



Summary Report Exploring Low Uptake of Bowel Screening by Men in Rural West Sussex

Summer 2022

healthwatch
West Sussex

How does the screening work?

The local Screening Hub send a letter to people who are registered with a GP currently there are three groups of people because of lowering the starting age to 50 being rolled out.

- Those who are turning 56 years
- Those who are turning 58 years
- Those who are turning 60 years

Next year (2023) those turning 54 years will start to be invited. Thereafter people are invited every 2 years.



The letter informs people they will be receiving a home testing kit (known as the FIT test) within a few weeks. The home test kit is sent in the post in an NHS branded white box. The home testing kit comes with supporting information in English. There are instructions on how to collect a sample. The completed test then needs to be posted back to the Screening Hub to be tested.

A letter, detailing the outcome of the test, is send out to the person in the post about two weeks' later. A large number of people receive a negative test and do not need to do anything more.

If the sample could not be tested successfully the person may be asked to complete the test again or if positive, the person will receive an appointment to speak with a specialist bowel screening practitioner to discuss next steps, which could mean attending the hospital for a colonoscopy.

Why screening is important?

Bowel cancer is a common type of cancer in both men and women. About 1 in 20 people will get it during their lifetime. It's the fourth most common type of cancer, with most people diagnosed with it being over the age of 60. Screening can help find it at an early stage, when it's easier to treat.

Everyone aged 60 to 74 (and those who are 56 years old) who are registered with a GP and live in England are automatically sent a bowel cancer home screening kit every two years. The NHS has the ambition to move toward everyone aged over 50 in the next few years.

More than 90% of people with bowel cancer have one of the following combinations of symptoms:

- **a persistent change in bowel habit** – pooing more often, with looser, runnier poos and sometimes tummy (abdominal) pain
- **blood in the poo without other symptoms of piles (hemorrhoids)** – this makes it unlikely the cause is hemorrhoids
- **abdominal pain, discomfort or bloating always brought on by eating** – sometimes resulting in a reduction in the amount of food eaten and weight loss.

(Note Constipation, where you pass harder stools less often, is rarely caused by serious bowel conditions.)






If you're worried about a family history of bowel cancer or have any symptoms, speak to a GP for advice.

What do the numbers tell us?

There has been a positive increase in the number of people, being screened for bowel cancer within six months of an invitation across England. The ease of testing is a key factor in this trend.

Bowel cancer screening programmes at a glance

February 2022

 Bowel	England 	Scotland 	Wales 	Northern Ireland 
Age	60-74 [a]	50-74	58-74 [a]	60-74
Frequency	2 yearly On request over 74	2 yearly On request over 74	2 yearly	2 yearly
Technology	FIT	FIT	FIT	FIT
Threshold	120ug/g	80ug/g	150ug/g	150ug/g
Uptake [b]	71% (2020/21)	65% (2020/21)	62% (2019/20) [c]	59% (2016/17)

[a] People aged 50–59 will be invited to participate, as a phased approach over the next few years.

[b] Caution should be taken when making comparisons across countries due to differences in time periods of data, age ranges and/or differences in the definitions of coverage and uptake of screening

[c] Bowel screening uptake data in Wales includes both FIT and gFOBT.

FIT: Faecal Immunochemical Test
gFOBT: guaiac Faecal Occult Blood Test

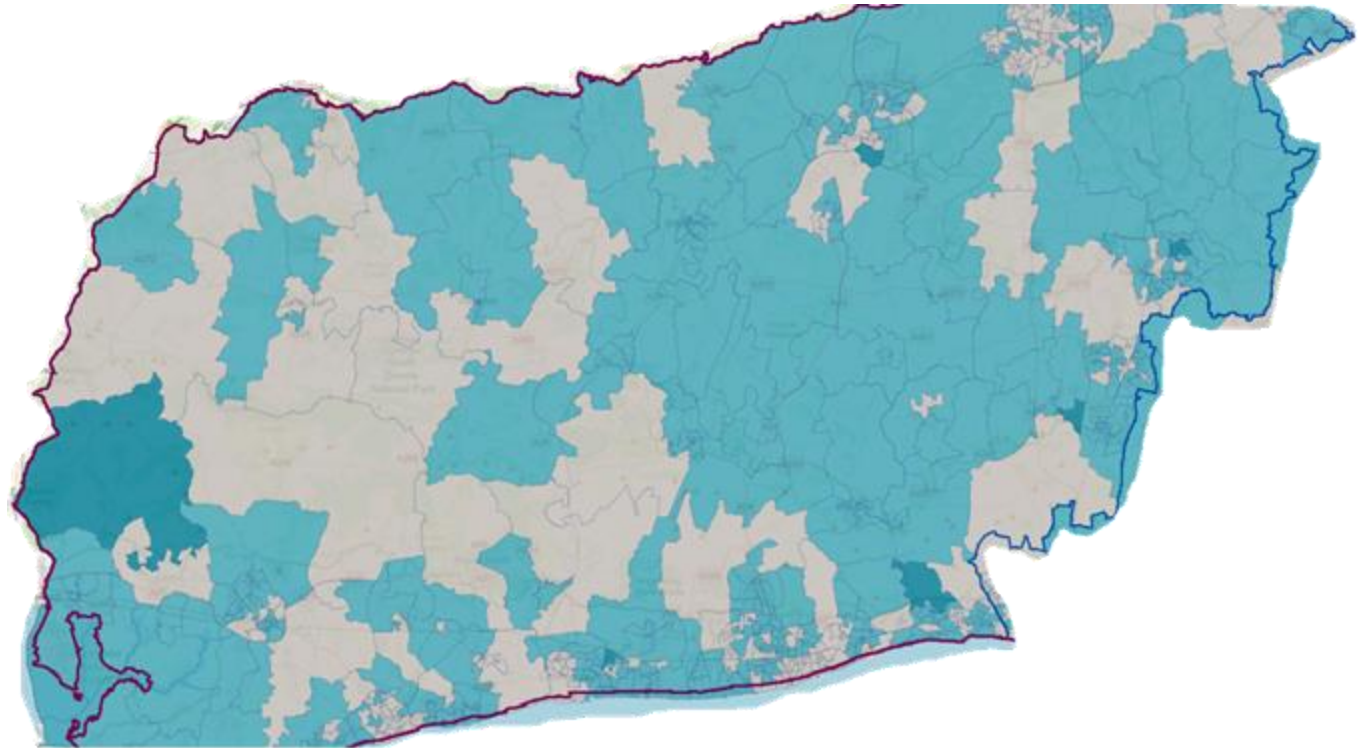
cruk.org
Together we will beat cancer



Sussex Bowel Screening Uptake – April 2018 to March 2021

However, Bowel Screening levels of uptake (as report by the Bowel Hub 2018-2021) in men aged 60-64 indicate there are small pockets in rural areas where completion levels need to improve.

This suggests we need to try to engage men in a different way, especially as the NHS looks to lower the screening age to 50 in the coming years.

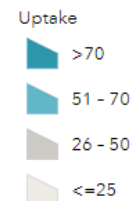


▼ Bowel Screening Uptake (Filtering)

AgeGroup_Invited is

Subject_gender is

LSOA Bowel Screening Uptake % (Filtering)



What people said may positively change the data?

Letters

- Consider adding the website information to identify where the nearest post box is into the letters sent
- Consider enclosing disposable gloves with the kits
- Have information and kit in an accessible format, including visual instructions
- Be clear on time sensitivity/insensitivity around the sample
- Feedback that the packaging of this test is similar to the COVID test kits (so some may be sitting in drawers.)

Marketing

- Awareness raising with high profile people – such as the [Bobby Moore Fund](#) which still operates under Cancer Research UK. Link with [Cancer Research UK](#) ambassadors and patrons programme to ensure people are aware of this and other screenings
- Promotion in social places people visit libraries, GP surgery, male publications -fishing world, fly fishing, snooker world and so on.
- Use tools from [Men's Health Forum](#).

What people had to say about this testing?

Information

- There needs to be clarity around the age the test starts and ends. People are confused.
- Errors meant some people didn't get the test when they expected them (in correct addresses, wrong advice from General Practice, and people having to wait longer due to the effect of the pandemic.)
- Issues with completing and returning the test - written information too small and/or difficult to follow – a lack of visual guidance.

Practical issues

- Health conditions preventing collection, difficulties in collecting the sample (including the size of the tube).

Emotive barriers

- Not wanting to know the outcome and having to make decisions
- Having to provide such a sample, embarrassment issues around knowledge and awareness (not knowing about the test, not thinking it applied to men, age the screening ends and not wanting to complete the test.) Or have been advised by their GP not to complete the test. And sceptical about the capability of the NHS to treat appropriately if diagnosed, given the pressures it is currently under.

What people had to say about this testing?

Conversations with men

Our conversations with men provided a rounder view with the following themes being identified as barriers.

Information provided by the Screening Hub: generally, the process was easy to do and follow. Some of the practical issues were around the level of dexterity needed to access the sample. There was a request that a local screening hub – or somewhere to go, if the person experiences difficulty in completing the test, when at home with other family members around.

A big area seems to be not being aware of different screenings available, the age when different screening begins and ends.

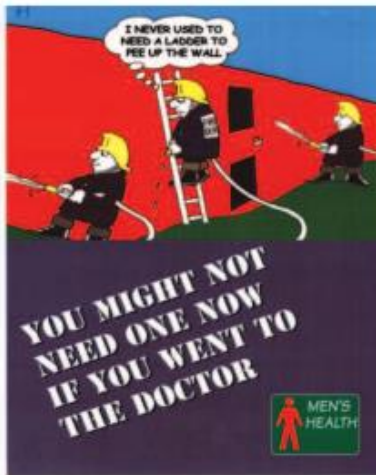
Some felt embarrassed by having to complete the test and needed support from family members. Communication: it was suggested that this needs to be considered carefully and need to use the right language to engage with the population.

Not trusting the accuracy of the testing process, as influenced by what they read about prostate cancer testing and the high number of false positives. Some ignored the testing information, as they do not want to know if they have bowel cancer or not.

How can we better raise awareness of the testing amongst men?

It was suggested that to reach men, the NHS needs to promote the test around male' activities: sports, exercise gyms, and social - fishing, golf, football, the local pub as examples (https://youngfoundation.org/wp-content/uploads/2012/10/INVISIBLE_MEN_-_FINAL.pdf.) ... *men do not tend to sit and chat but need an activity element.*

With the screening age moving down to one where more people will be working, the NHS may need to consider out of hours activities, social connections, and networks. These could be ideal places to promote screenings, to compliment the usual advertising venues (GP Practices, libraries), and wider media channels based on sport -football, golf, and hobby publications.



Humour can be a valuable tool to conveying serious health messages to men, in a less formal manner. Humour can provide a means to provide serious health promotion messages, while still maintaining a light hearted tone that is often appreciated by men.

[Men's Health Forum](#) has examples of what might work

How can we better raise awareness?

As the age for screening comes down, this younger group is more likely to have more exposure and usage of technology – smart mobiles etc. will have replaced letters. So many may not use post boxes as frequently as the 60+ age group.

Academic evidence has shown that men respond well to peer support and friendships – so long as they can see the benefits others have gained and that this benefit is something they want for themselves.

Going to where men are is therefore important, but recognising that conversations need to be short and to the point (as does any material).

This means:

- Finding the connections/resources to build partnerships with group leaders and gatekeepers.
- Working with men as advocates, who are willing to share their story as examples.
- Consider incentivising engagement – such as paying for a round of golf or snooker (helpful when engaging with smaller groups). This is a way of showing respect and value.

Recognising the role of women and partners and the important role they play in supporting and prompting the completion of screening and other health related testing. This is also helpful for other Sussex engagement.

For more information

You can find more detailed insight in our accompanying project report. This has both the survey findings and the case studies from the interviews.

[Click here](#)



Exploring Low Uptake of Bowel Screening
by Men in Rural West Sussex

APPENDIX REPORT – DETAILED FINDINGS



Report written by Cheryl Berry Community Partnership Lead
September 2022

Is there a poo taboo?

It is well understood that discussing health, beyond the physical image and activities, with men can be challenging - as we have found with this project.

The initial plan was to set up two focus groups, with a male facilitator, for between 6 to 8 men. We contacted workplaces to explore holding a focus group with their staff - one *merchant* was initially interested but due to COVID-19 absences and increases in workload, had to pull out. However, they are circulating the information provided to all staff.

We spoke to local pubs, clubs, community and sports groups and were told we could not speak with their members, some citing GDPR issues and others declining due to the social nature of the group. *'People come here to socialise, to get away from the day to day, this topic is not suitable.'*

We shared our information with local GP surgeries who supported by passing information onto patients who may not have completed the test. A massive thank you to their staff for this help.

We raised awareness of our participation opportunity during men's health awareness week. We reached 176 people.

However, after a few weeks. Only two men had contacted us to join a focus group. We realised this may not be a topic for a focus group and needed a Plan B.

Exploring Low Uptake of Bowel Screening by Men in Rural West Sussex

Bowel screening data shows that men in rural West Sussex seem more reluctant to take up the bowel cancer screening. We want to understand the reasons why to influence change.

We would like to set up a men's focus group to focus on the issues, and how men feel these can be overcome to help increase bowel screening take up.

 If you are interested in joining a focus group, or just want to share your views, please get in touch: healthwatchwestsussex.co.uk/contact-us



Plan B

Working with our male facilitators we developed a Plan B. A two-question survey was suggested, recognising the need for simplicity and survey fatigue. The two questions being:

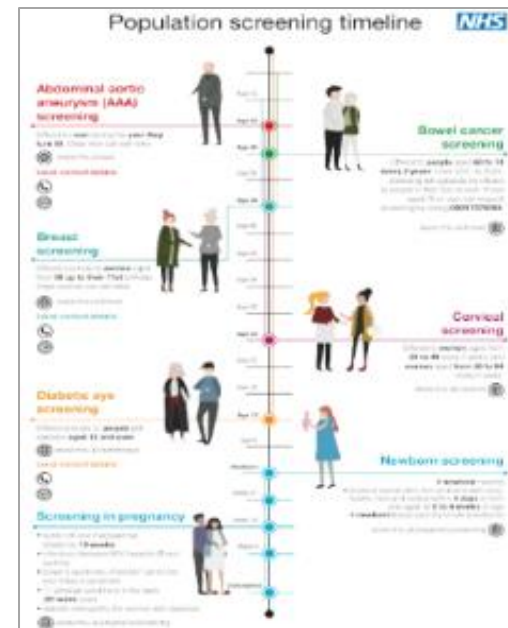
- 1) I have completed and returned the Home Screening check?
- 2) I have not completed the Home Screening check. (Please provide the reasons).

This was set up, and widely promoted through our contacts, and has led to answers from 203 people. (145 people completed the survey fully [n103 females, n41 males, n1 other], and 58 answered the 2 questions only.)

We were also able to have 14 follow up conversations (n9 males and n5 females.)

We were supported in this work by five male volunteers who spoke with family, friends and others in the Crawley, Horsham, and Mid Sussex areas.

In addition, we were able to have conversations with **67 people** (n56 males and n11 females) at various engagement events, including four walking football groups in Arun. These conversations were formed around the NHS screening timeline leaflet and Cancer Research UK booklets, which many people took away. In fact, the timeline leaflet was re-printed three times (60+ copies) during the project.



Acknowledgements

We would firstly like to acknowledge the tenacity of Cheryl Berry our Community Partnerships Lead, who has delivered on this project, despite the access challenges we encountered.



Our two-question survey was coproduced with male volunteers. This was live from 27 July to 4 September 2022. Thank you to the 203 people who participated in this survey.

Thank you to our community partners, and NHS and council colleagues who advertised the survey via their social media, and text message services.

We would especially like to thank our male volunteers: Nigel, Leslie, John, Trivelle, and Ian, who tirelessly supported this project.

We are truly grateful to all who have supported us with this work.

Extra outcomes

There has been some unexpected outcomes from this work.

- A NHS Nurse Advisor in the Prevention Assessment Team – who completes NHS Health Checks* – is interested in joining events and possibly working together.
- We've developed a special relationship with the Age UK [Laburnum Sports Center](#) Manager - Bognor and Ford. He would like to develop screening options for members. Our plan is to link the NHS Nurses and Age UK together.
- During a conversation with a resident, they challenged the data – as rural West Sussex is no different from other rural County areas.
 - Is the data correct?
 - Is there a higher prevalence of cancer in West Sussex than other areas?

* The [NHS Health Check](#) is a health check-up for adults in England aged 40 to 74. It's designed to spot early signs of stroke, kidney disease, heart disease, type 2 diabetes or dementia. As we get older, we have a higher risk of developing one of these conditions. An NHS Health Check helps find ways to lower this risk.

Next steps

Before publishing the reports, we shared draft information with the commissioner and:

- The West Sussex Cancer Alliance Group
- West Sussex County Council's public health cancer consultant
- The Surrey and Sussex Cancer Alliance
- Local Screening Hubs

This report goes to NHS Sussex, NHS England and Healthwatch England.

We will now discuss with NHS Sussex and the local screening hubs how they can use these findings, so we can report together on what has changed to encourage more men to complete the screening.

For more information

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