtaining of medication on release. These disparities encompassed not only the amount of medication provided (ranging from one week to one month) but in some instances individuals receiving no medication at all on release; it is possible however that this could result from an unexpected release from court. Differences were also visible in experience depending on ethnicity, where more people from ethnic backgrounds reported receiving no medication upon leaving prison.

It was clear from responses that a more robust and consistent healthcare focus on release planning reduced medication breaks. Participants raised a number of ways in which the transition from prison to the community could be improved to reduce such breaks in medication.

Upon release, almost half of participants needed to access healthcare services and, whilst a range of services was required to meet the various needs, GP and pharmacy services presented as the most common.

Community services were seen as an effective means by which to connect to wider healthcare services, with specialist charities being the most enabling (despite less people using these). Family and friends were also noted to be supportive in aiding access to healthcare services.

Over half of participants reported a decline in their mental health when leaving prison, with women and people from minority ethnicities reporting a greater decline than others. Less than a fifth coped well with daily life after prison, and additional support was felt to be needed with living skills, reintegration into the local community, trauma management and obtaining secure accommodation. Importantly, women hoped for additional dedicated single-sex services and accommodation that was both safe and suitable.



KEY FINDINGS

UNDERSTANDING AND LEARNING ABOUT HEALTH

- Poor diet, high blood pressure and lack of physical activity were considered the most significant risks to heart health, although mental ill-health, illicit drug use and the prolonged use of certain medications were also seen as contributors.
- Chest pain, heart palpitations and breathing difficulties were the most frequently understood symptoms of poor heart health.
- TV, conversations with friends and family, hospital and prison 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.
- Cigarette packets, GP surgeries and hospitals were the most common locations in which individuals had heard or seen information concerning lung health.
- Harmful drinking/drug use, poor diet and genetics were considered the greatest risks to liver health.
- Abdominal or back pain, jaundice and yellowing of the eyes were the most commonly understood symptoms of poor liver health.
- TV, GP surgeries and hospitals were the most common locations in which participants had heard or seen information about heart health.
- During the previous year, fewer people had seen or heard information about liver health (30%), compared to heart health (42%) and lung health (40%), albeit a greater number were unsure when they had last seen or heard any such information.
- A greater number of respondents had seen or heard something about mental health during the previous year, compared to the other health conditions.
- Stress, being in prison and past experiences were considered to pose the most significant risks to mental health.
- Over three quarters of participants reported a mental health need; rising for those aged under 21, women and Asian participants.
- The internet or social media, GP surgeries and TV were the most common locations in which individuals had heard or seen information concerning mental health.
- Of all the health conditions, more people wanted to gain additional knowledge about mental health than any other condition.
- Social media, leaflets and TV were viewed as the most effective ways in which to share health messages.

LEARNING

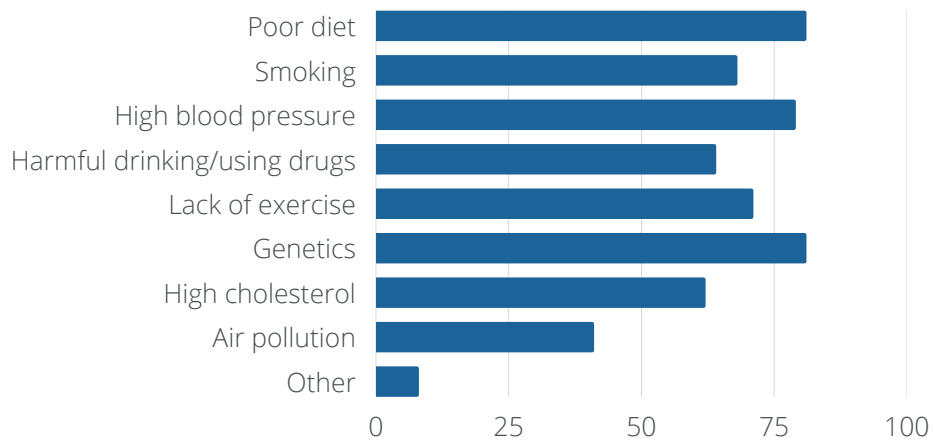
UNDERSTANDING & LEARNING ABOUT HEALTH

Heart health

When asked to identify the causes of poor heart health, the respondents cited the contributors shown in the table below; more than one box could be checked. Poor diet, high blood pressure and a lack of physical activity were seen to pose the greatest risks to heart health.

In the free text section, mental ill-health, drug use and prolonged use of certain prescribed medications were also cited as increasing the risk of 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:

- 39% related to chest pain.
- 27% noted breathing difficulties.
- 9% stated heart palpitations.
- 4% reported a change in blood pressure.
- 3% stated fatigue or lethargy.
- 3% stated weakness.
- 3% suggested an irregular heartbeat.
- 2% reported sweating.
- 4% highlighted being overweight or obese.
- 1% stated coughing.
- 1% reported pins and needles or tingling.

13% of participants reported having undergone previous treatment for heart health.

It was recognised by some that misuse of drugs had caused their poor heart health.

“I took steroids though and had chest pain but it was ok.”

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

Yes	13%
No	84%
Unsure	3%

“My heart problems were drinking related. Collapsed at the prom with chest pains. It was dehydration.”

“I call ambulances all the time when I go on a coke binge where my heart is hurting.”

“I’ve had bacterial endocarditis (drug induced).”

When asked what helped them feel better, most individuals responded that medical treatment had been beneficial, although some spoke of support from family and friends or a change to their lifestyle.

“Moving more and cutting out salt. 10,000 steps is a great way to get fitter. I got started with that.”

“When I’ve sniffed coke in the past, I’ve [had] heart palpitations. Ended up in hospital after pregabalin addiction. Living a healthier lifestyle now, swimming, eating better, not using drugs and alcohol.”

“Communication with a health worker. Support from family and friends.”

Importantly, one person mentioned a previous experience with poor heart health, but not fully understanding the diagnosis he was given.

“I have something with my left ventricle – but it wasn't explained to me very well in prison – can't be too much of a problem though – as I'm still here.”

Under half of respondents (42%) had seen or heard something about heart health in the last year. Most were unsure when they had last seen or heard any information relating to heart health.

Of those who could recall when they had last seen or heard any such information, the highest proportion noted that this had occurred within 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 locations/situations:

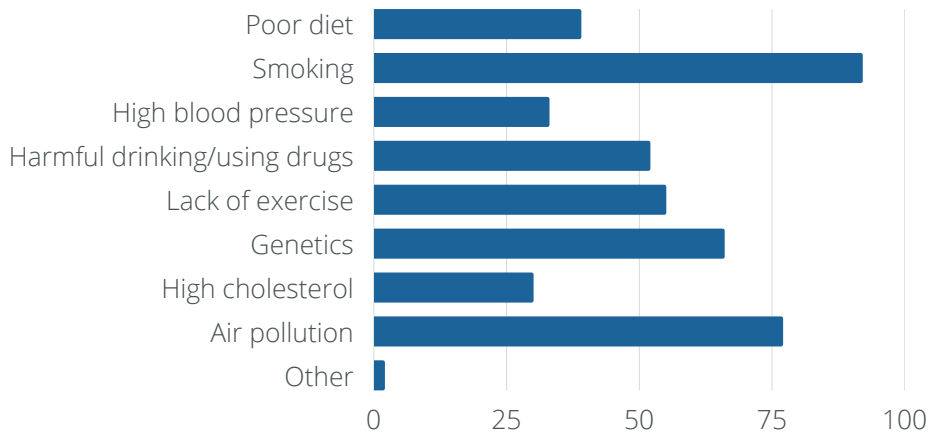
- 33% on TV.
- 13% in conversations with family or friends.
- 10% at the hospital.
- 10% in prison.
- 8% at a GP surgery.
- 8% on social media or online.
- 8% in a newspaper or magazine.
- 5% from a specialist charity.
- 5% in a public space (bus stop or car park).
- 2% in probation.

Lung health

When thinking about lung health, almost all (92%) respondents identified smoking as a contributor to poor lung health. The next most common answers were air pollution at 77% and genetics at 66%.

In the free text box, exposure to carbon monoxide, COVID-19 and chest infections were all seen to be further potential contributors to poor 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:

- 51% related to breathing difficulties or wheezing.
- 10% related to coughing.
- 9% reported chest pains.
- 14% spoke of an existing diagnosis (asthma and COPD).
- 10% reported coughing up blood.
- 1% said struggling to walk a long distance.
- 1% noted back pain.
- 1% noted persistent phlegm.

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

Yes	22%
No	70%
Unsure	8%

Over a fifth (22%) of participants had undergone treatment for lung health – almost double the number requiring treatment for heart health.

“I’ve got COPD and prone to chest infections like Bronchitis.”

When asked what had helped them feel better, receiving medical treatment was most commonly noted by respondents, as well as ongoing support from asthma nurses for those with this condition.

“Yes, for asthma. The medication made me feel better, Ventolin inhaler.”

“Checks by GP and asthma nurse.”

Several individuals had received hospital treatment for lung health, at the time of the survey and in the past.

“I have got cystic fibrosis and was in hospital 18 weeks, I have currently got pneumonia.”

“I’ve got COPD, it was so bad I was hospitalised, and have to be checked regularly.”

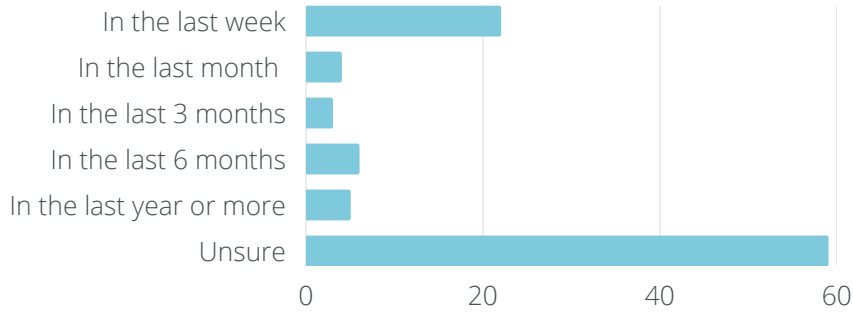
Some people recognised that lifestyle changes had improved, not just their lung health, but their overall health also.

“I’ve asked questions and got help with exercising more, which has helped with the breathing.”

“I gave up smoking because of COPD, it’s made a difference.”

Again, most participants were unsure of the last time they had heard or seen any information relating to lung health, although 41% had seen or heard something in the last year. Of those who could recall, a fifth (22%) had seen or heard something as recently as within the last week. Far fewer people had seen or heard something when reflecting on longer periods of time.

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



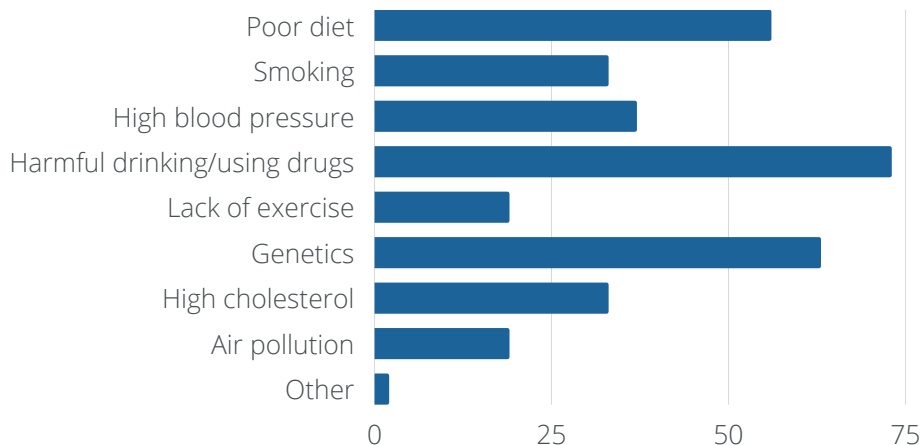
Exploring the locations or situations in which lung health messaging was last seen or heard:

- 30% were on cigarette packets or tobacco pouches.
- 16% were by way of the GP or the GP surgery.
- 16% were in a hospital.
- 11% were on TV.
- 7% were in prison.
- 4% were by way of family or friends.
- 4% were online.
- 2% were by way of probation.

Liver health

Exploring participant views on the causes of poor liver health, the most common cause identified was harmful drinking or drug use, as highlighted by 72% of participants and aligning with the views of those on probation. This was followed by genetics (63%) and consuming a poor diet (56%). In the free text box, participants suggested that the prolonged use of prescription medications and contracting a bloodborne virus were additional 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:

- 33% spoke of abdominal or back pain.
- 16% mentioned yellowing of the skin or jaundice.
- 11% mentioned yellowing of the eyes.
- 8% mentioned fatigue or tiredness.
- 6% said changes to urination.
- 5% said nausea.
- 4% mentioned swelling.
- 3% spoke of breathing difficulties.
- 3% mentioned changes to the appearance of the skin.
- 3% reported weight loss.
- 2% said uncontrollable shaking.
- 1% mentioned gallstones.
- 1% spoke of digestive problems.

Less than a tenth (9%) of respondents had required treatment for liver health – fewer than had required treatment for heart or lung health.

When reflecting on what had made these participants feel better, medical treatment alongside lifestyle changes were noted as having helped.

Have you ever needed treatment, care or support for liver health?	
Yes	9%
No	81%
Unsure	10%

“I had Hep C treatment and detoxed.”

“I have seizures from over drinking, and medical help was given.”

“I had to stop drinking, but have regular scans.”

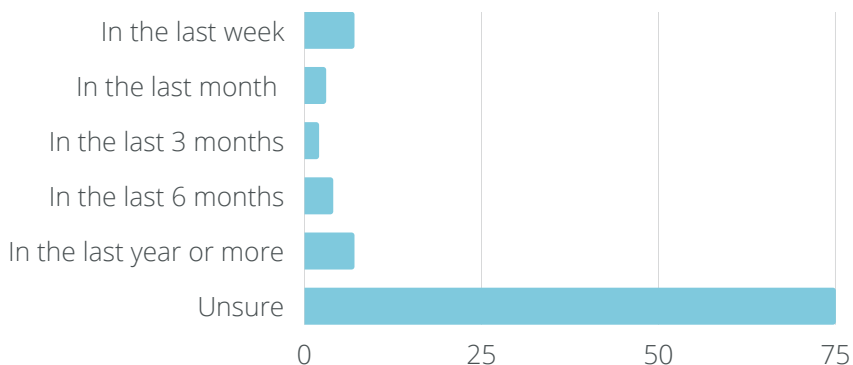
Others were still looking to improve their health, although some respondents had complex issues to manage.

“I have a damaged liver due to drug and alcohol abuse – I wanted an alcohol detox but they said I can’t since I’m on methadone.”

“Still working on it! It’s complicated as [I] have a few things to deal with.”

During the previous year, fewer people had seen or heard any information relating to liver health (30%), compared to heart health (42%) or lung health (40%), and a greater number were unsure when they had last seen or heard any such information.

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



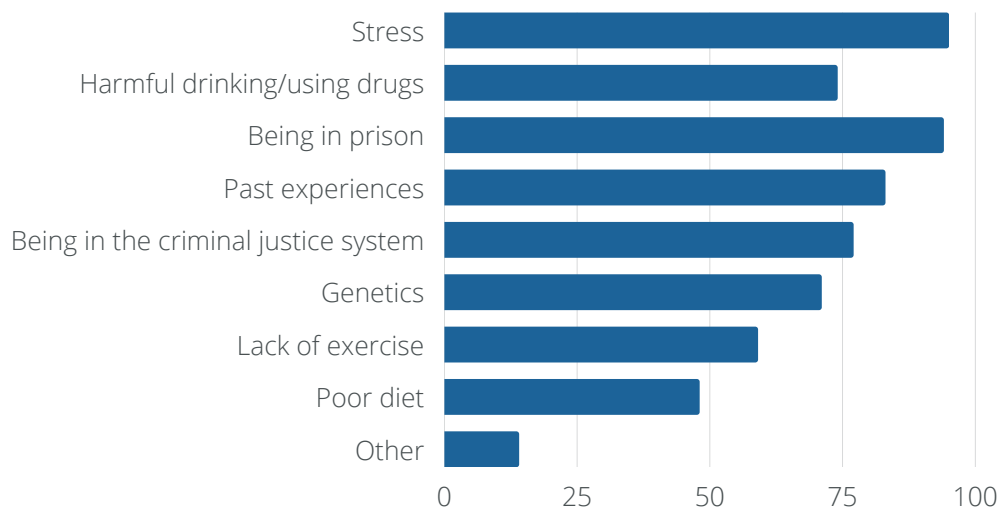
Around a fifth of participants responded to this question – significantly lower than the response level to the same question concerning health and lung health. However, information had been observed in the following locations/situations:

- 27% on TV.
- 23% when seeing a GP or at their GP surgery.
- 15% in a hospital.
- 15% from family or a friend.
- 12% from a specialist service (Hep C Trust or substance misuse service).
- 15% in a hospital.
- 3% in their place of employment or education.
- 8% online.
- 4% on the packaging of alcoholic drinks.
- 4% in prison.

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. Stress, being in prison and past experiences – as highlighted by almost every participant – were seen as the three most significant contributors.

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



In the free text box, social isolation, abuse and trauma, bereavement, homelessness, finances and relationship problems were all mentioned as further contributors to poor mental health.

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

Yes	76%
No	18%
Unsure	6%

Over three quarters of all participants spoke of needing treatment, care or support for mental health – around a fifth higher than the level of need of people on probation.

Notably, 100% of under 21 year olds reported needing support. Looking at the ethnicities of those needing help with their mental health previously, Asian participants were more likely to need support than any other group (88%).

Women were seen to be over a third more likely to need support with their mental health than men.

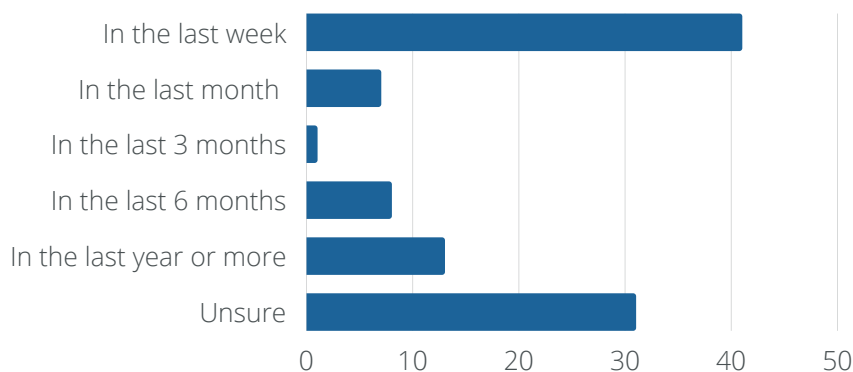
Participants provided a range of interventions that had helped them manage their mental health, the most common response being prescribed medication alongside talking therapies. Engaging in exercise and being able to talk to others had also helped make people feel better, as listed below:

- 40% said taking medication whilst engaging in talking therapies
- 14% reported medication (in isolation of any other intervention)
- 9% had benefitted from exercise
- 7% mentioned talking therapies (with no mention of medication)
- 7% mentioned talking (in general)
- 6% benefitted from support groups
- 4% said wellbeing activities such as yoga, mindfulness or meditation
- 3% highlighted faith based support, including chaplaincy in prison
- 4% reported keeping busy
- 3% said specialist services
- 3% had benefitted from speaking with someone with lived experience of prison
- 2% spoke of music
- 1% reported effective support from probation

In addition, 7% reported either receiving no support for their mental health or no support that had helped.

Some 69% of participants had seen or heard something about mental health during the previous year and 41% of these had encountered information within the previous week. More people 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?



The locations/situations in which individuals had heard or seen information in relation to mental health are listed below:

- 25% on the internet or social media (Instagram and TikTok were specifically mentioned).
- 16% when seeing a GP or at their GP surgery.
- 9% on TV (adverts or programmes).
- 8% from prison.
- 8% in a leaflet.
- 5% at probation.
- 4% felt that mental health information was everywhere.
- 4% from a mental health service.
- 3% on a poster.
- 2% in a public place (shopping centre).
- 1% on the radio.
- 1% in a hospital.

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

- 56% wanted to learn more about heart health.
- 53% wanted to learn more about lung health.
- 60% wanted to learn more about liver health.
- 89% wanted to learn more about mental health.

More men than women were keen to learn about heart health and liver health, although similar proportions of men and women wished to learn about lung health. Women were more interested in learning about mental health than men (98%-79%).

No discernible differences were apparent when considering the various ethnicities alongside keenness to learn more about health. Interestingly, however, and in contrast to people on probation, younger participants wished to learn more about mental health than physical health, with 100% of those aged under 21 years showing an interest in mental health, as well as 85% of 21-29 year olds.

Participants shared their views on which aspects of health it would be most helpful for them to have more knowledge. Most wished to be more informed generally about the various health conditions discussed herein, as noted by nearly a third (32%).

“Just learn a little more on it would be useful as it all helps.”

“Anything that can help me improve health. You get to my age and you need to know it all because everything gets broken.”

This was followed by 25% of participants who wished for improved understanding of where they could obtain help or support.

“Where can we get help? Organisation that can provide arts & crafts activities that help with my mental health.”

“Services that are available and how long the waiting time is when accessing it, please.”

A fifth wished for a deeper understanding of the signs and symptoms of ill-health.

“How to spot it, where to go and how to get better.”

“It will be helpful for me to know the signs and symptoms of heart health.”

Over a tenth (11%) would like to be provided with more information around how to manage symptoms.

“How to overcome it and coping strategies, thanks.”

“Effect of lifestyle on organs and how things can be improved, diet etc.”

A tenth indicated that they were caring for others and wanted further information either to help those they were caring for or to feel more supported themselves.

“Caring for someone suffering from one or all related ailments, seeking assistance financially for a loved one. I’m living with someone suffering from a mental health condition. What are the ways to cure being depressed?”

“How to cope with a loved one’s health issues.”

Seven percent of respondents spoke about the need for enhanced preventative measures.

“Things that stop any illness starting or getting any worse.”

“It would be nice to have everything that's easily accessible with correct information so people can take preventative action. Google can be a minefield of false information.”

It was apparent that participants had learnt the most about health through personal experiences, although nearly half had learnt the most about their health during their time in prison (46%). Government adverts were seen to be the least impactful when learning about health, at 22%.

Where did prison leavers learn the most about health?

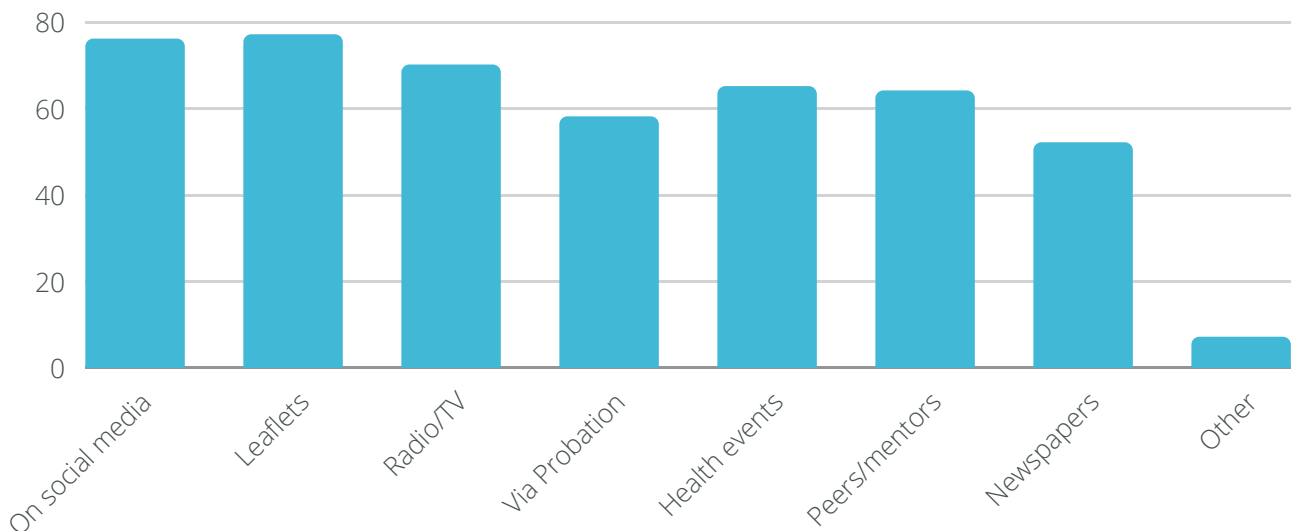
It was evident that people learnt the most about their health from talking to family and friends, by learning gained through their own experiences and by way of their GP.



In the free text box, people reported also learning about health via probation, online and by reading information provided to them with prescribed medication.

How can we best inform people who have been in prison about health?

It was clear from responses that individuals would like to be informed about health conditions in a variety of ways, with social media, leafleting and TV being considered the most effective means of sharing such health messages.



It was also suggested that prison and probation could take a more proactive role in informing these communities. Suggestions included probation sending text messages to individuals on probation to make them aware of health promotion days, and prisons developing health education programmes which could be co-led by prisoners. For those aged under 21 years and over 70 years, learning from peers was less preferable than other learning options. This was similarly the case for those from an 'other' ethnicity.

“Probation are bloody awful – though they could text people stuff like on mental health days and that – World Aids Day.”

“The health champions in prisons could do proper courses in prisons, not just drugs and addiction stuff.”

SECTION SUMMARY

People were able to recognise a range of risk factors and symptoms related to the heart, lungs, liver and mental health, as well as to cancer more generally.

Looking at where individuals 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 commonly highlighted and, in the case of lung health, tobacco products were mentioned.

Over three quarters of participants had personal experience of mental ill-health, compared to much lower levels of experience with heart, lung or liver ill-health. Previously being in prison was seen a significant contributor to mental ill-health, with young people, women and Asian people seemingly disproportionately impacted.

A range of interventions were helpful in supporting people to manage their mental health, with a combination of medication and talking therapies noted most often by participants.

Participants appeared to learn about their health through a range of ways, with most information being gained from their own personal experiences. Prison was also seen as an important place and time in which to learn about health.

An appetite was evident for individuals to learn more about all health conditions, although more wished to learn about mental health than physical health conditions, and this was especially the case for young people and women.

Whilst participants learnt about health in a range of ways and wanted to be informed about health through a variety of channels, social media and more traditional media were viewed to be effective and accessible for most.



KEY FINDINGS

CANCER SCREENING

- Individuals were able to identify a range of cancer symptoms; an unexplained lump or swelling, unexplained bleeding and coughing up blood were the most easily recognisable.
- Having a close relative with cancer, smoking and sunburn were viewed as the greatest contributing factors to developing cancer.
- 25% understood the eligibility criteria for bowel screening.
- 22% knew how health services screen for bowel cancer.
- 13% had completed a bowel screening kit the last time they had been invited (around 12% were eligible by age).
- If provided with a bowel screening test, most (65%) stated that they would probably complete it.
- Those who would not complete a bowel screening test were all male and two thirds were from an ethnic minority.
- An absence of bowel cancer symptoms appeared to be the greatest barrier to completing a bowel screening kit test.
- 22% understood the age criteria for prostate screening and 35% knew how health services screen the prostate for cancer.
- 20% had attended a prostate screening appointment, aligning with those who were eligible by age, although 60% of refusals were of an ethnic minority.
- 62% said they would attend a prostate screening appointment if offered one.
- Asian and black men were least likely to accept an invite to be screened.
- White men and men of an 'other' ethnicity were most unsure if they would accept an invite to be screened.
- The most common barrier to attending a prostate screening appointment was an absence of symptoms.
- Less than 10% felt that nothing would put them off attending.
- 41% of women understood the age criteria for cervical screening and 47% had attended their last cervical screening.
- 47% said that they were likely to attend their next cervical screening, with only one woman saying she would not.
- Women were put off mostly by feeling that cervical screening would be painful, although 22% said that nothing would put them off attending their next appointment.

- 61% of women were not aware of when they would become eligible for breast screening.
- 47% of women said they were likely to attend a breast screening appointment when invited, with all of those who were unsure being of an ethnic minority.
- Embarrassment, fear that the test would be painful and an absence of symptoms were the most common reasons not to attend a breast screening appointment.
- 25% of women knew how to check their breasts for lumps.



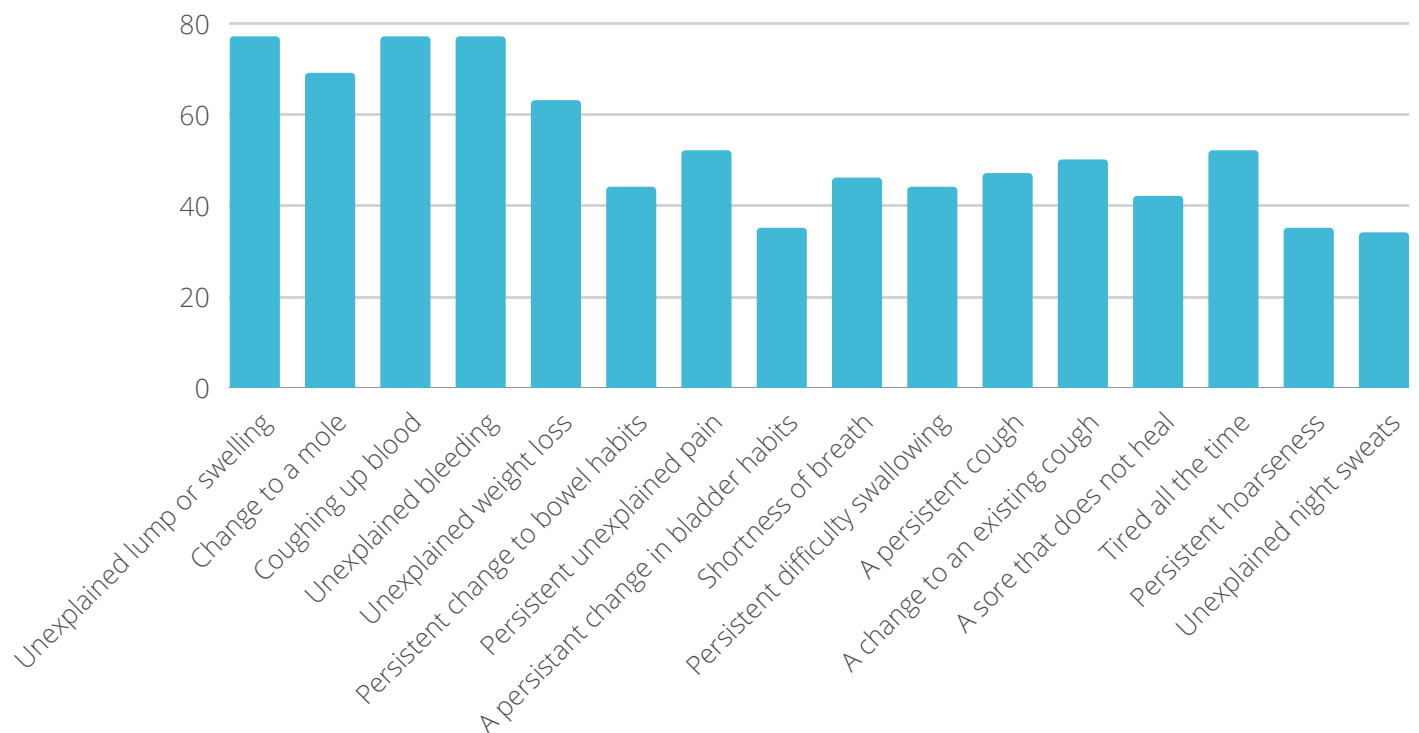
LEARNING CANCER

Warning signs and symptoms of cancer

Participants were able to identify a range of signs and symptoms of cancer; here, they were able to select more than one box. The symptoms most highlighted by participants were an unexplained lump or swelling, unexplained bleeding and coughing up blood, as noted by 77% of participants.

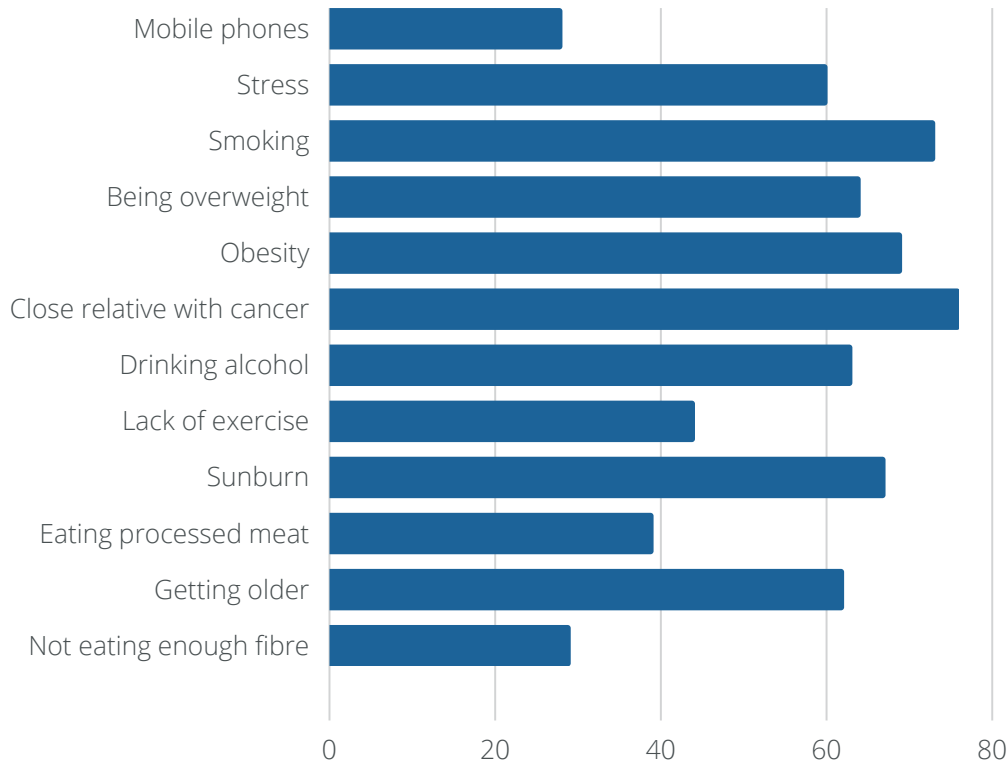
Unexplained night sweats, persistent hoarseness and a sore that does not heal were less likely to be viewed as warning signs of cancer, at 34%, 35% and 42% respectively.

In the free text box, loss of appetite was also cited as a warning sign or symptom.



Respondents were asked to consider what could increase a person's chance of developing cancer. Having a close relative with cancer, smoking, sunburn and obesity proved the most easily identified factors. A poor diet, and exposure to radio waves and 5G were also believed to increase the risk of cancer.

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



Bowel Screening

All participants were asked their views on bowel screening test kits, although only 84 responded to these questions.

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

Yes	25%
No	60%
Unsure	15%

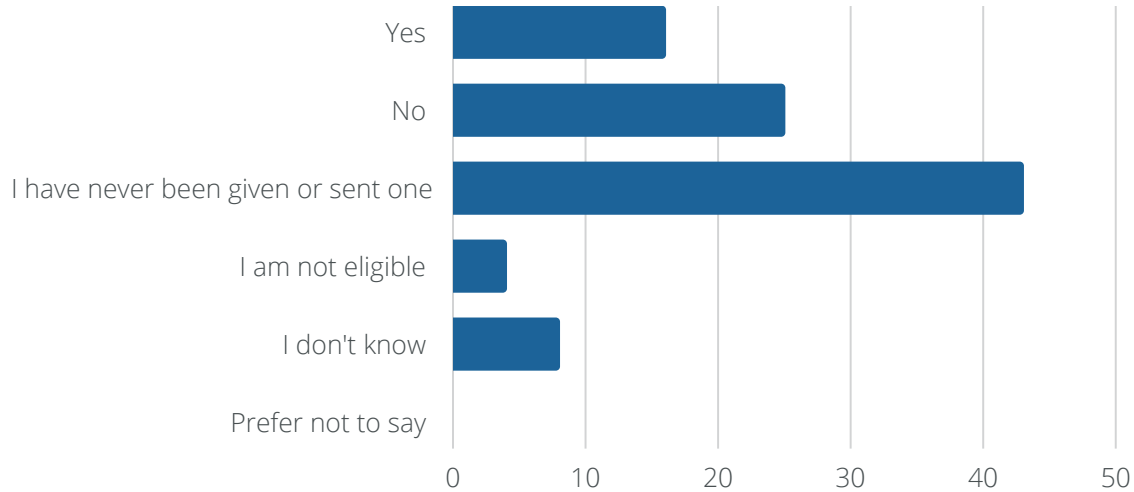
Do you know how health services screen your bowel?

Yes	22%
No	63%
Unsure	15%

Only around a quarter of individuals knew when they would become eligible for bowel screening and around a fifth were confident that they knew what the screening process involved.

When asked if they had completed a bowel cancer stool test kit the last time they were given or sent one, 16% of respondents had; 11% of participants may have been eligible for bowel screening when considering age. .

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



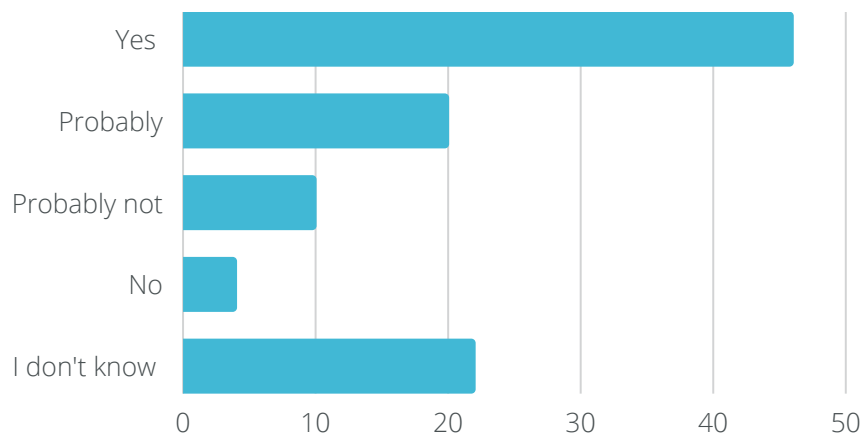
Thinking about the future, nearly half of participants said that they would complete a bowel screening test the next time they were sent or given one, while 19% stated that they probably would. A further 10% reported that they probably would not complete a screening test while 4% said that they would not.

Those who would not complete a bowel screening test were all male and two thirds were from an ethnic minority.

Of those who would probably not complete a test, 91% were male and, again, around two thirds (63%) were from an ethnic minority.

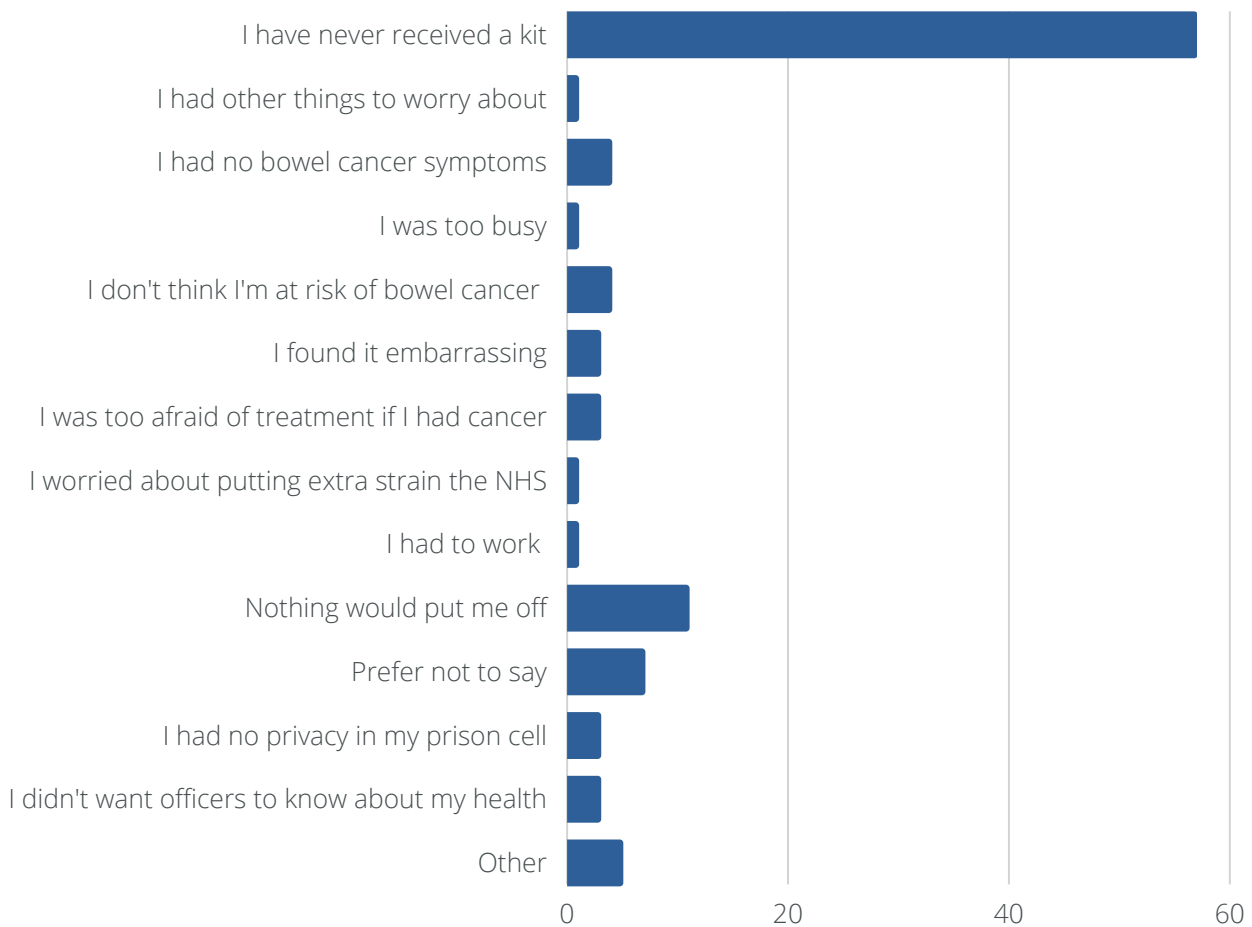
Nearly everyone who would not or probably would not complete a test was under 50 years old (91%).

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



Discounting those who have never received a kit, when asked what had previously discouraged participants from completing a bowel screening test kit, most of those showing no symptoms of bowel cancer were reluctant. Others did not feel at risk. In prison, privacy was a concern for some and others did not wish officers to know about their health.

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 50 men took part.

These participants were firstly asked if they knew when men became eligible for prostate screening, and only 22% responded that they did.

Do you know when people are eligible for prostate screening?

Yes	22%
No	76%
Unsure	2%

Do you know how health services screen your prostate?

Yes	35%
No	58%
Unsure	7%

A higher proportion (35%) of respondents were confident that they knew how health services complete prostate screening.

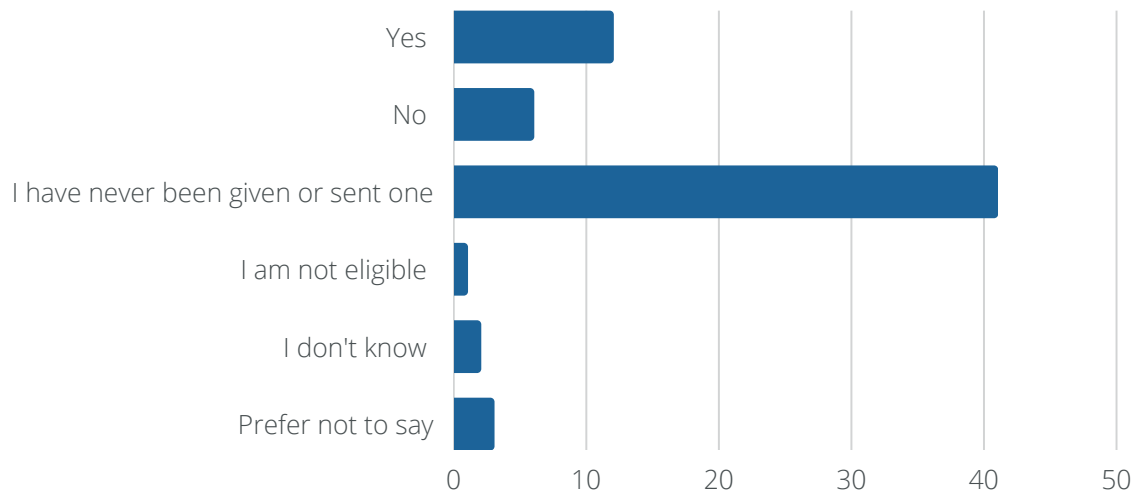
Over half (58%) did not know and under a tenth (7%) were unsure.

Most participants had not been invited to complete a test and it is understood that prostate screening is managed through an informed choice programme for prostate specific antigen (PSA) testing.

Nearly a fifth of participants had attended prostate screening when it was last offered, with 10% stating that they had not, fitting with the 20% who were aged 50 years or older who participated in this section of the survey.

Over half, 60% of refusals came from participants of an ethnic minority.

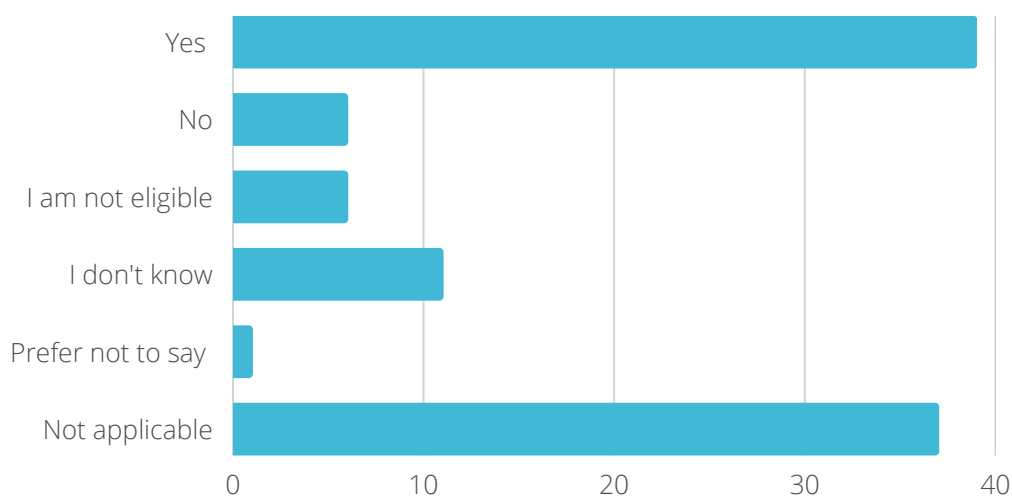
Did you accept a prostate screening last time you were offered one?



Less than half of male participants, 38% would accept prostate screening the next time it was offered, although 6% said they would not.

Asian and black men were least likely to accept prostate screening in the future. White men and men of an 'other' ethnicity were least certain as to whether they would attend a screening appointment.

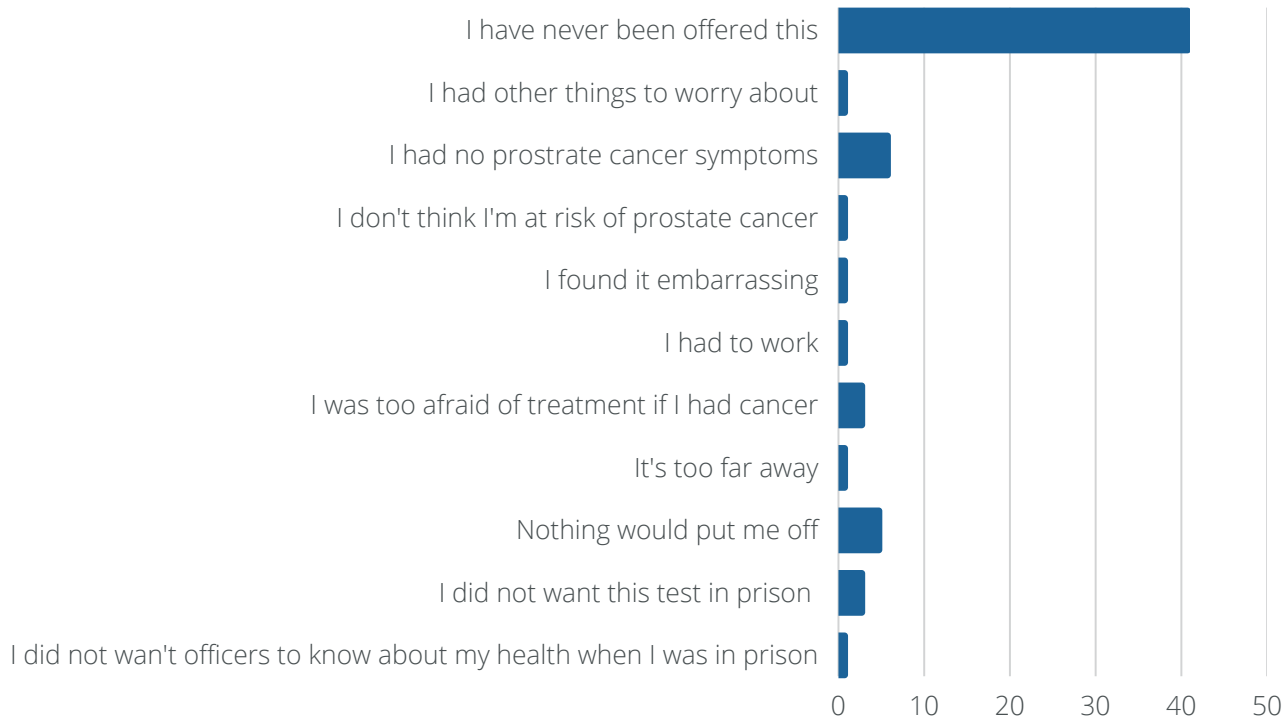
Will you accept a prostate screening next time you are offered one?



Looking at why someone might not attend a screening, and excluding the ineligible, the most common reasons include experiencing no prostate cancer symptoms, being afraid of treatment if cancer was detected and not wanting to be tested in prison.

Just 5% of participants said that 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

Those identifying as women were asked about their views on cervical and breast screening appointments, and 43 women took part.

The responses show that fewer than half of the women (41%) who participated understood when they would become eligible for cervical screening.

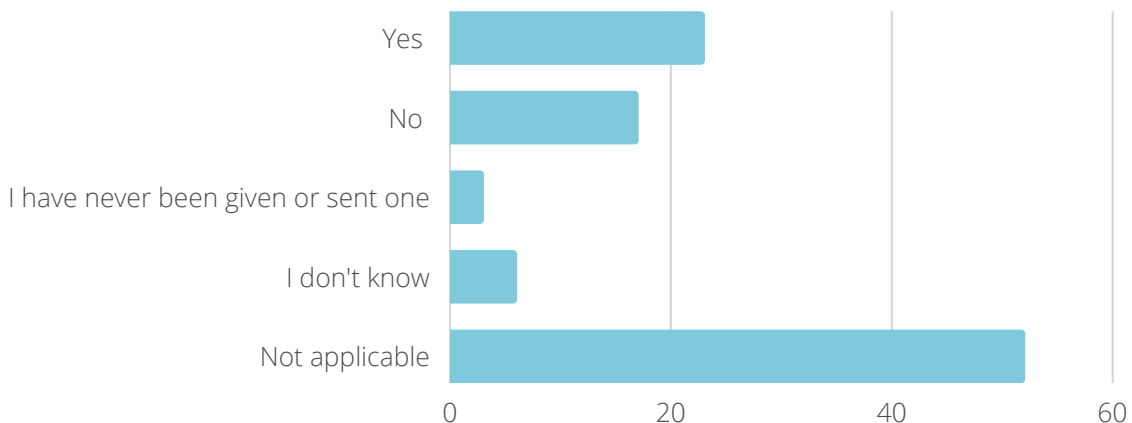
Over half (59%) did not know and 6% were unsure.

Less than a quarter, 23%, of the women had attended their last cervical screening, with over a third (35%) having not attended. If the responses from women aged under 21 years are removed, this reduces to 23%.

Some women were unsure whether they had attended, while 3% had never been invited to attend.

Do you know when women are eligible for a cervical screening?	
Yes	41%
No	59%
Unsure	6%

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

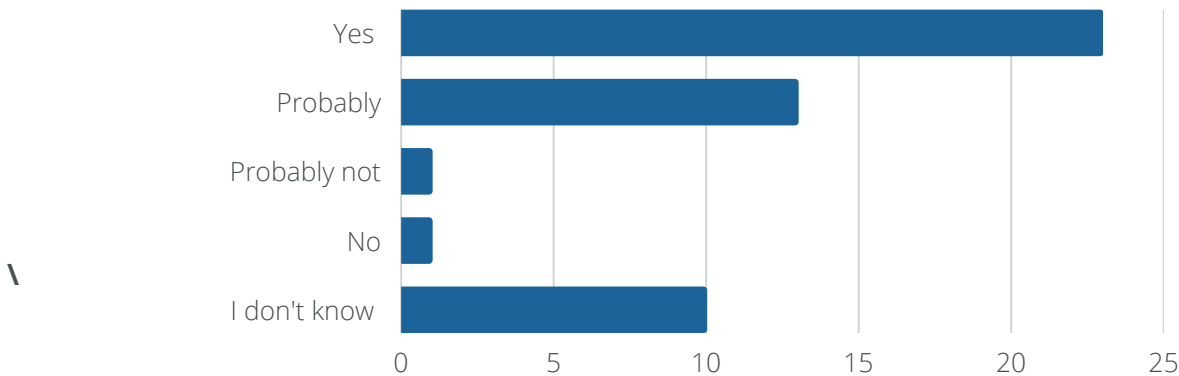


Thinking about the next time they are invited to attend cervical screening, 23% said that they would attend an appointment, with a further 13% explaining that they probably would attend.

Only one woman would not attend, although this may be due to her not needing a screening.

Only 11% demonstrated hesitancy, reporting that they were unsure whether they would attend future cervical screening or stating they would probably not attend.

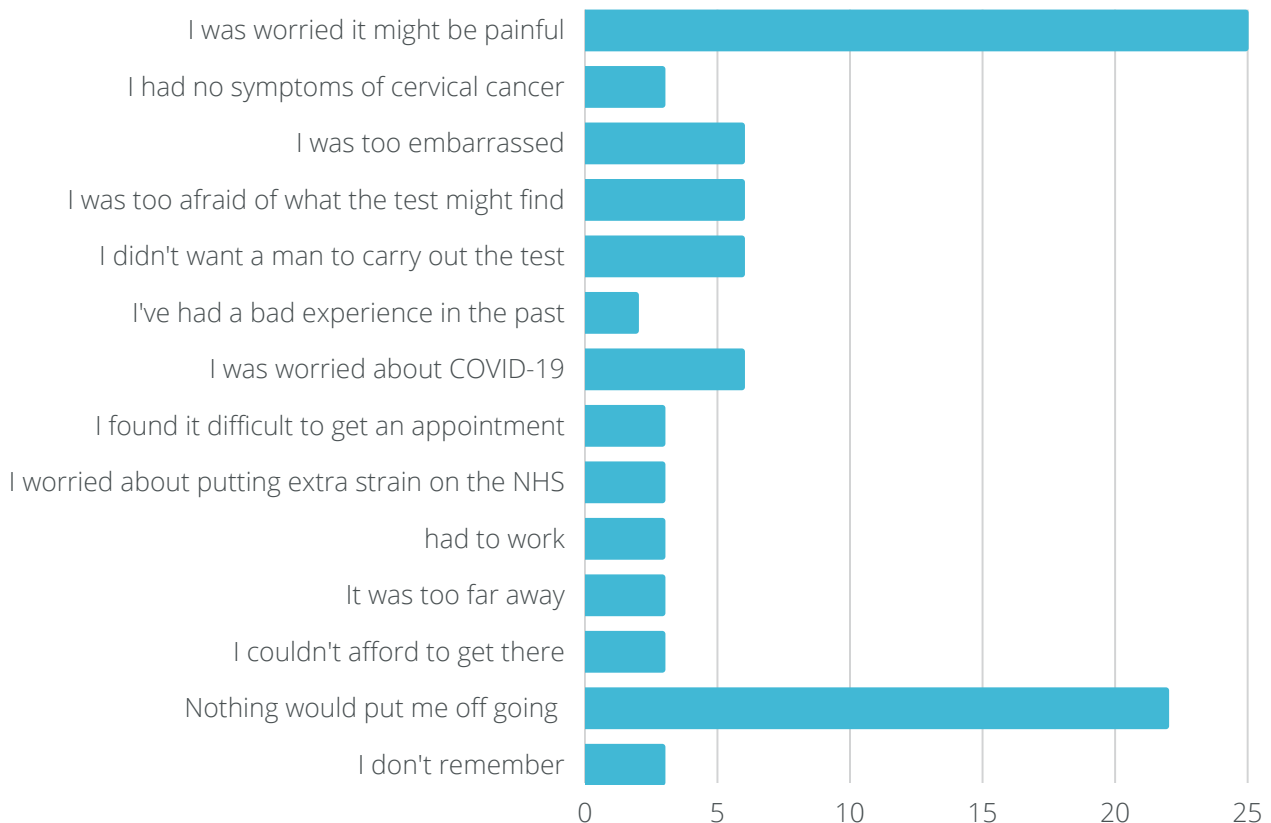
Will you go for cervical screening next time you are invited?



Pain emerged as the most common factor discouraging women from attending a cervical screening appointment. Embarrassment, not wishing a man to carry out the test and fear of what the test might find were equally discouraging factors.

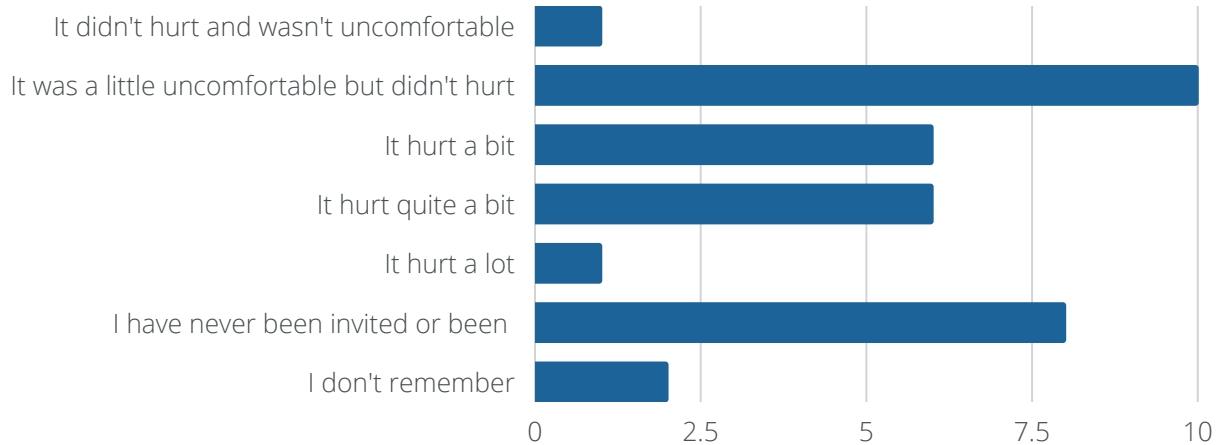
For over a fifth of women, nothing would put them off attending their next cervical screening invitation.

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



When asked to reflect on previous experiences of cervical screening, a tenth of women found the screening uncomfortable but not painful (10%). A similar number described that it hurt to varying degrees (13%). Only 1% of these found the screening hurt a lot.

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

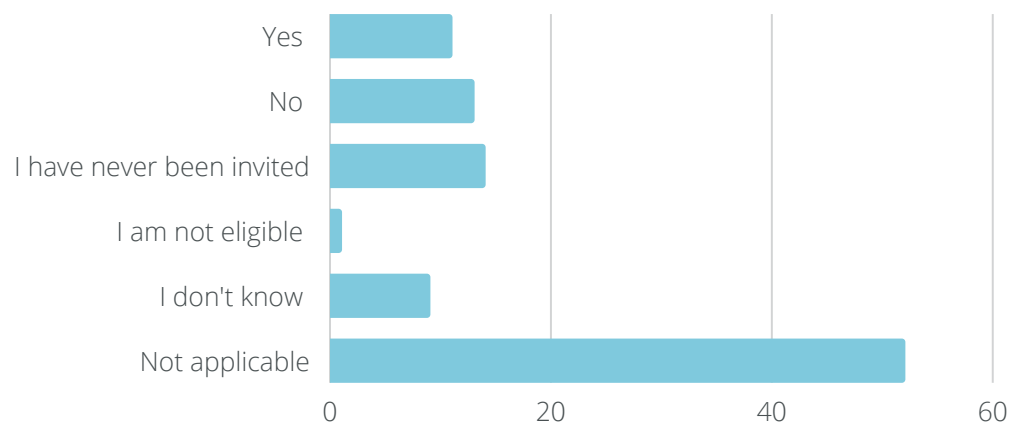
Do you know when women are eligible for a breast screening?

Yes	39%
No	61%
Unsure	0%

Turning to breast screening, nearly two thirds of women (61%) did not know when they would become eligible.

For most women it was not applicable for them to attend a breast screening (52%). Though we heard that 11% had attended a breast screening appointment, this is unsurprising given the ages of the participants. 14% explained they had never been invited and 13% said they had not attended when they were last invited. Of those who did not attend their last screening, none were of eligible age.

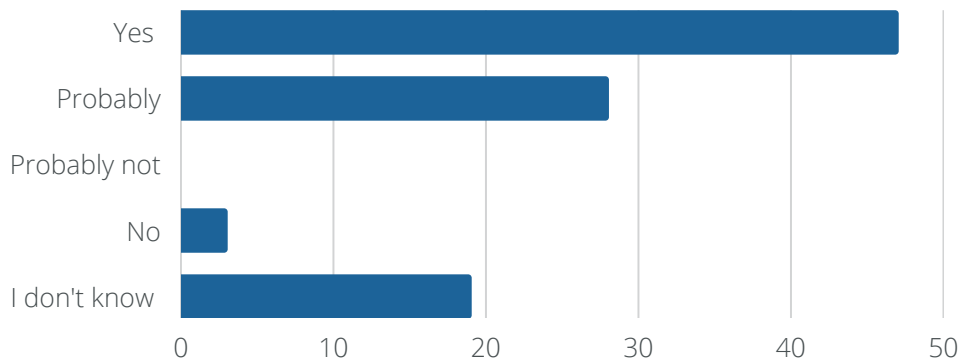
Did you attend a breast screening appointment last time you were invited?



Thinking about the next time they are invited to attend a breast screening appointment, less than half (47%) of the women said they would attend. Those who would not attend provided no reason.

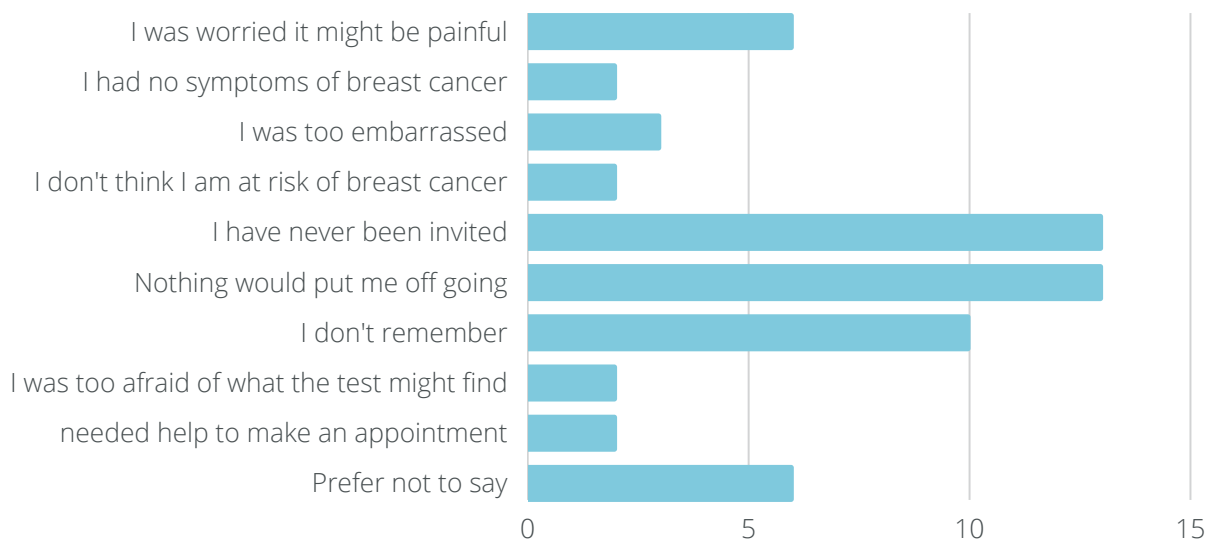
However, it is important to note that those who were uncertain whether they would attend breast screening if invited were all of an ethnic minority.

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



When looking at what can discourage women from attending breast screening, those who had previously attended an appointment reported concerns around pain, embarrassment and experiencing no symptoms.

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



Our final question asked whether women knew how to check their breasts for lumps, to which 25% responded that they did know, a further 62% were unsure and 13% did not know.

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

Yes	25%
No	62%
Unsure	13%

SECTION SUMMARY

Only a quarter of people understood the eligibility criteria for bowel screening, and even less knew how healthcare services screen for bowel cancer, meaning that those with experience of prison would benefit from additional health promotion aimed at this topic. It was interesting that being in prison was seen to discourage the completion of bowel screening kits in terms of privacy and individuals not wishing officers to know about their health. Only a small number had undertaken bowel screening, although this broadly aligned with those who may have been eligible by age.

Encouragingly, most would complete a screening kit when next provided with one; 10% of those who would not complete the test were male and most were of an ethnic minority.

With only around a fifth of men understanding when they would become eligible for prostate screening, and around a third knowing how prostate cancer is tested for, this strengthens the case for enhanced targeted health promotion. Again, distinct differences were apparent in relation to ethnicity, with more men from ethnic minorities failing to take up invitations to undertake the test than white men. This was compounded by Asian and black men also being the least likely to accept a test in the future, predominantly if no symptoms of bowel cancer were present.

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

Perceived pain during the screening was the most significant contributor to increasing reluctance to attend cervical screening, but only one woman said she would not attend her next appointment.

Nearly two thirds of women were unaware of when they would become eligible for breast screening and around half would likely attend their next breast screening appointment. All of those who were uncertain were from ethnic minorities.

Again, embarrassment presented as a common barrier to women taking up breast screening invitations. It was notable that only a quarter of women were confident in checking their breasts for lumps, highlighting the need for improved health promotion.

Indeed, it could be advantageous to provide additional information to all individuals in prison, to increase their knowledge around all health conditions and help them make informed choices to allow them greater autonomy over their health.



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.