Wessex Academic Health Science Network

NHS Dorset

InHip Dorset: Baseline findings to support intervention

# Summary of findings from focus groups and a survey

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# Introduction to InHIP Dorset

The Innovation for Healthcare Inequalities Programme (InHIP) aims to address local healthcare inequalities experienced by deprived and other under-served populations.

The InHIP Dorset team identified early cancer diagnosis for colorectal cancer (CRC) as a priority for this programme. Dorset Integrated Care System (ICS) has a population that is older than the national average and with significant pockets of high social deprivation in its coastal and rural communities. Nearly half of those diagnosed with CRC in Dorset in 2021/2022 were classed as late stage diagnoses (i.e. stage 3 and 4). InHIP Dorset is focused on the deprived communities which experience poorer cancer outcomes.

Use of the NICE-approved *Faecal Immunochemical Test (FIT) is one way to detect CRC earlier. However, its use and completion rates in Dorset are low (only 40-50% of FIT required for suspected CRC cases are completed). The InHIP project aims to increase awareness of CRC and FIT to support both primary care clinicians and local communities in the uptake of these tests. The aim is to improve earlier and faster diagnosis of CRC in the targeted deprived communities.

*A home test kit, called a faecal immunochemical test (FIT) that collects a small to collect a small faecal sample and send it to a lab. This is checked for tiny amounts of blood.

# Introduction to focus groups

Each focus group was facilitated by members of staff from DCP. They gathered thoughts from underserved communities which included a support group for vulnerable and marginalised individuals and a learning disability group.

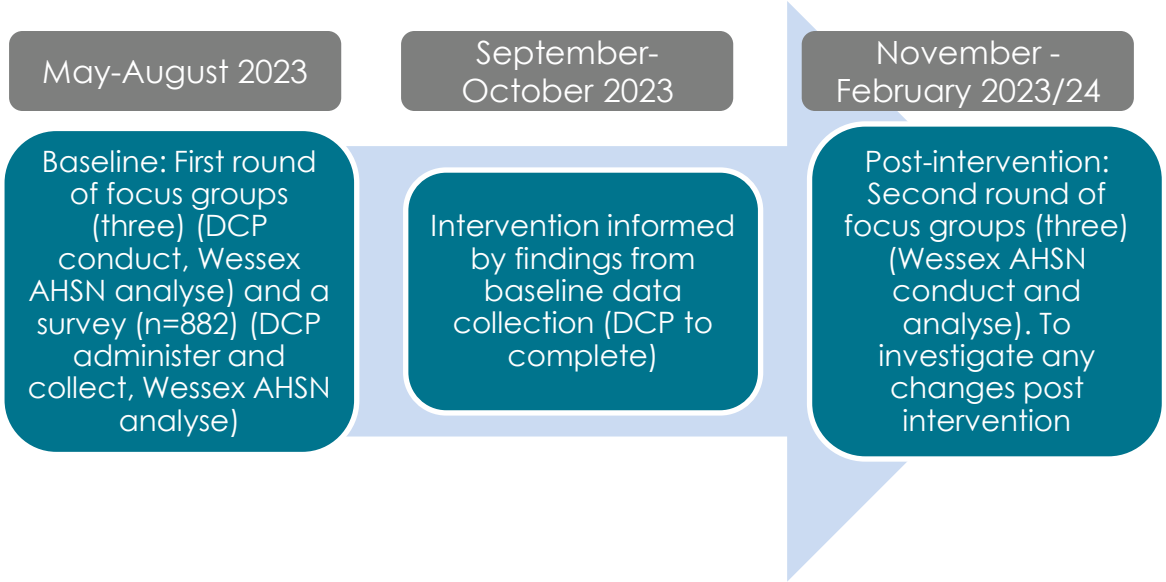
Each focus group was designed to learn about participants' knowledge and awareness of bowel cancer, its symptoms, and FIT. A total of 17 individuals participated in the focus groups throughout summer 2023.

Wessex AHSN analysed the focus groups in Nvivo* using thematic analysis to code, categorise and theme the data.

*NVivo is qualitative data analysis computer software

# Approach and methods

For part of the project, Dorset Cancer Partnership (DCP) is working with Wessex Academic Health Science Network (AHSN) to undertake a 'pre-test and post-test' project approach to understand local communities' awareness and understanding of CRC and FIT.




This slide deck includes only a high-level summary of the 'baseline' findings from two focus groups (two not three: an explanation is in the limitations slide) and a survey to understand the local communities' current level of awareness and to inform the intervention.

# Focus groups:
# Awareness of colorectal cancer

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# Focus group limitations

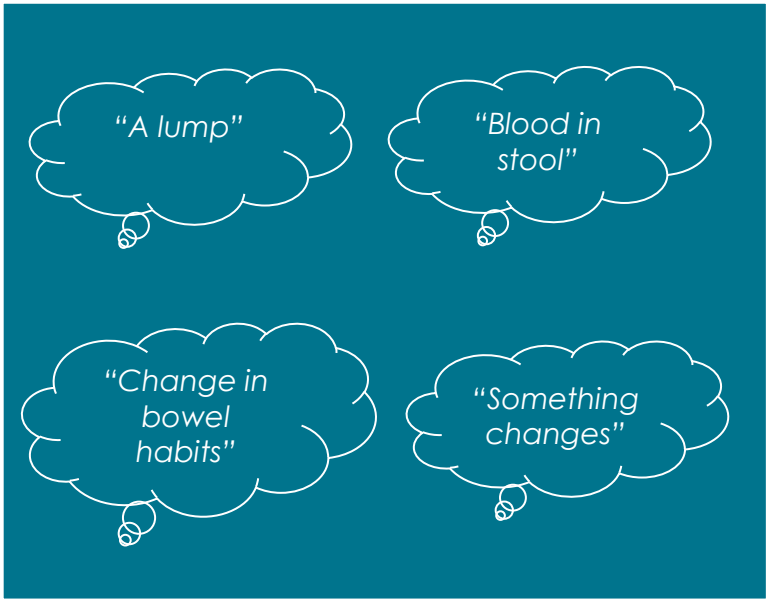
There were numerous limitations for the 'baseline' part of the project:

1. Due to project delays, only three of the five intended focus groups were completed. Due to participants not providing consent to recording, only two of these three focus groups were recorded and transcribed; these two were analysed.
2. Wessex AHSN was unable to determine how many participants contributed with each focus group because of the format of the transcriptions provided by DCP. There was no indication of which participants were speaking (i.e. whether it was mostly one participant speaking or more); only the interviewers were identified.
3. There are limited findings because a number of questions only yielded limited responses.
4. These findings can only be used to support decisions to aid the development of the intervention.

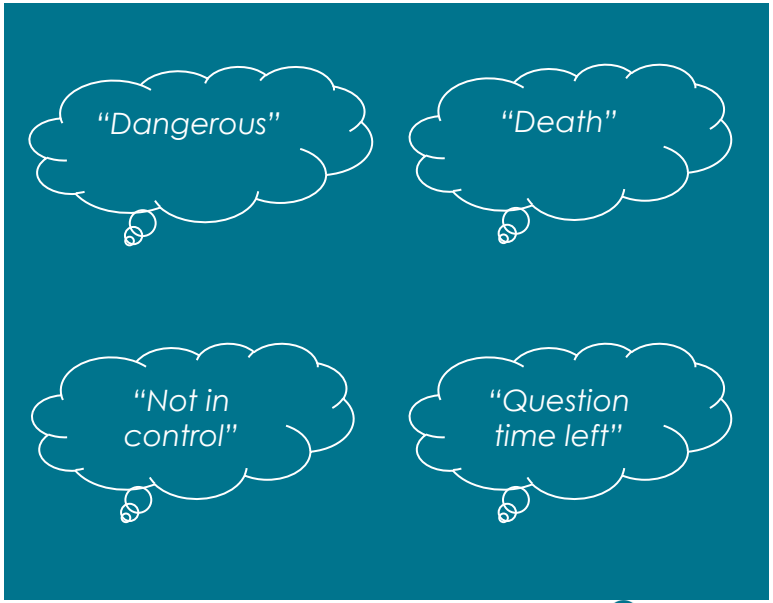
# What do you think about when you hear the phrase “bowel cancer”*?

This question yielded short answers from both focus groups; therefore, a summary of direct quotes is shown below. The reactions were a combination of symptoms and subjective feelings that people had upon hearing the phrase.

Symptoms mentioned in focus group




Subjective feelings




*CRC = bowel cancer

# Can you tell us some symptoms of bowel cancer?

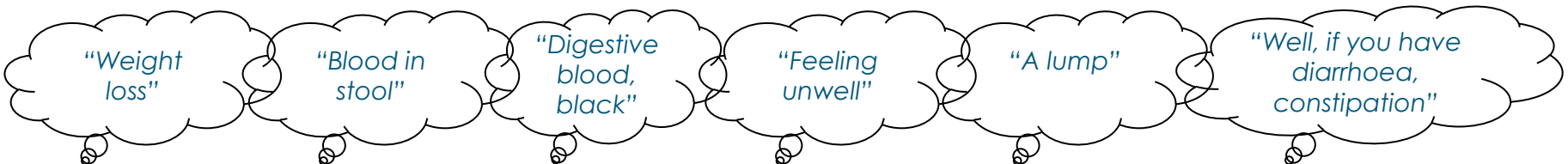
From both focus groups, individuals were aware of four out of eight symptoms of bowel cancer, NHS bowel cancer symptoms (link to website):

- changes in your poo, such as having softer poo, diarrhoea or constipation that is not usual for you
- blood in your poo, which may look red or black
- tummy pain
- losing weight without trying.

However, neither focus group considered or discussed the following symptoms:

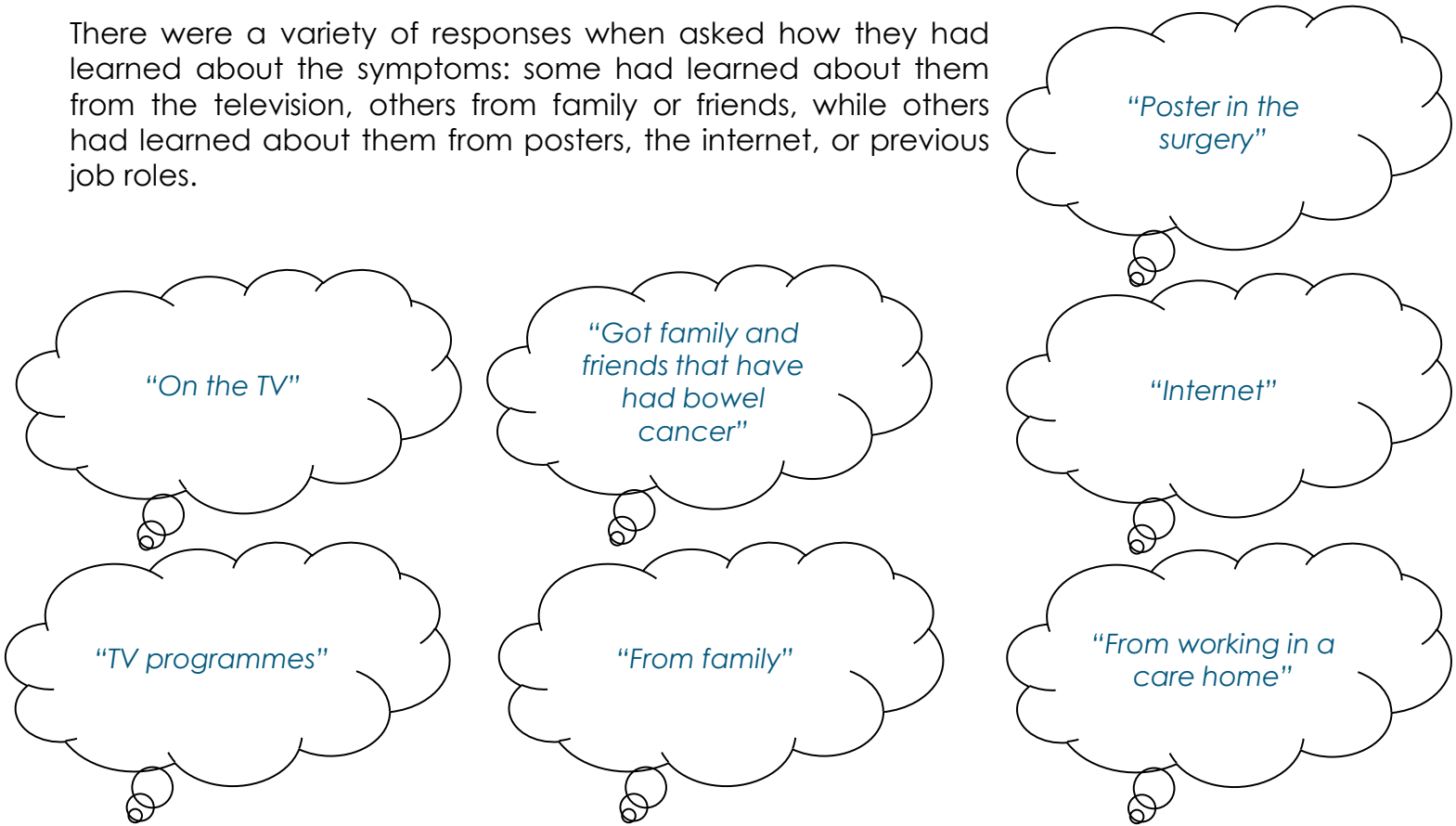
- feeling very tired for no reason
- bloating
- often feeling like you need to poo, even if you've just been to the toilet
- bleeding from your bottom.

This shows that while some symptoms are recognised by participants, more awareness is required.



# Where did you hear about bowel cancer symptoms?

There were a variety of responses when asked how they had learned about the symptoms: some had learned about them from the television, others from family or friends, while others had learned about them from posters, the internet, or previous job roles.

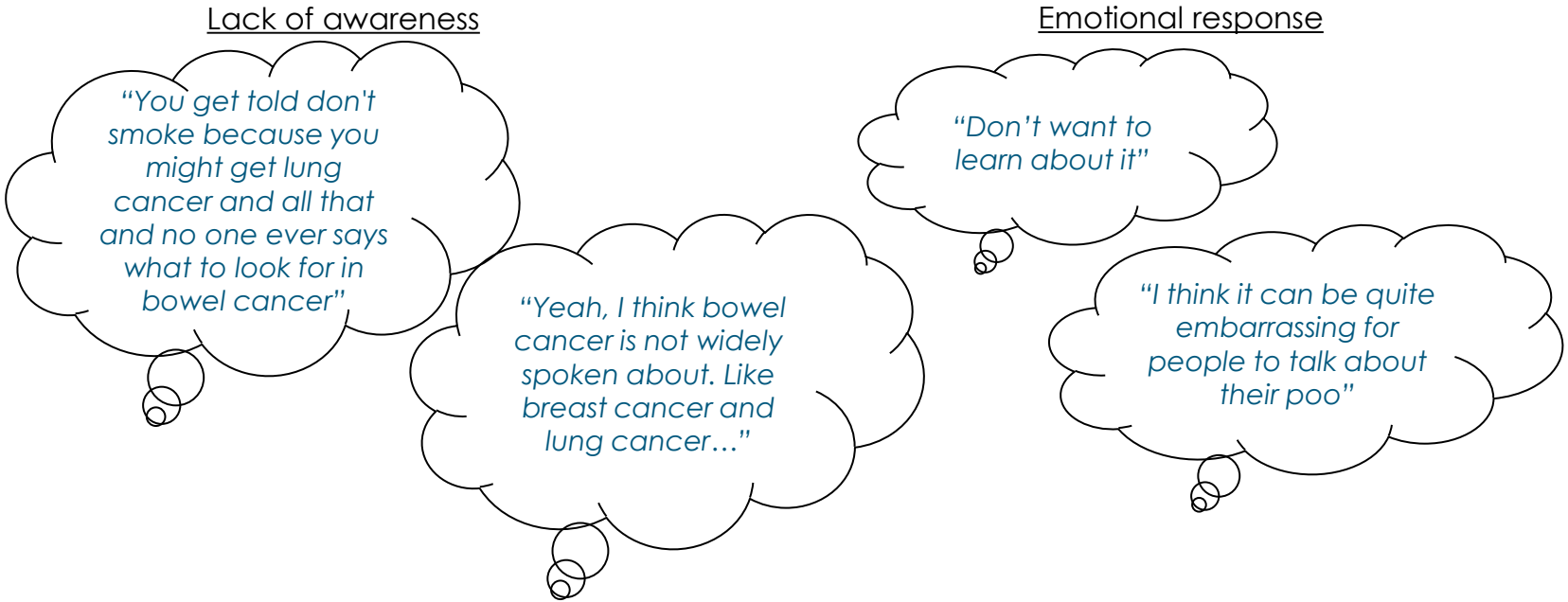


# Reasons why individuals were unaware of bowel cancer symptoms

A few participants brought up the fact that, in contrast to other cancers like breast or lung cancer, bowel cancer is not commonly discussed. Participants thought the lack of awareness was linked to a lack of conversation about bowel cancer.

Others felt that discussing bowel habits and bowel cancer was inappropriate because it was a "taboo" topic, and they did not want to learn about it or felt ashamed to bring it up.

The following quotes highlight this.



# Focus groups:
# Awareness and barriers to a FIT

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# Awareness of a FIT

## Have you seen a FIT before?

Focus group 1: 1/7 individuals had seen a FIT test before.

Focus group 2: 8/10 individuals had seen a FIT test before, although there was some confusion between going to the GP to test and the postal FIT test.

From the focus group transcripts, it was not completely clear who was familiar with the test, however, awareness seemed limited in focus group 1 with some confusion about the test and its process with focus group 2. Overall, the responses indicate a low level of awareness about the screening programme.

## Initial thoughts about the FIT?

There was hesitancy on the mechanics of the FIT test including the procedure and application,

> *"I'm confused about the mechanics; I mean do you fish it out?"* [focus group 2].
>
> *"So you catch it in a bowl?"* [focus group 1].
>
> *"Do I have to put it in a dessert bowl kind of thing?"* [focus group 2].

One individual commented on the size of the test, *"glad it's only small"* [focus group 1], whilst another individual mentioned they would discuss it with their family due to being nervous to do the test.

Other than hesitancy, one individual described they would be reluctant to physically do the test as it would be difficult for them to do, "I'd heave" [focus group 2].

Others would fear the outcome,

> *"You're doing it because somebody wants you to, but you're scared of the outcome and the results of what it is."* [focus group 2].

# Focus groups:
# Further discussion

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# Barriers and challenges to complete or return a FIT

This table shows the views from individuals on the barriers to complete and return a FIT. The difficulties related to the ambiguity of how to complete a FIT or a subjective assessment of how difficult it was to return a test.

| Barriers to complete a FIT | Barriers to return a FIT |
|---|---|
| The process was mentioned to be a barrier as it *"could get messy"* completing the test. | Embarrassed to collect the FIT at the GP, especially considering the test is given in a see-through bag. This was followed by the embarrassment to return the test to reception. |
| Confusion between FIT requested by the GP compared to the postal FIT, what they both test, and when individuals would need to complete either test. | Fear of generally receiving results. |
| | Fear of going into the GP to receive results. |

# Further considerations

Focus group 2 briefly touched on health inequalities and the link between cancer and lower-income families. Some participants stated that they had limited access to nutritious food due to financial constraints and had no option but to eat more processed food, which was concerning because it results in a poorer diet and over time can increase the risk of health conditions and diseases, such as cancer.

> *"I love fresh fruit and veg but I can't afford to eat a decent diet. So, I eat plenty of processed meat and crap because that's all I can afford."* [focus group 2]

> *"If I visit the food bank but they're kind of tied by what they have available"* [focus group 2]

> "*They are meant to be subsidising food banks with fresh produce because you know for health reasons. They are meant to subsidise them and then there's those donations as you say that come through from the supermarkets and that."* [focus group 2]

Men's health was also brought up, along with the necessity of promoting it. Some of the participants think that it is "taboo" to discuss health issues due to stigma of societal pressures, however, participants thought that men might return more FITs if men's health issues were discussed and promoted.

> *"I think there's a lot more that could be done to promote men's health because it's not only women that get everything it's men as well…"* [focus group 2]

> *"…women do have a lot to deal with so they're a bit more inclined to talk to each other about it and also go to the doctor and things like that whereas men are just like I don't know"* [focus group 2]

> *"I think it's also this fear of being perceived to be weak"* [focus group 2]

> *"If you talk about it in your groups that's sort of taboo."* [focus group 2]

# Summary of focus group findings

1. In total, participants knew half of the main symptoms of bowel cancer; more awareness is required.
2. Participants had heard about the symptoms from a range of sources including the TV, others from family or friends whilst others had been informed through posters, the internet or previous job roles.
3. Bowel cancer is not being widely spoken about and some individuals felt it is a taboo subject matter and felt embarrassed to talk about bowel habits and bowel cancer.
4. There was some hesitancy to do a FIT due to the procedure and its application.
5. Barriers to complete or return a FIT included the uncertainty on the process of completing a FIT (the nature of the test or confusion between other tests) or a subjective response on the difficulty to return a test (fear or/and embarrassment).
6. There was some discussion about the association between poverty and cancer. Participants mentioned that, in comparison to middle-income families, lower-income families are more likely to have limited access to nutritious food because of financial constraints which was discussed to increase the risk of cancer.
7. Men's health was discussed, along with the worry that men are reluctant to talk about their health issues. Participants commented that if men's health and cancer were talked about and promoted, it might generate more FIT returns.

# Survey:
# High level summary

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# Introduction to survey

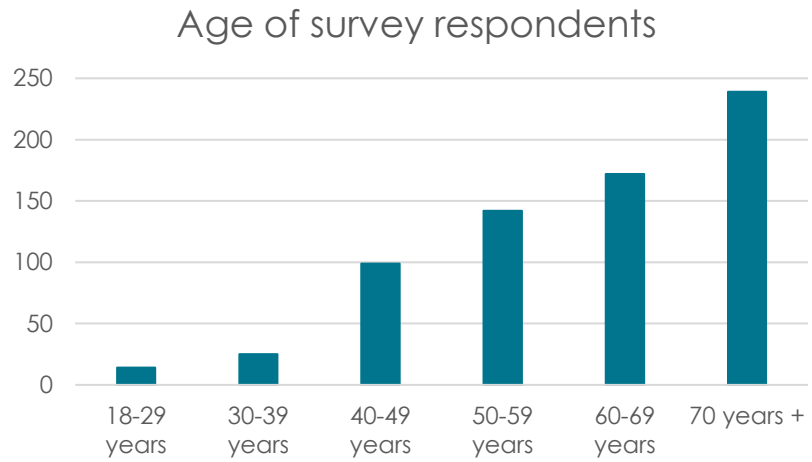
The survey was developed to understand the awareness of bowel cancer symptoms and FIT (among a wider audience than the focus groups).

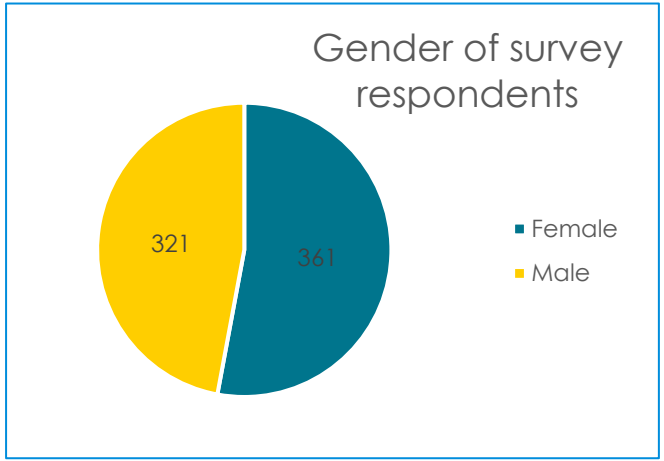
The survey comprised six questions. It was created and administered by DCP who then sent the anonymised findings to Wessex AHSN to analyse. The survey was distributed using survey management platform SurveyMonkey and was open for one month for individuals to complete.

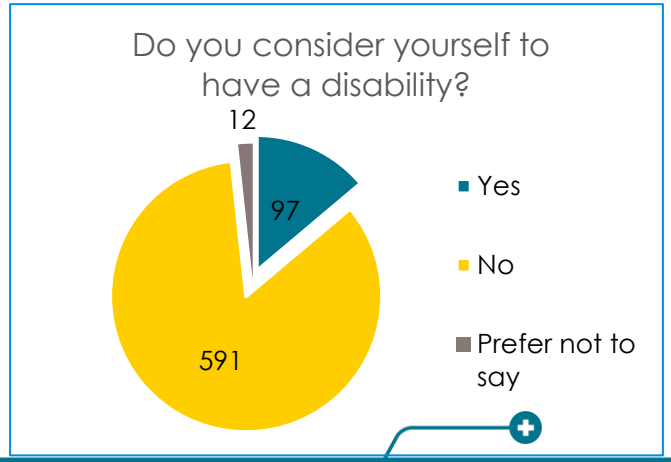
There were 882 responses.

The following slides summarise the findings.

# Respondent demographics



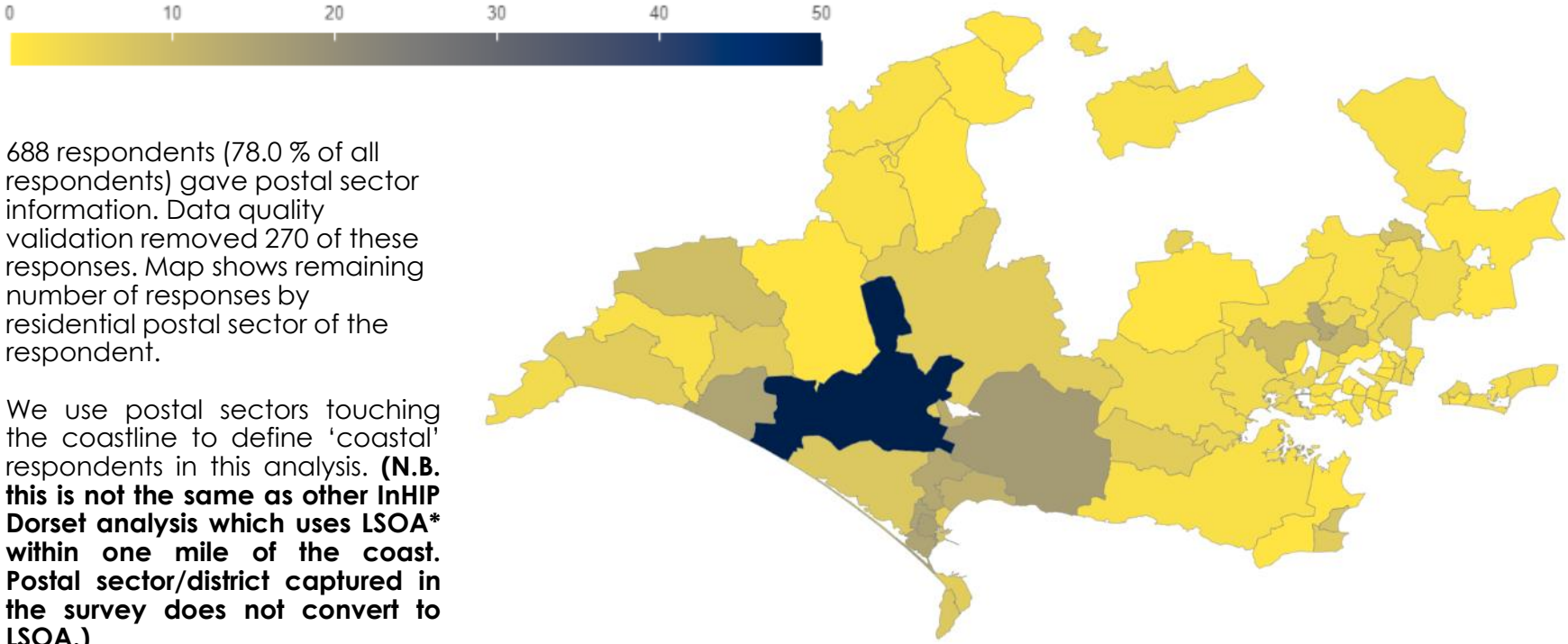




There were 882 responses to the survey. Of these, 698 (79.1%) gave details of their ethnicity – 676 (96.9%) identified as White - English, Welsh, Scottish, Northern Irish or British

13 respondents identified as Asian or Asian British, Black, Black British, Caribbean or African, Mixed or multiple race

# Number of survey responses by postal sector

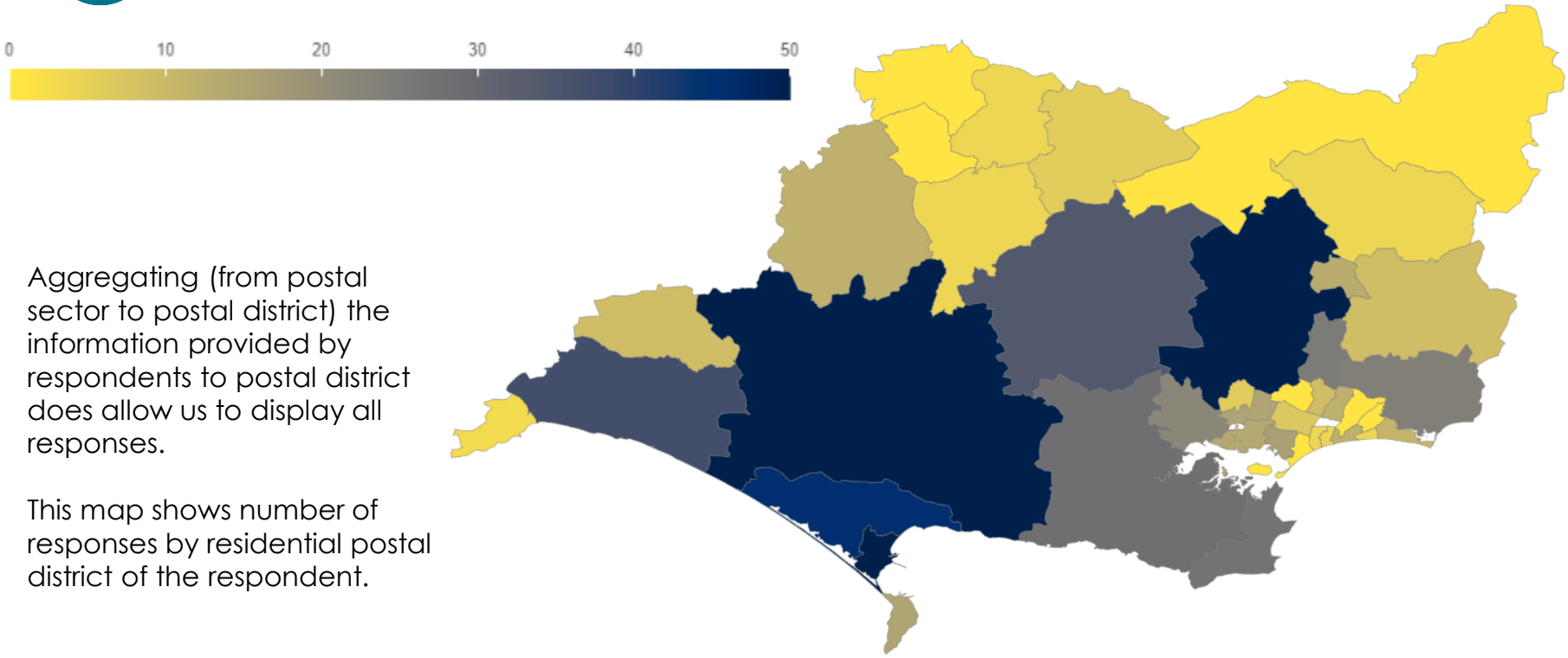



688 respondents (78.0 % of all respondents) gave postal sector information. Data quality validation removed 270 of these responses. Map shows remaining number of responses by residential postal sector of the respondent.

We use postal sectors touching the coastline to define 'coastal' respondents in this analysis. **(N.B. this is not the same as other InHIP Dorset analysis which uses LSOA* within one mile of the coast. Postal sector/district captured in the survey does not convert to LSOA.)**

* Lower Super Output Area

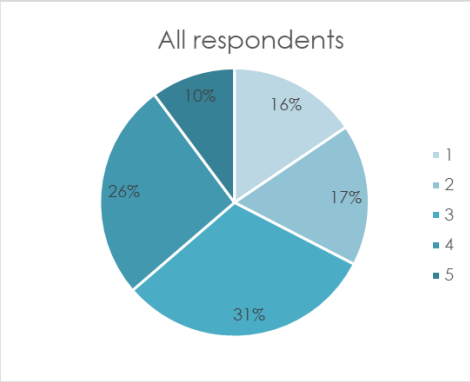
# Number of survey responses by postal district

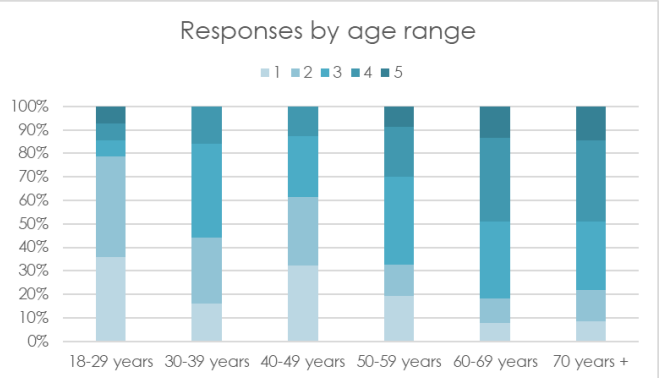


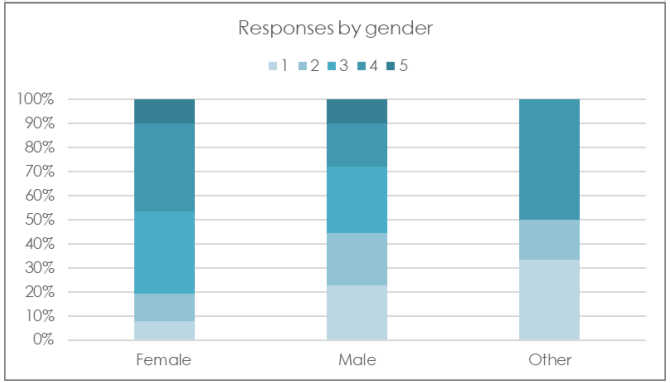

Aggregating (from postal sector to postal district) the information provided by respondents to postal district does allow us to display all responses.

This map shows number of responses by residential postal district of the respondent.

# On a scale of 1-5, how confident do you feel in spotting signs of bowel cancer? (1 - not confident, 5 - very confident)



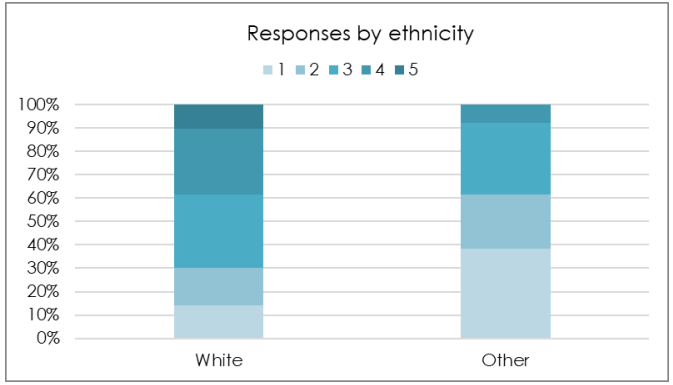



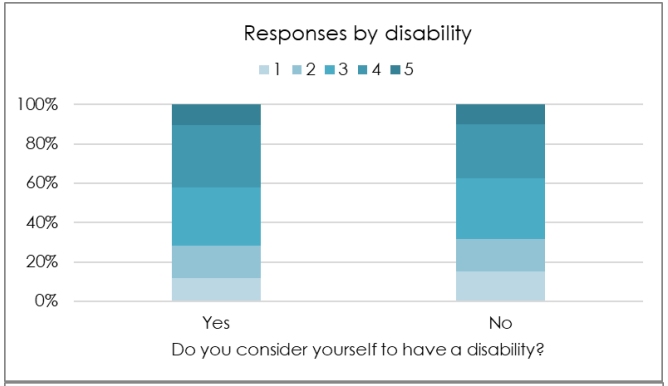

856 respondents answered. Average score for the survey was 3.0.

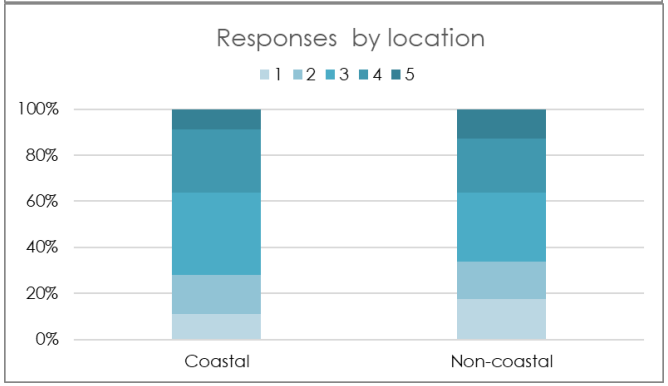
Confidence was lowest in the 18-29 and 40-49 age ranges - average score of 2.1 and 2.2 respectively.

Average confidence was lower in the 'Male' and 'Other' gender identities – average score of 2.7. ('Female' average score – 3.3)

# On a scale of 1-5, how confident do you feel in spotting signs of bowel cancer? (1 - not confident, 5 - very confident)



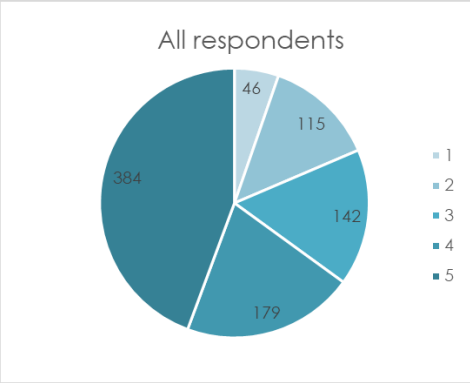




Non-white respondents had a lower average confidence – 2.1 compared to 3.0 for White respondents

Confidence was similar for those who considered themselves to have a disability and those who did not (3.1 and 3.0 respectively).

Confidence was similar for those who lived in coastal and non-coastal areas (3.0 and 2.9 respectively).

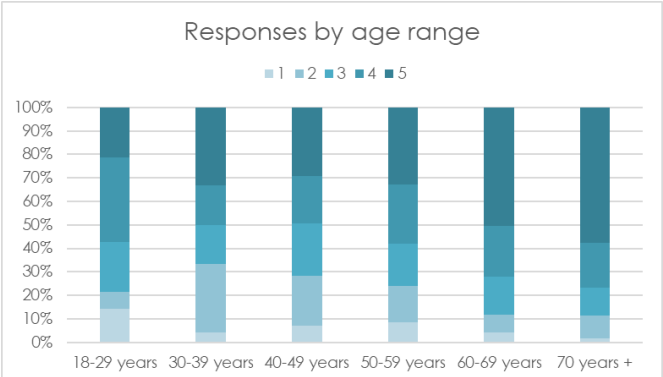
# On a scale of 1-5, would you feel confident to contact your GP / Practice if you thought you might have symptoms of bowel cancer? (1 - not confident, 5 - very confident)

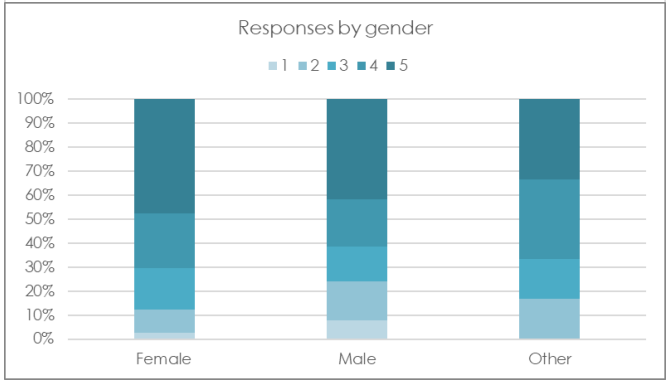



866 respondents answered. Average score for all respondents was 3.9.

Confidence was lowest in the 18-29 and 40-49 age ranges - average score of 3.4 for both.

Average confidence was lower in the 'Male' and 'Other' gender identities – average score of 3.7 and 3.8 respectively. ('Female' average score – 4.0)



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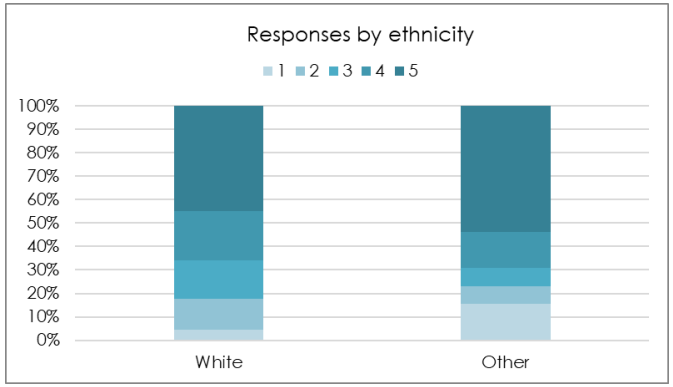
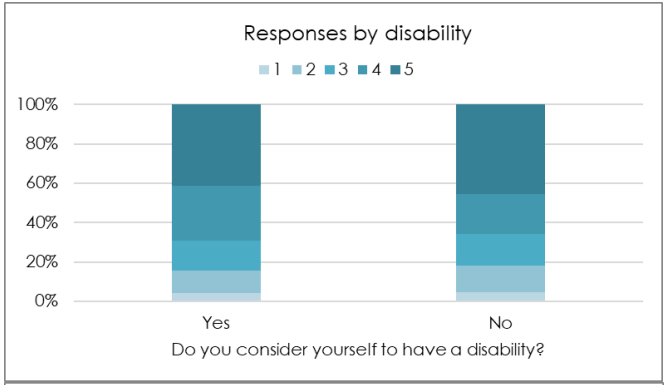
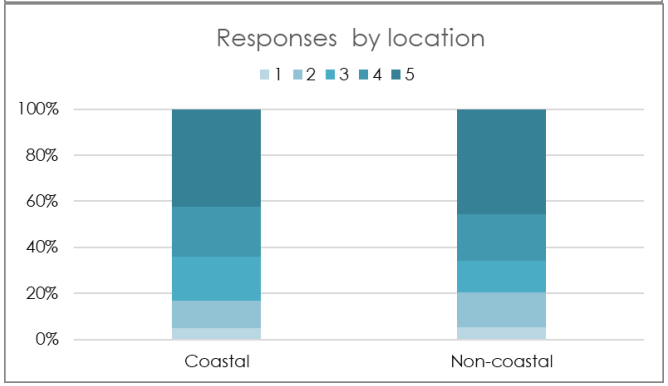


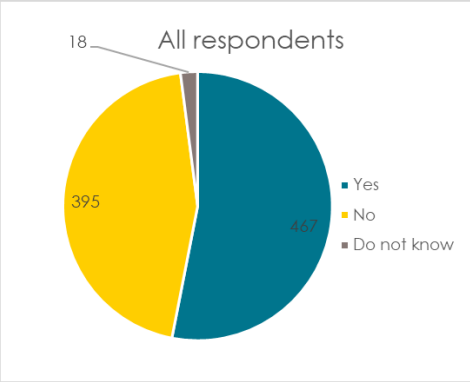



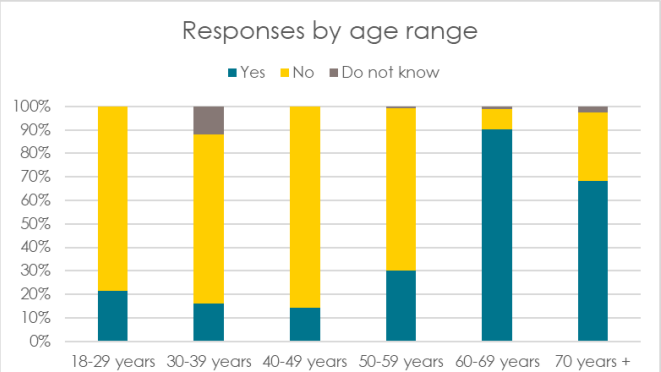

Non-white respondents had a slightly lower average confidence – 3.8 compared to 3.9 for White respondents

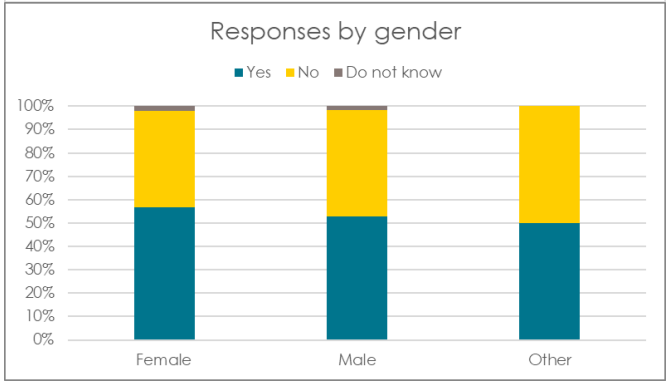
Confidence was similar for those who considered themselves to have a disability and those who did not (3.9 for both).

Confidence was similar for those who lived in coastal and non-coastal areas (3.8 for both).

# Have you ever received a FIT kit?



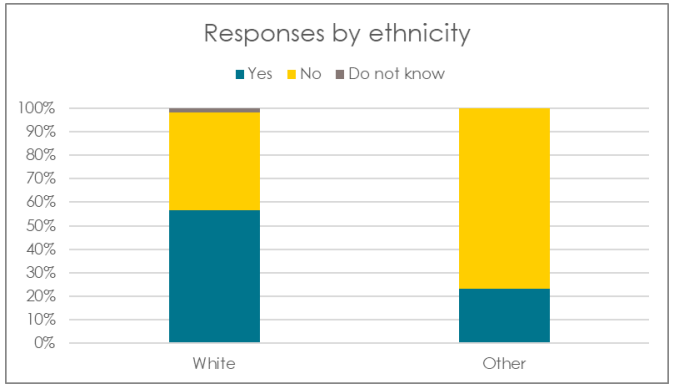



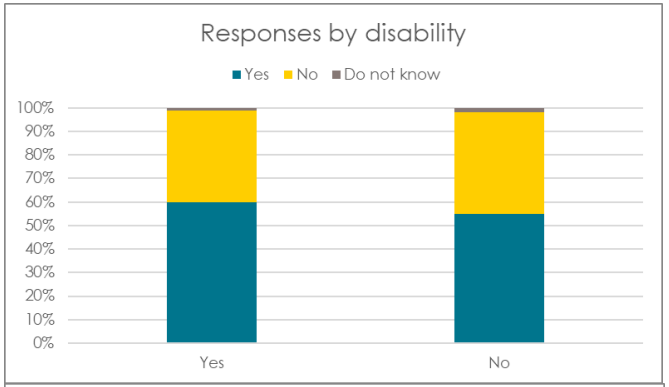

880 respondents answered. 53% of responses indicated they had received a FIT kit at some point.

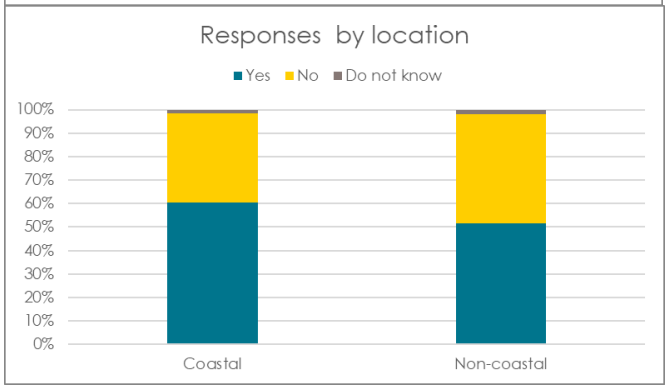
40-49 year-olds had the lowest number of 'Yes' responses (14%).

'Yes' responses were similar across gender, slightly higher for Female (56.8%) compared to Male (53.0%) and Other (50.0%)

# Have you ever received a FIT kit?



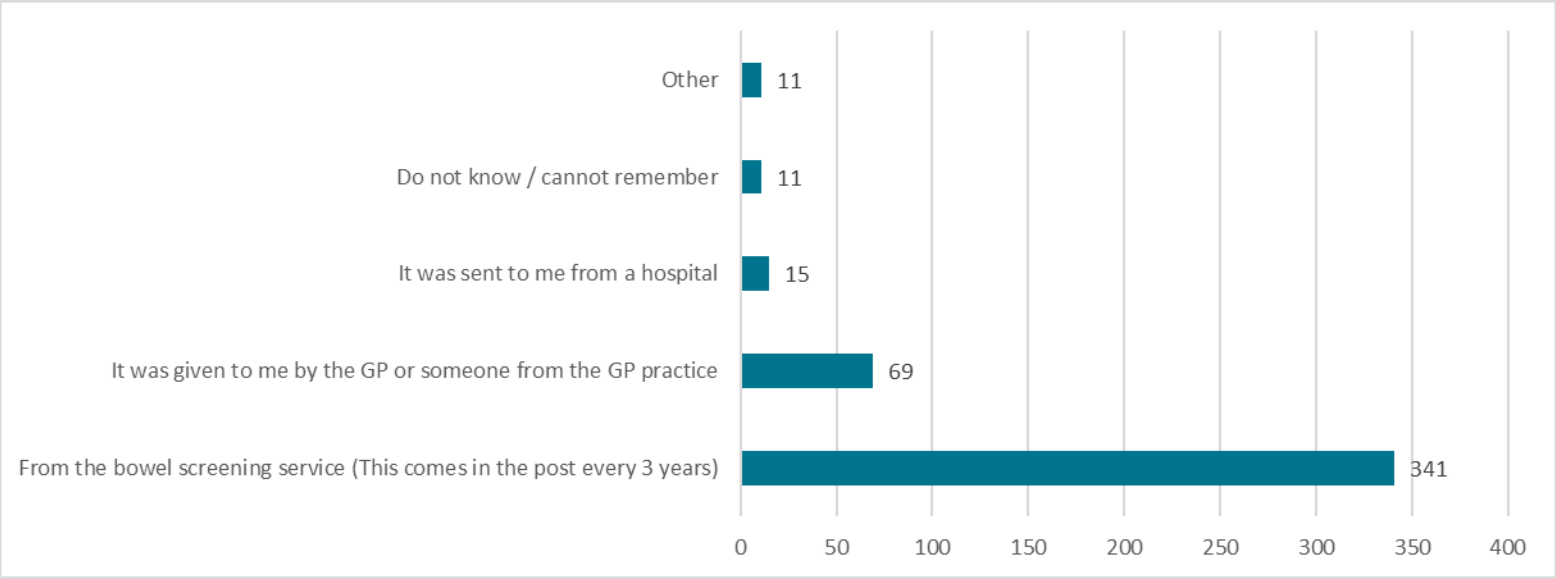




A lower number of non-white respondents indicated they had received a FIT kit – 30.0% compared to 56.5% for White respondents.

There was a slightly higher number of respondents who indicated they had a disability and had received a FIT kit – 59.8% compared to 54.8% for non-disabled

There was a slightly higher number of respondents who indicated they lived in a coastal area and had received a FIT kit – 60.4% compared to 51.4% for non-coastal.

# How was the FIT kit given to you?



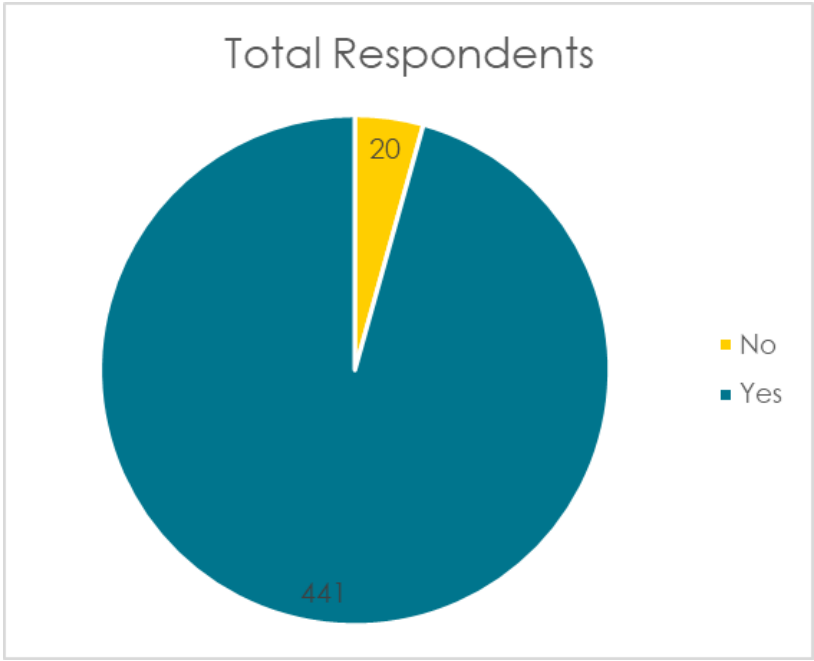

447 respondents answered this question (95.7% of those who indicated they had received a FIT test). Respondents indicated that the majority of FIT were received via the bowel screening service.

# Did you complete the FIT test?

Of the 467 respondents who indicated that they had received a FIT, 461 answered this question (98.7%).

441 (95.9%) of those who answered indicated that they had completed the FIT.

For those who said they had not completed the FIT, there was no outstanding reason for this. Most options in the survey for the reason for not completing had been selected by 1 – 2 respondents. There were also no respondent characteristics prevalent with non-completers.



# Comments on participants' understanding of bowel cancer symptoms or FIT

Participants were invited to add additional comments about their comprehension of FIT or bowel cancer. In the survey, there were 212 open text comments (excluding 'no'/not relevant). The comments were coded, categorised and then calculated as a percentage of the total sum of comments; the following slide demonstrates all the categories in a tree diagram (see slide 31).

Overall, the response to this question was positive.

Individuals who had completed a FIT thought the test was straightforward and were confident in its ability:

> *"Fairly confident in test as have known people referred from these."*
> *"I think these tests are brilliant. Easy to use and great for early detection…"*

Just over 7% of individuals said they preferred the most recent FIT over earlier tests because it was more user-friendly for a variety of reasons:

> *"I think the newer FIT test is much easier to do than the last version and should help older folk who are perhaps not so dexterous."*

There was some misunderstanding regarding the age requirements to be sent and complete a FIT; some people were curious as to why younger or older people were not 'eligible':

> *"It should be open to all ages, even if those younger and less at risk have to pay a nominal fee. For peace of mind this should be an option."*

In addition, some individuals said that because of practical considerations, a test would be challenging to finish:

> *"Physically difficult to do plus actually posting afterwards nigh on impossible (not mobile, no one else to post for me)"*

7.5% of individuals reported limited knowledge of bowel cancer, its symptoms or the FIT:

> *"Wouldn't even know what to look for to be honest"*

# Tree diagram from open text comments on participants' understanding of bowel cancer symptoms or FIT


"We found the kits very helpful and easy to use" "I think the tests should continue throughout your life regardless of how old you are"

# Next steps for InHIP Dorset

To consider the findings of this component to develop the intervention...

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