



Staffing, activities, and infrastructure in 96 specialised adult congenital heart disease clinics in Europe



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ABSTRACT

Background: Clinical guidelines emphasise the need for specialised adult congenital heart disease (ACHD) programmes. In 2014, the working group on Grown-up Congenital Heart Disease of the European Society of Cardiology (ESC) published recommendations on the organisation of specialised care for ACHD. To appraise the extent to which these recommendations were being implemented throughout Europe, we assessed the number of patients in active follow-up and available staff resources in European ACHD programmes.

Methods: We conducted a descriptive, cross-sectional, paper-based survey of specialised ACHD centres in Europe in late 2017 concerning their centre status in 2016. Data from 96 ACHD centres were analysed. We categorised ACHD programmes into seven different centre types based on their staff resources and composition of interdisciplinary teams.

Results: Only four centres fulfilled all medical and non-medical staffing requirements of the ESC recommendations. Although 60% of the centres offered all forms of medical care, they had incomplete non-medical resources (i.e., specialised nurses, social workers, or psychologists). The participating centres had 226,506 ACHD patients in active follow-up, with a median of 1500 patients per centre (IQR: 800–3400). Six per cent of the patients were followed up in a centre that lacked a CHD surgeon or congenital interventional cardiologist.

Conclusions: A minority of European ACHD centres have the full recommended staff resources available. This suggests that as of 2016 either ACHD care in Europe was still not optimally organised, or that the latest ESC recommendations were not fully implemented in clinical practice.

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1. Introduction

The growing number of adults with congenital heart disease (CHD) has prompted the establishment of an adult congenital heart disease (ACHD) medical subspecialty, and dedicated ACHD programmes have been founded in many health institutions [1]. Numerous guidelines and recommendations have been published over the past two decades,

with the aim of standardising and optimising care for ACHD patients throughout Europe and North America [2–11]. Some of these guidelines have addressed the organisation of specialised care [4–8,11]. The latest recommendations on this subject, released by the working group on Grown-up Congenital Heart Disease (GUCH) of the European Society of Cardiology (ESC) in 2014 [11], defined the staffing requirements for specialised ACHD centres (see Supplementary material online, Table S1). To date, it is still unclear to what extent these recommendations are being implemented in European ACHD centres.

The first such evaluation of specialised ACHD centres was conducted in 2003–2004 as part of the Euro Heart Survey on ACHD [12]. This survey included 48 specialist ACHD centres, which had a median of 500 outpatient clinic visits per year [12]. A few years later (2007–2008), a more extensive survey was conducted with 53 centres [13]. The median number of outpatients per year was 800 in that survey [13], suggesting an increase in caseload of 60% in only 4 years. Almost all centres (94%) had at least two ACHD cardiologists and two surgeons dedicated to ACHD surgery. Furthermore, 68% of the centres had a nurse specialist on staff.

Since the last survey was performed over 10 years ago and because the feasibility of the 2014 recommendations has not been assessed to date, a new evaluation of European ACHD centres is warranted. The aim of this study was to assess the current situation regarding the status of (i) staff resources and the number of patients in active follow-up; (ii) clinical activities; (iii) education offered to health professionals; and (iv) available support services.

2. Methods

2.1. Participating centres and procedure

We carried out a descriptive, cross-sectional, paper-based survey of specialised European ACHD centres. The content of the survey was similar to the 2007–2008 survey [13]. We used the previously used definition for specialised ACHD centres: (i) having on staff at least one cardiologist with ACHD certification or equivalent training and (ii) having at least 200 ACHD patients in active follow-up [13].

Through the ESC working group on GUCH, one or more ACHD representatives for each country were identified and asked to provide a list of active ACHD programmes in their jurisdiction. Directors of all these programmes were contacted and invited to participate in the survey. They were also asked to list other centres that we might have overlooked in their own country or neighbouring countries. As a result, we identified 152 candidate ACHD centres, which we contacted by email. Along with the survey questionnaire, we provided in the email detailed information on the study aim, design, and confidentiality specifications. If after four weeks no response was received, we emailed three more reminders.

Data collection took place between September and December 2017. We made clear in the survey that all questions referred to the status of the centres in 2016. The questionnaire comprised 38 questions, including ones on (i) facility and staff resources, (ii) patient population and clinical activities, (iii) education offered to residents and cardiologists, (iii) the equipment available, and (iv) supportive services. We reviewed the returned questionnaires to determine whether all items were fully completed.

According to the Institutional Review Board of Leuven, Belgium, ethical review was not necessary since the study was considered to be a service quality evaluation.

2.2. Categorisation of centres

In order to group centres with similar staffing characteristics, we defined seven types of centres (see Supplementary material online, Table S2). These types were based on an adapted version of the latest recommendations on organisation of care by the ESC working group on GUCH, which defined staff requirements and number of specialists for an ACHD centre (see Supplementary material online, Table S1) [11]. The two adaptations are as follows. First, the presence of a cardiovascular pathologist was considered optional, because their involvement in the clinical routine for ACHD patients has decreased recently with the increasingly important role of cardiac imaging. Second, we did not specifically query whether a centre had an anaesthesiologist with CHD experience, because if the centre had a CHD surgeon (which we did query), it would also likely have an anaesthesiologist with CHD training and experience. ACHD cardiologists, ACHD imaging specialists, congenital interventional cardiologists, CHD surgeons, and interventional electrophysiologists were categorised as medical staff, whereas psychologists, social workers, and Master's-prepared nurses were categorised as non-medical staff. Type 1 centres had all medical and non-medical staff according to the latest recommendations. At the other side of the spectrum, type 7 centres were characterised with incomplete medical and non-medical staff. Hence, it can be questioned if such centres can fully operate as an ACHD centre.

2.3. Statistical analysis

Categorical data are presented as absolute numbers and percentages, whereas non-normally distributed discrete data are presented as median and interquartile range (IQR). Spearman's rank correlation coefficient was used to measure the strength and direction of two non-normally distributed variables. For normally distributed data, a Pearson product-moment correlation coefficient was computed. To evaluate statistical differences between groups, we used one-way ANOVA. Missing values for full-time equivalents (FTEs) were imputed by the average FTE values adjusted for number of ACHD cardiologists in the centre. All analyses were performed with IBM SPSS Statistics 24 (IBM Corp. Released 2016. IBM SPSS Statistics for Windows, Version 24.0; Armonk, NY: IBM Corp.). $P < 0.05$ was considered statistically significant.

3. Results

Out of the 152 questionnaires emailed, 104 were returned, producing a 68% response rate. After the data review, eight questionnaires were excluded, because they failed to fulfil our inclusion criteria for a specialist ACHD centre. Hence, data from 96 centres in 24 countries were analysed. The median age of the centres was 13.5 years (IQR: 9–21.3). Supplement material online, Fig. S1 shows the number of European specialist ACHD centres established per year, as well as the cumulative growth in number of centres over time.

3.1. Characteristics of ACHD centres

Of the 96 specialist ACHD centres, only 4 (4%) were Type 1 centres; i.e., those that fulfilled all medical and non-medical staffing requirements as outlined in the latest recommendations [11] (see Supplementary material online, Table S2). Ten centres (10%) were Type 2 centres, those that had all types of medical and non-medical professional specialists on staff, but lacked two or more CHD surgeons, imaging specialists, interventional cardiologists, or nurses with Master's degrees in their team. More than half of the centres ($n = 58$, 60%) were Type 3 or 4 centres, possessing all of the recommended medical staff specialists but lacking, or only partially having non-medical support staff.

3.2. Staff resources

In total, 389 ACHD cardiologists worked in the 96 participating centres, corresponding to 236 FTEs. Details of the staff composition of the seven different types of centres are summarised in Table 1. Overall, centres had a median of 4 (IQR 2–5) ACHD cardiologists, corresponding to a median of 2.4 FTE per centre. Of the 389 ACHD cardiologists, 246 (63%) had training and expertise in adult cardiology, and 143 (37%) had training and expertise in paediatric cardiology. ACHD-certified adult cardiologists, or physicians having equivalent training, provided care exclusively in 39 (41%) centres. For 3 (3%) centres, care was exclusively provided by ACHD-certified paediatric cardiologists—or physicians having equivalent training—and in 54 (56%), an ACHD team comprising cardiologists trained in adult and paediatric care provided care. Participating centres had a median of two ACHD surgeons, two congenital interventional cardiologists, and two electrophysiologists. In the vast majority (97%) of the centres, a cardiac magnetic resonance imaging (MRI) specialist was available. Among non-medical staff, the number of Master's-prepared nurses slightly outnumbered the number of social workers or psychologists.

To determine whether greater country wealth was associated with greater staff resources, we compared the 24 participating countries' gross domestic product (GDP) per capita across the different types of centres. One-way ANOVA revealed no significant difference between countries' GDP and the type of centre ($F_{7, 96} = 0.081$).

3.3. Patient population

Altogether, the centres had 226,506 ACHD patients in active follow-up, with a median of 1500 patients per centre (IQR: 800–3400). The four Type 1 centres had a total of 8354 patients in active follow-up. In other words, only 4% of ACHD patients received care in a Type 1 centre

Table 1
Staffing resources stratified by type of centre (N = 96).

	Type 1 ^a 4 (4)	Type 2 ^a 10 (10)	Type 3 ^a 40 (42)	Type 4 ^a 18 (19)	Type 5 ^a 4 (4)	Type 6 ^a 6 (6)	Type 7 ^a 14 (15)
Overall medians (IQR)							
Specialist type							
ACHD cardiologist	8 (5–8.8)	3.5 (2.8–5)	5 (3–6)	4 (2–4.3)	3.5 (2.3–4)	2 (1.8–2.5)	2 (1–2.3)
FTE ACHD cardiologist	4.7 (2.8–7.0)	2.3 (1.9–3.8)	2.5 (1.6–3.9)	1.8 (1.1–2.5)	2.8 (2.1–3.0)	0.7 (0.2–1.4)	1.0 (0.5–1.4)
Adult cardiologist with ACHD training	1.5 (0.3–5)	3 (2–3.3)	3 (2–4)	2 (1.8–3.3)	2.5 (1.3–3.8)	1.5 (1–2.3)	1 (1–2)
Paediatric cardiologist with ACHD training	4.5 (2–8.5)	0.5 (0–2.3)	2 (0–3)	1 (0–2)	0.5 (0–1.8)	0.5 (0–1)	0.0 (0–1)
CHD surgeon	2.5 (2–3.8)	1 (1.8–3)	2 (2–3)	2 (1–3)	0.0 (0–0)	–	0.0 (0–2)
Congenital interventional cardiologist	2.5 (2–3)	1 (1.8–3.3)	2 (1.3–3)	2 (1–2)	1.0 (0.3–2.5)	0 (0–1)	1 (0–2)
Cardiac MRI specialist	2 (2–2.8)	1 (1–2)	2 (1–3)	1 (1–2)	1.5 (1–2)	1 (1–1.3)	1 (0.8–1)
Electrophysiologists with ACHD experience	1 (1–2.5)	2 (1–2)	2 (2–2.8)	1 (1–2)	1 (1–1.8)	1.5 (1–2.3)	0.0 (0–0.0)
Master's-prepared nurse	2.5 (2–3)	1 (1–2)	0 (0–1)	–	1 (0–0)	–	0.0 (0–0.5)
Psychologist	1 (1–1)	1 (1–2)	1 (0–1)	–	1 (1–1)	–	–
Social worker	1.5 (1–2)	1 (1–1.3)	0 (0–1)	–	1 (0–0)	–	0.0 (0–0)

ACHD, adult congenital heart disease; CHD, congenital heart disease; FTE, full time equivalent; MRI, magnetic resonance imaging.

^a Data presented are N (%).

(Table 2). The majority of the patients (56%) were followed up in a Type 3 centre. This is in line with the fact that the four biggest centres in Europe are all Type 3 centres; each of these centres oversees the care of >8000 patients. Six per cent of patients ($n = 14,950$) were followed up in a centre that lacked a CHD surgeon or congenital interventional cardiologists (Type 5 and 6 centres). The number of patients in active follow-up and the composition of the interdisciplinary teams are summarised in Fig. 1. The number of patients in active follow-up and the age of the ACHD programme were positively correlated ($r = 0.354$, $p < 0.001$). In general, older centres had more CHD patients in active follow-up than newly established centre.

3.4. Clinical procedures

3.4.1. Transfer

Systematic transfer, which is defined as “an event on which adolescent and their parents move their care from the paediatric to the ACHD programme” [14], occurred in 89% of the participating centres (Table 2).

3.4.2. Outpatient activities

Overall, the 96 centres treated a median of 25 patients per week (IQR: 15–49) in their outpatient clinics. Type 1, 3, and 5 centres treated

a median of 40 patients per week (IQR 20–60), whereas Type 6 and 7 centres treated a median of 14 outpatients per week (IQR 7–27). The median time spent by cardiologists in outpatient care per week was 24 h per centre (IQR: 14.25–40). Fig. 2 shows the relationship between the total time ACHD cardiologists spent on ACHD outpatient care per visit per week.

Statistical analysis revealed a strong positive linear relationship between the average number of patients seen per week and time spent per week for outpatient care ($r_s = 642$, $p < 0.001$). Nevertheless, there was much variability across centres and even within the same type of centre.

3.4.3. Inpatient activities

In 2016, the 96 participating ACHD centres had a total of 14,331 hospital admissions, with a median of 100 (IQR: 40–250) hospital admissions per ACHD centre per year. Type 1 centres had the highest median number of hospital admissions at 306 per year (IQR: 118–860), while Type 6 centres had the lowest number of admissions at 30 (IQR: 20–45). In 2016, 4613 surgical procedures (median: 43 [IQR: 15–70]) were performed. Almost 60% of the surgical procedures took place in Type 3 centres. In the 96 centres, 5240 catheter procedures were

Table 2
Patient population and clinical activities stratified by centre type (N = 96).

	Type 1 (N = 4)	Type 2 (N = 10)	Type 3 (N = 40)	Type 4 (N = 18)	Type 5 (N = 4)	Type 6 (N = 6)	Type 7 (N = 14)
Characteristics							
Patients in active follow-up, count (%)	8354 (4%)	20,100 (9%)	127,468 (56%)	38,349 (17)	7300 (3%)	7650 (3%)	17,285 (8%)
Patients in active follow-up per centre, median (IQR)	2100 (991–3175)	1500 (1175–2000)	2000 (1299–4875)	1365 (865–3175)	1300 (525–3650)	700 (388–1775)	550 (438–1125)
Patients seen per week in the outpatient clinic, count (%)	172 (5%)	232 (7%)	1729 (54%)	522 (16%)	186 (6%)	102 (3%)	275 (9%)
Patients seen per week at the outpatient clinic per centre, median (IQR)	40 (19–70)	22 (13–38)	40 (20–60)	24 (14.8–40)	40 (15–84.5)	14 (7–27.5)	13 (9.5–17.5)
Total hours per week expended for outpatient care	192	317	1208	665	188	79	219
Hours expended for outpatient care per centre, median (IQR)	18.5 (5.5–120)	22.5 (14.3–42)	30 (15.3–44)	25 (15–46.3)	46 (22–73)	12 (7.8–20)	13.5 (11.5–16.5)
Hospital admissions in 2016, count (%)	1712 (12%)	1992 (14%)	7113 (49%)	2394 (17%)	250 (2%)	160 (1%)	710 (5%)
Hospital admissions 2016 per centre, median (IQR)	306 (118–860)	143 (68–357)	165 (86–293)	55 (29–131)	80 (20–80)	30 (20–45)	40 (21–65)
Surgical procedures 2016, count (%)	460 (10%)	552 (12%)	2683 (57%)	592 (13%)	75 (2%)	76 (2%)	175 (4%)
Surgical procedures in 2016 per centre, median (IQR)	87.5 (38.8–218.8)	55 (26.3–85.3)	53.5 (38.3–91)	28.5 (14.3–48.8)	15 (0–15)	1 (0–37.5)	10 (0.5–18.8)
Surgical procedures per CHD surgeon, median (IQR)	40 (16.9–62.5)	26.8 (12.5–49.8)	26.3 (15.4–43.5)	15 (8.8–21.8)	60 (60–60)	–	10.8 (5–17.5)
Catheter interventions in 2016, count (%)	567 (11%)	583 (11%)	3068 (59%)	632 (12%)	77 (1%)	15 (0.3%)	298 (6%)
Catheter interventions in 2016 per centre, median (IQR)	130 (107.8–187.5)	32 (17.5–100)	60 (25–120)	27 (10.3–57.5)	4 (3–4)	0 (0–7.5)	10 (2.5–20)
Systematic transfer from paediatric to adult service, count (% per type)	2 (50%)	9 (90%)	36 (90%)	16 (88.9%)	4 (100%)	5 (83.3%)	13 (92.9%)

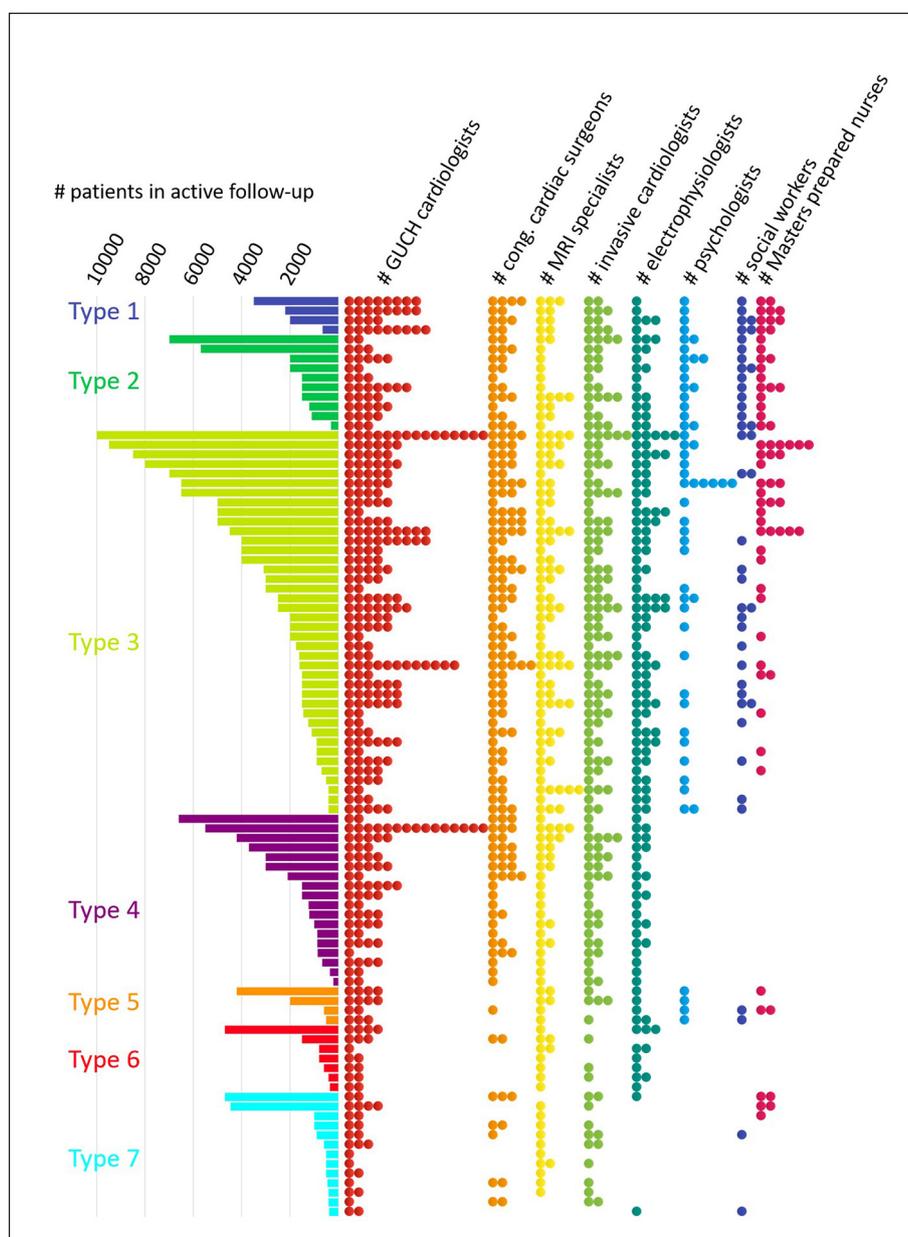


Fig. 1. Cumulative patient and individual specialist histograms of staffing resources and number of patients in active follow-up in 96 European ACHD centres.

performed, with a median of 30 (IQR: 0–342). Again, most procedures were performed in Type 1 centres (median: 130 [IQR: 107.8–187.5]).

3.4.4. Continuing education

Ninety-two of the 96 ACHD centres were engaged in educating physicians interested in ACHD care. By 2016, a total of 501 ACHD fellows had finished their subspecialty training in one of the participating centres. The vast majority were trained in Type 1–4 centres. More than half of the centres (68%) offered training for residents in paediatric cardiology, and 88% trained residents in general adult cardiology. Detailed information about educational programmes offered in centres can be found in Supplementary material online, Table S3.

3.4.5. Support services

Obstetric services for the care of high-risk pregnant ACHD patients were available in 87 centres (91%). A total of 60 (63%) were also heart transplant centres, and 35 (37%) had the capacity to perform lung transplantations. In addition, 90% of the centres offered genetic services and

82% offered cardiac rehabilitation (Supplementary material online, Table S4).

4. Discussion

The results of this study provide information on the structure and activities of European ACHD centres surveyed in 2016, updating and expanding on the findings of a similar study that analysed data on European ACHD centres for 2006 [13]. Since that study, expert-based recommendations and guidelines have been published on how to set up ACHD centres. The present study, therefore, aimed to summarise the current staffing, infrastructure, and activities of ACHD centres in Europe and to discuss how our findings match up with the latest recommendations.

A total of 96 centres were included in the present study, which is 41% more (43 additional centres) than in the survey of 2006 by Moons et al. [13]. The response rates were similar in the two studies (68% in the present study vs. 76% in Moons et al.). The 96 participating centres had 226,506 ACHD patients in active follow-up, which is more than

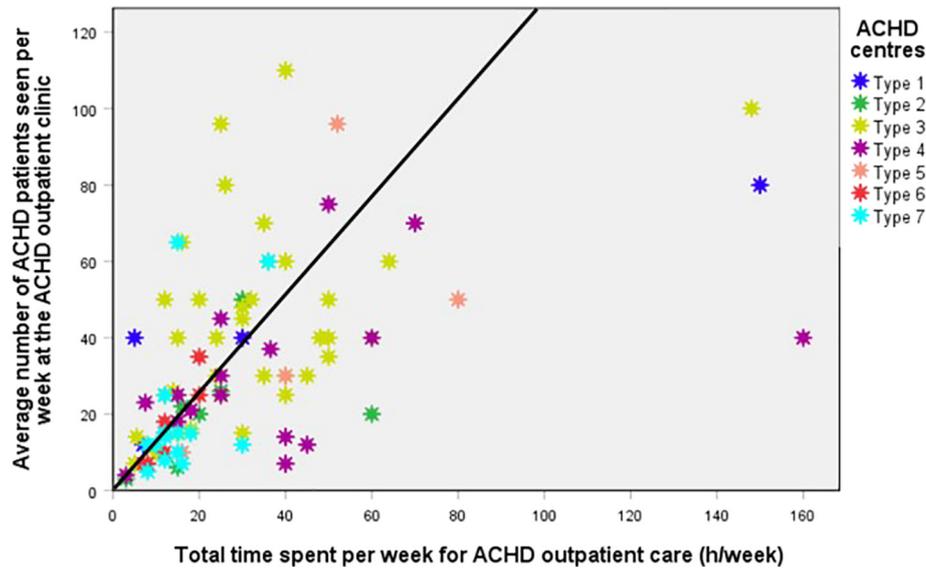


Fig. 2. Scatter plot of number of outpatients seen per week versus total number of hours worked by cardiologists at the ACHD outpatient clinic per week. The diagonal line in the plot represents the average time spent on ACHD care versus the average number of visits per week in each centre (0.8 h/patient).

double the number of patients noted in the Moons et al. survey [13]. Extrapolating from this number to the 152 potential GUCH centres that we initially identified, but were not included for analysis because they either failed to return a survey or did not meet inclusion criteria, we estimate that about 330,000 patients are in ACHD care in Europe [15]. Given a population of 480 million inhabitants in the 24 participating countries and a total population of 1.5 million ACHD patients in these countries, we estimate that only about 22% of all European ACHD patients are receiving specialised ACHD care [16]. This is significantly less than the estimated 50% of GUCH patients (ACHD patients with moderate or complex defects) that are assumed to require GUCH care [3,5,17]. Our findings mirror those from a similar study of Canadian centres published in 2012. At that time, the 15 centres of the Canadian ACHD network had 27,739 CHD patients in active follow-up, corresponding to 23% of the estimated ACHD population in Canada [15].

Several possibilities may explain the discrepancy between the estimated number of ACHD patients and the actual number of patients receiving specialised ACHD care. First, some uncounted patients requiring care may actually be under ACHD surveillance by non-specialist clinics or general cardiologists, and are thus were missed by our survey. Second, some uncounted patients may indeed not be under ACHD surveillance, since lapses in care are common in adults with CHD [18]. Finally, the number of ACHD patients per region may be overestimated. Further research is needed to distinguish these possibilities. Regardless, our results suggest that at least some ACHD patients in Europe requiring specialised care are not receiving it.

With a median of 1500 patients per centre, the number of patients across centres appeared to remain stable between the 2006 and 2016 surveys [13]. At first glance, there appears to have been an increase in the number of ACHD centres in Europe over the past 10 years but not in the size of the centres, as defined by the number of patients in follow-up. This does not imply, however, that the numbers of patients across European centres is more or less the same. Rather, this may be due to the fact that older centres generally have more patients in regular follow-up than newly established centres, leading to a temporally stable median.

Given that clinical guidelines emphasise the need for specialised ACHD care with appropriate specialists, it is of interest to determine the interdisciplinary staff composition of the centres. Only four centres fulfilled the criteria for specialised ACHD centres, according to the 2014 ESC recommendations on optimal organisation of ACHD care [11]. Overall, there was great variability in the number of patients per

centre and its staffing resources. While some Type 7 centres with few staff members offered care to >4000 patients, there was also a Type 1 centre with all recommended staffing that served <600 patients. Furthermore, some large centres had on staff all types of cardiological medical staff, but no CHD surgeons. This was due to centralisation of heart surgery centres in Nordic countries, which required that heart surgeries be performed only in a few larger hospitals [19,20]. This would explain why centres lacking a CHD surgeon did not have fewer patients in follow-up than centres having a CHD surgeon.

Compared to 2006, the median number of ACHD cardiologists per centre increased from 2 to 4. Unfortunately, all conclusions related to numbers of ACHD specialists must be applied with care, since in most European countries no official ACHD subspecialty certification exists or is mandatory. One such exception is Germany, where ACHD subspecialty certification was established [21].

While 72 centres (75%) had all the recommended types of medical staff, only 14 centres (14%) also had the recommended non-medical staff. One in four centres (25%) completely lacked non-medical staff. Likewise, <50% of the centres had a low proportion of psychologists, social workers, and nurses. In the Euro Heart Survey 2006, 42% of the ACHD centres had a specialised nurse, and this percentage rose to 68% in the 2010 study [12,13]. In the present survey, only 40% of the centres had a specialised nurse in their team. Direct comparison, however, is difficult because in the current survey additional centres were included, and we explicitly asked about Master's-prepared nurses. Although studies emphasise the need for non-medical staff [12,22,23], not all countries have established the appropriate educational programmes, especially master programmes for nurses, for these staff.

Since European countries may vary in economic and infrastructural healthcare resources, not all countries may set the same healthcare priorities. Based on our study results, only four centres in Europe completely adhered to the working group recommendations for staff requirements. The majority of centres in our survey have all types of medical staff required but incomplete or missing non-medical staff (Type 3 & 4). Given, that anxiety, depression or problems coping with the medical condition are well known concerns in adult patients with CHD [24], non-medical staff can play a pivotal role in the care of ACHD patients [23,25,26]. It looks like the need for non-medical staffing in ACHD centres is not yet fully recognized or other reasons may come into play (e.g. financing of non-medical staffing may be more difficult to justify than for the medical staff).

Most ACHD guidelines and recommendations are based on expert opinions, and outcome measures to support the recommendations on staff requirements are lacking. In addition, these recommendations have not taken into account recent organisational developments in the care of ACHD patients, such as centralisation of surgery. Future recommendations, therefore, should consider these developments and emphasise research on the outcome of different types of care settings. In the meantime, putting in place minimal requirements for the organisation of health care services for patients is warranted, rather than devoting optimal resources. In this respect, a customised approach to staff resources may be more suitable. This type of approach would be based on patients' needs, for example, on the need for regular follow-ups or for interventional therapy, rather than be based solely on the complexity of a defect. This approach would also reflect the current organisational developments in ACHD care in Europe.

Concerning the future need for cost-effective ACHD programmes and our finding that resource deployment is highly variable across centres, the use of established quality indicators for future benchmarking between centres could play an important role. This suggestion is supported by various recent publications [27,28]. For example, Beauchesne et al. argues that care services need to be linked to outcomes in order to determine more precisely what the ideal staffing numbers should be for ACHD centres.

5. Limitations

Since the data reflected the status of ACHD specialist centres in 2016, some of the information presented here may already have changed by the publication date. In addition, although we were diligent in our efforts, we cannot assume that we identified all specialised ACHD centres in Europe. Furthermore, the data are self-reported, and verification was not possible. Therefore, our conclusions are based on estimates, albeit we believe reasonable ones. In addition, definitions for specific terms used in the survey questions may vary somewhat from country to country and/or from centre to centre. For example, the definition of an ACHD specialist is not based on formal qualifications but on self-declaration. Similarly, no formal definition exists for the terms 'cardiac MRI specialist', 'congenital interventional cardiologist', 'electrophysiologist with ACHD experience', 'ACHD fellow', or even 'CHD surgeon'.

6. Conclusion

The present findings showed that only 4% of the ACHD centres in Europe are organised strictly according to the latest recommendations, while the majority of ACHD patients are seen in centres with incomplete or missing non-medical staff. This means either ACHD care in Europe is still not optimally organised or that the current recommendations are not yet fully implemented in clinical practice. The next step to improve ACHD care according to recommendation papers is to integrate or expand their non-medical staff.

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ijcard.2019.04.077>.

Declaration of interest

None.

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