

PATIENT PERSPECTIVES



CORE20 PLUS5



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BACKGROUND



Three surveys were co-produced with partners including NHS England and NHS Improvement and Cancer Research. They were sense-checked by individuals with lived experience of prison. The purpose of this engagement was to enable people in prison to share their views and support the work of NHS England's Core20PLUS5 improvement approach; and to inform health promotion in prison.

EP: IC comprises a team encapsulating lived and learned experience of criminal justice, and exists to centre lived experience within justice-based research and consultations. EP: IC's work always involves direct engagement with those experiencing a system, a service or a process. It seeks to present learning in such a way that it informs, with an overall aim of promoting co-production and improving outcomes for individuals facing social disadvantage.

This report is based on the outcomes of all surveys. Details of the focus of which are outlined in the table below.

Survey 1 	Heart health, lung health, mental health, health promotion and cancer awareness. Within the survey, a short explanation was provided around each health condition, with examples given.
Survey 2 	Bowel cancer screening.
Survey 2 	Cervical and breast cancer screening.

The surveys were distributed at the following prisons:

- HMP New Hall - (survey 1 and 3)
- HMP Coldingley - (survey 1 and 2)
- HMP Swaleside - (survey 1 and 2)
- HMP/YOI Rochester - (survey 1 and 2)
- HMP Standford Hill - (survey 1 and 2)
- HMP Elmley - (survey 1 and 2)
- HMP East Sutton Park - (survey 3 only)



A peer-led approach was applied. In each prison, individuals were trained and supported to gather views from their community and assist fellow prisoners with the completion of surveys. Our team met with peers weekly to support them and check on progress. A peer-led approach was championed for this work in the hope this overcame any language or literacy issues that may have existed for those who wished to participate.

In total, 510 surveys were returned.

- 312 people completed survey 1
- 134 people completed survey 2
- 64 people completed survey 3

The following tables given a quick view of overall participants across all surveys in terms of ethnicity, age and gender, though more details about characteristics can be found in each section of the report.

Gender

	Survey 1	Survey 2	Survey 3	Total
Male 	267	131	1	399
Female 	37	0	54	91
Did not say	8	3	9	20

Ethnicity

	Survey 1	Survey 2	Survey 3	Total
Asian	17	8	2	27
Black	33	12	4	49
Mixed heritage	20	2	4	26
Other	9	2	1	12
White	213	105	43	361
Did not say	20	5	10	35

Age

	Survey 1	Survey 2	Survey 3	Total
Under 21	7	0	0	7
21-29	68	1	14	83
30-39	83	0	26	109
40-49	63	5	6	74
50-59	46	63	9	118
60-69	27	41	6	74
70 +	12	23	0	35
Did not say	6	1	3	10

This report outlines the learning attained from all engagement.

It is broken into sections and key learning is provided at the beginning of each section. A summary is provided at the end of each section.

Where possible quotes have been included to enable the direct voices of people to be heard and illustrate points of interest throughout.



KEY LEARNING - SURVEY 1



- When asked about heart health, a mixture of responses were received in terms of knowledge and insight. The most common response related to people's understanding of preventative measures, such as taking exercise and eating a healthy diet.
- Only 3% stated that they knew 'enough or a lot' about heart health.
- Poor diet was seen as the most significant contributor to poor heart health, followed by family history and high blood pressure.
- Pain in the chest and arms were seen as the most crucial warning sign of poor heart health.
- When asked about lung health, most spoke of the perceived risks or preventative measures.
- Again, 3% stated they knew a lot about lung health, while 6% felt they knew only a little.
- Nearly all respondents (92%) recognised that smoking could cause poor lung health; 78% felt that air pollution was a contributor, while lack of physical activity was noted by 65%.
- Breathlessness was the most common response when considering the warning signs of poor lung health.
- When asked about mental health, the most common theme to emerge (noted by 24% of respondents) connected the term 'mental health' with negative or difficult emotions and feelings, or with a specific diagnosis.
- 13% viewed mental health as something changeable or as being part of a spectrum of feelings and emotions.
- Nearly three quarters, 70%, had heard about heart, lung or mental health on TV.
- Although mixed views were received around the question of the health issues individuals wished to hear more about, mental health was favoured (44%) over heart health and heart health (43%) was preferred to lung health (39%).
- People wished to hear about risk factors and warning signs, preventative measures and how to seek help.
- 14% of people had needed to know about heart health due to personal experiences.
- 13% of people had needed to know about lung health due to personal experiences.
- Double this, 30% of people had needed to know about mental health due to personal reasons.
- The majority learnt the most about their health from family and friends (41%), followed by a GP (39%) and then through their own personal experiences (38%).
- Individuals tended to favour receiving information by way of leaflets, health newsletters and through attending wellbeing events.

- Three quarters of respondents knew their height and just under two thirds knew their weight. Average BMI values were 29.5 for men and 26.7 for women.
- 58% were offered a blood pressure test upon arrival at prison, and 90% of those accepted the offer.
- 15% were offered a cholesterol check upon arrival at prison, and 95% of those accepted the offer.
- Reasons for declining testing included fear or worry of the outcome, feeling rushed through the reception process, not being asked and not feeling it was a priority in the early days of custody.
- 39% stated they had not exercise at all during the previous seven days, while 10% reported exercising every day.
- Reducing in-cell time, increasing gyms sessions and offering individuals choices around exercise were seen as the greatest encouragers to engage in physical activities.
- Many participants were making healthier lifestyle choices: 53% were increasing their physical activity, 50% were choosing healthier meals and 27% were reducing the amount they vaped.



PARTICIPANTS - SURVEY 1

Gender

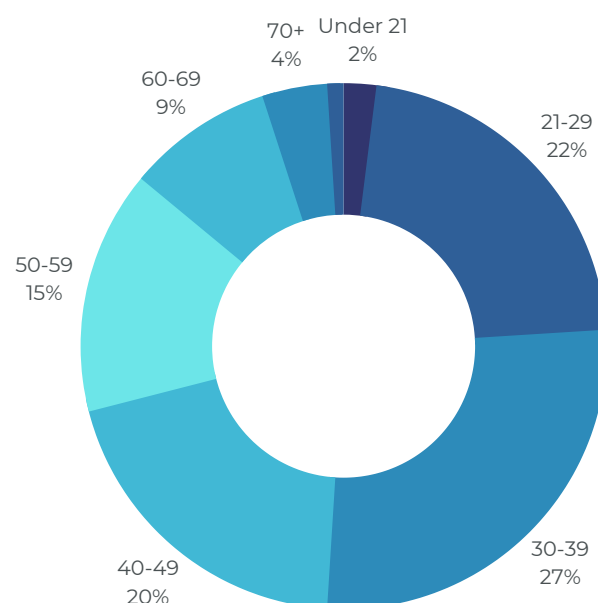
Most participants were male (88%). Women comprised just 10% of the overall total while the remaining 2% preferred not to state their gender. When asked whether they identified with the gender registered as their sex at birth, 2% stated that they did not.

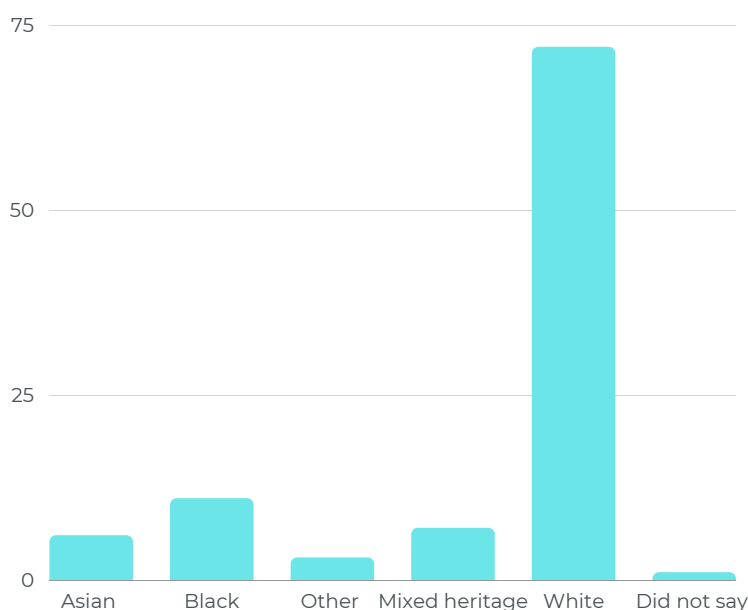


Age

A broad range of ages participated in the survey. The largest group of individuals, when banded by age are in the 30-39 year age category (27%), followed by those aged 21-29 years who comprised around one fifth of all respondents (22%).

A further fifth (21%) were 40-49 years old. Those of 50-59 years of age made up 15%, and those aged 70 years and older made up a further 4%. The smallest group by age were aged under 21, forming just 2% of the overall number.





Ethnicity

By far the most common ethnic identity of respondents to survey 1 was white at 72%.

Just over one tenth of respondents were black at 11% while 7% of mixed heritage took part.

Six percent of responses were from Asian participants, and just under one tenth were of an 'other' ethnicity.

A small number (1%) preferred not to state their ethnicity. In total, those from ethnic minorities make up over one quarter of all respondents (27%).



FINDINGS

What is known about heart health?

The survey asked individuals what they knew about heart health and provided a free text box in which answers could be expanded upon, which resulted in a range of responses. One common response (13%) saw respondents stating that they knew nothing about heart health.

“Nothing really except the heart keeps us alive.”

Similar numbers (12.5%) stated that they did not ‘know much’ about heart health.

“Not a lot, but my mum died from poor heart health due to cancer.”

Only 6% knew a little about heart health, with a further 3% stating they knew either a reasonable amount or a lot. In some cases, this was due to personal experience of managing poor heart health.

“Lots, as I have a heart condition.”

In once case knowledge came from a specialist publication sent to the person and training to become a cardiac mentor.

“Quite a bit. I receive Heart Matters magazine and am on a cardiac mentor course.”

Of the 3% who felt reasonably confident in their knowledge all were male, and all but one were white (the other person was of mixed heritage).

However, it is important to acknowledge the most common response when asked about understanding of heart health related to the preventative measures individuals can take to reduce poor heart health. Some 16% of respondents linked good heart health to a healthy diet and/or exercise. A smaller number linked smoking to poor heart health.

“It needs to be looked after. Do not smoke or eat high fat foods.”

“We need to eat healthy and exercise to keep a healthy heart.”

Interestingly, 6% of participants spoke about their knowledge of the function of the heart.

“It beats blood around your body.”

“Is the main organ in the body, it transports blood and oxygen around the body to keep you alive.”

Some spoke about the risks relating to poor heart health and the importance of maintaining good heart health or associated health conditions. These making up 15% of all respondents.

“You can get heart failure, angina, heart muscle disease, and they need eradicating quickly.”

“If you have a condition you need to take medication, as it is life threatening.”

Family links and genetics were highlighted by 3% of those who participated.

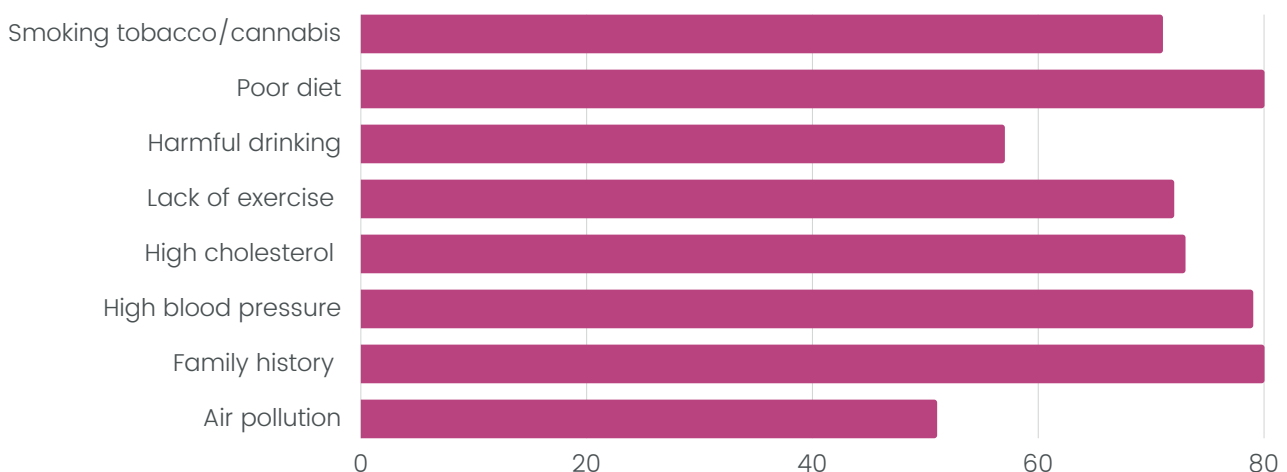
“I know you need to look after it as my father died from poor heart health.”

“A lot of people in my family suffer heart health – had heart attacks, cardiac arrests and stents.”

Finally, two individuals noted that heart failure was the biggest killer in the UK, while two further participants stated that they suffered from poor heart health.

The below chart shows responses to the question of what individuals thought caused poor heart health (more than one box could be checked). Poor diet, genetics and high blood pressure were seen as the greatest risks. Harmful drinking and air pollution were seen as the smallest risks to heart health, although remained a common response and highlighted by over half of all respondents.

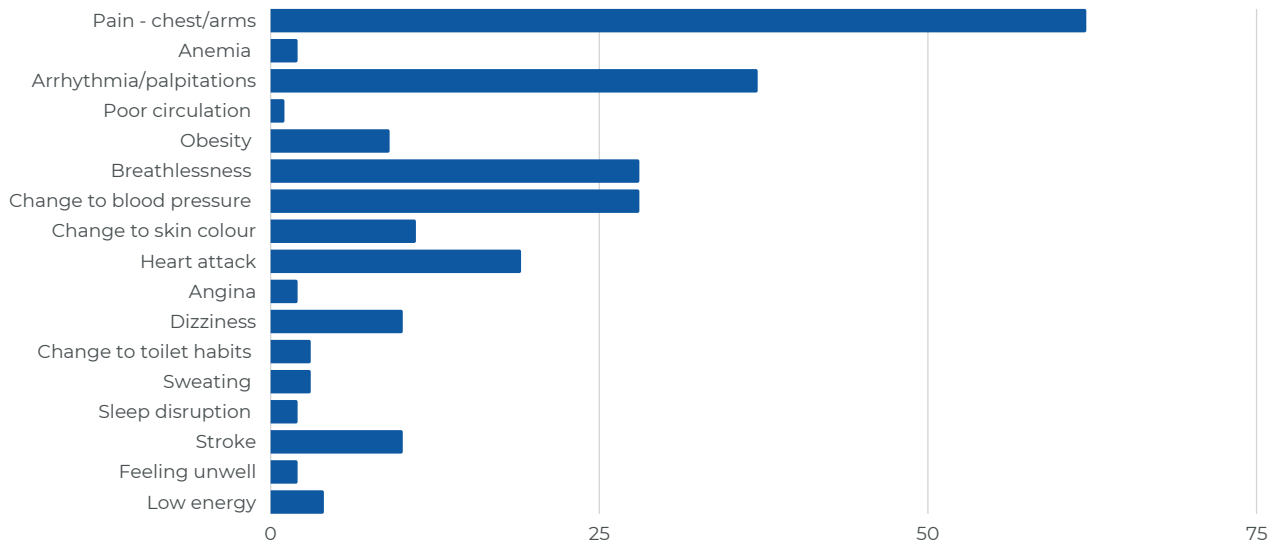
What do you think can cause poor heart health?



Stress, anxiety and substance use were all noted as further risks to heart health, shared by participants in the free text box provided.

The graph below outlines responses regarding participants' understanding of the warning signs of poor heart health. By some way, pains in the chest and arms were noted by the largest proportion - 68 individuals (22%). Experiencing palpitations or arrhythmia was mentioned by 12%. Around a tenth, 9%, highlighted breathlessness and changes in blood pressure.

Warning signs of poor heart health.



What is known about lung health?

When provided with a free text box for people to share their knowledge of lung health, 6% of participants stated they knew 'a little', with some of this knowledge being gained through personal experience.

Only 3% reported knowing quite a lot about lung health. Again, these respondents explained this understanding was gained through health conditions they had experienced.

"Quite a bit as I have got asthma and me mum's got COPD."

"I know a lot as I had pneumonia. I had a collapsed lung."

A small number spoke about the functions of the lungs when asked what they knew.

"The lungs provide oxygen to the body and most importantly the brain. Even a few minutes without oxygen to the brain can be fatal or cause lasting damage."

"Not much" was a response received from 11% of individuals.

"Not a great deal, only what I have heard and seen on the radio."

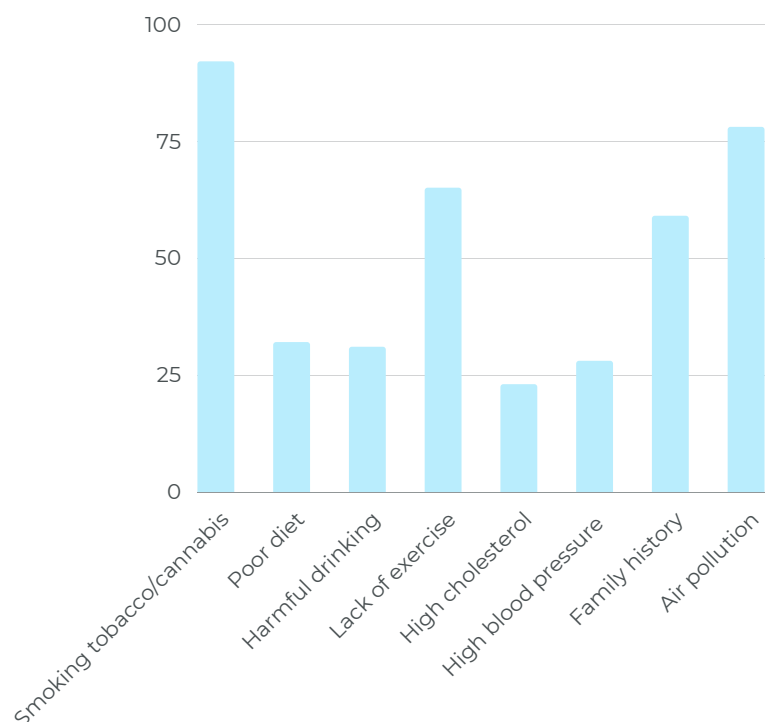
"Not a lot except it is good to keep lungs healthy by not smoking."

We asked about the causes of poor lung health (participants could check more than one box).

Smoking tobacco or cannabis was seen as the greatest risk at 92%, followed by air pollution at 78% and then a lack of physical activity at 65%.

High cholesterol (23%), high blood pressure (28%) and harmful drinking (31%) were viewed as least harmful to lung health from the options provided, although all were represented.

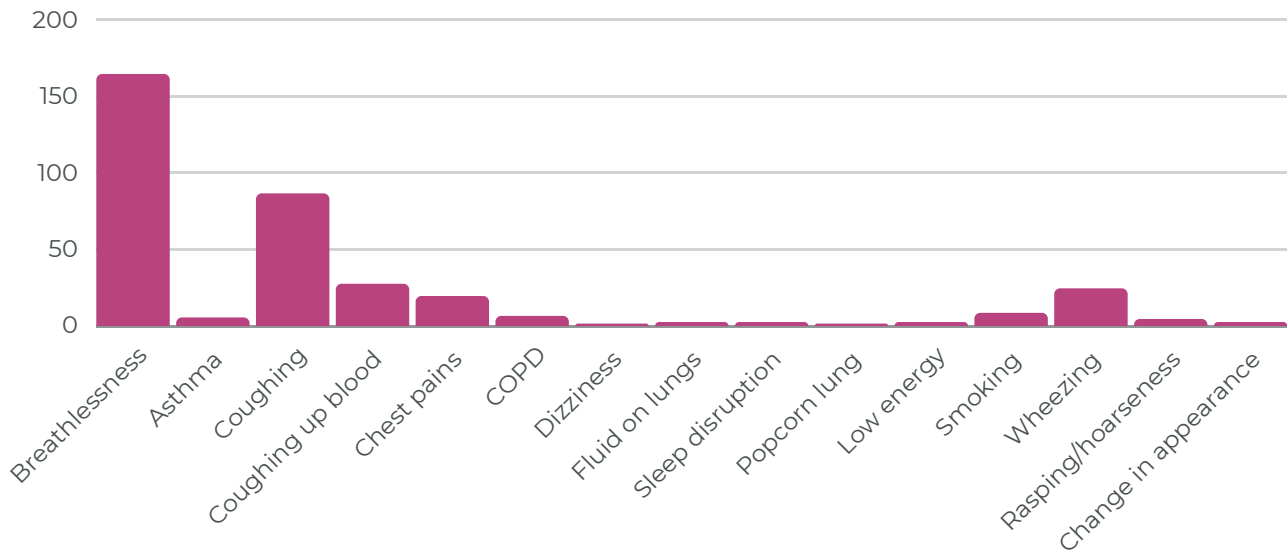
What causes poor lung health?



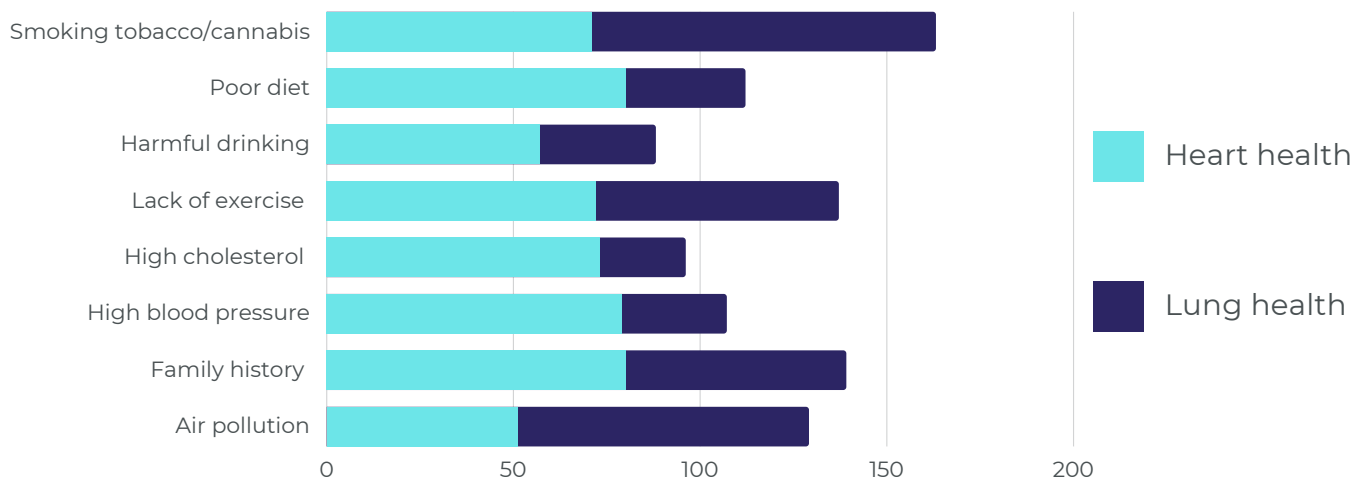
Wider comments included working with hazardous substances and not wearing appropriate health and safety workwear, while other health conditions such as mental health and TB were also mentioned as potential causes for poor lung health.

When asked about the warning signs of poor lung health, participants provided a range of responses, the most common being breathlessness or breathing problems which was highlighted by over half of all respondents (n=164). Second to this was coughing which 86 people mentioned (28%), while coughing up blood was specifically mentioned by 27 people. Wheezing was the third most common response, reported by 24 individuals (8%).

Warning signs of poor lung health



The graph below graph compares how people responded to the potential causes of lung and heart health.



- 71% said smoking can cause poor heart health compared with 92% for lung health.
- 80% felt that a poor diet causes poor heart health compared with 32% for lung health.
- 57% stated harmful drinking causes poor heart health compared with 31% for lung health.
- 72% agreed lack of exercise causes poor heart health compared with 65% for lung health.
- 73% said high cholesterol causes poor heart health compared with 23% for lung health.
- 79% felt high blood pressure causes poor heart health compared with 28% for lung health.
- 80% stated family history cause poor heart health compared with 59% for lung health.
- 51% agreed air pollution causes poor heart health compared with 78% for lung health.

What is known about mental health?

When asked what was understood about mental health, individuals again provided a variety of responses. 3% felt they knew only a little about mental health, and this was even the case for some who had received a mental health diagnosis.

“Very little but have been diagnosed about a year ago.”

Less than one tenth (9%) of participants felt confident that they knew “a reasonable amount or a lot”. Some had gained their knowledge through personal experience or by way of courses available in prison. In some instances, becoming a mental health champion had enabled increased understanding and learning.

“Quite a lot as I have suffered with it in the past, done a lot of psycho educational courses and also been a mental health champion and an emotional well-being mentor.”

“I know a lot about mental health as I have experienced it myself.”

Less than a tenth (7%) said they did not know much about mental health, and this again included some who had been directly impacted by poor mental health. Only 4% of respondents stated that they knew nothing about mental health.

“Not much but I am on anti-depressants.”

The most common theme to emerge, as noted by nearly one quarter of all participants (24%), connected the term ‘mental health’ with negative or difficult emotions and feelings, or with a specific diagnosis such as depression or anxiety which could often feel ‘fixed’ or unrelenting.

“Problems with the head.”

“It's not a good thing to have as it affects your whole life.”

“It makes you weak as a person.”

Far fewer participants (13%) viewed the term mental health as something that is changeable.

“Poor MH can affect every aspect of your life. Good MH can have a positive impact in every area of your life.”

“How you feel, thoughts and emotions.”

“Fitness of mind.”

“Affects people's state which can have a knock on to their personality, routine, self-care. It affects your moods and the way you feel and do.”

A small number of people directly linked imprisonment with mental health.

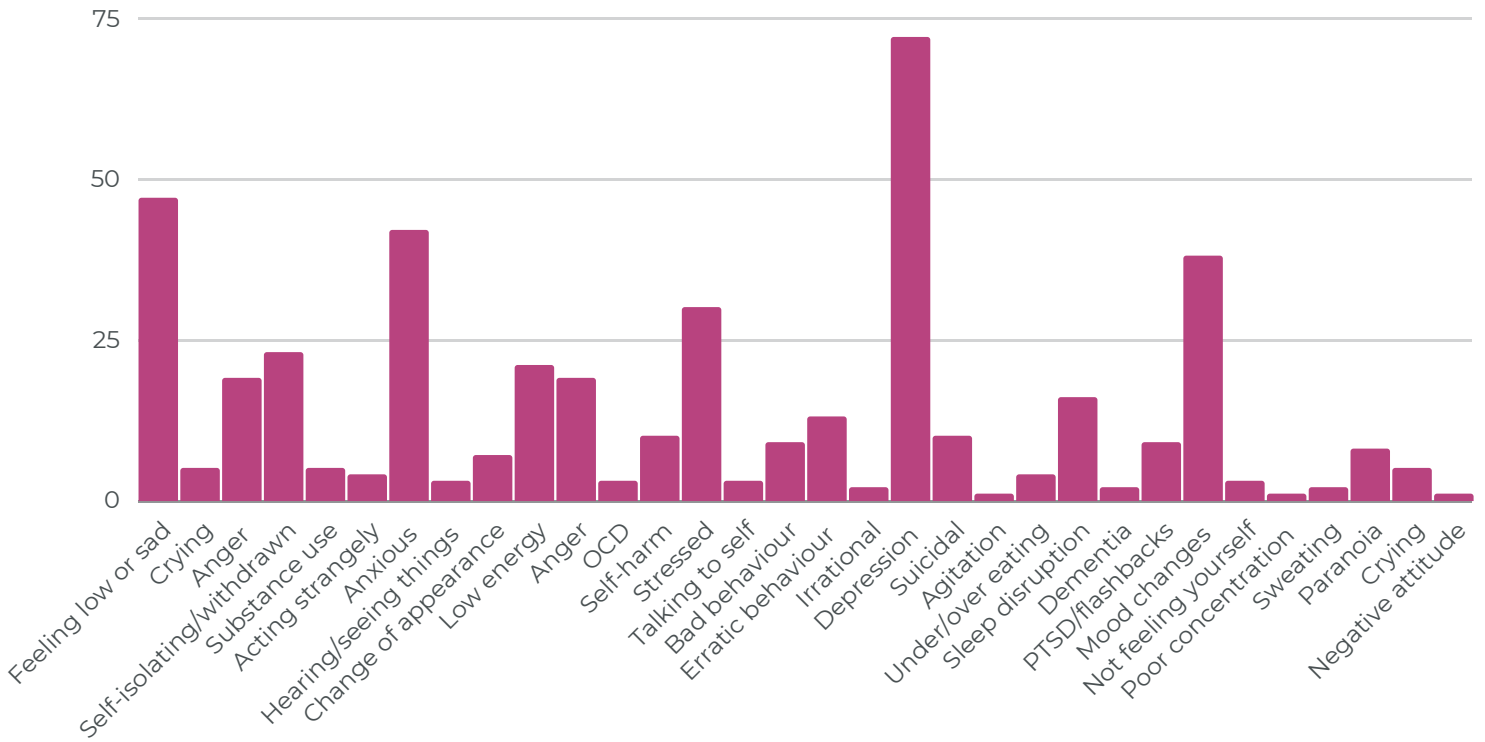
“Being on your own in prison is not good for you especially without support.”

“It's been a long unrecognised thing. It's a big thing in prison. We need to get more people talking.”

“Seems to be on increase in prisons.”

We asked about the warning signs individuals understood relating to mental health. The below graph outlines the wide range of responses provided. Feeling depressed was the most common theme, with 72 people mentioning this (23%). Relatedly, feeling low or sad was second, with 47 individuals highlighting this (15%). Anxiety was the next most frequent response with 42 people reporting this (13%).

Warning signs of mental health



When did participants last hear or see something about heart, lung or mental health?

We can see from the graph below that over 120 (38%) participants had seen or heard about mental health during the previous week. They heard or saw something relating to lung health far less often, with around 40 (13%) hearing something in the previous week.

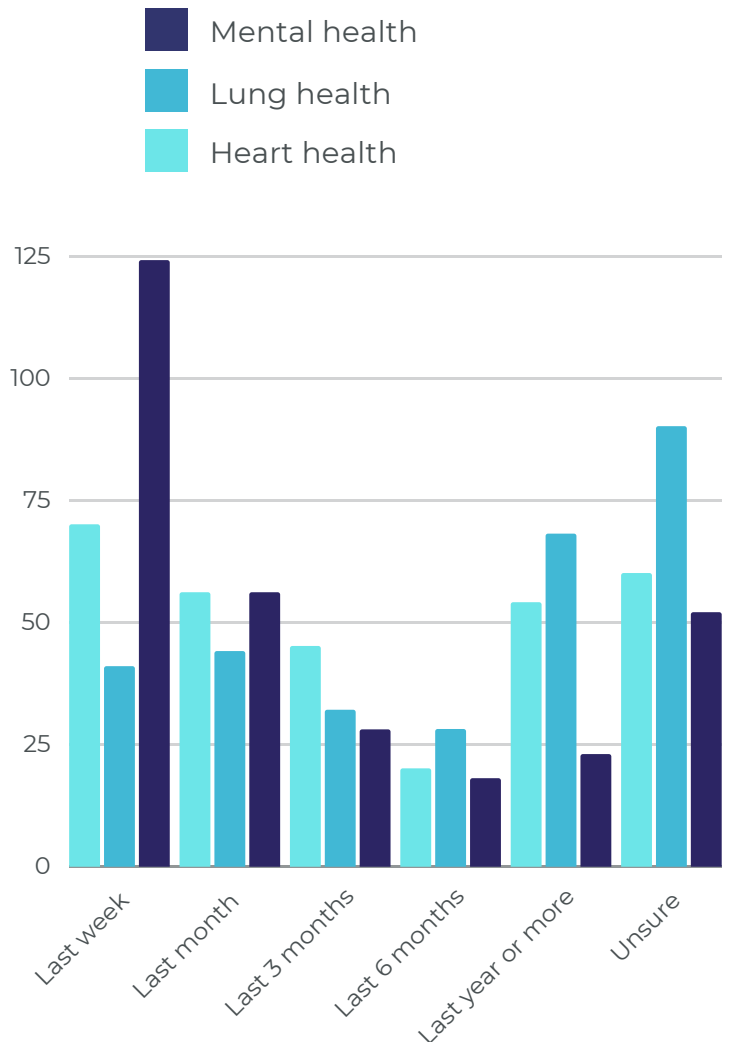
Over the previous month, respondents heard or saw something concerning mental health and heart health in equal measure, but saw less about lung health.

As time went on, it is evident that most participants saw or heard something about lung health more frequently over the last year or more.




For those who were uncertain when they had heard or seen anything relating to any of the conditions, there was most uncertainty surrounding lung health.

This comes as some surprise following the last two years' coverage of COVID-19 and its impact on the respiratory system.

The graph, and table below outlines these results.



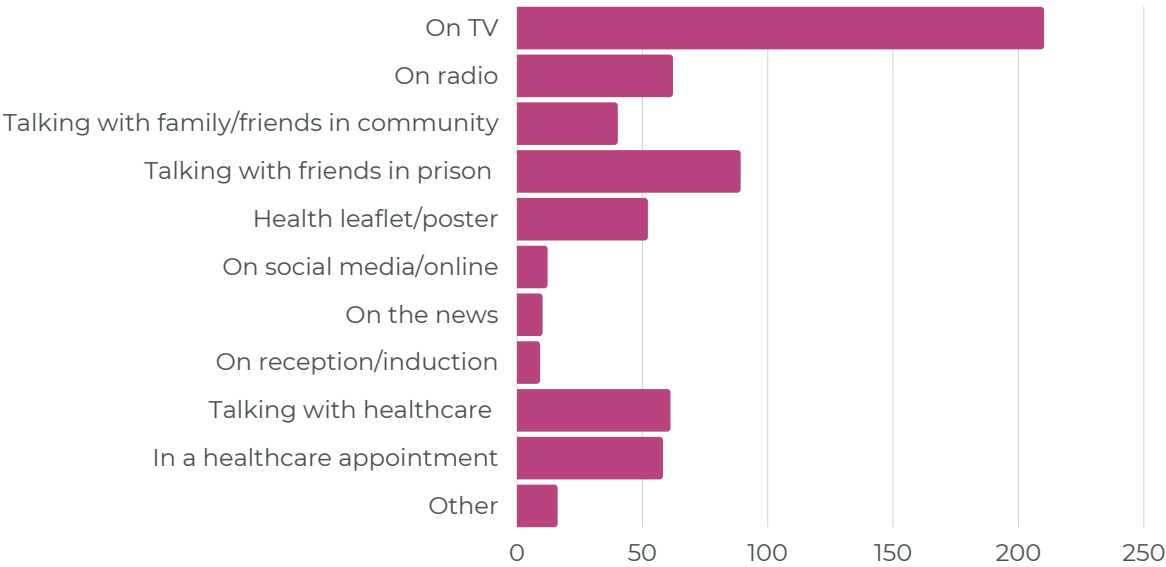
When did participants last see or hear something about heart, lung or mental health?

	Heart health	Lung health	Mental health
			
Last week	70	41	124
Last month	56	44	56
Last 3 months	45	32	28
Last 6 months	20	28	18
1 year or more	54	68	23
Unsure	60	90	52

When asked where people had heard or seen something relating to heart, lung and mental health, most participants (70%) reported that they had heard or seen it on TV.

Nearly one third (31%) had read about one of the conditions in a leaflet, while 29% had heard about one of the conditions whilst talking with a friend in prison; this is more than the number who had spoken about it with those outside of prison, highlighting the importance of being about to discuss health with peers in prison.

When did participants last see or hear something about heart, lung or mental health?

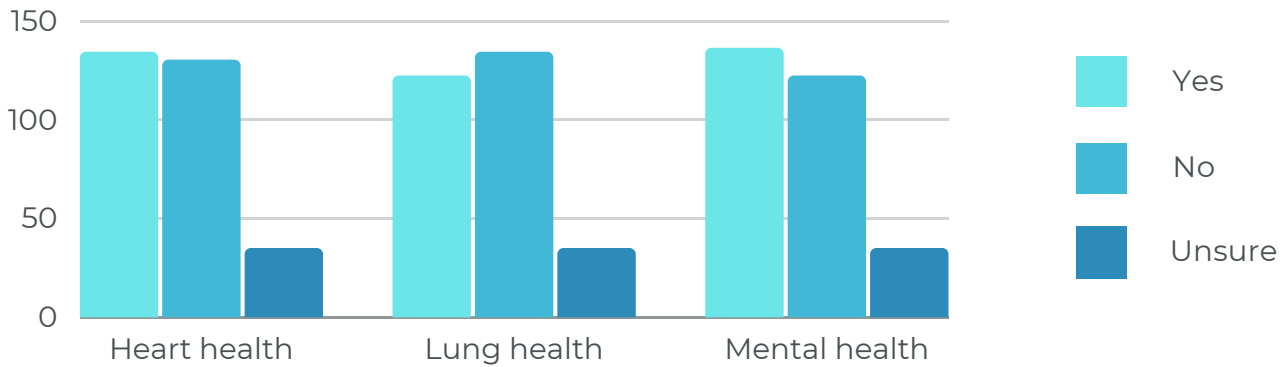


Health warnings on cigarette packets were raised as one memorable example of health messaging, when participants were invited to explain where they had last seen something about health.

Moreover, when asked if they would like to learn more about heart, lung and mental health, an average of 42% of participants showed interest in further learning.

Similar numbers indicated an appetite for further understanding around the three health needs.

What would people like to know more about



- Regarding heart health, 134 respondents stated they would like to know more, with marginally less (130) saying that they would not. A further 35 were unsure.
- When considering lung health, 122 individuals stated they would like to know more, with a greater number (134) saying that they would not. 35 people were unsure.
- Relating to mental health, 136 respondents were interested in knowing more whilst 122 were not. Again, 35 were unsure.

Participants shared their views on what they felt it would be helpful to know. Generally, it was agreed more advice and guidance around each health need would be beneficial, including understanding 'the basics', how to stay healthy and what to do if they felt unwell.

The table below specifically relates to what respondents said they would like to hear more about in relation to heart health.

Heart health



Risk factors	What is a healthy heart rate?	Exercises that reduce the risk of poor heart health
Help with healthy food choices	Warning signs and symptoms	Symptom management
When to seek help	How to manage associated conditions (blood pressure and weight gain)	Help with healthy food choices

Suggestions were further made for lung health



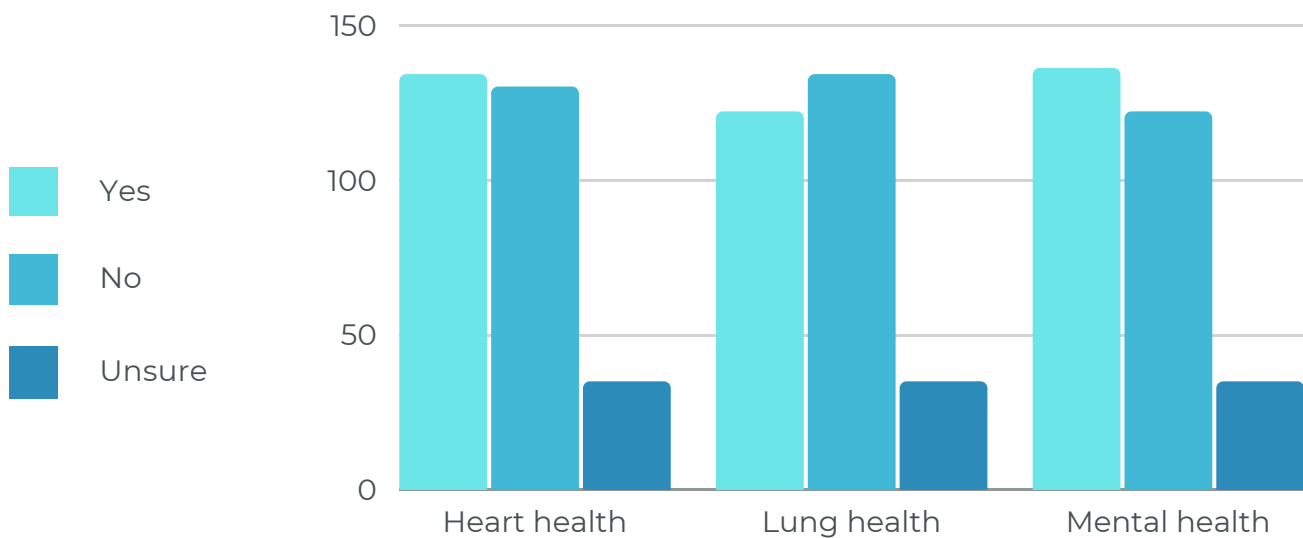
Risk factors	Warning signs and symptoms	More information about asthma and COPD
Help with healthy food choices	Risks of vaping	Which exercises help keep lungs healthy?
Warning signs and symptoms	When to seek help	Lung function

For mental health, the following were regarded as being helpful:



How to cope in prison	When to seek help	Warning signs and symptoms
Why talking about mh is important	Self-help techniques	Understanding trauma and personality disorders
Warning signs and symptoms (inc. how to spot them in others and how to help)	Signposting to services that can help (in prison and the community)	Courses aimed at MH that cover the different conditions

When asked if they had personally ever needed to know about heart, lung or mental health, mental health elicited by far the greatest number of responses:



- 43 (14%) participants said they needed to know about heart health, while 242 said that they did not.
- 42 (13%) respondents stated they needed to know about lung health, while 243 stated that they did not.
- 122 (30%) individuals needed to know about mental health, while 172 did not.

When asked what helped people feel better, hospital treatment and medication were deemed to *help those needing treatment for heart and lung health*.

“Medication for high blood pressure.” (heart health)

“Have had my bloods taken for testing quite a bit and it has been all clear which gave me peace of mind.”

For those experiencing poor mental health, talking to others both informally (family and friends) or more formally (counselling or with a mental health support worker) was considered to help make individuals feel better. Self-help was also said to be helpful, as was medication, although this was mentioned far less frequently.

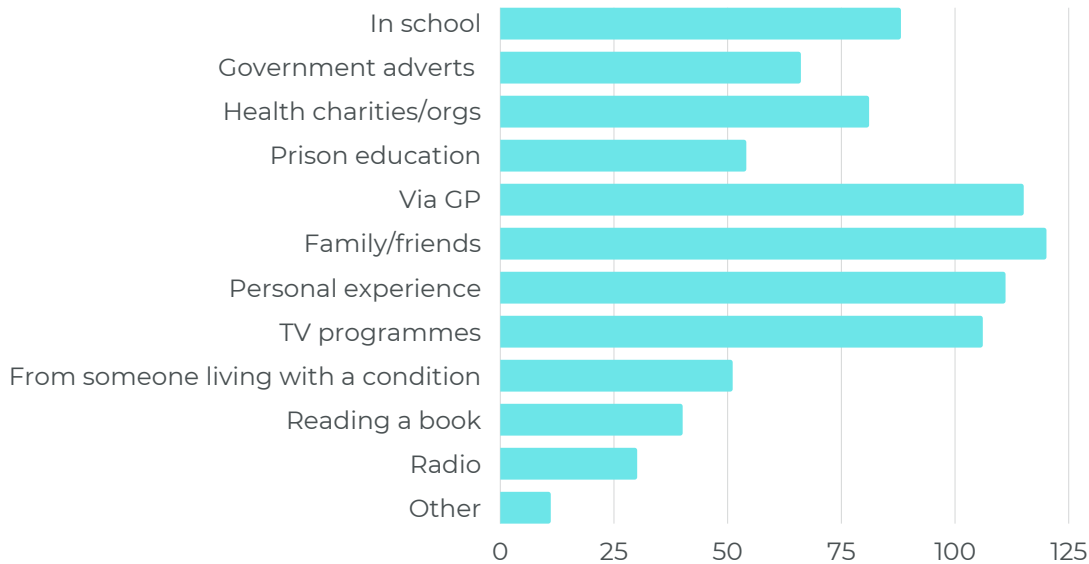
“Talking, being listened to and thinking you are not alone.”

“Being able to talk to people about my issues.”

Where did you learn the most about your health?

Respondents learnt most about their health by talking to family and friends (40%), followed closely by interaction with a GP (39%). Unsurprisingly, personal experience also enabled individuals to learn more about their health while, in contrast, over one third learnt about their health from watching TV (36%).

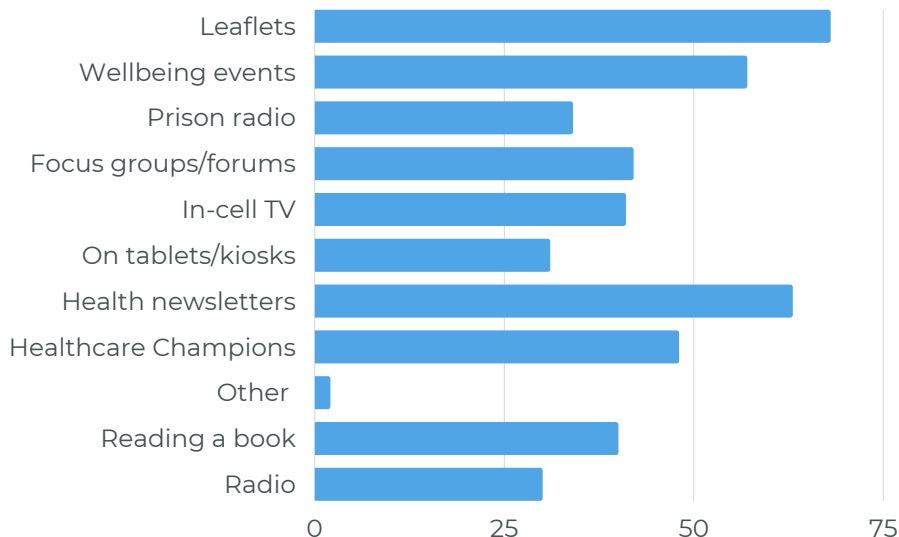
Other ways in which respondents learnt about their health included through their own research (such as through the internet), from leaflets from healthcare, TV adverts, discussions with prison officers, attending prison-based courses and newspapers.



How can we best inform prison communities about health?

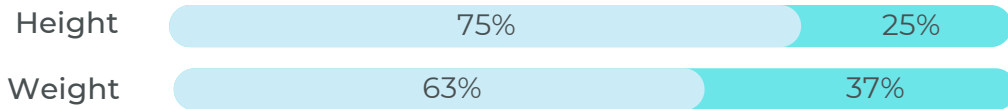
Over two thirds of participants (68%) believed health leaflets and literature to be effective means by which to share health messaging. Health-based newsletters were also seen as beneficial by 63% of participants. Wellbeing events were well regarded in informing individuals about health, with over half checking this response. Just under half (48%) felt health champions are a good way in which to inform people, while kiosks and prison radio were considered less effective means of communication.

Other suggestions relating to sharing health messaging included adding a health channel to in-cell TV, holding regular forums and focus groups, and utilising the in-prison newspaper, Inside Time.





General health questions

Three quarters of people in the consultation knew their height and just under two thirds knew their weight.

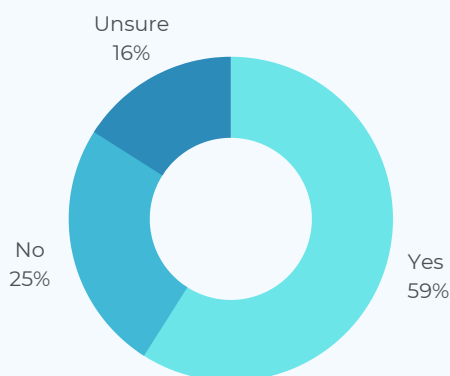


Looking at those who gave their height and weight the average BMI is provided below broken down by gender.

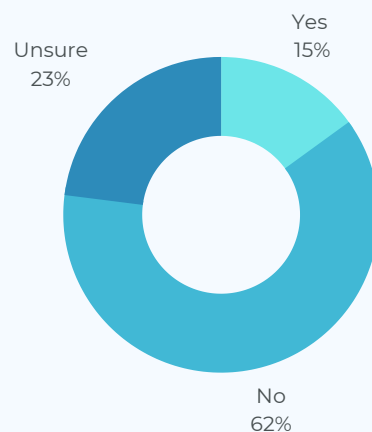
	Male 	Female 
No. of respondents	n=141	n=22
Average height	1.76m	1.66m
Average weight	91.7kg	73.8kg
Average BMI	29.5	26.7

Participants were asked if they were offered blood pressure tests and cholesterol checks upon arrival in prison. Over half (59%) said that they were offered a test, while over a quarter said that they were not, the remainder were unsure. Of those who were offered a blood pressure test, 90% accepted. Only 15% of respondents were offered a cholesterol check on arriving at their prison, while 62% were not. Of those that were offered a check, 5% declined.

Blood pressure test on arrival?



Cholesterol test on arrival?



When asked why some individuals choose not to take up the offer of reception tests and checks, fear and worry concerning the outcome was said to be of influence.

“A fear of finding out could be stronger than taking a test.”

“Worry might find something wrong.”

It was discovered that individuals could feel rushed through the reception process, subsequently impacting on their ability to request or accept a test. It was felt by a number of people there was a lack of staff available to undertake tests.

“Lack of staff which makes them busy, no time to deal with everyone. Coming to prison and rushed through it's probably the last thing you think about. Plus, staff don't always ask.”

Not being offered a test or check was a frequent response, often coupled with a lack of awareness and knowledge that these were available.

“Maybe as simple as not being asked if wanted or being nervous to ask or just miss out and rushed through Reception.”

“Not knowing about what you can or can't have access to.”

Importantly, a recurring theme raised was the stress felt during the early days of custody, potentially impacting on individuals' choices relating to testing. It could be that the uptake of some tests would increase if individuals were asked at a more appropriate time, and certainly once they were more settled in the prison.

“It's probably the last thing you think about.”

“Also, when first entering prison, you have no idea about what is going on, and then no idea a week/month/year later as to what you had/didn't make.”

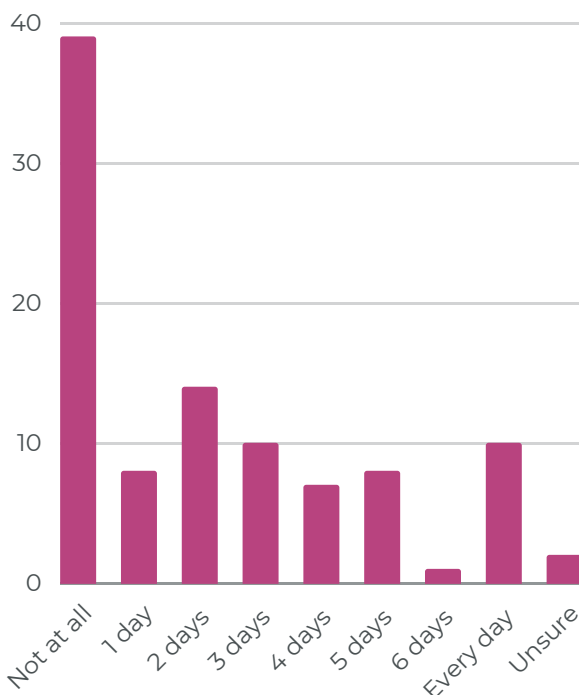
The final responses centred around either a general disinterest in being tested or a belief that a test was not required due to good health.

“Don't need it, laziness, not interested.”

“Don't need to, I'm too young.”

When asked how many days respondents had engaged in more than 30 minutes of exercise during the previous week, 39% reported participating in no exercise at all. Although the responses were varied, 8% exercised on only one day in the last week and 10% stated that they participated in exercise every day. Of those who did exercise, the highest percentage (14%) were seen to exercise for 30 minutes or more over two days within the previous seven.

How many days in the last week did you take 30 minutes or more of exercise?



Participants provided a range of suggestions to increase the amount of exercise being taken. The most frequent response – highlighted by 95 participants – was to improve access to the gym. Within these responses, dedicated gym sessions for those living with a disability, older adults and those committed to weight loss programmes would further encourage exercise.

Unsurprisingly, spending long periods of time in-cell during the pandemic had limited access to physical activity. An improved regime and more time outside of cell was considered conducive to increasing exercise levels.

Being offered choices, such as engaging in team sports, increased use of outdoor space, aerobic classes or circuits, were also seen as encouraging.

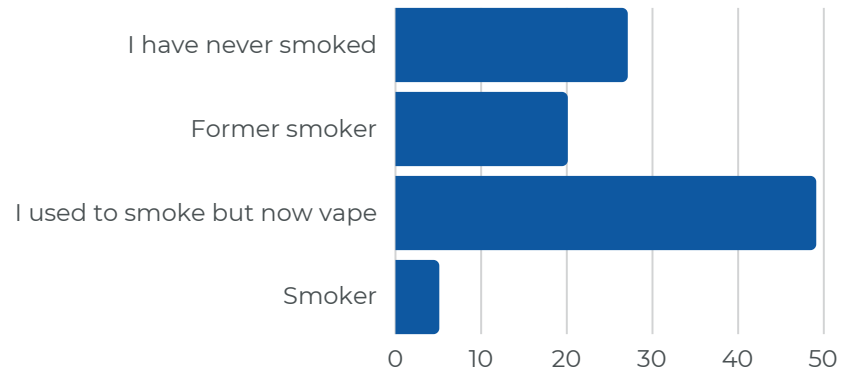
Being enabled more time on the yard and improved outside gym equipment were both mentioned as means to increase exercise. Those who worked out in-cell suggested that additional in-cell packs and physical challenges would help.

Finally, a small number of respondents felt more staff encouragement could help build confidence in those less sure about exercise, alongside rewards and incentives.

Smoking and vaping

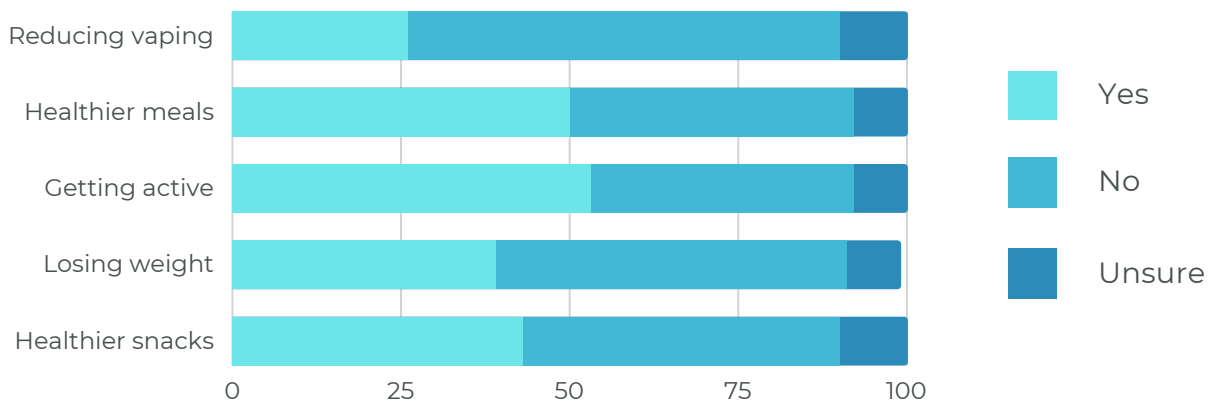
When asked about smoking and vaping, nearly half of all participants stated that they were former smokers, but now vape.

One fifth were former smokers but had given up. Over one quarter (27%) had never smoked and the final 5% reported that they were still smokers.



The survey explored the health choices reported by participants as currently being made:

- 27% were reducing how much they vaped while 64% were not.
- 50% were choosing healthier meals while 42% were not.
- 53% were increasing their physical activity while 39% were not.
- 43% were choosing healthier snacks from canteen while 47% were not.
- 39% were trying to losing weight while 52% were not.



SECTION SUMMARY

Individuals in prison have provided some useful insights into their understanding of heart health, lung health and mental health.

Their responses demonstrate a range of knowledge within prison communities with an appetite to learn more about each condition, although with a notably deeper interest in mental health, about which respondents appeared not only to know more, but also were more affected by.

When it came to heart and lung health, most knowledge seemed to centre around the perceived risks that can impact on keeping those organs healthy and the preventative measures that can be taken to stay well.

In terms of mental health, it was interesting that a greater number of participants shared negative definitions rather than understanding mental health as encompassing a broad spectrum of emotions or feelings. Often this patient group conflated mental health with 'mental ill-health', perhaps demonstrating a limited range of understanding about emotional wellbeing and underpinning wider stigmatising beliefs encompassed within some of the response comments.

Remarkably, some respondents explained that they were taking medication for mental health or had been given a diagnosis but nevertheless felt that they knew very little about mental health, suggesting a need for greater understanding in some cases.

In contrast to those who associated a fixed negative emotion to mental health, others couched their answers through a scale of feelings and emotions, reflecting on the fact that these can change and impact on how individuals feel.

More than twice the number of participants felt they needed to know about mental health for personal reasons compared to heart health or lung health, also suggesting that poor mental health was more prevalent than poor lung or heart health in these communities.

Most tended to learn about their health through discussions with family and friends, supporting the idea that family and friends should be included in care where possible. Relatedly, training peers in the community to help inform and support others to manage their health would be a beneficial health promotion approach, especially if peers are fully representative of the communities they serve.

GPs also play an important role in informing the community about their health, although importantly we learn later in the report that GP access can be difficult and sometimes appointments can feel rushed.

The report evidences a need for health promotion to be varied and, despite individuals favouring leaflets or newsletters, there is a need to ensure that face to face health promotion events and a range of media are available to reach a wide audience. This is especially important for those struggling with literacy, which is seen as a barrier for some, as noted later in this report.

Uptake of health testing and checks appeared to be well taken up when offered, although importantly early days screening does not appear to always be offered. Reception processes can feel rushed and individuals' minds and priorities can feel elsewhere at this stressful time. Some consideration as to the 'best time' for patients and clinicians to complete testing requirements during those early days might be worth thinking about.

Over a third of respondents had not exercised at all during the previous week, although this survey took place when prisons were at different stages of recovery from COVID-19 and regimes were still restricted in some settings. Despite this, notable efforts towards health improvement were reported across the prisons, including selecting healthier meals and snacks and trying to increase exercise. For those looking to increase their activity, some wished for increased gym access with dedicated time for those needing extra help either as a result of disability or age, to increase confidence. Alongside this, it was felt that enhanced variety and choice over exercise would encourage more participants to improve their health.

Though the sample number is relatively small it's worth noting the average BMI scores found within it, indicate BMI values are higher than considered optimum in terms of health, suggesting that some people within this consultation might need extra support to maintain a healthy weight. Though with long periods of in-cell time and limited activity during the pandemic, perhaps BMI scores reported are unsurprising.

KEY LEARNING - WARNING SIGNS AND SYMPTOMS OF CANCER



- 61% of respondents agreed that unexplained weight loss could be a warning sign or symptom of cancer – 9% had experienced this in the previous six months.
- 79% agreed that an unexplained lump or swelling could be a warning sign or symptom of cancer – 12% had experienced this in the previous six months.
- 65% agreed that a persistent change in bowel habits could be a warning sign or symptom of cancer – 15% had experienced this in the previous six months.
- 61% agreed that a persistent change in bladder habits could be a warning sign or symptom of cancer – just over 10% reported this during the previous six months.
- 55% agreed that a persistent unexplained pain could be a warning sign or symptom of cancer – 16% had experienced this in the previous six months.
- 56% agreed that persistent difficulty swallowing could be a warning sign or symptom of cancer – 3% had experienced this in the previous six months.
- 58% agreed that a persistent cough could be a warning sign or symptom of cancer – 4% had experienced this in the previous six months.
- 53% of respondents agreed that a change in an existing cough could be a warning sign or symptom of cancer – 2% had reported this in the previous six months.
- 73% agreed that coughing up blood could be a warning sign or symptom of cancer – 2% had experienced this in the previous six months.
- 69% of participants agreed that unexplained bleeding could be a warning sign or symptom of cancer – 4% had experienced this in the previous six months.
- 46% agreed that a sore that does not heal could be a warning sign or symptom of cancer – 6% had experienced this in the previous six months.
- 46% agreed that persistent hoarseness could be a warning sign or symptom of cancer – 2% had experienced this during the previous six months.
- 51% agreed that persistent tiredness could be a warning sign or symptom of cancer – 19% had experienced this during the previous six months.
- 60% of individuals agreed that shortness of breath could be a warning sign or symptom of cancer – 11% had experienced this in the previous six months.
- 59% agreed that having lung disease could increase a person's chance of developing cancer – 10% did not agree and 19% were unsure.
- Smoking, exposure to second-hand smoke, sunburn, obesity and family history were considered to represent some of the most significant risk factors affecting a person's chances of developing cancer.
- Most respondents would inform healthcare of any new symptom within one week, although some would wait as long as six months.

- Less than one fifth report being able to see a GP after submitting one application to healthcare, while most reported having to see a nurse first.
- Nearly half found the waiting time for healthcare off-putting, although nothing would deter one third of patients from reporting a concern to healthcare.
- 39% did not know how long to wait before informing healthcare about a new symptom, although over half felt confident returning to healthcare on multiple occasions about the same health concern.



Warning signs and symptoms

79% agreed that an unexplained lump or swelling could be a warning sign or symptom of cancer – 12% had experienced this in the previous six months.

Unexplained lump or swelling in last six months. (12% experienced)



Respondents reported lumps in the following areas:

Anus	Arm	Breast	Chest	Eyes	Genitals
Legs	Mouth	Neck/throat	Stomach	Testicles	All over body

The duration these individuals had lived with their lumps ranged from three weeks to one year.

61% of respondents agreed that unexplained weight loss could be a warning sign or symptom of cancer.

9% had experienced unexplained weight loss in the previous six months.

65% agreed that a persistent change in bowel habits could be a warning sign or symptom of cancer.

15% had experienced this in the previous six months.

Unexplained weight loss in the last six months (6% experienced)



Change to bowel habits in the last six months (15% experienced)



The table below includes some of the bowel changes experienced.

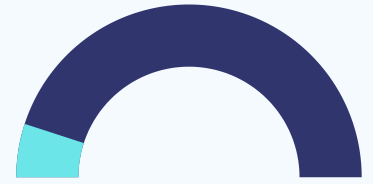
Constipation	Stoma	Loose bowels	Cramps	Urgency	Discomfort
Change to consistency	Irregular bowel movements	Blood when passing stools	Increased frequency	Pain from haemorrhoids	Wider health impacting on passing

Duration ranged from two months to seven years.

61% agreed that a persistent change in bladder habits could be a warning sign or symptom of cancer.

Just over 10% reported this during the previous six months.

Change to bladder habit in last six months.
(10% experienced).



Respondents reported the following changes:

Increased frequency	Blood in urine	Reduced frequency	Incontinence	Unusually Heavy flow	Difficulty urinating
Urinating more at night	Discharge when urinating	Urinating more at night	Not fully emptying bladder	Pain passing urine	Change in colour or cloudy urine

The duration individuals had experienced changes to bladder habits ranged from two months to two years.

55% agreed that a persistent unexplained pain could be a warning sign or symptom of cancer.

16% had experienced this in the previous six months.

Persistent pain in the last six month
(16% experienced).



Respondents reported pain the following areas:

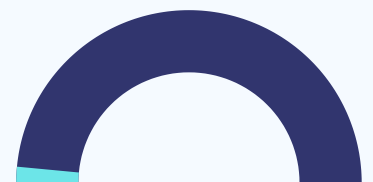
Arm	Back	Bowels	Breast	Chest	Eye
Finger	Foot	Groin	Head	Kidney	Knee
Kidney	Leg	Mouth	Pelvis	Penis	Rectum
Shoulder	Stomach	Testicles	Throat	Vagina	All over body

The duration of persistent pain was reported as ranging from two weeks to ten years.

56% agreed that persistent difficulty swallowing could be a warning sign or symptom of cancer.

3% had experienced this in the previous six months.

Persistent difficulty swallowing in the last six month
(3% experienced).



The time range for this symptom was more difficult to determine as responses such as “Since COVID” or “Since I was a teenager” were received.

One participant reported having stopped breathing whilst eating.

For those who commented on the duration they had experienced difficulty swallowing, responses ranged between a few months and four years.

58% agreed that a persistent cough could be a warning sign or symptom of cancer.

4% had experienced this in the previous six months.

Some individuals related this to COVID-19. Where a duration had been provided, this ranged from two weeks to five years.

53% of respondents agreed that a change in an existing cough could be a warning sign or symptom of cancer.

2% had reported this in the previous six months.

One person mentioned a connection to COVID-19 and another explained that this had occurred over the previous two weeks.

73% agreed that coughing up blood could be a warning sign or symptom of cancer.

2% had experienced this in the previous six months.

Of those reporting coughing up blood in the previous six months, the duration of the symptom ranged between three weeks and one year, with one person saying that this happened "sometimes".

69% of participants agreed that unexplained bleeding could be a warning sign or symptom of cancer – 4% had experienced this in the previous six months.

Most participants reporting unexplained bleeding spoke of

bleeding from their rectum, although two individuals reported passing blood whilst urinating. One woman had experienced unexplained bleeding from her vagina.

46% agreed that a sore that does not heal could be a warning sign or symptom of cancer.

6% had experienced this in the previous six months. One person reported managing the long term condition psoriasis. Three people reported having sores on their face for between one and two years. One

further individual had experienced sores simultaneously in their armpit and on their thighs for two years. Another had experienced a sore in their mouth and gums that struggled to heal for the last six months. The remaining participants reporting sores that do not heal spoke of experiencing these on their limbs (arms and legs) for a duration of up to six months.

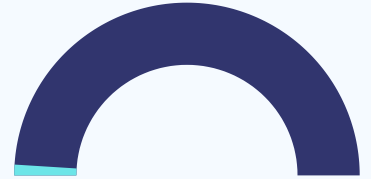
Persistent cough in last six months.
(3% experienced).



Change to an existing cough in last six months.
(2% experienced).



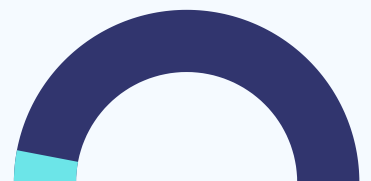
Coughing up blood in last six months.
(2% experienced).



Unexplained bleeding in last six months.
(4% experienced).



A sore that hasn't healed in last six months.
(6% experienced).

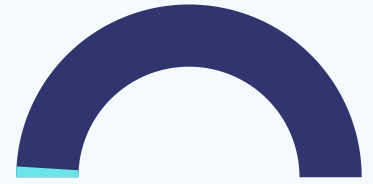


46% agreed that persistent hoarseness could be a warning sign or symptom of cancer.

2% had experienced this during the previous six months.

Hoarseness ranged in duration from our weeks to seven years. This had affected one individual throughout their entire adult life, and another reported that their hoarseness could “come and go”.

Persistent hoarseness in last six months. (2% experienced).



51% agreed that tiredness could be a warning sign or symptom of cancer.

19% had experienced this during the previous six months.

When considering duration, most have suffered with this between a few weeks to years. However, the most common duration reported (32%) sat between three and six months. One individual reported persistent tiredness following a medication change and another said that light physical activity such as climbing stairs exhausted them.

Persistent tiredness in last six months. (2% experienced).



60% of individuals agreed that shortness of breath could be a warning sign or symptom of cancer.

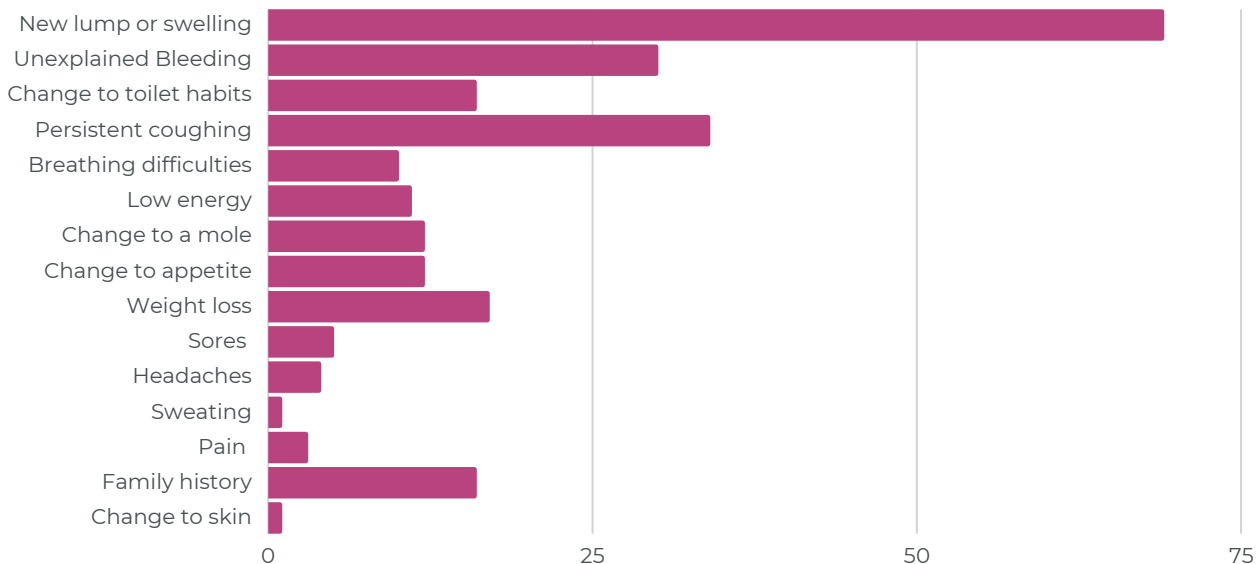
11% had experienced this during the previous six months.

The duration individuals reporting experiencing shortness of breath ranged between six weeks and “my whole life”. Some associated it with existing health conditions such as asthma and COPD. The shortest duration reported was six weeks. The most common response, mentioned almost one third (32%) had experienced shortness of breath in the previous six months.

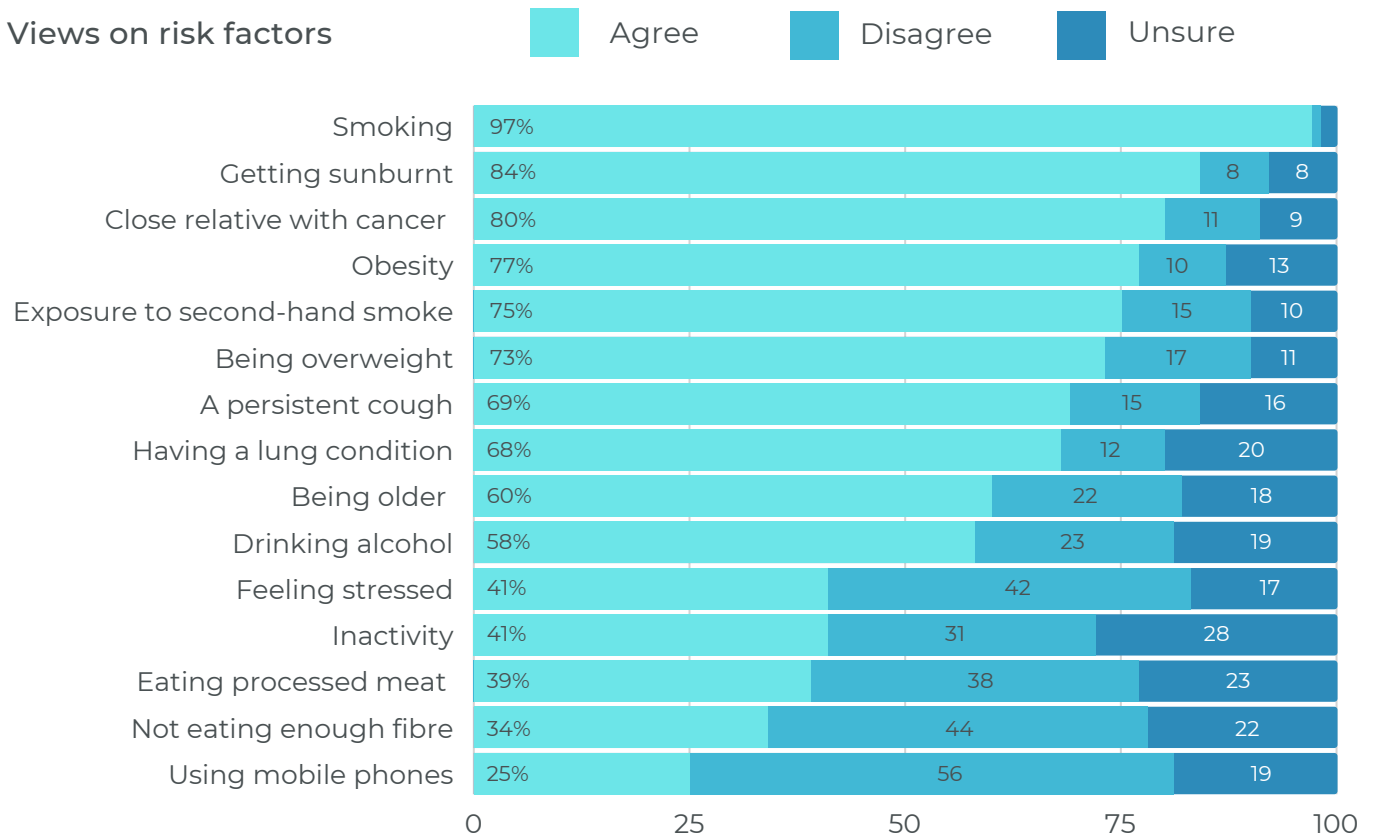
Shortness of breath in last six months. (11% experienced).



The below graph illustrates responses received in free text boxes when exploring the known early warning signs or symptoms of cancer.



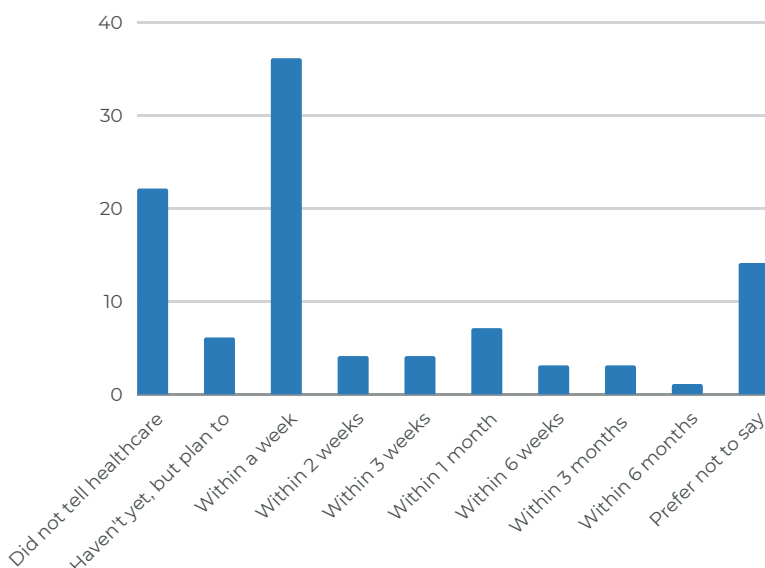
The most common answer related to the noticing of lumps, mentioned by over two thirds of respondents (69%). A persistent cough was highlighted by over a third (34%) of participants and unexplained bleeding (most commonly when passing stools or urine) by 30%. Respondents were asked their views on the risks that could impact on a person's chance of developing cancer. The graph shows all outcomes. These are ordered from the most commonly agreed to the least.



Further perceived risk factors shared by participants included unsafe sex, exposure to hazardous substances, mental health, limited access to healthcare and working long hours.

Informing and accessing healthcare

How long before you told healthcare about a new symptom?

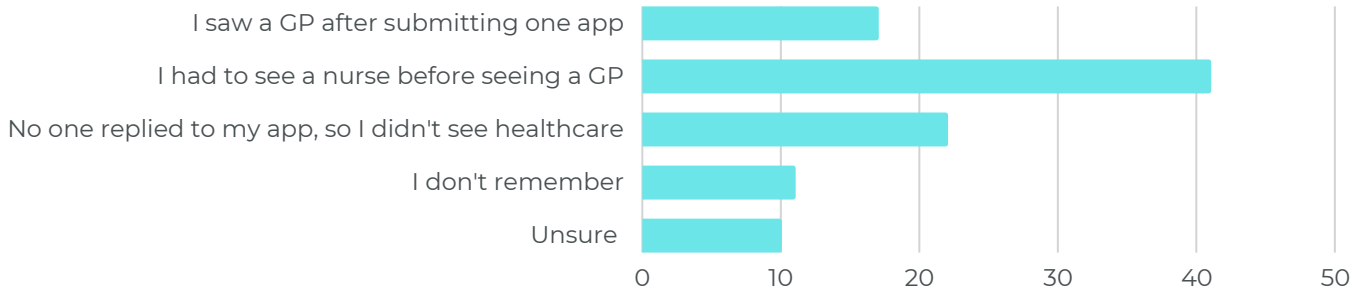


We found over one third (36%) of individuals reported new symptoms to healthcare within one week, followed by over a fifth who would not inform healthcare at all.

Fewer participants would report a symptom within three months of a new symptom, with 1% waiting for up to six months.

When attempting to access a GP, most respondents (40%) were made to see a nurse beforehand. One fifth reported receiving no response to requests to see a doctor, and only 16% were able to see a GP after submitting just one application. A tenth had no recollection of what had occurred when attempting to access a doctor in prison.

What best describes what happened when you last tried to see a GP?



In the free text box provided, a range of experiences were shared around accessing a doctor. It is evident that multiple apps must sometimes be submitted before any response is forthcoming.

"[I saw a doctor] after 2 months of putting 10 apps in. Always take too long and sometimes no reply back."

"I have put in loads of apps, but my GP appointments keep getting cancelled."

Numerous individuals spoke of delays in accessing a GP.

"I'm still waiting to see a dr as the nurses don't know what painkillers to give me."

"Weeks sometimes months for an appointment. By the time you actually go you are OK."

In some instances, respondents had resorted to submitting complaints as a means to seeing a GP after unsuccessful applications to healthcare.

"If you need quick access to GP you have to put in a complaint, otherwise you won't be seen."

"Took several apps and a complaint and about 6 weeks before seeing GP."

Others felt that, by the time they came to be seen by a GP, their health concern had resolved itself. Others reported that delays in seeing a doctor resulted in a break in medication.

"Had to put app in for meds that I need and took me a month to get them."

We also heard that obtaining test results could be problematic, alongside accessing regular health checks for long term conditions.

"Was promised blood tests – been waiting 6 months."

"I am supposed to have regular blood pressure checks and blood checks because of my high blood pressure medication but have not had any for the best part of a year now."

We heard for some, even upon accessing a GP, the quality of the contact could be improved.

"Waiting times too long and when seen too short. They rush you."

"Difficult getting to see GP – took too long and was seen too fast. Took 7 weeks to see a nasty GP."

Of those who responded to this question, one person spoke highly of the service received.

“They see me when it's a serious issue, the healthcare are there when you really need them, they do a good job thank you.”

Within the survey we asked people what might put them off reaching out to healthcare.

Nearly half of all respondents were put off reaching out to healthcare more generally due to the waiting times, as seen in the graph below. However, over a third reported that nothing would put them off seeking help.

“If I need them, I ask if I really really need them, I persist, and they see me.”

Some 14% considered embarrassment to be a barrier, with an equal number feeling they might not be taken seriously by a health professional in prison.

“Dr doesn't read notes by your GP. Also, due to being in prison they won't prescribe the medication that is required and what would be given in the community.”

One tenth of participants found it difficult to discuss their health concerns, and the same number disliked making a fuss.

“I have trouble explaining what I mean sometimes, especially when it's someone I don't know.”

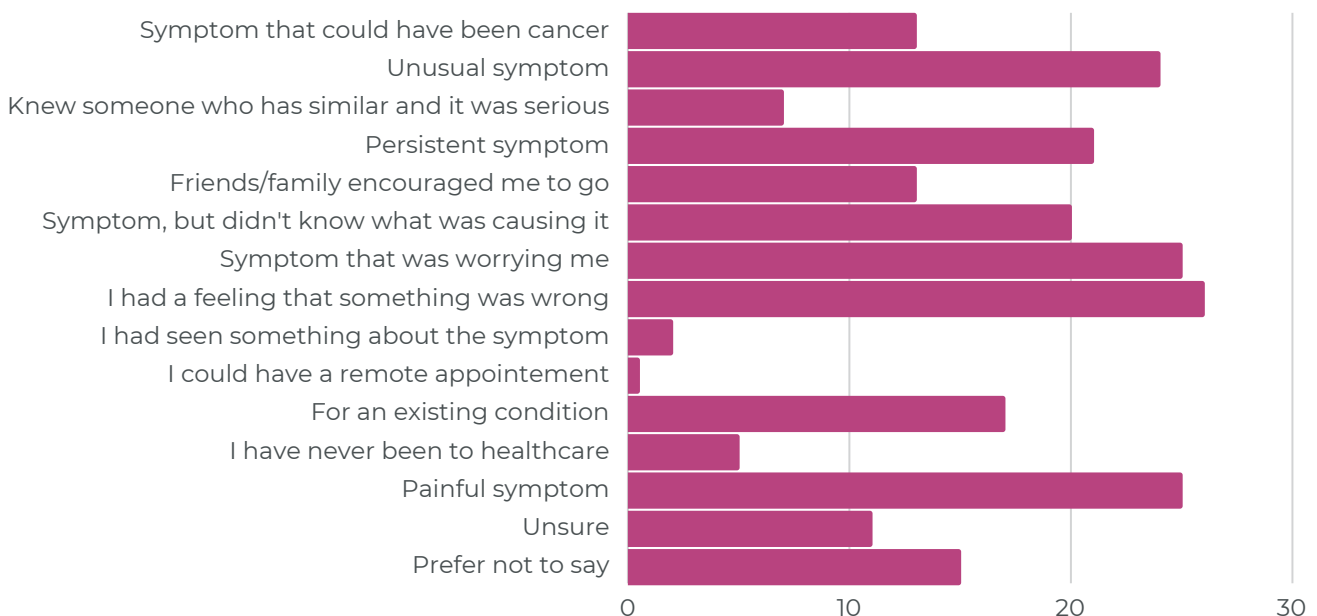
Importantly, although smaller in number, 7% of individuals were put off accessing healthcare due to literacy struggles. One respondent (a vulnerable prisoner) also felt put off because of his sentence type while another decided to wait until his release from prison to access a GP in the community.

“It's hard work getting an appointment. It is usually months away and you have to go and wait for ages in that unpleasant waiting room in health where others abuse you for being on the VP wing.”

“Thought I should wait until I was released.”

A range of responses were received as to why people had submitted their most recent application to healthcare (more than one box could be checked).

Why did you last see healthcare?



One quarter, the most common response, had a feeling that something was wrong. Another common response involved developing a symptom that was painful and/or causing worry. Close behind these was experience of an unusual symptom (24%).

One fifth of responses related to a symptom that would not subside. 16% of respondents knew of someone with a similar symptom that had proved serious which prompted them to see healthcare. 17% needed an appointment to manage an existing condition.

When considering the following, it was found that:

- 39% of respondents agreed with the statement “I am not sure how long I should wait before contacting healthcare about a change in my health” (this did not include those who stated unsure – 16%).
- 57% felt confident returning to healthcare with the same problem if it did not ease or worsened.
- 48% felt confident returning to healthcare with the same problem after a test result suggested it was nothing to worry about.



SECTION SUMMARY

Although responses varied, when asked about specific symptoms listed, at least half of all participants understood these to be potential warning signs of cancer. By some way, an unexplained lump or swelling was the most widely acknowledged warning sign, followed by coughing up blood and unexplained weight loss. Nevertheless, knowledge gaps were evident around lesser known symptoms such as unexplained sores that fail to heal, persistent unexplained pain, a persistent cough or changes to a cough.

To varying degrees, small numbers of individuals had experienced each symptom during the previous six months. The most significant related to feeling continuously tired and unexplained persistent pain, with very small numbers experiencing hoarseness or coughing up blood. Importantly, some had been managing these symptoms for several months, and sometimes years.

There is work to do in relation to cancer awareness health promotion in prisons to help increase understanding, but also in levelling up awareness across different prison communities.

Most tended to understand the well-known risks that can increase the chance of developing cancer, but it is evident within the responses that individuals are not always confident in their knowledge.

It was encouraging to note that most respondents would reach out to healthcare within one week of noticing a new symptom, although a small number would wait for up to six months. Reinforcing the message that early detection is an important factor in treating cancer might encourage those less likely to come forward to seek help earlier. Promoting early detection would also go some way towards reducing confusion apparent amongst the

40% of patients who did not know how long to wait before informing healthcare about a new symptom.

It is important to acknowledge alongside these factors that not everyone felt able to articulate their concerns with confidence:

"I have trouble explaining what I mean sometimes, especially when it's someone I don't know."

This is an important reflection for numerous reasons. If individuals are informed about health in relatable language, they are more easily able to connect with the issues and feel more confident verbalising their concerns, enabling these to be understood by clinicians and treated more promptly. If people can freely and clearly talk about their health, this supports them owning and managing it. Consequently, health promotion needs to cater for the range of communication needs in prisons.

Building on communication challenges, some participants could struggle to see a GP and most see waiting times as the most significant barrier, although perhaps this is unsurprising as we are living through a pandemic. Coupled with a feeling that healthcare would not take them seriously, language barriers or embarrassment (all notable barriers), accessing healthcare in a timely manner can feel like a larger challenge than first imagined, especially as over 40% of patients lacked the confidence to return to healthcare if the symptom did not ease.



BOWEL CANCER SCREENING - SURVEY 2



KEY LEARNING



- Responses suggest there is some uncertainty as to when people are eligible for bowel screening testing.
- There is further uncertainty regarding when people are up to date with bowel screening.
- Less than half of respondents (43%) had completed the last bowel screening test they were given or sent. A third of people have never received one.
- All those who said they would not complete a bowel screening kit were all over the age of 50 years old.
- The biggest reason given for not completing a bowel screening kit, was that people had never been given one -this included those who were eligible through age.
- Most of those who cited embarrassment as a reason not to complete a kit, were from minority communities.

- There is not enough cancer-related health promotion in prison.
- Privacy and discretion are important factors to consider for people completing screening kits .
- Some feel the risks outweigh the benefits of completing a kit, particularly when people do not feel they are at risk.
- 40% said that nothing would stop them completing a test kit and this cohort seemed to better understand the value of early detection and benefit from 'peace of mind'.
- In conversations on the wing people wanted to talk and learn more about prostate cancer.



PARTICIPANTS

Gender

All participants were male with one self-identifying as a different gender than that assigned to their sex at birth.

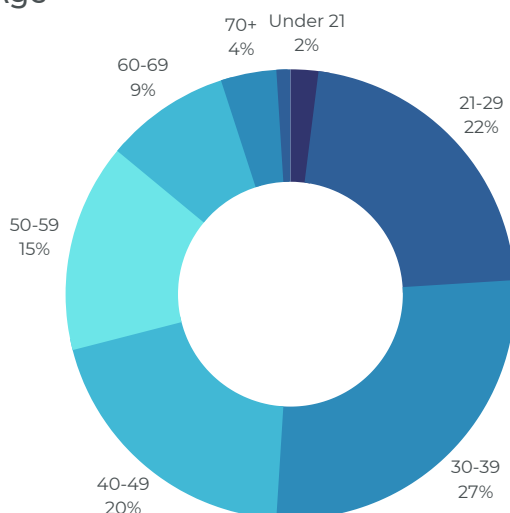
Age

It was intended to aim this survey towards older adults in male prisons. Of those who participated in this survey, most were aged 50 years and above, who made up 95% of all participants. The largest group when banded by age was the 50-59 year age category (47%), followed by those aged 60-69 years (31%). A further 17% were aged 70 years and older. Of the 5% aged under 50 years, 4% were aged 40-49 years and 1% were aged 21-29 years.

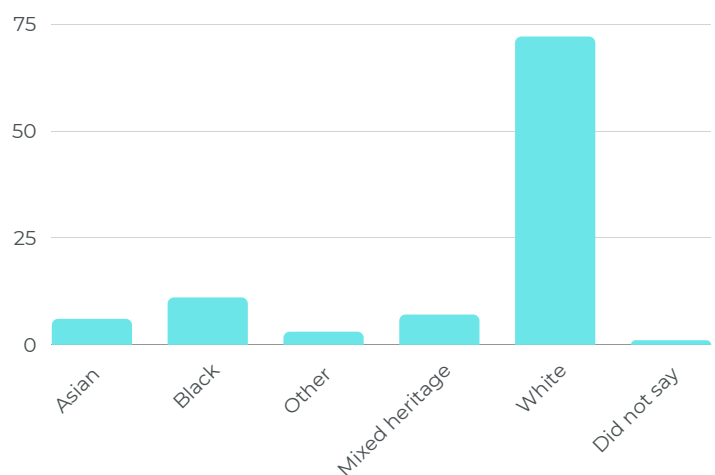
Ethnicity

Most participants were white, at 80%. Just under one tenth were black, at 9%, and 6% were Asian. A small number (2%) were of an 'other' ethnicity. Those of mixed heritage made up 1.5% of overall numbers and a further 1.5% preferred not to state their ethnicity. In total, those from ethnic minorities formed nearly a fifth of all respondents, at 18.5%.

Age



Ethnicity



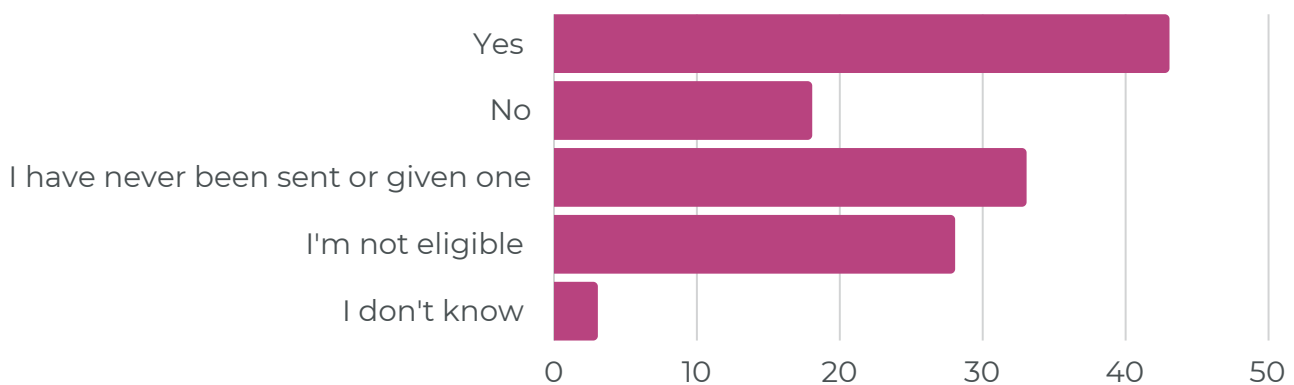
FINDINGS

Screening views

When asked if people had completed a bowel cancer stool test kit on the last occasion they had been given or sent one, less than half of respondents (43%) reported having done this.

One third of participants stated they had never been given or sent a testing kit, 28% said they were ineligible, though it is important to note that looking at age eligibility, most were within the eligible age group.

Did you complete a bowel cancer stool kit last time you were sent or given one?

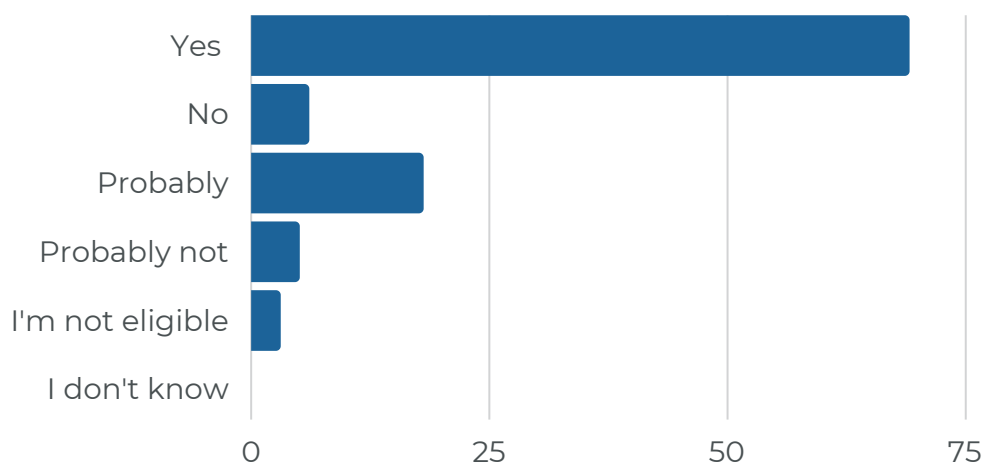


Despite any previous hesitancy from some, there was clear motivation to complete a bowel screening test kit on the next occasion, with over two thirds of participants reporting that they would and a further 18% saying that they probably would. A minority of 6% stated that they would not, with a further 5% showing some hesitancy by reporting that they would probably not take up the offer of a kit.

When considering those stating that they would not complete a test, they were all aged 50 years or older and, therefore perhaps, more at risk of bowel cancer than their younger peers. In terms of ethnicity, 57% of these individuals were white and the remainder were from minority communities (43%).

Of those who said that they would probably not complete a testing kit, again all were aged 50 years or older and there was an even split between men who were white and men who were from minority communities.

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



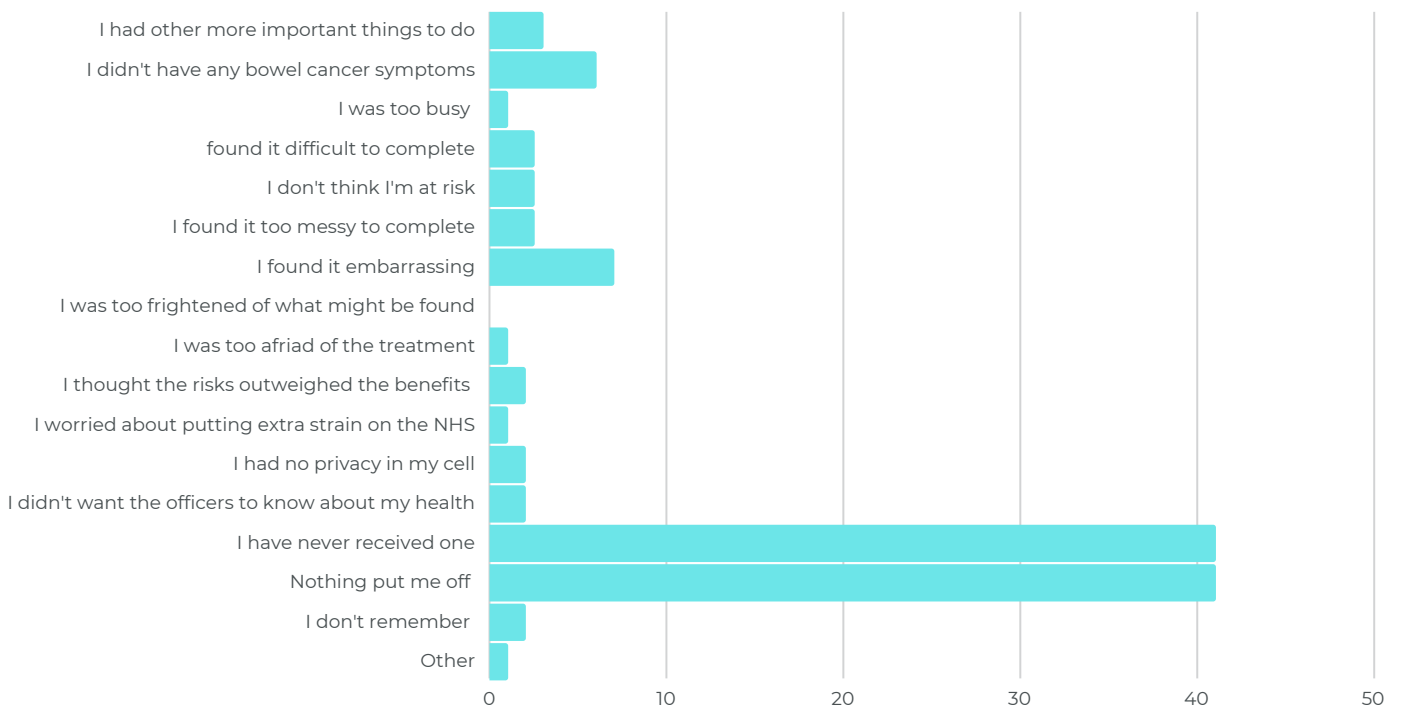
When reflecting on the last time individuals had been provided with an opportunity to complete a bowel screening test kit, it is evident that the most significant barrier was not being given or sent a kit, as reported by 40% of respondents. With the exception of one individual, all providers of this response were over 50 years old.

“The last test was at home 5 years ago.”

“I have never been sent a bowel cancer stool test kit in the 21 years I have been imprisoned!”

“I can't work out why I have not been given one. I have been here for over one year.”

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



Of those who found the test too embarrassing to complete, 80% were from a minority community. For one person, sharing toilet facilities put them off completing the test.

“Had one but embarrassing, also difficult to do in a public toilet.”

Some 6% said they had no symptoms of bowel cancer and so have not completed a screening kit when given, although importantly one individual felt there was a lack of understanding about the symptoms in prison.

“The prison does not offer enough info or understanding of cancer.”

We can see from responses that there was an appetite for greater understanding of cancer.

“Would like more info about cancer in general and better prison response.”

Although in much smaller numbers, there were a number of wider reasons why individuals did not complete a bowel screening test kit. These included finding the test too difficult to complete, feeling that the risks of testing outweighed the benefits and privacy issues. For some, assuring discretion was important.

“[I would complete it] if I was asked I would want it for me to discreetly hand it to healthcare from myself, in a bag or box.”

In contrast and importantly, 40% of respondents stated that nothing would prevent them from completing a kit, despite any challenges they may face in prison, such as obtaining test results.

“Simple to do – quick results (when out of prison).”

All participants within this cohort were 50 years or older and white (83%), potentially suggesting that those of a minority ethnicity would be less likely to complete a test. Of those who stated that they would let nothing stop them completing the test, it was clear that most understood the value of screening.

“It gave me peace of mind getting the all clear, proactive efforts to preserve good health is much better than trying to fix things if they go wrong.”

“I found it very necessary as it is a good thing to catch it early.”

Promoting these positive patient experience messages may be useful in acting as a motivator to completing the test.

Even those who had declined a screening kit previously had been prompted by the survey to complete a kit next time they were given one.

“I know it's important even though I did not do it. I will do it next time.”

One former prisoner we spoke to who was diagnosed with bowel cancer in prison leaves us with these final thoughts.

“I know screening, testing etc has to be targeted at those most at risk. But this can falsely lead to people and medical staff to not take seriously or misdiagnose cases. Whilst not the most common they certainly do occur. Anyone who feels the need for any test, screening, bowel cancer, heart, cholesterol should be encouraged to take one. I had symptoms at 41 and was misdiagnosed on several occasions because the profile was over 50s. This led me to me getting stage 3 cancer with a 15% survival chance. I am lucky to have survived. The problems stemmed from easily made assumptions by medical staff.”



CERVICAL AND BREAST CANCER SCREENING - SURVEY 3



KEY LEARNING



- Responses suggest there is uncertainty as to when people are eligible for cervical and breast screening.
- There is further uncertainty as to whether people are up to date with cervical and breast screening.

- Some, but not all, women understood early detection was important in terms of treatment and recovery for both cervical and breast screening.
- There is not enough gender-specific cancer-related health promotion in prison.
- Some women are put off by the thought of a man undertaking screening appointments.
- Nearly three quarters of women attended their last cervical screening appointment and 10% of women reported declining this when offered. 100% of those who were eligible based on age would attend their next one.
- Across all ages, 86% of women would attend their next breast screening.
- Those who stated they would not or probably would not attend a future appointment were all under the age of 40.
- All those who identified as a different gender to the sex assigned at birth would attend their next cervical screening.
- Over 70% of women experienced some discomfort or pain during their last cervical screening.
- A third of women report they felt reluctant to attend future appointments because of pain caused by cervical screening.
- 25% of women cite embarrassment as a potential barrier.
- A quarter of women said nothing would put them off attending their next cervical screening.
- Half of the women who agreed experiencing no symptoms was a reason not to attend were black; and all women afraid of treatment if abnormal cells were discovered were from ethnically minority communities.
- Pain was the most common reason to put women off attending a breast screening (12%)
- 10% of women suggested not experiencing symptoms could put them off attending.
- A further 10% agreed embarrassment was a barrier.
- For a fifth of women, nothing would put them off attending a breast screening appointment.



PARTICIPANTS

Surveys were distributed to those who were happy to share their views, and these were facilitated by peer researchers in prison.

Gender

Most participants stated they were female, with two identifying as male. 9% participants told us they identify as a different gender to that assigned to their sex at birth.

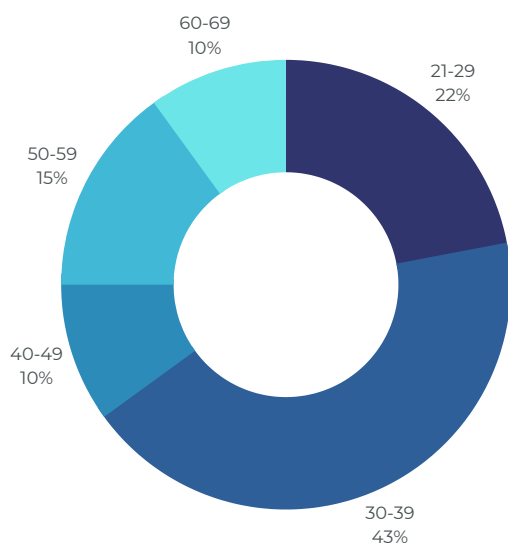
Age

Of those who participated in survey 3, most were aged 30 to 39 years old, making up 43% of all participants. The next largest group were women aged 20-29 years old who form nearly a quarter of all responses, (23%), followed by those aged 50-59 years (15%). A tenth were aged 40-49 years old, and a further tenth were 60-69 years old. None were over 70.

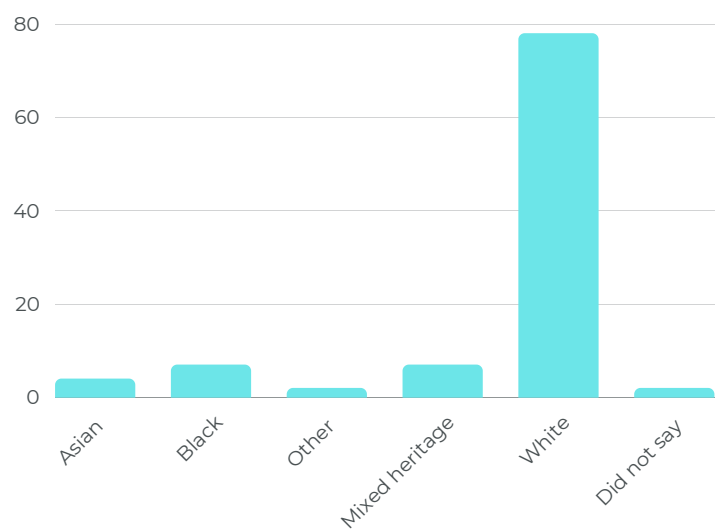
Ethnicity

Most participants were white, at 78%. Black and mixed heritage participants each make up 7% respectively. Asian participants form 4% of the overall numbers and a small number (2%) were of an 'other' ethnicity. A further 2% preferred not to state their ethnicity. In total, those from ethnic minorities formed around a fifth of all respondents.

Age



Ethnicity



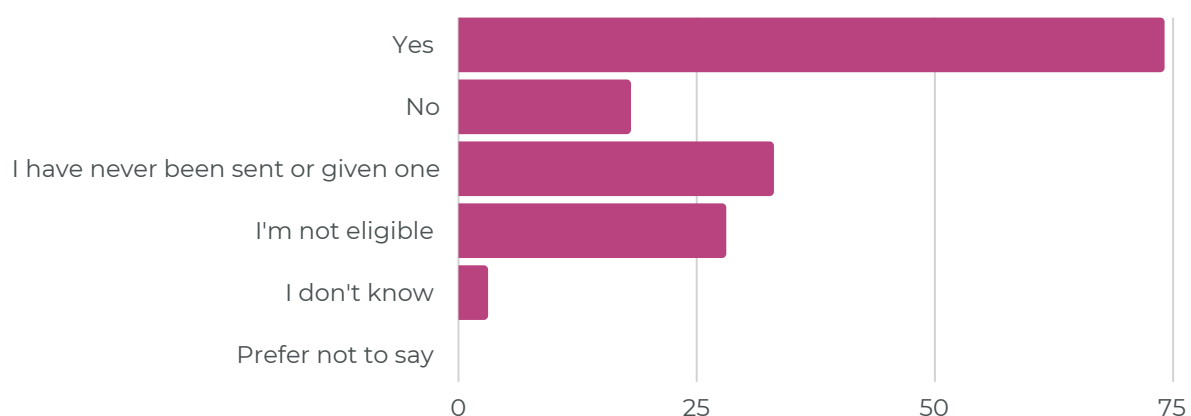
FINDINGS

Cervical screening

When asked if participants attended a cervical screening appointment last time they were offered, most people responded positively, with nearly three quarters of women stating they had at 74%.

Of the 18% who said they had not attended, there were multiple reasons.

Did you go for your cervical screening last time you were offered one?



A minority, 8%, stated they had never been given or sent a testing kit. Of these women 80% were also aged 21-29, so may not yet be eligible for screening, though the remaining 20% were eligible when considering age criteria only. One woman who had previously discovered abnormal cells, explained she had not been offered a screening since coming to prison.

“I haven’t had a cervical test the whole time I have been here even though 4 years ago I had to have Lentz procedure done to remove pre-cancerous cells.”

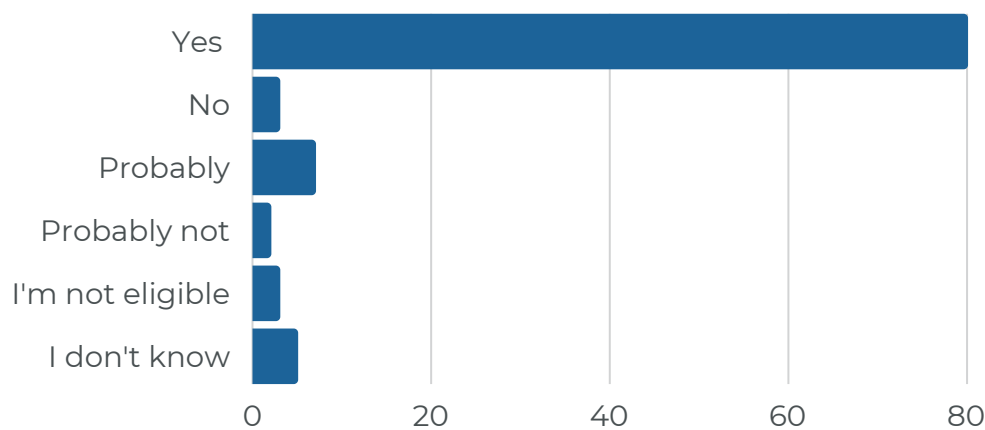
A smaller number stated they were ineligible for screening, and whilst a third of these were eligible due to age, we recognise that wider factors such as medical procedures like a hysterectomy, may exclude them.

2% were unsure if they had attended.

One woman who had previously discovered abnormal cells, explained she had not been offered a screening since coming to prison.

“If the tests were available, I would make every attempt to go and always have done so.”

Will you attend next time you are invited?



Of those who said they were unlikely to attend, only 5% stated they would not or would probably not attend. These 5% were all under the age of 40 years old and where ethnicities had been provided, all were white. The remaining numbers were made up of those who either felt they were ineligible or who did not know.

When considering the last time individuals were invited to a cervical screening appointment, the most common reason for reluctance was concern that the appointment would be painful, mentioned by around a third of women (32%).

A quarter of women told us they were embarrassed by the screening, and this put them off attending. One suggestion to overcome this was to enable women to complete the test themselves.

“I think a lot more women would use a ‘do it yourself’ test if one was available to avoid embarrassment.”

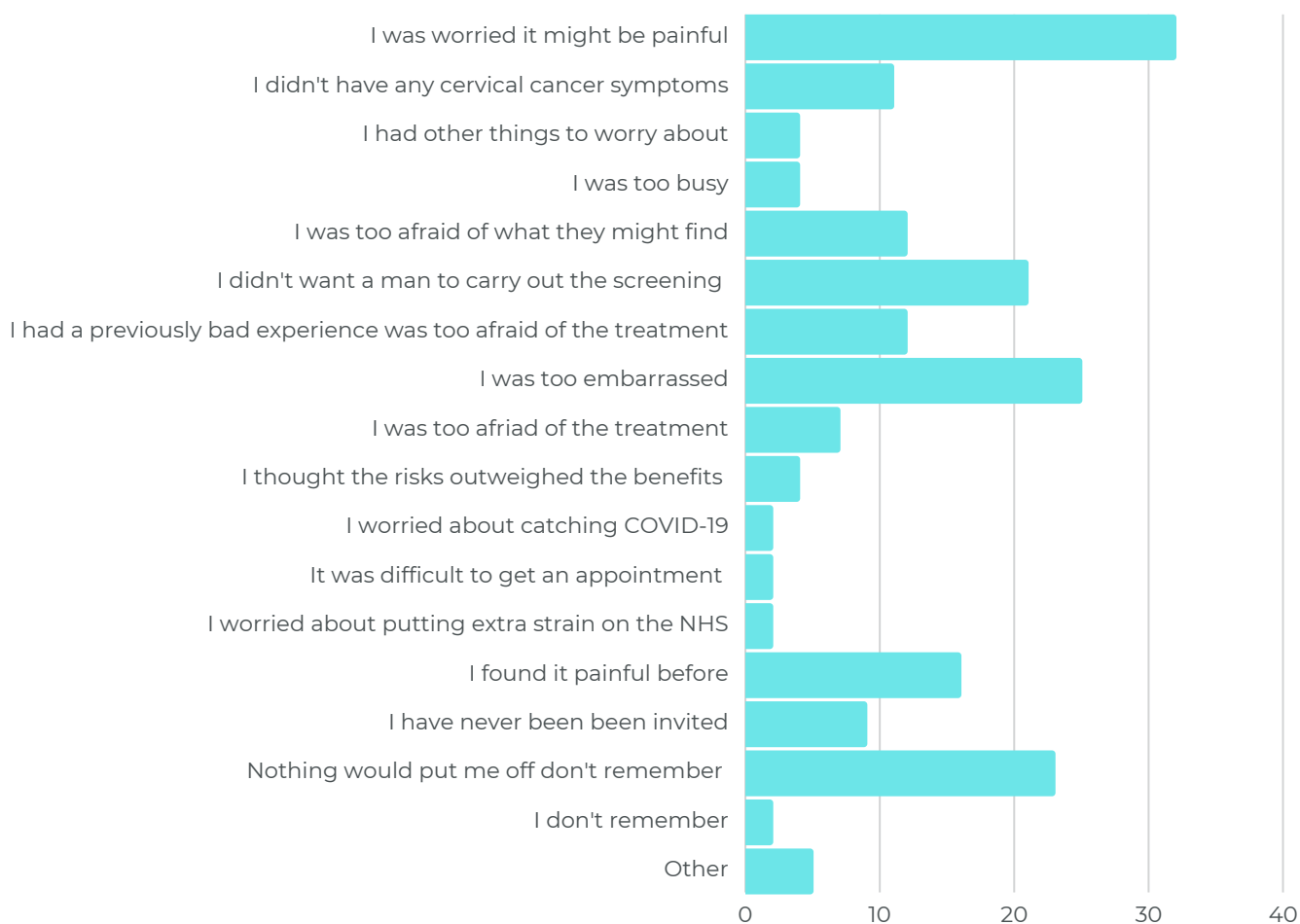
A fifth of women were hesitant at the idea of a man completing the screening, highlighting a need for female healthcare staff to be available for women concerned by this, or provided with reassurance on the appointment slip that the test would be conducted by a female member of staff.

Encouragingly, nearly a quarter of women (23%) would let nothing put them off attending a cervical screening appointment, though this is somewhat lower than men when asked about bowel screening intentions in survey 2.

Other notable responses included over a tenth of women feeling that not having symptoms can feed into reluctance in being screened, indicating a lack of understanding about the purpose of screening programmes. Of these women, half were black. Further, 12% reported having had a previously bad experience of a cervical screening appointment.

Of those who were afraid of the treatment if they were found to have an abnormal result – all these women were from minority communities.

Thinking of the last time you were invited to a cervical screening, did any of the following put you off?



Of the 5% who had a different reason not to attend, one had wider health concerns they felt they needed to prioritise over screening, and another explicitly felt it was difficult to show their body to a stranger.

“Worried about a stranger seeing my privates.”

“I was awaiting knee surgery and wanted to get that out the way.”

One person found everything about their health difficult to manage, but contrastingly understood the importance of staying healthy.

“Everything puts me off but my health and nothing is more important than it, just a thought.”

Similarly, another did not want to know if they were unwell.

“I don't want to know if I'm ill.”

One woman suggested the pandemic had impacted on her ability to obtain an appointment

“No appointments due to covid.”

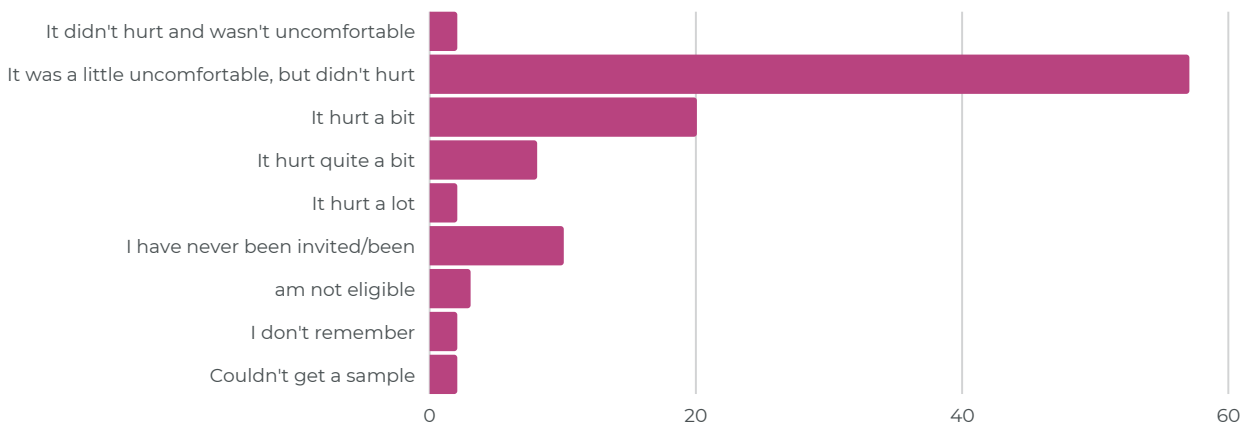
We asked participants about their experience last time they attend a cervical screening appointment. Over half found the screening a little uncomfortable and further 20% of women said it had hurt a little.

A tenth of women explained it hurt either quite a bit or a lot.

“The reason my last cervical test was bad as I’ve not had sex in many years, and it’s got a lot smaller and it made me bleed quite bad.”

A minority of women report healthcare professionals undertaking the screening being unable to collect a sample.

Which of the following statements best describes how it felt when you attended your last cervical screening appointment?



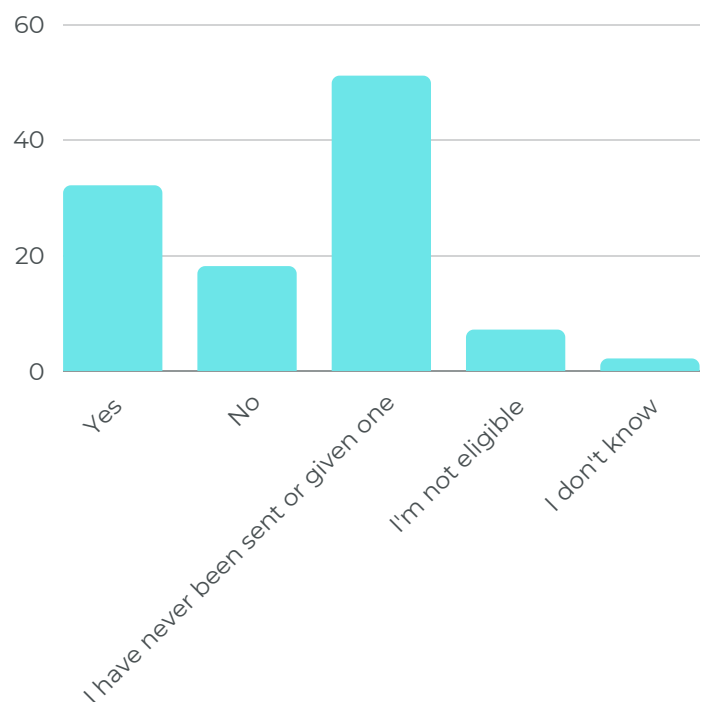
Breast screening

Women were asked if they had attended their last breast screening appointment. Over half of the women (51%) said they have never been invited to an appointment. All these women were aged under 50 years and so ineligible in line with the national screening age.

Of the 9% who said they had not attended, all were under 50 years old so may yet have been invited to a screening. Further, 7% noted they were ineligible, which included one woman who was aged 60-69 years old who had undergone a double mastectomy, and survived cancer.

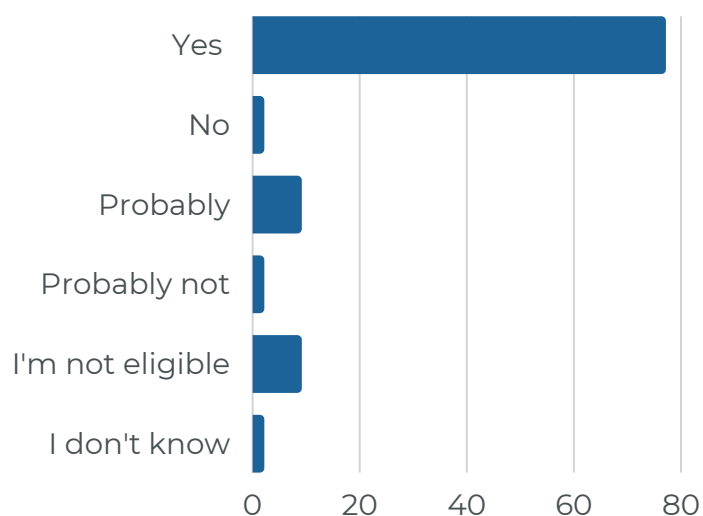
Positively, of those eligible for testing based on age alone, 73% of women said they attended their last breast screening appointment and 100% of women (eligible by age alone) said they would attend their next appointment.

Did you go for breast screening last time you were invited?



A minority of those eligible, 7%, said they were yet to receive an appointment.

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



Looking more broadly at women's attitudes towards attending a future breast screening appointment, across all ages 77% of women said they would attend with a further 9% saying they probably would.

For the small number of women who would not or probably not attend, all women were under 40 years old and cite embarrassment and not wishing to know if they were unwell as reasons.

We found the most common response that fed into a reluctance to attend a breast screening appointment were concerns the screening was painful, highlighted by 12% of women.

A tenth suggested not having any symptoms would put them off, with the same number of women finding the appointment embarrassing, especially if it was with a male member of staff, though some overcame this.

"I've had ultrasound on breasts and treatment for abnormal cells on cervix although I was treated very respectfully it feels awkward the specialists seem to mostly be men."

"It's important to go to all appointments. It may be a little embarrassing, but your health is the most important thing and if you do have a problem it's best to catch it early."

A minority of women, 8% said they needed help to get an appointment and 5% were concerned about the treatment if something was discovered following screening.

Wider comments made by smaller numbers of women included believing they weren't at risk of cancer, feeling they shouldn't put extra strain on the NHS or finding it difficult to obtain an appointment. One suggestion was to make appointments easier for women in prison, as on occasion this could lead to under reporting of concerns.

"It would be a good idea if some women's prisons had the mobile breast screening to visit them as it is hard to get appointments in a closed prison and many women do not report lumps so on until maybe it is too late."

Whilst no one stated they were too busy to attend, we did hear that wider concerns could impact on women prioritising their health.

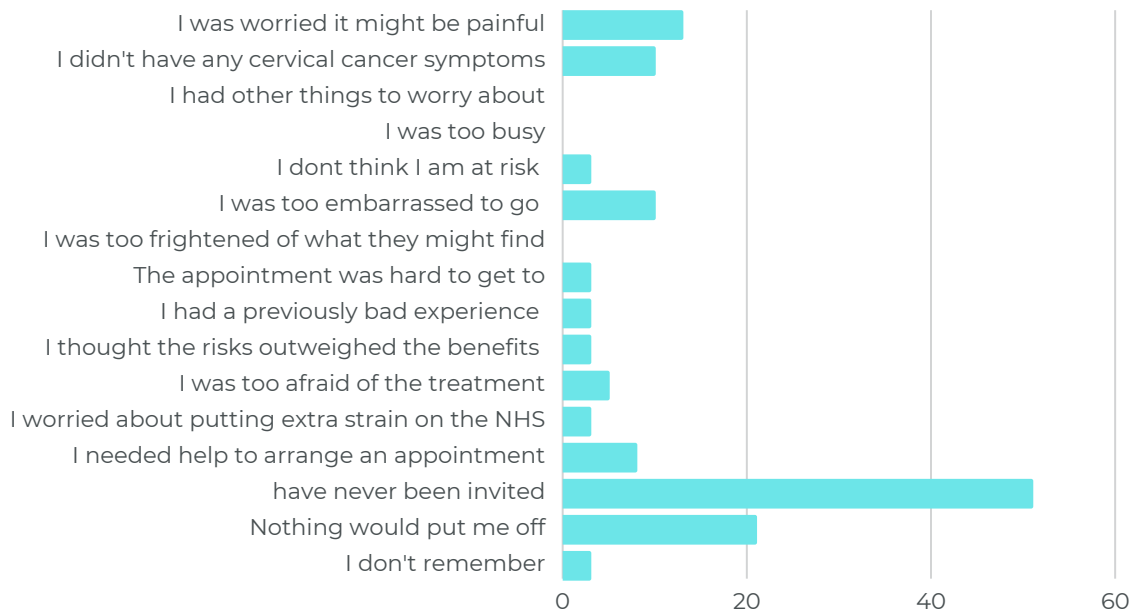
"Not enough women check themselves in prison as they have far too many other things to worry about."

Further comments evidenced women understood the importance of screening and early detection of any concerns.

"Please, to anyone folk who is put off over the thought of how it sounds or from anyone's word of mouth My opinion is - your health and actually knowing if you've got bad or abnormal cells is more important so you could actually get the process in motion to get rid of bad cells if doable. Better safe than sorry."

"I think all women should go and get cervical screening and breast screening. It's very important, life is too short anyway. Some ladies leave it way too late so please, please get it done ladies."

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



Some women were keen to attend appointments but unsure about eligibility.

"I would like to go for breast screening, but I don't know how to find out about it. I think at my age of 48 I would have been invited for breast screening."

"I'm not sure how old you have to be for the screenings."

Importantly, we can see from the quotes above, women were often unsure how to find further information about breast screening in prison, but there appeared to be an appetite to learn more about this and health in general

"I would like to be invited to all and any event relating to my body and health."

"Healthcare staff should make us aware of this, but they don't."



SECTION SUMMARY

Across both bowel, cervical and breast screening responses it's evident there's a lack of confidence in people's understanding around eligibility. Across both surveys, some people understood the importance of early detection and the impact this can have on treatment and recovery, though felt there was little health promotion relating to cancer awareness in prisons.

The fact some referred to a lack of symptoms as a reason to not attend suggests a lack of understanding within these cohorts. This was particularly evident for those from ethnic minorities. However, there appeared an appetite from most to learn more in order to stay healthy. Of course, men and women in prison are frequently managing multiple stressors relating to imprisonment, which can impact on their ability and their likelihood of seeking

out information on their own accord, especially if they feel they aren't always taken seriously as mentioned earlier in the report. COVID-19 and associated challenges in accessing healthcare may heighten this further.

Less than half of men had completed their last bowel screening kit, when we look at this compared to women attending gender-specific screenings, this is much lower than their female counterparts.

Embarrassment was an important factor for all communities in terms of completing a kit or attending an appointment. For men in prison, enabling discretion and privacy to complete a kit needs to be a consideration, and for women, it is crucial they are supported by female healthcare staff.

Interestingly younger women appeared to be less likely to take up screening appointments in direct contrast to younger men who were more likely to complete a bowel screening kit, which could be an important consideration when designing and targeting health promotion to populations.

Where we might have expected to see some hesitancy at attending gender-specific screenings from those not identifying as women but living in women's prisons, it was encouraging to see that 100% of this cohort would attend their next screening appointment.

A fear of pain presented as the most common reason for women to not attend screenings and this spanned across all ages and ethnicities, but notably those from minority communities were also more fearful of treatment leading to a reluctance to attend appointments in the first instance.

However, it's useful to see from responses the range of factors that can impact on both women and men when they think about testing and screening processes. You can see the number of reasons provided can cumulatively add to and increase hesitancy in attending appointments or completing screening kits.

The responses overall provide valuable insights from people in prison relating to their experiences of cancer screening and future intentions. One final thought offered across both communities was a suggestion COVID-19 had disrupted routine screening. We heard from both men and women who felt they were eligible (and appeared to be, solely on age) who had never received a kit or been invited for cervical or breast screening.

It may be worthwhile prisons undertaking a 'stock taking exercise' to ensure those who are eligible have been given the chance to participate, alongside increasing internal health campaigns to encourage uptake.



ACKNOWLEDGEMENTS

Our thanks, as always, to;

Every person in prison involved in the consultation, especially our peer researchers who engaged with their communities to support this work.

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