

## PRACTICE

## QUALITY IMPROVEMENT REPORT

# Bridging the gap: an integrated paediatric to adult clinical service for young adults with kidney failure

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## Abstract

**Problem** Transition from paediatric to adult care of young adults with chronic diseases is poorly coordinated, often delayed, and usually managed through a single referral letter. About 35% of young adults lose a successfully functioning kidney transplant within 36 months of transfer from paediatric to adult services.

**Design** Before and after study of the impact of a new integrated paediatric-adult clinical service for patients with kidney failure.

**Setting** Adult renal centre in Oxford and two paediatric renal centres in London.

**Strategies for change** An integrated paediatric-young adult joint transition clinic and care pathway was established in 2006, in conjunction with a young adult clinical service with regular community based clinics. Previously, young adult transplant recipients were transferred by a single referral letter to an adult renal consultant and managed in a conventional adult clinic.

**Key measures for improvement** Rates of acute rejection and loss of kidney transplants five years before and five years after the introduction of the integrated young adult care pathway.

**Effects of the change** Nine young adult kidney transplant recipients were transferred directly to adult care between 2000 and 2006 (group 1). From 2006 to 2010, 12 young adult transplant recipients underwent integrated transition into the new young adult service (group 2). Six transplants were lost in group 1 (67%) compared with no transplant losses in group 2.

**Lessons learnt** Implementing an integrated transition clinic, coupled with improving young adults' healthcare experience through a young adult clinic, improved patient adherence to regular medication and engagement with healthcare providers, as judged by reduced transplant failure rates. This model may be applicable to other young adult populations with chronic disease transferring to adult healthcare.

## Background and description of context

End stage renal disease is rare in paediatric practice, with a prevalence of 9–50 per million population.<sup>1</sup> Kidney transplantation is the treatment of choice compared with dialysis, as it restores growth and pubertal development and reverses symptoms of renal failure. Consequently, more than 80% of young adults with end stage renal disease transferring to adult care have a functioning kidney transplant.

Adolescence is a time of increasing independence, experimentation, and rebellious behaviour influenced heavily by peer behaviour. However, experimentation may lead to risk taking behaviour, which can result in non-adherence to regular medication and reduced engagement with healthcare providers.<sup>2,3</sup> Registry data from the United States shows reduced five year survival rates of kidney transplants in young adults (70%) compared with those in children aged <11 years (85%).<sup>4</sup> Transfer from well resourced, small, paediatric care programmes to resource limited, large, adult kidney care programmes can be associated with significant non-adherence with immunosuppressive drug regimens that can lead to premature transplant failure. One UK study showed that 35% of young renal transplant recipients had lost their transplants by 36 months after transfer to adult renal care.<sup>5</sup>

Historically there has been a disconnect between paediatric and adult renal and transplantation services, often associated with inadequate communication of important medical and social information.<sup>6</sup> This lack of cohesion can lead to confusion over the management of rare paediatric diseases in the adult service and a lack of trust between the young adult patient and immediate family and the new adult healthcare team. Current services for young adults moving from childhood to adult services are inadequate, with insufficient training in managing

adolescent health outside mental health in the UK. This may result in the underuse of healthcare services seen in men aged 20–29<sup>7</sup> and the poorer levels of satisfaction of delivered healthcare in NHS surveys of 16–24 year old patients.<sup>8</sup>

This problem has been recognised by national healthcare bodies in the UK,<sup>9</sup> Canada,<sup>10</sup> US,<sup>11</sup> and internationally,<sup>12</sup> with the development of guidelines on transition and young adult care for patients with end stage renal disease. Guidelines in the UK have been developed jointly by the Royal College of Physicians and Royal College of Paediatrics and Child Health from consensus meetings of clinicians from various specialties and patient representatives. These recommend increased integration of paediatric and adult renal healthcare and the establishment of specific regional young adult renal services.<sup>13</sup> Most of the literature is descriptive with little evidence of the impact of such service reform.<sup>14</sup> Limited evidence of improved outcomes comes from the management of young adults with type 1 diabetes through dedicated transition clinical staff, targeted patient education programmes, and adjustments in service delivery including dedicated young adult clinics.<sup>15</sup>

## Outline of the problem

Within three months of starting his first consultant post in the 1990s one of the authors (PH) took over the long term care of a 16 year old with a stable functioning kidney transplant. Although the young man was a model patient studying for university entry, within 12 months he had developed two late acute rejection episodes due to non-adherence to his immunosuppressive drug regimen, resulting in the loss of his transplant within two years of transfer.<sup>16</sup> This experience led to the establishment of an integrated paediatric-adult nephrology transition clinic at Birmingham Children's Hospital in 1999. When PH moved to Oxford in 2002 he found no transition service. Adolescents moving from paediatric care were randomly allocated to any one of six adult nephrologists in clinics at different sites. Young adults and their families suddenly found themselves isolated in a large adult clinic full of much older patients.

We set out to reduce non-adherence with immunosuppressive medication and improve engagement with clinical services by young adults with renal failure moving to adult renal services by establishing a joint paediatric-adult nephrology clinic coupled with a new young adult nephrology service in Oxford in 2006. We aimed to reduce the rate of late rejection of kidney transplants and improve renal allograft survival. The key objective was to ensure young adult patients continued to lead normal lives made possible by maintained renal allograft function.

## Key measures for improvement

We compared the clinical outcomes of patients transferring through this new integrated service (years 2006–11) with those of a historical set of patients transferred directly to the Oxford adult renal service in 2000–05. Non-adherence with immunosuppression is often covert and difficult to detect and measure reliably. Late acute rejection (>6 months after transplantation) is a marker of non-adherence with immunosuppressive medication, is difficult to treat, and usually results in a significant reduction in transplant survival time and occasionally immediate transplant failure.<sup>17</sup>

## Information gathering, analysis, and interpretation

In 2000–05 nine patients (three male, six female) with functioning kidney transplants were transferred from London paediatric centres to the care of six different adult consultant nephrologists in Oxford by single referral letter (group 1). They were then seen in standard adult nephrology clinics of mixed ages with average consultation times of 20 minutes within a four hour clinic schedule of 20 patients. Median age (range) at transfer was 18 (16–18) years.

In 2006–11, 12 paediatric transplant recipients (seven male, five female) aged 17.5 (16–18) years went through integrated transition from the paediatric nephrology units at Great Ormond Street Hospital and Evelina Children's Hospital in London to the adult nephrology centre at Oxford (group 2). They were managed by a young adult clinical team comprising a single nephrologist, transplant nurse specialist, youth worker, and pharmacist.

The demographic details of the two groups are shown in the table. Hospital electronic and patient records were accessed to record end points of transplant function at transfer and latest follow-up. Episodes of acute transplant rejection, transplant failure, and death were documented.

## Strategy for change

### Joint transition clinic

The pathway was designed through a period of joint consultation (fig 1) and modelled on the joint transition clinic between Birmingham and the University of North Staffordshire Hospital in 1999. The pathway involves joint medical clinics at the paediatric centres including a paediatric nephrologist and paediatric renal transplant nurse specialist jointly working with an adult nephrologist and adult renal transplant nurse specialist from Oxford. Since 2009 the team has also included a youth worker from the adult team. These joint transition clinics occur every four months and see a cohort of paediatric patients who live in the transplantation region of the adult centre (general population about three million). Patients are seen jointly by the two teams from the age of 15–18 years, and transfer to the adult clinic occurs by the age of 18 years by mutual consent of the patient, family, and the paediatric and adult clinical teams.

At each of the three hour joint medical clinics held at the paediatric centre, typically four or five patients are seen, with individual multidisciplinary consultations lasting 30–45 minutes. The patients are seen alone by the healthcare teams to promote autonomy and in preparation for the young adult clinic, when patients are usually seen individually and encouraged to take full responsibility for their healthcare. Subsequently, they are seen with family members to discuss progress and future management (fig 1). Before transfer to the adult clinic the youth worker will arrange at least one community visit, and the transferring patient will visit and look around the adult unit informally.

The resultant integrated transition pathway allows the young adult patient and his or her family to progressively gain trust in the adult healthcare team before final transfer. In addition the adult team have an opportunity to obtain a thorough de-brief from the paediatric team and gain a valuable update on rare paediatric nephrological conditions, leading to more effective and comprehensive individual adult care plans.

## Young adult clinic

An additional development was the establishment of a dedicated young adult clinic in the adult unit, bringing together patients with a median age of 22 (range 16–28) with advanced chronic kidney disease or receiving renal replacement therapy. Patients attending the young adult clinic include those transferring from paediatric care (50%) and young adults directly presenting to adult services (50%). The young adult clinic was initially held in the adult hospital outpatient department, though at a different time from standard clinics. It had only partial success because of limited peer interaction, which was substantially hampered by the hospital environment.

In December 2008 the clinic was moved out of the hospital into a student college and sports centre in central Oxford, where it is held every six weeks. The objective was to develop a normal young adult environment mirroring a youth club to catalyse peer interaction between all the patients. An essential addition was the appointment of a youth worker, made possible financially by the Supporting Young Adults project from NHS Kidney Care. The youth worker (DL) acts as a bridge between the healthcare team and the patients. He coordinates the clinic day, which includes an “ice breaker” session in a nearby coffee house, lunch in the college, and use of the students’ common room and games room or sports centre during the afternoon while clinical consultations take place (fig 2⇓). His role ranges from facilitating the introduction of new young adult patients to running team events such as pool or squash competitions to catalyse peer interaction and rebuild self esteem and organising social events such as 10 pin bowling or go-karting to foster peer support. He works on a one to one basis in the community with individual patients who require extra support, which may include help with preparations for job applications and interviews and identification of issues requiring help from other members of the medical or social care team.

## Transfer to a standard adult clinic

Timing of transfer to a standard adult clinic varies between individual patients and relates to educational, employment, and social development. In most circumstances the exact age of transfer is determined by the patients, who become more independent and require less support as they get full time jobs or start a family. However, some individuals remain in the clinic until their late 20s.

This strategy required restructuring of existing clinical services in Oxford and a change for the other clinicians previously managing these patients who had to relinquish clinical care to the young adult care team. Many initially had doubts about the added benefit of the young adult service. Internal progress updates and direct feedback from young adult patients at multidisciplinary unit meetings have changed attitudes and referral practice, such that 90% of eligible patients are now managed by the young adult service (62 patients were offered the new care pathway). A small proportion of eligible patients remain in standard adult clinics through patient or clinician choice, although all the patients transferred from paediatric to adult care now follow the integrated young adult care pathway. Young adult patients attending the clinic have regularly participated in helping to design and reshape the young adult service through surveys.

Establishing the medical, nursing, and pharmacy resource for the clinic was cost neutral since this service was previously provided in multiple existing adult clinics. Job plans have been adjusted to redistribute existing clinical activity. The youth worker post was initially created as a voluntary post in 2009

and extended to a part time post in August 2010. In addition, Corpus Christi College and Esporta North Oxford have donated their premises and facilities. Peer support social events have been supported by local fund raising both within the Young Adult Patient Group and from the Six Counties Kidney Patient Association. Even within the current financial limitations of the NHS an outreach community clinic can be established with the support of the local business and charitable community.

## Effects of change

In the historical control group (group 1), six of nine patients developed transplant failure at a median of 40 (1–62) months after transfer to adult care. In group 2 there have been no transplant failures at a median follow-up of 26 (18–60) months after transfer (fig 3⇓). Late acute rejection occurred in 33% of group 1 and none in group 2. Transplant survival in group 2 compared favourably with that in a historical cohort of teenage kidney transplant recipients transferred to standard UK adult services.<sup>5</sup>

## Next steps and discussion

The introduction of an integrated transition service for teenage kidney transplant recipients has led to a reduction in the rate of transplant loss and reduced morbidity and admissions. Since we have only before and after data, it is possible that other aspects of clinical management may have influenced the outcome. However, during this time there has been no important change in the standard immunosuppression protocols used by the two paediatric nephrology units. Furthermore, the rate of renal allograft loss is substantially lower than the 35% loss found in another cohort of young adult kidney transplant recipients in the Trent region of the UK, where no dedicated transition or young adult service was in place.<sup>5</sup>

The impact of the combined approach of an integrated paediatric-adult transition clinic coupled with transfer into a young adult clinic at the adult service is consistent with improved short term outcomes (improved haemoglobin  $A_{1c}$  levels) observed with dedicated transition clinics for patients with diabetes.<sup>15</sup> Non-adherence with clinic appointments is an additional outcome marker, and improved attendance rates have been observed in a diabetic population within joint paediatric-adult transition clinics.<sup>18</sup>

The Oxford-London model is consistent with the need to start transition early<sup>19</sup> and the beneficial effect on clinical trust when a young adult patient meets the adult clinicians before transfer, as shown in an adult heart transplant service.<sup>20</sup> The recognition that development of the adolescent brain extends to beyond the age of 20 years supports the concept of emerging adulthood and the potential benefit of the young adult clinic model.<sup>21 22</sup> A key theme supported by this model is the gradual transfer of responsibility for care from the parent or carer to the individual young adult.<sup>23 24</sup> The integrated approach enables progressive transfer of clinical responsibility of care to the adult healthcare team while the paediatric team and adult youth worker can work on increasing autonomy of care from the parent or carer. Youth workers predominantly work with young people aged between 11 and 25 years in the community, and most hospital healthcare teams will not be familiar with them. Key components of youth work are facilitating personal and social development, providing personal support, building and enhancing self esteem, and promoting young people’s views.<sup>25</sup> Support from the youth worker and interaction with peers in a similar medical situation can help individual teenage patients overcome the issues faced by managing a chronic illness while going through the

challenges of adolescence. In a model without integration at transfer fewer than 20% of young adults with chronic kidney disease were perceived to function autonomously.<sup>26</sup> It is important to consider other outcome measures, including educational achievement, vocational attainment, and psychosocial outcomes, which are known to be reduced in young adults with chronic disease.<sup>27</sup> We are currently conducting a questionnaire and structured qualitative interview study of the people attending our young adult clinic population to determine the impact of end stage renal disease on these measures.

It is important to design clinical pathways for young adults that suit their lifestyles. The use of text messaging in young adults with liver transplants has, for example, led to improved compliance with immunosuppression regimens and reduced rejection rates.<sup>28</sup> The creation of a youth environment by hosting the follow-up clinics in a college, sports centre, and coffee shop is core to the customisation of the clinic to our teenage patients. We also regularly use text messaging, emails, and social network sites to facilitate interaction between the patients, youth worker, and healthcare team.

Delivery of a comprehensive young adult service requires the participation of multidisciplinary healthcare and social care professionals. We show that this can be delivered in an effective way with minimal implementation costs, in line with similar observations by Bent, who found young adult team care for patients with physical disabilities was no more expensive than ad hoc services for adolescents and young adults.<sup>29</sup> Our integrated service potentially reduced healthcare costs by reducing the number of failing kidney transplants and offsetting the need for expensive maintenance dialysis and its associated morbidity.

Integrated paediatric-adult transition services in nephrology still seem to be the exception. At a recent workshop of trainee paediatric nephrologists at the European Society of Paediatric Nephrology, only one of 35 major paediatric nephrology centres across Europe had an integrated transition clinic with adult care (personal communication, PH). In the UK, however, similar integrated transition and young adult clinics have recently been established in several other regions of England, including Birmingham, Bristol, London, Nottingham, Leeds, Newcastle, and Sheffield. NHS Kidney Care is currently providing financial support to explore improved care models for this age group across England, and we have stimulated international collaborations with the University of Colorado and Yale medical centres to explore development of a similar service in a different healthcare system.

A similar strategy may also be applicable to young adults with other major chronic illnesses, including diabetes, chronic joint and connective tissue disorders, cystic fibrosis, inflammatory bowel disease, and haematological disorders. All such young adult patients experience geographical and peer group isolation, and our integrated approach is equally applicable to patients with relatively common diseases such as diabetes or rarer ones such as kidney disease and inflammatory bowel disease.

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Contributors: PNH developed the new care model and designed this clinical practice study. He collected the data and performed the analysis and wrote the main draft of the manuscript. He will act as guarantor. The other authors were all involved with the design and implementation of the new care pathway. They reviewed the results and contributed to editing and writing the manuscript.

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Competing interest: PNH is currently a clinical adviser to NHS Kidney Care on transition and young adult renal care in the UK. Otherwise there are no potential conflicts of interest. All other authors have completed the Unified Competing Interest forms and declare no support from any organisation for the submitted work; no financial relationships with any organisation that might have an interest in the submitted work in the previous three years and no other relationships or activities that could appear to have influenced the submitted work.

This clinical practice study did not require ethical approval.

Patient consent obtained.

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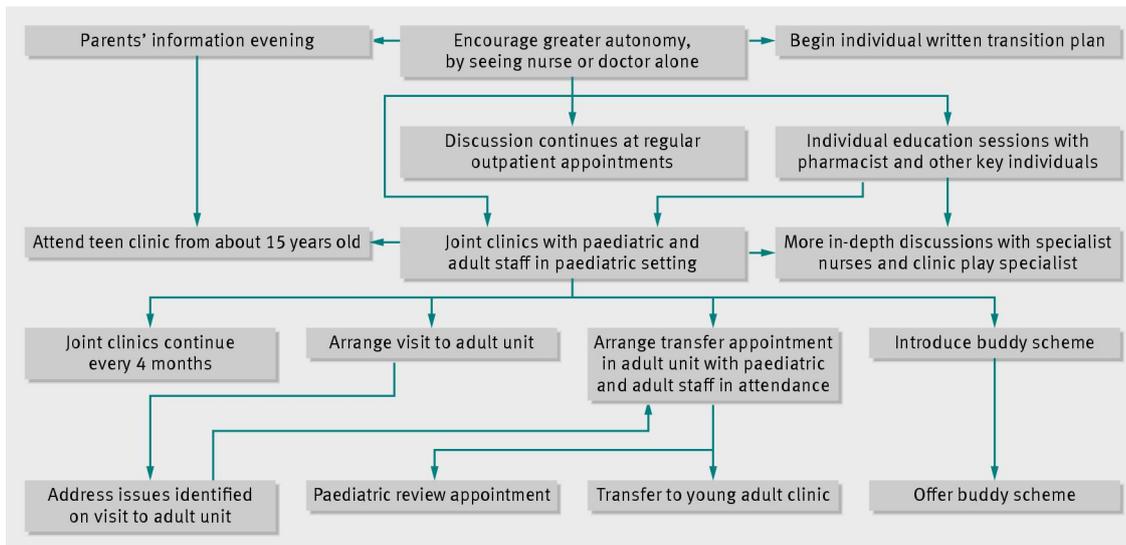
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## Table

**Table 1 | Outcomes for young adult kidney transplant recipients before and after introduction of integrated transition from paediatric nephrology care to adult care and a young adult clinic service**

	Model of transfer from paediatric to adult care	
	Direct transfer	Integrated transition and young adult service
Time period	2000–05	2006–11
Transfer process and adult care team	Single referral letter, 6 adult nephrologists	Young adult team (1 nephrologist, 1 nurse specialist, and 1 youth worker)
No of patients (male, female)	9 (3 male: 6 female)	12 ( 7 male: 5 female)
Median (range) age at transfer to adult care (years)	18 (16–18)	17.5 (16–18)
No (%) of late acute rejections	3 (33)	0
No (%) of renal allograft loss	6 (67)	0
Median (range) time to renal allograft loss	40 (1–62)	—
No of deaths	1 (due to miliary tuberculosis)	0

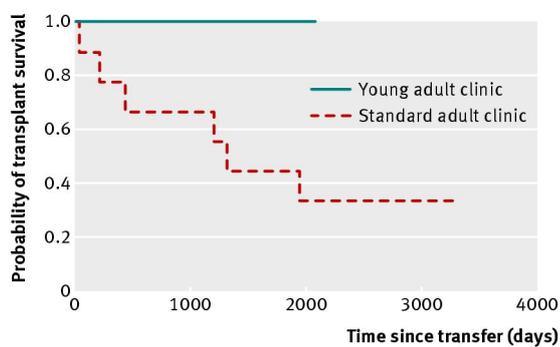
## Figures



**Fig 1** Integrated pathway for transition of paediatric patients with end stage kidney disease to care in an adult renal unit



**Fig 2** Oxford Young Adult Clinic at Corpus Christi College in April 2010: clinical consultation with a transplant physician (top), pool competition in the games room (bottom). (Reproduced with patients' permission)



**Fig 3** Renal allograft survival (days) before and after introduction of an integrated paediatric to adult transition and young adult clinical service for patients with end stage kidney disease (log rank test,  $P=0.015$ ).