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CONSTIPATION

Premature death, the side effects of medications, and the use of laxatives, for people with a learning disability in England.

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A 2022 Deep Dive report

Learning from Lives and Deaths - People with a learning disability and autistic people (LeDeR) report for 2022 (LeDeR 2022).

Autism and learning disability partnership.

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Key Points

- A large portion of the LeDeR sample were at risk of developing constipation as a result of their prescribed medications.

- Laxatives prescriptions were very common, with 40% of the people with a learning disability included in this sample being prescribed at least one laxative.

- Over 50% of people with a learning disability included in this sample were taking two or more medications commonly or very commonly associated with constipation as a side-effect.

- Constipation did not appear on any of the death certificates for the people included in this sample either as a contributory factor or more proximal cause of death.

- Of those recorded as having constipation, 6 (13.0%) died of bowel obstruction or perforation. In comparison, none of the people without constipation died of bowel perforation or obstruction, suggesting that these avoidable complications may be associated with constipation.

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- Low numbers of people were recorded to have an understanding of what constitutes normal bowel function or have received appropriate education on normal bowel habits.

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Abbreviations

BMI - Body Mass Index
BNF - British National Formulary
LeDeR - Learning from Lives and Deaths - People with a Learning Disability and autistic people
MCCD - Medical certificate of cause of death
NHS - National Health Service
STAMP - Supporting Treatment and Appropriate Medication in Paediatrics
STOMP - Stopping over Medication of People with a Learning Disability, Autism or both with psychotropic medicines
KCL - King's College London
UCLan - University of Central Lancashire

Abstract

This report explored constipation in people with a learning disability using a sample of 97 people who died in 2021 and had focused review from the LeDeR programme. We reported the risk of constipation based on the side effects of medications, the prevalence of constipation and the frequency of laxative and antipsychotic prescriptions, along with the demographics and causes of death of people with constipation. Our findings support previous research suggesting constipation is a significant issue for people with a learning disability. Over 50% of the sample obtained a risk score based on their prescribed medications equivalent to taking two or more medications commonly or very commonly associated with constipation as a side effect. Rates of laxative prescription were high, with 40% of the sample being on at least one prescription laxative. Constipation did not appear on any part of the death certificate of any of the people who died in the sample, but 13% of those with constipation died of causes of death such as bowel perforation which are related to constipation. Very few people were recorded to have an understanding of what constitutes normal bowel function or to have received education on normal bowel habits.

Implications for Healthcare Professionals:

- Accessible advice and education about constipation should be offered to people with a learning disability and their caregivers, particularly those with, or at risk of developing, constipation.
- Regular medication reviews should be completed to mitigate the effects of constipating medications, particularly for individuals with multimorbidity and polypharmacy. The Maudsley BRC has developed an app which can be used to identify medications with high risk of causing constipation. The app could be used routinely in prescribing decisions.
- Bowel monitoring is essential for those at high risk for developing constipation to ensure it is identified and treated early before laxatives become necessary. Clinicians should keep in mind the multitude of risk factors people with a learning disability may be predisposed to (such as obesity, hypothyroidism, mobility problems and multimorbidity) when prescribing medications.
- STOMP and STAMP guidance should be followed when considering prescription of psychotropic medication. Holistic, person-centered medication reviews should be completed at least annually by an experienced practitioner in learning disability.

For research:

- The risk stratification procedure should be replicated in community samples of people with a learning disability to more comprehensively assess the risk of secondary constipation. Statistical modelling could be used to account for other potential risk factors of constipation.
- Sub-groups of people with a learning disability could be compared for their risk of developing constipation as a side-effect of medications. This could include research looking at people at specific risk, such as those with Down syndrome, multimorbidity or severe learning disability.
- A greater understanding of the similarities and differences between people with a learning disability and the general population could be gained from comparing these populations.
- Other data sources could be accessed to better understand the age at which people with a learning disability develop constipation and how non-medication treatments are implemented.
- Research investigating prescribing practices for laxatives and psychotropics would be useful in establishing how well current practice adheres to guidelines such as STOMP and STAMP.

Introduction

Constipation is a common clinical condition defined by 'infrequent or difficult passage of stool, hardness of stool or incomplete evacuation' (Bharucha, Pemberton & Locke, 2013). It is a partly subjective condition and can be diagnosed according to the presentation of a collection of different symptoms relating to bowel habits. The Rome IV diagnostic criteria defines constipation as 'spontaneous bowel movements occurring fewer than three times a week' (NICE). The condition is considered chronic if symptoms have been present for at least 3 months (NICE). Constipation can be further defined as functional (primary or idiopathic) if the condition is chronic without a known cause, or secondary (organic) if the condition is caused by medication or an underlying medical condition (NICE).

Constipation is common in people with a learning disability. Robertson et al. (2018) conducted a systematic review of prevalence rates of constipation in people with a learning disability and found that 14 of 31 studies reported prevalence rates of over 50%. It should be noted that estimates vary widely depending on the population used and the definition of constipation adopted. LeDeR has provided prevalence estimates of constipation as a long-term condition in people with a learning disability who have died, with over 23% of people who died in 2019 having constipation as a long-term condition (Heslop et al., 2020). This compares with findings of a global systematic analysis of constipation prevalence rates in the general population of 10.1%-15.3% (Barberio, 2021).

Constipation can be a serious problem in people with a learning disability. The consequences of severe, chronic constipation can be disabling (for example, faecal incontinence) and lead to life-threatening complications such as bowel perforation (Leung, Riutta, Kotecha & Rossa, 2011). Constipation can also be hard to detect in people with a learning disability, which makes it more likely to become a severe or chronic problem. People with a learning disability may be less likely to recognise the symptoms of constipation and be able to communicate their symptoms (Coleman & Spurling, 2010). Difficulties in communicating pain can mean discomfort relating to constipation presents differently; pain can present itself in the form of behaviour such as food refusal, agitation or self-injury (Doody & Bailey, 2017). Carers may not always be able to recognise constipation in people with a learning disability because they may not know the signs, or may attribute the resulting behaviours to the person's learning disability (Christensen et al., 2009).

People with a learning disability are at greater risk of constipation due to numerous factors relating to lifestyle and comorbidities. Risk factors for constipation include female sex, advancing age, obesity, poor diet (particularly lack of fibre), low fluid intake, reduced mobility, lack of exercise and psychological disorders such as anxiety and depression (NICE). A number of these risk factors are common in those with a learning disability, for example obesity (Melville et al., 2007) and low levels

of exercise (Hawkins & Look, 2006). People with a learning disability have higher levels of immobility (Cleaver, Hunter & Oullette-Kuntz, 2009). People with Down syndrome are at particularly high risk of constipation. This is partly due to comorbidity with hypothyroidism (Goday-Arno et al., 2009) and coeliac disease (Du et al., 2018). Increased risk of constipation in people with Down syndrome may also be due to gastrointestinal malformations, hypotonic bowel and increased risk of Hirschprung's disease (Holmes, 2014; Friedmacher & Puri, 2013). This report focuses on the people with a learning disability who died in 2021 with completed focused reviews who were identified by reviewers as having constipation.

Constipation and premature mortality

The role of constipation in contributing to the premature mortality of people with a learning disability is not well understood. Constipation has been identified as a risk factor for early death in people with a learning disability (Cooper et al., 2020), although deaths due to constipation are not commonly described in the literature. Maslen et al. (2022) suggest two factors could cause this, firstly the tendency for researchers to use 'umbrella' ICD-10 chapters for analysis ('diseases of the digestive system'), rather than specific disorders, and secondly issues with the accuracy of medical certificates of cause of death (MCCD) in people with a learning disability. Learning disability and associated conditions can be inappropriately recorded as an underlying cause of death (Dunwoodie Stirton & Heslop, 2018), making it difficult for researchers to truly measure the causes of mortality in people with a learning disability.

Lack of mention of constipation (or terms related to bowel obstruction) on the MCCD has been an issue for the LeDeR programme in quantifying deaths which were associated with constipation. The 2019 LeDeR report (Heslop et al., 2020) reported deaths from specific urgent or ambulatory care sensitive conditions, described as 'conditions that should not regularly require hospital admission if appropriate and timely care is provided'. Constipation would be included as such a condition (alongside DVT, diabetes, asthma and influenza), though researchers were unable to describe deaths with constipation as a contributory factor due to constipation (or related terms) rarely being included in the MCCD. Thus, only anecdotal evidence has been provided by LeDeR in the past about deaths associated with constipation in the form of quotes from reviews.

Constipation due to side effects of medications

In addition to increased risk of constipation due to high rates of risk factors, people with a learning disability may also be at risk of secondary constipation due to the medications they are prescribed. Many drugs include constipation as a potential adverse side-effect, such as opioids, many psychotropics, (especially with anti-cholinergic side effects) dietary supplements (e.g. iron and calcium), certain analgesics, and anti-seizure medication (Ueki & Nakashima, 2019). A Public Health England report (Glover et al., 2015) investigated the rates and patterns of prescription of psychotropic drugs in people with a learning disability and autism. The report found that people with a learning disability and/or autism have high rates of prescription of all psychotropic drugs and a large proportion of people received longer-term prescriptions for psychotropic medications. This is concerning, particularly because systematic review evidence suggests up to 50% of people on antipsychotic drugs have constipation (Ozbilen & Adams, 2009), and life-threatening complications of severe constipation are well-documented in antipsychotic treated cohorts (Every-Palmer, Newton-Howes & Clark, 2014). Although much of this prescribing may be appropriate, in line with a mental health diagnosis, some may be outside of licensed indication such as in cases where

behaviour is thought to be challenging. This has motivated guidelines such as STOMP and STAMP which were produced to address concerns about over-prescription of antipsychotics in people with a learning disability (NHSE). Certain medications which are used to treat epilepsy, such as anticonvulsants, have also been associated with constipation. For example, Garcia-Contreras et al. (2019) found an association between use of anticonvulsants and hard stool in a sample of children with cerebral palsy. Given epilepsy has an estimated prevalence of 22.2% in people with a learning disability (Robertson et al., 2015), exposure to anticonvulsants is also high in this group.

Laxative use in people with a learning disability

Guidelines (Emly & Rochester, 2006; Emly & Marriott, 2017) recommend a holistic, individualised approach to bowel management is important for treating constipation. This involves clinicians making personalised plans around toileting (posture, adapted seating etc), exercise and diet (particularly intake of fibre and fluid) and alternative strategies (such as abdominal massage) to alleviate symptoms. When these strategies prove ineffective, laxatives are recommended for short-term use and should be regularly reviewed. Despite this, the rate of laxative prescription in people with a learning disability remains high. The 2019 LeDeR report found that 33% of people who died were prescribed laxatives (Heslop et al., 2020) compared to 0.5% in the general population. Further, Carey et al. (2017) estimated that 25% of people with a learning disability were on regular laxatives using a large cohort of patients accessing primary care.

There may be barriers that limit the effectiveness of non-laxative treatments for constipation in people with a learning disability. Cockburn-Wells (2014) reported that one issue for people with a learning disability who are dependent on carers is a lack of carer understanding of constipation, which can lead to poor monitoring of bowel habits and a lack of appropriate adjustments to lifestyle and diet. In addition, for those with mobility issues adjustments such as exercise and adapted toileting posture may be challenging to implement. Nevertheless, there is evidence of successful non-pharmacological interventions for constipation in people with a learning disability. For example, Connor et al. (2014) demonstrated bowel management programmes addressing factors such as diet, exercise and toileting are effective in managing symptoms of constipation. Further, Emly et al., (1998) found that abdominal massage was as successful as laxatives in helping adults with a learning disability living with constipation.

In summary, previous research indicates that people with a learning disability are at increased risk of constipation due to a multitude of factors relating to lifestyle, comorbidities and prescribed medication, especially those who take antipsychotic drugs. Despite guidance that non-medication treatments are exhausted before laxatives are used, laxative prescription remains high in people with a learning disability. In view of this, the current work aimed to explore the reviews of people who died with constipation in 2021 in further detail, including laxative use and the risk of constipation due to prescribed medication in a sample of people with a learning disability who died.

Aims of this report (using current LeDeR data)

1. describe the demographic characteristics of people with a learning disability who died with constipation.
2. describe the causes of death of people with constipation.
3. analyse medication prescribed at the time of death for risk of causing constipation.
4. report the frequency of prescription of laxative and antipsychotic medications.
5. explore the factors associated with constipation.
6. explore the factors associated with prescription of medications associated with constipation.
7. describe the information about the management of constipation in people who had constipation at the time of death.

Method

Sample

A total of 97 people who died in 2021 and had a focused review that was completed in the same year were included in this analysis. Focused reviews were introduced in June 2021. They explore in detail the life and death of a person who died and the lessons that can be learnt from the death. Data from focused reviews were used because focused reviews include information about medications a person was prescribed at their time of death.

Not everyone reported to LeDeR receives a focused review. People only receive a focused review if the reviewer feels there is significant learning to be gained from the death or the person's family has requested a focused review. From summer 2021, people who are from ethnic minority backgrounds are automatically forwarded for a focused review.

Cause of death

To investigate causes of death in people with constipation, we used the 'Death information' part of the LeDeR focused review form. This includes information from the MCCD. We looked at information in Part I(a), Part I(b), Part I(c) and Part II of the death information form. Part I(a) is 'the disease or condition leading directly to death'. Part I(b) is 'other disease or condition, if any, leading to I(a)', and Part I(c) is 'other disease or condition, if any, leading to I(b)'. The lowest available line in Part I of the death certificate is taken as the underlying cause of death for the purpose of cause of death statistics. Part II contains 'other contributory conditions contributing to the death but not related to the disease or condition causing it'.

Laxative use

To assess laxative use, the medications a person was prescribed at their time of death were each coded as 0 (non-laxative medication) or 1 (laxative medication). The total score for each person was calculated and reported as a 'laxative score', indicating the number of different laxative medications a person was prescribed at the time of their death. Laxatives that were only prescribed in the week before death were not counted because they were considered not to be part of someone's routine medication. Examples of laxative medications can be found overleaf in Table 1: Types of laxatives.

Table 1: Types of laxatives

Medication name examples	Type
Senna	Stimulant laxatives
Macrogol (Movicol, Laxido)	Osmotic laxatives
Lactulose	Osmotic laxatives
Docusate	Stool softener laxatives
Glycerol	Suppository/enema
Sodium acid phosphate with sodium phosphate	Enema
Prucalopride	Prokinetic laxatives
Ipsaghula husk	Bulk-forming laxatives

Risk stratification of prescribed medication

To assess the risk of constipation from other medications, the medication record for each review was compared to a list of medications with constipation as a side-effect compiled by researchers at KCL and the Maudsley BRC. The list was made by collating medications listed in the British National Formulary (BNF) that mention constipation in the drug side-effect profile. It included 535 medications, which were grouped based on BNF's frequency for people taking the medication to experience constipation and given a score. The groupings were as follows:

- A common or very common side-effect: An estimated prevalence between 1 in 10 and 1 in 100 people taking the medication. Constipation risk score = 4.
- An uncommon side-effect: An estimated prevalence between 1 in 100 and 1 in 1,000 people taking the medication. Constipation risk score = 3.
- A rare or very rare side-effect: An estimated prevalence between 1 in 1,000 and 1 in 10,000 people taking the medication. Constipation risk score = 2.
- Medications associated with constipation in certain circumstances or when administered with other drugs were scored 1.

Medications which were not listed in the KCL and Maudsley BRC list of medications were scored as 0 (not known). The medications provided in the 97 focused reviews were reviewed and scored according to the above scoring system. Constipation risk was calculated by adding together the risk scores of every medication a person was prescribed at the time of their death. Medications only prescribed in the week before death were not included as they were not considered to be part of someone's routine medication.

Results

Demographics of the overall sample

The sample included 97 people who died in 2021 and had a focused review that was completed in the same year. 58.8% were male and 41.2% were female. The most frequent age at death for those in the overall sample was between 50-59 years, which comprised 23.7% of the sample, followed by 60-69 which comprised 22.7% of the sample and 70-79 which comprised 17.5% of the sample. The overall sample was mostly white (72.2%), with 10.3% from Black, African, Caribbean or Black British ethnic backgrounds. The percentage of people from Asian/Asian British backgrounds was 8.3%. The number of people from mixed and other ethnic backgrounds was too small to report. There was a greater proportion of people from ethnic minority groups in this sample than reported in some sections of the annual LeDeR report, this is in part because as of summer 2021, people from ethnic minority backgrounds are automatically eligible for a focused review. 17.5% had a mild learning disability, 33.0% had moderate learning disability, 33.0% had severe learning disability, 8.3% had profound/multiple learning disability. The number of people with no recorded level of learning disability was less than 5. 18.6% of the overall sample had Down syndrome. The majority (69.1%) of the sample had impaired mobility. The most common place of residence was residential/nursing home (41.2%), followed by supported living (22.7%) and family home (21.7%. 12.4% of people were obese (BMI >30kn/m2).

Long-term conditions of people in the overall sample

The median number of co-morbid long-term conditions each person in the overall sample had in addition to a learning disability was 2 (IQR = 2). The 5 most common comorbidities were: Sensory impairments (49.5%), Dysphagia (42.3%), Respiratory conditions (39.2%), Epilepsy (38.1%) and Musculoskeletal problems (37.0%). The proportion of the sample with at least one mental health condition was 41.2%. The four most common co-morbid mental health conditions were: depression (25.8%), anxiety (14.4%), other mental health need (10.3%), psychosis (10.3%). The percentage of long-term conditions is shown in the Appendix 1.

Demographics of people with constipation

Of those included in the overall sample, 46 were recorded as having constipation (47.4%). Here we report the demographics of the 46 people who died and were recorded as having constipation. Of the people who died and had constipation (n = 46), 58.7% were male and 41.3% were female. The most common age at death of those with constipation was between 60-69 years, which constituted 32.6% of the sample, followed by 50-59 and 70-79 which each constituted 19.6% of the sample. The sample with constipation was predominantly white (67.4%), with 10.9% from Black, African, Caribbean or Black British ethnic backgrounds. The number of people with constipation in the Asian/Asian British, mixed and other ethnic groups were too small to report. 10.9% of the sample with constipation had Down syndrome. 34.8% had moderate learning disability, 37.0% had severe learning disability, 13.0% had profound/multiple learning disability. The number of people with mild learning disability was too small to report. The majority (76.1%) had impaired mobility. The most common place of residence was residential/nursing home (43.5%), followed by supported living (30.4%) and family home (17.4%). The number of people who were obese (BMI >30) in the sample was <5.

Long-term conditions of people with constipation

The median number of co-morbid long-term conditions each person with constipation had in addition to a learning disability was 2 (IQR = 2). The 5 most common comorbidities were: Sensory impairments (49.5%), Dysphagia (42.3%), Respiratory conditions (39.2%), Epilepsy (38.1%) and Musculoskeletal problems (37.0%). The proportion of the sample with at least one mental health condition was 41.2%. The four most common co-morbid mental health conditions were: depression (25.8%), anxiety (14.4%), other mental health need (10.3%), psychosis (10.3%). The percentage of long-term conditions is shown below in Appendix 2.

Causes of death in people with constipation

Of the 46 people who died and were recorded as having constipation, none had constipation recorded on any part of their death information form. 10 (21.7%) people had bowel conditions in the death information form, e.g. bowel perforation, bowel cancer etc. The most common disease or condition in Part I(a) of the death information form was pneumonia (encompassing a range of types of pneumonia such as aspiration pneumonia and including COVID-19 pneumonitis), which was the Part I(a) cause of death for 39.1% of people who died. The proportion of people included in the LeDeR annual report for 2021 that had either pneumonia, aspiration pneumonia or COVID-19 pneumonitis recorded as an underlying cause of death was 29.4% (White et al., 2022).

41.3% of people had a disease or condition listed in Part I(b) of the death information form and 15.2% had a disease or condition listed in Part I(c) of the death information form. 69.5% had a contributory condition listed in Part II of the death information form. Of the 10 people who had a bowel condition listed in the death information form, 6 had conditions that could have been caused by constipation (e.g. bowel perforation and bowel obstruction) as the Part Ia primary cause of death. The remaining 5 people had a bowel condition in another part of the death information form (Part Ib, Ic or Part II). In comparison, no people without constipation had bowel obstruction or perforation recorded on their death certificates.

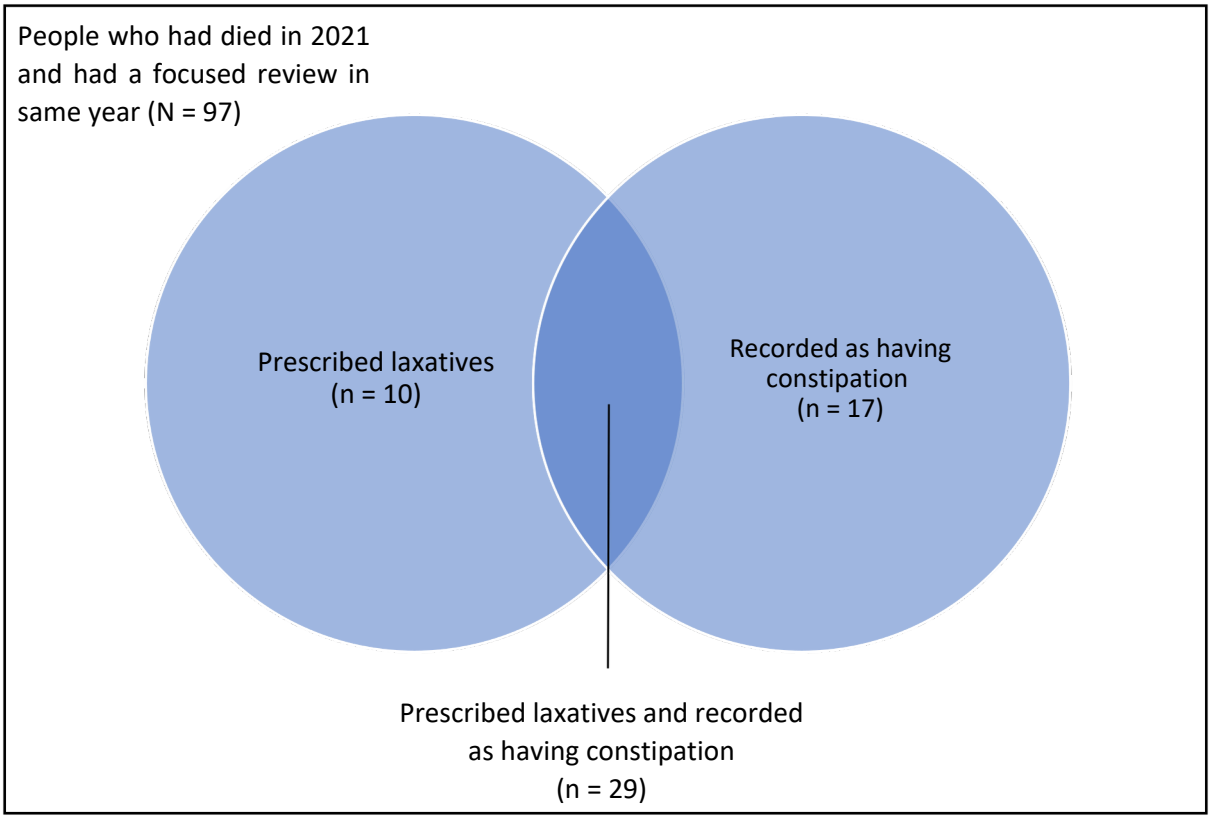
We looked at the recording of constipation in reviews for the 10 people who died with bowel conditions listed in any part of the death information form. 70.0% had every part of the constipation form completed. 60.0% had evidence of non-medication treatments in their review form, including ‘balanced diet’, support from dietician or gastroenterology team.

Laxatives

Of the 97 focused reviews, 39 (40.2%) were prescribed laxatives at the time of their death. Of the 46 people recorded to have constipation, 63.0% were prescribed laxatives and 37.0% were not prescribed laxatives (see Figure 1: Venn diagram showing number of people prescribed laxatives and recorded as having constipation1).

Most people who were prescribed laxatives were prescribed one laxative medication (51.3%); over a third (35.9%) of people were prescribed two laxative medications, and 12.8% were prescribed 3 laxative medications. The frequencies of the most common laxatives that were prescribed to members of this sample are shown overleaf in Table 2: Frequency of laxative use.

Figure 1: Venn diagram showing number of people prescribed laxatives and recorded as having constipation



29 (74.4%) of the people who were prescribed laxatives were recorded as having constipation. The remaining 10 people were prescribed laxatives but were not recorded as having constipation. Constipation as a diagnosis is therefore under recorded based on the level of prescribing of laxatives. The medication records accessed in focused reviews reflect the drugs prescribed to the person at their time of death. Over-the-counter medications are not included; therefore it is possible the rate of laxative use is higher than the estimated 40.2% from focused reviews.

Table 2: Frequency of laxative use

Medication name examples	Type	Frequency
Macrogol (Movicol, laxido)	Osmotic laxatives	21
Lactulose	Osmotic laxatives	12
Senna	Stimulant laxatives	10
Docusate	Stool softener laxatives	7

Note: Other laxatives included Glycerol, Sodium acid phosphate with sodium phosphate, Prucalopride and Ispaghula husk. These medications were each prescribed to fewer than 5 people.

Antipsychotics
We looked at the number of people who were prescribed antipsychotic medication, as these medications are commonly associated with constipation and previous literature has found high rates of prescription of antipsychotics in people with a learning disability.

Of the 97 focused reviews, 28 people (28.9%) were prescribed antipsychotics at the time of death. 59 people (60.8%) were not prescribed antipsychotics. This information was not known or was unavailable for 10 people (10.3%).

Risk of constipation from medication
The median risk score for constipation was 8 (IQR = 8). This means that 50% of the overall sample obtained a constipation risk score that was equivalent to being prescribed two or more medications that are commonly or very commonly associated with constipation. A constipation risk score that is equivalent to being prescribed four or more medications that are commonly or very commonly associated with constipation was obtained by 20% of the overall sample.

Correlation between number of prescribed laxatives and constipation risk score
There was a small, positive correlation (r = 0.37) for the constipation risk score and the number of laxatives someone was prescribed.

Regression analyses

Factors that predict constipation
A logistic regression was used to determine the factors that predict constipation. The independent variables were age, sex, ethnicity, level of learning disability, impaired mobility, Down syndrome, living situation and number of long-term conditions.

Several of the variables were associated with higher odds ratios for constipation in the adjusted analysis (see Table 3: Results of a logistic regression exploring factors predicting constipation). For example, increasing age (in years) was associated with an odds ratio [OR] for constipation of 1.05 (95% CI 1.01, 1.09). A person's level of learning disability was a predictor of constipation after taking account of the other variables in the adjusted analysis. Having a profound disability or multiple disabilities was associated with the highest odds ratio for constipation (OR 48.15, 95% CI 2.88, 806.12). Having a severe disability was associated with an odds ratio for constipation of 8.24 (95% CI 1.51, 44.91). The number of people included in the sample with a profound disability or multiple disabilities was small and resulted in large confidence intervals. Caution is required when interpreting this result.

Down syndrome was the only variable in the adjusted analysis that was associated with a lower odds ratio for constipation (OR 0.16, 95% CI 0.03, 0.72), although there were only a small number of people in the sample who had Down syndrome. This finding needs to be interpreted with caution. Sex, ethnicity, impaired mobility, living situation and the number of long-term health conditions were not associated with having constipation. coefficient was 1.98 (t = 2.79; p = .01) which indicates that on average someone's constipation risk score increases by approximately 1.98 points for each long-term health condition they have due to medication they have been prescribed.

Table 3: Results of a logistic regression exploring factors predicting constipation

Variable	With constipation (n, % of total)	Without constipation (n, % of total)	Overall total (n, %)	Adjusted Odds Ratio	Confidence interval
Age (in years)	(46 (100%)	51 (100%)	97 (100%)	**1.05**	**1.01, 1.09**
Male (reference = female)	27 (58.7%)	30 (58.8%)	57 (58.8%)	1.25	0.42, 3.72
Minority Ethnic background (reference = white)	15 (32.6%	12 (23.5%)	27 (27.8%)	2.34	0.64, 8.46
Level of learning disability (reference = mild learning disability)					
Moderate	16 (34.8%)	16 (31.4%)	32 (33.0%)	4.55	0.93, 22.18
Severe	17 (37.0%)	15 (29.4%)	32 (33.0%)	**8.24**	**1.51, 44.91**
Profound / multiple	10 (21.8%)	6 (11.8%)	16 (16.5%)	**48.15**	**2.88, 806.12**
Impaired mobility (reference = unimpaired mobility)	35 (76.1%)	32 (62.8%)	67 (69.1%)	1.75	0.50, 6.08
Down syndrome (reference = no Down syndrome)	5 (10.9%)	13 (25.5%)	18 (18.6%)	**0.16**	**0.03, 0.72**
Supported living**	14 (30.4%)	8 (15.7%)	22 (22.7%)	1.52	0.39, 5.94
Family home**	8 (17.4%)	13 (25.5%)	21 (21.6%)	0.53	0.10, 2.79
Other**	*	10 (19.6%)	> 10	0.59	0.12, 2.98
Number of long term health conditions	46 (100%)	51 (100%)	97 (100%)	1.06	0.69, 1.63

**Note: Living situation (reference = residential or nursing home)

Table 4: Overall regression output for the model predicting risk of being prescribed medications with constipation

Source	SS	df	MS	Number of observations	89.00
				F (12,76)	1.80
Model	1298.76	12.00	108.23	Prob > F	0.06
Residual	4566.86	76.00	60.09	R-squared	0.22
				Adjusted R-squared	0.10
Total	5865.62	88.00	66.65	Root MSE	7.75

Table 5: Factors predicting risk of being prescribed medications associated with constipation

Variable	Beta coefficient	Standard error	**t value**	**p value**	**Confidence interval**
Age (in years)	0.06	0.06	0.98	0.33	-0.06, 0.18
Male (reference = female)	1.83	1.76	1.04	0.30	-1.68, 5.34
Minority Ethnic background (reference = white)	-1.05	2.05	-0.51	0.61	-5.14, 3.03
Level of learning disability (reference = mild learning disability)					
Moderate	0.43	2.39	0.18	0.86	-4.34, 5.20
Severe	0.62	2.52	0.25	0.81	-4.40, 5.63
Profound / multiple	0.97	4.00	0.24	0.81	-7.00, 8.95
Impaired mobility (reference = unimpaired mobility)	1.88	2.02	0.93	0.36	-2.14, 5.90
Down syndrome (reference = no Down syndrome)	-3.81	2.26	-1.69	0.10	-8.31, 0.69
Living situation (reference = residential or nursing home)					
Supported living	3.54	2.23	1.59	0.12	-0.89, 7.97
Family home	2.78	2.63	1.06	0.29	-2.54, 8.01
Other	-0.86	2.66	-0.32	0.75	-6.16, 4.43
Number of long term health conditions	**1.98**	**0.71**	**2.79**	**0.01**	**0.57, 3.39**

Constipation history, education and management

Reviewers input information on focused review forms about specific conditions the person had at their time of death. Separate forms are available for different health conditions. The form which details information about constipation was available for 46 reviews of people who were recorded as having constipation at the time of their death. Seven fields on the constipation form were assessed (see Table 6: Constipation form questions and responses). 29 (63.0%) records had information about whether the person understood what constitutes as normal bowel action and stools; of these, 6 (20.7%) were recorded as understanding normal bowel habits. 29 (63.0%) records had information about whether appropriate education around normal bowel habits was provided, and 14 (48.3%) were recorded as having received appropriate education. The 17 (37.0%) records with information available for the 'non medication treatments' question predominantly reported dietary adjustments, such as 'balanced diet', 'high fibre diet' or 'gluten free diet'.

We were unable to report findings for the 'age at diagnosis or onset' question due to a high number of entries of '0' in this field.

Table 6: Constipation form questions and responses

Question	Number of records with valid data	Findings
Did the person who died have a history of constipation	37	Yes: 78.4% No: 16.2% Not known: 5.4%
Is there evidence of the persons bowel movements being monitored	29	Yes: 79.3% No: 13.8% Not known: 6.9%
Did the person understand what constitutes as normal bowel action and stools	29	Yes: 20.7% No: 37.9% Not known: 41.4%
Is there evidence of appropriate education around normal bowel habits being facilitated for the person who died	29	Yes: 48.3% No: 20.7% Not known: 31.0%
Was dietary advice around the management of constipation provided	28	Yes: 57.1% No: 14.3% Not known: 28.6%
Non medication treatments	17	Mainly dietary adjustments such as 'healthy diet' or 'gluten free diet'.

Discussion

The aim of this report was to provide an in-depth investigation of constipation in people with a learning disability using data from recent LeDeR focused reviews. We showed that constipation is a significant issue for people with a learning disability and is consistent with previous research which estimated the rate of constipation to be between 25% and 50% in people with a learning disability (Robertson et al., 2018). There are four main findings. The first is that a large portion of the LeDeR sample were at risk of developing secondary constipation as a result of their prescribed medications. The second is that laxatives prescriptions were very common, with 40% of the people with a learning disability included in this sample being prescribed at least one laxative. The third main finding is that constipation did not appear on any of the death certificates for the people included in this sample either as a contributory factor or more proximal cause of death. Of those recorded as having constipation, 6 (13.0%) died of bowel obstruction or perforation. In comparison, none of the people without constipation died of bowel perforation or obstruction, suggesting that these avoidable complications may be associated with constipation. The fourth main finding is that low numbers of people were recorded to have an understanding of what constitutes normal bowel function or have received appropriate education on normal bowel habits. Interpretation of the findings is provided below with reference to the relevant academic literature and limitations of this study. The implications for healthcare and research are provided.

To our knowledge, this was the first time that the prescribed medications of people with a learning disability have been reviewed collectively to determine the risk of developing constipation as a side-effect. We found that a score equivalent to taking two or more medications commonly or very commonly associated with constipation was obtained by 50% of the sample, and 20% of the sample obtained a score that was equivalent to taking four or more medications commonly or very commonly associated with constipation. Prescriptions of anti-epileptic and antipsychotic medications, which are both frequently associated with constipation, contributed to the elevated constipation risk scores observed in this sample. The overall sample contained a high proportion (43.5%) of people with epilepsy, which is estimated to have a prevalence of 22% in people with a learning disability (Robertson et al., 2015). Additionally, almost 30% of the sample were prescribed antipsychotics at their time of death, in keeping with previous estimates of antipsychotic medication use in people with a learning disability (Glover et al., 2015). For comparison, it is estimated that less than 1% of the general population have epilepsy (Bell, Neligan & Sander, 2014) and around 1% are prescribed antipsychotics (Shoham et al., 2021).

Logistic regression was used to explore the factors predicting constipation. There were three variables associated with higher odds ratios for constipation: age (OR 1.05, 95% CI 1.01, 1.09), having a profound disability or multiple disabilities (OR 48.15, 95% CI 2.88, 806.12) and having a severe disability (OR 8.24, 95% CI 1.51, 44.91). Caution is needed when interpreting these findings as the number of people in the sample that had a profound disability or multiple disabilities was small. Having Down syndrome was the only variable in the adjusted analysis that was associated with a lower odds ratio for constipation (OR 0.16, 95% CI 0.03, 0.72), although there was only a small number of people in the sample who had Down syndrome and this finding needs to be interpreted with caution given the additional risk factors for constipation in this cohort of people. Some of these results are replicated in a systematic review which demonstrated that increasing age and profound disability are associated with constipation (Robertson et al., 2017). However, the finding that Down syndrome was associated with a lower odds ratio for constipation opposed Robertson et al.'s (2017) results which identified Down syndrome as a risk factor for constipation. Robertson et al. (2017) identified immobility as a risk factor for constipation. However, immobility was not associated with a higher or lower risk of constipation in the LeDeR dataset, perhaps because it only included people who have died and thus frailer than the community-dwelling population of people with a learning disability.

Multiple regression analyses were used to explore the factors associated with the likelihood of being prescribed medications that are more likely to cause constipation. Several variables including age, sex, ethnicity, level of learning disability, impaired mobility, Down syndrome and living situation were not significantly associated with the risk of being prescribed medications associated with constipation. Previous research has found that age, sex and reduced mobility are risk factors for constipation. Although our findings suggest that these factors are not associated with the risk of being prescribed medications, this is likely because they are not, of themselves, health conditions requiring medication. Instead, health conditions related to these factors (for example, frailty in old age) may be associated with increased risk of being prescribed medications associated with constipation. Multimorbidity was significantly associated with increased risk being prescribed medications that are more likely to cause constipation. This finding is unsurprising as people who have several health conditions are more likely to be prescribed a greater number of medications to treat these conditions, some of which may be associated with constipation. A high proportion (40%) of the sample were prescribed laxatives. It was not possible to determine how commonly people received other, non-medication treatments for constipation due to large quantities of unavailable data. The high rates of laxative prescriptions found in this sample have been replicated previously using data from the LeDeR programme, which found 33% of people with a learning disability were prescribed laxatives (Heslop et al., 2020). Laxative prescription only had a small correlation with constipation risk score. In addition, 36.9% of people who had constipation were not prescribed laxatives. However, as our analysis does not account for over-the-counter laxative use, it could be that the actual rate of laxative use is higher than reported. It could also be the case that people with constipation were following plans of non-medication treatment for constipation, however due to the lack of complete data on non-medication treatments we were unable to confirm this.

Constipation did not appear in any part of the death certificates of the 46 people who died with constipation. Bowel conditions, such as bowel perforation, bowel cancer etc., which may be associated with constipation, appeared on the death certificates 10 times. This report has several limitations. The sample of people who died that was used in this report is a subset (n= 97) group of people died in 2021 and had focused reviews completed by LeDeR. Focused reviews are only conducted in certain circumstances (e.g. where there are concerns about a death) and the results should be interpreted in the light of this. In addition, some data fields were less complete, particularly in the constipation forms which had many fields unavailable. This could be due to the information required not being available to the reviewer rather than oversight by reviewers, but it meant that we were unable to complete any in-depth analyses on factors such as constipation onset and non-medication treatments for constipation. It should also be considered that the medications reviewed were only the medications prescribed to the person who died, over-the-counter medications are not accounted for. Therefore, laxative use could be even more common than the estimates we provided. We were unable to account for medication adherence which is a limitation when attempting to draw conclusions about potential effects of medication for people with a learning disability. Furthermore, we did not have sufficient information to comment on the appropriateness of prescriptions of laxatives and psychotropics. We did not have information about length of prescription for any medications or details of medication reviews to assess the extent to which prescription of laxatives and psychotropics adheres to guidelines. The implications of our findings for clinicians are related to the risk of constipation in people with a learning disability.

People with a learning disability should be given accessible advice and education about diet and lifestyle adjustments; education about normal bowel function should be offered to people with a learning disability and their caregivers, particularly those prone to constipation, being prescribed medication that could affect bowel function, or with known bowel conditions (Public Health England, 2016).

To mitigate the constipating effects of medications, regular medication reviews should be undertaken, particularly for individuals with multimorbidity and polypharmacy. To assist with this, the Maudsley BRC has developed an app which can be used to identify medications with high risk to cause constipation. The app could be used routinely at medication review meetings and before adding new medications to an individuals' regimen.

In those at high risk for developing constipation, bowel monitoring is essential to ensure constipation is identified and treated early before laxatives become necessary. Clinicians should keep in mind the multitude of risk factors people with a learning disability may be predisposed to (such as obesity, hypothyroidism, mobility problems and multimorbidity) when prescribing medications that have constipation as a side effect.

STOMP and STAMP guidance should be followed when considering prescription of psychotropic medication for behavioural and non-licenced indications. Holistic, person-centered medication reviews should be completed at least annually by an experienced practitioner in learning disability. Future research should replicate the risk stratification procedure in community samples of people with a learning disability to more comprehensively assess the risk of constipation from medications. Using statistical modelling to account for other potential risk factors of constipation would allow more reliable estimates of risk of constipation based on medication in this population. Other data sources could be accessed to better understand the age at which people with a learning disability develop constipation and how non-medication treatments are implemented.

Research investigating prescribing practices for laxatives and psychotropics would be useful in establishing how well current practice adhere to guidelines such as STOMP and STAMP. Future research could compare people with a learning disability to the general population in terms of constipation risk from medications. This may aid clinical decision-making by providing clinicians with a greater understanding of the similarities and differences between people with a learning disability and the general population. Research using larger samples could compare sub-groups of people with a learning disability. This could include research looking at people at specific risk, such as those with Down syndrome, multimorbidity or more severe learning disability.

Apendix

Appendix 1 : Percentage of the overall sample with long-term health conditions

Long-term condtion	**Percentage (n = 97)**
Physical health:	
Dysphagia	57.7%
Sensory impairment	50.5%
Respiratory problems	39.2%
Epilepsy	38.1%
Cardiovascular (excl. hypertension)	32.0%
Diabetes	26.8%
Musculoskeletal problems	23.7%
Cancer	16.5%
Dementia	15.2%
Kidney problems	12.4%
Hypertension	11.3%
Deep vein thrombosis (DVT)	*
Parkinson's	0%
Mental health:	
Depression	25.8%
Anxiety	14.4%
Other mental health need	10.3%

Long-term condtion	Percentage (n = 97)
Mental health:	
Psychosis	10.3%
Bipolar affective disorder	*
Eating disorder	0%
Any mental health condition	41.2%
	Summary statistics
Median number of long term conditions (IQR)	2 (2)

Appendix 2: The proportion of people with constipation with long-term conditions

Long-term condtion	Percentage (n = 97)
Physical health:	
Dysphagia	56.5%
Sensory impairment	52.2%
Epilepsy	43.5%
Respiratory problems	39.1%
Musculo skeletal problems	37.0%
Cardiovascular (excl. hypertension)	26.1%
Cancer	21.7%
Diabetes	17.4%
Dementia	15.2%
Kidney problems	15.2%

Long-term condtion	Percentage (n = 97)
Physical health:	
Deep vein thrombosis (DVT)	*
Hypertension	*
Parkinson's	0%
Mental health:	
Depression	25.8%
Anxiety	14.4%
Psychosis	10.3%
Bipolar affective disorder	*
Other mental health need	*
Eating disorder	0%
Any mental health condition	47.8%
	Summary statistics
Median number of long-term conditions (IQR)	2 (2)

Appendix 3: Demographics of people prescribed laxatives vs people not prescribed laxatives

Variable	Laxatives (n = 58)
Age (mean, SD)	53.9 (16.00
Sex:	
Male	53.5%
Female	46.6%
Ethnicity:	
White	72.4%
Ethnic minority groups	27.6%
Level of learning disability:	
Mild	24.1%
Moderate	32.8%
Severe	29.3%
Profound	*
Impaired mobility:	
No	37.9%
Yes	62.1%
Down syndrome:	
No	77.6%
Yes	22.4%
Living situation:	
Residential/nursing home	44.8%
Supported living	19.0%
Family home	20.7%
Other	15.5%

Variable	Not prescribed laxatives (n = 39)
Age (mean, SD)	56.2 (18.8)
Sex: Male Female	 66.7% 33.3%
Ethnicity: White Ethnic minority groups	 71.8% 28.2%
Level of learning disability: Mild Moderate Severe Profound	 * 33.3% 38.5% 12.8%
Impaired mobility: No Yes	 20.5% 79.5%
Down syndrome: No Yes	 87.2% 12.8%
Living situation: Residential/nursing home Supported living Family home Other	 35.9% 28.2% 23.1% 12.8%

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