Improvements in surgical and medical care have markedly changed the demographics of congenital heart disease (CHD). In a Canadian population-based study, 66% of all persons living with severe CHD in 2010 were adults. Following the development of Canadian guideline for adult CHD (ACHD), there were increased referrals to ACHD centers and a temporally associated decrease in mortality. Yet how patients transfer from pediatric to adult care varies greatly in many communities. Some patients transfer to regional ACHD care centers, some to general adult cardiologists and others maintain longitudinal care with their pediatric cardiologists.

In this issue of the Journal, Ochiai and colleagues seek to better understand the variation in transfer practices. The investigators surveyed pediatric cardiologists regarding current ACHD care within their own departments, transfer practices and if their pediatric facilities intended to be ACHD centers. There was a robust response, with replies from 113 of 149 centers across Japan. A majority of responders (54%) believed their facility would serve the role of an ACHD, including 5 free-standing pediatric hospitals. There was a high degree of variability in the volume of care currently being delivered. Among all respondents, 43% of facilities followed fewer than 50 patients per year and 54% had fewer than 10 ACHD surgeries per year; 26 centers had more than 200 patients per year and were estimated to be seeing 80% of the ACHD population. Only 3 centers performed more than 50 ACHD surgeries annually. Among the 61 centers intending to serve as ACHD centers, 9 met the minimal criteria set by the authors and only 1 met all of the optimal criteria.

Regarding current transfer patterns, 43% (49 of the 113 facilities) either routinely transfer their pediatric patients or consider transfer on a case-by-case basis. Regarding future intentions, 49% (55 facilities) aspire to transfer to dedicated centers.
ACHD facilities while 30% (34 facilities) would prefer to keep them within a pediatric setting.

These percentages are relatively similar to a 2009 survey of pediatric cardiology programs in the United States. Among 69 centers that participated in the survey, 36% (25 of 69 centers) had an optional transfer policy, 38% (26 centers) had a mandatory transfer policy and 26% (18 centers) did not intend to transfer patients.

Although there is anticipated benefit from dedicated ACHD centers, there is controversy regarding whether this care should be centered at a pediatric or an adult institution. In analyses of the Nationwide Inpatient Sample, a cross-sectional database of approximately 20% of the non-federal hospitals in the USA, mortality was lower for pediatric heart surgeons operating on adult patients at pediatric centers vs. pediatric heart surgeons operating on adults at adult hospitals. Non-pediatric heart surgeons had higher mortality rates than their pediatric colleagues. There was a survival advantage with increasing surgeon annual pediatric volume. Favorable surgical results have been obtained by congenital heart surgeons at high-volume adult hospitals with dedicated ACHD teams. Overall, the data suggest a benefit to higher volume congenital heart surgery centers. High volume alone does not insure quality, but it can justify expenditure of resources towards specialized personnel and equipment, building team experience, and refining processes.

Pediatric heart centers may have extensive expertise with the surgical, interventional, electrophysiological and imaging aspects of CHD, but they often have limitations for caring for adults beyond the scope of their disease. Non-cardiac comorbid conditions may warrant adult specialist care. Increasing numbers of women with CHD are becoming pregnant and frequently warrant a team-based approach between ACHD specialist, high-risk obstetrical providers and obstetrical anesthesiologists. Patients with the Fontan circulation may develop complications from congestive hepatopathy that may be better served by adult hepatologist/gastroenterologist care. With increasing numbers of ACHD patients reaching the 6th and 7th decades of life, we can expect to encounter increasing prevalence of age-related conditions such as atherosclerosis, renal disease, and cancer. Non-cardiac surgery is a particular challenge because patients are frequently at increased risk of adverse events. Non-cardiac surgery warrants strong collaboration between the ACHD cardiologist, the surgeon and the anesthesiologist.

As Ochiai et al. demonstrate, it is currently uncommon to have all of the elements for optimal care for the ACHD patient at a single institution. In many communities, it may be advantageous to develop a robust partnership between pediatric and adult institutions rather than trying to duplicate the resources of the other institution. The Figure elegantly illustrates the additional challenges of offering highly specialized resources in less densely populated communities. Coordination between local health centers and regional referral centers is likely necessary to achieve high-quality care across a wide geographic area.

Transfer from pediatric to adult congenital specialists should occur as the culmination of a multi-year process of transition education. Education should include anticipatory guidance regarding residual lesions, potential late sequelae, implications for vocation and lifestyle issues as well as contraceptive and pregnancy planning. The importance of lifelong care should be emphasized at a young age, as Mackie and colleagues demonstrated many patients fail to follow up with pediatric cardiology before adulthood. In their series, only 30% of patients with simple shunt lesions and 79% of patients with severe lesions were seen after the 18th birthday. Yet 93% of those patients still had contact with primary care or other physicians within the healthcare system.

This report significantly adds to the understanding of the current practices and perspectives of pediatric cardiologists in Japan. The findings will help inform collaborations between pediatric and adult providers striving to improve the outcomes for the rapidly growing number of adults with CHD.

References