


Norah Y.S. Yap¹ , Parth Patil², Carole Phoenix³, Katie Bradly Russell⁴, Clive Lewis³, Robert Yates⁵ and Wilf Kelsall⁴

Original Article

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Address for correspondence:

Dr Norah Y. S. Yap, Paediatric Cardiology Trainee, Southampton General Hospital, Tremona Road, Southampton SO16 6YD, England, UK.
E-mail: norahyap@doctors.org.uk

¹Department of Paediatric Cardiology, University Hospital Southampton, Tremona Road, Southampton SO16 6YD, England, UK; ²School of Clinical Medicine, University of Cambridge, Addenbrooke's Hospital, Hills Road, Cambridge CB2 0QQ, England, UK; ³Department of Cardiology, Royal Papworth Hospital, Papworth Everard, Cambridge CB23 3RE, England, UK; ⁴Department of Paediatrics, Addenbrooke's Hospital, Hills Road, Cambridge CB2 0QQ, England, UK and ⁵Department of Cardiology, Great Ormond Street Hospital, Great Ormond Street, London WC1N 3JH, England, UK

Abstract

Purpose: National standards to ensure effective transition and smooth transfer of adolescents from paediatric to adult services are available but data on successful transition in CHD are limited. The aim of this study is to assess the effectiveness of our transition pathway. **Methods:** Adolescents with CHD, aged 15–19 years, who attended the joint cardiac transition clinic between 2009 and 2018 were identified from the Patient Administration Systems. Patient attendance at their first adult CHD service appointment at Royal Papworth Hospital was recorded. **Results:** 179 adolescents were seen in the joint cardiac transition clinic in the 9-year study period. The median age of the patients when seen was 16 (range 15–19) years. 145 patients were initially planned for transfer to the Royal Papworth Hospital adult CHD service. Three patients were subsequently excluded and the success of the transfer of care in 142 patients were analysed. 112 (78%) attended their first follow-up in the adult CHD clinic as planned, 28 (20%) attended after reminders were sent out with 5/28 requiring multiple reminders, and only 2 (1.4%) failed to attend. Overall, transfer of care was achieved in 140 (98.6%) patients. **Conclusion:** A dedicated joint cardiac transition clinic involving multi-professional medical and nursing teams from paediatric and adult cardiology services appears to achieve high engagement rates with the adult services. This approach allows a 'face' to be put on a named clinician delivering the adult service and should be encouraged.

It is estimated that 1 in every 125 babies in the United Kingdom is born with CHD. Fifty years ago, 70% of these children would have died before their tenth birthday.¹ The great success of CHD surgery and medical care over the past five decades has resulted in majority of children with CHD surviving into adulthood. CHD, once a disease confined to childhood must now be thought of as a disease that continues into adult life. Between 1979 and 2008, the absolute numbers of deaths from CHD in children under 15 years have declined by 83% in the United Kingdom.² As these surviving patients are at high risk of late cardiac complications such as arrhythmia and cardiac failure, with many requiring further cardiac intervention, there is now increasing attention from CHD providers to ensure transition of care well into adulthood. This is paramount to provide specialised care for this steadily growing population which has now overtaken the number of children born with CHD.

The United Kingdom Department of Health defines transition, as “a purposeful, planned process that addresses the medical, psychosocial and educational, or vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems”.³ Transition of healthcare acts as a bridge from a paediatric family-orientated care to the adult patient-orientated care. It is recommended to be a gradual process that helps prepare and support the young adults for the actual transfer of medical care and prepares them for taking charge within their adult lives.^{4,5} Young people face many challenges when preparing for adult life and one of the most difficult is the safe transfer of care to an adult environment. There should be flexibility in transition planning and timing of transfer depending on the developmental maturity and health status of the individual adolescent, as well as the capabilities of the adult services.^{5,6}

Recommendations for transition programme by the British Cardiac Society,⁷ American Heart Association,⁸ and United Kingdom Department of Health,³ are available but successful transition model for young adults with chronic diseases is lacking. The National Institute for Health and Care Excellence published a quality standard for transition that aimed to improve the experience of transition within health and social care. Transition plans should be jointly agreed with the young person, include a named worker, and be developmentally appropriate and person centred for the individual.⁹ Arranging an efficient transfer for adolescents from

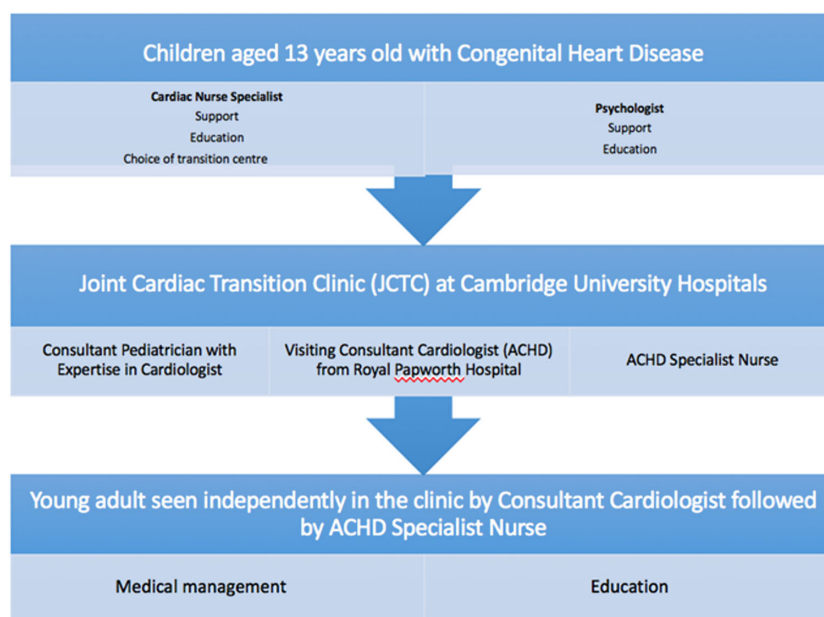


Figure 1. Cambridge cardiac transition process since 2009.

paediatric family-centred care to adult patient-centred care is often hindered by the general lack of awareness of the need for transition planning and effective transition service guidelines and protocols. Poorly organised care has been implicated as a factor causing deaths in young adult patients, which were avoidable.¹⁰ Planning for transition is recommended to start at the latest around 13–14 years and be guided by the patients' emotional maturity and developmental level. The National Institute for Health and Care Excellence guidelines recommend a named worker to ensure that patients who do not attend their first appointment are given further opportunities to attend.^{10,11}

Cambridge cardiac transition process

Since 1995, there has been a well-coordinated foetal and paediatric cardiology services in Cambridge, running as a hub and spoke model with the specialist congenital surgical centre in Great Ormond Street. Prior to 2009, the transition of paediatric cardiac patients was arranged on an ad hoc case-by-case basis. Building on success of the paediatric cardiac service, it was suggested that Cambridge University Hospital should establish an outreach transition clinic with specialists from The Heart Hospital, London/Great Ormond Street, coordinated by the local consultant paediatrician with expertise in cardiology. This service was discontinued in 2003 due to lack of adult cardiology input. Further, specialist adult nursing support in Cambridge was lacking meaning young people lacked information around "adult" issues such as employment, contraception, pregnancy advice, and management of ongoing medical problems such as arrhythmia.

In 2008, a dedicated adult CHD service comprising consultants and specialist nurses with a specific interest in adult CHD was established at Royal Papworth Hospital. In 2009, a formal joint cardiac transition clinic, initially running biannually was reinstated at Cambridge University Hospital. This service was again coordinated by the local consultant paediatrician with specialty expertise in cardiology working with the Royal Papworth Hospital adult

CHD multi-professional team, Great Ormond Street Hospital consultant paediatric cardiologist, the young adult, their family, and carers. The model for joint cardiac transition clinic is illustrated in Figure 1. Since 2009, the transition process has evolved. With growing confidence in the quality of the transition service, paediatrician with special interest in cardiology and adult congenital cardiologist continued the service without direct involvement of the visiting paediatric cardiologist. The frequency of the clinic has increased up to four per year with between six and eight patients attending each clinic. With the appointment of specialist cardiac nurses and clinical psychologists to the Cambridge paediatric team, we initiated a separate joint specialist nurse and psychologist transition clinic which invited patients aged 13–16 years to attend before they were seen in the established joint cardiac transition clinic to help support the child and their parents through their adolescent years.

All adolescents aged 13 and above were assessed for suitability for transition and the process was initially discussed with the patient and their parents from around this age in the Great Ormond Street outreach clinic by the specialist paediatric cardiologist. Patients who were ready for transition to the adult CHD service are seen at least once in the joint cardiac transition clinic held in the paediatric outpatient department. Meeting with the adult professionals during the transition process has been recommended by the National Institute for Health and Care Excellence guidelines.¹¹ During the joint cardiac transition clinic review, the patient and their family separately meet the Royal Papworth Hospital adult CHD specialist nurse to further discuss transition details: contraception, lifestyle activities and given adult CHD and patient association contact details. An agreed transfer plan is made with the patient and the adult CHD service prior to discharge from paediatric cardiology. All previous paediatric clinic letters, investigation results, surgical procedure reports, and images are copied to the adult CHD service.

All patients receive either postal, telephone, or text reminders about their first clinic appointment at the Royal Papworth Hospital adult CHD service. If they fail to attend this appointment, their contact details including addresses are checked with the

paediatric and General Practice team. Reminder letters are also sent out to the patients and copied to their general practitioner to remind them of the importance of engaging with regular follow-up. The aim of this study was to assess the effectiveness of the Cambridge Cardiac Transition Pathway and the joint cardiac transition clinic for adolescents with CHD in terms of first attendance in the Royal Papworth Hospital adult CHD service.

Methods

A retrospective study was conducted to review all patients who attended the joint cardiac transition clinic at Cambridge University Hospital between 01/09/2009 and 29/11/2018. This study received approval from our institutional audit department. Patients were identified from the Patient Administration System at the Cambridge University Hospital and Royal Papworth Hospital. Case notes were reviewed to record patients' demographics and attendance at their first appointment in the adult CHD service.

Results

Over the 9-year period, a total of 179 young people attended the joint cardiac transition clinic. Of these, 145 (81%) were planned for transfer to the Royal Papworth Hospital adult CHD service, 18 were transferred to other institutions, 14 to the heart failure service in Royal Papworth Hospital, and 2 to the Electrophysiology clinic at the Royal Papworth Hospital. Of the 145 patients planned to be seen in the Royal Papworth Hospital adult CHD service, 2 moved overseas in the intervening period between the transition clinic and the proposed adult clinic, and 1 patient was discharged from hospital care.

After excluding the ineligible patients, a total of 142 patients were included in the final analysis. Of these, 87 (61%) were male. 40 (28%) had a fetal diagnosis of CHD. The median age at transition was 16 (range 15–19) years. Surgical procedures were undertaken in 72 (50%), catheter-based interventions in 15 (11%), both surgical and catheter-based interventions in 13 (9%), and 42 (30%) were under long-term surveillance for unoperated CHD. The cardiac conditions in this cohort which are classified according to the Task Force for the management of adult CHD of the European Society of Cardiology guideline¹² are further detailed in Table 1.

The number of first-attendance patients in the adult CHD clinic was 112 (79%). The interval between attendance at the Cambridge Transition Clinic and their first Royal Papworth adult CHD clinic was 17 (1–53) months. Twenty-eight (20%) patients did not attend their first appointment. 23/28 (82%) patients attended after a second reminder and 4/28 (14%) following a third reminder. One (4%) required multiple reminders with repeated telephone calls, letters to both patient and general practitioners before eventually attending. Only two patients have currently failed to attend despite numerous reminders. Overall, successful transfer of care to the adult CHD service was achieved in 98.6% of patients.

Discussion

This study demonstrated that a high transfer rate of care from paediatric to adult CHD services was achievable using our pathway. Moons et al showed that transition programmes improved continuity of care in adolescence with CHD with only 12.7% discontinuity of care after transfer of care to adult CHD services compared to 36.2% in those without transitional care.¹³ In another

Table 1. Cardiac abnormalities n = 142.

Conditions	Number (%)
MILD	46 (32)
Aortic valve disease	21 (14.7)
Aortic root dilation	5 (3.5)
Atrial septal defect	8 (5.6)
Intramural right coronary artery	1 (0.7)
Kawasaki disease with coronary artery aneurysms	1 (0.7)
Left atrial isomerism	2 (1.4)
Mitral valve disease	6 (4.2)
PDA	2 (1.4)
MODERATE	88 (62)
Atrioventricular septal defect	5 (3.5)
Coarctation of the aorta/hypoplastic aortic arch	19 (13.3)
Critical pulmonary stenosis	8 (5.6)
Tetralogy of Fallot	19 (13.3)
Transposition of the great arteries with intact ventricular septum	8 (5.6)
Transposition of the great arteries + ventricular septal defect	5 (3.5)
Total anomalous pulmonary venous drainage	2 (1.4)
Ventricular septal defect	22 (15.4)
COMPLEX	8 (6)
Interrupted aortic arch	1 (0.7)
Single ventricle with Fontan circulation	6 (4.2)
Hypoplastic left heart	1 (0.7)
Tricuspid atresia	
Tricuspid atresia	

study, Kipps et al. compared different models of transition in young adults with type 1 diabetes and their study demonstrated that prior contact with the consultant from the adult clinic is an important determinant factor for successful transition and transfer of care; this is also recommended by the National Institute for Health and Care Excellence guideline 2016.^{9,14} Our model of transition which involves the adult CHD cardiologist in the transition clinic also resulted in a good first appointment attendance rate of young people with CHD successfully transferring to an adult CHD service. For patients who missed their first clinic appointment, counter-checking the patients' telephone numbers and addresses with the paediatric and general practitioner teams including phoning and writing to the patient and their general practitioners boosted the overall follow-up rate to more than 98%.

A good doctor–patient relationship is fundamental for the delivery of high-quality care. Patient satisfaction stems from the experience of care they receive from a team of healthcare providers. This satisfaction along with the development of trust in the doctor–patient relationship can help to shape a patients' behaviour and attitudes to take a more active role in their disease management process and continue to engage with a specific organisation.^{15,16} This is reflected in our study by the high-engagement rate of young people with the adult cardiology services after transfer of care. Our model of care delivered by a team

of dedicated clinicians with transition discussed by paediatricians and meeting the adult CHD team, in a stepwise fashion encourages young people to trust the adult CHD service.

The transition process cannot be completed without close working between the multidisciplinary teams delivering care, the young person, and their family. The transition period is not complete until the patient is able to take responsibility for their own health and lifestyle. The role of the congenital cardiac nurse specialists and adult CHD nurses as transition champions cannot be underestimated. Their appointment into the paediatric service allowed the identification of a named key worker who coordinates the transition process by liaising with the administrative staff to ensure timely transfer of all essential medical and social information to the adult cardiology centre. In addition, they also act as a point of contact for families throughout their paediatric care, providing counselling and support to the young person. Nurse-led transition service has been shown to provide young adults and their family the time and opportunity to develop an understanding and knowledge of their condition required to engage with the adult services, as well as giving them access to a named worker to coordinate the process with the young person^{9,17} Therefore, early introduction of the congenital cardiac nurse specialist to the young person and families helps to prepare them for differences they are likely to face at the point of transfer. With guidance and gradual introduction to the concept of transition of care, these young people can be prepared for medical independence. Separate specialist nursing clinics with psychologist participation have been part of our transition pathway for the last 2 years.

One of the many reasons for loss to follow-up among young people with adult CHD service is the poor understanding of the implications of their medical condition either due to parental overprotection or lack of direct discussion.^{18,19} Many children reach young adulthood with limited knowledge about their condition and consequently are insufficiently prepared for transition and transfer of care. A self-report survey showed that there are significant gaps in education regarding unprotected intercourse, health of future offspring, birth control, pregnancy, illicit drug use, and future careers.²⁰ A study assessing transition readiness and cardiac knowledge of young adults with CHD conducted in Stollery Children's Hospital, Canada demonstrated significant improvement in self-management and cardiac knowledge scores after a 1-hour nurse-led transition intervention.²¹ The role of trained specialist nurses in providing life-long continuous education in this group of high-risk patients cannot be underestimated.²² It is vital for young people with adult CHD to understand their underlying medical condition in order to promote healthy lifestyle living. Factors associated with successful transition have been identified and include early planning, the collaboration between paediatric and adult services and increasing the young person's confidence in decision-making.²³

Unfamiliarity or lack of trust in a new service provider and reluctance of the parents to handover the responsibility of the young person's health to the adolescent remains some of the reasons why young people and their families refuse to graduate from child-centred to adult-centred healthcare. Our study shows that joint transition clinics and early introduction to the adult CHD team help to develop the doctor-patient and family relationship allowing an organisational belonging that helps to improve the attendance rate when reminders are sent.

Conclusion

A high engagement rate with the adult CHD service after transfer of care can only be achieved by a purposeful, planned joint cardiac transition clinic centred around individual patient's needs. This is essential for patients with CHD because many of these patients are at risk of complications and premature mortality and morbidity. Review of The Cambridge Cardiac Transition Pathway shows that the development of the transition process involving a dedicated team of clinicians from both paediatric and adult CHD services is a successful model of care. The transition process should start early and be tailored according to the pace of the patient and their family and ensure the young person has an allocated named worker to support them through the process.

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Data collection and analysis: NY, PP, KBR, CP.
Write-up: NY, CL, RY, KBR, WK.
Critical review and revision of manuscript: NY, CL, RY, KBR, WK.

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References

- Somerville J. The grown-up congenital hearts: good care is the profession's responsibility. *Brit J Cardiol* 1998; 3: 135.
- Townsend N, Bhatnagar P, Wichramasinghe K, Williams J, Vujcich D, Rayner M. *Children and Young People Statistics*. British Heart Foundation, London, 2013: 15.
- National Service Framework for Children, Young People and Maternity Services. Department for Education and Skills, Department of Health. *Transition: Getting it right for young people*, 2006: 14
- Sawyer SM, Blair S, Bowes G. Chronic illness in adolescents: transfer or transition to adult services? *J Paediatr Child Health* 1997; 33: 88–90.
- Dimopoulos K, Favocchia C, Shaughnessy Lm Alonso-Gonzales R. Transition to adult care in adolescents with congenital heart disease. *Prog Pediatr Cardiol* 2018; 51: 62–66. DOI [10.1016/j.ppedcard.2018.10.002](https://doi.org/10.1016/j.ppedcard.2018.10.002).
- Blum RW, Garell D, Hodgman CH, et al. Transition from child-centred to adult health-care systems for adolescents with chronic conditions. A position paper of the society for adolescent medicine. *J Adolesc Health* 1993; 14: 570–576.
- Report of the British Cardiac Society Working Party. Report of the british cardiac society working party. Grown-up congenital heart (GUCh) disease: current needs and provision of service for adolescents and adults with congenital heart disease in the UK. *Heart* 2002; 88: i1–i14.
- Sable C, Foster E, Uzark K, et al. Best practices in managing transition to adulthood for adolescents with congenital heart disease: the transition process and medical and psychosocial issues. A scientific statement from the American heart association. *Circulation* 2011; 123: 1454–1485.
- NICE guideline 43, 2016. <https://www.nice.org.uk/guidance/ng43/resources/transition-from-childrens-to-adults-services-for-young-people-using-health-or-social-care-services-pdf-1837451149765>.
- Somerville J. Near misses and disasters in the treatment of grown-up congenital heart patients. *J R Soc Med* 1997; 90: 124–127.
- Kerr H, Price J, Nicholl H, O'Halloran P. Transition from children's to adult services for young adults with life-limiting conditions: a realist review of the literature. *Int J Nurs Stud* 2017; 76: 1–27.
- Baumgartner H, De Backer J, Baby-Narayan S, et al. 2020 ESC guidelines for the management of adult congenital heart disease. The task force for the

- management of adult congenital heart disease of the european society of cardiology. *Eur Heart J* 2021; 42: 563–654.
13. Moons P, Skogby S, Bratt EL, et al. Discontinuity of cardiac follow-up in young people with congenital heart disease transitioning to adulthood. A systemic review and meta-analysis. *J Am Heart Assoc* 2021; 10(6): e019552. DOI [10.1161/JAHA.120.019552](https://doi.org/10.1161/JAHA.120.019552).
 14. Kipps S, Bahu T, Ong T, et al. Current methods of transfer of young people with type 1 diabetes to adult services. *Diabetes Med* 2002; 19: 649–654.
 15. Plessis KD, Peters R, Culnane E, d'Udekem Y. Traversing the liminal: what can Fontan adults' transition experiences and perspectives teach us about optimizing healthcare? *Int J Adolesc Med Health* 2018; 32(6). DOI [10.1515/ijamh-2018-0020](https://doi.org/10.1515/ijamh-2018-0020).
 16. Dorr Goold S, Lipkin M. The doctor-patient relationship: challenges, opportunities, and strategies. *J Gen Intern Med* 1999; 14: S26–S33.
 17. Habibi H, Emmanuel Y, Chung N. Process of transition for congenital heart patients: preventing loss to follow-up. *Clin Nurse Spec* 2017; 31: 329–334.
 18. Dore A, de Guise P, Mercier LA. Transition of care to adult congenital heart centres: what do patients know about their heart condition? *Can J Cardiol* 2002; 18: 141–146.
 19. Heery E, Sheehan AM, While AE, Coyne I. Experiences and outcomes of transition from pediatric to adult health care services for young people with congenital heart disease: a systemic review. *Congenit Heart Dis* 2015; 10: 413–427.
 20. Fernandes S, O'Sullivan-Oliveira J, Landzberg M, et al. Transition and transfer of adolescents and young adults with paediatric onset chronic disease: the patient and parents perspective. *J Pediatr Rehabil Med* 2014; 7: 43–51.
 21. Mackie AS, Islam S, Magill-Evans J, et al. Healthcare transition for youth with heart disease: a clinical trial. *Heart* 2014; 100: 1113–1118.
 22. Alexander JA, Hearld LR, Mittler JN, Harvey J. Patient-physician role relationship and patient activation among individuals with chronic illness. *Health Serv Res* 2012; 47: 1201–1223.
 23. Uzark K, Wray J. Young people with congenital heart disease- transitioning to adult care. *Prog Pediatr Cardiol* 2018; 48: 68–74.