Project Definition

Supporting Young Adults with Kidney Disease

Author:  
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Better Kidney Care for All
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1 About This Document

The purpose of this document is to clearly define the work of the Supporting Young Adults with Kidney Disease project, part of the Patient Experience workstream, within the overall programme of work, which will contribute towards the implementation of the National Service Framework (NSF) for Renal Services.

2 Background

There is growing recognition that young adults with complex health needs such as kidney disease need support. Concordance issues are very prominent in young adults: the loss of kidney transplants and adjustment issues after transfer to adult units can have a great personal and financial cost. A study in 2000 found that 35% (7 of 20) of patients with a renal transplant transferred to an adult nephrologist had lost their graft within 36 months of transfer1. Adult service provision differs considerably from paediatric care in terms of expectations around active participation in self-care.

Teenagers and young adults presenting directly to adult renal services with progressive CKD are equally vulnerable and frequently have major issues with denial and adherence. Therefore all young adults managed in adult renal units may benefit from support to access adult services.

3 Business Strategy

The National Service Framework for Children, Young People and Maternity Services highlighted the importance of ensuring safe and effective transition throughout children’s services but also dedicates a standard to growing up into adulthood. Government policy emphasises that this is not solely a matter for healthcare professionals, since long-term conditions also have important educational, social and financial implications. Transition planning in the National Health Service must secure optimal health care for the young person but it is equally important to ensure that their wider needs and their aspirations for their future are at the centre of the planning process.

These principles were incorporated into the White Paper, Our health, our care, our say: a new direction for community services and the Department for Education and Skills Green Paper, Youth Matters. Fundamental to the Departments’ work programme is the drive to ensure that health related services, within and outside of the NHS, are equipped and coordinated to meet young people’s needs long term.

The NSF for Children, Young People and Maternity Services (2004) Standard 4: “Young people supported to make the transition to adulthood and to achieve their maximum potential in terms of education, health, development

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and well-being. Young People taking responsibility for their own health and making informed choices and decisions regarding their emotional and social development, and health and well-being both now and in the future. Services and staff who are able to respond in a sensitive way which encourages engagement and provides high-quality support for young people.

You’re Welcome quality criteria (2007) set out principles to help health services both 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) and Transition: moving on well (2008) that outlines the role of key workers and health plans.

The NSF for Renal Services published in 2004 and 2005 sets out five standards and four quality requirements which all apply to young adults with kidney disease.

Standard one: a patient-centred service aims to optimise the role that people with kidney disease can take in the management of their care: “All children, young people and adults with chronic kidney disease are to have access to information that enables them to make informed decisions and encourages partnership in decision-making, with an agreed care plan that supports them in managing their condition to achieve the best possible quality of life.”

In 2006 a supplement to the Renal Services NSF: Working for children and Young People 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
- Making decisions about, and taking responsibility for medicines.

“Driving Service Improvement through Patient Focus” A report of Renal Action Learning Sets 2006-2007, a DH sponsored project published in February 2008, 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

The Royal College of Physicians of Edinburgh guidance document “Think Transition” 2008 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 BAPN and RA have published joint guidance “Helping Adolescents and Young Adults with end stage renal failure” (2009) 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 recommended 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)."

4 Vision

The Renal NSF offers an opportunity to transform the quality of kidney care by reducing kidney disease and improving both the experience and outcome of care for those who develop kidney disease. It challenges the whole system – clinicians, commissioners and regulators to use information to drive innovation, safety and productivity.

This project aims to support trusts to develop approaches to supporting young adults who have kidney disease including those who have had a kidney transplant and those currently receiving dialysis. This will include both those transferred from paediatric services and those presenting in young adulthood. Approaches will be informed by the population and geography served by different units.

This project meets this vision by enabling services to deliver support to young adults with kidney disease funding approaches that are designed to meet the needs of the population they serve.

5 Objectives

[What specific outcomes do you expect to achieve from this work?]

This project will
- identify a range of suitable approaches and resources for supporting young adults with kidney disease, which will adapt to different localities.
- raise awareness of existing best practice and disseminate effective models of care via presentations and/or published papers, abstracts and reviews at professional meetings.
- consider health inequalities experienced by young adults with kidney disease including ethnicity and co-morbidities.
- involve young people from the outset in project development and staff recruitment
- be independently evaluated.
6 Benefits

[What will be the specific business benefits to patients, public & staff?]

➢ The identified approaches will aim to support young adults with kidney disease resulting in greater concordance with treatment, fewer missed appointments and “drop-outs”, less staff time following up and ultimately reduce the number of lost transplants in young adulthood that subsequently require dialysis.

➢ Feedback from young adults, family and professionals will inform service developments. Participating units will be encouraged to implement transition policies and health plans in accordance with national strategy.

➢ This work will inform other service areas caring for young adults with complex health needs and/or long term conditions.

7 Success Criteria

[What will constitute success & how will we measure it?]

Evidence of success will include some or all of the following:

• Attendance at clinics, (pre service change vs post), reduced loss to follow up and/or impact on staff time following up missed appointments

• Reduced emergency admissions and out-patient visits, Length of Stay (LOS) and/or infection rates

• Quality of life measures including education, employment, relationships

• Increased vocational readiness markers e.g. work/volunteering experience; awareness of rights under Disability Discrimination Act; and/or involvement of Connexions

• Concordance including transplant loss and need for dialysis

• Patient, family and staff satisfaction

• Improved documentation of adolescent psychosocial screening

• Number of patient-held records/copy letters e.g. use of HealthSpace on the NHS site for over 16 year olds

• Number of young people who meet the adult team prior to transfer

• Audit of transition health plans

• Written transition policy agreed with paediatric and adult providers, young people and families and all major stakeholders.

• Increased prevalence of self-management skills e.g. independent health care utilisation; self-medication; independent visits

• Number of You’re Welcome quality criteria achieved
• Staff training and development e.g. number of staff who have completed the adolescent health project e-learning modules (www.e-lfh.org.uk/ahp)

Project success criteria including participating service recruitment, milestones delivered to time, financial probity, and effective dissemination of findings, including those that identify best practice and influence future service provision.

8 Scope

[What is the scale of the work involved? What are the boundaries?]

In the first year (2009/2010) five kidney services caring for young adults in different SHA areas will be funded to develop innovative approaches to improve their services. Further funding may be available subsequently. These approaches are expected to centre on the role of a key worker. Posts will be based in an adult service but staff will work across adult and paediatric kidney services as well as primary care, social care and other settings. Pump-priming funding for eighteen months may be used for new posts (fixed-term or secondments) or to protect time of existing team members. Commissioner engagement will be essential to ensure sustainability as well as support opportunities to influence tariff.

Services taking part will need senior-level support: the CEO will need to commit to You’re Welcome quality criteria and to providing clear clinical leadership, with annual reports to the Trust Board. Services need to consider any necessary clinical, phlebotomist, administrative and analytical support. Support from kidney networks will also be essential. Different localities may need to consider dimensions such as patient numbers, ethnicity and rural areas vs. inner city. Gender will be an important consideration in designing and evaluating approaches as approximately 70% of patients are male. Posts may be part-time. Services are encouraged to consider posts which though largely focused on kidney care, also encompass young adults with other long term conditions such as cystic fibrosis. All patient needs will be accommodated including physical disability, learning disability, cultural needs, language needs (interpreters and written information), limited literacy and cognitive impairment.

8.1 Included

Fund posts based in five adult services in different SHA areas
Young adults receiving Renal Replacement Therapies, including transplantation
Young adult patients with CKD 4 preparing for Renal Replacement Therapy
Young adult patients with any form of progressive kidney disease

8.2 Excluded

Funding is time-limited for a maximum of eighteen months (2009-2011).
Patient with early CKD being managed in Primary Care (i.e. CKD 1, 2 and 3)

9 Organisation / Governance
The governance structure for this programme is presented below:

Roles and responsibilities are outlined in appendix A.

What management/governance structure is required and what are the associated roles and responsibilities?

Eg. Project/programme board terms of reference

10 Approach

How are we going to deliver the objectives and measure success?

Who are our delivery partners?

Include approach to Impact Assessment and Procurement where appropriate

NB: for a programme, this chapter might provide information relating to the structure of the programme and a short description for each of the associated projects (these projects will also need a project level PID of their own in which to present the detailed delivery focused information)

This project is part of the patient experience workstream. Each participating unit will outline its approach to improving care for young adults with kidney disease in their Expression of Interest. This outline will include outcome measurement and spending plans. These will be subject to the approval of the Project Board with quarterly updates from each unit’s named project lead. Key equality dimensions such as gender and ethnicity will be monitored. The NHS Kidney Care Programme Lead for Patient Experience will liaise with each project team based in each participating service.
Each unit will need to consider the skills they require to complement their existing team. It is envisaged that a key or support worker will probably have a background in youth work, but recognise that essential skills include credibility (both to young adults and clinicians), advocacy, empathy, emotional and psychological support, communication and care planning skills. Approaches should be flexible, and have potential to be made bespoke for each young adult. Innovative approaches that use newer technologies such as mobile text, email and social networking sites (e.g. facebook my space contact) will be encouraged.

11 Plan / Milestones

A detailed, consolidated programme plan is held and maintained in the Enterprise Project Management (EPM) System.

- PID submitted to Executive Team: Sept 09
- PID approved by Executive Team: Sept 09
- Group established: Sept 09
- Sites identified via Expressions of Interest
- Monitoring / evaluation processes agreed
- Monthly progress reports
- Interim report September 2010
- Final report April 2011
- Presentation/ event to report outcomes/findings
- Published papers, abstracts and posters at professional meetings.

12 Stakeholders

[Who has the authority or ability to influence outcomes and who will be affected by such outcomes?]

- [What are their roles and responsibilities?]
- Provider trusts caring for young adults with kidney disease
- Provider trusts with paediatric renal units
- Key decision makers such as Chief Executives, managers, budget holders
- Department of Health Children team
- Department of Health Renal Policy team
- NHS Kidney Care
- British Association for Paediatric Nephrology
- British Renal Society
- National Kidney Federation
13 Communication

[What, when and how will we communicate with stakeholders?]
Stakeholder comments have been sought during August 2009, and these have informed project development.
Offer opportunities for expressions of interest via targeted letter to Senior Nurses and Clinical Directors in Trusts with a Kidney Service and via Kidney Care Matters
Communication plan here as part of PID, including dissemination of good practice – to be developed

14 Finance

[Itemised breakdown of likely costs.]
Funding available 2009-2011
A total of 350k will be available to participating sites. An independent evaluation of this project will be funded from additional monies.

15 Resources

Clinical Advisor
Programme Lead
Director input
Administrative support
Project Sites

16 Risks

Please see risk register kept in EPM system.
Initial risks:
- Trust/unit engagement
- Recruitment to posts (fixed term and location)
- Epidemiology (population gender and ethnicity, location and numbers)
- Economic recession.

17 Dependencies

[What/who are we reliant on? What/who is reliant upon us?]
None.

18 Constraints
What restrictions/limitations need to be managed?
Sustainability of posts funded by this project.

19 Project Controls

19.1 Planning
The project will develop and maintain a project plan that clearly shows how their objectives will be achieved in terms of deliverables and activities. These plans will be consolidated to form an overall programme plan. Progress will be monitored against the programme plan and reported on a regular basis.

19.2 Reporting
Progress will be reported by the project manager to the relevant NSF programme managers meeting and a consolidated report will be prepared for the Programme Board, which will present progress made within the work streams and highlight any specific programme level issues for discussion, agreement or resolution. The progress reports will be based on a DH standard reporting template and will provide the following information:
- Overall Status
- Management summary
- Achievements
- Exceptions
- Planned activities for next reporting period
- Finance summary
- Change requests
- Risks

19.3 Risk Management
Risks are potential problems that would have an adverse impact on the progress of the project if they were to actually happen. Since risks threaten the success of a programme of work, it is important to control them within a formal risk management process. The Programme Lead is responsible for managing project risks. Risks may be highlighted at any time, but will normally be highlighted in progress meetings. They will be logged on a risk register and will be reviewed at project meetings. Major risks will be reviewed at the Kidney Care Programme Board. The risk register will record the following information:
- Description of risk and the effect it might have
- Probability of it happening
- Impact if it did happen
- Action(s) required to reduce/ remove the risk
- Risk owner
19.4 Finance
This project will be funded by NHS Kidney Care. The NHS Kidney Care Programme is funded as a part of NHS Diabetes and Kidney Care through the bundle via its host organisation Bradford and Airedale PCT. NHS Kidney Care Programme Director manages the NHS Kidney Care budget according to the agreed priorities.
The procurement, processing and payment of invoices will be managed by NHS Diabetes & Kidney Care.

19.5 Change Control
Whenever there is a request for work which is not covered within the agreed, baselined scope of the programme, a standard Change Request (template obtained from the DH intranet) will be raised by the person requesting the change (in writing), to the project/workstream manager. Requests for change which require more resource must be escalated to the Programme Board for discussion and agreement. This ensures that due consideration is given to the desired programme outcomes/outputs/priorities and their associated impact on timescales and resource requirements.
The status of outstanding change requests will be monitored at the programme progress meeting. Change requests that are ready for approval will be presented to the Programme Board for sign-off. Once approved, the work associated with Change Requests will be incorporated into the programme scope, documentation and plans.

20 Appendix A – Roles and Responsibilities

20.1 Project Executive/Sponsor
Donal O’Donoghue
National Clinical Director for Kidney Care
Department of Health

Beverley Matthews
Director,
NHS Kidney Care
Chair of Project Board

20.2 Project Board
The Young Adults with kidney disease Project Board exists to approve all major plans and authorise deviation from those plans. It will act as the steering group for this project. It provides the overview and scrutiny for all stakeholders and the Executive Sponsor to ensure that the project is effectively executed and delivers the desired outcomes. Specifically the Project Board/steering group will:
Authorise any expenditure and/or resources required to deliver the success of the project at each phase

Provide overall direction and guidance to the Project Teams

Assume ultimate project authority and control and is responsible for the initiation, direction, review and eventual closure of the project. Cascades communication to stakeholders

Reports progress and outcomes to the Kidney Care Programme Board
Members of the Project Board:

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| Chair | National Clinical Director for Kidney Care  
NHS Kidney Care |
| Programme Lead | National Clinical Director for Children, Young People and Maternity Services  
Renal Policy Team, Department of Health |
| Clinical Advisor | Representative from British Association of Paediatric Nephrologists  
Representative from Renal Advisory Group |
| | Patient representative, National Kidney Federation  
Representative from Specialised Commissioners for Kidney Care Forum |

20.3 Programme Lead
NHS Kidney Care

20.4 Project Team
Clinical Advisor
Programme Lead – NHS Kidney Care
Project Leads (from each Development Site)