

# LeDeR

## Learning from lives and deaths – People with a learning disability and autistic people



## Research Digest: August 2022

Welcome to the first of our planned quarterly research digests. With these, we aim to bring you the latest research from across the globe that focuses on premature mortality in people with a learning disability, summarised in an easy digestible format. In this edition we bring you a selection of 10 papers covering a wide range of topics relevant to the needs of people with a learning disability, care providers and NHS commissioners to give an overview of the current research landscape. For each paper we have provided a summary of 1) the population, 2) the setting and 3) the rating of the level of evidence provided, based on the 5 point rating summary [provided here](#), where 1 is the best level of study and 5 an expert review. In future editions, we aim to provide an overview of selected, specific topics relevant to the field to keep our partners up to date with the latest findings. Please feel free to reach out with any questions, feedback on the format of these digests.

We hope you find these summaries useful.

## In this edition

1. Health checks for adults with intellectual disability and association with survival rates: a linked electronic records matched cohort study in Wales.

2. Tackling increased risks in older adults with intellectual disability and epilepsy: Data from a national multicentre cohort study.

3. Stress and social isolation, and its relationship to cardiovascular risk in young adults with intellectual disability.

4. Development and validation of a shortened and practical frailty index for people with intellectual disabilities.

5. The consequences of hyperphagia in people with Prader-Willi Syndrome: A systematic review of studies of morbidity and mortality.

6. The willingness of UK adults with intellectual disabilities to take COVID-19 vaccines.

7. An observational cohort study of numbers and causes of preventable general hospital admissions in people with and without intellectual disabilities in England.

8. An Examination of the Validity of the Health Risk Screening Tool: Predicting Mortality in People With Intellectual Disabilities.

9. Understanding inequalities in COVID-19 outcomes following hospital admission for people with intellectual disability compared to the general population: a matched cohort study in the UK.

10. Medical vulnerability of individuals with Down syndrome to severe COVID-19-data from the Trisomy 21 Research Society and the UK ISARIC4C survey.



@Aliveleder



leder@kcl.ac.uk



<https://www.kcl.ac.uk/research/leder>



## Health checks for adults with intellectual disability and association with survival rates: a linked electronic records matched cohort study in Wales, UK.

Kennedy, N, Kennedy, J, Kerr, M, Dredge, S, Brophy, S  
DOI: [10.1136/bmjopen-2021-049441](https://doi.org/10.1136/bmjopen-2021-049441)  
April 13th 2022

- 1) Sample: GP records of 26954 adults with a learning disability in Wales.
2. Setting: primary care between 2005 and 2017.
3. Level of evidence: 2

This study investigated health checks and found that, if these were started before a chronic condition was diagnosed, then this would correspond with better chance of survival. This was shown to be particularly important to autistic people and down syndrome people, however there was no evidence of an improved survival rate for people who were diagnosed with diabetes or cancer. The authors also found that the people most likely to have a health check were likely to be older, have epilepsy and were less likely to have autism or down's syndrome. This suggests increasing efforts to improve access to health checks for people with down's syndrome or autistic people could be beneficial.



## Tackling increased risks in older adults with intellectual disability and epilepsy: Data from a national multicentre cohort study.

L V Watkins, W Henley, J J Sun , B Perera, H Angus-Leppan, I Sawhney, K Purandare, M Eyeoyibo, M Scheepers, G Lines , R Winterhalder, R Shankar  
DOI: [10.1016/j.seizure.2022.05.022](https://doi.org/10.1016/j.seizure.2022.05.022)  
October 1st, 2022

- 1) Sample: 405 adults over 40 years old compared with 499 adults over 18 years old but under 40 years old.
- 2) Setting: Analysis of a 10-site retrospective cohort study.
- 3) Level of evidence: 3

This study focused on adults over the age of 40 with a learning disability and epilepsy. It found that people with a learning disability who are over the age of 40 years old and who also have epilepsy are more likely to die prematurely, potentially experience harm related to medical treatment and have worse clinical outcomes than those who do not. The authors also note that the overall health profile of people with a learning disability over the age of 40 can be compared to the health profile of someone aged 65 years or over in the general population.



## Stress and social isolation, and its relationship to cardiovascular risk in young adults with intellectual disability.

Zwack, C, McDonald, R, Tursunalieva, A, Vasan, S, Lambert, G, Lambert, E.  
DOI: [10.1080/09638288.2022.2046186](https://doi.org/10.1080/09638288.2022.2046186)  
21st March 2022

- 1) Sample: 35 young adults aged 18-45 with a learning disability and 29 matched controls.
2. Setting: participant questionnaire.
- 3) Level of evidence: 3

Stress is often linked to the development of cardiovascular disease and people with a learning disability are often exposed to many stressful challenges every day. This study showed that adults aged 18-45 reported higher levels of stress when compared to people without a learning disability. Stress was also shown to be strongly associated with increased social isolation. The authors suggested work to help people improve their self-efficacy, support decision making and improve community integration could help reduce social isolation and may decrease perceived stress in young adults.



@Aliveleder



leder@kcl.ac.uk



<https://www.kcl.ac.uk/research/leder>



## Development and validation of a shortened and practical frailty index for people with intellectual disabilities

Schoufour, J, Oppewal, A, van Maurik, M, Higlenkamp, T, Elbers, R, Maes-Festen, D.

DOI: [10.1111/jir.12907](https://doi.org/10.1111/jir.12907)

23rd December 2021

This study investigates a new tool to assess the frailty of people with a learning disability, called the ID-Frailty index Short Form, a shorter version of the ID-Frailty Index. With contrast to the longer form, the authors conclude it to be a promising tool to help assess the frailty of people with a learning disability and adminsterable in a shorter time frame.

- 1) Sample: 982 adults aged 50 or over with a learning disability.
- 2) Setting: general hospital, primary care, own homes etc.
- 3) Level of evidence: 2



## The consequences of hyperphagia in people with Prader-Willi Syndrome: A systematic review of studies of morbidity and mortality.

Bellis, S, Kuhn, I, Adams, S, Mullarkey, L, Holland, A.

DOI: [10.1016/j.ejmg.2021.104379](https://doi.org/10.1016/j.ejmg.2021.104379)

5th November 2021

This review showed that improving life expectancy for people with Prader-Willi Syndrome is related to managing the consequences of excess hunger through improved support. The development of new treatments that help reduce the drive to eat are likely to help decrease obesity and the related health consequences of this, therefore improving quality of life and life expectancy.

- 1) Sample: 500 people with Prader-Willi Syndrome.
- 2) Setting: systematic review.
- 3) Level of evidence: 1



## The willingness of UK adults with intellectual disabilities to take COVID-19 vaccines.

Hatton, C., Bailey, T., Bradshaw, J., Caton, S., Flynn, S., Gillooly, A., Jahoda, A., Maguire, R., Marriott, A., Mulhall, P., Oloidi, E, Taggart, L., Todd, S, Abbott, D., Beyer, S., Gore, N., Heslop, P., Scior, K., Hastings, R.,

DOI: [10.1111/jir.12884](https://doi.org/10.1111/jir.12884)

16th September 2021

This study found that there is a high willingness amongst people with a learning disability to get the Covid-19 vaccine in the UK (87% of people said they were willing to get the vaccine). This could have implications for further policy regarding vaccination regarding prioritising people with a learning disability.

- 1) Sample: 621 adults with a learning disability and 348 family carers or support workers.
- 2) Setting: (online interview or online questionnaire)
- 3) Level of evidence: 4



@Aliveleder



leder@kcl.ac.uk



<https://www.kcl.ac.uk/research/leder>



## An observational cohort study of numbers and causes of preventable general hospital admissions in people with and without intellectual disabilities in England.

Glover, G., Williams, R., Oyinlola, J.

DOI: [10.1111/jir.12722](https://doi.org/10.1111/jir.12722)

5th March 2020

- 1) Sample: Patients admitted to hospital for preventable reasons with a learning disability between April 2010 and March 2014.
- 2) Setting: general hospitals.
- 3) Level of evidence: 1

A large-scale study, covering 5.2% of the population of England, aimed to determine the rate and duration of admissions to Accident and Emergency departments for conditions where effective community care and case management would have prevented the need for a hospital admission. The study used the Clinical Practice Research Datalink GOLD primary care database and the linked Hospital Episode Statistics Admitted Patient Care dataset.

People with a learning disability were found to be almost 5 times more likely to attend hospital for conditions which should not lead to hospital admissions. Additionally, hospital admissions were almost 5.4 times longer for people with a learning disability compared to those without a learning disability. For people with a learning disability, one in six hospital admissions and one in four days in hospital were caused by conditions which could have been managed in the community. Each of these rates were higher than those observed in people without a learning disability.

The authors concluded that efforts should be made to improve support for people with a learning disability in the community. This could involve improving health literacy, basic self-care and the accessibility of primary care. Particular attention should also be paid to a few conditions which are specifically associated with premature death in people with a learning disability. Finally, local monitoring of preventable hospital admissions could be used to indicate the effectiveness of local primary health services in providing support to people with a learning disability.



## An Examination of the Validity of the Health Risk Screening Tool: Predicting Mortality in People With Intellectual Disabilities.

Roszkowski, M., Thomas, M., Conroy, J., Ivy, C., Gravitt, G.

DOI: [10.1891/JNM-D-18-00041](https://doi.org/10.1891/JNM-D-18-00041)

22nd January 2020

- 1) Sample: 12582 people with a learning disability living in Georgia, USA.
- 2) Setting: general hospitals.
- 3) Level of evidence: 2

The Health Risk Screening Tool (HRST) is a 22-item instrument specifically designed to assess the health risk of persons with developmental disabilities. The predictive validity of the HRST was investigated in a sample of 12,582 people with an intellectual or developmental disability living in Georgia (U.S.).

Using a six-level health risk classification to predict mortality was supported, even after accounting for other factors which may have explained the results such as gender, ethnicity and race.

The Health Risk Screening Tool could be used to predict mortality in the England, once tested. Therefore, it could serve as a basis for establishing healthcare needs and determining nursing care acuity for people with a intellectual or developmental disability.



@Aliveleder



leder@kcl.ac.uk



<https://www.kcl.ac.uk/research/leder>



## Understanding inequalities in COVID-19 outcomes following hospital admission for people with intellectual disability compared to the general population: a matched cohort study in the UK.

Baksh, R., Pape, S., SMith, J., Strydom, A.

DOI: [10.1136/bmjopen-2021-052482](https://doi.org/10.1136/bmjopen-2021-052482)

4th October 2021

- 1) Sample: 506 patients matched to controls with a learning disability.
- 2) Setting: general hospitals.
- 3) Level of evidence: 2

This study examines the differences between people with a learning disability and the general population in the first wave of the Covid-19 pandemic and hospitalisation. The authors found there were significant disparities in healthcare between people with a learning disability and the general population, and that this may have contributed to the excess mortality of these people. People with a learning disability were admitted with higher respiratory rates and were more likely to require oxygen therapy however they were 37% less likely to receive non-invasive respiratory support, 40% less likely to receive intubation and 50% less likely to be admitted to the Intensive Care Unit while in hospital. They also had a 56% higher chance of dying from Covid-19 after they were hospitalised and were dying 1.44 times faster than people without a learning disability. .



## Medical vulnerability of individuals with Down syndrome to severe COVID-19-data from the Trisomy 21 Research Society and the UK ISARIC4C survey.

Hüls et al.

PMCID: [PMC7897934](https://pubmed.ncbi.nlm.nih.gov/348797934/)

22nd February 2021

- 1) Sample: 1046 patients with Down syndrome matched to general population controls.
- 2) Setting: general hospitals.
- 3) Level of evidence: 3

An online survey was completed by 1,046 clinicians or caregivers between April and October 2020 to collect information about patients with COVID-19 and Down Syndrome. Responses were compared to the UK ISARIC4C survey of hospitalised COVID-19 patients, a large scale survey administered to people with and without Down Syndrome in over 200 hospitals in England and Wales. Their analyses indicated that while the leading signs and symptoms related to COVID-19 are similar to those in the general population, patients with DS who are hospitalized with COVID-19 were more likely to experience a severe course of disease with higher rates of medical complications and mortality than the general population, particularly adults older than 40 years of age. They observed an increased mortality rate from age 40, at much earlier age than in the general population. This emphasizes the need to protect older individuals with Down Syndrome from COVID-19 infections. They also found that congenital heart defects were associated with more severe infections.

Special caution should be applied to people with Down Syndrome who are older than 40 when aiming to prevent infection by sheltering/shielding people. Prioritising individuals with Down Syndrome for COVID-19 immunisations as well as for flu and pneumococcal vaccination are also important in reducing the risk of more severe outcomes following COVID-19 infection.



@Aliveleder



leder@kcl.ac.uk



<https://www.kcl.ac.uk/research/leder>