Supporting people with learning disabilities through flagging within the Bowel Cancer Screening Programme

Project/process evaluation

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1.0 Introduction

People with a learning disability (PWLD) have poorer health and are more likely to die at a younger age than the general population\(^{i}\). Their uptake of cancer screening is much lower and they are at a much higher risk of gastrointestinal cancer\(^{ii}\). Bowel screening was identified through the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) as being particularly problematic\(^{iv}\).

The North East and Cumbria Learning Disability Network, with support from the ACE programme developed the work stream ‘Improving NHS cancer screening for people with a learning disability’, aiming to: Reduce the inequality for PWLD in accessing the offers and processes; Increase uptake and Embed sustainable reasonable adjustments into services.

The work has developed a number of projects focusing locally, regionally and nationally making significant progress in reducing the inequality.

The bowel screening flagging project is a part of this broader piece of work aiming to offer support to PWLD through the active use of flagging. This enables support structures to be put in place throughout the screening process.

1.1 The bowel screening flagging project

To develop the bowel screening flagging project the North East and Cumbria Learning Disability Network worked in collaboration with; the local bowel screening hub, Clinical Commissioning Group (CCG), GP practices, community learning disability team (CLDT) and Cancer Research UK primary care facilitator.

The project was initially tested in South Tyneside Clinical Commissioning Group (CCG) area. This consists of 28 GP practices and is covered by; one bowel cancer screening hub, one bowel cancer screening centre and one CLDT.

The project developed a pathway that; identified, flagged and offered support to PWLD prior to point of invite to bowel cancer screening using the faecal occult blood test (FOBt). This enabled individually tailored work to support PWLD in making a choice about participation and being supported through the screening process.

The National Bowel Cancer Screening Programme made a change to the bowel cancer screening computer system (BCSS) in February 2016, this change enabled the flagging of individuals with an additional care need. Then in May 2016 it became possible to identify individuals with an additional care need note (such as a learning disability) through a search of the computer system, prior to an initial invitation being sent. This change in the computer system enabled the project to test the use of this system change through the flagging project. We started the project on 9\(^{th}\) May 2016 and this report discusses our results up to the 1\(^{st}\) November 2016.
2.0 Method

The project worked in partnership to identify and test a system of flagging and support for PWLD invited for bowel cancer screening using the faecal occult blood test (FOBt). The process we devised is discussed below. The project aimed to test the process and adjust before offering to other CCG areas covered by the North East and Cumbria Network and North East Bowel Screening hub.

2.1 The process

The full process is described below in text and through the diagram on the next page.

An initial introduction letter regarding the project was sent to all GP practices by the GP cancer lead for the CCG, this introduced the project and its pathway. The letter also discussed the need to gain consent to share information with other health professionals through the enhanced learning disability annual health check.

The hub then contacted each GP practice requesting information regarding individuals with a learning disability, who had consented to have information shared, age 53 plus. The age of 53 was chosen as this is the age information is collated onto the bowel screening system, and it is anticipated that in the future the early identification of individuals being invited for bowel scope screening (at age 55) can be added to the project.

As information was received, from the GP practices by the hub, it was uploaded onto the system as an additional care needs note by a designated team leader. The Team Leader then ran a report using the bowel cancer screening system once a month to identify individuals who would be invited for screening in the following 4 weeks.

Once a PWLD was identified the team leaders contacted the CLDT with the individual’s details and the estimated arrival date of their invitation.

The CLDT then made an assessment of the level of support needed and offered tailored support to individuals. This could include but is not limited to; providing easy read information, providing one to one discussion, support in completing the FOBt, support attending appointments, support making best interest decision.
2.2 Information share pathway, for people with learning disabilities, invited for bowel cancer screening

**GP practice to ensure learning disability lists are up to date.**
Local community learning disability team can help with the checking of lists.

**GP practice to gain consent to share information through the annual learning disability health check.**
At annual health check for people with a learning disability ensure the individual has been asked if they are happy to have information shared to support their health and record answer.

**Annual information request from the NHS bowel cancer screening programme (BCSP) hub**
Information request for year one will be for all individuals that consented to information sharing aged 53-74.
Information request in subsequent years will be all individuals that consented to information share aged 53-55, have registered with the practice in the last year or aged 53-74 and have changed consent to share information.
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, DOB & address from age 53 of general population.
Hub to complete manual upload of learning disability information provided by GP practice into the additional care needs notes.

**BCSP hub**
4 weeks prior to pre invite letter the hub to complete a search of all individuals with additional care needs notes. Hub to action notes.

For individuals identified on the hub system as having a learning disability in the additional care needs notes and requiring additional support contact will be made with the relevant community learning disability team.

Hub to inform CLDT of the pre invitation.

**CLDT receives information on pre invite approximately 2 weeks prior to pre invite being sent**
CLDT to assess if person with a learning disability requires additional support.
For individuals that need additional support to understand / complete screening the CLDT offers support.
3.0 Results

The results are divided into three sections.

1. Quantitative data collated on the numbers of PWLD identified and supported.
2. Workload data collected by the main organisations involved in the delivery of work and estimating time spent on tasks.
3. Case studies

3.1 Quantitative data

Of the 28 GP practices, at time of writing, all have returned information to the bowel cancer screening hub regarding PWLD who have consented to share information aged 53 – 74.

Prior to the project 7 PWLD were known to the bowel cancer screening hub. They have now 209 PWLD flagged on their system as having a learning disability under the additional care needs note.

The hub have identified and passed information on 12 PWLD to the CLDT for additional support.

Number of PWLD who were identified by the hub and information shared with the CLDT, by month of invite

![Graph showing number of PWLD by month](image)

Of those PWLD notified to the CLDT the following outcomes are recorded. (Note; at time of writing a number of the individuals screening episodes are still open with results not yet inputted.)

- 3 individuals normal result, episode closed
- 1 individual, weak positive, awaiting additional test kit to be returned
- 3 individuals not yet responded, standard reminder letter sent
- 1 individual received abnormal result, later ceased due to unsuitability for diagnostic test, GP informed.
- 2 recent invites, no results currently received
- 2 about to be invited
3.2 Workload – hub

The work relating to the project in the hub is currently being completed by a team leader. It is anticipated all future work; communicating with GP’s, inputting additional care needs notes and sharing information with the CLDT will be completed by a team leader, band 4 or above.

This information relates to the work completed within South Tyneside with the 28 GP practices.

In total it has taken approx. 6 hours to add the 209 individuals, identified by GP practices as having a learning disability and being within the age criteria in the South Tyneside CCG area, onto the bowel cancer screening system (BCSS) as an additional care needs note.

An average of, 2 minutes per individual.

It’s takes on average, 13 minutes per practice, to add individuals onto the BCSS.

It takes approx. 8 minutes per referral to the community learning disability team per individual – total time taken so far 1 hour 18 mins for 12 referrals.

3.3 Workload – CLDT

Upon identification of an individual about to be invited for FOBt screening the community learning disability team allocated the individual to a health care support worker. For the PWLD identified to date this workload has averaged out at 3 visits to the client of approximately 30 minutes each, plus travel time.

When an individual is not previously known to the CLDT they approach sensitively and offer a needs assessment that could lead to further support being offered.

Individuals are kept on the case load of the health care support worker until they have chosen to not participate or they have participated and the screening round is completed.

3.4 Case Studies

The two case studies below describe the involvement of the community learning disability team in supporting PWLD to make choices on screening. Without the flagging project these individuals would have not been identified as about to be invited and would not have received support. Their names have been changed.

Moira

The Health Care Support Worker (HCSW) visited Moira, who has a learning disability, at her home. The HCSW explained the advantages of having bowel cancer screening; being able to pick up early signs that may be cancer which is easier to treat if identified in the early stages. Moira clearly looked really pleased saying her father had already being treated for bowel cancer and wanted to
take part in this herself, she was eager to get started. The pack was sent to her home and the HCSW supported completion.

Jack

Jack received his bowel screening test kit and was offered support through a phone call. Jack decided to complete the kit himself. He completed the kit and sent it away. Jack received a letter asking him to repeat the test as it was incomplete; no dates were put on the test card. He decided he would complete another test kit, Jack completed the test kit and sent it away, unfortunately this was again not dated and Jack had put too much sample on the card. When he received a request for a further test kit to be completed he refused and put the test kit in the bin. Jack told the HCSW he had not received it and would not complete any more. HCSW visited Jack who was adamant he was not completing the screening again. After a discussion with the HCSW about the benefits, using easy read leaflets he reluctantly said he would complete another set of samples, the screening was completed with the HCSW support and the results came back fine, the kit did not need to be repeated. Jack was very pleased he had accepted the support from CLDT and thanked the HCSW involved.

4.0 Discussion and comments

The discussion and comments have been divided into a number of sub sections to describe some of the thinking and issues that arose as part of this project.

4.1 Consent to share information

When you are supporting individuals and sharing their information between services there are always questions around consent to be answered. We all have a right to our information remaining private. The screening programmes are not identified as direct patient care therefore consent is needed before personal information can be shared with screening services.

The enhanced learning disability annual health check is the ideal opportunity to identify with a PWLD if they are happy for information to be shared with screening services and start discussions about screening.

Where an individual lacks the capacity to consent a best interest decision would need to be made regarding the sharing of information.

When we look to roll out this work into other CCG areas we will be clearly stating in all communication the need to gain consent to share information.

4.2 Sign up by GP Practices

South Tyneside CCG and the Cancer Research UK Primary Care Facilitator supported the sign up of GP practices through discussing the project whilst doing practice visits.
Not all GP practices shared information immediately, but all had signed up and shared information by October 2016.

It is worth noting this project has not been part of an enhanced payment scheme for GP’s and the additional work has been completed as best practice for their patients with a learning disability.

4.3 Training CLDT

Prior to the project the South of Tyne Bowel Cancer Screening Centre completed a training session for the CLDT. This ensured the team understood the process of screening and choice for the individual being invited.

CLDT members also attended a number of training events held by the North East and Cumbria Learning Disability Network including; primary care training and the Good Bowel Health and Bowel Screening train the trainers course.

It will be expected that all new CLDT’s coming on board with the project will receive training from the bowel cancer screening centre to ensure their knowledge base and make links with the screening centre staff.

5.0 Conclusion and moving forward

We have a legal responsibility through the Equalities Act to provide reasonable adjustments for people with learning disabilities, to make changes in our approach/provision and to ensure that services are accessible to disabled people as well as everybody else.

The bowel screening flagging project has tested and evaluated a process that can be replicated to improve the invitation process and support structures for PWLD.

Following this trial period it is anticipated the project will look to roll out into other CCG areas and look to share its learning to enable other areas to develop similar work.

This work shows the benefits of flagging in enabling support for PWLD and should feed into the wider work on reducing the inequalities faced by PWLD trying to access services.
References


