Flagging to reduce inequalities in bowel screening for people with learning disabilities.

Introduction
People with a learning disability have poorer health and are more likely to die at a younger age. Uptake of screening is much lower and risk of gastrointestinal cancer much higher. Bowel screening was identified in the CIPOLD inquiry as being particularly problematic.

The North East and Cumbria Learning Disability Network, developed a work stream to improve NHS cancer screening. The bowel screening flagging project is a part of this work.

Aim
Use the Bowel Cancer Screening System (BCSS), additional care needs note, to offer support reducing the inequalities in bowel screening for people with a learning disability.

Methods
February 2016 BCSS enabled flagging of additional care needs. May 2016 possible to search and identify individuals with an additional care need note, prior to invitation.

An information share pathway was developed to; identify, flag and offer support to people with a learning disability prior to point of invite to faecal occult blood test screening. This enables individually tailored work to support people in making choices about participation and support during screening.

Tested, South Tyneside, 28 GP practices.

Results
9th May 2016 to 30th January 2017.

207 people aged 53 – 74 with a learning disability flagged as having an additional care need on BCSS.

29 people with a learning disability referred for additional support with the community learning disability team.

Full results available for 16 people

3 of the 16 people had previously not responded to their invitation to be screened.

Information share process

GP ensure learning disability lists are up to date.
Local community learning disability team (CLDT) can help.

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 spreadsheet and returned via nhs.net

BCSP hub populates software
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 inform CLDT of people due invitation
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 CLDT.

Hub to inform CLDT of the pre invitation.

CLDT receives information on pre invite approximately 2 – 4 weeks prior to pre invite being sent
CLDT to offer person with a learning disability if required additional support/ reasonable adjustments.

Challenges
Consent to share information is the biggest challenge. Screening is not direct patient care, so consent is needed to share information with services. The annual health check for people with a learning disability is used to gain consent. Confirmation of consent is completed annually.

Future rollout
The bowel screening flagging project has tested and evaluated a process that can be replicated to improve the invitation process and support structures for people with a learning disability.

We are now working on spread and adoption across the North East and Cumbria.