

Bowel cancer screening in County Durham

Research into the uptake of bowel cancer screening in
County Durham



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Healthwatch County Durham (HWCD)

On the 1st April 2013 under the provisions of the Health and Social Care Act 2012 152 local Healthwatch organisations established throughout England.

These Local Healthwatch have been set up across England to create a strong, independent consumer champion whose aim is to:

- Strengthen the collective voice of citizens and communities in influencing local health and social care services to better meet their needs
- Support people to find the right health and social care services for them by providing appropriate information, advice and signposting
- To encourage and support people and groups to share their views about services; listen to people's needs and experiences of services

We achieve this by:

- Listening to people, especially the most vulnerable, to understand their experiences and what matters most to them
- Influencing those who have the power to change services so that they better meet people's needs now and into the future
- Empowering and informing people to get the most from their health and social care services and encouraging other organisations to do the same



We advise



We listen



We speak up

Executive Summary

April 2017 was Bowel Cancer awareness month and Healthwatch County Durham (HWCD) took the opportunity to research the uptake of bowel cancer screening in the county to see why some eligible people were not taking part in the screening programme and if there was anything that could be done to encourage more people to participate.

A survey questionnaire was created and staff and volunteers attended venues throughout the county to gather the views and experiences of local people. The questionnaire was also placed on survey monkey. In total there were 593 responses, 224 online and the remaining 369 through face to face interviews. A wide range of venues were used which included CREE groups, pharmacies, GP surgeries and building societies throughout the county.

Some of the higher performing surgeries for uptake of screening were also contacted to see if there was any good practice which could be identified and shared. Their responses are included in this report.

Of the 593 people who responded, 81% were aged 60 years or over. 70% of respondents told us they had received the kit, those eligible but not receiving the kit included some who had recently reached the age of 60 and the kit had not yet been issued. Of the 70% who had received the kit, 62% of them had returned it. There were also some people completing the survey because they had an interest linked to family or friends and also those aged over 74 years. Any eligible people who had not received the kit were provided with details of how they could request one.

We asked the people who had not completed the test if there were any specific reasons. Their responses form the basis of many of our recommendations in this report. The main themes were that they were fearful or too embarrassed to do the test. Some people thought because they were “symptom free” they didn’t need to complete the test. Interestingly there were also comments made which implied that where a person was receiving treatment for another cancer, for example breast cancer, there was a belief that they did not need to be tested as they were already being treated and checked by the hospital. This assumption is not correct and making sure patients understand this included in our recommendations.

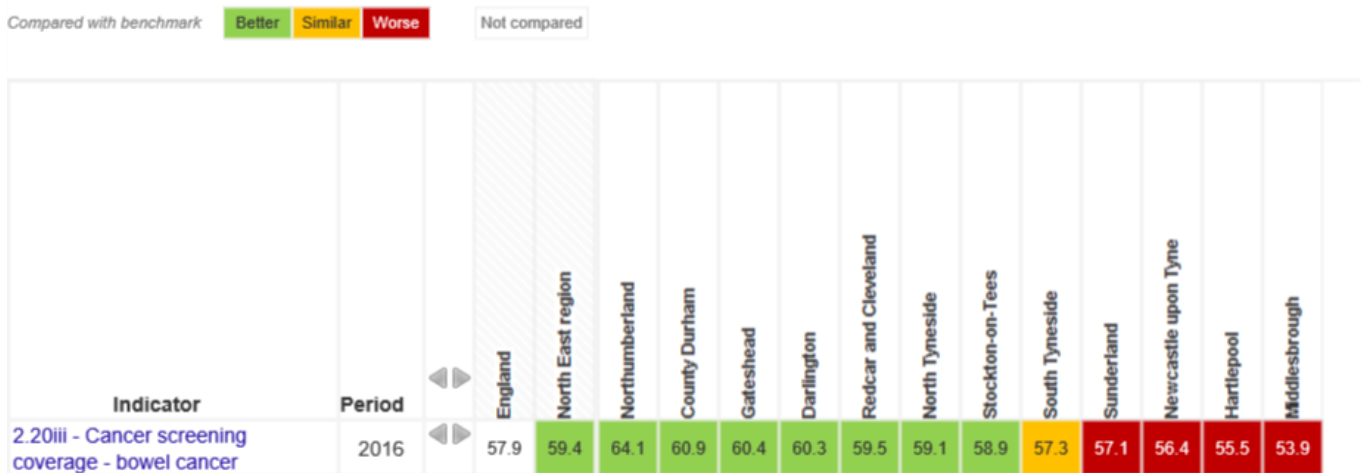
Following a review of our findings we would recommend the following actions:

- Consider enclosing disposable gloves into the kits which may encourage more people to take the tests
- Awareness raising to make people aware that they can still be screened after the age of 74

- Give advice to patients with other forms of cancer that it is still important to carry out the test, explaining they will not necessarily have had any tests for bowel cancer as part of their ongoing treatment
- Provide clearer instructions and easy read as this may encourage more people to take the tests

Background to the work

April 2017 was Bowel Cancer awareness month and Healthwatch County Durham (HWCD) took the opportunity, as well as promoting the campaign, to research the uptake of bowel cancer screening in the county. As you can see from the graph below, data in 2016 showed that in the previous 2.5 years, 60.9% of eligible people in the county had been screened for bowel cancer. Whilst the figure is above the national average of 57.9% there is still room for improvement. HWCD wanted to understand what barriers there were, which prevented people from accessing the screening programme.



Public Health profiles- The % of people in the resident population eligible, who were screened within the previous 2.5 yrs. (Age range 60-74)

Why this work was necessary

This work was necessary as HWCD and the Clinical Commissioning Groups (CCGs) in County Durham are keen to increase the uptake of screening. To do this we need to understand why people do not access the service and what we can do to overcome the barriers.

What we did

An online survey was created and the link to this was included in our e-bulletin in April and May, shared in social media posts and widely promoted by partners.

There was a mixture of face to face interviews and surveys collected as part of focus groups and surveys left and collected at one site.

Sites visited included; Cheveley Park Surgery, Meadowfield Surgery, Sacriston Surgery, Brandon Surgery, North Durham Medical Group, Cree's Groups, Stanley Asda, Stanley Front Street, Darlington Building Society Bishop Auckland and Barnard Castle

Cree Groups around County Durham

We contacted all CREE groups in County Durham by email to ask if we could come and chat with the members about bowel cancer screening. We received nine replies who were happy for us to attend the groups. We engaged with 57 members in the groups based at Shildon, Blackhall, Stanley, Murton, Newton Aycliffe, Durham, Barnard Castle and Witton Gilbert. Interesting discussions took place over a cup of tea and a biscuit. During general conversations at the CREE groups, we were also able to signpost and support members regarding other health issues.



Members of Blackhall men's CREE completing our survey with staff member Julia Catherall

Outreach engagement with Volunteers

We contacted our HWCD engagement volunteers to see who would like to take part. The response was good with six volunteers agreeing to work with us. We tried to match volunteers up to areas within their own locality. After contacting the venues linked to the interested volunteers, the following places were visited; Boots the Chemist, Tanfield View surgery, Bearpark Surgery, Sacriston Surgery, Brandon Lane Surgery, Stanley Asda (street), Stanley Front Street, Darlington Building Society-Bishop Auckland and Darlington Building Society-Barnard Castle

To maximise the number of people given the opportunity to share their experiences volunteers carried out interviews both inside venues and outside on highstreets.

Volunteers working and having conversations in their own locality proved invaluable as many people were more willing to talk to people they knew, therefore in many cases the survey was really answered as part of a friendly conversation. This was also useful because of the sensitive nature of the survey subject. It helped to break down barriers.

We spoke to many people within the targeted age range of 60-74, but also to others who were concerned about another family member, so, as the exercise was also around raising awareness generally, this met our criteria.

During our engagement it was apparent that people did not know who to contact should they still wish to be screened after the age of 74. Healthwatch recognised this and produced a pocket size card with the Bowel Screen helpline number.



GP surgeries and the uptake of screening

To compliment the work undertaken asking people in County Durham about their experiences Healthwatch County Durham also contacted some of the better performing GP surgeries for bowel cancer screening in the county. The purpose of this was to investigate whether there was any good practice which could be identified and shared.

Five surgeries throughout the county were contacted and listed below are some of the positive things that are being done to increase the uptake of screening:

- Leaflets and posters in the surgery and advertising on their TV screens in waiting rooms
- Doctors promoting the value of screening to appropriate patient groups
- Looking at the list of patients who did not respond to screening request and contacting them to try and encourage them to be screened
- A nurse from Cancer Research talking to staff, clinicians and the patient reference group to promote all screening

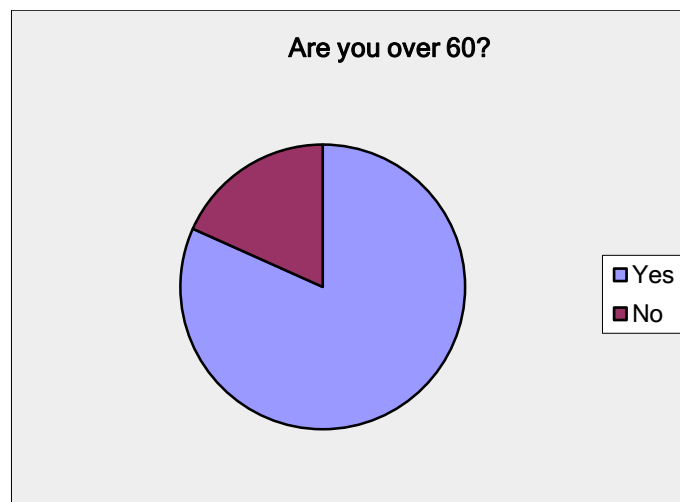
- All patients who did not attend their screening appointment being sent a letter from their GP telling them how important screening was

Whilst many other surgeries will also be promoting Bowel Cancer screening it is worthwhile for all surgeries to consider how they might promote this valuable service in their own locality.

What we heard

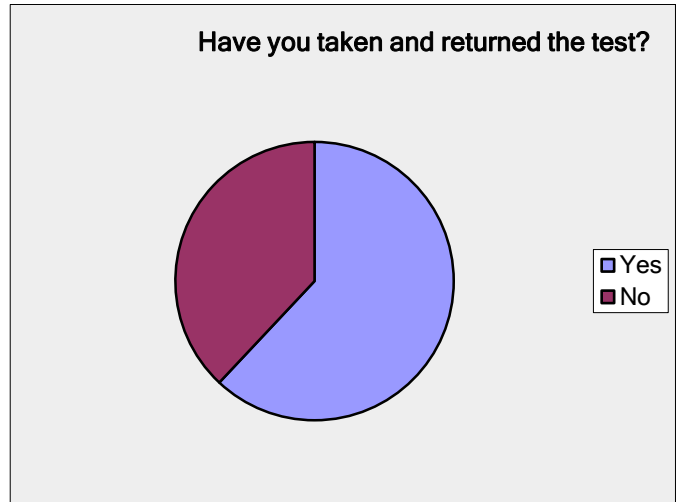
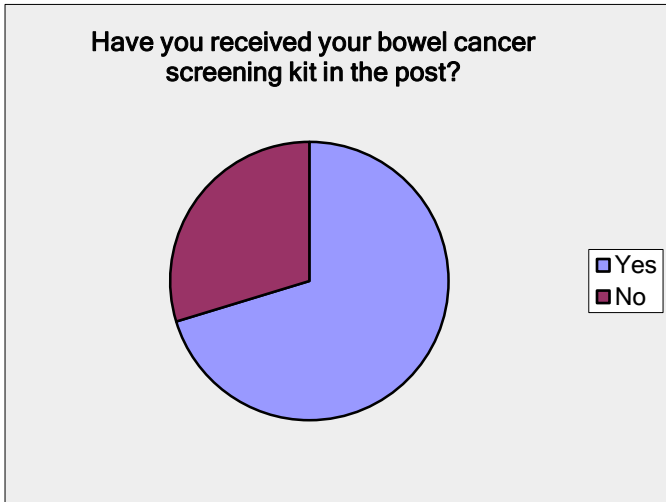
From the 593 completed surveys, 224 were completed on line, 369 were from engagement activities.

- 81% were over 60
- 46% completed surveys by men



Graph showing that 81% we spoke to were over the age of 60

We asked people if they had received the screening kit in the post, the graph below left shows that 70% had received it, however 62% had taken the test and returned it.



The common themes for not taking the test was that they were frightened or too embarrassed to do it.

“If I needed to take this test I would and also encourage others to do so. Having an Uncle who passed away due to this, would encourage me”

“I am being treated for another cancer elsewhere, so I assumed that I don’t need to do this test as they will already have checked me for Bowel cancer!”

Analysis of data and what we found

The issues captured below are from general comments and conversations when carrying out the survey. It was felt that some of these feelings and more general impressions about the issue were very important to capture as they covered areas that the survey questions did not account for:

- People assumed that because they are being treated for another cancer or illness, that checks for bowel cancer are undertaken as part of ongoing treatment, so they didn't feel the need to return the kit
- Some people indicated that it was dirty or disgusting and would not return the kit because of this. It was mentioned that including a pair of disposable gloves with the kit, might encourage people to carry out the test
- People indicated that "they did not have time", or "this was not a priority" for them, balancing work, children, home and other caring responsibilities (mainly female but not always)
- There was an element of fear, people would rather not know and were afraid to find out
- People indicated that they were happy to just go to doctors when they had symptoms rather than take a pro-active approach
- People felt that if they had no symptoms there was no need to take the test
- People suggested the instructions were too confusing and complicated

Recommendations

Following a review of our findings we would recommend the following actions:

- Consider enclosing disposable gloves into the kits which may encourage more people to take the tests
- Awareness raising to make people aware that they can still be screened after the age of 74
- Advising cancer patients what they are being screened for as some assume that they are screened for bowel cancer and are not returning the home kits
- Clearer instructions and easy read may encourage more people to take the tests

Thank you.....

Healthwatch County Durham would like to thank those who have contributed to this piece of work:

Healthwatch County Durham Volunteers

Boots the Chemist

Sacrison Surgery

Brandon Lane Surgery

Meadowfield Medical Group and volunteers from Patient Reference Group

Volunteers from North Durham PRG

Mens CREE Groups in County Durham

Age UK County Durham

Durham County Carers Support

Durham Voice

Durham Dales, Easington and Sedgefield & North Durham Clinical Commissioning Groups

Durham Deafened Support

Darlington Building Society

Advice in County Durham

Teesdale Day Services

Pioneering Care Partnership

Durham Community Action

Appendix 1

There are not as many people in County Durham taking and returning their free bowel cancer screening test as in other areas. Healthwatch County Durham would like to find out why, and to share that information with the NHS. All men and woman aged 60-74 are invited to carry out a faecal occult blood (FOB) test. Every two years a test kit is sent home to collect a stool sample. Please take five minutes to answer the following questions and help us understand the barriers people face.

1. Are you male or female?

- Male
- Female
- Prefer not to say

2. Are you over 60?

- Yes
- No

3. Have you received your bowel cancer screening kit in the post?

- Yes
- No

4. Have you taken and returned the test?

- Yes
- No

5. If you answered no, please can you tell us why, and what would make you more likely to take the test?

6. If you would like more details on bowel cancer screening please leave your contact details