



## **Project Report**

# **Improving cancer services for people with a learning disability in the North East and Cumbria**

Report to cover period from: October 2017 to April 2019




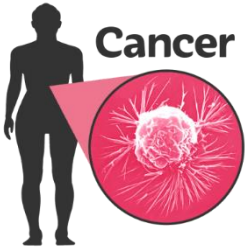

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Learning Disability Network













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## Section 1- Executive summary, easy read

|   |   |
|---|---|
| <br>    | <p>This is the Project Report for the</p> <p><b>Macmillan cancer learning disability project</b></p> <p>This project is funded by Macmillan Cancer Support. It is part of the North East and Cumbria Learning Disability Network.</p> <p>The report covers things we have done between October 2017 and April 2019.</p>                   |
| <br> | <p>The project aims to improve cancer services and experiences for people with a learning disability, their families and carers.</p> <p>This is important because cancer is one of the top 3 reasons of premature deaths for people with a learning disability.</p> <p>A premature death is when a person dies earlier than expected.</p> |
|    | <p>The project covers the North East and Cumbria.</p> <p>The project also supports work nationally.</p>   |

|   |   |
|---|---|
|    | <p>The project works in partnership with people with learning disability, families, carers and health professionals.</p>  |
|    | <p>This report tells you some of the things we have been doing as part of the <b>Macmillan cancer learning disability project</b>.</p>  |
|   | <p>The report tells us about some of the projects highlights.</p> <p>These are things that we think are good.</p>   |
| <br><br> | <p>Our highlights include:</p> <p>Be Cancer Aware – We worked with people with learning disability to make and deliver cancer awareness courses.</p> <p>Making cancer screening in mental health and learning disability inpatient settings accessible.</p> <p>Helping Macmillan make an easy read holistic needs assessment – this will help people who have cancer get good support.</p> <p>Organised a conference sharing learning of projects from across the country.</p> <p>Helping make national easy read booklets for screening and immunisation programmes, such as breast screening and bowel screening.</p> |

|  |   |
|--|---|
|   | <p>The project is having a good impact on services and the experiences of people with learning disability.</p> <p>The full report includes lots more information about what we have done</p>  |
|  | <p>If you want more information or would like to get involved please contact Julie Tucker</p> <div data-bbox="600 689 794 815">  </div> <p><a href="mailto:Julie.tucker11@nhs.net">Julie.tucker11@nhs.net</a></p> <div data-bbox="651 833 734 990">  </div> <p>0113 824 9693 or 0786 0177 981</p> |

## Section 2 - Introduction

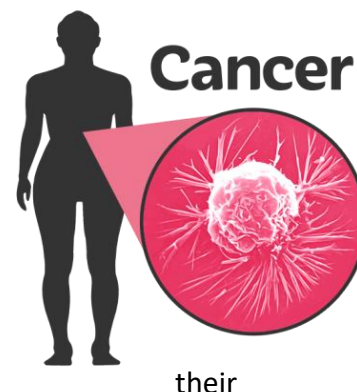
The North East and Cumbria Learning Disability Network hosts the **Macmillan cancer learning disability project**. The project has completed two years as a Macmillan project (2016-2018) building on the work of the ACE programme improving cancer screening for people with learning disabilities.

<http://www.cancerresearchuk.org/health-professional/diagnosis/ace->

In October 2018 Macmillan Cancer Support identified the importance of the work and progress that had been made agreeing to fund the work for a further two years taking the project through to October 2020.

This report covers an 18-month period from October 2017 through to April 2019.

The **Macmillan cancer learning disability project** looks to improve cancer services and experiences for people with a learning disability, families and carers.



The **Macmillan cancer learning disability project** is made up of the fulltime project manager and part time (one session a week) clinical lead. These two are supported by a steering group who meet regularly to look at individual projects, monitor the project plan and offer support where needed. The **Macmillan cancer learning disability project** is integrated into the work of the North East and Cumbria Learning Disability Network and works closely with the Northern Cancer Alliance.

Improving cancer services and focusing on inequalities for people with learning disability is a priority nationally, it is part of the:

- NHS England Long Term Plan

- NHS England 5 Year Forward View, where cancer and inequalities are both priority areas.

- NHS England Building the Right Support

- NHS England GP 5 Year Forward View

As Integrated care systems develop across regions cancer and inequalities remain a high focus along with improving the lives of people with learning disabilities.



Through continuing research and reports we understand the differences and difficulties facing people with a learning disability in accessing cancer services.

Evidence tells us that people with learning disability have a higher risk of gastro-intestinal cancers.

Cancer is known to be in the top 3 reasons for premature deaths of people with a learning disability.

People with a learning disability are 2.5 times more likely to have a health problem, and the LeDeR work tells us, die up to 29 years younger than people without a learning disability.

Improving cancer services for people with a learning disability is important because we know they are less likely to:

- Take part in screening programmes
- Be informed of their cancer diagnosis and prognosis
- Be given pain relief during cancer treatment
- Be involved in decisions about their cancer care
- Receive palliative care

### Section 3 - Demographic profile of the population

The project covers the geographical area of the North East and Cumbria consisting of;

1 Integrated Care System with 4 Integrated Care Partnerships

The North East and Cumbria Learning Disability Network

The Northern Cancer Alliance

11 clinical commissioning groups (CCGs)

13 local authorities

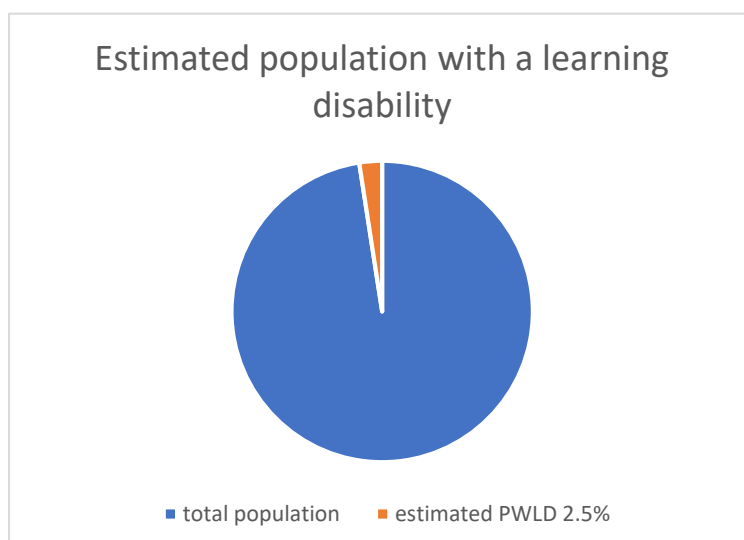
10 acute hospital trusts

3 specialist trusts



The total population for the area is estimated at 2,873,208.

We would expect 2 – 2.5% of this population to have a learning disability, this would mean between 57,464 and 71,830 people in the North East and Cumbria have a learning disability, although the numbers of individuals registered on health and social care systems as having a learning disability is far lower. Currently prevalence of people on learning disability registers in GP practices is around 0.6% or 17,239.



We are aware the numbers of people with a learning disability are relatively small, but we need to strive for equality of access to all services, ensuring all of the population are able to get help when they need it and the reasonable adjustments they require.



## Section 4 - Project aim

The **Macmillan cancer learning disability project** aims to:  
**Improve cancer services and experiences for people with a learning disability throughout the cancer journey**

We are achieving this through:

- working in four key theme areas of
  - information and support
  - education and training
  - communication
  - focus on issues to be tackled nationally
- effective partnership working linking organisations and individuals, building relationships to enable a broad breadth of work.
- keeping people with a learning disability at the centre of all our service and pathway design using our best practice guidance and the ladder of participation.
- improving support for people with a learning disability to help them make informed choices and where required for professionals to make best interest decisions.
- working to ensure all organisations respect an individual's right to confidentiality and organisations' needs to maintain good information governance while understanding the importance of sharing information when relevant to support a person's care.



## Section 5 – Project highlights

The project highlights describe some of the projects which are part of the **Macmillan cancer learning disability project**. For each project we have included information on the aim, action to date, future plans and impact of the project.

To support all the projects under the **Macmillan cancer learning disability** umbrella we produced the [best practice guidelines](#). This helps guide all our work and ensure we engage with people with learning disability in an effective and fair manner considering inclusion and co-design in all of our work.

The best practice guidelines were produced by Gateshead People through consultation with people with learning disability, families and carers from across the North East and Cumbria.



## Be cancer aware – A cancer awareness, co-production project

**Partners:** Cancer Research UK, Gateshead People, Larchfield Camphill Village Trust, Macmillan, People First Independent Advocacy, Skills for people, Sunderland People First

### Aim

**To co-produce a cancer awareness course with a group of experts by experience and cancer experts.**

**To train people with a learning disability to educate others using the course.**

Co-production means experts by experience are involved at every stage alongside cancer experts who can advise on the accuracy of content and support development. All members of the co-production team are; equal, work together, sharing decision-making, take responsibility for actions and review progress.

Through this we aim to:

- Increase the knowledge of the co-production team
- Increase the skills and empower peer educators to share cancer information in the learning disability community
- Increase the knowledge of the learning disability community and empower them to talk about their health and cancer
- Create a package that could be replicated by others



**Methods** - The project used 5 stages.

|  |  |
|--|--|
| <b>Stage 1</b><br><b>Project set up</b>                | <ul style="list-style-type: none"><li>• gain support from partners</li><li>• Identify funding, ensure experts by experience can be reimbursed</li></ul>  |
| <b>Stage 2</b><br><b>Development of course</b>         | <ul style="list-style-type: none"><li>• co-production team asked peers what they want to know about cancer</li><li>• development days- designing course, delivery and facilitation pack</li><li>• Test course content</li></ul>            |
| <b>Stage 3</b><br><b>Training peer educators</b>       | <ul style="list-style-type: none"><li>• 5 organisations train as peer educators</li><li>• Introduction of the facilitation pack and course content</li><li>• Training on; delivery, content, practice sessions and peer feedback</li></ul> |
| <b>Stage 4</b><br><b>Delivery of 'Be cancer aware'</b> | <ul style="list-style-type: none"><li>• Commitment from each organisation to deliver 10 courses over 12-month period</li><li>• Peer support sessions</li><li>• Evaluation/data collection</li></ul>  |
| <b>Stage 5</b><br><b>Evaluation</b>                    | <ul style="list-style-type: none"><li>• Evaluation of the process of co-production</li><li>• Evaluation of the outcomes of the course (ongoing)</li></ul>  |

## Action to date

The project is currently at stages 4 and 5.

Our 5 teams of peer educators are delivering in the community.

The process evaluation is complete and available at <http://www.northerncanceralliance.nhs.uk/wp-content/uploads/2019/04/Be-cancer-aware-Process-evaluation.pdf>

The outcomes evaluation is ongoing.



At time of writing 9 sessions have been delivered reaching nearly 100 participants.

An additional training course was co-delivered in North Yorkshire to the Botton Hill community with support from Larchfield, Be Cancer Aware peer educators.

## Future plans

As with any course the product will adapt and develop over time. The peer support sessions will be an important element of this work gaining feedback from the individuals delivering the training and course participants.

Ensuring our peer educator continue to develop their skills and understanding of cancer will happen through additional training sessions, these are planned to link to the peer support sessions and will include topics identified by the peer educators plus updates on practice such as changes to the bowel screening programme.

Funding was obtained to train 5 organisations and for them to then deliver 10 Be Cancer Aware courses each. At the end of this funding we will aim to identify additional funding to continue the work and roll out the model to other areas to enable a greater awareness and understanding of cancer within the learning disability community.

## Impact

The benefits are much greater than just co-producing a product. The process used has been empowering. The work has been enjoyable and yet still focused, we have seen individuals grow in confidence, they have learnt new skills and can take these skills with them into other areas of their life.

Broader outcomes of the project will continue to be evaluated and feed into future work.

Comments from co-production team:

*"I met new friends. It was interesting to work together to make the course. I felt happy because I knew how far I could push myself. My confidence is a lot better now."*

*"I couldn't believe I got up and presented. I was so nervous but I did it and everybody was really helping me. It felt good to know that I did it!"*



## Cancer screening in mental health and learning disability inpatient settings

**Partners:** North East Yorkshire and Humber Bowel Screening Hub, Northumberland Tyne and Wear Mental Health Foundation Trust (NTW), Tees Esk and Wear Valley Mental Health Foundation Trust (TEWV), Public Health England, NHS Digital

### Aim

**To ensure people in mental health and learning disability inpatient settings have access to cancer screening, particularly those who are not registered with a GP.**

If an individual is not registered with a GP they will not receive an invitation for screening as part of the national screening programme. This project aims to develop pathways to enable individuals to receive a cancer screening invitation, so they can make choices about whether or not to take part in screening

### Methods

The project has initially focused on bowel screening. Through discussion with partners a pathway was developed which allows individuals to be identified and linked to a code on the bowel screening computer system, this allows an invitation to be created and shared with the individual.

The pathway was tested and roll out planned. See overleaf for condensed pathway.

### Action to date

The pathway has been developed and tested by in patient settings in Northgate Hospital, NTW. NTW are looking to roll out the pathway across additional sites. TEWV are testing the pathway at Roseberry Park before planned roll out across all their sites.

The roll out is currently paused due to the change in the bowel screening test kit. Once the new test kit is in place further roll out will commence. This pause is to ensure inpatient staff have the correct knowledge of the screening programmes test kit. The new test kit also has a number of advantages for use in the inpatient settings, primarily only a single sample of faeces is needed.



## Future plans

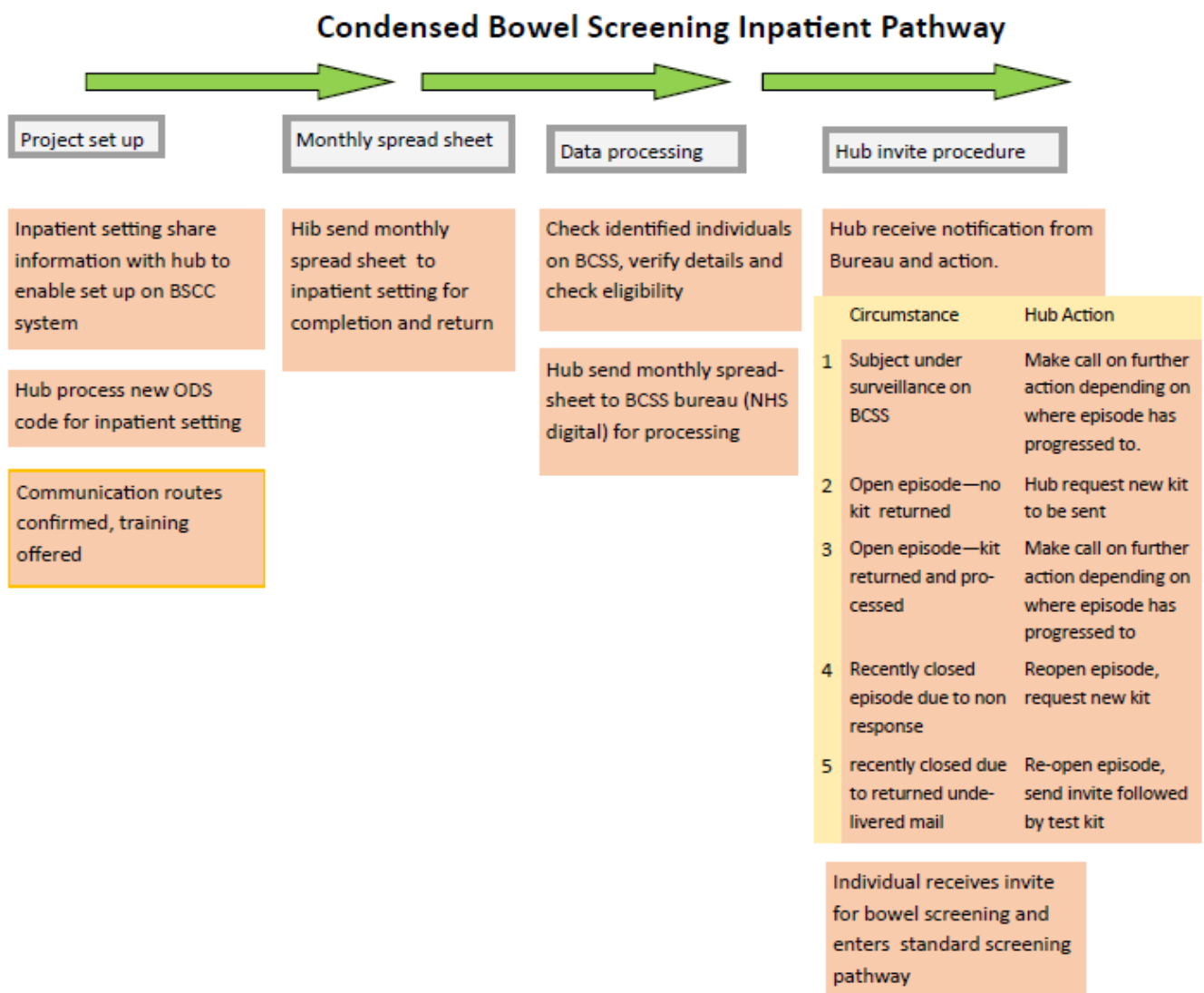
Roll out will continue across NTW and TEWV.

Discussions with Cumbria Partnership Foundation Trust and the Bowel Screening Hub in Rugby re roll out in Cumbria.

The project needs to engage private health providers of care to ensure residents have access to the cancer screening programmes.

Once the pathway is fully established all resources will be shared with the National Cancer Screening Inequalities group to enable other areas to take advantage of the work completed.

A pathway for breast screening and cervical screening is to be developed to ensure fair access across all programmes for people in inpatient settings.





## Living with and beyond cancer – Easy read holistic needs assessment

**Partners:** Macmillan design team, Northern Cancer Alliance, Northumbria Health Care NHS FT, Northumberland Community Learning Disability Team

### Aim

**Develop an easy read online holistic needs assessment, to be used to support individuals following a cancer diagnosis as part of the recovery package.**

### Methods



Following initial discussions, it was decided to work with Macmillan to co-design a resource.

The **Macmillan cancer learning disability project** arranged 2 workshops to gain the views of people with a learning disability. Workshops included people with a lived experience of cancer and support workers.

Macmillan will develop a draft web version for further consultation and review by people with a learning disability, before the product is made nationally available.

To support this work a wider consultation, to look at what style of images people prefer to represent the words used in the holistic needs assessment, has been completed with a range of partners including: Health Watch, community learning disability teams and Inclusion North.

### Action to date

Workshops held in December 2018 and January 2019. At the workshops groups looked at the questions the holistic needs assessment asks and ordered them into themes to make the information easier to understand. Groups thought about the different pages of a website and how navigating the material could be made as easy as possible.

Following the workshops, a survey was developed and shared asking what style of images people prefer. The survey results, shown below, were shared with Macmillan.

The Macmillan design team took the learning from the workshops and survey, they are currently working with the web designer. Once a draft product is made it will be shared with workshop participants for comment and testing.

### Future plans

The online version will be tested and further adjusted before rollout. At rollout education sessions will be offered to staff who use the holistic needs assessment.



















Macmillan will evaluate the effectiveness of the resource.

## Results, images to represent words

117 people completed the survey identifying their preference to three image options, a cartoon, line drawing and photo option.

The results show in the majority of options the line drawing was preferred, receiving the highest number of votes. For one option the cartoon received the highest number of votes. The photo images were not preferred for any options and came third in all but one option.

**Table showing results of survey – Images to represent words**

|                              |   |  |   |
|------------------------------|---|--|---|
| <b>Angry or frustrated</b>   |    |    |    |
| TOTAL                        | 33  | 63   | 20  |
| <b>Sad / depressed</b>       |   |   |   |
| TOTAL                        | 59  | 29   | 29  |
| <b>Support groups</b>        |  |  |  |
| TOTAL                        | 33  | 59   | 21  |
| <b>Weight changes</b>        |  |  |  |
| TOTAL                        | 35  | 46   | 28  |
| <b>Feeling/being sick</b>    |  |  |  |
| TOTAL                        | 21  | 53   | 32  |
| <b>Exercise and activity</b> |  |  |  |
| TOTAL                        | 34  | 77   | 7   |

## Sharing learning, saving lives -Improving cancer services for people with a learning disability

### Aims

The learn and share conference aimed to **give the audience an opportunity to learn from projects which focus on cancer and learning disabilities and share experiences, successes and challenges.**

Following the success of our conference in 2017, Working together to improve cancer services and experiences for people with a learning disability which had a focus on work completed in the North East and Cumbria. On 21<sup>st</sup> January 2019, we invited friends and colleagues from across the country to present their work on improving cancer services and experiences and share some of the learning from **the Macmillan cancer learning disability project**, broadening our understanding of work being completed across the country, making new contacts and sharing experiences.

### Method

Following an education grant from Macmillan we formed an organising committee to deliver the conference. Invites were sent for speakers and an agenda planned. To ensure people with a learning disability were at the centre of our thinking throughout the conference we had representation from the learning disability community involved in the organising committee, chair the event and present throughout the day.

### Actions to date

100 people attended the day. Attendees were from a broad range of backgrounds including:

|  |   |
|--|---|
| Acute and primary care liaison nurses    | National cancer charities                   |
| Cancer Alliances                         | Palliative care                             |
| CRUK Primary care facilitators           | Primary & secondary care cancer specialists |
| Learning disability self-advocacy groups | Screening programmes                        |
| Local Authority Public Health            | Social care                                 |
| Macmillan nurse specialists              |   |

The conference was chaired by Jodie a self-advocate from Sunderland People First, Jodie shared this role with Judith Thompson, North East and Cumbria Learning Disability Network Manager. A range of different projects presented at the day, all presentations and resources are available at: <http://www.northerncanceralliance.nhs.uk/event/improving-cancer-services-for-people-with-a-learning-disability/>

Evaluation from the day included the following comments

*'I found this extremely useful, and stimulating and heartening and encouraging'*

*'Thank you for organising the event, I found it to be very informative. It was great to see a range of different professionals and patients by experience there.'*

*'I particularly found the focus on user-led and co-produced resources and projects helpful. The conference showcased excellent examples of meaningfully working alongside people with a learning disability to improve cancer outcomes. '*

*'I had chance to speak to lots of people – really inspiring, I chatted to several colleagues from NHS and cancer charities. A useful networking opportunity.'*



## Sharing learning, saving lives - Agenda

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Be cancer aware – co-production, peer education project

**Julie Tucker - MacMillan project manager, Gateshead People and Skills for People (Peter, Paul, Suzie and Lyndsey)**

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Stopping people dying too young

**Stuart Chappell, Gavin Barr, Karen Parry, North East & Cumbria Confirm and Challenge group**

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Improving cancer screening for people with a learning disability

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- Improving the experience for women with a learning disability attending cervical screening

**Jill Fozzard- Colposcopist and Cervical Screening Training Facilitator**

**Jilly Goodfellow- Nurse Colposcopist & Sister Women's Health Unit**

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- Making cancer screening services more accessible for people with a learning disability

**Rachel Hunt and Mary Burke, Screening and Immunisations Co-ordinators**

**Anna Fellows, Screening and Immunisations Manager**

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- Cancer screening in inpatient settings

**Julie Tucker - MacMillan project manager**

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- Good bowel health and screening, accessible information and awareness training

**Claire Finlayson-Bowel Cancer UK**

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Developing an inclusive approach to public involvement

**Jo Mackintosh-Macmillan Co-production project manager, Northern Cancer Alliance**

**Kirsty Douglas-Co-production steering group**

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Considerations for easy read cancer information online

**Hiten Vaghmaria-CRUK, Digital Specialist**

**Katie Patrick-CRUK, Health Information Officer**

**Rich Stenning-CRUK, User Experience Designer**

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Table top talks

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- Targeted training for care providers

**Kim Woolnough- Community Nurse/Health Facilitator, TEWV**

**Yvonne Anderson- Macmillan Primary Care Nurse, County Durham**

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- Increasing the uptake of screening for people with a learning disability

**Jackie Fleeman-Learning Disability Lead, Derbyshire Healthcare NHS FT**

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- Living with and beyond cancer – improving the holistic needs assessment

**Dr Jenni Lawrence – Macmillan Lead for SRCCG**

**Lynne Taylor-Strategic Health Facilitator, TEWV**

**Victoria Stenhouse-Harrogate and District NHS FT**

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- Attitudes and opinions of women with a learning disability, family carers and paid care workers towards cervical and breast cancer screening

**Kate Byrnes, Tees University**

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## National easy read booklets for screening and immunisations

**Partners:** Lead by Public Health England, North East and Cumbria partners – **Macmillan cancer learning disability project**, Gateshead People First, Gateshead Foundation Trust screening programmes.



### Aim

To update existing and develop new easy read information booklets for all Public Health England screening and immunisation programmes.

### Methods

Teams from across the country have met, on a number of occasions, to develop easy read materials. These meetings have included people with learning disability, families, carers and health specialists. Following each of the meetings a draft document is produced and shared with participating partners for further comment before publication.

To support the development of the new cervical screening booklet and bowel screening FIT booklet the **Macmillan Cancer Learning Disability Project** arranged two workshops inviting people with a learning disability, families and carers from across the North East and Cumbria.

### Actions to date

To date new documents have been produced for:

[Abdominal Aortic Aneurysm screening](#)

[You and your baby \(8 booklets\)](#)

[Breast screening](#)

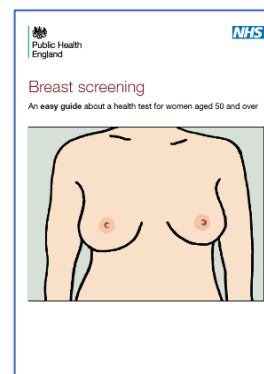
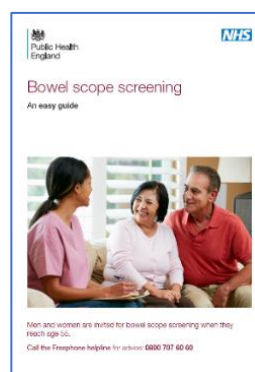
[Diabetic Eye Screening](#)

[Bowel Scope Screening](#)

[Cervical screening](#)

Workshops held in February 2019 -

<https://phscreening.blog.gov.uk/2019/03/20/north-east-experts-by-experience-help-develop-new-screening-easy-guides/>



### Future plans

Partners from the North East and Cumbria are keen to remain involved in the work ensuring good easy read materials for all the screening and immunisation programmes. This will include attending future workshops and supporting development of draft and final documents. The project is now starting to look at developing easy read letters. The work will continue developing letters while further work looks at how we can best integrated into practice.

## Section 6 - Future plans and targets

The **Macmillan cancer learning disability project** is funded until October 2020. During this time period we will be working towards:

**Improving the information and support for people with a learning disability, families and carers at all stages along the cancer journey**, including: living with and beyond cancer and palliative care. Support the development of accessible pathways and support materials for the lung case finding pilot with the Northern Cancer Alliance.

**Spread knowledge and understanding through training and education sessions** including: completion of 50 Be Cancer Aware training courses, training of GP practice nurse trainees through Northumbria University and work with the Northern Cancer Alliance to ensure accessible education materials for FIT symptomatic roll out.

**Share our learning with others to improve services and experiences for all people with a learning disability**, including: presenting at conferences, GP training sessions, supporting other learning disability projects across the country, being a member of the national screening and immunisations learning disability working group, newsletter updates and learning and sharing conferences.

**Working on improving services and experiences through national engagement**, including: linking with Public Health England and NHS digital to develop accessible pathways, being the North East and Cumbria representative on the SIT learning disability inequalities screening group, working with Macmillan development team developing an easy read holistic needs assessment and continue to highlight inequalities on the national stage, increasing the awareness of inequalities for people with a learning disability accessing cancer services.

**MACMILLAN  
CANCER SUPPORT**



[www.macmillan.org.uk](http://www.macmillan.org.uk)



0808 808 00 00 7 days a week, 8am - 8pm

For more information or help from Macmillan cancer support you can contact them via the website or telephone help line.