



How to guide -

Improving bowel cancer screening for people with a learning disability using flagging

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1.0 Aim of document

This document aims to support the setup of a bowel screening flagging pathway to improve the opportunity for people with a learning disability to make informed choices about bowel cancer screening by providing specialist help and support at the pre-invite stage.

2.0 Introduction

The North East and Cumbria Learning Disability Network, Macmillan Cancer Project and North East, Yorkshire and Humber Bowel Screening Hub started looking at improving the bowel screening pathway for people with a learning disability in 2016.

We wanted a pathway that enabled an offer of support to go to all people flagged as having a learning disability who were invited for screening. This offer of support would be tailored to the individuals needs and may include; support to understand the invitation and screening process enabling an informed choice, support to understand how to complete the kit, support to complete the kit, support with results letters.

We worked locally with community learning disability teams and CCG leads to identify a pathway that offered individuals with a learning disability support to understand their bowel screening invitation, at point of pre-invite, and make informed choices about bowel cancer screening by providing an offer of specialist help and support.

This document is designed for areas who would like to improve their bowel screening offer for people with a learning disability, it discusses how we did this across 11 CCG's in the North East and Cumbria and who were the important people in helping to make this happen. We have included a process plan, documents and challenges to support taking the work forward.

3.0 How to Guide:

3.1 Partners

These are the partners who were essential to making the project happen in each CCG area. In the North East and Cumbria, the work was co-ordinated by the Macmillan Cancer Learning Disability project manager. This co-ordinator role could be taken on by any of the partners.

- Local bowel cancer screening hub (Hub manager and team leader)
- Local bowel cancer screening centre (lead specialist screening practitioner)
- Local community learning disability team lead / primary care liaison lead
- CCG cancer lead
- CCG learning disability lead
- Cancer Research UK primary care facilitator
- Local authority public health team representative (we didn't have this for all areas)

3.2 Pathway

The pathway shown below was updated in May 2019 following work on the requirements around consent to share information. Additional information on this is available in section 3.5.

The pathway shows the link between GP practices, the hub and the community learning disability team.

GP practice to ensure learning disability lists are up to date.

Local community learning disability team may be able to support checking of lists.

GP practice to identify individuals meeting criteria ready to share information through secure nhs.net email with hub



Annual information request from the NHS bowel cancer screening programme (BCSP) hub

Information request for all individuals aged 53-74.

Information to include Name, NHS no., DOB, address, reasonable adjustments required (if known)

Information to be shared with the hub on the provided excel spread sheet and returned via nhs.net



BCSP hub

BCSP software populated with names, NHS no., DOB & address from age 53 for general population.

Hub to complete manual upload of learning disability information provided by GP practice into the additional care needs notes.



BCSP hub

6/8 weeks prior to pre-invite letter hub to complete search of all individuals with additional care needs notes. Hub to action notes.

For individuals identified as having a learning disability contact is made with the local community learning disability team.



CLDT receives information on pre-invite approximately 5/7 weeks prior to pre-invite being sent

CLDT make contact with and assess if person with a learning disability requires additional support.

For individuals that require additional support to understand / complete screening, CLDT offers support.

3.3 Process for setting up flagging project

Suggested process for setting up a bowel screening flagging project to improve the opportunity for people with learning disabilities to make informed choices about bowel cancer screening by providing specialist help and support.

Actions are identified in order with additional notes and identification of person responsible.

ACTION	DETAIL/NOTES	RESPONSIBLE
Identify project co-ordinator	Project co-ordinator to support process and have project overview.	
Communicate with partners to gauge interest.	Essential partners are: Local bowel cancer screening hub (hub) Local bowel cancer screening centre (centre) Local community learning disability team lead / primary care liaison lead (CLDT) CCG cancer lead and/or CCG learning disability lead	Project co-ordinator
Set up initial meeting of all partners		Project co-ordinator
Agreement to progress bowel flagging pathway	Agreement from all essential partners is needed to enable project to progress	All
Hub ensure SOP's in place for managing pathway	Allocation of hub team leader to take charge of pathway and SOP's	Hub
Bowel screening centre to offer training to CLDT	Short training session to enable CLDT to understand the bowel screening pathway.	Centre and CLDT
Secure nhs.net email contact agreed between hub and CLDT	This should not be a single person's email to ensure cover during holiday/illness etc.	Hub and CLDT
Confirm information to be shared with GP practices to endorse work	Suggested content appendix 1. This is to be shared by CCG leads.	CCG leads
Set project start date for roll out	This date is the start of the process to enable the hub to send information to GPs This may be done as a whole CCG or by smaller practice groups.	All

Roll out process STEP 1 (day 1) CCG endorsement - Information shared with GP practices	Information from CCG leads shared with GP practices. This can be through email, news bulletin or/and GP education session. CRUK facilitator to support	CCG leads CRUK facilitator
Roll out process STEP 2 (day 14) Hub information request to GP practices	Hub send request for information on flagged individuals to GP practices. Information to be shared via nhs.net.	Hub
Hub collect and upload information	Information uploaded as per SOP	Hub
Roll out process STEP 3 (day 28 / week 4) Bowel screening hub start monthly search for flagged individuals	Following SOP hub identify individuals flagged on additional care needs note as learning disability 4/8 weeks prior to pre-invite letter and share information with CLDT	Hub CLDT
Roll out process STEP 4 (day 42 / week 6) Information request reminder	Hub resent information request to all GP practices not yet engaged	Hub
Roll out process STEP 5 (day 84 / week 12) Project progress report meeting	All parties to meet to identify any concerns or issues. Hub to share names of practices not engaged. (Cancer Research UK facilitators may be able to support discussions with practices) Hub to share number of individuals flagged on system.	All
Roll out process STEP 6 (12 months) Annual information request from bowel screening hub	Annual request to GP's to identify any new individuals on practice list or any individuals who have left practice.	Hub

3.4 Challenges and Comments

There have been a number of challenges we have had to overcome to get this work rolled out across the North East and Cumbria. Below is a list of some of the challenges and comments, they are in no particular order and we don't have all the solutions.

- We offered no payment or incentives to anyone as part of this work.
- The hub and CLDT need to agree a quick and easy route to share identified individuals' information. The hub does not have the capacity to complete formal referral forms for individuals they identify. This was only an issue in a couple of areas and was resolved through discussion between project co-ordinator, CLDT and hub. The hub shares basic information with CLDT via a spread sheet each month.
- Some CLDT's had to ensure bowel flagging support could be offered without normal formal referral being made. For some areas this was difficult if the individual was not known to the CLDT.
- Some GP practices have chosen not to engage with the work, we have recently changed the pathway which makes the GP's role much easier and we will hopefully get better engagement. (see section below on consent) Having said this some areas we have 100% of GP's sharing information.
- Not all people with a learning disability are flagged on GP systems, it is estimated there is 2% of the population with a learning disability, GP practices only have on average 0.6% flagged. This has been noted as a limitation of the project.
- We request information from age 53 to 74 years. A decision was made to do this so the pathway could equally be used to support bowel scope or bowel screening using the home test kit. We have not yet rolled out the pathway for bowel scope screening.
- We had an occasion where the individual was flagged, information shared with CLDT, CLDT contacted the individual and identified individual did not have a learning disability and was wrongly flagged by GP. We are aware lists are not perfect and a process needs to be discussed on how CLDTs would deal with this type of incident. We would suggest as a minimum CLDT inform the hub and individuals GP.

3.5 The consent question – consent to share information

In 2016, when we set up the flagging project, the National screening team advised us that screening was not direct patient care and because of this direct consent to share information from the GP practice to the hub was required. Our initial pathway included the GP gaining consent from the individual through the learning disability annual health check or another consultation or making a best interest decision to share information. This restricted the number of individuals who are flagged by the hub and required direct involvement from the GP.

Following a PHE blog in summer 2018 (<https://phescreening.blog.gov.uk/2018/07/30/gps-duty-to-share-information-can-be-just-as-important-as-duty-to-protect-confidentiality/>) we contacted the national team for further guidance regarding the consent to share information. Following discussions with Public Health England Screening Inequalities Oversight Group and Information Governance & Policy Office plus our Chief Medical Officer we updated advice regarding the sharing of information.

We have now changed our pathway and recommend GP's do not need to gain consent to share information as part of the bowel flagging project as NICE state screening is direct patient care. Appendix 2 and 3 give the information we shared with GP's regarding the change in our pathway and links to the legal information to back this decision.

Following the change in the pathway we expect a greater uptake by GP practices as this is now an administrative task and does not require involvement from the GP.

Appendix 1 – Suggested content for GP information

Clinical Commissioning Group

Insert Date

Dear Doctor

Re: Learning disability bowel cancer screening flagging project

Bowel cancer is the fourth most common cancer in the UK and if detected at an early stage, it is easier to treat and survival rates increase.

To detect bowel cancer earlier, the NHS offers two types of bowel cancer screening to adults registered with a GP. Bowel scope screening is being rolled out to all at age 55, while the faecal immunochemical test is offered every two years between the ages of 60 - 74. Research shows taking part in bowel cancer screening reduces your chances of dying from bowel cancer and removing polyps in bowel scope screening can prevent cancer.

People with a learning disability statistically are far less likely to take part in cancer screening, often this is because they do not understand the information sent to them or do not have the support to enable them to make an informed choice on participation.

The learning disability flagging project aims to provide a method of ensuring people with a learning disability invited for screening have the opportunity to engage with additional support in understanding the screening programme and making an informed choice on participation.

To enable patients with a learning disability, from your practice, to have this support we have developed a pathway. As part of the pathway we are asking GP practices to share information on the individuals on their practice list who are flagged as having a learning disability between the ages of 53 and 74.

The pathway shows the links between GP practices, the bowel screening hub and the community learning disability team. By following the pathway, we will be able to support people with a learning disability in accessing bowel cancer screening.

From ADD DATE the bowel screening hub will be in touch to ask for a list of individuals who meet the criteria. From the end of the month the bowel screening hub will start to make reasonable adjustments and contact support for individuals.

Yours faithfully

CCG Cancer Lead

CCG Learning Disability Lead

INCLUDE COPY OF PATHWAY

Appendix 2 – Consent to share information GP letter

Dear Colleague

The North East and Cumbria Learning Disability Network Cancer Project works to, improve the access to cancer services and experiences for people with a learning disability.

Over the past few years we have worked with cancer screening programmes to improve the service and reasonable adjustments they are able to provide for people with a learning disability.

One of our consistent challenges has been the perceived requirement for consent, from the individual with a learning disability, to share information between General Practise and the screening provider.

Following recent consultation with Public Health England Screening Inequalities Oversight Group and Information Governance & Policy Office we are offering updated advice regarding the sharing of information.

The GMC state: ***Under the current code, screening is considered “direct care” and it is therefore reasonable to assume that consent is implicit if it is in the patient’s best interest to share information.***

Further information and links to documentation are provided in the attachment.

Please consider this information when completing:

- Bowel screening flagging project information request, from the screening hub
- Breast screening prior notification list, information on disability
- Abdominal aortic aneurism screening prior notification list, information on disability

This means that you can share on the spread sheet, the individuals and the reasonable adjustments they require providing that:

1. Your information is up to date
2. You have no reason to think that the individual would be surprised that you have shared this information.
3. You indicate to your patients that you will be sharing information about them for this purpose.

We recommend including information on your practice website and other appropriate information sources for the practice. The suggested wording would be:

Your GP wants to make sure that you have the information you need to choose if you want to join in with the screening programs. Screening is a way of finding and treating changes in your body before they turn into something serious like cancer.

Your GP will send information about you to the screening programme so that they can offer to help you understand about screening.

If you want to know more about this, please ask your GP or practice manager

Thank you for your support in improving access to screening services for people with a learning disability.

Appendix 3 – Consent to share information guidance



North East and North Cumbria – information sharing to reduce inequalities in access to screening

The North East and Cumbria Learning Disability Network Cancer Project works to improve the access to cancer services and experiences for people with a learning disability.

Following recent consultation with Public Health England Screening Inequalities Oversight Group and Information Governance & Policy Office we are offering updated advice regarding the sharing of information from general practice to screening providers including bowel, breast and abdominal aortic aneurism (AAA) screening.

The sharing of information between primary care and screening providers, about learning disability status, is not mandatory but subject to individual decisions by each GP based on the GMC guidance on sharing patient data. Under the current code, screening is considered “direct care” and it is therefore reasonable to assume that consent is implicit if it is in the patient’s best interest to share information.

As screening is considered direct care, GMC guidance on implied consent and sharing information for direct care should apply. The relevant extract is below. For the full documentation *Using and disclosing patient information for direct care* use the link:

<https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/confidentiality/using-and-disclosing-patient-information-for-direct-care#paragraph-26>

27 Most patients understand and expect that relevant information must be shared within the direct care team to provide their care(19). You should share relevant information with those who provide or support direct care to a patient, unless the patient has objected (see paragraphs 30 and 31).(11)

28 The usual basis for sharing information for a patient’s own care is the patient’s consent, whether that is explicit or implied (see paragraph 13 for definitions). You may rely on implied consent to access relevant information about the patient or to share it with those who provide (or support the provision of) direct care to the patient if all of the following are met.

- a) *You are accessing the information to provide or support the individual patient’s direct care, or are satisfied that the person you are sharing the information with is accessing or receiving it for this purpose.*
- b) *Information is readily available to patients, explaining how their information*

will be used and that they have the right to object. This can be provided in leaflets and posters, on websites, and face to face. It should be tailored to patients' identified communication requirements as far as practicable.

- c) You have no reason to believe the patient has objected.*
- d) You are satisfied that anyone you disclose personal information to understands that you are giving it to them in confidence, which they must respect.*

29 If you suspect a patient would be surprised to learn about how you are accessing or disclosing their personal information, you should ask for explicit consent unless it is not practicable to do so (see paragraph 14). For example, a patient may not expect you to have access to information from another healthcare provider or agency on a shared record

Further consideration

Further legal considerations to be considered are:

Organisations providing NHS services are required under the [Equality Act 2010](#), to reduce any inequalities which may result from a patients' disability. Personal information is used for the purpose of the provision of care and treatment. This information is kept confidential and in accordance with the [Data Protection Act 2018](#).

Information may be shared from general practitioners to the screening programs to allow reasonable adjustments to the offer of screening, to people with disabilities under the [Equality act 2010](#). These adjustments may include but are not exclusive to: an invitation and information in easy read or other accessible format; longer appointments; support to make an informed decision about taking part in the screening program. The information shared is maintained within the NHS at all times and limited to the information required to make the appropriate adjustments.

By law (section 250 of the [Health and Social Care Act 2012](#)), all organisations that provide NHS care or adult social care must follow the [Accessible Information Standard](#) in full from 1st August 2016.

The accessible information standard requires organisations providing NHS services to:

1. Ask people if they have any information or communication needs, and find out how to meet their needs.
2. Record those needs clearly and in a set way.
3. Highlight or flag the person's file or notes so it is clear that they have information or communication needs and how to meet those needs.
4. Share information about people's information and communication needs with other providers of NHS and adult social care, when they have consent or permission to do so.
5. Take steps to ensure that people receive information which they can access and understand, and receive communication support if they need it

References

1. **GMC Ethical guidance for doctors, Using and disclosing patient information for direct care**
<https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/confidentiality/using-and-disclosing-patient-information-for-direct-care#paragraph-26>
2. **National population screening programs: the information we use and why, and your options** Updated 16 July 2018
<https://www.gov.uk/government/publications/patient-confidentiality-in-nhs-population-screening-programmes/nhs-population-screening-confidential-patient-data>
3. **GPs' duty to share information can be just as important as duty to protect confidentiality**
<https://phescreening.blog.gov.uk/2018/07/30/gps-duty-to-share-information-can-be-just-as-important-as-duty-to-protect-confidentiality/>
4. **Accessible Information Standard: ensuring equal access to screening** [Mike Harris](#),
Posted on: 15 August 2016
<https://phescreening.blog.gov.uk/2016/08/15/accessible-information-standard-ensuring-equal-access-to-screening/>
5. **Accessible information standard**
<https://www.england.nhs.uk/ourwork/accessibleinfo/>
6. **Data protection act 2018**
<http://www.legislation.gov.uk/ukpga/2018/12/contents/enacted>
7. **Equality act 2010** <http://www.legislation.gov.uk/ukpga/2010/15/section/6>
8. **Health and social care act 2012**
<http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted>

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