

**Investigating the belief that men and women with learning disabilities receive poor quality healthcare when admitted to hospital: A single-site study of 30 day readmission rates.**

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**Investigating the widely held belief that men and women with learning disabilities receive poor quality healthcare when admitted to hospital:**

**A single-site study of 30-day readmission rates.**

**Abstract**

**Objective:** To use 30-day readmission rates to investigate the presumption that men and women with learning disabilities (LDs, known internationally as intellectual disabilities) receive poorer quality hospital care than their non-disabled peers.

**Method:** A 12-month retrospective audit was conducted using Hospital Episode Statistics (HES) at a single acute hospital in the East of England. This identified: all in-patient admissions; admissions where the person concerned was recognised as having a learning disability; and all emergency readmissions within 30-days of discharge. Additionally, the healthcare records of all patients identified as having a learning disability and readmitted within 30-days as a medical emergency were examined in order to determine whether or not these readmissions were potentially preventable.

**Results:** Over the study period a total of 66,870 adults were admitted as in-patients, amongst whom 7,408 were readmitted as medical emergencies within 30 days of discharge: a readmission rate of 11%. Of these 66,870 patients, 256 were identified as having a learning disability, with 32 of them experiencing at least one emergency readmission within 30-days: a readmission rate of 13%. When examined, the healthcare records pertaining to these 32 patients who had a total of 39 unique 30-day readmissions, revealed that 69% (n= 26) of these readmissions were potentially preventable.

**Conclusion:** Although overall readmission rates were similar for patients with learning disabilities and those from the general population, patients with learning disabilities had a

much higher rate of potentially preventable readmissions (PPRs) when compared to a general population estimate from van Walraven *et al.*, (2012). This suggests that there is still work to be done to ensure that this patient population receives hospital care that is both safe and of high quality.

## **Background**

Whether measured in terms of excess morbidity or mortality, men and women with learning disabilities (LDs, known internationally as intellectual disabilities) have poorer health than their non-disabled peers (Emerson *et al.*, 2012; Emerson & Hatton, 2013). These inequalities can be partially attributed to the socio-economic determinants of ill health, as people with learning disabilities are generally poorer than their peers in the general population, along with the presence of health conditions co-morbid with their disability (Emerson & Baines, 2010). However, there has been considerable concern for a number of years that men and woman with learning disabilities receive poorer quality healthcare than members of the general population, particularly when admitted to general hospitals (Emerson & Baines, 2010; Disability Rights Commission, 2005). These concerns came to wider public attention in 2007, when Mencap published *Death by Indifference*, which described the deaths in hospital of six patients with learning disabilities, alleging they were the victims of ‘institutionalised discrimination’ (Mencap, 2007). The report’s indictment of the healthcare received by these patients was so powerful that it prompted the government to commission an independent inquiry into healthcare for people with learning disabilities. The publication following this enquiry, *Health Care for All*, eschewed the term, ‘institutional discrimination’, but confirmed Mencap’s more general assertion that men and woman with learning disabilities were receiving poor quality healthcare, and that this was resulting in avoidable morbidity and mortality (Michael, 2008). Furthermore, there was evidence to suggest that the abuse and

neglect of patients with learning disabilities was widespread. This shocking observation was attributed to poor practices: healthcare practitioners were unaware of the special needs of patients with learning disabilities; the importance of communicating with their caregivers; and equalities legislation requiring them to make ‘reasonable adjustments’ to practices, procedures and policies. In addition, the inquiry also found that health and social care services were unable to plan and evaluate healthcare for people with learning disabilities because of a lack of basic information. Despite these findings being based almost entirely on evidence submitted by experts and interested parties - as opposed to peer-reviewed research - *Health Care for All* made ten recommendations which were accepted in their entirety when the previous government (1997-2010) published its 2009 White Paper, *Valuing People Now: a new three year strategy for people with learning disabilities* (Department of Health, 2009). Falling into three broad categories, the recommendations addressed: (i) the collection and dissemination of information and data on the health, and healthcare needs of people with learning disabilities (facilitated by the creation of a Public Health Observatory for learning disabilities and a confidential enquiry into avoidable deaths (Recommendations 2 and 5)); (ii) measures aimed at involving people with learning disabilities and those supporting them in the design and delivery of healthcare (Recommendations 1, 3, 4, 9 and 10); and (iii) changes to the commissioning and regulation of health services. These latter recommendations were intended to ensure compliance with equalities legislation, that the *Outcomes Framework for the NHS* safeguarded all vulnerable patients (including those with learning disabilities), and that the Boards of all healthcare Trusts publically demonstrated in their annual reports that they had quality systems for delivering health services to all client groups (Recommendations 6, 7, 8 and 10).

In the five years since the publication of *Valuing People Now* much has been done to improve the quality and safety of hospital care received by men and woman with learning

disabilities. These efforts include: the introduction of systems to electronically ‘flag’ patients with learning disabilities so that they can be readily identified; the appointment of specialist learning disability nurses whose role includes ensuring that appropriate adjustments are made to hospital practices and procedures; the introduction of ‘Hospital Passports’ which provide healthcare practitioners with accessible information about the care needs of individual patients (Brodrick *et al.*, 2011); and ‘Carers’ Agreements’ which help ensure that healthcare practitioners and family carers have a clear sense of what each can expect of the other. Many hospitals have also been providing staff with additional training in learning disabilities and their duties under equalities legislation and the *Mental Capacity Act*.

While much is being done to improve in-patient care for men and woman with learning disabilities, these efforts are underpinned by a slim evidence base that is largely unsystematic and anecdotal. Wishing to address this problem, but with limited resources, a decision was made to compare emergency readmission rates for patients with and without learning disabilities. Readmission rates, routinely collected as part of a hospital’s Hospital Episode Statistics (HES), are widely seen as an indicator of the success of healthcare in helping people recover (Department of Health, 2011). Under the government’s policy of Payment by Results, hospitals are not financially reimbursed (subject to certain criteria) for unplanned, or emergency, readmissions occurring within 30-days of discharge (Department of Health Payment by Results Team, 2013). These readmissions, despite the apparent complexity of the concept (Blunt *et al.*, 2014), are seen as attributable to poor quality care. Moreover, in an effort to reduce the number of patients being readmitted as medical emergencies, hospital managers are being advised to distinguish between readmission occurring within 7-days, which can be attributed to suboptimal medical management, and those occurring between 8-30 days post-discharge, which are said to signal the influence of

such social factors, as socio-economic circumstances, limited post-acute follow-up, and inadequate patient education (Sg2 Healthcare Intelligence, 2011).

## **Method**

### *Study approach*

A retrospective audit of HES records was undertaken of admissions into a regional teaching hospital trust in the East of England during a 12-month period between 1<sup>st</sup> April 2010 and 31<sup>st</sup> March 2011 (National Health Service England, 2014). Like many large hospitals, this Trust has a system for ‘flagging’ on admission those patients thought to have a learning disability. In addition, it employs a specialist learning disability nurse with responsibility for ensuring that appropriate adjustments are made to hospital practices and procedures, so that the special needs of patients with learning disabilities are recognised and met.

The data collected allowed the identification of in-patient admissions for persons aged 16 years and older, along with which of these patients had a learning disability as indicated by the ICD-10 codes F70 to F79 (World Health Organisation, 1992). All patients readmitted as medical emergencies within 30-days of discharge were identified. Where a patient with a known learning disability was readmitted as a medical emergency, their healthcare records were examined to gather the following demographic data: age; sex; level of learning disability; place of residence; whether the patient on admission was ‘flagged’ on the hospital’s electronic information system as having a learning disability; and whether or not the patient was accompanied, at admission, by a paid support worker, or a family member. Subsequently, two healthcare practitioners (a medical doctor and the specialist learning disabilities nurse) reviewed these healthcare records to determine whether each emergency readmission was potentially preventable or not.

A readmission was considered to be potentially preventable (see Box 1) if it could be considered clinically related to a prior admission (Goldfield *et al.*, 2006).

**Box 1:** Criteria for defining a readmission as potentially preventable.

A readmission can be considered as clinically related to an initial admission, and therefore not due to deficiencies in community care, if it is:

A medical readmission for a continuation or recurrence of the reason for the initial admission, or for a closely related condition (e.g., a readmission for diabetes following an initial admission for diabetes);

A medical readmission for an acute decomposition of a chronic problem that was not the reason for the initial admission, but was plausibly related to care either during or immediately after the initial admission (e.g., a readmission for diabetes in a patient whose initial admission was for an acute myocardial infarction);

A medical readmission for an acute medical complication plausibly related to care during the initial admission (a patient with a hernia repair and a perioperative Foley catheter readmitted for a urinary tract infection 10 days later);

A readmission for a surgical procedure to address a continuation or a recurrence of the problem causing the initial admission (a patient readmitted for an appendectomy following an initial admission for abdominal pain and fever);

A readmission for a surgical procedure to address a complication resulting from care during the initial admission (a readmission for drainage of a postoperative wound abscess following an initial admission for a bowel resection).

**Based on Goldfield et al (2006).**

This study was registered with the Research and Development department and Clinical Audit department of the hospital concerned, who deemed it to be a service evaluation as defined by the National Research Ethics Service, and as such did not require full ethical review.

### *Statistical methods*

The analysis presented focuses primarily on 30-day readmission because these are part of the *Outcomes framework for the NHS* (Department of Health, 2011) aimed at improving care quality. Nevertheless, some consideration is given to 7-day readmission rates as these are considered to specifically signal suboptimal care in hospital.

We begin by considering rates of readmission across all patients, and then between those with and without a learning disability with corresponding 95% Wilson confidence intervals (as preferred by Agresti & Coull, 1998). Rate differences are explicitly compared using a chi-squared test. The analysis then focuses solely on data relating to patients with learning disabilities where we consider patient characteristics, comparing differences between those admitted only once and those readmitted, and between potentially preventable readmissions (PPRs) and unavoidable readmissions. The unit of analysis then moves to considering readmission episodes, where we consider the number of readmission episodes, the causes of the PPRs, episode characteristics and the difference in rates of PPRs between 7-day and 8-30-day readmissions. Differences in variables between groups are tested using a two-sample t-test (or non-parametric equivalent) or chi-squared test as appropriate.

## **Results**

### *Readmission rates*

The total number of persons admitted during the study period was 66,870, of these patients 3,415 experienced an emergency readmission within 7 days of discharge, with a further 3,917



being readmitted between 8 and 30 days of post discharge. Of these 66,870 patients, 256 were identified as having a learning disability, of whom 15 were readmitted within 7 days and 17 were readmitted after 8 to 30 days. The 30-day readmission rate across all patients was 11% (95% Confidence Interval, CI=10.8%, 11.3%); splitting the patients into those with and without LD, the readmission rates were 13% (95% CI=9%, 17%) and 11% (95% CI=10.8%, 11.3%) respectively. A chi-squared test confirms that there is no statistically significant difference between the proportions of people with and without a learning disability who were readmitted ( $\chi^2(1)=0.3924$ ,  $p=0.5310$ ). The 7-day readmission rate across all patients was 5% (95% CI=5.0%, 5.4%). The 7-day readmission rates for those with and without learning disability were, respectively, 6% (95% CI=4.0%, 9.0%) and 5% (95% CI=5.0%, 5.4%). Again, there is no significant difference between the two groups ( $\chi^2(1)=0$ ,  $p=0.7348$ ).

**Table 1:** Among those patients with learning disabilities (LD), comparisons between those who were admitted once and those who experienced at least one 30-day readmission;<sup>1</sup> further, within those patients with a learning disability and were readmitted, comparisons between those with potentially preventable readmissions (PPRs) and those with non-avoidable readmissions.<sup>2</sup>

Demographic		Patients with LD		Patients with LD who were readmitted once or more within 30 days	
		Admitted once only	Readmitted within 30 days	PPR readmissions	Non-avoidable readmissions
<b>N (people)</b>		<b>224</b>	<b>32</b>	<b>22</b>	<b>11</b>
<b>Sex (%)<sup>3</sup></b>	Male	56	56	68	46
<b>Age (years)</b>	Mean	39.8	45.1	47.9	37.9
	Range	16-104	16-88	16-88	20-66
	SD <sup>4</sup>	19.6	19.8	20.2	18.6
<b>Severity of learning disability (%)<sup>3</sup></b>	Mild	35	12	18	9
	Moderate	34	34	27	64
	Profound	31	53	55	27
<b>Place of residence (%)<sup>3</sup></b>	Living Independently	36	25	18	36
	Family home	22	12	14	9
	Supported living	5	12	9	9
	Care home	35	47	55	46
	Nursing home	1	3	5	0
<b>Carer present at admission<sup>5</sup> (%)<sup>3</sup></b>	None	39	19	14	27
	Family	21	12	18	0
	Paid	41	69	68	73
<b>“Flagged”<sup>6</sup> (%)<sup>3</sup></b>	Yes	33	72	73	73

<sup>1</sup>Individuals who are admitted multiple times are only counted once in this table.

<sup>2</sup>One individual had both a potentially preventable readmission and two non-avoidable readmissions, so they are counted once in both the PPR and non-avoidable readmission groups.

<sup>3</sup>Percentages may not sum to 100 due to rounding.

<sup>4</sup>SD=standard deviation.

<sup>5</sup>Amongst those who had learning disabilities and were readmitted, there were no changes in the relationship of the carer present at first admission and any subsequent readmissions.

<sup>6</sup>Flagging refers to a note on electronic patient records which logs that an individual has a learning disability.

### *The characteristics of patients with learning disabilities*

With respect to the 256 patients with an identified learning disability, Table 1 compares the 224 who were admitted only once, with the 32 who experienced at least one emergency readmission within 30-days. Patients with a profound disability were more likely to experience a readmission ( $\chi^2(2)=8.30$ ,  $p=0.016$ ). Readmitted patients were also more likely to have been accompanied by a paid support worker ( $\chi^2(2)=9.05$ ,  $p=0.011$ ), and/or have had their learning disability flagged ( $\chi^2(1)=15.88$ ,  $p<0.001$ ). There were no other statistically significant differences, although those in the readmitted group were more likely to live in care homes and nursing homes. When those patients who were readmitted within 7-days are compared to those who were admitted only once, the readmitted group (like those readmitted with 30-days) were more likely to have a severe learning disability, to have been accompanied by a paid carer when admitted to hospital, and to have had their learning disability flagged. In accordance with the literature, these findings support the hypothesis that patients with more severe disabilities have more complex healthcare needs, and are therefore at greater risk of being readmitted.

### *Unavoidable and potentially preventable readmissions*

An examination of the healthcare records pertaining to the 32 patients who were readmitted within 30-days, revealed that 69% (95% CI = 51%, 82%) had experienced at least one PPR. There were no statistically significant differences between those patients who had experienced a PPR and those whose readmission was judged to be unavoidable (see Table 1). This may, however, be due to the small sample size which reduces statistical power. While severity of disability was not statistically significant ( $\chi^2(2)=4.06$ ,  $p=0.131$ ), the majority (55%, 12/22) of PPRs related to patients with a profound disability, while the majority (64%, 7/11) of unavoidable readmissions related to patients with a moderate learning disability. Of the 15 people readmitted within 7 days of discharge, 9 experienced a PPR, a rate of 60% (95% CI: 36%, 80%). As above, those with a PPR were more likely to have a severe learning disability but this was not statistically significant.

**Table 2:** The number of readmission episodes (within 30 days or less of previous admission) experienced by individuals.<sup>1</sup>

<b>Characteristic</b>		<b>All people with a learning disability who were readmitted</b>
<b>N (people)</b>		32
<b>Readmission episodes experienced (%)<sup>2</sup></b>	1 episode	85
	2 episodes	9
	3 episodes	6

<sup>1</sup>One individual had both a potentially preventable readmission, and two non-avoidable readmissions.

<sup>2</sup>Percentages may not sum to 100 due to rounding.

### *Readmissions episodes and their causes*

Table 2 shows the number of separate readmissions experienced by each readmitted patient. Most readmitted patients, whether readmitted within 7-days or 30-days, experienced only one readmission. Table 3 shows the reasons for potentially preventable readmissions within 30-days of discharge. The most common cause of readmission for PPRs, for both 7-day and 30-day readmissions, was a recurrence of the medical condition that caused the initial admission.

**Table 3:** Distribution of reasons for the potentially preventable readmissions (PPRs) within 30 days of previous admission.

<b>Reason for potentially preventable readmission<sup>1</sup></b>	<b>% (n=26 PPR episodes)</b>
Continuation or recurrence of the reason for the initial admission, or for a closely related condition	77
An acute decompensation of a chronic problem that was not the reason for the initial admission, but was plausibly related to care either during or immediately after the initial admission	15
An acute medical complication plausibly related to care during the initial admission	8
A surgical procedure to address a continuation or a recurrence of the problem causing the initial admission	0
A surgical procedure to address a complication resulting from care during the initial admission	0

<sup>1</sup>Based on Goldfield et al. (2006)

### *Characteristics of readmission episodes*

Information concerning the 39 readmission-episodes occurring within 30 days of previous discharge, including PPRs, are shown in Table 4. Across all readmission episodes we find that people are, on average, readmitted 11.9 days after their previous admission (be it a first admission or previous readmission). Most readmission episodes are treated by general medicine (14/39) or in the emergency department (8/39), and on average the treating department will change in just over half of all cases. There were no statistically significant differences between those readmissions that were potentially preventable and those that were

unavoidable. However, episode duration does seem be higher in the PPR group, but there is considerable variation within this group (Wilcoxon test for differences between groups:  $W=213.5$ ,  $p=0.186$ ). We found a similar pattern with respect to readmission episodes occurring within 7-days: they were most common in general medicine and tended to be for longer periods. There was no statistical difference between the rates of PPR at 7-days, and between 8-and 30-days ( $\chi^2(1)=0.6286$ ,  $p=0.4279$ ): 60% (11/19) and 75% (15/20) respectively.

**Table 4:** Descriptive statistics of readmission episodes occurring within 30 days of the previous admission involving patients with a learning disability.<sup>1</sup>

Characteristic		All 30-day readmission episodes	PPR <sup>2</sup> episodes	Non-avoidable readmission episodes
<b>N (episodes)</b>		39	26	13
<b>Time since previous admission<sup>4</sup> (days)</b>	Mean	11.9	13.1	9.6
	Range	1-30	1-30	1-30
	SD <sup>3</sup>	10.8	10.9	10.6
<b>Treating department (frequency)</b>	General medicine	14	10	4
	Emergency	8	4	4
	Gastroenterology	4	2	2
	Surgery	4	3	1
	Diabetic medicine	2	2	0
	Elderly medicine	1	1	0
	Nephrology	1	1	0
	Neurology	1	1	0
	Obstetrics	1	0	1
	Paediatrics	1	1	0
	Respiratory medicine	1	1	0
	Thoracic medicine	1	0	1
<b>Treating department changed since previous admission<sup>4</sup> (%)</b>	Yes	51	50	54
<b>Complex discharge planning at previous admission<sup>4</sup> (%)</b>	Yes	13	19	0
<b>Episode duration (days)</b>	Mean	7.7	9.5	4.0
	Range	1-66	1-66	1-9
	SD <sup>3</sup>	11.3	13.4	2.9

<sup>1</sup>An individual can have multiple readmissions.

<sup>2</sup>PPR=potentially preventable readmission.

<sup>3</sup>SD=standard deviation.

<sup>4</sup>Previous admission can be either the first admission or another readmission.

## **Discussion**

The first of two important findings in this study is that there is no significant difference between 30-day readmissions rates for patients with and without a known learning disability. This is one potential indicator that the quality of hospital care received by adults with learning disabilities is comparable with that received by the wider population. This finding, in light of the Mencap Report (Mencap, 2006), is unexpected and encouraging, since it suggests that the actions taken by acute hospitals to improve healthcare for this population are a success. However, the second important finding is that a high proportion (69%) of the readmissions of patients with a known learning disability are potentially preventable. This compares very poorly with the rate of PPRs in the general population, which is estimated to be 23% (van Walraven *et al.*, 2012). This comparison appears to suggest that the effectiveness of efforts to improve the care and treatment received by patients with learning disabilities is somewhat inconsistent in its impact. One conclusion to be drawn from this is that efforts should be made to distinguish between unavoidable readmissions and those that are potentially preventable, for only then can we ascertain if patients with learning disabilities are receiving care and treatment that is broadly comparable to that received by their non-disabled peers.

Our study also points to the possibility that patients with more profound learning disabilities are at greater risk of experiencing poor quality care, if poor quality care is what causes readmissions. Patients with profound learning disabilities more commonly experienced an emergency readmission within 30-days, and these adults also comprised over half of the PPRs. A possible explanation for this is that caring for patients with profound disabilities is highly complex, and with increased complexity comes a greater risk of readmission. Such patients may: experience severe difficulties communicating their symptoms; lack the capacity to make decision about their own care and treatment, relying on



others to make decisions in their best interests; exhibit challenging behaviours that could undermine compliance with clinical interventions; and present with atypical symptoms. These factors are known to pose clear challenges to healthcare practitioners (Mansell, 2010); a supposition that is supported by that fact that most of the PPRs (77%) reported in our study resulted from a continuation or a recurrence of the illness that had been the reason for the initial admission. An additional concern is that the treating department changed in just over half of all admissions, conceivably because hospital staff were unsure as to the precise nature of the health condition needing treatment. The absence of complex discharge planning, which is highly recommended for patients with learning disabilities (National Patient Safety Agency, 2004), is also worrying. Complex discharge planning is an important means for identifying changes in a patient's health and social care needs, and, where these changes are substantial, ensuring that there is provision to meet them post-discharge. Clinicians need to satisfy themselves that paid support staff and/or family caregivers, who will be assuming responsibility for their patient upon discharge, are aware of and can meet the person's needs.

Our study has limitations. Like the majority of research on readmissions it focuses on a single hospital (van Walraven *et al.*, 2012). Therefore, we cannot say with confidence that our findings are representative of other acute hospitals, especially since the overall 30-day readmission rate at the study site is just over double the 5.6% reported to be the national average (Sg2 Healthcare Intelligence, 2011). A possible explanation for this disparity is that the study hospital, as well as being a major trauma centre for the region, is also a tertiary referral centre for a number of medical specialities. Our study is also reliant upon Hospital Episode Statistics (HES) and health records, with all their known deficiencies (Greenhalgh *et al.*, 2009). Thus, while the hospital where the study was undertaken prides itself on the reliability of its recording of HES data, it is likely that patients with milder learning disabilities, a significant proportion of who are unknown to specialist services and possibly

their General Practitioner (Department of Health, 2009), will have been missed from this study. Additionally, assessments of the severity of people's learning disability (where identified) are notoriously unreliable (Royal College of Nursing, 2013).

As such, this study raises a number of questions requiring further investigation. Most pressing, it is unclear what role family carers and paid support workers play in preventing emergency readmissions for patients with learning disabilities. Efforts should also be made to determine whether people with milder learning disabilities, and who therefore may be unknown to specialist services, are at greater or less risk of experiencing a preventable readmission than their peers whose learning disability is 'flagged' on admission into hospital. Moreover, future studies in this area should recruit a random control sample of patients from the general population at the hospital under study, as this would enable an estimate of PPRs in the local non-learning disability population to be calculated. Lastly, efforts should be made to maximise and measure inter-rater reliability when determining whether a readmission was preventable or unavoidable.

## **Conclusion**

Our study invites reflection on the *NHS Outcomes Framework*, and in particular, 30-day readmission rates as one of the two main indicators within the domain of "helping people to recover from episodes of ill health or following injury" (Department of Health, 2012). As discussed, 30-day readmission rates may not be a particularly informative indicator of healthcare outcomes for people with learning disabilities, despite these rates being relatively straightforward to calculate from HES data when compared to examining individual patient healthcare records to ascertain the rate of PPRs. To date, the Department of Health has yet to publish disaggregated data showing 30-day readmission rates for patients with disabilities, and these will not identify patients with learning disabilities as a sub-group (Department of

Health, 2012). However, there is nothing to stop individual hospital Trusts from following our methodology and comparing, year-on-year, PPRs rates for patients with learning disabilities. In the absence of an appropriate centrally imposed indicator of outcomes for patients with learning disabilities, it may be up to individual hospital Trusts to refute the charge of ‘institutional discrimination’. Before effective improvements can be made to both procedures and policies there is a need for further research: what is the impact of diagnostic uncertainty and the inherent complexities of treating patients with learning disabilities upon the quality of care received, and why is complex discharge planning routinely overlooked? Moreover, evidence-based improvements to the care and treatment of patients with learning disabilities are likely to benefit other vulnerable populations, such as those whose care is complicated by dementia, mental illness or brain injury.

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