Brief report

Validation of self-reported diagnosis of diabetes in the 1946 British birth cohort

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ABSTRACT

The aim of this study was to validate self-reported diabetes and age at diagnosis among a sample of the British population, using general practitioners (GPs) as the reference standard. Using data from the Medical Research Council National Survey of Health and Development (NSHD), self-reported diabetes was determined either in response to a direct question at five follow-ups between 1977 and 2010, or from other self-reported medical information. A validation questionnaire was sent to the GP for all participants who reported a diagnosis of diabetes and gave permission to contact their GP (172). The validity of self-reported diabetes was assessed by calculating the percentage of self-reported diabetes cases that were confirmed by their GP, i.e. the positive predictive value (PPV). The difference between self-reported and GP-confirmed age at diagnosis was analysed with a Bland–Altman plot. Completed questionnaires were obtained from 157 GPs (91.2%). Of these, 149 confirmed their patient self-reported diabetes diagnosis (PPV = 94.9%). Results were similar when self-reported diabetes was assessed by responses to direct questions only (PPV = 95.4%). The average difference between self-reported and GP-reported age at diagnosis was 0.6 years (95% CI 0.2–1.1). We conclude that among the British population questionnaires are a valid method to assess GP-diagnosed diabetes, as measured by responses to a direct question or by patient-reported medical information.

1. Introduction

Several studies have assessed the validity of self-reported diabetes using either medical records or physical examination as the reference standard [1–13]. The agreement between self-reports and medical records, including family practitioners records [6,9,10,14], is usually good for conditions with well-defined diagnostic criteria, such as diabetes [9,10]. However, most validation studies of self-reported diabetes were based on a small number (<50) of diabetes cases [4,6,8] or were restricted to specific groups [1,7,8,11,13]. Furthermore

none of these studies were conducted in the UK population. General practitioners (GP) are an optimal source of information on disease status in the UK as nearly all British citizens are registered with a GP practice. Moreover, during the last decade diabetes care in the UK has moved into general practice. The aim of this study was to evaluate the accuracy of participant-reported diabetes, and age at diagnosis, by comparing self-reported diabetes cases with GP-confirmed cases in a representative sample of the British population.

2. Subjects and methods

Data were taken from the Medical Research Council National Survey of Health and Development (NSHD). Details of the study have been described previously [14]. In brief, the NSHD is a socially stratified nationally representative sample originally consisting of 5362 single births in the first week of March 1946 in England, Scotland and Wales [14]. The cohort has been followed up 23 times between birth and the latest data collection at age 60–64 years [15]. The present study was based on information on hospitalisation from birth up to 60–64 years and of health questionnaires from the 1977, 1982, 1989, 1999 and 2006–2010 data collections. At the most recent follow-up, 3164 participants were still available for follow-up. Of these, 2661 (84%) provided information. Self-reported diabetes was determined in two ways. Firstly, in response to a direct question (at age 36 study members were asked: "Do you have diabetes all or most of the time?" at age 43, 53 and 60–64: "In the last ten years have you had diabetes? Has a doctor said you had this problem?"). Secondly, from all relevant medical information that study members reported. From birth, all hospital attendances and reasons for attending were recorded. Dates of diagnosis and medications were reported at 31, 36, 43 and 53 years.

Table 1 shows the follow-up process for the validation of self-reported questionnaires and the overall GP response rate. Of 230 study members who reported a diagnosis of diabetes, 184 (80%) were seen at the latest follow-up, when 172 (75%) gave permission to contact their GP. A validation

questionnaire was developed and sent to the GP of all consenting participants with a self-reported diabetes diagnosis. The questionnaire consisted of questions on diabetes status and type, date of diagnosis, how the diagnosis was established and which type of treatment patients were currently receiving (diet, oral hypoglycaemic agents, insulin or other). The validity of self-reported diabetes was assessed by calculating the percentage of self-reported diabetes cases that were confirmed to have diabetes by their GP, i.e. the positive predictive value (PPV) with GP confirmation as the gold standard (PPV = $b/a \times 100$, where a = number self-reported and b = those confirmed by GP). The difference between self-reported and GP-confirmed age at diagnosis was analysed with a Bland–Altman plot [16]; the mean difference, 95% CI and limits of agreements were calculated.

3. Results

Completed questionnaires were obtained from 157 GPs (91.2%). Of these, 149 self-reported diagnoses were confirmed by the GP (PPV = 94.9%). Results were very similar when the analyses were performed using only responses to a direct question on diabetes diagnosis (PPV = 95.4%). Of the GP-confirmed cases 143 (95.9%) were type 2 diabetes and six (4%) were type 1 diabetes. Of the eight cases that were not confirmed two had pre-diabetes (GP-reported impaired fasting glycaemia or glucose intolerance). Of the remaining six, four reported having been diagnosed at age 26, 49, 61 and 62 years and two said they were diagnosed between 53 and 63 years. Of these six, three said they were prescribed a diabetic diet, but no tablets, from their doctors, and one had FPG > 7 mmol/L at the NSHD 2006–11 data collection round. Information on the test used to diagnose diabetes was available for 121 participants. Fasting plasma glucose (FPG) (n = 68, 56.2%) and oral glucose tolerance (OGT) (n = 15, 12.4%) were the most common tests. FPG was also used in combination with OGT by 10 (8.26%)

| Table 1 – Participants available for validation and GP response rate.		
	No.	%
Total self-reported diabetes 1977–2008	230	
Died	19	
Withdrew	9	
Lost to follow up	15	
Emigrated	2	
Seen at the latest follow-up	184	
Refused consent to contact their GP	7	
Died after follow-up	5	
Available for validation study	172	74.7
1st questionnaire sent to GPs	172	
GPs telephoned	27	
Study members telephoned	11	
Questionnaire resent to GPs	24	
Questionnaire sent to new GPs	11	
Questionnaires returned (GP response rate)	157	91.2
GP = general practitioner.		
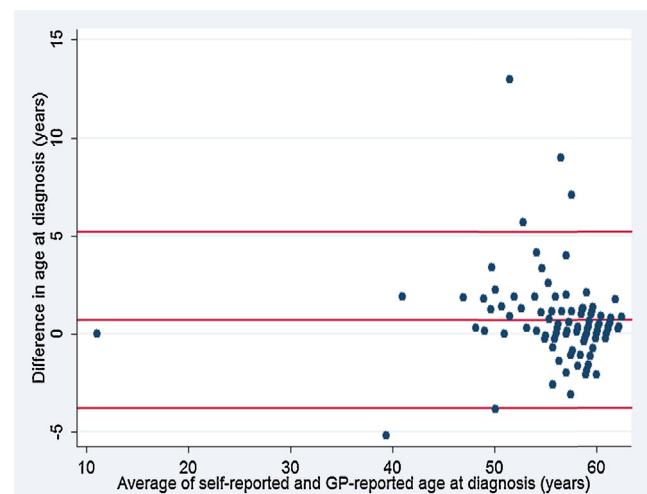
Fig. 1 – Differences in years between self-reported and GP-confirmed age at diagnosis plotted against the average difference. Horizontal lines denote the mean difference (0.6 years), and the upper (5.1 years) and lower (−3.7 years) limits of agreement (mean difference ± 1.96 SD of the differences).