

Patient- and carer-held health records:

can they improve annual health checks for patients with learning disability?

BACKGROUND

Learning disability (LD) is a condition characterised by significant impairments of both intellectual and adaptive functioning, and an onset before the age of 18 years.¹ The prevalence of LD in England is estimated to be around 2 million.^{2,3} This population has a significantly high representation of mental and physical health comorbidities, and are vulnerable to both acute and chronic health problems.⁴ Patients with LD can often struggle with issues such as communication, creating difficulties when making informed choices. Patients with LD have a shorter life expectancy and increased risk of early death when compared with the general population.⁵

Current evidence suggests that patients with major mental health problems on average live 20 years less than the general population.⁶ Those with epilepsy are associated with significant premature mortality.⁷ The factors influencing this are complex and include individual lifestyle choices, side effects of treatment, and disparities in healthcare access and provision. These contribute to these poor outcomes and are not fully understood.⁸

There is robust evidence that certain categories of drugs prescribed for certain mental health problems such as psychosis and medication for seizures can adversely influence physical health outcomes, especially without regular monitoring. National initiatives and guidelines^{9,10} have attempted to address the need for regular check-ups to ensure that the medication is doing no harm. There is a focus on increasing awareness of the need for monitoring, especially given the long-term damage and risk to the individual through the medication, as well as the costs to the health service thereof.

Medicines in both these categories can cause a rise in glucose, lipids, or prolactin, which can cause health problems. They can also disrupt kidney, liver, and thyroid function as well as affecting the production of blood cells in the bone marrow. Both a raised glucose and/or raised lipids increase the risk of cardiovascular disease. These are recognised long-term side effects of second-generation antipsychotics. Typical antipsychotics and risperidone can cause a rise in prolactin, which causes amenorrhoea, galactorrhoea, infertility, loss of libido, and erectile dysfunction.

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Resulting hypogonadism may cause osteoporosis, mainly in women and with subsequent fragility fractures. Commonly prescribed anticonvulsants, such as sodium valproate, can also cause both metabolic disturbances and bone density problems. Another important risk issue is pregnancy among women with epilepsy on certain antiepilepsy drugs (AEDs). The risks to mother and baby in such a situation would naturally be more amplified if the mother has LD.

CURRENT SITUATION

The prevalence of psychiatric disorders as identified by primary care is significantly higher among adults with LD when compared with the general population.^{11,12} Similarly, the prevalence rate of seizures is considered 20 times higher with poorer prognosis, treatment resistance, and higher mortality.^{13,14}

A significant minority might suffer from both illnesses. For some patients with LD, antipsychotics and/or anticonvulsants are prescribed to manage challenging behaviours. It is therefore not uncommon for patients with LD to be prescribed either or both antipsychotics and anticonvulsants.

It is normal practice that patients who are stable and on established treatment in secondary care are discharged back to

the care of their GP if and until they have problems and need a re-referral. Thus the responsibility for both the prescribing and monitoring is passed to their GPs. The same is true for patients with mental health problems and an LD.¹⁵ Patients with LD on antipsychotics and AEDs, whose presenting needs have been addressed, are discharged back to primary care. There is the expectation that any antipsychotics or anticonvulsants at time of discharge are reviewed as per national guidance.^{9,10}

The Annual Health Check (AHC) District Enhanced Scheme² was introduced in 2009 for patients with LD. The scheme recognised the many health inequalities that patients with LD face, such as difficulties in making informed choices, communication issues, higher risk of comorbidities, poor access to health care, and being at higher risk of continued long-term medications. A natural extension would be that this framework be used to capture the enhanced needs of vulnerable individuals with LD. This is particularly the case for those on antipsychotics and AEDs, who often lack a ‘voice’ in their own care.

The uptake nationally of AHCs is variable, as is conformance to recognised national guidance for psychosis and epilepsy around physical health monitoring. A recent audit in east Cornwall, across 27 primary

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care practices, showed that, in spite of recommendations given on discharge from specialist to primary care of the tests required for a select high-risk group of patients with LD and on antipsychotics/anticonvulsants, only 50% had received satisfactory follow-up monitoring. Seventy-five per cent of them had an AHC, but clearly only two-thirds had received a review of their biochemistry as suggested by good-practice documents.¹⁶ There was little evidence of tests not being offered or declined, or of the use of either the Mental Capacity Act (ensuring the vulnerable individual could make an informed choice) or a best-interest process. This brought to light concerns that the most vulnerable were being failed in spite of such national guidance as the Mental Capacity Act 2005, the Autism Act 2010, the Equality Act 2010, and the introduction of the AHCs in 2009. The last was thought to safeguard against the health inequalities that patients with LD and comorbid physical and mental health issues are at significant risk of.

In light of the concerns, a further audit was undertaken in Cornwall and Devon in random primary care practices to capture data on the following:

- population served by the GP surgery;
- number of patients on the LD register;
- number of patients with LD prescribed AEDs and antipsychotics as referenced from appropriate sections of the *BNF*;
- number of patients prescribed AEDs and who received an AHC in the last year; and
- number of those prescribed receiving all relevant blood tests in the last year.

We also examined if there had been formal assessment and recording of mental capacity of those patients who declined their bloods. If found to be lacking capacity we further examined if a recorded best-interest decision/meeting to conduct or not conduct bloods had been done.

The results showed that 30–50% of patients on the GP LD register in each surgery were on antipsychotics, AEDs, or both. The uptake of AHC varied from 70% to 100%. Blood tests were done in 60–90% of patients. It was noticeable that smaller surgeries with fewer patients with LD did better for both AHCs and bloods. However, no GP surgery did a complete set of all relevant bloods in all patients and this heterogeneous presentation was difficult to measure. No surgery also addressed or followed up on patients who declined, nor was there any associated documentation

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of a mental capacity assessment or best-interest decision (if appropriate) linked to any patient who had missed their AHC or bloods.

DISCUSSION

The continued surveillance of an individual with LD who may have limited ability to hold responsibility to ensure their health is appropriately monitored is a complex issue. There are potentially various stakeholders in any such continued engagement. This includes in many cases the patient's family or paid carers, who have the responsibility of ensuring that the vulnerable individual's needs, including health needs, are appropriately met. Unfortunately, on most occasions the carers are unaware of the exact specifics in question; for example, the relevance of certain periodic blood tests when an individual is on certain medication.

Although primary care has a duty to ensure the wellbeing of this vulnerable group in keeping with the general population, a partnership approach between patient stakeholders and health providers could facilitate better outcomes. The potential barriers to health improvement could benefit from a more informed, person-centred approach to allow health professionals to support their LD patients.

Many patients with LD with mental health issues and/or epilepsy live in a supported setting. They have employed carers or family members to ensure their needs are being met. If patients' carers or family members had resources to identify the key issues relevant to the individual for their AHC, these could facilitate focused input.

In the information-rich world in which we live, patients increasingly want to know more about their and their family's medical conditions, treatment, and their possible risks. A patient- or carer-held record can inform both patients and carers of the health areas on which their health provider could focus on and the periodicity of the checks. It could help both clinician and patient to focus on risk factor minimisation and promote safety. It is a tool to individualise

discussions with patients and other key stakeholders. The authors envisage the record being similar to a personal child health record, which tracks the milestones and immunisation schedules for a child under 5 years of age. A similar record for patients with LD on long-term medication, especially antipsychotics and AEDs, could be a person-centred link to the AHCs. It could have sections and a schedule for relevant biochemistry, other investigations, best-interest decisions and other health parameters. Alternatively it could take the approach of a Health Action Plan written using SMART (Specific, Measureable, Achievable, Realistic, and Timely) targets in respect of AED and antipsychotic medication for this population.

The obvious negative is that there is a risk that a minority of the 'empowered population' lose or misplace their records. A scoping review into patient-owned personal health records¹⁷ showed some interesting findings. It highlighted that self-management is an important part of disease prevention. It also acknowledged that differences exist in patient motivation to use patient-held records. Interestingly, in the disabled, chronically ill, or caregivers for the elderly, the adoption rates are high and these groups have the most interest in patient-held records. Patients in this population felt that access helped reinforce trust and confidence in doctors, and made them feel more like partners in health care. Patients with LD on long-term medication and their carers or family may be expected to fit into this highly motivated group.

Importantly, as these would be patient-held records, there would be shared ownership between all stakeholders including secondary care, patient stakeholders, and primary care. Interestingly Devon is piloting shared access to computer records across primary and secondary care in recognition that the utility would be huge and immediate. This could be a possible argument against the relevance of patients not needing to be responsible for holding their data.

However, it is to be considered that, with the increased discharges from hospitals or secondary care, this intervention may be limited in its impact of addressing the core issue raised of ensuring safety of patients in primary care.

Health care can be risky. Preventable mistakes are not uncommon. Shared ownership of health would allow better understanding of individual needs. Where there is a lack of engagement on repeated 'invites' to participate in person-centred checks, an audit trail would identify where responsibility lay. For example, unearthing a carer organisation or home not realising its duty of care to bring a vulnerable individual lacking mental capacity for health checks could give rise to consideration of safeguarding processes. Initiatives such as patient-held records satisfy the need for organisations to put in place effective, evidence-based management systems for patient safety and to protect the clinical staff from potential litigation by demonstrating they have discharged their 'duty of care'. This can demonstrate effective clinical and corporate governance while enhancing patient safety.

A service development project to put

patient- or carer-held records in practice in the LD population will soon commence in Cornwall. If successful, the principles of this project could be extended to other health subgroups such as the mentally ill, especially including patients who are discharged to primary care on long-term psychotropic preparations.

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