Learning Disabilities Physical Health Strategy 2022-2024

Stage One Spring 2022

Overview

This Learning Disability Physical Healthcare strategy has been developed to support delivery of Oxford Health NHS Foundation Trust's objective, to provide **"Outstanding care delivered by an outstanding team"** This policy also reflects our values of **"Caring, safe and excellent"** It aligns with our mission "*to help people of all ages live their lives to their full potential by supporting them to keep mentally and physically well'*.

This policy has been developed in close partnership by Oxford Health Foundation Trust (OHFT) working with: Oxford University Hospital Trust (OUH), Oxfordshire County Council (OCC), Oxfordshire Family Support Network (OFSN), Oxfordshire Association of Care Providers (OACP) and NHS Oxfordshire Clinical Commissioning Group (CCG).

Background

This strategy recognises that to provide great care and achieve great outcomes the physical health of our service users and their carers must be well supported. This needs to start from birth and be continued through to end of life, regardless of diagnosis. The physical health of people with a Learning Disability (LD) is known to be significantly worse than that of the general population; these individuals on average die 15-20 years prematurely. The vast majority of these premature deaths are not due to genetic factors related to their LD, but instead are caused by chronic medical conditions which are prevalent as a result of a number of modifiable risk factors such as, poor healthcare, (often exacerbated by communication issues or the lack of "reasonable adjustments"), poor diet, a sedentary lifestyle and lack of physical activity.

By aiming to effectively address known and modifiable risk factors, we believe the physical health outcomes of service users can be significantly improved. The disparity in life expectancy and physical health outcomes between people with a Learning Disability and the general population has the potential to be considerably reduced.

Aims This strategy identifies a number of overarching objectives:

I. To ensure LD service users living in Oxfordshire are enabled to achieve the best possible physical health status, in addition to us as organisations, providing excellent health and social care and support. We are aware that there is a **lack of recognition by patients, carers and in primary care, of the health conditions more prevalent** in people with a Learning Disability which we need to redress. We need to ensure that families and carers are confident in their knowledge and skills to support service users in achieving their best possible physical health outcomes.

II. To **achieve a year-on-year improvement** across a range of physical indicators for our service users (e.g., Uptake of Annual Health Checks and screening programmes and improvements in findings from our local Learning from lives and deaths (LeDeR) Programme)

III. **Specific objectives**

1) More work is needed to help carers **Identify and managing deteriorating/unwell person.** We would like to promote more the use of "Restore 2" and similar tools
2) Family/paid carers/individual's awareness of **good bowel management** is poor, and we need to do more work in this area to improve understanding.
3) **Respiratory care** – developing a clearer pathway across services that can reduce the number of cases of pneumonia.

IV. Promote timely conversations about **proactive care planning** (life choices) for any individual living with a learning disability. We want to ensure that as a person ages, their expressed wishes about their care and treatment are respected. To also, reduce the number of people with LD dying in hospital to be more in line with the general population.

V. **Screening & Vaccinations Uptake**: to work with other healthcare agencies to improving flu/covid/ vaccination uptake rates and to develop better "reasonable adjustment "in this area**.**

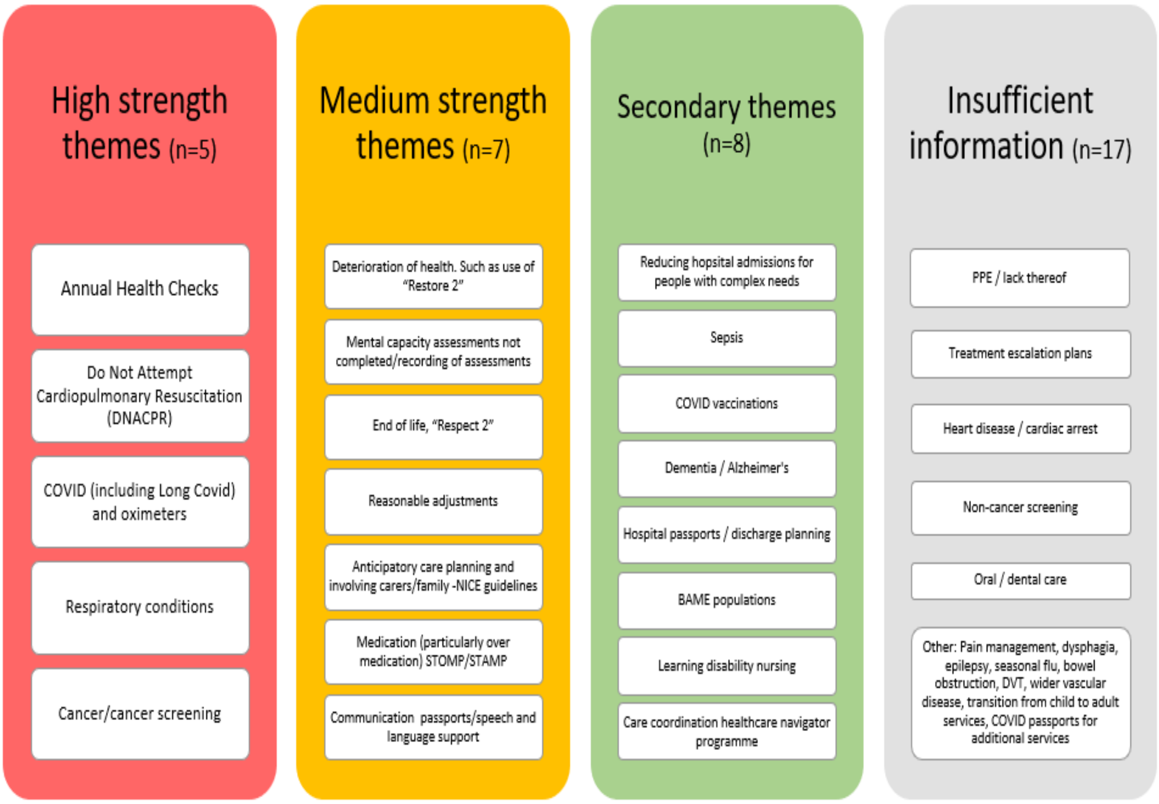
VI. To continue to work in collaboration with partner organisations such as the CCG, Primary care, Acute care and family carers to achieve better physical and mental health outcomes for the local LD population.

The National Context

Findings from the Learning from Deaths of people with a learning disability Review (LeDeR): This initiative has identified that people with a learning disability frequently have poorer physical and mental health than other people and may face barriers to accessing health and care to keep them healthy. Too many people with a learning disability die prematurely, many due to preventable or treatable reasons.

The LeDeR review was established in 2017 as a national service improvement programme to explore why people are dying and what we can do to change services locally and nationally to improve the health of people with a learning disability and reduce health inequalities. By finding out more about why people died we can understand what needs to be changed to make a difference to people's lives.

The most recent published LeDeR review (2020/21) analysed the areas that progress was being made within, but also noted the areas where further emphasis is needed, see diagram below. Our local strategy reflects these priorities.



High strength themes (n=5)

- Annual Health Checks
- Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)
- COVID (including Long Covid) and oximeters
- Respiratory conditions
- Cancer/cancer screening

Medium strength themes (n=7)

- Deterioration of health. Such as use of "Restore 2"
- Mental capacity assessments not completed/recording of assessments
- End of life, "Respect 2"
- Reasonable adjustments
- Anticipatory care planning and involving carers/family -NICE guidelines
- Medication (particularly over medication) STOMP/STAMP
- Communication passports/speech and language support

Secondary themes (n=8)

- Reducing hospital admissions for people with complex needs
- Sepsis
- COVID vaccinations
- Dementia / Alzheimer's
- Hospital passports / discharge planning
- BAME populations
- Learning disability nursing
- Care coordination healthcare navigator programme

Insufficient information (n=17)

- PPE / lack thereof
- Treatment escalation plans
- Heart disease / cardiac arrest
- Non-cancer screening
- Oral / dental care
- Other: Pain management, dysphagia, epilepsy, seasonal flu, bowel obstruction, DVT, wider vascular disease, transition from child to adult services, COVID passports for additional services

Local Context

- From January 2017 to December 2021 there has been little variance in the number of deaths over time. There has been a small increase from Oct-Dec 2021 for patients aged 75 and over, similar to the national picture. On average we have around 470 deaths each month, including current and discharged patients, expected and unexpected. Most deaths for patients with an open referral (83%) aged 75 and over. Except for significant peaks in April 2020 (n=946 deaths) and January 2021 (n=732 deaths) which related to deaths as a result of COVID-19.
- Over the last 5 years 51% of deaths were females and in relation to ethnicity – this was recorded for 34% of patients and showed 94% of patients were White British.
- Our trend over time mirrors the national pattern from 2017 to 2021 including the peaks in April and January. In the Trust the peak in April 2020 was followed by a lower-than-average number of deaths between June to Sept 2020.
- Since March 2020 there seems to have been a small increase in the number of deaths for patients aged 19-64. Although the number has dropped in Nov and Dec 2021. In 2021 there were 636 deaths of patients aged 19-64. Most of the deaths related to people aged 51-60 (44%), with an open referral to a physical healthcare service i.e., District Nursing. Most are expected deaths, 94 were reported as unexpected, 9 as COVID related and 38 identified as suspected suicides (10 confirmed at inquest to date). 29 deaths identified as PSIs (previously known as SIs).
- In 2021 there were 34 deaths for patients aged under 18 (compared to 28 in 2020), 27 with open physical health referral (i.e., health visiting), 3 with open mental health referrals and 4

discharged at time of death. 18/34 deaths were unexpected, and the Coroner has confirmed 2 were suicide. All deaths are reviewed through the multi-agency child death overview process (CDOP) led by the safeguarding board and in some cases will also have a serious care review.

- We have had 100 inpatient (John Radcliffe & Horton) deaths in 2021, this includes patients who die within 2 days of an inpatient stay (compared to 97 in 2020):
- Most inpatient deaths occurred in the community hospital wards (90%) for patients aged over 75 and the death is expected.
- The number of acute inpatient deaths in community hospitals is the same as 2020 and declined from 2019 possibly as a result of people having more choice about where they die.
- In 2021 we had 10 COVID-19 related inpatient deaths (compared to 24 in 2020).
- In the last 12 months there were 9 deaths for patients on a mental health ward or within 2 days of a stay: 3 related to COVID-19, 1 expected, 3 unexpected/ natural and 2 unexpected/ unnatural. 5/9 deaths were older adults.
- In 2021 we also had 4 deaths of detained patients while on long term leave.
- In 2021 there have been 63 confirmed/ suspected suicides for known patients, a decline compared to 80 in 2020. 41/64 suicides were by men. In nearly half of the cases the person was not open to services at the time they died, further analysis is underway to understand this and identify any actions to take.
- In relation to total suspected suicides in the Thames Valley area, including people not known to our services, the Police held surveillance data shows from January to September 2021 49 suicides in Oxfordshire and 34 in Buckinghamshire, in the majority of months there has been a decline from the previous year (2020) except for June and July 2021 in Oxfordshire.
- An initial screening should be completed for all known patient deaths by at least 2 senior clinicians which includes speaking to the bereaved family. After this screening the following types of deaths are reported onto Ulysses for further scrutiny; unexpected deaths, suspected suicides, expected deaths where there are any care concerns identified, all learning disability deaths, all mental health inpatient deaths, all COVID inpatient deaths and all deaths of a patient detained. In relation to number of deaths reported onto Ulysses this varies by the type of service and over time– in the previous 12 months 8% (n=405) deaths were reported onto Ulysses for further review.

<u>Our Workstreams:</u>

I. **Health Education:** To ensure our service users are supported to achieve the best possible physical health status, in addition to providing excellent health care and support. We are aware that there is a lack of recognition by patients, carers and primary care, of the health conditions more prevalent in people with a Learning Disability which we need to redress. We need to ensure that families and carers are confident in their knowledge and skills to support service users in achieving their best possible physical health outcomes.

To address this matter, we are working collaboratively with OFSN, the CCG, OCC and OHFT to develop an Online Health and Wellbeing Information and Guidance Repository such that individuals and their carer can access a single site for all their healthcare information needs. The gathering of information is being carried out by a project team led by OFSN and the information resource will be hosted by OHFT

II. **Indicators:** To achieve year on year improvement across a range of physical indicators for our service users (e.g., Uptake of Annual Health Checks and screening programmes and improvements in findings from our local Learning from lives and deaths (LeDeR) Programme)

This data is being gathered by the CCG and the local LeDeR agency.

III. **Focus Areas**

1) **Identify and managing deteriorating/unwell person.** We would like to promote more the use of “Restore 2” and similar tools
2) **Bowel Care**: Family/paid carers/individual’s awareness of good bowel management is poor, and we need to do more work in this area to improve understanding.
3) **Respiratory care** – developing a clearer pathway across services that can reduce the number of cases of pneumonia.

The above areas will be specifically addressed in the work to create an Online Health and Wellbeing Information and Guidance Repository.

In addition, we are creating a Health & Wellbeing Register (HWR) of individuals with a LD who have significant physical health issues and are at risk of acute hospital admission or rapid decline in health status. This will be maintained by the OHFT CLDTs and shared with OCC, OUH and the CCG. This work is being done utilising resources developed by Cheshire and Wirral Partnership NHS Trust. **Individuals on this register will also be enabled to access, as below, Advance Care Planning plus having a Hospital Passport and a Health Action Plan.**

IV. **Promote proactive care planning** (life choices) for any individual living with a learning disability. We want to ensure that as a person ages, their expressed wishes about their care and treatment are respected. To also, reduce the number of people with LD dying in hospital to be more in line with the general population.

This item will also be specifically addressed in the work to create an Online Health and Wellbeing Information and Guidance Repository and as above via the HWR initiative.

V. **Screening & Vaccinations Uptake**: we want to work with other healthcare agencies to improving flu/covid/ vaccination uptake rates and to develop better “reasonable adjustments“ in this area**.**

We are planning to hold a major Screening and Healthcare Event in Oxford at the end of June. We already have funding and various health screening services have agreed

to have stalls and also deliver seminars in an adjacent lecture room from the main exhibition hall.

VI. **Healthy Living:** Promoting healthy lifestyles by offering advice, information and signposting opportunities to engage in physical exercise, outdoor activities, likeminded social groups etc.

This will be an integral element of the above Event plus featuring prominently on the Online Health and Wellbeing Information and Guidance Repository.

VII. **Joint Working**: To continue to work in collaboration with partner organisations such as the CCG, Primary care, Acute care and family carers to achieve better physical and mental health outcomes for the local LD population.

The development of this strategy is a pivotal part of the joint working.

Conclusion

As you will see from the above we have some very specific objectives which we believe will help raise the profile of the issues we are concerned about and provide sufficient energy and information to make a real difference to people lives.

This is stage one of the strategy and will be update in the later part of 2022 to reflect achievements and the further work identified as requiring our next attention.

Simon Jones QN, MA, RNLD

Learning Disability Nurse Consultant 1/4/2022