Use of Read codes in diabetes management in a south London primary care group: implications for establishing disease registers

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Abstract

Objective To establish current practice in the use of Read codes for diabetes.
Design Cross sectional study.
Setting 17 practices in the Battersea primary care group in southwest London.
Data sources Computerised medical records.
Main outcome measures Number of codes in use in all practices; variation in the use of codes between practices; and prevalence of Read code use in diabetic patients.
Results At least 9 separate Read code groupings and 25 individual diabetes codes were in use in the 17 general practices. Only one Read code (C10, diabetes mellitus) and its subcodes was being used in all 17 practices, but its use varied from 14% to 98% of patients with diabetes. The use of other key Read codes for monitoring the care of patients with diabetes also varied widely between practices; for example, $<20\%$ of practices used the code for the location of care. Less than half of patients (45%) with diabetes had their type of diabetes coded, and even fewer (21%) had measures such as the examination of the retina coded.
Conclusions The use of Read codes for diabetes needs to be standardised and coding levels improved if valid diabetic registers are to be constructed and the quality of care is to be monitored effectively. Until all patients with diabetes have the C10 Read code recorded, clinicians will have to use a wide range of Read codes and prescribing data to ensure that diabetes registers are complete.

Introduction

In 1998 about 1.2 million people were receiving treatment for diabetes in England and Wales.[1] This number is predicted to increase substantially in the next few decades because of factors such as better case ascertainment, rising levels of obesity, and the ageing of the population.[2 3] Hence, because diabetes is associated with considerably increased morbidity and mortality, improving its management is a national priority.[4 5]

To help achieve this objective, the government envisages a much greater role for primary care in the management of diabetes[6 7] and has launched several initiatives. Firstly, the NHS Plan is leading to an expansion of services for patients with diabetes through greater investment in primary care and through initiatives such as the creation of specialist general practitioners.[8] Secondly, the national service framework for diabetes requires primary care trusts to undertake a baseline assessment of current services to help plan the long term development of services for diabetes.[9] Thirdly, the NHS Information Authority has developed a draft national specification for diabetes registers.[10] Fourthly, the NHS National Strategic Programme for Information Technology plans to improve patient care through a large investment in information and communication technology.[11]

The construction of accurate disease registers will be essential if these initiatives are to be successful in improving the care of people with diabetes.[12] These registers are needed so that people with diabetes can be identified and key aspects of their care monitored.

Read codes were developed in the 1980s and are currently used to code clinical data in primary care in the United Kingdom.[13] New codes are released regularly by the NHS Information Authority. In addition, producers of general practice clinical computer systems can add their own codes, as can individual practices. Few countries use Read codes; many more use the international classification of primary care (ICPC).[14]

The box gives an example of a Read code hierarchy. The Read coding system is complex, and a disease can be coded in many different ways—for example, through a specific disease code, history and symptoms, or investigations and procedures.

This can lead to wide variations in the way in which general practitioners code clinical problems. We examined the Read codes used in recording information on the management of diabetes in one primary care group. The objective was to identify the range and frequency of use of these codes as the first step in developing a local disease register and examining the quality of care for people with diabetes.

Methods

We used a two stage process to identify Read codes currently being used to record the management of diabetes in primary care in 17 general practices in the

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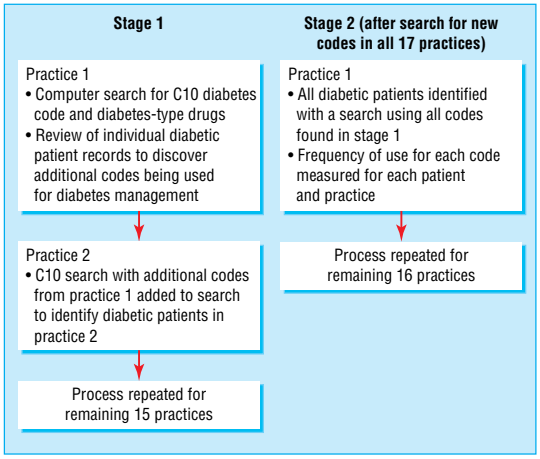
An example of the Read code hierarchy

C	Endocrine or metabolic disease
C1	Other endocrine disease
C10	Diabetes mellitus
C100	Diabetes mellitus with no complications
	C108-1 Insulin dependent diabetes mellitus
	C109-1 Non-insulin dependent diabetes mellitus
	C108-2 Type 1 diabetes mellitus
	C109-2 Type 2 diabetes mellitus
	C108-3 Type I diabetes mellitus
	C109-3 Type II diabetes mellitus
C1000	Diabetes mellitus of juvenile onset with no complications
C1001	Diabetes mellitus of adult onset with no complications

Battersea Primary Care Group in southwest London (figure). Firstly, we tried to identify all patients with diabetes and all the Read codes associated with their management. We then calculated the proportion of patients for whom each code was used. All 17 practices used the EMIS computer system.

In the first practice searched, we identified patients with diabetes by using the C10 code for diabetes (and all its lower level codes) and drugs used to treat diabetes (*British National Formulary*, section 6.1). We identified additional Read codes used in managing diabetes by viewing all the codes used in patients with diabetes and selecting those that were relevant to diabetes. This included codes for the complications and management of diabetes. In the second practice, we repeated this search using all the codes for diabetes identified in the first practice in addition to drugs used in treating diabetes. We repeated this process in the remaining practices and continued to add codes for diabetes. We also checked patients' computerised records to confirm that they had diabetes.

After the computerised records in all 17 practices had been searched once, we searched each practice again using all the codes for diabetes that we had identified, as well as drugs used in the treatment of diabetes. We then calculated the proportion of practices that had used each Read code for diabetes and the proportion of patients with diabetes who had the code in their electronic medical record. We also examined how often other relevant Read codes—such as those for blood pressure recording and measurement of serum cholesterol concentration—were used in patients with diabetes. These "non-diabetes" codes, however, were not used to identify patients with diabetes.



Method used to identify Read codes associated with management of diabetes

Results

We identified 2512 patients with diabetes in the 17 practices (total list size 98 705), an overall prevalence of diabetes of 2.54%. By the time we reached the final few practices, no further Read codes for diabetes were found.

In addition to Read code C10 and its subcodes, we identified several others related to diabetes. Only one code (C10, the generic code for diabetes) and one EMIS specific code (EGTOND1, denoting that dietary advice was given) were in use in all of the 17 practices. Fourteen codes were used by more than 60% of the practices, and two practices used codes that were found only in their own practice (table). Although a code may be found in a practice, it will only be used to code a proportion of patients with diabetes—for example, the percentage of patients coded with the C10 code in each of the 17 practices ranged from 14% to 98%. We found similarly large variations in the use of other codes related to diabetes.

Of the patients with diabetes, 1593 (63%) had been given the C10 code for diabetes or one of its subcodes. Among patients with a C10 code, 872 (55%) had no subcode identifying their type of diabetes—for example, type 1 or type 2. Eleven (65%) of the 17 practices used Read codes identifying the type of treatment given—66A3 (diet only), 66A4 (oral hypoglycaemic agents), 66A5 (insulin). In total, 963 (38%) patients had a treatment code recorded. Place of care codes—66AF (hospital clinic), 66AP (primary care), 66AQ (shared care)— were used in only three (<20%) practices and in only 197 (8%) patients.

The process of care code 66A (diabetes monitoring), which indicates that a consultation about diabetes has taken place, was used in 94% of practices. More specific monitoring codes that record aspects of care for people with diabetes were used much less commonly. Examination of the ankle reflex, for example, was used in 71% of practices but in just 11% of patients, and examination of the retina was used in 82% of practices and 21% of patients. Codes for measurement of blood pressure, HbA_{1c}, and cholesterol were used in 86%, 62%, and 51% of diabetic patients respectively. Only 4% of patients had a record of being assessed for their risk of an acute coronary event on the basis of the Framingham risk score.

Discussion

Producing disease registers in inner city areas is difficult.[15] Our study has shown that a wide range of Read codes needs to be used, with information from prescribing records, to ensure that the register is as complete as possible. We found that only about two thirds of patients with diabetes were coded using the Read code for diabetes (C10) or one of its subcodes. Because of this, many patients were identified from other codes related to diabetes or from prescribing records. Practices also varied widely in the codes they

used and in the proportion of patients in each practice in which each code was used.

Strengths and limitations

We found that the overall prevalence of diabetes was 2.54%—similar to the prevalences of 2.4% in males and 2.0% in females in a recent large study covering England and Wales[1]. This suggests that the search process was comprehensive.

All 17 practices in one locality participated, so the findings are for an entire population and not from a selected group of practices that have volunteered to take part in a study. The findings therefore are likely to give a true representation of everyday practice. Furthermore, the Battersea area of London varies widely in its socioeconomic characteristics and has a high proportion of patients from ethnic minority groups.[16]

The study will have identified only the diabetic patients who had a Read code for diabetes or another diabetes related code or who had been prescribed medication for diabetes. Some patients, particularly those with diet controlled diabetes, may have been missed by this strategy, as would people whose diabetes had not been diagnosed. Furthermore, the process of care in actual practice is likely to be better than suggested by the coding data. This is because many general practices may be providing care but not coding this information on practice computers. Some patients will also be receiving treatment in hospital clinics, and because of the current low level of integration between hospital and general practice clinical information systems, information on care in hospital clinics may not be recorded in primary care.

Comparison with previous research

The most common method of developing diabetes registers in primary care has been through identifying patients with a diagnostic code for diabetes. Our study suggests that this method may underestimate the prevalence of diabetes because many patients do not have the C10 Read code or one of its subcodes recorded in their computerised medical record. This conclusion is supported by the substantially higher prevalence of diabetes in our study than the 1.2-1.5% reported in previous studies.[17–20] However, some of these differences may be because the populations in which these previous studies were conducted had different ethnic and socioeconomic characteristics from those in Battersea.

An alternative method of producing disease registers is to use record linkage to combine information from different databases, but this is currently difficult to do in many parts of the United Kingdom. A study using record linkage in Tayside found a prevalence of diabetes of 1.9%[21]—lower than the prevalence reported in our own study, but this may have been because of the smaller proportion of people from ethnic minorities in the Tayside population.

Implications for practice

The findings of this study have some important implications. Firstly, with the introduction of the new contract, a substantial component of general practitioners' income will come in the form of "quality payments" for providing care that meets specified standards. Much of the information used to measure care against these standards is likely to come from computerised medical records. Hence, as well as providing high quality care, general practitioners will also need to ensure that the process of care is recorded and adequately coded on their practice computers. Furthermore, if general practices do not record key information on their computers, then the systems being put in place to monitor the national service framework for diabetes will assume that the process of care being measured has not been carried out (see www.quids.org.uk).

Secondly, the findings illustrate how much work needs to be done to improve coding levels in primary care and standardise the use of Read codes to allow electronic health records to be used for purposes such as measuring the quality of care. Such improvements will require substantial investment in hardware, software, and training, as well as developing methods of providing more structured chronic disease management. Thirdly, much better integration is needed between hospital and primary care information systems to prevent the unnecessary duplication of entry of data and to ensure that general practice information systems provide a complete and accurate record of the management of patients with diabetes.

Use of selected Read codes in 17 general practices and proportion of patients with diabetes for which each code was used

Group (Read code)	% (No) of 17 practices using code	% (No) of 2512 patients with code
Diabetes		
Diabetes mellitus (C10):	100 (17)	63 (1593)
Diabetes subtypes (C10 subcodes)	82 (14)	45 (721)
Diabetes treatment method		
Diet only (66A3)	65 (11)	12 (302)
Oral treatment (66A4)	59 (10)	17 (422)
Insulin treated (66A5)	65 (11)	10 (239)
Place of care		
Outpatients (66AF)	6 (1)	<1 (1)
Primary care (66AP)	18 (3)	3 (76)
Shared care (66AQ)	18 (3)	5 (120)
Attends diabetes clinic (9NMO)	12 (2)	<1 (2)
Care is taking place		
Diabetes monitoring (66A)	94 (16)	38 (959)
Diabetes monitor (9OLA)	35 (6)	6 (142)
Process of care		
Ankle reflex (2A4)	71 (12)	11 (277)
Retinal inspection (2BB)	82 (14)	21 (538)
Feet examination (66AE)	12 (2)	<1 (9)
Footcare advice given (EGTONFO1)	94 (16)	33 (830)
Dietary advice given (EGTOND1)	100 (17)	30 (762)
Organ related diabetes		
Diabetic retinopathy (F420)	53 (9)	4 (111)
Diabetic neuropathy (F372-2)	18 (3)	<1 (9)
Disease management codes		
Framingham cardiac risk score (EMISFR4)	6 (1)	4 (111)
Serum cholesterol (44P)	100 (17)	51 (1269)
Serum triglycerides (44Q)	71 (12)	14 (364)
HBA_{1c} (42W)	88 (15)	62 (1555)
Blood pressure (2469)	100 (17)	86 (2172)
Urine protein (467)	100 (17)	64 (1604)
Other diabetes codes		
Diabetic diet (13B1)	6 (1)	<1 (1)
History of diabetes (1434)	12 (2)	<1 (8)
Good diabetes control (66A1)	12 (2)	4 (96)
Practice created codes		
Attends eye clinic (QUENSAT1)	6 (1)	3 (75)
Non-insulin dependent diabetes (ZAFARN1)	6 (1)	2 (55)

What is already known on this topic

The prevalence of diabetes in Britain is increasing, so improvement in the management of people with diabetes is a national priority

Accurate diabetes registers are needed in primary care to improve quality of care for people with diabetes

What this study adds

Only 63% of patients with diabetes in one primary care group in south London had the C10 Read code for diabetes recorded; the rest had diabetes related codes or prescription codes

Until all patients with diabetes have the C10 Read code for diabetes recorded in their computerised medical records, doctors will have to use a range of codes to identify people with diabetes

Conclusions

Our findings illustrate the size of the task that faces the NHS in improving the quality of electronic health records in primary care, developing disease registers, and implementing important components of the NHS information technology strategy. As a minimum, all patients with diabetes should have the C10 Read code and the appropriate subcode recorded on the practice computer system. Until this happens, clinicians will have to use a wide range of Read codes together with prescribing data to ensure that diabetes registers are complete.

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1 Newnham A, Ryan R, Khunti K, Majeed A. Prevalence of diagnosed diabetes mellitus in general practice in England and Wales, 1994 to 1998. *Health Statistics Quarterly* 2002;14:5-13. Available at www.statistics.gov.uk/
2 Gatling W, Budd S, Walters D, Mullee MA, Goddard JR, Hill RD. Evidence of an increasing prevalence of diagnosed diabetes mellitus in the Poole area from 1983 to 1996. *Diabet Med* 15;1998:1015-21.
3 Amos AF, McCarty DJ, Zimmet P. The rising global burden of diabetes and its complications: estimates and projections to the year 2010. *Diabet Med* 1997;14(suppl):S1-85.
4 Laing SP, Swerdlow AJ, Slater SD, Botha JL, Burden AC, Waugh NR, et al. The British Diabetic Association cohort study, I: all-cause mortality in people with insulin-treated diabetes mellitus. *Diabet Med* 1999;16:459-65.
5 Currie CJ, Kraus D, Morgan CL, Gill L, Stott NC, Peters JR. NHS acute sector expenditure for diabetes: the present, future, and excess in-patient cost of care. *Diabet Med* 1997:14:686-92.
6 Khunti K, Ganguli S, Baker R, Lowy A. Features of primary care associated with variations in process and outcome of care of people with diabetes. *Br J Gen Pract* 2001;51:356-60.
7 Khunti K, Ganguli S. Who looks after people with diabetes: primary or secondary care? *J R Soc Med* 2000;93:183-6.
8 Department of Health. *The NHS plan: a plan for investment, a plan for reform.* London: Stationery Office, 2000. (Cm 4818.) Available at www.nhs.uk/nationalplan (accessed 9 April 2003).
9 Department of Health. *National service framework for diabetes: standards.* 2002. www.doh.gov.uk/nsf/diabetes/index.htm (accessed 9 April 2003).
10 www.nhsia.nhs.uk/phsmi/datasets/files/DUD_draft.doc (accessed 9 April 2003).
11 Department of Health. *Delivering IT in the NHS.* 2002. www.doh.gov.uk/ipu/whatnew/deliveringit/index.htm (accessed 9 April 2003).
12 Buxton C, Gibby O, Hall M, Home P, MacKinnon M, Murphy M, et al. Diabetes information systems: a key to improving the quality of diabetes care. *Diabet Med* 1996;13(suppl):S122-8.
13 Benson T. Why general practitioners use computers and hospital doctors do not— part 2: scalability. *BMJ* 2002;325:1090-3.
14 Okkes IM, Jamoulle M, Lamberts H, Bentzen N. ICPC-2-E: the electronic version of ICPC-2. Differences from the printed version and the consequences. *Fam Pract* 2000;17:101-7.
15 Burnett SD, Woolf CM, Yudkin JS. Developing a district diabetes register. *BMJ* 1992;305:627-30.
16 Bardsley M, Morgan D, Dawson I. *Mapping health for primary care groups: the changing geography of health in London.* London: Health of Londoners Project, 2000.
17 Whitford DL, Southern AJ, Braid E, Roberts SH. Comprehensive diabetes care in North Tyneside. *Diabet Med* 1995;12:691-5.
18 Connolly V, Unwin N, Ditta R, Sayer E, Bilous R, Kelly W. Age prevalence of known diabetes in a typical British district: evidence for an increase especially in the elderly. *Diabet Med* 1995; 12(suppl): S31.
19 MacKinnon M. Diabetes care: city wide known and unknown. *Diabet Med* 1995;12(suppl):S10.
20 Howitt AJ, Cheales NA. Diabetes registers: a grassroots approach. *BMJ* 1993;307:1046-8.
21 Morris AD, Boyle DIR, MacAlpine R, Emslie-Smith A, Jung RT, Newton RW, et al. The diabetes audit and research in Tayside, Scotland (DARTS) study: electronic record-linkage to create a diabetes register. *BMJ* 1997;315:524-8.

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