Compiling a register of patients with moderate or severe learning disabilities: experience at one United Kingdom general practice

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ABSTRACT

Background Identifying patients with learning disabilities within primary care is central to initiatives for improving the health of this population. UK general practitioners (GPs) receive additional income for maintaining registers of patients with learning disabilities as part of the Quality and Outcomes Framework (QOF), and may opt to provide Directed Enhanced Services (DES), which requires practices to maintain registers of patients with moderate or severe learning disabilities and offer them annual health checks.

Objectives This paper describes the development of a register of patients with moderate or severe learning disabilities at one UK general practice.

Methods A Read code search of one UK general practice’s electronic medical records was conducted in order to identify patients with learning disabilities. Confirmation of diagnoses was sought by scrutinising records and GP verification. Cross-referencing with the practice QOF register of patients with learning disabilities of any severity, and the local authority’s list of clients with learning disabilities, was performed.

Results Of 15 001 patients, 229 (1.5%) were identified by the Read code search as possibly having learning disabilities. Scrutiny of records and GP verification confirmed 64 had learning disabilities and 24 did not, but the presence or absence of learning disability remained unclear in 141 cases. Cross-referencing with the QOF register (n=81) and local authority list (n=49) revealed little overlap.

Conclusion Identifying learning disability and assessing its severity are tasks GPs may be unfamiliar with, and relying on Read code searches may result in under-detection. Further research is needed to define optimum strategies for identifying, cross-referencing and validating practice-based registers of patients with learning disabilities.

Keywords: identification, learning disabilities, primary care
Introduction

In the light of increasing evidence of health inequalities experienced by people with learning disabilities (also termed ‘intellectual disabilities’ or ‘mental retardation’), improving the health of this population has become a priority for UK policy makers. UK general practitioners (GPs) receive financial incentives to maintain registers of patients with learning disabilities and to provide annual health checks to those with moderate or severe learning disabilities. This paper discusses the problems encountered in compiling a register of patients with moderate or severe learning disabilities at one UK general practice.

Approximately 1.2 million people in the UK have mild or moderate learning disabilities; another 210,000 people have severe learning disabilities. It is estimated that a UK GP providing care for a list size of 2000 patients will have six patients with severe learning disabilities and 44 with mild or moderate learning disabilities. Learning disability is characterised by three core features: reduced ability to understand new or complex information or learn new skills (impaired intelligence), reduced ability to cope independently (impaired social functioning) and onset before adulthood, having a lasting effect on development. The World Health Organization uses the term ‘mental retardation’, improving the health of this population has become a priority for UK policy makers. UK general practitioners (GPs) receive financial incentives to maintain registers of patients with learning disabilities and to provide annual health checks to those with moderate or severe learning disabilities. This paper discusses the problems encountered in compiling a register of patients with moderate or severe learning disabilities at one UK general practice.

Degrees of mental retardation are conventionally estimated by standardized intelligence tests. These can be supplemented by scales assessing social adaptation in a given environment. The diagnosis will also depend on the overall assessment of intellectual functioning by a skilled diagnostician. Intellectual abilities and social adaptation may change over time, and, however poor, may improve as a result of training and rehabilitation. Diagnosis should be based on the current levels of functioning.

Learning disability severity can thus be categorised on the basis of the intelligence quotient (IQ) and social functioning as described in Box 1.

Box 1: Categories of learning disability severity

- Mild: IQ 50–69. Many adults with mild learning disability are able to work, contribute to society and maintain good relationships.
- Moderate: IQ 35–49. Most adults with moderate learning disability have some degree of independence in self-care, with adequate communication and academic skills, and need varying degrees of support to live and work in the community.
- Severe: IQ 20–34. Adults with severe learning disability are likely to need continuous support.
- Profound: IQ under 20. Adults with profound learning disability have severely limited self-care, communication, mobility and continence.

Compared with the general population, people with learning disabilities have higher levels of gastrointestinal cancer, respiratory disease, cardiovascular disease and mental illness, reduced participation in screening and reduced life expectancy. One recent survey of 157 people with learning disabilities also found low levels of participation in exercise and healthy eating, whereas 68% were overweight or obese. Baxter et al suggest reasons underlying these health inequalities are complex, including ‘characteristics of individuals, such as genetic disposition; difficulties in communicating health needs; and deficits in service provision’.

In one UK study, health checks for 181 patients with learning disabilities revealed that 51% had previously unrecognised comorbidities, including diabetes, hypertension, thyroid disorders, dental problems, asthma and mental health problems. In another UK study, 56 patients with learning disabilities were offered annual health checks, with an intervention rate of 1.56 per patient per year, with half of the interventions required being actioned in primary care. Similarly, in New Zealand a register of 2500 patients with learning disabilities was compiled. Of those patients receiving a health check, 73% required interventions, including provision of a pacemaker and surgery for previously undetected melanoma. More proactive approaches to primary healthcare provision for patients with learning disabilities may therefore help identify unmet health needs and reduce health inequalities experienced by this population. Consequently, UK general practices are encouraged to identify patients with learning disabilities, and provide them with annual health checks.

Since 2006, a Learning Disabilities Indicator has been included in the Quality and Outcomes Framework (QOF), providing extra income to UK general practices which maintain a register of all patients aged 18 years and over with learning disabilities (of any severity). Since 2008, GPs have also been able to opt to provide Directed Enhanced Service (DES) for learning disabilities, which rewards practices for maintaining registers of patients with moderate or severe learning disabilities.
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severe learning disabilities (as defined by the local authority (LA) social services) and to offer them annual health checks. It is deemed that as LA criteria for access to social services is based on complexity of need, the list of clients known to the LA is likely to include individuals with more severe learning disabilities. As it cannot be assumed that all people with moderate or severe learning disabilities will be known to the LA, practices are required to cross-reference LA lists with practice lists of patients with learning disabilities.19

Identifying patients with learning disabilities within primary care is a prerequisite for improving the health of this population. This paper describes one UK general practice’s attempts to develop a DES-relevant register of patients with moderate or severe learning disabilities, and the difficulties encountered in doing so.

Setting

One UK general practice, with 11 GP partners and 15 001 registered patients, which uses the Egton Medical Information System (EMIS) electronic patient records system.

Methods

Medical records were searched to identify those with EMIS Read codes attached to the following diagnoses: learning disability, learning difficulty, mental deficiency, mental handicap, mental retardation, chromosomal abnormalities, Down’s syndrome, Prader-Willi syndrome, Noonan syndrome, Klinefelter’s syndrome, neurofibromatosis, Sturge-Weber syndrome, Fragile X syndrome, phenylketonuria, cerebral palsy, autism, suspected autism, Asperger’s syndrome, developmental delay, developmental problems and global delay. Patient records thereby identified were scrutinised to confirm the presence of learning disability.

Lists of patients identified were distributed to GP partners for verification. GPs were asked to give their opinion on learning disability severity where this was not clear from the records, and on whether each individual should be included on a DES-relevant register of patients with moderate or severe learning disabilities to be offered annual health checks. GPs were also asked to add details of any other patients with learning disabilities known to them that had been missed by the Read code search. They were then asked to complete a short questionnaire to give feedback on this verification process.

The health facilitator for people with learning disabilities on the community learning disability team (CLDT) was contacted to obtain a list of clients with moderate and severe learning disabilities known to the LA. These lists were cross-referenced with the practice’s existing QOF register of all patients with learning disability of any severity.

Results

Compiling a practice-based register of patients with learning disabilities

Of 15 001 registered patients, 229 (1.5%) were identified by the Read code search as potentially having learning disabilities. Scrutiny of medical records revealed that 24 of these patients did not have learning disabilities. Of these, three had been assessed by the CLDT as having borderline learning disabilities. Eight who had the Read code of reproduction/developmental problems had reproductive problems only, for example infertility, and had neither learning disabilities nor learning difficulties. The other 13 had learning difficulties, but no evidence of learning disabilities, despite having a Read code of ‘Learning disability not otherwise specified’ attached to their records. Inspection of the remaining 205 patients’ medical records confirmed that 64 had learning disabilities. Of these, 16 had Down’s syndrome, four had autistic spectrum disorder and learning disabilities, and one had Rett syndrome with learning disability.

Two patients who had a Read code of learning difficulties attached to their records, had actually been assessed by the CLDT as having a learning disability. In the 141 other cases, it remained unclear whether they had learning disabilities or not, as summarised in Figure 1.

Information on the source of, or evidence for, learning disability diagnosis was missing in most cases. Minimal information was present in other cases; for example, one patient had an entry in their record dated 1960 stating ‘mental retardation’, with no further information to verify this diagnosis. Another had been diagnosed with ‘mental retardation’ on the basis of an IQ test in 1974, with no more recent evidence to support this diagnosis despite WHO recommendations that diagnosis should be based on current levels of functioning.

As summarised in Table 1, 16 individuals were documented as having mild, nine moderate, and 12 severe learning disability. No patients were recorded
as having profound learning disability. Severity had either been ascertained following CLDT assessment – in these cases, information explaining how the diagnosis had been arrived at (for example, reports of psychological assessments) was available – or had been previously assigned by a GP. Definitions of learning disability severity used by GPs were not documented. In 27 cases, although there was evidence to suggest the patient had a learning disability, there was no evidence to define learning disability severity.

The list of patients generated from the Read code search was categorised according to which GP each patient was registered with and distributed to each partner for verification of the presence of severity of learning disability. Standard definitions of different learning disability severities (see Box 1) were provided to each partner to aid this process. Lists were returned by a total of seven GPs (64%). None added extra names to the lists. Three partners stated they were unsure of the severity of particular patients’ learning disabilities, and would need to assess these individuals in person to determine this. Others categorised particular patients as having ‘mild/moderate’ learning disability, although the criteria GPs used to determine learning disability severity were not clear, given that these patients did not have documented IQ scores, and it remained uncertain whether these patients should be included in the DES-relevant register of patients with moderate or severe learning disabilities or not.

All GP partners were sent a short questionnaire asking for feedback on their experience of verifying the patient lists. Five of 11 GPs (45%) completed and returned the questionnaire, all reporting that other priorities had taken precedence over verification.

Cross-referencing with the QOF register

As the practice’s pre-existing QOF register was comprised of all patients with any severity of learning disability, it was expected that it would include all patients on the DES-relevant Read code search list. Of the 229 patients identified by our Read Code search, only 66 appeared on the practice’s QOF register (n=81), as illustrated in Figure 2.

Scrutiny of medical records revealed that seven QOF register patients did not have learning disabilities. Thirty-one patients on the QOF register were confirmed as having learning disabilities, all of whom appear on the Read code search list. In the

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**Table 1 Learning disability: severity of cases identified as having a learning disability (n=64)**

<table>
<thead>
<tr>
<th>Learning disability severity</th>
<th>Number of cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>16</td>
</tr>
<tr>
<td>Moderate</td>
<td>9</td>
</tr>
<tr>
<td>Severe</td>
<td>12</td>
</tr>
<tr>
<td>Profound</td>
<td>0</td>
</tr>
<tr>
<td>Unclear</td>
<td>27</td>
</tr>
</tbody>
</table>

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**Figure 1** Flow chart of findings from Read code search, scrutiny of medical records and GP verification of presence and severity of learning disability (n=229)
remaining 43 cases, it was unclear whether the QOF register patients had learning disabilities or not.

Cross-referencing with the local authority

The DES requires practices to identify patients with moderate or severe learning disabilities as defined by the LA. Individuals consent to inclusion on the LA client list, but are not asked whether they consent to information being shared with healthcare providers. Consequently, the CLDT health facilitator had to seek legal advice when asked for a list of clients with learning disabilities to facilitate cross-referencing. It was eventually agreed that the practice GPs could request a list of people on the LA’s list of clients, with a main client category of learning disability, recorded as being registered at the practice.

Cross-referencing revealed that 18 patients on the LA list (n=49) appear on the practice’s existing QOF register. Thirty-five LA list patients appear on the DES-relevant Read code search list. Figure 3 illustrates that only 17 people appear on the LA list, the QOF register and the DES-relevant Read code list. However, 13 people on the LA list were not identified by either the QOF register or by the DES-relevant Read code list.
Discussion

Our experience of compiling a practice-based DES-relevant register of people with moderate or severe learning disabilities in order to offer them annual health checks highlighted several problems in identifying which individuals should be included.

There was little overlap between patients identified by the Read code search (n=229), patients on the practice’s existing QOF register of patients with learning disabilities of any severity (n=81) and the LA list of clients with learning disabilities (n=49), with only 17 patients appearing on all three. Similar disparities were found by Allgar et al., who designed a template of Read codes which, when used by 30 general practices, identified a total of 852 patients as potentially having learning disabilities, 488 also appeared on a database of people with learning disabilities derived from LA, primary care trust-led therapeutic services and dietetics, the mental health trust, education and voluntary organisations. However, another 570 people were identified by this database, who had not been identified by the practice-based registers. Relying on Read code searches of practice lists alone may therefore, result in under-detection of people with learning disabilities.

In another study, practice records were checked against both the local CLDT’s register and local special education school records, and a register of 57 patients with learning disabilities was thereby compiled from a total practice list of 14 410 patients. It has been suggested that more proactive approaches could be taken to identifying patients with learning disabilities for inclusion on the DES register – for example, advertising locally via posters, leaflets and newspapers, alongside opportunistic identification of patients in GP consultations.

The initial Read code search revealed that codes attached to medical records may not be accurate. Thirteen patients had a Read code of ‘Learning disability not otherwise specified’ attached to their records, but scrutiny of their records revealed they had learning difficulties, not learning disabilities. Two other patients had a Read code of learning difficulties attached to their records, but actually had a learning disability. Similarly, scrutiny of medical records revealed that seven patients on the practice’s existing QOF register of patients with learning disability of any severity did not have a learning disability. Interestingly, there seems to be no requirement for practices to validate these QOF registers, nor the DES-relevant registers.

Patients on the practice’s QOF register have the relevant QOF Read code attached, such as Eu81z-1 (‘learning disability’) or E3%, Eu7% (‘mental retardation’) or 918e (‘on learning disability register’). Codes attached to the individuals on the QOF register do not differentiate individuals according to learning disability severity. However, the DES register should comprise individuals with moderate (Read code 13VC1) and severe (Read code 13VC2) learning disability only. Thus, a patient with moderate learning disability on the QOF register (i.e. with a Read code of Eu81z-1, E3%, Eu7% or 918e) would also need to have a Read code of 13VC1 or 13VC2 attached to appear on the DES list. Adding these additional codes to patient records is likely to be time consuming, and may be a source of confusion to practice staff adding Read codes to patient records.

Further inaccuracies may be introduced by cross-referencing with the LA. The DES register should comprise individuals with moderate or severe learning disabilities as defined by the LA, yet, in our locality, the LA does not differentiate between clients on the basis of learning disability severity. It is assumed that patients known to the LA are likely to have more severe learning disabilities, but there may be individuals with moderate or severe learning disabilities who are not known to the LA who may, therefore, be missed by relying on LA lists for cross-referencing. Furthermore, information on which GP clients on the LA list are registered with is not routinely updated by the LA in our locality, leading to further inaccuracies when cross-referencing.

Asking GPs to verify presence and severity of learning disability gave rise to further problems, and in 27 cases, learning disability severity remained unclear following GP verification and medical record scrutiny. Three GPs stated they would need an appointment with particular patients to determine learning disability severity, whereas others categorised patients as having ‘mild/moderate’ learning disability – thus it remained unclear whether these patients should be included on the DES register. Identifying learning disabilities is a task that many GPs may be unfamiliar with. Indeed, a survey of 215 UK GPs found that 75% said they had not received any training on learning disabilities during their medical career. The need for undergraduate and postgraduate medical education on learning disabilities has been highlighted by a UK Government White Paper, which also promotes the development of GPs with a special interest in learning disabilities. It is suggested that CLDTs could provide training for multidisciplinary staff at general practices on identifying and assessing learning disability severity, providing annual health checks and implementing health action planning. Such training should also focus on differentiating between learning disability and learning difficulty (see Box 2), as our study revealed that these terms had erroneously been interchangeably used. People with a learning difficulty have a significant, persistent problem with a
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Specific area of learning, such as language (for example, dyslexia), maths (for example, dyscalculia), organisational skills (for example, dyspraxia) or short-term memory, which might arise from physical, psychological, sensory or emotional problems, but performance in other areas is unimpaired.

It is perhaps not surprising that GPs found it difficult to assess learning disability severity in 27 cases, as differentiating between mild, moderate and severe learning disabilities is a specialist task requiring assessment by psychologists with expertise in administering the Weschler Adult Intelligence Scale to people with learning disabilities. In a minority of cases, information on the source of learning disability diagnosis and severity was available, but in the majority of cases, this information was missing, and it was not clear on what basis learning disability severity had been decided. Allgar et al report that, when asked to identify their patients with learning disabilities, GPs at five UK practices struggled and did not utilise a standard definition of learning disabilities. Agreed definitions of learning disability, for use by both health and social services, are needed, along with a consistent method for accurately identifying patients with learning disabilities in primary care.

Although the DES register should include patients with moderate or severe learning disabilities, there may be other individuals who would benefit from annual health checks, for example those with profound learning disabilities, or those with mild learning disabilities and additional sensory, behavioural, physical or mental health needs. Whether GPs may use their discretion in deciding which patients should be included on the DES-relevant register and offered annual health checks, and whether they will receive financial rewards for doing so, is ambiguous, particularly as there is no requirement for practices to validate their registers of patients with learning disabilities.

The DES register requires patients aged 18 years or over to be identified. However, whether children with learning disabilities should be included is debatable, although doing so may enable practices to coordinate annual health checks once these individuals reach the age of 18 years. How the DES register and information from annual health checks should link into other chronic disease registers, for example asthma, cardiovascular disease, diabetes, epilepsy, mental health and older people, is yet to be established.

Overall, the process of compiling a DES-relevant register of patients with moderate or severe learning disabilities proved complicated and time-consuming for the GPs, information technology staff and CLDT staff involved, despite the practice’s access to coded electronic health records. How patients with learning disabilities can be identified in primary care in middle and low income countries, where electronic medical records may not be available, and where identifying such patients and taking a proactive approach to their health care may not be a public health priority, is uncertain. For general practices within the UK, and in higher income countries in which promoting the health of people with learning disabilities is a priority, it is likely that once a verified practice-based list has been created, maintaining the register and adding individuals identified as having moderate or severe learning disabilities at new patient assessment should be straightforward.

Limitations

The validity of our Read code search strategy is difficult to assess as only seven of 11 GP partners returned verified lists of patients with learning disabilities, and these had not used standardised definitions of learning disability severity.

Conclusions

Identifying patients with learning disabilities in primary care is a prerequisite for providing annual health checks to those with moderate and severe learning disabilities. Exactly who should be included on these registers, and how to optimise chances of
identifying these individuals, remains unclear. Relying on Read code searches alone is likely to result in under-detection of relevant patients. Cross-referencing with QOF registers and LA lists may add further confusion. In particular, the requirement that the DES-relevant register should be comprised of patients with moderate or severe learning disabilities as defined by the LA seems unhelpful given that LAs may not categorise clients by severity. These problems may result in inaccurate registers. If compiling a DES-relevant register of patients with moderate or severe learning disabilities proves difficult and time consuming, there is a risk that general practices may decide not to opt in to providing this service. Standardised definitions of learning disabilities, and agreements on data-sharing with LAs, are needed to make the process of compiling and cross-referencing primary care registers of patients with moderate or severe learning disabilities more straightforward, in order to maximise the chances of identifying those individuals who should be offered annual health checks.

Sensitive and specific Read code search strategies for identifying patients with learning disabilities from general practice lists need to be established in future studies, utilising different Read code search strategies to provide a validated search strategy which could then be used by general practices across the UK. How best to cross-reference and verify such registers is yet to be determined. Establishing optimal methods for identifying patients with learning disabilities in primary care would facilitate both provision of initiatives such as annual health checks and future research involving patients in this population.

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FUNDING
This work was not supported by any designated funding.

ETHICAL APPROVAL
Following discussion with a local research and ethics committee, no ethical approval was required.

CONFLICTS OF INTEREST
None.

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Accepted November 2010