From the start:
Engaging young adults with long term conditions in their care

March 2013
# From the start: Engaging young adults with long term conditions in their care

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<tr>
<td>Authors</td>
<td>Clare Beard, NHS Kidney Care</td>
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<td>Six project groups commissioned by NHS Kidney Care to develop new approaches to supporting young adults with kidney disease</td>
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<td>Circulation list</td>
<td>• Kidney community – clinical directors, lead nurses, specialised commissioners, network managers, professional bodies, patient groups&lt;br&gt;• Department of Health&lt;br&gt;• NHS Commissioning Board&lt;br&gt;• LTC professional bodies&lt;br&gt;• LTC networks&lt;br&gt;• LTC patient groups&lt;br&gt;• Young people's patient groups - Association for Young People's Health and Young People's Health Special Interest Group&lt;br&gt;• NHS Improving Quality&lt;br&gt;• Local Authority You’re Welcome leads&lt;br&gt;• Renal Registry</td>
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<tr>
<td>Description/purpose</td>
<td>This report brings together the evidence and learning from six project groups supported by NHS Kidney Care to develop innovative approaches for supporting young adults with kidney disease. The emerging success principles detailed in this report have wide ranging implications for the way transitional care is delivered across the NHS.</td>
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<td>Superseded docs</td>
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<td>Action required</td>
<td>Commissioners and service providers should consider how to use the information from this report to improve and implement effective care for young adults with long term conditions.</td>
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<td>Timing</td>
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Foreword

Typically in the UK, around a third of young adults who have received a kidney transplant and then transfer from paediatric to adult services reject their kidney within three years. This figure is shocking, but will not be a surprise to healthcare professionals working with young adults who have long term conditions.

I have been the clinical advisor for a national NHS Kidney Care project in which groups covering 22 adult units and five paediatric centres across England were commissioned to develop innovative approaches for supporting young adults. These projects have produced a wealth of valuable experience and expertise about how to tailor services for young adults to improve their quality of life and their clinical outcomes. This report sets out many of the ways that have been explored to improve the organisation of services for young adults.

These have been truly innovative projects, bringing a nationwide focus to local partnerships involving hospital, community and social services. While they have been unique among specialties looking at chronic conditions in the UK, they have developed models of care that are equally applicable elsewhere, for example in diabetes, chronic rheumatic diseases, congenital heart disease and cystic fibrosis.

Young people with long term conditions will have a lifelong relationship with their health services. It is imperative that we invest the time and resources from the outset to get that relationship right. The supporting young adult projects have shown that by redesigning services, focusing on our patients’ needs and preferences, and with only modest costs, we can achieve significantly improved outcomes. By getting services right for young adults, we can offer them the best opportunities for life and the future.

Work carried out by my team at Oxford University Hospitals NHS Trust has provided evidence which demonstrated, for the first time, the clinical benefits of offering dedicated clinics for young adults and integrating transfer between paediatric and adult services. In the research, which was published in the BMJ¹, two thirds of patients transferred under traditional models of care rejected their kidney within four years of transfer. However, following the introduction of a new integrated approach, none of the 12 patients studied rejected or lost their transplant.

This research demonstrates the importance of the work described in this report. The fact that young adults with long term conditions have specific emotional and social needs has been recognised for many years now. But for too long, care for this group of patients has been fragmented and outcomes have been patchy and sometimes poor. I believe that we are now reaching a point where we have sufficient momentum, evidence and experience to begin making a real difference for young adults with kidney disease and other long term conditions.

Paul Harden Consultant Nephrologist at Oxford University Hospitals NHS Trust and clinical advisor to NHS Kidney Care on supporting young adults

¹ Bridging the gap: an integrated paediatric to adult clinical service for young adults with kidney failure, PN Harden et al, BMJ 2012;344:e3718
Providing better support to people with long term conditions is a priority for the NHS. For teenagers and young adults with long term conditions, this means addressing the specific emotional and social needs of this group of patients. Many will be entering relationships or starting work. They may be leaving home for the first time or moving away to university and for many it is a difficult time as they experience greater independence. In kidney care, young adults who transfer from paediatric services or present directly to adult services often struggle with adjustment issues and problems with denial and concordance. This can have devastating consequences, including the rejection of a transplant and a return to dialysis.

Improving the care of all people with long term conditions is embedded throughout the NHS Outcomes Framework. In addition, transitional care is also given prominence in The Mandate for the NHS which stresses the importance of ensuring “people experience smooth transitions between care settings and organisations, including between… children’s and adult services...”

In 2010, NHS Kidney Care commissioned six project groups to develop innovative approaches for supporting young adults with kidney disease. The aim was to identify a range of proven approaches, adaptable to different locations, which would deliver:

- Greater concordance with treatment
- Fewer rejected transplants and patients returning to dialysis
- Better clinical and psychological outcomes for patients
- More efficient use of resources.

This report draws together the evidence and learning from the work undertaken by the project groups during the initial 18 months of the programme and details the different approaches taken to support young adults. It also looks at collaborative working to support young adults both in kidney care and across other long term conditions.

Each project group received funding to appoint a key worker to support young adult patients, working across both adult and paediatric services as well as primary and social care. Their exact role was decided by each project group, and included direct patient contact, broader young adult engagement, training healthcare professionals, and developing resources and reviewing pathways.

This report shows how by engaging clinicians, health and social care professionals, managers and young adults, the projects have created a real case for change. They have raised awareness and developed services that acknowledge and focus on the distinct needs of young adults. The projects have led to reduced admissions, fewer missed appointments, cost savings and improvements in long term health outcomes. They have generated real momentum and all of the projects now plan to continue their work beyond the life of the original NHS Kidney Care project.

A key part of the project was to support shared learning between the projects. NHS Kidney Care established a learning network and online forum to support the sharing of resources and good practice examples for feedback and to avoid duplication of effort. Evaluation of the learning network showed that it was a highly valued resource and it has left a legacy that can be built upon and adapted elsewhere (see Better Together: Sharing Learning to Improve Care http://www.kidneycare.nhs.uk/document.php?o=1450). The commitment of the project groups to the dissemination of learning is evident from the number of submissions, poster and oral presentations at professional meetings, and published papers. Much of the learning from these projects is generic and applicable to other long term conditions.

The emerging success principles detailed in this report have wide ranging implications for the way transitional care is delivered across the NHS. If implemented and rolled out across kidney services and other specialties, they have the potential to make a very real difference to the lives and health of young people with long term conditions.
A number of key themes have emerged from the projects which should inform future service improvements:

**Understand the needs and wishes of young adult patients.** An understanding of the needs and wishes of young adult patients must underpin and drive all changes. They must be involved in assessing needs and service redesign.

**Collaborative working is essential.** Young adults with kidney disease are not a heterogeneous population and may be preparing for dialysis, preparing for transplantation, or living with a transplant. Engaging wider clinical and multidisciplinary teams is essential.

**Effective team working and management buy-in is a must.** The support of senior clinicians, managers and commissioners helps to embed the culture change necessary for improvements to be sustainable. Involving staff to address the needs of young adults raises awareness of the issues and empowers them to achieve sustainable improvements.

**Good planning is crucial.** Time needs to be spent on patient and stakeholder engagement, reviewing existing provision and identifying how to address gaps. Projects found they worked best with multidisciplinary steering groups, including representation of all the units involved in the project, encompassing both paediatric and adult services.

**The key worker role is pivotal.** Given the need to engage patients and a wide range of stakeholders and to generate buy-in and support, as well as to provide direct patient support, the key worker role is pivotal. It is essential to determine the skills needed that cannot be met by the existing team and recruit appropriately.

**Dedicated young adult clinics are an effective service development.** In addition, support services including one-to-one support from a named key worker or other team member, contactable by text, phone and e-mail provided effective and flexible services to meet young adult's needs.

**Social events and social media are valued by young adults.** Promoting peer support using social and residential events was valued greatly. Using social media to improve and enhance communications with and between young adults and kidney services was also well received, although it is important to follow local trust protocols and encourage patients to take ownership themselves.
Ensuring that young people get the best possible care as they make the transition from paediatric to adult services is a top priority for the NHS. This report summarises the findings from NHS Kidney Care’s ground-breaking work on supporting young adult patients with kidney disease.

The report considers the findings from six project groups commissioned by NHS Kidney Care to develop innovative approaches to supporting young adults with kidney disease; the North East Renal Network, South West Renal Network, East Midlands (Derby and Nottingham), South Central (Oxford and Reading), London plus the South East Coast, and the West Midlands. In total, these project groups covered 22 adult renal units and five paediatric trusts.

The report draws together the evidence and learning from the work undertaken by the renal networks during the initial 18 months of the programme and details the different approaches taken to support young adults. It also considers collaborative working both in kidney care, and across long term conditions. The emerging success principles detailed in this report have wide ranging ramifications for the way transitional care is delivered across the NHS. If implemented and rolled out to other long term conditions, they have the potential to make a very real difference to the health of young people.
1. Introduction
1.1 Background and rationale

There is growing recognition that young people with long term conditions are at a greater risk of having poorer outcomes than other patient groups. They also need very specific support\(^2\),\(^3\),\(^4\),\(^5\). Many will be entering relationships or starting work. They may be leaving home for the first time, or moving away to university. For many, it is a difficult time as they experience greater independence, even without the added strain of managing a long term condition. Sometimes the pressure of this responsibility can lead the young adult to stop taking their medication or stop attending doctor's appointments, simply in a bid to feel more ‘normal’. This can have devastating consequences.

Policy context

Improving the care of young people with long term conditions such as kidney disease is embedded throughout the NHS Outcomes Framework. This work addresses domain 2: Enhancing quality of life for people with long-term conditions; domain 3: Helping people to recover from episodes of ill health or following injury; and domain 4: Ensuring that people have a positive experience of care (2012/13)\(^1\).

Transitional care is also given prominence in the Mandate\(^6\) for the NHS which expressly mentions the importance of ensuring “people experience smooth transitions between care settings and organisations, including between … children’s and adult services … thereby helping to reduce health inequalities.”

The National Service Framework (NSF) for Children, Young People and Maternity Services\(^7\) also highlighted the importance of ensuring safe and effective transition throughout children’s services and dedicates a standard to growing up into adulthood. Transition planning in the NHS must secure optimal health care for the young person but it is equally important to ensure that their wider needs and aspirations for the future are at the centre of the planning process.

You’re Welcome quality criteria (2011\(^8\), 2007\(^9\)) set out principles to help health services in the community and in hospitals to ‘get it right’. The quality criteria cover ten topic areas: accessibility; publicity; confidentiality and consent; the environment; staff training, skills, attitudes and values; joined-up working; monitoring and evaluation, and involvement of young people; health issues for adolescents; sexual and reproductive health services; and child and adolescent mental health services. Other key documents include *Transition: getting it right for young people* (2006)\(^10\) and *Transition: moving on well* (2008)\(^11\) which outline the role of key workers.

The NSF for Renal Services published in 2004\(^12\) and 2005\(^13\) set out five standards and four quality requirements which all apply to young adults with kidney disease. In 2006 a supplement to the Renal Services NSF: Working for children and Young People\(^14\) was published. This outlined approaches to supporting young adults to take increasing responsibility for their life and managing their condition including: patient-held records rather than parent-held, copied into clinical correspondence, being seen without parents at appointments and making decisions about, and taking responsibility for medicines.

*Driving Service Improvement through Patient Focus*, a report of Renal Action Learning Sets 2006-2007, a Department of Health sponsored project published in 2008\(^15\), set out key principles for making a smooth and planned transition through empowering and equipping young people and their families in preparation for transfer including:

- Achieving clarity regarding roles and responsibilities with the adult and paediatric teams
- The need for cultural change to acknowledge and respond appropriately to the issues facing young people in transition
- Having a named co-ordinator such as a key worker to facilitate a smoother transition
1. Introduction

1.1 Background and rationale

The Royal College of Physicians of Edinburgh guidance *Think Transition* 2008\(^{16}\) includes a section on chronic renal disease, outlining best practice and key messages including the development of services for young adults within the adult service. The British Association for Paediatric Nephrology (BAPN) and the Renal Association (RA) have published joint guidance *Helping Adolescents and Young Adults with End Stage Renal Failure* (2009)\(^{17}\) which makes a number of recommendations including establishing the role of support worker for young adults. This guidance also recognises the needs of 16–20 year olds presenting directly to adult services, who may account for about 40–50% of the young adults managed in adult care, but can be overlooked in the paediatric-driven agenda. The guidance recommends that “Young adults less than 20 years of age presenting to an adult renal unit with end stage renal failure, or with chronic kidney disease and anticipated to require renal replacement therapy within one year should be allowed to choose between remaining under the care of their local adult renal unit or transferring to the nearest Young Adult Renal Unit (YARU).”

The Royal College of Physicians young adult and adolescent initiative aims to improve healthcare outcomes for patients in the 16–24 year age group through greater involvement of adult “physicians” in the development and implementation of standards of care and quality indicators. The initiative also encourages collaboration with other colleges and specialist societies to influence policy makers.

In June 2012 *The Children and Young People’s Health Outcomes Forum*\(^{18}\) published proposals on how health-related care for children and young people can be improved. They noted the challenges to effective transition in long term conditions including in renal care, recommending “a new outcome in the NHS Outcomes Framework to ensure that effective and healthy transitions take place between child-centred and adult-centred health care” and also proposed using Hospital Episode Statistics (HES) data to monitor whether children and young people continue to receive the care they need following transfer from paediatric services.

The forum suggested that “an approach combining both a pull (from adult care) as well as a push (from paediatrics) needs to be adopted. To achieve this, the Forum recommends that the Royal College of Physicians works with the Royal College of Paediatrics and Child Health (RCPCH) and other Colleges to develop a plan, by 2014, to ensure that health outcomes and the experience for transition are improved.” The Forum also recommended that NICE produce a Quality Standard for age and developmentally appropriate care of teenagers and young adults, including through transition.
1. Introduction

1.2 NHS Kidney Care approach

Costs of kidney disease

Around a third of kidney transplant recipients who transfer from paediatric to adult services reject their kidney within three years. This contrasts with the average life-span of a transplanted kidney which is ten years for a deceased donor kidney, and about 20 years for a living related transplant. Kidney disease has serious effects for young people and their families as well as cost implications for the NHS. Each lost transplant costs the NHS approximately an extra £25,000 per year whilst the patient remains on dialysis.

As part of this project an audit in Reading reviewing the period June 2008 to June 2009 found that missed and rescheduled dialysis sessions for three patients between the ages 18–25 years cost the service £13,911. However this did not take into account the high resource burden involving specialist staff (namely renal matron, renal social worker, renal consultant, specialist nursing staff, clinical psychologist, administration staff and transport providers) in the following activities: phone calls, meetings, locating patients, negotiating about treatment, rearranging transport and additional blood tests.

The East Midlands project group baseline audit of 80 young adults found high clinic non-attendance rates (22.1%) with a total of 161 outpatient appointments missed. 38.7% of young adults had had an admission to hospital during the 12 months of the audit totalling 98 admissions and 416 bed days.

1.2.1 The initiative

Project groups were commissioned by NHS Kidney Care to develop innovative new approaches to supporting young adults who have kidney disease. These approaches have centred on the role of a key worker based in adult renal units, working across adult and paediatric kidney services as well as primary care, social care and other settings. Unlike many other developments that have focused on paediatric care, NHS Kidney Care placed this work firmly in adult services.

In this project, the term key worker is used to describe the funded posts, with dedicated roles defined by each project group. These roles could include direct patient contact, broader young adult engagement, training healthcare professionals, developing resources, reviewing process or service pathways, dissemination of learning, as well as work to influence cultures.

Project groups used the You’re Welcome criteria, designed to help providers and commissioners transform health services by improving acceptability, accessibility, quality and choice for young people, to develop holistic patient care.

1.2.2 The support

Alongside funding, NHS Kidney Care provided a package of support to the project teams. This provided them with opportunities to access specialist advice, and share experiences and knowledge with others. This helped ensure the long-lasting impact and success of the initiative, as well as ensuring the project teams remained motivated as they progressed towards project delivery. This support involved the input of the NHS Kidney Care Programme Lead for the Supporting Young Adults with Kidney Disease projects who provided regular coaching contact and project progress monitoring to the projects. NHS Kidney Care also set up a monthly reporting system which helped the project teams to document their progress and key learning from the project implementation, address exceptions and risks, and escalate where appropriate.
1. Introduction

1.2 NHS Kidney Care approach

Other support included:

- **Project board**
  NHS Kidney Care established a project board to oversee this work. This board regularly reviewed progress by project groups and advised on opportunities to spread innovation and influence. Board membership included senior NHS and Department of Health executives, clinical experts both from the kidney community and from other long term conditions, as well as project group representation. The board was chaired by an experienced and highly skilled Chair. A full list of members of the project board can be seen in appendix 1.

- **Learning network and forum**
  A learning network was set up to bring together members from all project groups, to learn from each other. Membership was wide ranging and included project leads, clinical leads and specialist clinicians from the project groups, as well as members of the NHS Kidney Care team. Face to face meetings were held quarterly in a central location, accessible to all project groups. An evaluation of the learning network via interviews of network members found this to be a valuable resource, whilst identifying key learning which is shared at [http://www.kidneycare.nhs.uk/document.php?o=1450](http://www.kidneycare.nhs.uk/document.php?o=1450)

  In addition, NHS Kidney Care created and facilitated an online learning forum for the project which aimed to provide opportunities for the project groups to share learning and good practice. This was primarily used to share key resources both for feedback and to avoid duplication of effort, thus becoming a useful project archive.

  Evaluation of the learning network showed that it was a highly valued resource and left a legacy that can be built upon in future and adapted for other long term conditions.

- **Sharing work with wider audiences**
  This work has been shared with wider audiences via external e-seminars, presentations at events, journals and other publications. The e-seminars were open to healthcare professionals and other interested parties, allowing project groups to share their work and disseminate key learning. They attracted national and international attendees. Feature articles appeared in Nursing Times and in many other media outlets. An asset based approach was used to identify key messages, project champions and outputs. (See appendix 2.)

- **Communications support**
  NHS Kidney Care provided support and resources to help the project teams share key learning and news of their work. When the project began, a template press release was created that could be tailored for each team and issued to the local media and used in trust newsletters. Feature articles were placed in the nursing press, which were co-written with some of the project teams. Examples of key learning from each project team were developed into ‘how-to guides’ and shared with other units through the NHS Kidney Care website and e-newsletter. These how-to guides included:

  You’re Welcome quality criteria lead to out of hospital kidney clinic for young adults
  [http://www.kidneycare.nhs.uk/howto_guides1/youre_welcome_quality_criteria](http://www.kidneycare.nhs.uk/howto_guides1/youre_welcome_quality_criteria)

  Facebook group connects young adult patients
  [http://www.kidneycare.nhs.uk/howto_guides1/facebook_group_connects_young_adult_patients](http://www.kidneycare.nhs.uk/howto_guides1/facebook_group_connects_young_adult_patients)

  Staff education improves services for young adults
  [http://www.kidneycare.nhs.uk/howto_guides1/staff_education_improves_services_for_young_adults](http://www.kidneycare.nhs.uk/howto_guides1/staff_education_improves_services_for_young_adults)
1. Introduction
1.2 NHS Kidney Care approach

Members of the communications team held an interactive workshop for the project teams, focusing on writing and presenting skills. This also included guidance for preparing posters for display at events. An additional e-seminar was also carried out to provide further support on poster preparation. Towards the end of the project, a resource pack was created that brought together guidance and resources from each of the project teams. Packs have been distributed at local events, and promoted through the website and e-newsletter.

- **Conference poster presentations**
  As an acknowledgement of the important work being carried out by the project teams, NHS Kidney Care encouraged and supported them to submit abstracts and present posters in major academic and professional conferences. These presentations offered opportunities for the aims and objectives of the Initiative and the variety of approaches by the individual project teams to be communicated widely.

- **Project evaluation**
  In 2010, Matrix Decisions Ltd, a commercial research and consultancy company was commissioned to deliver an external evaluation of the project groups over an 18 month period. The aims of the evaluation were to: explore the different models of care/approaches adopted by each of the project groups in terms of how they have impacted young adults and staff and how they have brought about improvements in service delivery; reflect on the feasibility of delivering models and approaches; and identify both drivers and barriers to achieving a smooth transition process for young adults and improved support in adult care. The interim evaluation report was published in May 2012 [http://www.kidneycare.nhs.uk/document.php?o=1264].

  To inform the evaluation and service delivery by the project groups, Matrix Decisions Ltd conducted a literature review in order to examine the evidence base for models of care in renal, juvenile arthritis and cystic fibrosis services to support young adults through transition and those whose first point of contact is adult services. Specific focus was given to the different types of transition models available; areas of good practice; the strength and challenges that have been demonstrated; how models of care have improved patient outcomes; and the outcome and process indicators used to measure the improvements made by the models of care. The literature search is available at [http://www.kidneycare.nhs.uk/document.php?o=564].

  Project groups undertook the second wave (time 2) of data collection for the SYA evaluation in February 2012 to enable comparison with time 1 data with project groups. The time 2 data was received from three of the six project groups (North East, South West and South Central) and the outcome of the analysis will be presented to the individual project groups in March 2013.

  The SYA evaluation project has put in place a system for collecting data in each project which will provide them with a database to capture the characteristics, needs and treatment options of the young adults, as well as some simple interim indicators of impact. As a result of the work, NHS Kidney Care is at the forefront of developing indicators for young adults in kidney care, and will be making recommendations to the UK Renal Registry regarding the indicators and measures for young adults with kidney disease to be considered in the development of the renal national minimum data set. To this end, a report is being produced which will provide information on available data and highlight areas where the data available is deemed inadequate, either because of complete or partial absence of the relevant data, or inadequate quality of the data which is available. This report will be presented to the Renal Registry in April 2013 and will be recommending that the Renal Registry should set up a structure to continue to capture the young adult information from renal units in England.
2. The project learning and outcomes

2.1 Overview of coverage

The geographical distribution of the renal centres in the six project groups participating in the programme is shown in Table 1 below.

Table 1– Participating units

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<tr>
<th>Location</th>
<th>Unit coverage</th>
<th>Work with other long term conditions</th>
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<tbody>
<tr>
<td>North East</td>
<td>Across whole region: units in Newcastle, Middlesbrough and Sunderland.</td>
<td>Linking with cardiology and cardiac transplant services.</td>
</tr>
<tr>
<td>South Central</td>
<td>Oxford and Reading units.</td>
<td>Working to improve care for young adults who have had other organ transplants. Providing chlamydia screening, working with sexual health services.</td>
</tr>
<tr>
<td>East Midlands</td>
<td>Derby and Nottingham, sharing learning with Leicester.</td>
<td>Linking with diabetes, gastroenterology, oncology and youth work service at Nottingham University Hospital NHS Trust.</td>
</tr>
<tr>
<td>London and the South East</td>
<td>Led by team at Guy's and St Thomas’ working with: Kings College, Barts Health, East Kent (Canterbury Hospital), Brighton and Sussex, St George’s, Epsom and St Helier, The Royal Free, Imperial College (Hammersmith Hospital).</td>
<td>Linking with glomerular disease, urological conditions and haematology (sickle cell).</td>
</tr>
<tr>
<td>West Midlands</td>
<td>University Hospitals Birmingham NHS Foundation Trust and Birmingham Children's Hospital.</td>
<td>Commissioned to audit their young adult transition clinic and took part in the project evaluation.</td>
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2.2 Project engagement

A call for Expressions of Interest was sent to all renal units in England in 2009. This resulted in 11 applications. These were independently reviewed and scored by a panel who agreed which projects should be funded. The members of this panel can be seen in appendix 3. Two applications were from trusts in the same network and these were asked to work together to submit a joint application. Five project groups were approved and asked to develop detailed project profiles, with delivery plans. A sixth project from the West Midlands was subsequently commissioned to audit their young adult transition clinic and took part in the project evaluation.
2. The project learning and outcomes

2.3 Common challenges and solutions

All of the groups achieved substantial service improvements, developing a range of innovative approaches, methods and resources to support young adults who have kidney disease. Resources and approaches have been informed by local geography, population and infrastructure. Individual project reports are available on the NHS Kidney Care website.

Project groups worked with other kidney care services, made links with local agencies and shared learning with services for young adults with other long term conditions in order to raise awareness of existing best practice and to disseminate effective models of care. The participating groups addressed different challenges in order to achieve their project aims. However some common challenges and solutions have emerged which could serve as key learning points:

Project planning

Those who had successfully submitted an expression of interest were charged with developing detailed project profiles and delivery plans with explicit milestones and timescales. Some submissions had been made by a single individual or small group, due to the timescales involved. It was essential to engage a wider group of stakeholders to plan projects but this was not always straightforward. Renal network managers, where in post and involved in projects, were invaluable in supporting project groups and in engaging multiple organisations, particularly hospital trusts. They were also often more familiar with project planning principles and costs. Establishing a multi-disciplinary steering group, which met regularly with all stakeholders, working collaboratively with shared focus to develop and improve services for young adults appeared to be the most successful approach.

Within their project planning, each group had to carefully define their target population. This included considering the age range and the extent of work with paediatric services. Project groups were clear that they should not focus on transition alone, recognising the needs of those diagnosed with kidney disease in young adulthood.

Time spent planning projects enabled project groups to be creative and innovative in their approaches to service improvement, recognising that one size would not fit all units across England. In this way other units could learn what worked and adapt different elements from the different projects to their own unit and situation. Another key aspect for several project groups was securing senior level support for their work. Nationally an asset based approach was used to identify key messages, project champions and outputs. This also informed targeting of key messages to reach appropriate audiences.

Reviewing existing provision

Before developing new service models, project groups recognised the importance of reviewing existing provision and identifying the limitations of existing services, knowledge and skills. Project groups developed a number of resources including survey tools to assess young adults’ needs developed by the South West and London project groups, and a South West framework to benchmark services. These are available on NHS Kidney Care’s website:

http://www.kidneycare.nhs.uk/our_work_programmes/improving_choice_for_kidney_patients/supporting_young_adults_with_kidney_disease/tools_to_help_you

Recruiting key workers

All project groups managed to successfully recruit to key worker posts, despite challenges around fixed-term employment. One key worker left post relatively quickly, as the project group became clearer that the post needed to focus on cultural change rather than direct contact with young adults. Another key worker was recruited and all other key workers remained in post throughout the project.
2. The project learning and outcomes

2.3 Common challenges and solutions

Key workers were recruited from a range of different backgrounds including youth work (both qualified and unqualified), psychology and nursing. It was essential to identify the skills needed, consider existing strengths and gaps in current teams and to explicitly define roles: was the primary focus on intervention delivery or organisational development and training? It was also necessary to consider patient numbers, and the number of organisations involved as well as geography. Some project groups appointed to job share part time rather than full time posts to take advantage of skill mix.

Project groups recognised the importance of considering key worker recruitment and retention at as early a stage as possible. One group advertised in media aimed at youth workers, which resulted in a large number of high-quality candidates. A common challenge experienced by project groups was that of completing the Criminal Record Bureau (CRB) checks and induction process, especially where post holders worked across multiple organisations. Other key points included agreeing key worker support and supervision, personal development and access to training.

All project groups noted the pivotal role of key workers to the success of their projects. In particular these roles were essential in promoting awareness of young adult issues and liaising between multiple staff groups and services.

Engagement of young adults

Projects have secured new ways of working and approaching young adult care, particularly in the use of age appropriate technology and communication channels. Some successes have involved very minor adjustments to service provision, such as ensuring young adults are signed up to receive text reminders for clinic appointments, a facility widely available across most trusts. Extending services, which have for several years been offered to young adults with transplants, across all treatment settings, has ensured that all young adults with kidney disease regardless of their treatment mode can now expect age appropriate care from their kidney care providers.

Other approaches to actively engaging young adults included direct contact, and collaborative work with patient support groups including Young@NKF. In Reading, young adults have been closely involved in the development of the Young Adult Group identity, designing the logo and contributing to the leaflet and newsletter.

One on-going challenge has been to ensure engagement of a wide spectrum of patients including those on dialysis.

Project groups identified that young adults often have unmet social needs and peer support is very important. They have worked to encourage opportunities for young adults to gain peer support from other renal patients as well as support to maintain and develop general relationships. A national residential event organised collaboratively across all of the project group areas, and involving young adults from each area was held in February 2012, funded by the British Kidney Patient Association (BKPA).

Social media

Recognising the value of social media for young adults, project groups prioritised this area. Key lessons from the South West project group are reported in a how-to guide about the use of Facebook: http://www.kidneycare.nhs.uk/document.php?o=996.
2. The project learning and outcomes
2.3 Common challenges and solutions

Several groups found social media developments had to fit with their local trust approaches, seeking to minimise the risks of inappropriate use. There were also concerns expressed by some clinicians about how young adults may use such resources, particularly in terms of confidential information. In order to address these concerns, a standard disclaimer was made available for project groups to post on the Facebook page advising users not to share any confidential information.

Several project groups have agreed to hand over responsibility to young adult patients who have volunteered to manage the page. This has led to greater engagement from those young adults who wanted to be actively involved. Key workers have administrator rights so that they can still post information about clinics and events, as well as useful links.

Guy's Kidney Patient's Association worked with the London project group to develop the 'MyKidneyCare app', a handheld personal information and self-management tool for young adults to support them in managing their kidney care through transition. The app is available for all android smartphones and is free to download. Visit play.google.com and search for 'mykidneycare'.

Dedicated clinical champions

Motivated clinical champions committed to the projects were important in this work. Much of the development focused on cultural changes, so engaging key stakeholders including young adults with kidney disease, other clinicians, commissioners and senior trust staff was essential. Project groups had to respond appropriately to challenges, including those who felt that services for young adults should not be a priority area or should be tackled within paediatric care. Some project groups found they lacked adequate clinical champion capacity and at times this constrained their ability to deliver as planned.

Engagement with staff

It was fundamental to engage staff, across all disciplines, to actively plan how to address the needs of young adults in their own service areas. This was a challenge, especially at the outset of these projects. Embedding a young adults’ service within wider kidney care services needed skill and determination to be successful. Key approaches included sharing learning about young adults’ needs including the national evidence base and those identified via surveys, networking events to update staff about the project and regular newsletters to keep people informed about progress. It was identified that key workers needed to establish their presence across all units involved in their project, to avoid being perceived as ‘owned’ by the unit where they were based.

Staff training

Several project groups recognised that staff training was vital to address the needs of young adults, not only raising their awareness of the issues but also empowering them to achieve sustainable cultural change. Successful solutions included establishing clinical champions or lead nurses in each unit involved in projects; creating a forum on NHS Networks for staff, holding information events for staff and promoting the adolescent e-learning module.

The London project group successfully developed a formal training presentation for use around the region. At the lead project trust this is now given to all qualified nurses attending yearly mandatory sessions. Within this presentation, advice and information is discussed in relation to meeting age appropriate needs and supporting the process of transition from paediatric units. http://www.kidneycare.nhs.uk/howto_guides1/staff_education_improves_services_for_young_adults
2. The project learning and outcomes

2.3 Common challenges and solutions

Service developments

Project groups focused on developing services to meet the needs of young adults with kidney disease. Key service developments included:

- **Young Adult Clinics**
  Many project groups worked to extend clinic provision to meet the specific age appropriate needs of their young adults in both onsite and offsite young adult clinics and also in ensuring appointments for similar aged young adults are arranged for the same days and times. Many found establishing Young Adult Clinics (YACs) was effective, although they had to overcome re-design issues including administrative support. There is a need for flexibility as not all young adults may wish to attend a dedicated YAC, especially where these are held centrally. For some they will prefer to be able to access support locally. The need to establish excellent communication links with primary care and across kidney care services was recognised, for example to support patients in acute episodes such as infection or requiring dialysis. Where patient population is small in number with diverse needs YACs may not provide adequate flexibility; units found that tailored one-to-one support may be more effective.

  In Birmingham a single adult nephrology consultant and transplant nurse run clinics jointly with a paediatric nephrology consultant and paediatric transplant nurse. These clinics run every two months and patients are seen in this clinic until they are deemed ready to engage fully with adult services.

  Oxford and Reading groups established YACs outside NHS settings such as local sports centres or colleges. This entailed considerable challenges including access to medical records, appropriate arrangements for blood collection, funding arrangements and contingency plans. Some groups felt this remains an effective approach despite these issues but recognised the time and determination required to address these. Key lessons are reported in: [http://www.kidneycare.nhs.uk/document.php?o=433](http://www.kidneycare.nhs.uk/document.php?o=433). Oxford’s young adult clinic is the subject of a short film: [http://www.kidneycare.nhs.uk/vid.php?o=86](http://www.kidneycare.nhs.uk/vid.php?o=86).

- **Support services**
  All project groups examined support for young adults. The importance of one-to-one support was highlighted, especially for those young adults with complex needs or those dealing with concordance issues. Some key workers had a caseload and supported young adults dealing with complex issues such as homelessness or debts. Key aspects to effective support included a named key worker who could be contacted via phone, text and email. Other key workers worked with clinical colleagues supporting such patients. In the latter case, an effective solution was to develop tools so staff can identify appropriate agencies to signpost young adults to.

  Support was also delivered via groups. Some project groups examined the role of peer support for young adults. The Oxford group have successfully used buddying approaches for young adults having transplants, together with their living donors where appropriate.
2. The project learning and outcomes

2.3 Common challenges and solutions

- **Planned transition**
  Project groups recognised the importance of planned transition rather than simple transfer for those in paediatric care. Key strategies to support transition include facilitated meetings with adult services, transition tours and joint multidisciplinary hand over clinics. It was also noted that timing should be flexible in order to avoid modality changes as well as other significant events such as exams, allowing service provision changes to occur during optimum periods of stability for patients. For example the North East project group established transition clinics for 17 to 19 year olds. This service has been highly rated by young adults, and appointments attendance by this population has improved. This service is multidisciplinary in nature, including sexual health and Connexions (youth work) services. It has promoted collaborative working across paediatric and adult services in the region.

  In Birmingham the team offer transitional tours to young adults moving from paediatrics to adult care as part of transition package for 16 to 25 year olds. The team are piloting a MyHealth online forum.

  The Oxford team have established an integrated transition model for young adults transferring from London units to Oxford. Evidence of the effectiveness of this has been reported in the British Medical Journal.²⁰

- **Other approaches**
  Other approaches included pathway mapping and development as well as social events including participating in British and World Transplant Games.

**Complex needs, diverse needs**

The population of young adults with kidney disease is diverse, including those transferring from paediatrics and those arriving as young adults. Some young adults have not yet started RRT; some may have had a transplant, whilst others are on dialysis. Whilst some may be at school, others may be employed. Some will live with their parents whilst others live independently and may themselves be parents. This diversity should be recognised and individual care planning needs to be responsive to each young adult’s needs. It is important not to underestimate the time it can take to support a young adult with complex needs.

Project groups have recognised the importance of further service developments in the future in order to meet the needs of some young adults, such as those with learning difficulties and disabilities. The Birmingham team are developing care plans for young people with learning disabilities.

**Holistic care**

Project groups sought to adopt holistic approaches. The North East group developed an assessment tool which includes a distress thermometer as well as needs assessment of emotional, social, medical, physical, and transition issues. This group also devised an education and employment questionnaire that identified needs around benefits access, dealing with fatigue and specific support around applying for jobs.

Groups worked with other agencies and were successful in gaining their support in raising awareness of the needs of young adults with kidney disease. Both the South West and Reading groups developed tools to facilitate appropriate sign posting to agencies.

These resources are available on NHS Kidney Care’s website: [http://www.kidneycare.nhs.uk/our_work_programmes/improving_choice_for_kidney_patients/supporting_young_adults_with_kidney_disease/tools_to_help_you](http://www.kidneycare.nhs.uk/our_work_programmes/improving_choice_for_kidney_patients/supporting_young_adults_with_kidney_disease/tools_to_help_you)
2. The project learning and outcomes

2.3 Common challenges and solutions

Working together

Project groups were asked to work together. This was facilitated by NHS Kidney Care’s Learning Network, forum and key worker collaborative work such as planning the national residential event.

After initial resistance from some project groups to the You’re Welcome quality criteria, due to the fact they are not tailored for specific conditions, over time these were used to inform service developments.

All project groups sought to work locally with other long term conditions teams. This included other transplanted organs, cancer, urology and diabetes. This was not always straightforward but over the long term delivered very real benefits. Time and capacity constraints were key challenges to sharing learning.

Data

As part of the external evaluation Matrix Decisions Ltd built a bespoke Microsoft Access database to enable each of the project groups to record the following data on their young adults: demographic characteristics; care modality; treatment regime; care plan and transitional information. Project groups experienced considerable challenges in collecting some of this data including some data being held by different providers and some data not being collected routinely. NHS Kidney Care is working with the UK Renal Registry to recommend a routine dataset for this patient population that will enable long term audit of outcomes.

Local research and evaluation

Several project groups undertook research as part of their work. The East Midlands group explored the needs of young adults (aged 18 to 26) with CKD (stage 3 and above) who were under the care of the adult renal teams at Derby and Nottingham. This highlighted three overarching themes which were: transition and entry to the adult service; home and hospital treatment and the impact of CKD on partners, friends and family. An audit was undertaken to assess the impact of the young adult project in the East Midlands. Data were collected for 12 months prior to the project and then for the subsequent 12 months. The baseline data population includes all young adults aged 18–25 with a diagnosis of CKD 3-5, who were accessing adult renal care at Nottingham and Derby hospitals. This group was then followed up for the next data collection period of 12 months. Clinic non-attendance reduced from 22.1% to 14.3%, total number of missed appointments dropping from 161 to 98. The number of admissions associated with non-concordance reduced from 24 to 17. Home therapy uptake increased from 21.1% to 33.3%.

As part of their work, the North East project group retrospectively audited transplant outcome data over a 15-year period. This concluded that young adults are at a high risk of graft loss. Non adherence and previous psychological difficulties may contribute to this. Intensive support from a young person’s kidney care coordinator may be of benefit by providing additional support, information and education around the management of their kidney disease and other health, social and emotional issues however longitudinal data is required.

The group from University Hospitals Birmingham and Birmingham Children’s Hospital collected data on objective outcomes in order to audit their young adult transition clinic and to improve current services for young adult kidney patients. The results of this will be published later in 2013.

The Oxford group undertook a mixed methods study of 14 young adult patients examining important themes influencing educational achievement and employment attainment in young adults with End Stage Renal Disease (ESRD). The project was undertaken by a medical student who has ESRD and has been submitted for publication.
2. The project learning and outcomes

2.4 Emerging success principles

A number of key themes have emerged across all the Supporting Young Adults with Kidney Disease projects which should inform future successful service improvement:

- **Good planning is crucial.** Time needs to be spent on stakeholder engagement, reviewing existing provision and identifying how to address gaps. Utilising group members who have project management skills can greatly assist projects. Projects found they worked best with established multidisciplinary steering groups, including representation of all units involved in the project and encompassing both paediatric and adult services.

- **Effective teamwork and management buy-in is a must.** The contribution of network managers in supporting projects throughout should also be noted. Senior management, including commissioner support and trust acceptance may help to embed the culture change necessary for sustainability of the project.

- **All available tools to review existing provision should be used.** A number of tools have been developed to assess local needs and provision. These should be used to inform service developments. These tools are available through the NHS Kidney Care website at 
http://www.kidneycare.nhs.uk/our_work_programmes/improving_choice_for_kidney_patients/supporting_young_adults_with_kidney_disease/tools_to_help_you

- **The key worker role is a pivotal one.** It is essential to determine the skills required that cannot be met by the existing team and recruit appropriately. The skills needed may change over time; for example project groups found that engaging wider clinical teams was a critical issue at the outset but once clear communication approaches, such as link workers, were agreed this required much less time. It is essential to establish if key aspects such as clinical engagement are the responsibility of the key workers, project lead or senior clinician.

- **Engaging young adults is fundamental.** Effective approaches include assessing needs and re-designing services to take account of these. Other more innovative approaches included involving young adults in web design, branding and social media. Promoting peer support using social and residential events was also valued.

- **Social media is a key support tool but local protocols must be followed.** Local communications teams need to be involved in setting up social media communications to ensure approaches comply with trust policies and procedures on the use of social media. It is important to involve patients and if possible, encourage them to take ownership and set the group up themselves. Establish more than one nominated administrator to share the burden and responsibility of making new posts and monitoring the page. Where possible, link to existing groups and networks, rather than create a new group.

- **Involving staff to address the needs of young adults is central.** This raises their awareness of the issues and also empowers them to achieve sustainable cultural change. Using a range of approaches is most likely to produce optimal results.

- **Having highly motivated clinical champions is essential.** They promote the service and drive up acceptance among staff and patients. Any motivated and experienced member of the kidney healthcare team can take on the clinical champion role; however they need dedicated time and capacity.

- **Young Adult Clinics are a very effective service development.** In addition, support services including one-to-one support by a named key worker (or other team member), contactable by text, phone and email provided effective and flexible services to meet young adult needs.
2. The project learning and outcomes

2.4 Emerging success principles

- The small numbers and diversity of the population of young adults with kidney disease should be noted. Approaches suitable for those with more complex needs such as learning difficulties or co-morbidities need to be further developed. The impact of diagnosis not only on the young adult but also on parents, siblings and friends should also be considered.

- Data issues need to be addressed. As already noted there was no routine collection of a common set of data across the project groups and the collection of some data points for the external evaluation proved difficult and cumbersome. As a result of the learning gleaned during the course of the project, NHS Kidney Care is working with the UK Renal Registry to recommend the routine collection of a core dataset for this population of young adults.

- National level support and endorsement is helpful and motivating. During the lifespan of this project the project board visited each group in order both to hear about their local experiences as well as to provide high level national endorsement. These visits were welcomed by project groups and often resulted in greater recognition of their work by trust senior managers.

- Transferability to other long term conditions should be considered. The learning network evaluation identified recommendations, which may be relevant across many long term conditions. These include ensuring that members are committed from the beginning and have the time and resources to attend and host meetings, having clear objectives with agreed scope, and establishing meeting dates on a long-term basis in advance and adhering to them. Whilst virtual meetings allow for valuable conservation of time and money they only work well when individuals know each other and therefore should not occur in isolation. Face-to-face meetings are essential at the beginning as networks become established to allow relationships to develop.

- The support of the NHS Kidney Care was highly valued by the project groups as driving forward this work. The communications team supported project groups to successfully submit a number of abstracts and publications to a diverse range of events and journals. For example, the work of the Oxford project group appeared in the British Medical Journal in June 2012.
3. Project implications and future development

This project demonstrates the vital importance of getting transitional care for young people right. It sets out how this can be done by using a range of innovative new approaches and resources. Key to the success of the project was the appointment and role played by key workers working in adult kidney services, and collaborating with paediatric services, primary care, social care and other settings.

Resources and approaches have to be informed by local geography, population and infrastructure. By including young adults who have had a kidney transplant and those currently receiving dialysis, the project shows how even with the most complex long term conditions, real improvements can be made.

In order to raise awareness of existing best practice and to disseminate effective models of care, project groups worked with other kidney care services. They also made links with local agencies and shared learning with services for young adults with other long term conditions, such as other organ transplants and diabetes. These projects have raised the profile of renal services in England as they deliver developments in care quality which will stand the test of time and have lasting positive benefits for patients and service providers. Projects were recognised locally and regionally but also nationally and internationally, both across kidney care and other long term conditions.

The commitment of the project groups to dissemination of learning is evident from the number of submissions, poster and oral presentations at professional meetings, and published papers. Much of the learning from these projects is generic and applicable to other long term conditions. Whilst these projects focused on young adults with kidney disease, some of these young adults are also living with other long term conditions.

The contribution of patient support groups has been underlined by this work and on-going collaboration will be essential in the future. Project groups worked hard to involve and engage young adults in their work. They considered the health inequalities experienced by young adults with kidney disease, including ethnicity and co-morbidities. There are areas that require further work. These include supporting carer needs, sexual and reproductive health and supporting those who present to hospital acutely unwell.

Other key benefits have included collaboration across trusts, sometimes at a network level to share learning but also on other unrelated projects.

All of the project groups involved in this work have secured future funding. Several have been funded by the British Kidney Patient Association (BKPA), whilst others have identified resources locally. The project groups plan to collaborate to share learning not only with each other but with other kidney care centres both across the UK and internationally and with healthcare professionals involved in the care of young adults with other long term conditions. This future collaboration will also include links to other key organisations including work with the UK Renal Registry and the British Association of Paediatric Nephrology (BAPN) to agree an appropriate dataset in order to audit care going forward. This will be essential to develop business cases for future funding; potentially including developments such as generic key worker posts encompassing several long term conditions. This project demonstrates that it is feasible to have young adult services across more than one NHS hospital trust. This is an effective and cost-efficient way of providing support to young adults.

The work of NHS Kidney Care’s Supporting Young Adults with Kidney Disease project demonstrates that by using cost effective, innovative and tailored solutions, significant improvements in outcomes can be achieved. The project learnings should be scaleable for use across the long term conditions community. With concerted and coordinated action and effort, there is a real opportunity to make a huge difference to the lives of young people.
Appendix 1 – Members of the project board

Elisabeth Buggins  Chair, Birmingham Women’s NHS Foundation Trust
Beverley Matthews  Director, NHS Kidney Care
Donal O’Donoghue  National Clinical Director, Department of Health
Paul Harden  Clinical Adviser, NHS Kidney Care
Grace Sweeney  Head of Research & Evaluation, NHS Diabetes & Kidney Care
Clare Beard  Programme Lead, NHS Kidney Care
Janet McDonagh  Clinical Senior Lecturer in Paediatric and Adolescent Rheumatology, Institute of Child Health, Birmingham Children’s Hospital NHS Foundation Trust
Katrina Kirkby  Communications Manager, NHS Kidney Care
Cherry Yip  Young Person Representative, National Kidney Federation
Rosemary Macri  British Kidney Patient Association
Mary McGraw and Jane Tizard  British Association of Paediatric Nephrologists
Ann Murdoch  British Renal Society representative
Donna Hilton  Youth Service Manager, Nottingham

Visitors to board meetings included project group leads, key workers and network managers: Wendy Hope, Margaret McQuade, Rachel Gair, Clare Nottage, Sue Cox, Katy Priddis, Dan Lonsdale, Laura Baines, Lorraine Lentell, Ramona Loveridge and Ronny Cheung from the Department of Health.

Meeting papers were distributed to Sheila Shribman, Karen Turner and Heather Gwynn at the Department of Health.
Appendix 2 – Media coverage and events presence

Publications and media coverage

- British Medical Journal
- Nursing Standard
- Nursing Times
- Nursing in Practice
- CNO Bulletin
- British Journal of Renal Medicine
- Kidney Care Matters
- Renal Association website
- Children, Maternity and Families e-bulletin
- Journal of Renal Nursing
- National Youth Agency website
- Children and Young People Now
- Kidney Life
- Derby Telegraph
- BBC Radio Oxford
- Jack FM
- Newcastle Evening Chronicle
- Nottingham Evening Post
- BBC Oxford TV
- BBC Radio Tees
- Synapse (Trust magazine at Nottingham)
- Your Local Guardian

Events:

- British Renal Society, Renal Association
- Kidney Education Network
- European Working Group On Psychosocial Aspects of Children with Chronic Renal Failure
- European Dialysis and Transplant Association
- European Society Of Transplantation
- Association for Young People’s Health
- Young People’s Health Special Interest Group
- Diabetes UK
- British Cardiovascular Society
- Royal College of Physicians
- Long term conditions
Appendix 3 – Expressions of interest review panel

Elisabeth Buggins  Chairman of Birmingham Women’s NHS Foundation Trust and Chair of Supporting Young Adults with kidney disease project board

Donal O Donoghue  National Clinical Director for kidney care, Department of Health

Beverley Matthews  Director of NHS Kidney Care

Paul Harden  Consultant Nephrologist and Clinical Advisor to NHS Kidney Care's Supporting Young Adults project

Grace Sweeney  Head of Research & Evaluation, NHS Diabetes & Kidney Care

Clare Beard  Programme Lead, NHS Kidney Care
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6. References


