

APPENDIX 6

LeDeR actions into learning

Cancer

North East and Cumbria Learning Disability Macmillan cancer project

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Below are a range of projects that have taken learning from the LeDeR reviews or have direct relevance to the learning.

Margaret's Story (page 3)

Co-produced resource using train the trainer model to share learning of best practice. Enabling participants to stop and think about how we can better support people with a learning disability and what good quality care looks like.

Condensed evaluation.

Supporting people with a learning disability to access palliative care (page 5)

Building on the learning of Margaret's story guidance regarding referrals of palliative and End of Life patients was shared with CCG cancer and Learning Disability leads and Learning Disability Community Liaison teams.

Tackling inequalities in cancer – Slides from National screening inequalities operational group November 2019

Information on the following projects

1. Bowel screening flagging

Development of pathway to support people with a learning disability to make choices regarding bowel screening and if wanted receive support to complete screening.

Rolled out across region, national interest to implement pathway supported by National Bowel Screening Quality Assurance Lead.

2. Access to screening for people in inpatient settings

Patients in mental health and learning disability inpatient settings not registered with a GP, for what ever reason, do not receive routine invites to adult screening programmes. We worked in partnership to develop, pilot and roll out a pathway to support initially bowel screening, then breast screening, cervical and AAA screening using learning from the work completed with the prison population.

To date:

Pathway tested and agreement to roll out. Agreed to be priority of MH ICS inequalities work.

3. Social Care Provider Screening Resource Pack

Developed in partnership with Durham community learning disability team, experts by experience and the Macmillan Cancer project.

1500 printed resources have been distributed to providers through community learning disability teams, CRUK facilitators, social care providers, Northern Cancer Alliance and GAPs.

Pack has been shared in other regional.

Available through Northern Cancer Alliance website.

4. Cervical screening support pack

Online resource pack to support providers of cervical screening provide a reasonably adjusted quality service to women with a learning disability accessing cervical screening.

Accessible through Northern Cancer Alliance website.

Shared with national screening inequalities group.

Shared through cervical screening trainee and refresher programmes.

5. Be Cancer Aware

A co-produced peer education programme providing training on cancer awareness, signs of cancer, screening, risk behaviours and support.

To date:

Eight groups of peer educators are delivering training across North East and Cumbria

181 people have received the session 1. 134 have received session 2.

Main delivery programme is currently paused.

Group are meeting to develop adapted resources focusing on signs of cancer and when to go to you GP or hospital for delivery during current restriction.

Video produced for NHSE showing Be Cancer Aware as example of co-production.

6. Health Quality Checker Programme for Breast and Bowel Screening

To support breast and bowel screening centres to better understand and provide quality services for people with a learning disability Health Quality Checker Tools have been developed.

To date: Breast screening tool kit complete, health quality checkers trained and ready to pilot. Bowel screening initial visit to hub complete and report in draft. Full toolkit in development. Project currently on hold due to COVID

7. No Fear cervical screening campaign

Working with regional project to ensure accessibility of resources for people with a learning disability.

Project currently focusing on online resources.

8. PHE Easy read materials

Working with experts by experience from across our region we have supported PHE to develop the national easy read screening and immunisations materials.

Recent work has also included working with the Targeted lung Health Check national team to develop easy read materials for the project pilot. In the

Newcastle.Gateshead TLHC pilot we have worked to develop a learning disability pathway taking our learning from the bowel screening pathway.

Access to two week wait cancer referrals

Where an individual is not supported by their GP a two week wait referral for cancer diagnosis cannot be made.

Working with the Northern Cancer Alliance clinical lead to adapt 2ww referral documents for use in inpatient settings.

Margaret's Story



Story-based learning facilitator training

'Margaret's story is a very powerful and emotive it will hopefully improve people's lives.'

Margaret's story is produced with the permission of Margaret Thornton, and support from the North East and Cumbria Learning Disability Network, St Benedict's Hospice and the Sunderland Community Learning Disability team.

At the point of recording Margaret's story, summer 2019, Margaret was palliative. Margaret agreed to share her story to help others learn from her journey. In March 2020 Margaret died.

We are immensely grateful to Margaret for sharing her story, it gives us the opportunity to stop and think about how we can better support people with a learning disability and what good quality care looks like.

Following the recording of Margaret's story, we developed facilitator training to train others to use Margaret's story to deliver story-based learning. The resource was also shared through the Northern Cancer Alliance website.

The North East and Cumbria Learning Disability Network worked with Palliative consultant Colette Hawkins to develop and deliver the facilitator training and online training resources.

In March 2020 we planned to deliver 4 face to face facilitator training sessions. Due to the policies brought in for COVID 19 we delivered the initial 2 sessions.

Aims of Margaret's story Facilitator training:

Give facilitators skills and resources to use story-based learning for supported discussion and increase awareness of the additional support/care an individual may need.

Allow people to think about their individual rolls within health, social care or the third sector, how and when they offer support and what good quality care looks like.

Why story-based learning. This style of learning enabled participants to learn from each other, with multiple teams and sectors represented it enables: Discussions with professionals from diverse areas and the development of broader understanding.

By training a range of facilitators from a variety of sectors and organisations we aim to snowball Margaret's story to a range of people from primary, secondary, social and third sector organisations who support individuals with a learning disability on disease pathways.

Evaluation

50 people attended two facilitator training sessions.

People were from; care homes, social care providers, transforming care team, LeDeR reviewer, hospice staff, community learning disability teams, Cancer Research UK regional team, Macmillan regional team, integrated care, community volunteers, voluntary sector, CCGs/primary care, health watch and palliative care teams.

The majority, 67% were looking to improve their knowledge and skills.

“To gain a client view of care and treatment, to offer support when needed to my clients within Northumberland. Education and insight”

23% identified specifically they wanted the ability to train others.

“To deliver training to providers to raise awareness of health inequalities experienced by people with learning disabilities.”

Margaret’s story enabled participants to think about areas of their practice, including:

- Support
- Time, time out, time to talk to others
- Communication
- Identification / flagging
- Training others
- Reasonable adjustments
- Personal awareness

The key messages participants identified they would take from the training included:

- Communication
- Don’t assume understanding.
- Tailored support
- Professional engagement

Participants identified elements of their own practice or your organisations practise they might change including:

- Time and having/making time to support people.
- Understanding where and when to signpost people who may need additional support.
- Acknowledgement professionals need to check individual understanding more thoroughly and take action where needed.
- Acceptance that emotional support is as important as physical health support.

‘This has been really informative and support given to help deliver the training is excellent.’

Moving forward: Margaret’s story has been delivered virtually to the Hospice at home team in Gateshead. Post COVID facilitator training sessions and facilitator refresh sessions planned.

Supporting people with a learning disability to access palliative care

Building on the learning of Margaret's story The North East and Cumbria Learning Disability Network, Cancer Clinical lead worked with St. Benedict's Hospice and the Sunderland Community Learning Disability team to develop guidance for primary care regarding patients flagged as palliative or end of life, when to refer to palliative services and when to engage the community learning disability team.

Guidance requests:

Identification of people with a learning disability and on the palliative or end of life register.

Gain consent for early referral to community learning disability team for assessment and support.

Guidance was shared with community learning disability teams through the GAP's Network, due to the possibility of additional work load only those community learning disability teams who requested had additional information sent to their CCG cancer leads and CCG learning disability leads for dissemination to all GP practices.

Guidance was distributed specifically in Sunderland, South Tyneside, North Tees, South Tees and Northumberland.

Following the initial distribution within primary care, guidance was adapted and shared with secondary care colleagues through the A2A (access to acute) network.