

## Leeds Cancer Programme Engagement Summary

**Name of Project Engaged about:** FIT Test

**Engagements Dates:** 4<sup>th</sup>-18<sup>th</sup> Feb 19

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### Project background Overview:

The FIT Test is a national Bowel Screening facility. It has 2 prongs. *The purpose of this engagement refers to Symptomatic only.*

1. Screening (of general population aged between 60-74.) Not discussed in this Engagement.

2. Symptomatic

If patients fitting the following criteria present to their GP and are classed as 'low risk, but not no risk'. Patients would fulfil the following criteria:

- Aged 50 or over with unexplained abdominal pain or weight loss
- Aged under 60 with changes in their bowel habit or iron-deficiency anaemia or
- Aged 60 or over and have anaemia without iron deficiency.

### Engagement Support:

FIT testing is a national programme that is happening across the UK. However, the Leeds Cancer Programme wants to make sure that the:

#### 1. GP's are involved to increase uptake of the test.

- Via a robust Communications plan consisting of: attendance at 3 Target session February (any comments will be collated and fed back to Project & Engagement Leads), 2 Comms updates in the Primary Care Bulletin in March; through Staff news at Leeds Teaching Hospital
- Feedback regarding the FIT Project Plan at Leeds Integrated Cancer Services board meeting and the Local Medical Committee (LMC) meeting.
- Representation on the FIT Project Steering Group (consisting of GP's Cancer specialists, Project leads & pathology)

#### 2. Patients and the public are involved in developing a leaflet that is easy to understand and accessible.

- Via targeted engagement with BME Groups & Socio-economic Deprived groups (as previous evidenced on Bowel screening suggests that these are the groups least likely to complete the test). Voluntary Action Leeds (VAL) will be the medium through which these groups are engaged with. VAL gained views from two organisations in Leeds who

are Engaging Voices partners – GIPSIL and Hamara – who predominantly provide a service to people from deprived areas and the South Asian Community respectively. A short survey was designed (attached at appendix A) which staff at the partner organisations used in order to gather and record responses. Overall, 30 service users shared their views about the leaflet, made up of older men and women from the South Asian community and 16-25 year olds who are homeless and living in inner East Leeds.

- Via focus group discussion with the Leeds Stoma Group based at the Robert Ogden Centre (consisting of patients & bowel care nurses)
- Via the CCG Reader Group to review the leaflet
- Via the Leeds Cancer programme Engagement Hub members to review the leaflet
- A conversation was had with Leeds Society for Deaf & Blind People who gave some basic advice on how best to cater for visually impaired people)
- The Leaflet was shared with LYPFT Health Facilitation Team to discuss accessibility for people who have Learning Disabilities.

### **Background to the change:**

The FIT test is a test that GP's can offer to patients within a specific age bracket who present with certain symptoms (detailed below). These patients are classed as 'low risk but not no risk' of having colorectal cancer (as recommended by NICE Guideline for Suspected Cancer (NG12) 2015)

Evidence shows that Bowel Cancer screening tests reduces bowel cancer mortality by identifying signs and symptoms of Bowel cancer at an early stage.

- The new FIT test is designed to detect blood you can't see or 'occult' blood in stool (poo) samples. Unlike the previous test, FIT uses antibodies that specifically recognise human haemoglobin (blood) so there is no need for patients to undergo dietary restriction prior to using the test. (The previous test would pick up blood that had been eaten from animal products)
- As it is antibody based, FIT is a more sensitive and specific test than the previous test, and reduces the chances of false positives. An abnormal result suggests that there may be bleeding within the gastrointestinal tract that requires further investigation. Those with an abnormal result are then invited for further testing via a colonoscopy.

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Since bowel cancer screening began in the UK, it has been done through a Faecal Occult Blood Test (FOBT). It should be noted that the Bowel SCREENING Test purposes will continue to be posted out to anyone aged between 60-74 years. It will however, from 1st April 2019 this test will be replaced by the Faecal Immunochemical Test – the FIT test.

We know that this will reduce the need for some people to have more invasive procedures such as Colonoscopy.

We know that some people (for cultural or personal reasons) don't like the idea of handing their own Stool/Poo sample and that this puts some people off testing. Likewise, some people don't feel they are at risk and therefore are unlikely to complete the test. Others felt they did not want to know if something was wrong, or have further more invasive tests.

The FIT test a reactive test and will be rolled out in addition to the national bowel screening test (a routine test). While the FIT test is a new initiative there is some important learning from the national screening test that helps us to understand the potential impact on equality groups.

A report on interventions to increase uptake of the national bowel screening test by Cancer Research UK, Macmillan and NHS England found that 'Evidence suggests there is a strong socio-economic gradient in FOBT uptake, with studies reporting screening rates lower in areas of deprivation and in certain ethnic groups. The feedback is that the gFOBT is impractical, unhygienic, unacceptable, and has social and cultural taboos for many population groups'.

A key finding from the report was that GP endorsement & primary care engagement was important in increasing uptake. This suggests that it will be important to engage primary care staff in the rollout of this test.

[https://www.cancerresearchuk.org/sites/default/files/interventions\\_to\\_increase\\_bowel\\_screening\\_uptake\\_v1.0.pdf](https://www.cancerresearchuk.org/sites/default/files/interventions_to_increase_bowel_screening_uptake_v1.0.pdf)

Evidence shows that Bowel Cancer screening tests reduces bowel cancer mortality by identifying signs and symptoms of Bowel cancer at an early stage.

### **Key themes from the feedback:**

#### **General Feedback:**

- The main barrier that participants said could prevent them from taking the test was the "embarrassment" factor as well as a "lack of courage" and "awareness" about dealing with the issues which come with a test that is felt to be personal and rarely talked about. One respondent cited the "fear of finding out" as a reason that would prevent them taking the test.
- Several cited having to physically perform the test as a barrier, with one respondent saying 'it's not very nice but needs to be done' '
- For homeless people one of the main barriers was also the cost of transport which made "getting to the GP in the first place" a barrier.
- The main method that participants said would help to promote FIT testing within communities would be with more home visits to patients as well as visits to existing groups such as Hamara and GIPSIL to raise awareness.
- Some female respondents from the South Asian community suggested that being able to attend a clinic to complete the test rather than completing at home would encourage greater uptake.
- Due to their barriers accessing the GP it was suggested that a person friendly venue/clinic would help people who are homeless or living in poverty overcome their barriers.
- Comments about the test were '

### Regarding the Instructional Leaflet:

- **Clarity:** The response to the clarity of the Instructional leaflet was that it was generally easy to follow and understand; 'well-presented' and 'clear', with one respondent saying 'overall this leaflet does this job effectively'.
- **Other Formats:** Many felt that the one way the leaflet could be improved was through the use of more than one language in order to encourage uptake within BME communities, with one person stating, "the leaflet is good and effective but not for the Asian [community]". Having the leaflet in other languages would help break down barriers.
- **Cancer or not?** Respondents were split between whether or not the word 'Cancer' should be on the leaflet. The **majority thoughts were against** the term saying 'that it invokes fear' and that 'people panic when hearing the word cancer' and it's 'scary & unnecessary'. Those for the use of the word cancer said 'Yes! It helps in highlighting the importance of the information' and 'Yes. It is a bowel cancer screening test'
- **Images:** People generally thought that the images were appropriate. However, A number of respondents found diagram 5 very confusing with some describing it as 'unintelligible' and another saying 'I had to look at it a couple of times to realise that the illustration at the bottom of the picture was showing not to put it on the 'handle' of the stick' a suggestion was made to 'Perhaps the stick could be a different colour to the handle you could then be instructed to e.g. 'only use the yellow area'.
- **'Poo'** A number of respondents discussed the term 'Poo' with one saying the word made them cringe, but that they couldn't think of a 'better colloquial alternative'.
- **Easy Read:** If this leaflet were to be in true Easy Read style all images should be on the left with associated text on the right.

### Recommendations:

1. Check the instructions in the video match EXACTLY the advice given in the leaflet; the video demonstrates use of a loop of paper provided – this isn't referred to on the leaflet which could cause confusion. It's important they give same message.
2. There needs to be a clear note about the different formats this leaflet is available in – to include different languages (Punjabi & Urdu were requested), and to cater for those with a Visual Impairment (suggestion Yellow, Arial, Bold, size 18 font on black background is best for those with visual impairments as a general rule)
3. Explain what a QR code is & do not assume everyone is able to access it this way.
4. Instead of saying 'post-test straight away' (red box at top & image 7) it would be better to say 'post same day sample is taken' or underline, and put in bold font 'Post Immediately'. One suggestion was to add 'Post Immediately' after the text on diagram 7.
5. Consider changing wording of 'Essential Test' to 'simple, routine test' – this may help to reduce worry and encourage people to do the test.
6. Consider more user friendly term for 'diagnostic purposes' (Red box at top)
7. Consider ways in which people could complete the test in a supportive environment (not at home) as this will help to increase uptake.
8. Consider alternative wording for 'Diagnostic Test' & 'Continued overleaf'
9. There is no note about carers who may need to assist.

10. Suggest Image 5 is re-looked at as many respondents found this one the most confusing.
11. Clarify what the 'GP referral form is (diagram 7 text)
12. Do not use the word Cancer on the leaflet.
13. For Easy Read purposes all images should be on the left with associated text on the right. If this can't be changed on both pages, the advice would be to leave it as is; with one amendment – to move image 3 on Page 1 to the left with text on the right to make it less confusing.

### **What will we do with the information?**

The report will be shared with all the people involved in the project.

The report will also be available on the Leeds Cancer Programme website.

The project team will use the report to make any amendments to the Instructional leaflet, as per the recommendations. An update will be produced once the project has begun to show to what extent the recommendations have been implemented. This briefing will be shared with the people involved in the project.

The patient feedback will also be used to inform a wider strategy for enhancing communication, access and the quality of services.

### **What have we done with the information?**

#### **As per feedback from the Reader Group**

<b>Theme</b>	<b>Response (to be completed by requesting staff member)</b>
Consider some of the images and diagrams used and see if clearer alternatives could be included – some of it was confusing	Following feedback from Reader group & from VAL we have adapted (image 5) with was the one that was picked up as being the most confusing. The image of not dipping the handle into the sample has been removed to make it simpler to understand.
Make the 'post immediately' more highlighted – easier to see and highlight the importance of	This has been placed in a red box at the top of the leaflet and the word 'immediately' is underlined and in bold font.
Clarify what a GP request form is (Point 7)	This test would only be given to someone by their GP.
Do people who are not online able to get support if they are unsure with something, is it clear on the leaflet?	Yes – GP's have been involved in the designing of this test and will be fully briefed on how to support those individuals who may struggle to complete the test by themselves.  The leaflet now states 'if you have any additional queries please contact your GP' on it (box 8)

Don't include the word 'cancer'	This prompted a wide discussion in the feedback, however most people wanted to avoid the use of the word 'cancer' Therefore it has not been included in the leaflet.
Is it clear what formats this leaflet is available in?	Following feedback this leaflet will be available in Urdu & Punjabi. It can be adapted (as and when required) for people who are partially sighted. It has been looked at by LYPFT who have advised that they feel it is of a good standard for people who would have a learning disability.

#### As per feedback from VAL

Comments	Response (to be completed by requesting staff member)
Check the instructions in the video match EXACTLY the advice given in the leaflet; the video demonstrates use of a loop of paper provided – this isn't referred to on the leaflet which could cause confusion. It's important they give same message. Is it included with the FIT Test?	We have included a statement under link to video to explain the paper loop doesn't come with the kit, and to direct people to other methods of collection diagram.
There needs to be a clear note about the different formats this leaflet is available in – to include different languages (Punjabi & Urdu were specifically requested), and to cater for those with a Visual Impairment (suggestion Yellow, Arial, Bold, size 18 font on black background is best for those with visual impairments as a general rule if we were requested to produce a specific one)	Translations into Urdu/Punjabi are in the process of being arranged.
Explain what a QR code is & do not assume everyone is able to access it this way.	We will add - QR Code available for Smart Phones
Instead of saying 'post-test straight away' (red box at top & image 7) it would be better to say 'post same day sample is taken' or underline, and put in bold font 'Post Immediately'. One suggestion was to also add 'Post Immediately' after the text on diagram 7	Change made to leaflet as suggested
Consider changing wording of 'Essential Test' to 'simple, routine test' – this may help to reduce worry and encourage people to do the test	We have agreed that 'essential' should be included in this context as the test is to eliminate colorectal cancer (even though patient is at low/no risk), it is important that the test is completed
Consider more user friendly term for 'diagnostic purposes' (Red box at top)	We have removed 'diagnostic purposes'
Consider ways in which people could complete the test in a supportive environment (not at home) as this will help to increase uptake	We will include this within GP information pack to ensure that patients are supported as much as possible.
Consider alternative wording for 'Diagnostic Test' & 'Continued overleaf'	Change made to 'Please turn over instructions continued'

There is no note about carers who may need to assist	This again will be included in the information pack for GP's – for them to check that the patient has someone to assist if unable to complete the test themselves.
Suggest Image 5 is re-looked at as many respondents found this one the most confusing – see quotes in doc	We have amended this diagram to remove the bottom kit handle picture to simplify the diagram
Clarify what the 'GP referral form is (diagram 7 text	This is a GP request form as outlined in the leaflet not a referral form.
Do not use the word 'Cancer' on the leaflet.	From the volume of feedback received it has been agreed not to include cancer in the leaflet
For Easy Read purposes all images should be on the left with associated text on the right. If this can't be changed on both pages, the advice would be to leave it as is; with one amendment – to move image 3 on Page 1 to the left with text on the right to make it less confusing.	This wasn't possible to amend on this version - however this will be taken into consideration this for future versions

END.

## Appendix

**1. Link to copy of Leaflet:**

[file:///nwh-fas-b/ccg\\_shared\\_drive/Commissioning%20\(shared\)/NEW\\_FOLDER\\_STRUCTURE\\_Planned\\_Care/Cancer/Macmillan\\_LCP/Programme/Engagement/Patient%20Public%20Engagement/Engagement%20Projects/FIT%20Docs/Leeds-IFU\\_Feb19\\_V2.1.pdf](file:///nwh-fas-b/ccg_shared_drive/Commissioning%20(shared)/NEW_FOLDER_STRUCTURE_Planned_Care/Cancer/Macmillan_LCP/Programme/Engagement/Patient%20Public%20Engagement/Engagement%20Projects/FIT%20Docs/Leeds-IFU_Feb19_V2.1.pdf)

**2. Copy of Reader Group Questions sent to Leeds Cancer Programme Engagement Hub & the CCG Reader Group**

<p><b>Name:</b></p> <p><b>Job title:</b></p> <p><b>Email:</b></p> <p><b>Document for review:</b></p>	<p><b>Toni Larter</b></p> <p><b>Macmillan Engagement Lead – Leeds Cancer Programme</b></p> <p><a href="mailto:Toni.larter@nhs.net">Toni.larter@nhs.net</a></p> <p><b>FIT Screening instruction leaflet for patients</b></p>
<p><b>a) How were patients involved in identifying the need for this resource? (<i>why has it been developed?</i>)</b></p>	<p><b>Background:</b></p> <p>The FIT Test is a national Bowel Screening facility. It has 2 prongs. This leaflet refers to Symptomatic only.</p> <ul style="list-style-type: none"> <li>• Screening (of general population aged between 60-74)</li> <li>• Symptomatic – If patients fitting the following criteria present to their GP and are classed as ‘low risk, but not no risk’. Patients would fulfil the following criteria:             <ul style="list-style-type: none"> <li>• Aged 50 or over with unexplained abdominal pain or weight loss</li> <li>• Aged under 60 with changes in their bowel habit or iron-deficiency anaemia or</li> <li>• Aged 60 or over and have anaemia without iron deficiency.</li> </ul> </li> </ul>
<p><b>b) What is the purpose of the resource? (<i>what does it aim to do?</i>)</b></p>	<p>To instruct patients of how to carry out a self-Faecal Test to send off to pathology for testing.</p>
<p><b>c) How have patients been involved in developing this draft of the leaflet?</b></p>	<p>This is a nationally produced leaflet, however the Leeds Cancer Programme would like to ensure that it</p>

<i>(this might include patient experience/feedback)</i>	will meet the needs of the people of Leeds.
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## 2. Questions for the patient reader group

### Initial impressions

1. Is it clear who the leaflet is for, who it is from and what it is about?	
2. Is the design eye catching? Would you pick it up if you saw it in a GP surgery?	<b><u>DO NOT ANSWER</u></b>  Not applicable - this leaflet would only be given to a patient if a GP decides if a FIT test is needed. It wouldn't be generally available.

### Content

1. Are the instructions simple and easy to understand? Does it contain unexplained medical terms?	
2. Does this leaflet emphasise the importance of completing and returning the test? i.e. don't leave it and send off later.	
3. Does it speak to the reader? i.e. using 'you' and 'your' instead of 'the patient'	
4. Are there any errors in spelling, accuracy or grammar?	
5. Does it tell the patient everything they need to know? What other questions might the reader ask?	
6. Is there a contact name and number for queries?	
7. Are there links to other information, useful websites etc.?	
8. Is the leaflet sympathetic and sensitive?	
9. Do you think this instruction leaflet should have the word 'Cancer' on it. If yes – why?	

<b>If no-why not?</b>	
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**Layout**

<b>1. Is there plenty of space between images/instructions so the page looks easy to follow?</b>	
<b>2. Is there sufficient contrast between the background and the text colour used?</b>	
<b>3. What do you think of the images/photos used? Are they appropriate?</b>	
<b>4. Is the resource offered in an alternative format?</b>	