



Valuing Individuals - Transforming participation in Chronic Kidney Disease (CKD) Programme

Project Initiation Document

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1. Introduction

NHS England is required by the NHS Mandate 'to ensure the NHS becomes dramatically better at involving patients and their carers, and empowering them to manage and make decisions about their own care and treatment'. To 'enhance quality of life for people with long term conditions' and 'embracing opportunities created by technology'. The Mandate also requires all people with a long term condition to have a personalised care plan. This programme will build on existing programmes and technological infrastructure within the area of Chronic Kidney Disease (CKD). Scaling up to deliver an increase in participation in personalised care planning and support for self-management for people with renal disease at the acute end and with more patients earlier in the pathway. Support for and identification of patients with CKD is varied across the country. This programme aims to deliver a patient centred pathway of care in two health communities building the evidence and case for change.

More recently, The NHS Five Year Forward View sets out how the health service needs to change, arguing for a more engaged relationship with patients and communities to promote wellbeing and prevent ill-health. It makes a specific commitment towards supporting people to manage their own health and care - by investing in evidence-based approaches such as group-based education for people with specific conditions and self-management educational courses, as well as encouraging independent peer-to-peer communities to emerge.

"Our most important relationships are with those we serve. We want to demonstrate this in practical ways. That is why we are committed to involving patients and the public directly in the development of our plans; encouraging and supporting active participation in improving care and services; and promoting openness and transparency both in the way we work and information about the work we do."

'Putting Patients First' – NHS England's Business Plan 2014/15 – 2016/17

2. Programme Definition

2.1 Vision

People with chronic kidney disease and their families will be supported and empowered to achieve the personal and clinical goals that are important to them, wherever they are in the pathway of care. Patients, carers and clinicians will be valued and supported to develop the

skills, knowledge and confidence to work together toward the best possible clinical and person centred outcomes.

2.2 Overall programme principles

Key Principles and the 'way of working' for the programme relate to the NHSE business plan aims, and to the following Kidney Health: Delivering Excellence ambitions

- Awareness: People - both healthcare professionals and the general public - understand the factors that increase the risk of kidney disease, and action is taken to reduce these risks.
- Identification: All people with kidney disease are correctly identified and monitored.
- Self-management: All people with kidney disease are offered as much information as they would like in order to understand and manage their condition.
- Person-centred care: Care is centred on the person, taking into account individual needs and preferences, quality of life, symptom burden and the presence of co-existing medical conditions.
- Preparation and Choice: All people approaching end-stage renal disease, or moving from one type of treatment for end-stage renal disease to another, understand and are given sufficient time and support to prepare for a treatment that is suitable for them, chosen from the full range of options.

The key over-arching principles for this programme are as follows :-

- Is it possible to routinely gather data around patient measures
- Is there any correlation between PAM and PROM/PREMS/Clinical Outcomes
- Could interventions modify PAM scores

2.3 Aim

The aim of this programme is to support, facilitate and measure the difference to improvement in care and outcomes 'with' and 'for' patients with chronic kidney disease and end stage renal failure. This will be achieved by commissioning a pathway of care in the local health community starting with peoples skills, knowledge and confidence and offering a full range of options to access information, support for self-management, self care, shared care and peer support to facilitate people to manage their condition, plan their care and improve their physical and mental wellbeing.

All patients with CKD (within two health communities identified) are supported to live as full a life as possible for as long as possible managing their health condition and sharing decisions about their care.

All people approaching end-stage renal disease, or moving from one type of treatment for end stage renal disease to another, are supported to understand and are given sufficient time and support to prepare for a treatment that is suitable for them.

2.4 Programme scope

A care pathway for people with CKD Stage 3, 4 and 5 will be developed which can be implemented at various stages of a patient's journey.

Development of support for self-management including educational programme for patients, carers and professionals which can be used at various stages of the patient's journey.

Development of an electronic patient record for patients and their carers (via Patient View) to provide patients with data obtained from their hospital, GP and pathology records. This database will also enable the patient to input additional data not usually held by these organisations.

Development of an audit and baseline process by using tools such as PAM (Patient Activation Measures), PROM's (Patient Reported Outcome Measures) and PREM's (Patient Reported Experience Measures).

2.5 Programme Objectives

The objectives of the Programme are to:

- Develop a patient-centred care pathway, based on patient's skills, knowledge and confidence which can be used at any stage of CKD from first diagnosis through the full life cycle of their renal care.
- Identify a minimum of 10 communities, with two invited to work as 'in-depth' communities. The communities chosen will include Clinical Commissioning Group areas referring to a local renal unit. (For ease of measurement). Levels of deprivation in the area along with prevalence of Local Term Conditions in the local population will be other factors in choosing the 10 areas.
- Accountability - How do we ensure person centred outcomes are as readily valued as bio-medical markers?
- Provide tools for patients and carers which will give them access to the information they need to:
 - self-manage their care
 - increase their knowledge and understanding of what may lie ahead and how choices made now may influence their outcome
 - feel better informed to discuss treatment options with the professionals providing the treatment.
- Ensuring that appropriate education, including skills based training packages are developed for all health professionals based on best available evidence.

- Ensuring that commissioners, health care professionals and managers are aware of the importance of early patient engagement and appropriate local strategies to help improve patient centred outcomes and minimise hospital stays.
- Involving patients and the public in understanding the risk of CKD and preventative measures through education and appropriate access to personal information and work with Public Health England
- Support the development of a commissioned pathway of person-centred care to allow local service configuration to include 'more than medicine' interventions.
- Ensuring that commissioners, health care professionals and managers are aware of the importance of early patient engagement and appropriate local strategies to help improve patient centred outcomes and minimise hospital stays.
- Develop incentives that can be used by commissioners.
- Need to measure not just that PAM has been implemented but the improvement seen as a result including improved outcomes for patients and efficiencies to the health system.

2.6 Programme Deliverables

Through the Transforming Participation in CKD Programme Board and workstreams we aim to achieve the following deliverables:

- A more effective and efficient infrastructure to allow a two way communication via the platform of Renal Patient View (RPV) using modern technologies.
- Expanding the reach of RPV to primary care and a greater number of patients.
- Offering the opportunity by the measurement system implemented behind RPV to prevent disease progressing for patients' with earlier stage CKD and an opportunity for care closer to home.
- To electronically gather and utilise measures and outcomes that are important to patients and personalising the presentation of those back into patient care. (PROM – EQ5D and POS-Renal)
- To support greater access to care records, facilitate care planning and self-management
- Whole system focus on the patient pathway for CKD

Specific objectives:

- In depth work through pilots with CCGs and specialist commissioning to develop a pathway, measurements, interventions and evidence of improved patient centred outcomes in a 'patient centred chronic kidney disease care pathway'. Including;
- Personalised care planning and the use of Patient Activation Measures to develop;
- A spectrum of self-care support including; patient led education, lifestyle related information and peer support, care navigators for patients and their carers.

- Shared decision making, and personal decision aids, PROMs/PREMs. A detailed description of the project deliverables, agreed quality standards and milestones relating to the PROM aspect of this programme can be found at appendix A.
- A patient centred pathway to include community based support for patients/carers. (To encourage CCGs/renal units to identify existing support in their local communities.)
- Training for clinical staff along the pathway to support collaborative working with patients.

2.7 Programme structure

The Transforming Participation in CKD Programme is a partnership between NHS England and the UK Renal Registry. The UK Renal Registry will deliver the programme on behalf of NHS England. The programme will also be delivered with the kidney patient community including the Kidney Health Partnership Board (Objectives listed above). The Programme will have its own Programme Board which will report into NHS England.

There are currently 3 identified workstreams for the Programme and these will report into the Programme Board. More detail on this can be found in section 10 of this document.

Objectives of the CKD Programme Board can be found in the Terms of Reference.

2.8 Dependencies

The programme is dependent on the following:

- Joint working between NHS England and the UKRR to make this programme a success
- Co-production with patients /patient organisations throughout the programme management and delivery.
- The recruitment and partnership working with the health communities to test this 'way of working'.
- Agreement by the Transforming Participation in CKD Programme Board to the aims and objectives of the Programme
- Time commitment from the workstream co-chairs

2.9 Constraints

The CKD Programme is subject to the following constraints:

- Availability of the right staff in place with appropriate expertise and experience to run a large scale national programme
- Availability of the key stakeholders to take an active role in the programme
- Commitment to the 'ways of working' and principles of this work

2.10 Interfaces

The programme has the following interfaces:

- UK Renal Registry
- NHS England
- The Renal Association
- Patients and the public
- The Kidney Health Partnership Board
- Health and social care system
- NHS Improving Quality
- CKD Programme Board
- Academic Health Science Networks
- Strategic Clinical Networks
- Renal Clinical Reference Group

2.11 Assumptions

The following assumptions have been made for this programme:

- The UK Renal Registry and NHS England will co-produce the outputs from the programme.
- Each workstream will consider the impact of scope and outputs on the other workstreams to avoid duplication.

3. Programme Tolerances

The programme will run over a period of two years in the first instance, beginning with initial PAM/PROM collection. The start date of the programme is April 2015. Collection of measures will start later in 2015.

4. Programme Controls

Report	Frequency	Audience
Highlight/Status Report (CKD Programme Board)	Monthly	NHS England/UK Renal Registry
Exception Report (workstream)	As needed	CKD Programme Board

Risk/Issues (Workstream and CKD Programme Board)	Monthly	CKD Programme Board
Lessons Learnt	Project close	CKD Programme Board UK Renal Registry NHS England

5. Programme Plan

The programme plan will be maintained by the UKRR Head of Programmes and will enable clear task and milestone planning and provide assessment of progress to plan. Each workstream, with support from the programme team, will maintain its own project plan agreed by the CKD Programme Board.

This document can be found at Appendix A.

6. Programme - people resources

Name	Role
Jonathon Hope	Co-Chair of the Transforming Participation in CKD programme Board
Richard Fluck	National Clinical Director – Renal, NHS England (Sponsor and Co-Chair)
Ron Cullen	Director, UK Renal Registry
Patricia Muramatsu	Senior Strategic Advisor, Patient Participation, NHS England
Karen Thomas	Head of Programmes, UK Renal Registry
Sarah Evans	Project Coordinator
Rachel Gair	Person Centred Care Facilitator

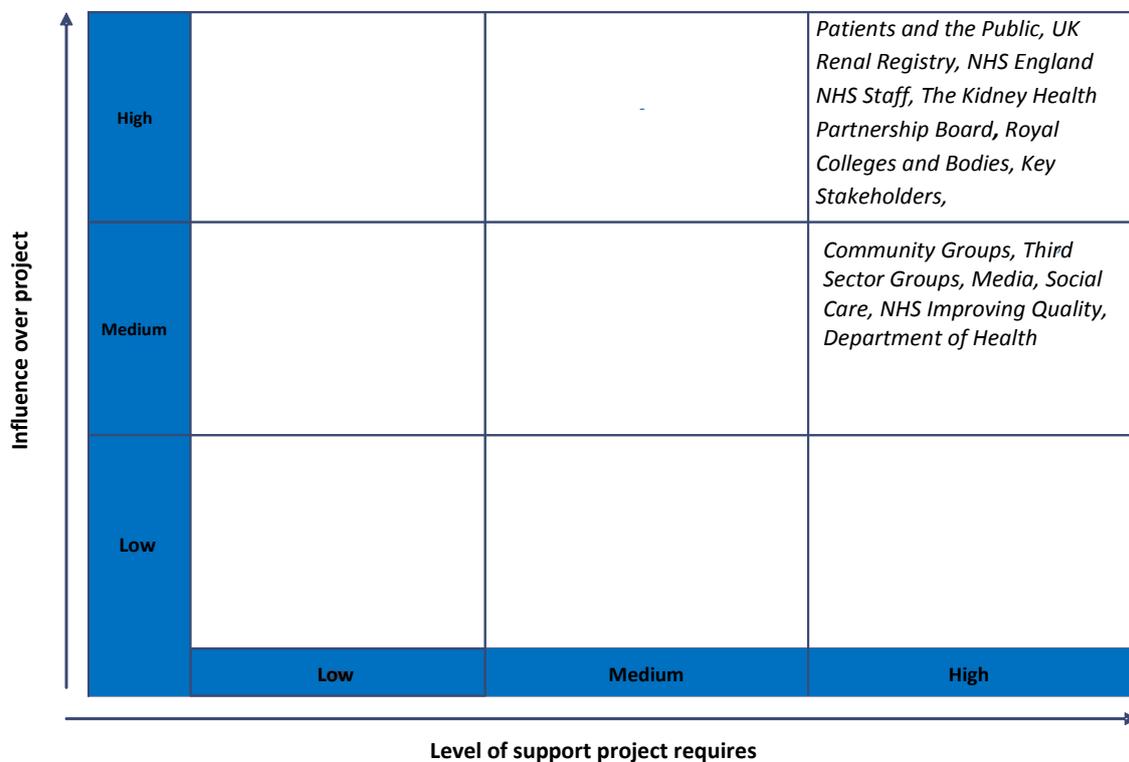
7. Risks

Please see Risk Register at Appendix B.

8. Stakeholder Engagement and Communications

The support of all key stakeholders to the programme is critical to the success of the Transforming Participation in CKD Programme. The method of communication will be through press releases and media engagement, the NHS England website, social media, key events and conferences, email, marketing collateral, newsletters, key networks and internal and external channels. It was agreed by the Programme Board in June 2015 that the overarching brand for this programme will be Think Kidneys. Key messages for this programme will need to be developed.

Communications will be as part of the governance process. A detailed stakeholder engagement and communications plan will be developed in due course.



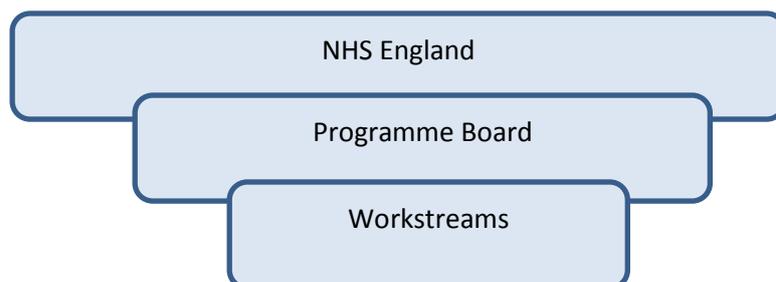
9. Governance

The programme will be managed in accordance with the overall governance structures and is covered in more detail in 10.1.

10. Programme Organisation

The Programme will be organised into the following work streams which will report to the Programme Board. The Programme Board is made up of key stakeholders.

10.1 Programme Reporting Structure



10.2 Transforming Participation in CKD Programme Board

The group will include:

- An aspirational figure of 50% patient/carer representation (including the co-chair)
- The core management team defined as
 - Patient co-chair
 - National Clinical Director for Renal as co-chair
 - Head of Programmes UKRR
 - Programme Sponsor, NHS England
 - Director, UK Renal Registry
 - Person Centred Care Facilitator, UKRR
- Project Coordinator, UKRR
- A representative of the Kidney Health Partnership Board
- Renal clinical representation with expertise in patient centred care
- Communication advice
- Health Economic advice
- Renal paediatrician
- Representation from NHS England Patient Participation Team
- Specialised commissioner for Renal
- CCG representation

11. Programme quality assurance plan

11.1 Quality checkpoints

Checkpoint	Defect Prevention Technique	Participants	Quality Record Produced
Transforming Participation in CKD Programme Board	Review of all programme plans	Programme Team	Board minutes

11.2 Quality responsibilities

Name	Role	Responsibility and authority
Jonathon Hope	Co-Chair of the Transforming Participation in CKD Board	Agrees overall programme plans and objectives
Richard Fluck	National Clinical Director – Renal, NHS England	Agrees overall programme plans and objectives

Ron Cullen	Director, UK Renal Registry	The UK Renal Registry oversees key deliverables and governance arrangements and ensures programme is delivered
Patricia Muramatsu	Senior Strategy Advisor, Patient Participation, NHS England	As the commissioning sponsor acts as the key link between NHS England's Person Centred Care Team and the UK Renal Registry
Karen Thomas	Head of Programmes, UK Renal Registry	Ensures that the programme is delivered to time and in budget
Transforming Participation in CKD Programme Team	UK Renal Registry	Ensures the programme is delivered within the planned timescales and budgetary requirements
Transforming Participation in CKD Programme Board		Provide advice, constructive challenge, and high-level influence