



Improving Cancer Outcomes of People with Learning Disabilities in London

Exploratory Workshop - 03rd May 2022

Evaluation Report

Acknowledgements

The Transforming Cancer Services Team (TCST) Primary and Community Care Education Group (PCCEG) are grateful to all who participated in the event including the speakers and facilitators who gave their time, expertise and support which contributed to the smooth running of the event. In particular we would like to thank Maggie O'Donnell, Learning Disability Nursing & Health Improvement Lead, NHSEI, who kindly supported with the development of the workshop content and encouraged experts in the learning disability settings to attend and participate in the drafting meaningful recommendations.

And finally, a huge thank you to the 56 delegates who attended the event and actively participated in the group discussions, providing valuable and honest contributions. Especially to the experts by experience who voluntarily gave up their time to attend and were an essential part of the day. There was fantastic energy in the virtual room and many constructive ideas and suggestions that will be vital for the development and success of the agreed next steps.

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1. Executive Summary

It is recognised that people with Learning disabilities die much younger than the general population: 13-20 years younger for men and 20-26 years younger for women with learning disabilities compared to those without learning disabilities (Learning Disabilities Observatory, PHE, 2016).

The 'Treat me right! Better healthcare for people with a learning disability' MENCAP report as early as 2004 identified that it was essential to:

- Reduce inequalities in cancer services for people with learning disabilities
- Improve training for all healthcare staff in how best to engage with people with learning disabilities to improve health outcomes.

A National Cancer Team priority for next year (2023/24) is to focus on improving cancer experiences and services for people with learning disabilities and autism. London's regional cancer Primary Care and Community Education Group (PCCEG) agreed to take steps now in London to move forward and prioritise this area.

The key driver for this priority is to reduce the gap in life expectancy for individuals with a learning disability.

A total of 56 delegates attended, with representation from experts by experience, each London ICS area, primary and community care and the acute and third sector.

Six presentations were made to set the scene and demonstrate good practice, and two facilitated breakout sessions were held to explore the following priority areas:

- To better understand the experiences of people with learning disabilities on a cancer pathway in primary care.
- To learn about best practice to improve support and experience of diagnosing cancer early and living well beyond cancer for people with learning disabilities in primary care and community services.

- To identify and agree opportunities and next steps for London to improve cancer outcomes for people with learning disabilities and those significant to them, in relation to education and training of health professionals in primary care and community services.

Using the feedback received the following five recommendations have been made for members of the Primary Care and Community Education Group to consider:

Recommendation 1: With the support of the Transforming Cancer Service Team, a short life Task and Finish Group should be established to scope, develop, and implement a detailed action plan to implement the following four recommendations pan London.

Recommendation 2: Perform an exercise to map current training and education regarding learning disabilities available to primary care and community HCPs in London and use this to identify gaps and inform a strategic approach to upskilling primary care and community staff.

Recommendation 3: London region to ensure that resources available to support staff to support people with learning disabilities to access cancer services can be consistently shared pan London.

Recommendation 4: It is vital that experts by experience voices are included in all that we do to ensure people with learning disabilities needs are understood and being consistently considered. Development of a shared pan London 'patient voice toolkit' resource will support us to achieve this.

Recommendation 5: Recognising that supporting people with learning disabilities to access other healthcare services is a priority area across the board, PCCEG should identify area of potential collaborative working / influencing opportunities to reduce duplication and ensure that primary care and community training needs in relation to people with learning disabilities are being considered in others planning.

2. Delegate Recruitment and Attendance

2.1 Recruitment

The workshop was advertised through a variety of different channels. In addition to advertising through the TCST contact list and dissemination through past participants and TCST contacts other strategies utilised for recruitment included:

- Eventbrite ticketing platform
- Members of the Primary Care and Community Education Group (PCCEG)
- Dissemination through relevant groups e.g., Personalised Care for Cancer Partnership Board, GP Leads Group and Personalised Cancer Care Inequalities Steering Group.
- Invitations to Cancer Alliance Leads and by email from members of the TCST team.
- Experts by experience approached by the TCST User Involvement and Patient Experience Coordinator and the Learning Disabilities Nursing Lead and an email circulate to the TCST Patient Advisory Group
- Direct invitations shared with all primary care leads.
- Cancer Research UK

Recruitment was then targeted towards different audiences in an attempt to ensure there was representation from all key stakeholder groups. Representation was sought from the geographical remit of the Transforming Cancer Services Team.

Key stakeholders were identified as:

- Patients and Carers
- Commissioners
- Cancer Alliance Leads
- ICS and CCG Leads
- Key stakeholders across learning disabilities settings and cancer.
- Health Professionals including GPs, Oncologists, Nurses, Allied Health Professionals
- Managers (including service, project and programme managers)
- Clinical leads
- Third sector organisations
- Anyone with relevant interest in the pathway

2.2 Attendance

A total of 56 people attended on the day. There was good representation across the ICS groups (including West Essex who had representation from only one participant who bordered both West Essex and South East London). The attendees came from a wide variety of backgrounds and HCPs including primary care, cancer alliances, project and program managers and third sector partners.

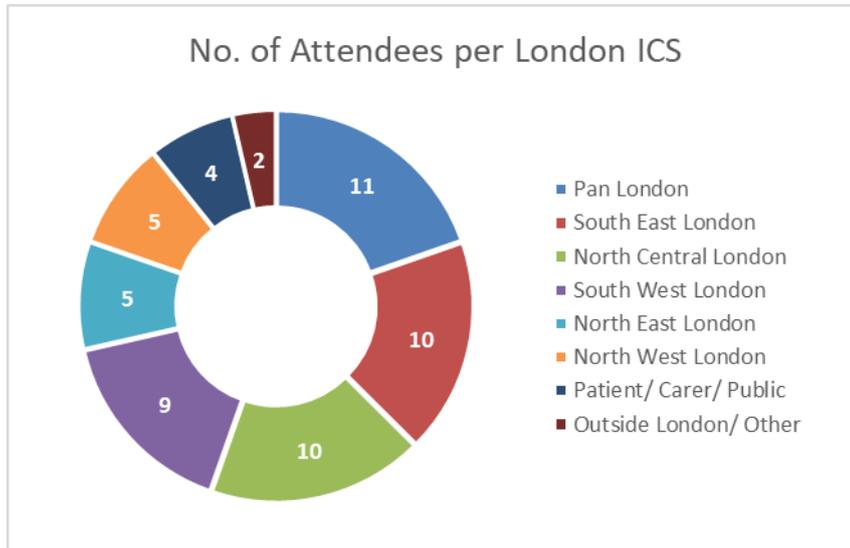


Chart 1: Number of attendees per London ICS footprints

3. Event Programme

The purpose of this workshop was to bring together subject matter experts across the cancer pathway to scope out opportunities for improvement projects to enable primary and community staff to access training and education to better support people with learning disabilities; to improve outcomes and experiences.

Attendees were invited to explore the following and recommend suggested next steps for London:

- To better understand the experiences of people with learning disabilities on a cancer pathway in primary care.
- To learn about best practice to improve support and experience of diagnosing cancer early and living well beyond cancer for people with learning disabilities in primary care and community services.
- To identify and agree opportunities and next steps for London to improve cancer outcomes for people with learning disabilities and those significant to them, in relation to education and training of health professionals in primary care and community services.

The program included a range of presentations to set the scene of the event as well as a number of facilitated discussions where attendees were allocated to their ICS groups. This was to ensure relevance of conversation, encourage networking and also allow for practical conversations to develop suggested pan London recommendations.

Key themes from the presentations can be found in [Appendix Two](#).

Facilitated Breakout Sessions

Two breakout sessions were held with attendees who were allocated to their ICS groups and asked to consider the following:

1. What experiences have you had of trying to improve cancer outcomes for people with learning disabilities?
2. What are the opportunities and next steps we can agree to improve cancer outcomes for people with learning disabilities across London?

A collation of these conversations can be found in [Appendix One](#).

4. Recommendations and Next Steps

4.1 Recommendations

It is recognised that there is a lot of amazing initiatives taking place across London to support people living with learning disabilities to access cancer services across the whole pathway, and that all London health and care organisations are committed to building on this to improve outcomes for these patients.

It is also recognised that there is a lack of consistency in offers and support available to people with learning disabilities across ICS footprints, which exasperates inequalities for people with learning disabilities living in London. There is also varying levels of training and education offers to HCPs in both primary and secondary care to empower staff to better support people with learning disabilities.

The following recommendations have been made pan London:

Recommendation 1: **With the support of the Transforming Cancer Service Team, a short life Task and Finish Group should be established to scope, develop, and implement a detailed action plan to implement the following four recommendations pan London.**

- This group should have membership from all London ICS footprints and regional project management and communications support from the Transforming Cancer Services Team.

Recommendation 2: **Perform an exercise to map current training and education regarding learning disabilities available to primary care and community HCPs in London and use this to identify gaps and inform a strategic approach to upskilling primary care and community staff.**

- Use mapping to develop a plan to encourage higher attendance to said training and education opportunities.
- Identify training and education gaps and explore how these areas of needs can be addressed.

Recommendation 3: **London region to ensure that resources available to support staff to support people with learning disabilities to access cancer services can be consistently shared pan London.**

- Develop a 'central repository' to host all London resources available to promote 'best practice', enabling ease of access for all London organisations, and reduce duplication.
- Develop a process that supports organisations to consistently share and promote new resources developed pan London.

Recommendation 4: **It is vital that experts by experience voices are included in all that we do to ensure people with learning disabilities needs are understood and being consistently considered. Development of a shared pan London 'patient voice toolkit' resource will support us to achieve this.**

- Build on existing, and develop new, patient case studies that can be used in the development of patient facing and training resources.

Recommendation 5: **Recognising that supporting people with learning disabilities to access other healthcare services is a priority area across the board, PCCEG should identify area of potential collaborative working / influencing opportunities to reduce duplication and ensure that primary care and community training needs in relation to people with learning disabilities are being considered in others planning.**

- Explore with ICS Leads, cancer screening programmes, and secondary care sector areas of opportunities for collaborative working.
- Develop an influencing strategy to maximise the opportunities to influence National Cancer & Screening Programmes to consider the needs of people with learning disabilities and embed best practice.

4.2 Next Steps

Pan London recommendations made via this workshop will be shared with members of the Primary Care and Community Education Group for consideration, with the aim to confirm next steps at the next PCCEG meeting on the 12th July 2022.

Workshop attendees have kindly offered their time to support with taking this work forward via a short life task and finish group. Responsibility of the group will be to develop an action plan, determining what sits within the remit of the PCCEG and highlighting areas of need that may need to be actioned elsewhere.

Appendix One: Collation of facilitated breakout sessions per ICS footprint

Breakout Session One: **What experiences have you had of trying to improve cancer outcomes for people with learning disabilities?**

Collation of responses during breakout session one	
ICS	
North & South West London	<ul style="list-style-type: none"> NHS South West London CCG reported that there is a need to focus on improving health checks for people with learning disabilities and that SWL are working with primary care and getting GP champions for this. SWL are running a project proactively reaching out to residential homes with a toolkit that checks whether patients have hospital passport, if they've had health checks and sign post to screening if they haven't been in last cycle. Imperial College Healthcare learning disabilities team noted that it is difficult when services are getting patients so late, and staff have little time to make it person centred. Teams are trying to plan ahead and get loads of easy read material (lots available from Macmillan) but there's too much to cover. It was noted that this has also been a challenge in cancer services in Chelsea and Westminster Hospital. With a lot of services under pressure following Covid and workforce issues. As a result, it is very difficult for secondary care services to try to offer something more person centred, which very much mirroring what we have heard from other hospitals. Really interesting projects to help improve the experience for people with learning disabilities. In SWL, a project to help improve the uptake of health checks. Managed to increase numbers by working with their local primary care and putting in place local GP champions. Very useful link (Macmillan-cancer-learning-disability-Project-Report-2017-19.pdf) to Macmillan easy read, but also stated that some of the material is still too long.
North Central London	<ul style="list-style-type: none"> One member of the group shared their personal experience of cancer: their son was on chemo drugs, which affected their learning and they struggled to access resources. This person worked in Learning Disabilities and therefore know how to access resources but for those not working in this field it would be difficult for them to know where to go. Barnet Mencap noted the low screening uptake rates in Barnet for people with learning disabilities. To address this Barnet Mencap made a film focusing on the main cancer screening programmes, which was delivered to providers in Barnet and NCL. Service providers should have a key role in these projects, it's about raising awareness with carers and workers: https://www.barnetmencap.org.uk/cancerscreeningpack/ Macmillan 'Be Cancer aware' co-produce awareness training and deliver these in the community. This training includes the three cancer screening programmes and are currently being piloted (to end in July). The team will evaluate the pilot and then collate and share resources on website: https://neclnetwork.co.uk/work-programmes/health-inequalities/cancer/be-cancer-aware/ Macmillan are also working to identify how H&SC carers have an impact on people understanding screening invitations. Have a resource pack which includes a checklist that families and carers can use but this is currently out of date because it includes bowel scope screening. Members of the group also discussed providing nurse training, offering learning disabilities awareness training to GP practice staff and the kind of help and support that should be offered e.g., double appointments. There could be an opportunity to focus the role of the GP liaison nurse.

North East London	<ul style="list-style-type: none"> • Members discussed examples of projects, which included ones to improve uptake of screening via education and training for cervical and will move onto bowel. • One member talked about ‘One step at a time’ lived experience of cancer group-planning to address learning disabilities. • Members discussed that the creation of one place to tap into for learning disabilities resources and resources about learning disabilities and cancer would be helpful as it is hard to find the relevant materials and to know what is out there. • Members added that it would be helpful to have case study examples of what’s worked (projects) with a central place to access resources. Research that looks at the success of various campaigns and data on local people with learning disabilities should be included on this central resource. • ELFT, NEL, are holding clinics in Hackney for people with Learning disabilities and Mental Health problems. These are reviewed and include health promotion, integrating health messages into her work.
South East London	<ul style="list-style-type: none"> • SELCA highlighted the importance of providing training to increase confidence in those staff delivering Health Checks. SEL received funding and developed a webinar about how to do a good health check. This was promoted via CEPN, incentivising e-attendance with Amazon voucher. When advertising any training, trainers need to highlight which training offered CPD points to support nurse revalidation and encourage uptake. • Members discussed the need to increase numbers of people with learning disabilities being registered with primary care and increase uptake and improve quality of health check across the region. However, even if registered, people with learning disabilities are often not eligible for support such as access to a learning disabilities team. • Group suggested workforce needs in primary care are poorly understood and the main barrier to delivery was lack of information about resource requirements needed in primary care. It was suggested what it would really help practices/PCNs/ICSs would be a site where workforce modelling information could be sourced e.g., 80 people with learning disabilities on registration list will take x minutes to undertake checks = x hours of care coordinator. • Members also discussed the national reasonable adjustment flag due to go live in 2 years. Kingston hospitals are piloting this and the national team are looking for a local out of hospital service to pilot it. There needs to be an interim solution ahead of the reasonable adjustment going live.

Breakout Session Two: What are the opportunities and next steps we can agree to improve cancer outcomes for people with learning disabilities across London?

Collation of responses during breakout session one	
ICS	
North & South West London	<ul style="list-style-type: none"> • Group emphasised the need to recognise that people with learning disabilities are all different, and the need to follow up after appointments so that people aren’t lost. It was noted that if patients are in residential care homes, they need more support as some are homes are really poor on support for appointments etc. • Annual health checks need to be more robust, and people need to be held to account e.g., GPs. • Screening and health promotion needs to be more accessible, and teams need to help familiarise patients with learning disabilities with environment before the appointment or do screening in the community. • Enfield Learning disabilities service are delivering training around mental capacity and offering support in decision making. This team were approached by North London hospice who are offering free education around end of life/ early diagnosis and identify when people require support with decision making. There is hope to accredit and spread the course further. • Upskilling all staff involved in learning disability care is important to help spot symptoms earlier. This was really highlighted during today’s patient story example of a missed cancer.

	<ul style="list-style-type: none"> Members agreed there were strong themes of staff education (e.g., healthcare professionals) and having better access to easy read resources for both staff and patients.
North Central London	<ul style="list-style-type: none"> Members discussed primary care annual learning disabilities health checks and concerns about this being a tick box exercise. There is a need for better communicated reasonable adjustments in primary care and fostering a good working relationship with GP and district nursing. This needs good partnership working, MDT approach and good care planning. There needs to be better support when sending patients with learning disability for diagnostics (e.g., mammogram, take bloods etc) and these need to consider other factors like needle phobia. Would be good to be able to contact team ahead of appointment to discuss any reason for hesitation. Members discussed where there might be up to date data on screening rates for local and national and see how this compares historically and perhaps better map inequalities barriers.
North East London	<ul style="list-style-type: none"> Members discussed the importance of having systems in place to share knowledge about whether someone has a learning disability, support them better and prepare people across cancer pathway. It was noted that people slip through the net at the moment, especially those with milder learning disabilities who may not be flagged to learning disabilities teams. Only 20% of people with learning disabilities are known to services. Members discussed how to tap into what is already going on in relation to learning disabilities and cancer and avoid reinventing the wheel. And identified a need for a central hub-asset mapping/service mapping/resources all available in one place. Members agreed that there is more work to be done to understand and embed what 'reasonable adjustments' are needed to improve cancer experience and outcomes. It was unclear if there is already data available on this and a suggestion to work with NHS digital to think how services can improve and flag up learning disabilities on the system.
South East London	<ul style="list-style-type: none"> Members discussed poor IT interoperability between screening and people with learning disabilities and discussed those who may have a learning disability but are currently not known to services. IT systems will be replaced in time, but screening providers need to be engaged and an interim solution ahead of this would be useful e.g., encourage HCPs undertaking the health checks and share patient information with third party. One of the national breast screening recovery programme priorities is supporting clients with learning disabilities to better access screening. This is an opportunity to influence that should be seized upon. Other members of the group stated that national screening teams have not been helpful with learning disabilities to date e.g., requests to start bowel screening programme earlier for people with LD have not been taken up nor have suggestion to improve the invitation letter to people with learning disabilities. There is one year funding being held with Oxleas NHS Trust for a project manager to scope initiatives already in place, identify barriers and opportunities to improve screening outcomes for people with learning disabilities. A meeting due to take place with IPLATO about bowel and breast text reminders for people with learning disabilities in particular. Members discussed a need to improve awareness of signs and symptoms of cancer and cancer screening programmes to people with learning disabilities, their carers and families. There was a suggestion to identify short and long-term priorities i.e., short-term priorities that do not need resources and funding and will therefore be easier and quicker to get off the ground and/or sharing resources already in place. SEL are piloting a training workshop using actors with learning disabilities and case studies, which aims to educate HCP about how to break bad news in secondary care. Members also discussed the need for data improvement e.g., LEDER identified a person with learning disabilities who died with pneumonia but does not necessarily highlight other conditions such as cancer that could have contributed. There is an opportunity in LEDER for ICSs to identify what types of cancers are being reported, trends for the region and if screening was/wasn't undertaken.

Appendix Two: Key themes from presentations

Session	Key themes
<p>Patient/Carer Experience <i>Jacqui Shepherd</i> <i>Aurora-Nexus</i></p>	<p>A patient's story was shared with attendees, with permission granted from the patient's parents.</p> <p>A person with learning difficulties who had input from many professionals and was supported by family to access health services. The patient never appeared to be sick prior to diagnosis and well informed about a range of health issues. The patient took ill during a volunteering event and went to hospital and was immediately admitted, and a cancer diagnosed. Sadly, the patient died a short period following diagnosis.</p> <p>Lessons Learned by Aurora-Nexus:</p> <ul style="list-style-type: none"> • Commissioned supported living services have a service level agreement which includes supporting people to manage their health. Providing an outreach service to someone living at home doesn't generally include supporting with health issues. • As part of the support package offered, we need to ask the family if the person is flagged on their GP system as having a learning difficulty and would then be eligible for the Learning Disabilities Health Check. • Often the focus for individuals who challenge services is on behaviour and often health is not considered. • Important to consider peoples lifestyle and how this can impact on related illnesses. • Very important to remember people's personal stories.
<p>Primary Care Learning Disability Knowledge Nursing Survey – Devon <i>Joyce Pickering</i> <i>General Practice Nurse</i> <i>National RCN General Practice Nurse</i> <i>Forum Chair</i></p>	<ul style="list-style-type: none"> • This project is UK wide covering four countries (England, Wales, Scotland, NI) with a focus on Devon. • A real feeling amongst the committee was that they could be doing a bit better in general practice. Joined forces with the Learning Disability Royal College of Nursing Committee. • Sent out a short questionnaire to GPNs and forum members across the RCN asking what the key issues were and what types of resources they would need to support patients with learning disabilities. • Using the results of the survey, RCN has created a 'RCN Clinical Pages'. The resource is interactive, with lots of different topics. The pages will equip nurses to deliver a 'GOOD' annual health check. • The RCN resource page can be found here.
<p>Learning from good practice: South East London, Community of Practice <i>Dr Ester Appleby</i> <i>GP, St John's Medical Centre</i></p>	<ul style="list-style-type: none"> • Working with Communities of Practice (COPs) who are self-organising and self-governing group of people who share a passion for improvement and strive to be better practitioners. • SELCA commissioned the HIN to develop CoP to support improvements in Early Diagnosis and Screening across the South East London Primary Care Network. Four meetings have been held to date. • Three priority areas developed, communication, improving cancer pathways, with a further group whose priority was strengthening supporting people with Learning Disabilities and their carers to advocate for themselves. • Communication group has had two further meetings. Applying for a grant and looking to run a pilot called 'Red Bag Scheme' which has been run in Wakefield. Looking at providing health information, particularly about bowel care and healthy eating. • Challenges identified with people with learning disabilities that do not attend their annual health checks due to difficulties with communication.

	<ul style="list-style-type: none"> • Issues with health checks. Difficult to add ‘Reasonable Adjustments’ to local care record. • Challenges faced with screening programmes not having visibility to local care records in some cases, e.g., breast screening. Until people with learning disabilities attend with their carers or contact them, they don’t have any awareness that patients have additional needs. • Bowel screening hub don’t know when they send kits out if patients have learning disabilities. • Challenges faced with cervical screening. Intrusive testing can be very distressing for patients. Difficult to explain the value of the assessment to someone that does have learning disabilities. Some alternatives available such as high-risk HPV testing that could be provided which is currently being evaluated by PHE. • LeDeR reviews tell us that people with a learning disability who have cancer can be diagnosed late; diagnostic overshadowing is sometimes an issue; access to investigations can be poor due to lack of reasonable adjustments and assumptions about ability or willingness to tolerate tests. Improving access to screening for people with a learning disability is a vital learning from local LeDeR reviews. • Many different barriers to help improve uptake. A lot are system issues and until we get TCST and the SELCA on board we can’t address some of these issues. Not just organisation issues but there is an educational element to it as well, which is a huge problem in primary care.
<p>People with Learning Disabilities: Background and context <i>Maggie O’Donnell</i> <i>Learning Disability Nursing & Health Improvement Lead, NHSE/I</i></p>	<ul style="list-style-type: none"> • Learning Disability as detailed by the White Paper, Learning Disability for the 21st Century: <ul style="list-style-type: none"> - Reduced ability to understand new/complex information or learn new skills (IQ less than 70). Important to note that an IQ is now always used as not everybody with a learning disability would have a cognitive assessment or IQ score - Reduced ability to cope independently - Onset before 18 with lasting effects on development • Because of these difficulties with learning, the person may have difficulties with several social tasks, for example communication, self-care, awareness of health and safety. • These impairments are present from childhood, not acquired as a result of accident or following the onset of adult illness. • The experience and presentation of someone with a learning disability will vary from individual to individual. • Only around 20% of the estimated learning disability population are known to services and those with more severe learning disabilities are more likely to be known. • In London just under 40,000 people who are on their GP learning register for their annual health check. Numbers low in comparison to the rest of the region. Reasons for this may include transient population, lack of learning disability services in London, patients are placed out of the area. • Community Learning Disability Teams varies across London and may comprise of integrated teams within health and social care working together or there maybe standalone teams who have very close working relationships with adult social care and mental health teams.
<p>LeDeR cancer learning <i>Jane Kachika</i> <i>Regional Lead for LeDeR, NHSE/I</i></p>	<ul style="list-style-type: none"> • A programme that reviews deaths among people with a learning disability – 4 years and older (now includes deaths from adults who had a clinical diagnosis of Autism but no learning disability at the time of their death). • Originated from the Confidential inquiry into Premature Deaths of people with a learning disability (CIPLOD), a report by University of Bristol, 2013).

- CIPOLD Findings – shorter life expectancy and a greater risk of early death than the general population of England and Wales. Many of these deaths were avoidable.
- LeDeR was established in 2015 as the first national programme in the world to look at premature mortality among people with a learning disability. It has now become part of the Long-Term plan for NHSE/I. LeDeR remains a service improvement programme and becomes part of the quality and service improvement frameworks with the ICS and no longer to be stand alone.
- Greater responsibility and accountability are now placed on ICSs to deliver the objectives of the LeDeR Programme and holding local systems accountable for actions coming out of the reviews.
- The policy outlines a number of changes to the existing LeDeR Processes including:
 - A new review process and a new web-based platform was implemented in June 2021
 - All deaths of Autistic adults are now being reviewed
 - All people from Black Asian and minority ethnic communities get a focussed review
- By 1 April 2022 all changes in the policy must be implemented by integrated care systems. The policy can be found at www.england.nhs.uk/learning-disabilities/improving-health/mortality-review
- Contracted ended 31 May 2021, five years since the starts of the LeDeR programme.
- Final report looks back to the most recent three years: (2018, 2019 and 2020).
- 2020 different due to pandemic, therefore, caution when drawing comparisons.
- Total deaths 9110 (622 children; 8488 adults) January 2018 – December 2020.
- Average monthly deaths 200-200 with increased deaths during winter: increased deaths at peak of pandemic March – May 2020.
- By 31 December 2020, 93% deaths reviewed, most receiving initial reviews; multi-agency reviews reduced (4% in 2018, 3% in 2019 and 2% in 2020).
- There are early indicators of improvements in the care of people, but this was not felt across all aspects of service provision or groups of people with a learning disability.
- Of particular concern are the significant inequalities in the experiences of people from minority ethnic groups.
- There is an encouraging overall picture in reduction in the proportion of preventable, treatable and overall avoidable medical causes of death.
- People with a learning disability are still however more than three times likely to die from avoidable medial causes with the majority due to treatable medical causes.
- Regionally the proportion of overall avoidable deaths among adults was greatest in London and North West regions, also proportion of treatable medical causes was greatest in London region.
- Some problematic aspects of care:
 - The most frequently reported problems with organisational systems and processes were the coordination of a person’s care
 - Deviation from recognised care pathways or organisational policy
 - The investigation and diagnosis of signs and symptoms
 - Referral to specialist care
 - Delays in instigating a treatment plan

Learning from good practice: Northern Cancer Alliance, Early Diagnosis and Primary Care Pathways

Julie Tucker

Macmillan Project Manager, NHSE/I

- the Northern Cancer Alliance are working with the North East and Cumbrian Learning Disability Network. It is recognised that it is lucky to have a learning disability network in the North East. The only one in the country that sits alongside other clinical networks in NHS England.
- Working collaboratively with partners and health and care experts to co-produce resources and ensure that resources are accessible to all.
- Working with various sub-groups which include Cancer Networks, Community Disability Liaison Nurses and the Clinical Leads Network. Meetings are held regularly with local authority learning disability leads and feed into the community and voluntary sectors.
- Priorities in work programme come from three different formats including GP data dashboards, LeDeR information, massively important data, Expert by Experience group who work alongside the LeDeR steering group who set priorities.
- Setting priorities from personal experience and supporting teams with challenges faced, sharing learning across the region. Testing things locally but sharing them regionally.
- Developed an [educational resource pack](#), 'Margaret's Story', to support people working within primary and secondary care, social care and third sector organisations who support individuals with a learning disability on a specific disease pathways.
- The film and resource pack aim to provide education and increase awareness, allowing people to think about their individual roles within health or social care and how and when they offer support to individuals.
- Launched Margaret's story in early 2020 and a 'train the trainer' programme. Unfortunately, this programme launched in the March 2020, managed to train 50 trainers in the first week of March and then paused during the first Covid lockdown. Managed to provide some training during the summer of 2020 via MS Teams. Looking to relaunch Margaret's story to support those trainers who we trained. Margaret's story is equally important for secondary and primary care, community and voluntary sector so it has a level of learning across all sectors.
- A number of other care resources have been developed including EASY READ guides and a pathway and standard operating procedure to support people with a learning disability get support to make choices and access TLHC, utilises community learning disability teams.

Appendix Three: Workshop Evaluation

Headline summary of delegate feedback

A total of 11 delegates completed evaluation forms after the workshop. Questions were focused on the content, speakers and presentations, and structure of the day (e.g., adequate time for discussion and networking).

100% of respondents thought the content of the event, quality of the speakers and the venue was either “excellent” or “good”

Attendees were invited to share what part of the event they found most useful.

The part of the workshop that was considered most useful by the majority was having the space and time together as a group to share examples of good practice and exploring how we can work collaboratively to better support the needs of people with learning disabilities. There was also recognition of the contributions made by the experts by experience in attendance.

“Speakers information shared”

“The NHS professional input”

“discussion / information about the Ledar”

“My interest was hearing what hopefully may change and there is lot of goodwill.”

“I was unaware of the issues for people with mild/moderate learning disabilities. This is a group that is easy to overlook, as they are often ineligible for support by local specialist learning disabilities teams. This puts more responsibility of the voluntary and community sector, who are more likely to support this group of people. It would be good to look at how their staff/volunteers can be helped to work effectively with health professionals.”

“How important it is to see how hard it is for people with learning disabilities to seek out help and to determine symptoms. How they can so easily be overlooked”

“Hearing about the patient journey as narrated by the relative. This gave a clear overview of how there still a need for training on diagnostic overshadowing”

“Allowing to talk about our own personal lived experience being a patient”

Attendees were invited to share what ideas they have about the next steps and action needed following the workshop.

Some respondents shared details of specific actions they were planning to implement locally:

“To raise awareness of lynch syndrome”

“The models in Cumbria were very interesting and I will be considering how to utilise some of the lessons from their experience in our local work”

“Supervision for LD professionals”

“To advocate for more cancer screening for people with learning disabilities”

“Should be based on the recommendations: Health checks – to include screening, Training for Staff, Info for Users and carers in easy-to-read format, User and carer education, Alternatives to invasive procedures i.e., blood tests as a diagnostic, endoscopy capsule”

Some respondents expressed a desire to continue the conversation and participate in the development of a collaborative plan:

*“A follow up meeting in a few weeks’ time to know what can be changed/improved and is anything really done about it.
There is and will always be the staffing problems”*

*“Now we have done the broad introduction we should develop further in-depth discussions focused on action and timeliness.
Sessions could examine what could be done by all to address issues that require no funding or resources, secondly a
discussion on med – long term solutions that would require commitment from funders etc.”*

“Continue to discuss and look at how we can get better at presenting the health needs of people we support”

*“How to work closely with GP in regards to enhancing the annual health checks. Sharing of pathways and good practice
across NCL and wider groups”*

Attendees were invited to share what they will do differently following the workshop.

Respondents indicated that they will be more proactive in advocating for people with learning disabilities needs, and shared details of actions they will take to achieve this:

“I will be using opportunities to ask about delays and the coordination of care for cancer patients with learning disabilities.”

“Will raise awareness to GP’s about the need for cancer screening for their patients who have learning disabilities”

*“I have already set up a NWL discussion in my borough challenging them on what actions we have in place following the
LeDeR recommendations. I have shared the workshop material and engaging the Assistant Director in the ICS on the matter
as well as engaging my local PCN.”*

“To make sure that the annual learning disabilities check for our people are no longer tick box.”

*“look at changing assessment questions to pick up if people receiving outreach services have an health action plan and if not
flag this up.”*

“To make sure I act as an advocate for any patients with learning disabilities to ensure they are heard”

Appendix Four: Workshop Agenda



Healthy London Partnership

People with Learning Disabilities and the London Cancer Pathway Workshop

With the Transforming Cancer Services Team (TCST): Primary and Community Care Education Group (PCCEG)

Date & Time: 3rd May 2022 (09:00 – 12:10)

Venue: Video conferencing via MS Teams

Meeting Objective:

To bring together experts across the cancer pathway to scope out opportunities for improvement projects to better support people with learning disabilities; to improve outcomes and experiences.

	ITEM	TIME	LEAD
1.	Objectives and scope of the meeting	09:00	Philippa Hyman and Julia Ozdilli, PCCEG chairs, TCST
2.	Patient/Carer experience	09:05	Jacqui Shepherd
3.	Primary Care Learning Disability knowledge nursing survey Devon	09:30	Joyce Pickering, General Practice Nurse, National RCN General Practice Nurse Forum Chair
4.	Learning from good practice: South East London, Community of Practice	09:45	Ester Appleby, GP, St John's Medical Centre
5.	People with Learning Disabilities: Background and context	10:00	Maggie O'Donnell, Learning Disability Nursing & Health Improvement Lead, NHSE/I
6.	Breakout: What experiences have you had of trying to improve cancer outcomes for people with learning disabilities? Rooms: 1 – North Central London 2 – North East London 3 – North and South West London 4 – South East London	10:15	
7.	Coffee break	10:45	
8.	LeDeR cancer learning	10:55	Jane Kachika, Regional Lead for LeDeR, NHSE/I
9.	Learning from good practice: Northern Cancer Alliance, Early Diagnosis and Primary Care Pathways	11:10	Julie Tucker, Macmillan Project Manager, NHSE/I

10.	Breakout: What are the opportunities and next steps we can agree to improve cancer outcomes for people with learning disabilities across London?	11:25	
11.	Next steps	11:55	Philippa Hyman and Julia Ozdilli, PCCEG chairs, TCST
12.	Close	12:10	