

# **Supporting young adults with Chronic Kidney Disease in Nottingham and Derby: Annual Report 2013-14**

**June 2014**

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*\*Names and genders in case studies have been changed*

## Executive summary

The young adult worker post within the adult renal units in Nottingham and Derby began in September 2010. The aim was to develop a service to support young adults (aged 18-25) with the various challenges that they face, to improve their long-term health and social outcomes. In April 2012, the British Kidney Patient Association provided a 3-year grant to continue funding this post. This report details the work of the young adult service between April 2013 and March 2014.

The young adult service provides support to young adults living with Chronic Kidney Disease (CKD) who are under the care of the adult renal units in Nottingham and Derby. One-to-one support and advice is provided on a range of health and social topics, and group activities are provided to support the development of peer support networks between young adults.

Over the past year, 54 young adults have accessed one-to-one support, totalling over 450 hours of support. 56 young adults have had contact with the service through group activities and informal support. This has totalled 103 unique contacts. The main areas of one-to-one support provided have been multi-disciplinary work (18.2% of interventions), financial support (17.7%) and emotional support (17.3%). This support has led to a number of referrals to external agencies, as well as a number of outcomes for young adults including relief of financial hardship, accessing volunteering or training, improved clinic attendance, and improved concordance with treatment.

Group events have included a day trip to Alton Towers, the British Transplant games, a residential to Center Parcs for patients undergoing the transition process and a day trip to take part in archery. Key themes to arise from these events include meeting new people and developing peer support networks, meeting other young adults in a similar situation to discuss challenges faced and share coping strategies, opportunity for respite, and taking part in new activities and experiences.

Service improvements over the past year have included developments to the transition process with joint transition clinics now established in each centre, inclusion of transition and caring for young adults on staff training programmes, involvement in national work to promote the needs of young adults, and research into the views and opinions of young adults.

Audit data have been collected to assess the impact of the service on clinical outcomes, the key findings are summarised below:

	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>
Population clinic non-attendance rate	22.1%	14.3%	15.4%	17.2%
Total number of admissions	98	75	48	30
Total number of bed days	416	333	197	149

## **Section 1: Background, aims and objectives**

### ***Introduction***

Living with Chronic Kidney Disease (CKD) can impact greatly on a young adult's life and various difficulties are often experienced. These include falling behind with education, struggling to find and retain employment, and difficulties developing and maintaining relationships with potential partners and friends (Lewis, 2010). A German study (Querfeld et al, 1997) found that people aged 18-34 who were receiving renal replacement therapy were more likely to have a lower income job than the general population. Bell (2007) speaks about young adults with CKD experiencing a range of issues including poor self-image, depression and anger. Waters (2008) identified multiple common negative factors for young people living with CKD including maintaining diet and fluid restrictions, difficulties experienced by trying to co-ordinate taking various medications at different times, and the inconvenience of frequent clinic appointments.

Young adults living with CKD are also connected with poor treatment outcomes. Watson (2000) reported that 35% of 20 participants had an unexpected graft loss within 31 months of transfer to an adult renal unit. Keith et al (2006) echoed this by showing that the risk of graft loss is greater for young adults with CKD than for older adults. Transitioning from paediatric to adult renal services is also a very challenging time as young adults have to leave their previous care setting and multi-disciplinary team to enter a new hospital service resulting in the need to develop relationships with a new staff team. Recent work has suggested the benefits of a specialist role to support young adults living with CKD (British Association of Paediatric Nephrology & Renal Association, 2009, NHS Kidney Care, 2013).

The young adult worker post within the adult renal units in Nottingham and Derby started in September 2010 as an 18-month pilot as part of the NHS Kidney Care 'Supporting young adults' project. The post was set up to develop a service to support young adults with the various challenges that they face, to improve their long-term health and social outcomes. In April 2012, following the success of this pilot, the renal units in Nottingham and Derby received a grant from the British Kidney Patient Association (BKPA) to continue funding the post for a further 3 years. This report details the work of the young adult service between April 2013 and March 2014.

## ***Aims and Objectives***

This grant was provided to continue building on the success of the supporting young adults project within these hospitals. The aims of the role are to:

- Offer an innovative approach to provide specialist support to young adults accessing renal care at the hospitals involved in the project
- Implement changes as part of the qualitative research project completed during the pilot phase of the project
- Continue to develop and implement improved processes to support young adults who attend adult renal services
- Raise awareness of the issues faced by young adults living with CKD to the staff teams within the renal units, and wider as appropriate
- Increase young adult's opportunities to offer feedback about the care they receive and offer suggestions for improvements

The objectives of the young adult worker role are to:

- Continue to develop the one-to-one support service set up to help address individual needs and issues faced by young adults
- Design and implement group interventions to facilitate increased peer support opportunities for young adults living with CKD
- Offer training to healthcare professionals to increase their awareness of issues faced by young adults living with CKD
- Provide opportunities and mechanisms for young adults to offer feedback about the care they receive and the issues that they are facing, and suggest and implement changes as a result
- Assist in the development of support processes for young adults with CKD as they transition from paediatric to adult renal services
- Assist in the identification of improvements in care offered to young adults living with CKD
- Set up new and innovative approaches to communication with young adults, for example through social networking

## ***Project Scope***

The young adult service provides support to young adults living with CKD stages 3-5, who are aged 18-25 and are accessing adult renal care at either Nottingham University Hospitals NHS Trust or Derby Hospitals NHS Foundation Trust. This includes renal transplant recipients and dialysis patients. The service also supports young adults in paediatric care who are preparing to transfer to the adult renal units in Derby and Nottingham.

## **Section 2: Support provided and outcomes**

### ***One-to-one support***

One-to-one support is provided by the Young Adult Worker, who is a qualified youth worker with no medical training. This means that they are able to offer a new skill set and perspective to both the young adult, and the team caring for this group of patients. The one-to-one service has been developed in line with youth work principles. Characteristics of the service include the voluntary participation of young adults, beginning with the young adult's view of the world, developing young adult's skills and behaviours, and promoting the voice of young adults (National Youth Agency, 2014). The one-to-one service seeks to develop young adult's skills and knowledge to empower them to take a greater control of their situation and health condition, which will hopefully lead to long-lasting change.

The one-to-one service offers individualised practical and emotional support to young adults with their specific needs and issues. The service provided is holistic and is not limited to a young adult's health condition. Support provided can include direct advice from the young adult worker, or signposting to other agencies or support services which can provide specialist advice.

The service is open to young adults of all treatment modalities, and young adults can either self-refer or, with their permission, be referred by a member of their care team. The service is responsive to the needs of young adults and has the flexibility to support young adults in the hospital setting as well as in the community. This flexibility is important in ensuring that young adults can access support in a setting of their choice where they feel comfortable.

Young adults often present to the service with a wide range of complex needs, and there are no set timescales or limits on the amount of support that is provided. Young adults who haven't accessed one-to-one support have either accessed group work activities or haven't been identified as needing this support. When young adults no longer require specific support they are discharged from the service and advised that they can re-access support at a later date if they would like to.

### ***Group activities***

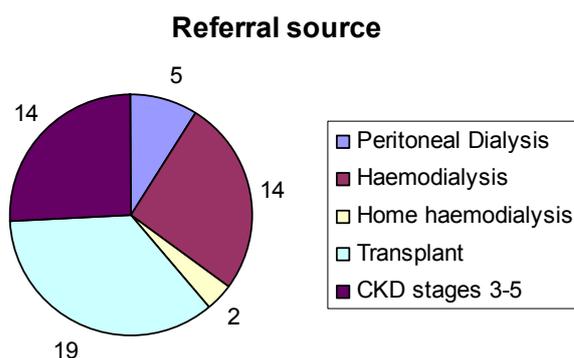
As part of the service, group activities are organised for young adults. The aims of these activities are to:

- Support young adults to meet others in a similar situation to develop peer support networks and reduce isolation faced
- Provide respite for young adults from the everyday challenges of living with CKD
- Provide an opportunity to take part in new activities and experiences

At the request of young adults, these activities are generally social events which allow young adults to meet each other in an informal environment to form friendships which can lead on to ongoing peer support. Specific activities are organised following feedback from young adults.

## One-to-one service outcomes (April 2013 – March 2014)

Over the past year, 54 young adults have accessed the one-to-one service, and a further 56 young adults have had contact with the young adult worker (group activities, informal support or conversations). In total, 103 different young adults have accessed support throughout the year. The graph and tables below show details of those that have accessed one-to-one support:



### Age:

	Number
18-20 years	16
21-23 years	16
24+ years	22

### Referral source:

	Number
Doctor	32
Self-referral	10
Nurse	8
Psychologist	4

### Jasmine's story

Jasmine was diagnosed with established renal failure 6 months ago following a blood test at her GP surgery. She was immediately admitted to the renal ward. Prior to this she was unaware that she had any problems with her kidneys, and her new diagnosis came as a big shock to both her and her family.

Jasmine was referred to the young adult worker during her inpatient stay to help her come to terms with her new diagnosis and what this would mean in her life. The Young Adult Worker spent time with Jasmine on the ward to help her understand more about her diagnosis and her feelings about the situation.

Jasmine was on a zero hours contract at work so received no sick pay for the time that she was off. This created some financial pressures for Jasmine and her partner. The young adult worker was able to provide advice on what benefits she may be able to apply for and also applied to the British Kidney Patient Association for a grant to cover Jasmine's rent costs during this time.

Jasmine has now returned to work. Support from the young adult worker was vital in supporting her and her partner through a difficult time for them as they adjusted to her new health diagnosis and the changes that this meant for them.

Over 450 hours of one-to-one support have been provided and on average 22 young adults have accessed support each month. An additional 50 hours of support have been offered by the Young Adult Worker outside of the one-to-one service. The most common interventions provided by the young adult worker were:

Multi-disciplinary work	18.2% (of total interventions)
Financial support	17.7%
Emotional support	17.3%
General support & advice	15.2%
Concordance with treatment	6.3%

Other interventions provided include housing, employment, treatment support and health education, inpatient support, transition from paediatric to adult services, education, exercise, holidays, sexual health, drugs and alcohol support and independence skills.

This support has led to 54 referrals to external agencies. The most common services referred to were grant making trusts (20 referrals) and benefits advice agencies (14 referrals). Other agencies referred to included housing associations, generic support organisations, employment support, renal dieticians, clinical psychology, young adult renal services in other geographical areas, drug and alcohol support, and volunteering opportunities.

This support had led to a number of health outcomes for young adults including improved concordance with medication, improved clinic attendance, decreased levels of hospital admissions, improved knowledge and awareness of health condition, and improved engagement with health services. Social outcomes experienced include increased employment opportunities through accessing volunteering or training, relief of financial hardship, access to welfare benefits, young adults being re-housed and improved confidence and independence skills.

### ***Group work outcomes***

Over the past year, a number of group activities have been provided for young adults including a day trip to Alton Towers, the British Transplant games, and activities for young adults who are soon due to transfer to adult services including a weekend residential at Center Parcs and an archery trip.

Key themes to come from the evaluation of these events include:

- Opportunity to meet new people and develop peer support networks
- Opportunity to share challenges and discuss coping strategies with others in a similar situation
- Respite from the daily challenges of living with CKD
- The opportunity to take part in new activities that they may not have done otherwise
- Reduced isolation and improved confidence
- Increased confidence and achievements (eg winning a medal at the British Transplant Games)

These outcomes have been maintained in the longer-term through young adults keeping in touch with each other through social media and through attendance at follow-up events. Many young adults have also taken up new hobbies and sports following participation in the transplant games which is expected to lead to longer-term positive physical and psychological benefits. Some quotes and pictures from young adults who have attended events can be found below:



### Joseph's story

Joseph was diagnosed with Chronic Kidney Disease at birth. He was referred to the Young Adult Service for support to access a college course. The Young Adult Worker met with Joseph to find out about his interests and they then together looked at potential courses that he could attend, taking into account Joseph's financial situation.

Joseph has now attended a number of short courses at his local college. These courses have helped him to meet people, improve his skills and improve his emotional state. These courses have also helped focus Joseph's thoughts on what he may like to do as a future career.

A further issue was highlighted regarding the space of Joseph's home as he was on home dialysis but had very little space for his supplies. This was having an impact on Joseph as he had constant reminders of his health condition and treatment around his house. The Young Adult Worker was able to make an application to the British Kidney Patient Association for some outdoor storage for Joseph which he now keeps his dialysis supplies in.

Support from the Young Adult Worker has helped build Joseph's confidence and has enabled him to think about his future career options. He is also now more comfortable in his home environment as he feels that he has more separation between his treatment and home life.

## Impact on clinical data

In an attempt to evaluate the impact of this work, the project has been collecting data on the same group of patients since 2010. The audit collected demographic and clinical data including hospital admissions and clinic attendance. Data were collected for 12 months prior to the project and then subsequently on an annual basis. The overall young adult population has changed in this time but this audit just follows up this initial group of 80 patients. The baseline data population includes all young adults aged 18-25 with a diagnosis of CKD stages 3-5, who were accessing adult renal care at Nottingham and Derby hospitals on 31<sup>st</sup> December 2010.

	2010 <sup>1</sup>	2011	2012	2013
<b>Number of young adults in audit</b>	80	76 <sup>2</sup>	75 <sup>4</sup>	69 <sup>6</sup>
<b>Population clinic non-attendance rate</b>	22.1%	14.3%	15.4%	17.2%
<b>Total number of outpatients appointments missed</b>	161	98	97	116
<b>Total number of admissions</b>	98	75 <sup>3</sup> (82)	48 <sup>5</sup> (53)	30 <sup>7</sup> (59)
<b>Total Number of bed days</b>	416	333 <sup>3</sup> (571)	197 <sup>5</sup> (489)	149 <sup>7</sup> (237)
<b>Number of admissions associated with non-concordance</b>	24 (89 bed days)	17 (80 bed days)	7 (24 bed days)	0 (0 bed days)
<b>Number of young adults with a hospital admission</b>	31	27	23	19
<b>Home therapy rate</b>	21.1%	33.3%	42.9%	13.3% <sup>8</sup>

<sup>1</sup>2010 data was collected as baseline data prior to the set up of the young adult project.

<sup>2</sup>2011 re-audit data was not collected on 4 patients. 3 stable CKD3 patients (2 female, 1 male) were discharged from the hospital to their GP during 2011. One female died during 2011.

<sup>3</sup>Bed day and admission data excludes the following 2 outliers (number in brackets is total including outliers):

Male 70 nights, 6 admissions due to EPS (admissions involved transfer to and from another hospital provider)

Female 168 nights, 1 admission due to complications related to hip replacement

<sup>4</sup>2012 re-audit data was not collected on 1 stable female CKD3 patient who was discharged from the hospital to their GP during 2012.

<sup>5</sup>Bed day and admission data excludes the following 2 outliers (number in brackets is total including outliers):

Female 221 nights, 3 admissions due to gall bladder complications

Male 71 nights, 2 admissions due to haematoma (admissions involved transfer to and from another hospital provider)

<sup>6</sup>2013 data was not collected on 6 patients. 3 stable CKD3 (2 male, 1 female) patients were discharged to their GP, 1 female HD patient and 1 male PD patient transferred their care to another centre, and 1 female died during 2013.

<sup>7</sup>Bed day and admission data excludes the following 2 outliers (number in brackets is total including outliers):

Female 66 nights, 17 admissions due to abdominal pain

Male 22 nights, 12 admissions due to hypocalcaemia

<sup>8</sup>Home therapy rate has fallen during 2013 due to 3 home Dx patients receiving transplants, 1 home Dx patient having to return to unit HD for medical reasons and 1 young adult having to return to unit HD due to housing issues. 2 young adults are planning to complete their home training in early 2014.

## Section 3: Service Developments

### ***Paediatric to adult transition process***

The past year has seen six-monthly transition clinics continue to run at both Nottingham and Derby. In attendance at these clinics are members of the paediatric and adult teams, and young adults see an adult and paediatric nephrologist together. These clinics allow young adults to meet the adult team who will be taking over their care prior to transfer in order to build a rapport and relationship. Patients attend these clinics a number of times prior to transfer and are seen for more regular follow-up in the paediatric department. Six-monthly multi-disciplinary team meetings are also held between paediatric and adult teams in Nottingham to discuss care plans for patients as they prepare to move to adult services.

These clinics and multi-disciplinary team meetings are complemented by visits to adult units for young adults and their families, which provide an opportunity to meet staff and become more familiar with the adult setting. A transition workshop is also provided for young people and their families, as well as a transition residential to Center Parcs which takes place each year. This residential is for young people who will shortly be moving to adult services and gives them an opportunity to access peer support from other young adults as well as workshops around sexual health, drugs and alcohol, communication skills and moving to adult services.



The transition process is designed to give a number of choices of activities for patients to access. Patients transfer to the adult unit at around the age of 18, this is a mutual decision between the patient and care teams. Once in adult services, the young adult worker provides support to help young adults settle in to the adult unit. Over the past year the adult units have started to use a document named 'Hello' which was developed by Southampton Childrens' Hospital. This document helps the adult staff to get to know the young person and highlight any issues where additional support may be required.

### ***Research activities***

Over the past year, the young adults steering group have partnered with the Leicester Kidney Exercise team on a research project to look into the attitudes of young adults towards exercise. Data collection on this study is ongoing and it is hoped that results will be published in late 2014.

The steering group have also prepared a paper for a journal submission following qualitative research completed during an earlier phase of the project.

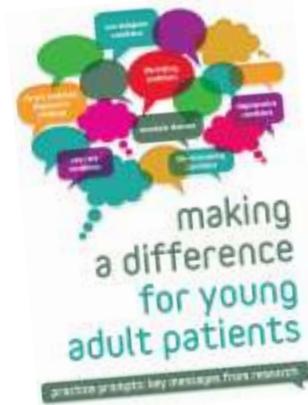
## **Staff training and development**

A key element of the young adult worker role is to raise awareness of the needs and issues faced by young adults living with CKD, and to provide support and advice to staff within the renal units at Nottingham and Derby.

Transition and caring for young adults is now an established part on the renal foundation programmes and renal modules at each trust. The young adult worker has delivered a number of sessions on these modules over the past year and has also liaised with an external company to arrange Motivational Interviewing training sessions for staff.

Outside of these formal sessions, updates on the work of the project and useful resources have been provided to staff periodically to support them in caring for young adults (e.g. Teens in hospital, Practice prompts from STEPP research project & Ready, Steady, Go programme). The Young Adult Worker has also provided support and advice to individual members of staff caring for young adults on a case-by-case basis.

These sessions have led to staff having a greater awareness of the needs and issues faced by young adults, and have increased their skills and knowledge to support young adults within the renal unit. Support and advice has also been provided to other renal units across the UK.



## **National Work**

The young adult steering group have been involved in promoting awareness of the needs and issues faced by young adults nationally throughout the year. This work has included:

- Membership of the working group of the newly formed CKD transition and young adult special interest group
- Supporting other units in the employment and induction of young adult support workers
- Involvement in the 'Transition Taskforce' project being run by Together for Short Lives
- The Young Adult Worker being invited and attending an NHS Improving Quality Event looking into the development of a service specification for transition within healthcare

### ***Media and Publications***

Over the past year, work of the young adult service has been presented through oral and poster presentations at a number of meetings including the British Renal Society annual conference, East Midlands regional nurses forum, East Midlands renal research showcase, Nottingham University hospitals research festival and to the local Clinical Commissioning Group. The young adult worker has presented information about the service internally within the hospitals and has contributed to a supplement on the subject of shared decision making, which was published alongside the British Journal of Renal Medicine in May 2014. Full details of these presentations and articles can be found in appendix 1.

### ***Links with other organisations***

Links have been established with a number of different organisations to achieve these outcomes and progress over this past year. These organisations include Nottingham University Hospitals Youth Service, Nottingham University Hospitals renal paediatric department, Derbyshire Childrens' Hospital, British Kidney Patient Association, National Kidney Federation, NHS Improving Quality, Leicester Kidney Exercise team, Southampton Childrens' hospital, National CKD transition and young adult network, Together for short lives, Transplant Sport and other young adult renal services from across the UK.

## **Section 4: Conclusion**

Between April 2013 and March 2014, the young adult service in Nottingham and Derby has continued to provide support to young adults living with CKD in a wide range of different health and social areas. This has led to young adults developing skills and knowledge to help manage their health condition, which has in turn led to a number of health and social outcomes. The number of young adults accessing this support throughout the year has remained high which demonstrates the need for specialist young adult support.

The transition process from paediatric to adult care has become more established with regular joint transition clinics taking place at each centre. This has led to an improved and smoother process which has increased engagement and relationships with young adults prior to transition. A number of other service developments have taken place including development of staff training and supporting national work in the area of transition and young adult care within CKD.

Although much of the support provided by the young adult worker has been to support with non-medical needs, audit data has continued to show improvements in hospital admissions. This has led to improved health outcomes as well as financial savings for the NHS. Following initial improvements at the start of the project, clinic non-attendance rates have increased within this population and over the next year the young adult steering group will be exploring ways to reduce these rates. This data will continue to be collected over the next year with the aim of showing the cost-effectiveness of the role to facilitate future funding.

### ***Acknowledgements***

We would like to thank the British Kidney Patient Association for their financial support of the Young Adult Worker post and group activities.

We would also like to acknowledge staff in the renal units at Nottingham University Hospitals NHS Trust and Derby Hospitals NHS Foundation Trust, and the NUH Youth service for their contribution, commitment and hard work towards making the young adult service the success it has been.

We would also like to say a big thank you to the young adults who have taken part in the project for their involvement, support and ideas which have helped develop and shape the service for others.

### ***Contact Details***

If you would like any further information about the young adult renal service, or have any questions about anything contained in this report then please contact Matt Tomlin, Young Adult Worker by e-mail on [matthew.tomlin@nhs.net](mailto:matthew.tomlin@nhs.net)

## **Appendix 1: List of articles and publications**

Elias, R (2013). *Sharing what works*. Contribution to an article in British Journal of Renal Medicine supplement 'Shared-decision making in Kidney Care' (May 2014).

Hall, J., Tomlin, M., Hilton, D. & Hackett, D (2013). An 'Expert patients' residential programme for young renal patients pre and post transition. *Poster presentation at the British Renal Society Conference: Manchester*.

Tomlin, M., Coyne, E., Hope, W., Bebb, C., Johnson, C. & Byrne, C. (2013). Specialist young adult support improves clinic attendance rates and decreases levels of hospital admissions. *Oral presentation at the British Renal Society Conference: Manchester. (Winner of best abstract)*

Tomlin, M., Coyne, E. & Roe, S. (2013). Exploring the feasibility of a young adult dialysis session. *Poster presentation at the British Renal Society Conference: Manchester*.

Tomlin, M., Tutton, S., Woodland, J., Nottage, C. & Lentell, L. (2013). A national residential project to increase peer support opportunities for young adults living with kidney disease. *Poster Presentation at the British Renal Society Conference: Manchester*.

Tomlin, M., Coyne, E., Hope, W., Bebb, C., Johnson, C. & Byrne, C. (2013). Specialist young adult support improves clinic attendance rates and decreases levels of hospital admissions. *Oral presentation at the East Midlands Renal Showcase meeting: Loughborough*.

Tomlin, M., Coyne, E. & Roe, S. (2013). Exploring the feasibility of a young adult dialysis session. *Poster presentation at the East Midlands Renal Showcase: Loughborough*.

Tomlin, M., Coyne, E., Hope, W., Bebb, C., Johnson, C. & Byrne, C. (2013). Specialist young adult support improves clinic attendance rates and decreases levels of hospital admissions. *Poster presentation at NUH Annual research festival. (Winner of best poster)*

Tomlin, M., Coyne, E. & Roe, S. (2013). Exploring the feasibility of a young adult dialysis session. *Poster presentation at NUH Annual research festival*.

Tomlin, M. (2013). *An example of innovative practice: East Midlands Young Adult Renal Service*. Case study in Together for Short Lives 'Transition Taskforce' newsletter (November 2013).

## Appendix 2: References

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Waters, A. L. (2008). An ethnography of a children's renal unit: experiences of children and young people with long-term renal illness. *Journal of Clinical Nursing* 17, 3103-3114.

Watson, A. R. (2000). Non-compliance and transfer from paediatric to adult transplant unit. *Paediatric Nephrology*, 14 (6), 469-472.