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Comorbidity, healthcare utilisation and process of care measures in patients with congenital heart disease in the UK: cross-sectional, population-based study with case–control analysis

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ABSTRACT

Objective: To determine the prevalence of comorbidities, patterns of healthcare utilisation and primary care recording of clinical indicators in patients with congenital heart disease.

Patients and methods: A population-based case–control study using data from general practices across the UK contributing data to the QRESEARCH primary care database. The subjects comprised 9952 patients with congenital heart disease and 29 837 matched controls. Outcome measures were prevalence of selected comorbidities; adjusted odds ratios for risk of comorbidities, healthcare utilisation and clinical indicator recording.

Results: The overall crude prevalence of congenital heart disease was 3.05 per 1000 patients (95% CI 2.99 to 3.11). Prevalence of key comorbidities in patients with congenital heart disease ranged from 2.4% (95% CI 2.1% to 2.7%) for epilepsy to 9.3% (95% CI 8.8% to 9.9%) for hypertension. After adjusting for smoking and deprivation, cases were significantly more likely than controls to have each of the cardiovascular comorbidities and an increased risk of diabetes, epilepsy and renal disease. Patients with congenital heart disease were more frequent users of primary care than controls. Patients with congenital heart disease were also more likely than controls to have lifestyle and risk factor measurements recorded in primary care, although overall levels of recording were low.

Conclusions: There is a significant burden of comorbidity associated with congenital heart disease, and levels of primary care utilisation and referral to secondary care are high in this patient group. The predicted future expansion in the numbers of adults with congenital heart disease owing to improvements in survival will have implications for primary and secondary care, and not just tertiary centres offering specialist care.

Congenital heart disease is one of the most common forms of congenital anomaly in the UK,¹ with an estimated incidence at birth of between 5 and 8 per 1000 live births.^{2–6} Congenital heart disease is also a common cause of congenital anomaly death. Over 40% of all congenital anomaly deaths in 2003 were due to a cardiovascular malformation.⁷

A diagnosis of congenital heart disease can have serious and lifelong consequences for patients and their families, with many patients with congenital heart disease requiring specialist follow-up into adulthood.⁸ Important long-term cardiac sequelae of congenital heart disease include heart failure, cardiac arrhythmias, infective endocarditis,

pulmonary vascular obstructive disease and sudden cardiac death. Owing to complications that arise later on in life, re-intervention and re-operation are frequently a feature of continuing care for this patient population. Adults with congenital heart disease also require specialist reproductive counselling.

Considerable attention has been devoted to improving the quality of care of children with congenital heart conditions, following the Bristol Inquiry in 2001⁹ and subsequent publication of the report of the Paediatric and Congenital Cardiac Services Review Group in 2003.¹⁰ In contrast, health services for adult survivors have long been neglected, arousing dissatisfaction among patient groups, and prompting clinicians involved in the care of “GUCH” patients (grown-ups with congenital heart disease) to call for service improvement.^{11 12} The government has responded to these pressures by establishing an external reference group, chaired by the National Director for Coronary Heart Disease. In May 2006, the Department of Health published a guide to commissioning services for young people and adults with congenital heart disease, which included indicators of high-quality care in primary, secondary and tertiary care settings.¹³

In developing services and standards of care for both children and adults with congenital heart disease, policy makers and planners are faced with a lack of high-quality data on the size of this patient population, their patterns of healthcare use and the morbidity burden associated with this disease. Studies of morbidity and outcomes of care have tended to lack a population dimension, instead focusing on short-term outcomes in infants and children with particular congenital heart lesions and/or undergoing specific surgical procedures. This paucity of studies examining longer-term outcomes for patients with congenital heart disease was noted during the Bristol Inquiry,⁹ and more recently by Knowles *et al.*¹⁴ Patterns of health service use, beyond admissions to, and surgical procedures performed in, tertiary centres,^{15 16} are also poorly understood. No studies have been undertaken looking at the burden of morbidity associated with congenital heart disease from a primary care perspective, and there are only a handful of studies describing the activity and case mix of services for adults with congenital heart disease in non-tertiary hospital settings.^{17 18}

Data from aggregated general practice databases have been used successfully to study disease

Box 1 Classification of congenital heart disease lesions by structural complexity**Complex**

- ▶ Fontan circulation
- ▶ Hypoplastic left heart
- ▶ Double inlet ventricle
- ▶ Double outlet right ventricle
- ▶ Eisenmenger's syndrome
- ▶ Mitral atresia
- ▶ Tricuspid atresia
- ▶ Pulmonary atresia (with or without intact ventricular septum)
- ▶ Congenitally corrected transposition of great arteries
- ▶ Complete atrioventricular septal defect
- ▶ Truncus arteriosus
- ▶ Other single ventricle physiology
- ▶ Other cyanotic congenital heart disease

Moderate

- ▶ Transposition of great vessels
- ▶ Tetralogy of Fallot
- ▶ Total or partial anomalous pulmonary venous drainage
- ▶ Ebstein's anomaly
- ▶ Coarctation of aorta
- ▶ Aortic stenosis
- ▶ Pulmonary stenosis
- ▶ Ostium primum atrial septal defect
- ▶ Sinus of Valsalva fistula/aneurysm

Simple

- ▶ Ventricular septal defect
- ▶ Atrial septal defect
- ▶ Persistent ductus arteriosus
- ▶ Mild pulmonary stenosis

epidemiology,¹⁹ the prevalence of comorbidities or complications^{20–21} and examine the process of care measures in primary care.²² Access to large and nationally representative samples of patients is a key advantage of such methods.²³

We undertook a population-based case-control study to describe and compare the prevalence of selected comorbidities, patterns of health service use and process of care indicators in patients with and without congenital heart disease. All patients with congenital heart disease and their matched controls were registered with UK general practices participating in the QRESEARCH primary care database.

METHODS**Study population, case definition and data sources**

Data for this study came from the QRESEARCH general practice database (version 5, downloaded on 16 May 2005), with a combined registered patient list size of over 3.2 million patients. We identified all patients with a recorded diagnosis of congenital heart disease who were alive and registered with a QRESEARCH practice on 1 January 2005 and for the previous 6 months. We sought to minimise information bias by excluding those patients with congenital heart disease who had been registered for less than 6 months. Cases were identified on the basis of a diagnostic Read code for congenital heart disease or for surgical correction of a congenital heart defect. As in previous epidemiological studies of congenital heart disease, we excluded patients with isolated arrhythmias,

cardiomyopathies, Marfan's syndrome, bicuspid aortic valve, mitral valve prolapse, isolated dextrocardia and cardiac tumours.⁴

Incidence density sampling was used to select three controls for each case, matched on age (in 5-year age bands), sex and practice. Incidence density sampling is regarded as the preferred method for obtaining unbiased results in case-control nested studies: controls are selected without replacement from all people at risk at the time of case occurrence, excluding the index case itself.²⁴ Controls had to be alive, and registered on 1 January 2005 and for the previous 6 months. For cases and controls we extracted details of year of birth, sex, deprivation quintile (based on the Townsend score of the 2001 census output area for each patient's postcode) and congenital heart disease diagnoses. In addition, we extracted the following information for each patient using the relevant Read codes:

- ▶ Ever-diagnosed selected comorbidities: atrial fibrillation, chronic renal disease, depression, diabetes, epilepsy, erythrocytosis, heart failure, hypertension, stroke and transient ischaemic attack;
- ▶ Number of general practitioner consultations (2002–4);
- ▶ Number of specialist referrals (2002–4);
- ▶ Number of prescriptions by BNF chapter (2002–4);
- ▶ Most recent recorded smoking status.

We also established whether the following clinical indicators had been recorded in the previous 24 months (ie, since 1 January 2003) for both cases and controls: smoking status, body mass index, cholesterol, systolic and diastolic blood pressure.

To examine variations in healthcare use by the complexity of congenital heart defects, we categorised cases into one of three broad categories: simple, moderate and complex. To undertake this categorisation, we first assigned a primary diagnosis to those cases of congenital heart disease with multiple congenital heart disease diagnoses using a modified version of the anatomical hierarchy previously developed by Wren *et al.*⁴ The diagnosis that appeared highest in this hierarchical list of congenital heart disease diagnoses was selected as the primary diagnosis. Patients were then classified into one of three "complexity" groups, based on their primary diagnosis (see box 1). Patients categorised as having either complex or moderately complex lesions correspond to those who would typically require follow-up at a regional or specialist centre.^{15–25}

Statistical analysis

Using all patients registered with a QRESEARCH practice on 1 January 2005 as the denominator, we calculated the crude point prevalence of congenital heart disease with 95% CIs. We also calculated prevalence by age and sex for 2005, the most recent year for which we had prevalence data. For cases and controls, we calculated the prevalence of each of the selected comorbidities, rates of specialist referral, prescriptions per 1000 population and mean numbers of annual primary care consultations. We also calculated the proportion of cases and controls with a recorded measure for each of the clinical indicators.

We used conditional (fixed effects) logistic regression for individually matched case-control studies to derive unadjusted and adjusted odds ratios with 95% CIs for risk of recorded comorbidities, measures of healthcare use and clinical indicator recording. Odds ratios were adjusted for deprivation using quintiles of Townsend scores and smoking status (smoker, non-smoker, not recorded) as appropriate. Analyses were carried out in STATA (version 7.0).

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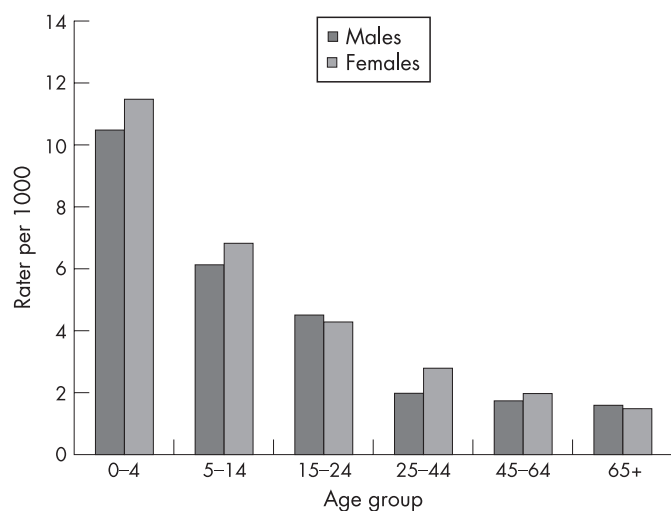


Figure 1 Prevalence of congenital heart disease per 1000 by age group and sex in 2005.

RESULTS

In January 2005, 10 209 registered patients with a diagnosis of congenital heart disease were identified in the QRESEARCH study population (crude prevalence 0.30% in men and 0.33% in women). Figure 1 shows the prevalence of congenital heart disease by age group and sex. After excluding patients registered with their general practice for <6 months, 9952 patients (5196 female, 4756 male) with congenital heart disease met our case definition, giving an overall crude prevalence of 3.05 cases per 1000 population (95% CI 2.99 to 3.11). Of these 9952 cases of congenital heart disease, 9497 (95.4%) could be categorised into one of the three complexity categories: 7250 (72.8%) were simple cases, 1885 (18.9%) were moderate cases and 362 (3.6%) were complex cases. In the remaining cases, the diagnostic Read code did not provide sufficient information to enable categorisation—for example, Read code “P6y: other specific heart anomalies”.

The average age of patients with congenital heart disease was 28; more than half were aged ≥ 20 years. There was a relatively even distribution of patients with congenital heart disease between population deprivation quintiles (table 1). We individually matched the 9952 cases to 29 837 controls by age, sex and practice. Table 1 shows the baseline characteristics of the patients with congenital heart disease and their matched controls.

Patients with congenital heart disease had a significantly increased risk of each cardiovascular comorbidity (atrial fibrillation, heart failure, hypertension and stroke/transient ischaemic attack) compared with controls, after adjustment for deprivation and smoking status (table 2). For example, patients with congenital heart disease had a much higher risk of atrial fibrillation than their matched controls, despite adjustment (adjusted OR = 7.6, 95% CI 6.1 to 9.3). Patients with congenital heart disease also had a significantly increased risk of diabetes, chronic renal disease and epilepsy. There were no significant differences between men and women in the unadjusted or adjusted risk of comorbidities.

Healthcare utilisation

Patients with congenital heart disease consulted their GP more frequently, were issued with more prescriptions and were referred to a specialist more often than their matched controls.

Table 1 Characteristics of cases and matched controls

Characteristic	Cases (n = 9952)	Controls (n = 29 837)
Sex		
Female	5196 (52.2)	15 578 (52.2)
Male	4756 (47.8)	14 259 (47.8)
Age band		
0-9	2524 (25.4)	7572 (25.4)
10-19	2142 (21.5)	6426 (21.5)
20-39	2324 (23.4)	6972 (23.4)
40-59	1807 (18.2)	5419 (18.2)
60-79	963 (9.7)	2883 (9.7)
≥ 80	192 (1.9)	565 (1.9)
Mean age, years (SD)	28.1 (22.3)	28.1 (22.3)
Deprivation quintile		
1 (least deprived fifth)	2072 (20.8)	6345 (21.3)
2	1949 (19.6)	5753 (19.3)
3	1875 (18.8)	5341 (17.9)
4	1717 (17.3)	5094 (17.1)
5 (most deprived fifth)	1967 (19.8)	5829 (19.5)
Not recorded	372 (3.7)	1475 (4.9)
Last recorded smoking status of adults (aged ≥ 16 years)		
Smoker	1166 (19.4)	3978 (22.0)
Non-smoker	3922 (65.1)	10 252 (56.8)
Not recorded	937 (15.6)	3826 (21.2)

Values are numbers (percentages) unless otherwise stated.

Between 2002 and 2004, the crude annual rate of specialist referral was 183.3 per 1000 cases (95% CI 175.7 to 190.1) and 142.4 per 1000 controls (95% CI 138.2 to 146.8). The crude annual number of prescriptions issued was 12 026.6 per 1000 cases (95% CI 11 958.6 to 12 095.0) and 10 883.5 per 1000 controls (95% CI 10 846.1 to 10 921.0). The mean annual number of GP consultations was 3.18 (95% CI 3.11 to 3.25) for cases and 2.80 (95% CI 2.76 to 2.84) for controls.

Table 3 shows the odds ratios for selected measures of healthcare use for cases, according to their complexity category, and their matched controls. Patients with complex or moderate congenital heart disease lesions were significantly more likely than controls to be heavy users of primary healthcare. For example, complex/moderate cases were 4.3 times as likely as their matched controls to have consulted their GP 20 or more times in the 3-year period 2002-4 (OR = 4.3, 95% CI 3.0 to 6.1). Patients with simple congenital heart disease lesions were also more likely to be heavier users of primary care than their controls.

Recording of clinical indicators

Overall, 27.2% of patients with congenital heart disease had had their body mass index recorded on computer within the past 24 months; 37.7% had their smoking status recorded; 41.9% had a blood pressure measurement recorded and 15.4% had a serum cholesterol measurement recorded. These proportions increased to 40.7%, 57.7%, 65.9% and 25.4%, respectively, if we just considered patients aged ≥ 16 years. Overall, for every clinical indicator, cases were significantly more likely than their matched controls to have had a measurement recorded on computer within the past 2 years (table 4).

Analysis by sex shows that, with the exception of cholesterol, a greater proportion of women than men had each of the clinical

Table 2 Prevalence and odds ratios for "ever diagnosed" selected comorbidities for 9952 cases and 29 837 controls

Comorbidity	Cases No (%)	Controls No (%)	OR (unadjusted) (95% CI)	OR (adjusted)* (95% CI)
Atrial fibrillation	425 (4.3)	206 (0.7)	8.4 (6.9 to 10.2)	7.6 (6.1 to 9.3)
Chronic renal disease	80 (0.8)	61 (0.2)	4.2 (3.0 to 5.9)	3.4 (2.3 to 5.1)
Diabetes	256 (2.6)	562 (1.9)	1.4 (1.2 to 1.6)	1.3 (1.1 to 1.5)
Depression	285 (2.9)	767 (2.6)	1.1 (1.0 to 1.3)	1.1 (0.9 to 1.2)
Epilepsy	241 (2.4)	283 (0.9)	2.6 (2.2 to 3.1)	2.4 (1.9 to 3.0)
Erythrocytosis	28 (0.3)	3 (0.01)	28.0 (8.5 to 92.1)	23.5 (7.1 to 77.8)
Heart failure	257 (2.6)	136 (0.5)	10.3 (8.2 to 12.9)	6.7 (5.2 to 8.5)
Hypertension	929 (9.3)	2008 (6.7)	1.6 (1.5 to 1.8)	1.4 (1.3 to 1.5)
Stroke and transient ischaemic attack	257 (2.6)	283 (0.9)	3.0 (2.5 to 3.6)	2.6 (2.2 to 3.2)

*Adjusted for quintile of deprivation and smoking status.

indicators recorded in their computerised records (table 5). However, because this was true for controls as well as cases, odds ratios for having each of the clinical indicators recorded were in fact higher in men than women. In both men and women, levels of clinical indicator recording were higher in complex or moderate cases of congenital heart disease than in simple cases.

DISCUSSION

Principal findings

In this population-based study, we found that the overall crude prevalence of diagnosed congenital heart disease is three people in every 1000. Just over one-quarter of patients with congenital heart disease have either moderately complex or complex lesions of the type that would typically require follow-up in a specialist centre. Unsurprisingly, we found that people with congenital heart disease have an increased risk of cardiovascular comorbidities and diabetes, yet they also have an increased risk of epilepsy and chronic renal disease. We also found that levels of healthcare use among people with congenital heart disease are high, even among simple or uncomplicated cases. Patients with congenital heart disease are more likely than

age- and sex-matched controls to have basic clinical indicators recorded in their primary care computerised records, however, the overall level of recording of each indicator is low compared with those reported in previous studies of patients with diabetes and coronary heart disease.^{21 22 26}

Strengths and limitations

Our sample of patients with congenital heart disease is derived from a large and nationally representative study population. The age and sex composition of the QRESEARCH database corresponds well to the national population (data not shown), and previous studies have validated the QRESEARCH database against other population and primary care data sources, and found high levels of consistency and completeness.²³ Consequently, our estimates of crude prevalence, prevalence of comorbidities, patterns of healthcare use and process of care measures have good generalisability.

Our case definition was based on diagnostic codes for congenital heart disease, and procedure codes specifically relating to congenital heart disease. The diagnosis of congenital heart disease has not been specifically validated in the QRESEARCH database, or in similar general practice research

Table 3 Odds ratios for selected measures of healthcare utilisation between 2002 and 2004 for cases and controls

	Cases		Controls (n = 29 837)	Complex or moderate CHD vs no CHD (adjusted OR* (95% CI))	Simple CHD vs no CHD (adjusted OR* (95% CI))
	Complex or moderate (n = 2247)	Simple (n = 7250)			
Specialist referrals, 2002–4					
0	1457	4880	22 744	1.0	1.0
1–3	726	2205	6495	1.8 (1.5 to 2.2)	1.7 (1.5 to 1.9)
≥4	64	165	598	1.6 (1.0 to 2.6)	1.3 (1.0 to 1.8)
Prescriptions, 2002–4					
0	190	812	5612	1.0	1.0
1–9	685	2976	11 264	1.6 (1.1 to 2.1)	1.5 (1.3 to 1.8)
10–19	345	1175	4125	2.3 (1.7 to 3.3)	1.8 (1.5 to 2.1)
≥20	1027	2287	8836	4.0 (2.9 to 5.4)	1.9 (1.6 to 2.2)
GP consultations 2002–4					
0	171	661	4773	1.0	1.0
1–9	1130	4092	15 982	1.9 (1.4 to 2.7)	1.7 (1.4 to 2.0)
10–19	579	1677	5853	2.8 (2.0 to 4.0)	2.0 (1.7 to 2.4)
≥20	367	820	3229	4.3 (3.0 to 6.1)	2.1 (1.7 to 2.6)

*Adjusted for deprivation and smoking. CHD, congenital heart disease.

Congenital heart disease

Table 4 Proportions and odds ratios (ORs) for clinical indicator recording in 9952 cases and 29 837 controls

Clinical indicator recorded in past 24 months	Cases No (%)	Controls No (%)	Unadjusted OR (95% CI)	Adjusted OR* (95% CI)
Body mass index	2703 (27.2)	7111 (23.8)	1.27 (1.20 to 1.35)	1.23 (1.16 to 1.31)
Smoking status	3754 (37.7)	9901 (33.2)	1.36 (1.28 to 1.44)	1.32 (1.24 to 1.40)
Systolic blood pressure	4173 (41.9)	10 421 (34.9)	1.73 (1.63 to 1.85)	1.68 (1.57 to 1.80)
Diastolic blood pressure	4167 (41.9)	10 415 (34.9)	1.73 (1.62 to 1.85)	1.67 (1.57 to 1.79)
Serum cholesterol	1535 (15.4)	3159 (10.6)	1.92 (1.80 to 2.08)	1.87 (1.72 to 2.04)

*Adjusted for deprivation.

databases. Babies who are born with severe congenital heart disease lesions, and who die before intervention are less likely to be registered with a general practitioner than those infants who survive. Consequently, these patients are less likely to have been included in our study population. We would also expect poorer clinical recording of congenital heart disease diagnoses in older patients, particularly among those who underwent surgical repair many years ago for simple lesions, and who have no residua or sequelae. Also our assignment of a primary diagnosis and classification of cases into complexity groups based solely on an assessment of anatomical severity is relatively crude, but reflects both the limitations of using routine data sources and the lack of a standardised approach to classification of congenital heart disease in either epidemiological or clinical studies.²⁷ Classifications based solely on the anatomical or structural nature of heart defects do not necessarily correspond to the clinical severity or functional importance of different lesions.

By excluding patients who had been registered with their practice for <6 months, we minimised possible information and recording bias. However, we were not able to study hospital records for the patients in this study and so could not examine rates of specialist cardiac interventions or the care received at specialist cardiac centres. Missing data may also introduce some bias into our study if the pattern of recording varied between cases and controls.

Interpretation

Data on the prevalence of key comorbidities and indicators of healthcare utilisation are useful in assessing current provision of services for this population and the burden of morbidity. We are not aware of previous population-based studies that have

examined the prevalence of key comorbidities in patients with congenital heart disease, or examined patterns of healthcare use from a primary care perspective. The increased prevalence of a range of cardiovascular and other comorbidities in patients with congenital heart disease found in this study serves to underline the considerable burden of morbidity associated with this patient population.

Given the increased prevalence of these key chronic conditions, coupled with the need of many patients with congenital heart disease for long-term specialist follow-up of their underlying heart malformation,²⁸ it is unsurprising that patients with congenital heart disease use healthcare services more often than patients without the condition. Our study also shows that the burden of morbidity associated with congenital heart disease clearly has an impact in primary care, as well as in secondary and tertiary care settings.

Unlike for coronary heart disease or diabetes,²⁹⁻³¹ there are no agreed quality indicators for the management of patients with congenital heart disease in primary care, and general practitioners do not receive payments for achieving quality of care targets. We examined the recording of key lifestyle and cardiovascular risk factors in primary care for patients with congenital heart disease, and in their age- and sex-matched controls. It is reassuring to see higher levels of clinical indicator recording in patients with congenital heart disease compared with controls. However, absolute levels of recording in this patient population, even when we excluded patients under the age of 16 years, were low when compared with levels reported in studies of patients with chronic diseases such as diabetes or ischaemic heart disease that are now included in the new contract for UK general practitioners.^{21 22 32}

Additional investment in the education of both patients with congenital heart disease and healthcare professionals outside the

Table 5 Proportions and odds ratios for clinical indicators recording by sex and congenital heart disease (CHD) severity

Clinical indicator recorded in past 24 months	Cases		Controls No (%)	Complex or moderate CHD vs no CHD (adjusted OR* (95% CI))	Simple CHD vs no CHD (adjusted OR* (95% CI))
	Complex or moderate No (%)	Simple No (%)			
<i>Males (n)</i>	1214	3321	14 259		
Body mass index	310 (25.5)	694 (20.9)	2583 (18.1)	1.63 (1.36 to 1.95)	1.3 (1.16 to 1.46)
Smoking status	450 (37.1)	993 (29.9)	3762 (26.4)	1.76 (1.49 to 2.09)	1.35 (1.22 to 1.51)
Systolic blood pressure	529 (43.6)	1013 (30.5)	3658 (25.7)	3.02 (2.50 to 3.65)	1.65 (1.47 to 1.86)
Diastolic blood pressure	528 (43.5)	1012 (30.5)	3655 (25.6)	3.02 (2.50 to 3.65)	1.65 (1.47 to 1.86)
Serum cholesterol	247 (20.3)	477 (14.4)	1484 (10.4)	2.62 (2.09 to 3.30)	2.00 (1.72 to 2.34)
<i>Females (n)</i>	1033	3929	15 578		
Body mass index	372 (36.0)	1169 (29.8)	4528 (29.1)	1.22 (1.02 to 1.46)	1.08 (0.98 to 1.19)
Smoking status	483 (46.8)	1612 (41.0)	6139 (39.4)	1.15 (0.96 to 1.39)	1.20 (1.08 to 1.32)
Systolic blood pressure	571 (55.3)	1828 (46.5)	6763 (43.4)	1.56 (1.26 to 1.92)	1.44 (1.29 to 1.61)
Diastolic blood pressure	571 (55.3)	1826 (46.5)	6760 (43.4)	1.54 (1.26 to 1.91)	1.44 (1.29 to 1.60)
Serum cholesterol	211 (20.4)	516 (13.1)	1675 (10.8)	1.96 (1.54 to 2.49)	1.65 (1.43 to 1.90)

*Adjusted for deprivation.

field of adult congenital heart disease is required to improve care quality, and to enable patients with congenital heart disease reach their full life potential.⁵³ The absolute number of patients with congenital heart disease that a typical general practice will manage is low, as is the absolute increase in workload in primary care. Despite this, general practitioners do have an important role to play in the care of these patients, particularly in areas such as secondary prevention and health promotion and in the early recognition of complications of congenital heart disease.

Although this patient population is relatively small when viewed in the context of the major chronic diseases such as coronary heart disease and diabetes, an increase in the numbers of adult patients with congenital heart disease owing to improved survival has been widely predicted.^{5 12 17 34} Consequently, the healthcare needs and demands of patients with congenital heart disease can only be expected to grow in future. The national review of paediatric congenital cardiac services published in 2003,¹⁰ and the development of new service standards for adults with congenital heart disease by the Department of Health,⁵⁵ signal a growing and welcome recognition of the particular needs of patients with congenital heart disease throughout their lives, and not just in childhood. Policy makers, clinicians and commissioners may find these recent data on the burden of congenital heart disease and patterns of health service utilisation useful for planning services for this patient group. They also serve as a reminder that any recommendations for standards of care for these patients with congenital heart disease need to embrace care provided in primary and secondary care settings, and not just in tertiary centres.

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Ethics approval: Approved through the QRESEARCH ethics process.

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