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

## First year results, South Tyneside

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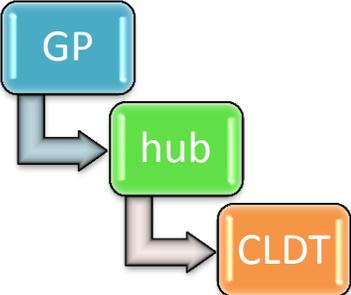
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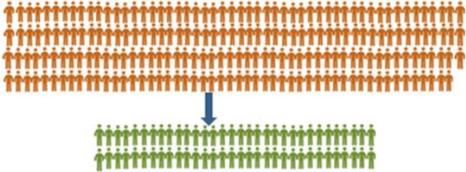
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## 1.0 Easy read executive summary

	<p>This is an easy read summary of the report; <b>Supporting people with learning disabilities through flagging within the Bowel Cancer Screening Programme</b></p>
	<p>The north east and Cumbria learning disability network, cancer project and the north east bowel cancer screening programme have been working together.</p>
	<p>They saw an opportunity for people with a learning disability to be offered support to make choices about bowel screening. They started the bowel flagging pathway project.</p>
	<p>The bowel cancer screening programme invites men and women, registered with a GP, every 2 years, from age 60 -74 to take part in Faecal Occult Blood test (FOBT) screening. This is an opportunity to reduce the risk of bowel cancer or identify it early when treatment is easier.</p>
	<p>The bowel flagging pathway was developed. It was tested in South Tyneside. This report gives 1 year results for South Tyneside.</p>

	<p>The pathway developed; identifies, flags and offers support to people with a learning disability before their invite for bowel screening.</p>
	<p>This helps people with a learning disability to make a choice about participation and support through the screening process.</p>
	<p><b>Results</b></p>
	<p>In South Tyneside all 28 GP practices took part.</p>
	<p>209 people were flagged as having a learning disability by the bowel screening hub. 64 people were invited for bowel screening in the first year. They were offered support from the community learning disability team.</p>
	<p>75% of people were supported to make choices regarding their invitation to screening and if required support in completing screening.</p>



50% were supported by the CLDT, 25% had support from family or carers.



Of those who did their screening, 9 had not completed screening when they were previously invited.  
Some people had received many invites over 10 years and never previously completed screening.



We are now in the process of rolling out the bowel flagging project, across the North East and Cumbria.



We have a legal responsibility through the Equalities Act to provide reasonable adjustments for people with learning disabilities.  
We need to make sure services are accessible to disabled people as well as everybody else.  
The bowel screening flagging project has tested and evaluated a process that enables reasonable adjustments.



This work shows the benefits of flagging in enabling support for people with a learning disability. It should feed into the wider work on reducing the inequalities faced by people with a learning disability trying to access services.

## 1.1 Executive summary

The North East and Cumbria Learning Disability Network, Cancer Project identified a gap in the opportunity for people with a learning disability to receive support to make choices regarding their bowel screening invitation.

We know people with a learning disability have poorer health, poorer uptake of screening and higher risk of gastrointestinal cancer. Bowel cancer screening is an opportunity to reduce the risk of bowel cancer and identify it early when treatment is easier. The screening programme invites all men and women registered with a GP every 2 years from age 60 -74 to take part in Faecal Occult Blood test (FOBT) screening.

This led to the bowel flagging project which was initially tested in South Tyneside; this report gives full year 1 results for South Tyneside.

The project developed a pathway that; identifies, flags and offers support to people with a learning disability prior to point of pre invite. This enables individually tailored work to support people with a learning disability in making a choice about participation and support through the screening process if required.

In South Tyneside all **28** GPs returned information, leading to **209** people being flagged as having an additional care need. In the first year **64** people identified through the additional care needs note received an offer of support from the community learning disability team (CLDT). **75%** were supported to make choices regarding their invitation to screening and if required support in completing screening. **50%** were supported by the CLDT, **25%** had support from family or carers. Of those who were supported **9** had not completed screening when they were previously invited and some individuals had received multiple invites over 10 years and never previously responded.

We are now in the process of rolling out the bowel flagging project, this has meant co-ordinating with 11 CCG's, 10 CLDT, 6 CRUK primary care facilitators and 5 bowel screening centres and 2 bowel screening hubs.

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 enables reasonable adjustments.

This work shows the benefits of flagging in enabling support for people with a learning disability and should feed into the wider work on reducing the inequalities faced by people with a learning disability trying to access services.

## 2.0 Introduction

People with a learning disability have poorer health and are more likely to die at a younger age than the general population<sup>i</sup> <sup>ii</sup>. Their uptake of cancer screening is much lower and they are at a much higher risk of gastrointestinal cancer<sup>iii</sup>. Bowel screening was identified through the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) as being particularly problematic<sup>iv</sup>.

The North East and Cumbria Learning Disability Network, Macmillan cancer project works closely with the Northern Cancer Alliance to improve cancer services for people with a learning disability. The Macmillan cancer learning disability project has developed a number of work streams focusing locally, regionally and nationally making significant progress in improving cancer services.

The bowel screening flagging project is a part of this broader work aiming to offer support to people with a learning disability through the active use of flagging. This enables people with a learning disability to make informed choices about their screening invitation and support structures to be put in place throughout the screening process.

## 3.0 Development of the bowel screening flagging project

The bowel cancer screening programme, invites all men and women registered with a GP every 2 years from age 60 -74 years to take part in Faecal Occult Blood test (FOBT) screening. This includes; a standard pre invite letter including information booklet, invitation to take part including screening kit, reminder letter if required, results letter and for those who receive an abnormal result referral to the local bowel screening centre for possible colonoscopy investigation. Further information on bowel cancer screening is available at: <https://www.gov.uk/guidance/bowel-cancer-screening-programme-overview>.

The North East and Cumbria Learning Disability Network, Cancer Project identified a gap in the opportunity for people with a learning disability to receive support to make choices regarding their bowel screening invitation.

To develop the bowel screening flagging project the North East and Cumbria Learning Disability Network, Cancer Project has worked in an enabling role, in partnership 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. This report gives full year 1 results for South Tyneside from May 2016 to June 2017.

South Tyneside consists of 28 GP practices, with a total population of 148,700. The geography is covered by; the North East, Yorkshire and Humber bowel cancer screening hub, the South of Tyne bowel cancer screening centre and South Tyneside CLDT.

The project developed a pathway that; identified, flagged and offered support to people with a learning disability prior to point of pre invite to bowel cancer screening using the faecal occult blood test (FOBT). This enabled individually tailored work to support people with a learning disability in making a choice about participation and support through the screening process if required.

The development of the project became possible when 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 additional needs in the additional care need note. 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 the initial pre invitation being sent. This change in the BCSS enabled the flagging project to progress. We started the project on 9<sup>th</sup> May 2016.

### 3.1 The process

The process used to establish and run the project is described below, this report gives results for South Tyneside although the same process has been used for all the CCG's who have rolled out bowel flagging in the North East and Cumbria.

<b>Step 1</b>	Agreement was reached with the bowel screening hub, community learning disability team and CCG to progress bowel flagging. The Cancer Research UK (CRUK) primary care facilitator agreed to provide support in promoting the project to individual GP practices.
<b>Step 2</b> (week 1 of roll out)	An initial introduction letter regarding the project was sent to all GP practices by the CCG GP cancer lead, this introduced the project and its information share pathway (see next page). The letter also discussed the need to gain consent to share information with other health professionals through the enhanced learning disability annual health check or another consultation.
<b>Step 3</b> (week 2)	The bowel screening hub contacted each GP practice requesting information regarding individuals with a learning disability, who had consented to have information shared, age 53 - 74. The age of 53 was chosen as this is the age information is uploaded 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.
<b>Step 4</b>	CCG cancer lead and CRUK primary care facilitator discuss the bowel flagging project at any practice visits.
<b>Step 5</b>	Information received by the hub, from the GP practises. The information uploaded onto the BCSS as an additional care needs note by a designated team leader.
<b>Step 6</b> (week 4)	Bowel screening hub send a reminder at 4 weeks to any GP practise that has not returned information.
<b>Step 7</b>	The hub team leader runs a report on BCSS once a month to identify individuals who will be invited for screening in the following 4 weeks. Once a person with a learning disability is identified the team leader contacts the CLDT with the individual's details and the estimated arrival date of their invitation.
<b>Step 8</b>	The CLDT make contact with the person with a learning disability and offer support. They assess the level of support needed and offer 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 kit, support attending appointments, support making a best interest decision.
<b>Step 9</b> (week 52)	The hub make an annual information request to GP practices to identifying any new patients who meet the requirement and have consented to have their information shared or any changes in the consent given by a person with a learning disability over the past year.

### 3.2 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 enhanced learning disability annual health check or other consultation**

At annual health check or other consultation 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 from age 53 of general population via spine.

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 prior to pre invite being sent**

CLDT to assess if person with a learning disability requires additional support.

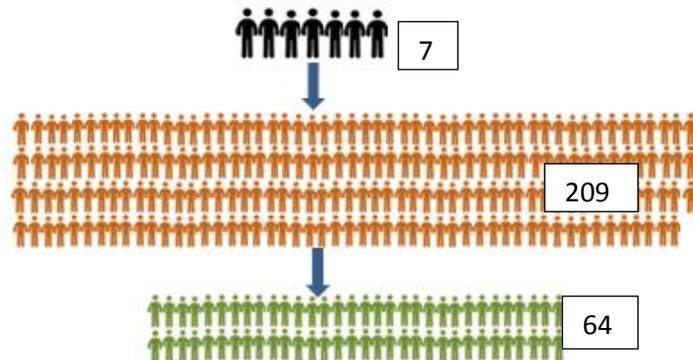
For individuals that want additional support to understand /make choices/complete screening the CLDT offers support.

## 4.0 Method and Results

Of the 28 GP practices in South Tyneside, all returned information to the bowel cancer screening hub regarding people with a learning disability who have consented to share information aged 53 – 74.

Prior to the project **7** people with a learning disability were known to the bowel cancer screening hub. They now have **209** people with a learning disability flagged on their system as having a learning disability under the additional care needs note an increase of **202** people.

During the period, May 2016 – June 2017, **64** people flagged as having a learning disability were identified through the additional care needs note by the bowel screening hub prior to pre invite and their information shared with the CLDT.



### 4.1 Method

The project worked in partnership to identify and test a system of flagging and support for people with a learning disability invited for bowel cancer screening using the faecal occult blood test (FOBt).

Year one results are for all episodes of individuals flagged in the BCSS additional care needs note as having a learning disability, within South Tyneside, who were referred to the CLDT.

Data on each individual's screening round was collated by the bowel screening hub. The screening round includes the complete process from pre invite letter through to results, for individuals identified as having an abnormal result this includes the possible further testing and results. Each episode can last up to 13 weeks.

Data on the numbers of people with a learning disability who were offered support was collated by the CLDT.

All results are described below.

## 4.2 Results from South Tyneside CLDT

64 referrals were received from the bowel screening hub into CLDT, the table below shows the support uptake of the 64 people with a learning disability.

Table showing the support received, by the 64 people with a learning disability invited for FOBt screening, from the CLDT

	<b>32 (50%)</b> Individuals accepted support from CLDT to understand/make choices/completing bowel screening episode
	<b>16 (25%)</b> Individuals supported by their own family/carers to understand/make choices/completing bowel screening episode and informed CLDT of results
	<b>11 (17%)</b> Chose to not accept support from CLDT to understand/make choices/completing bowel screening episode
	<b>2 (3%)</b> Individuals unclear if they have learning disability, refused cognitive screening in the past, chose not to engage with CLDT re bowel screening
	<b>2 (3%)</b> Did not have learning disability, coded wrongly by GP practice
	<b>1</b> No further action for this bowel screening episode due to cancer diagnosis and ongoing treatment

In summary the CLDT contacted all 64 people with a learning disability, 75% were supported to make choices regarding their invitation to screening and if required support in completing screening. 50% were supported by the CLDT, 25% had support from family or carers who reported results to the CLDT.

17% of people contacted chose not to accept support regarding screening from the CLDT. 3% did not engage and had previously refused cognitive screening and 3% were wrongly coded by the GP practice. The final individual was currently undergoing bowel cancer treatment thus not currently suitable for screening.

### 4.3 Case Studies from CLDT

The two case studies below describe the involvement of the community learning disability team in supporting people with a learning disability 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 completed another test kit and sent it away. This kit was again not dated. When he received a request for a further test kit he refused and put it in the bin. Jack told the HCSW he would not complete any more. The HCSW visited Jack. After a discussion with the HCSW about the benefits of screening, using easy read materials he said he would complete another kit. The screening was completed with the HCSW support and the results came back fine. Jack was pleased he had accepted the support from CLDT and thanked the HCSW involved.*

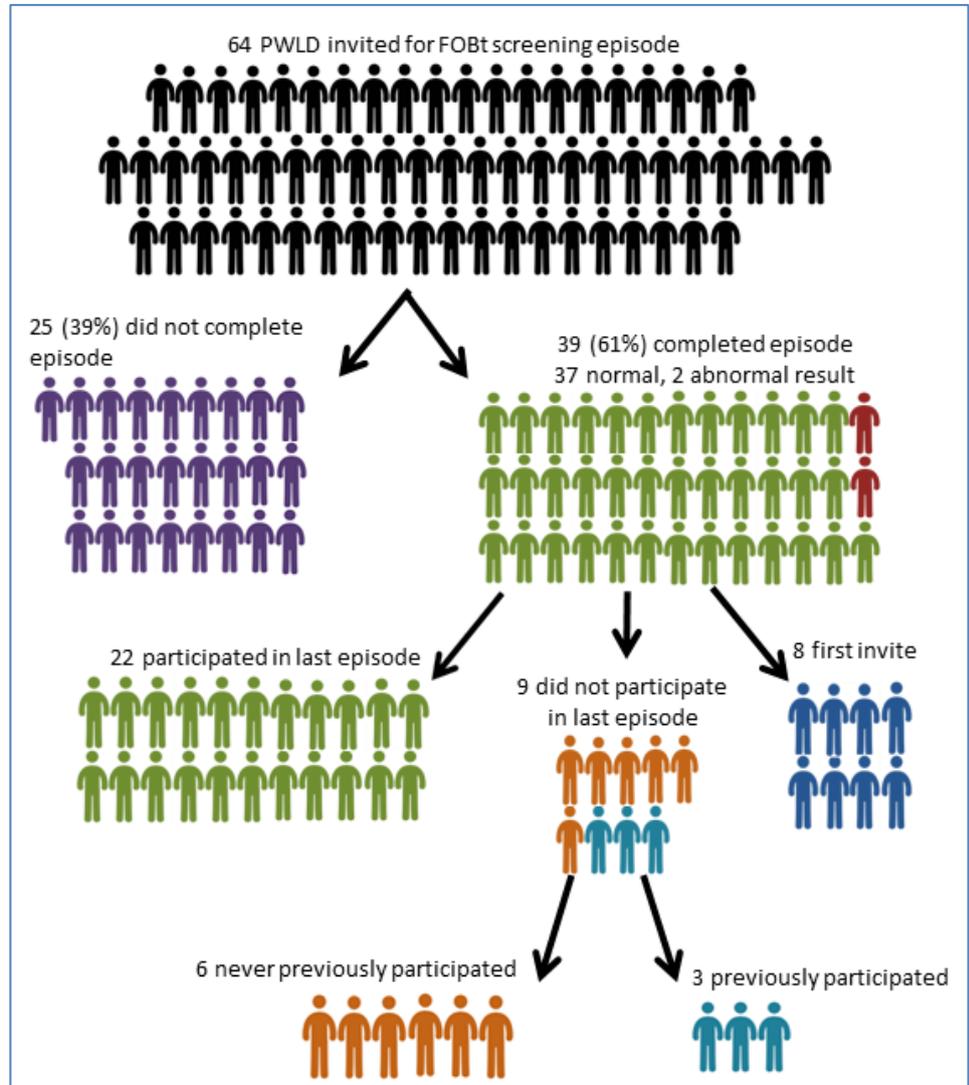
#### 4.4 Results from bowel screening hub

Of the 64 subjects invited for bowel screening using the FOBt kit the following data has been provided by the bowel screening hub;

- 25 (39%) did not complete the episode
- 39 (61%) episodes were completed
  - 37 (58%) episodes were completed with the subject being defined as 'definitive normal'
  - 2 (3%) episodes were completed with the subject being defined as 'definitive abnormal'

(The 2 subjects defined as definitive abnormal were invited for colonoscopy, the subjects were supported and best interest decisions made not to progress.)

When we looked at the screening results for individuals from previous invitations to bowel screening it was identified of the above 39 episodes;



- 22 (56%) subjects had a definitive result in the most-previous episode
- 8 (21%) subjects had their 1st invitation to participate after May 2016
- 9 (23%) subjects had a definitive result having not participated in their most-previous episode, of these 3 had received a definitive result from a prior screening episode
- 6 (15%) subjects had a definitive result having not participated in any most-previous episode

## 5.0 Considerations of the project

The considerations of the project have been divided into a number of sub sections to describe some of the thinking and important elements of the project. It is aimed to support areas who are considering replicating work.

### 5.1 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.

It is important to use an appropriate opportunity to gain consent; we suggest the enhanced learning disability annual health check or another consultation ensuring the person with a learning disability is 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.

### 5.2 Sign up by GP Practices

The South Tyneside CCG cancer lead 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.

### 5.3 Promotion of the project

As part of the roll out in other areas alongside the GP information letter (appendix 1) and CRUK / GP cancer lead involvement we have also used CCG newsletters, GP time out sessions, social care provider sessions, practice nurse meetings and the engagement of the Macmillan primary care nurses (in Durham).

### 5.4 Training CLDT

Prior to the project the South of Tyne Bowel Cancer Screening Centre and learning disability project manager delivered a training session for the CLDT. This ensured the team understood the process of screening and choices for the individual being invited. It also gave an opportunity to explain the project in detail and make links between the screening centre staff and CLDT. This has been offered to all areas rolling out the flagging work.

## 5.5 Reaching the widest population possible

The project is aware not all people with a learning disability are recorded on GP systems as having a learning disability; this means the bowel screening flagging project will miss a proportion of the population.

Mencap and NHSE have a current campaign to try and increase the numbers of people with a learning disability asking to be flagged on GP systems, <https://www.mencap.org.uk/advice-and-support/health/dont-miss-out> . Just 23% of people with a learning disability are registered as having a learning disability with their GP and just 44% receive an Annual Health Check. This is despite well documented evidence of the health inequalities experienced by people with a learning disability.

The North East and Cumbria Learning Disability Network is supporting the ‘Don’t miss out campaign’.

We note this as a limitation of the project.

## 6.0 Roll out

This project has meant co-ordinating with 11 CCG's, 10 CLDT, 6 CRUK primary care facilitators and 5 bowel screening centres.

In each area a task finish group was formed to support roll out. This included a core membership of: North East and Cumbria learning disability network, Macmillan cancer project lead, bowel cancer screening hub, CLDT, local screening centre, CRUK primary care facilitator and CCG. Additional membership was area specific and included Macmillan primary care nurses, social care providers, local authorities and commissioners.

### 6.1 North East

Since the start of the project in May 2016 we have successfully rolled out the bowel screening flagging project to the whole of the North East area, covered by the North East and Cumbria Learning Disability Network, except Newcastle where we are continuing discussions.

Rollout has involved the collaboration of a large number of people from a variety of organisations and we are currently in the situation where supported by the CRUK Primary Care Facilitators and individual CCG's we are continuing to promote the flagging project to ensure all those individuals flagged on GP systems have the conversation about sharing information and receiving additional support to make choices about bowel cancer screening.

The North East area is covered by the North East, Yorkshire and Humber Bowel Cancer Screening Hub.

### 6.2 Cumbria

In Cumbria we have started rollout from November 2017, roll out here involves working with small numbers of GP practices from 2 geographical areas to enable the Rugby Bowel Cancer Screening Hub to embed the processes into practice before full roll out.

## 7.0 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 people with a learning disability.

This work shows the benefits of flagging in enabling support for people with a learning disability and should feed into the wider work on reducing the inequalities faced by people with a learning disability trying to access services.

In the future we would like to look at rolling out the support provided by the CLDT using the additional care needs note flag to bowel scope screening, where all men and women are invited for a one off test aged 55. This would enable a valuable input of services to a screening opportunity which can be complex to understand.

We are also working with other areas in the country looking at the processes developed in the North East and Cumbria and supporting wider roll out.

## References

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<sup>i</sup> Emerson E, Baines S, Allerton L and Welch V. (2012) Health inequalities and People with Learning Disabilities in the UK:2012. Improving Health and Lives Learning Disabilities Public Health Observatory <http://www.ihal.org.uk/gsf.php5?f=16453> (accessed 03/11/2016)

<sup>ii</sup> Heslop P, Blair P, Fleming P, Hoghton M, Marriott A and Russ L. (2013) Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD): Final report. Bristol: Norah Fry Research Centre, University of Bristol <http://www.bristol.ac.uk/cipold/reports/> (accessed 15th 03/11/2016)

<sup>iii</sup> Connolly J. (2013) Barriers to access to cancer screening for people with learning disabilities: a review. *The Lancet*; 382(3): S29

<sup>iv</sup> Heslop P, Blair P, Fleming P, Hoghton M, Marriott A and Russ L. (2013) Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD): Final report. Bristol: Norah Fry Research Centre, University of Bristol <http://www.bristol.ac.uk/cipold/reports/> (accessed 15th 03/11/2016)