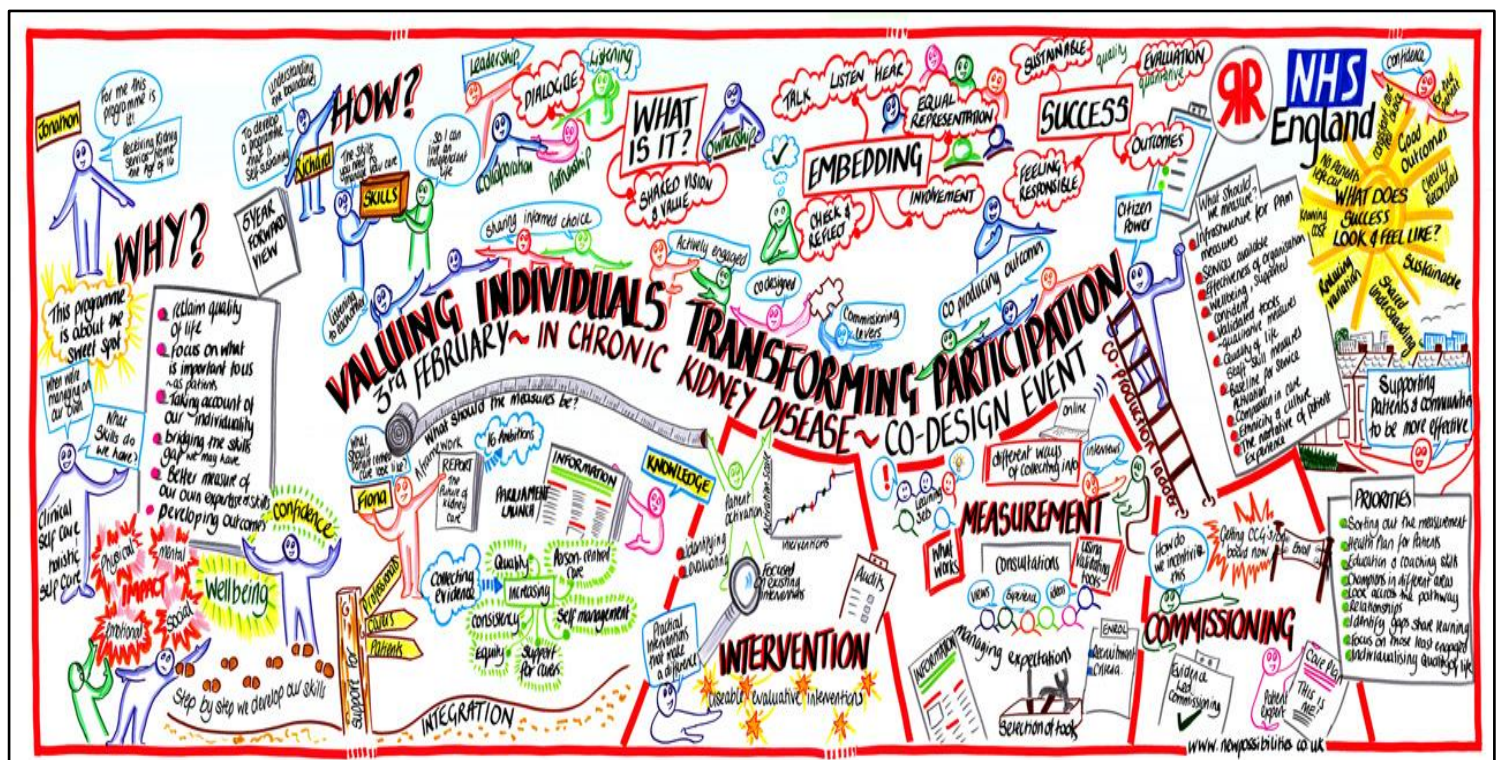




Aston University, Birmingham



1. Introduction

The NHS England Five Year Forward View states that ‘**We will do more to support people to manage their own health – staying healthy, making informed choices of treatment, managing conditions and avoiding complications.**’

The **Transforming Participation in Chronic Kidney Disease (CKD)** programme aims to develop a person centred pathway of care where people are supported to build the skills, knowledge and confidence to manage and make decisions about their own health to improve their quality of life.

2. Building on patient expertise - Jonathon Hope, Co-Chair

The challenge is in helping people to reclaim their quality of life, because everyone with CKD is an individual, striving to take on board the difficulties and challenges of living with a serious disease. Patients with CKD go from knowing nothing about the disease to needing to become experts. This is often a case of trial and error. There are currently no patient experts or disease specific self-management courses to help patients understand how to manage the day to day aspects of their life. The biggest challenge of all is that there is no systematic support for to build patients’ skills, knowledge and confidence. We hope that this project will help to change that.

3. Long term condition management - Richard Fluck, Co-Chair

The programme will use NHS England’s **House of Care** model (**Figure One**) as a framework for person centred and co-ordinated care.

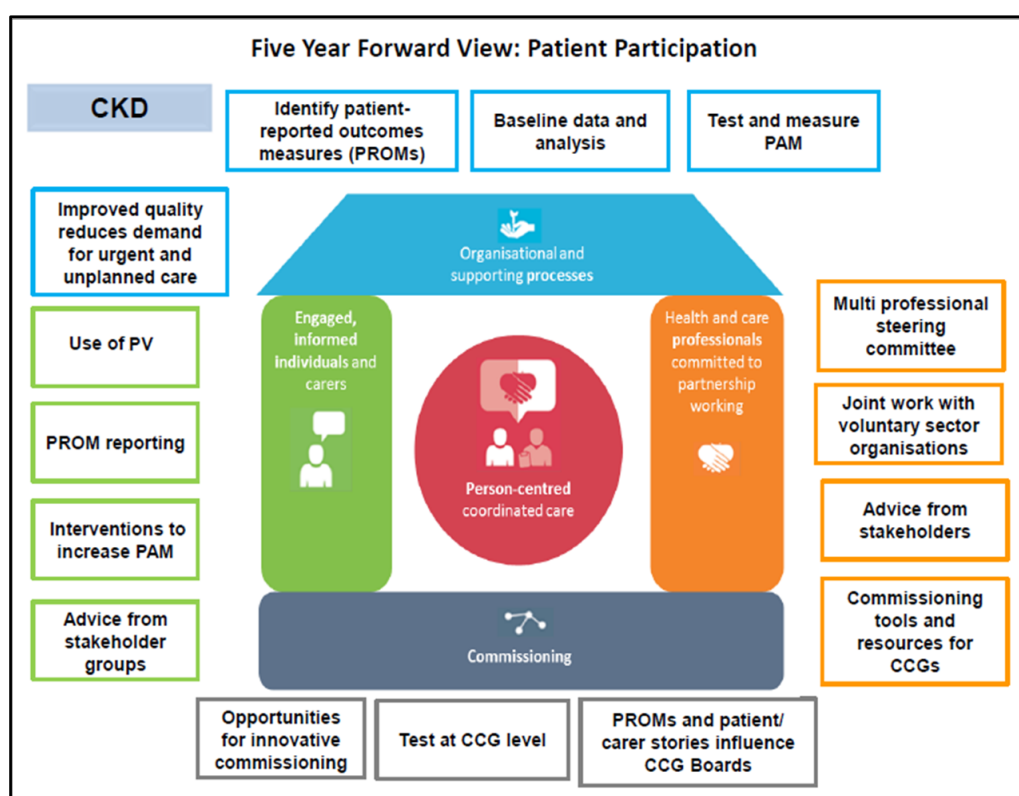


Figure One: *House of Care* model for patient participation

Patient activation is at the heart of this programme - ensuring that people have the knowledge, skills and confidence to take control of their health care. Highly activated people are more engaged, involved and actively taking part in their health management.

We need to emphasise to all clinicians that we must interact with patients. We need to set the standard for an excellent package of care. I totally believe in patient choice

Sat Vanga, Consultant Nephrologist,
University Hospital North Midlands

4. Delivering excellence in kidney health - Fiona Loud, BKPA

Key findings of the recently published [Kidney Health Report](#) include:

- Equity in regards to transplantation
- Ensuring patients are supported to minimise the impact of treatment on their lifestyle
- The importance of access to a specialist multi-professional team for everyone living with CKD

The **Kidney Health Partnership Board** was established in 2014 in order to promote the report and its ambitions, which include:

- deliver person-centred care
- measure and improve quality of life
- prevent or delay disease progression
- prevent and treat acute kidney injury
- improve the care of children and young people



Valuing individuals – transforming participation in Chronic Kidney Disease co-design event – executive summary

5. Group work - exercise 1 – understanding co-production

A. What does co-production mean to you?



B. How do we ensure co-production is embedded in the programme?

- Patients and carers recognised as equal members and represented on all workstreams
- Listen to everyone
- Create the vision and goals for the programme together
- Provide training and support for patients and professionals
- Understand each other's priorities

C. How will we know we have achieved co-production at the end of the programme?

- Shared ownership and delivery
- Continued involvement of everyone
- Testing with patients not involved in the programme
- When patients report that their outcomes have been achieved
- Patient activation increases
- Patient and carers feedback that they feel involved and empowered
- Evaluation from everyone involved in the programme's development

6. Group work - exercise 2 - priorities for measurement

A. What should the programme measure?

The patient experience

- Patient Activation Measures
- The service user's journey
- How supported, motivated and confident the patient feels to self-manage
- Compliance to medication
- Patient satisfaction

We need to measure the things we can see change in

Service and process measurement

- Service activation
- Staff skills measures
- IT infrastructure
- The care environment

A good quality of life captures the real patient pathway when we are on our own attempting to manage challenging symptoms which impact every aspect of life

Jonathon Hope - patient co-chair

B. What should the priorities of the programme be?

- Determining and refining support for the patient and their carers
- Developing service provision
- Identifying leadership and recognising responsibility for engaging the renal community

C. What does success look like for the programme?

- Increased patient understanding and confidence in their health goals
- Improved clinical outcomes
- Consistent care with real choice based around the patient's needs
- Standardised best practice
- Good management of resources for the programme



7. Group work – exercise 3 – workstream challenges and opportunities

The programme is divided into three workstreams.

Workstream	Objective	Priorities
Intervention	Consider a set of tools and approaches to support people living with CKD to manage their health and have a good quality of life	Audit use of interventions Survey renal units and patients
Commissioning	Focus on the learning and support required for commissioners to co-produce patient pathways	Get CCGs on board Gap analysis - what is already out there?
Measurement	Focus on how the Patient Activation Measure (PAM) will be administered and framed within the programme	Identify available tools Define assessment criteria

8. Authenticity of person centred care - Luke O'Shea, NHS England

Clinicians are very skilled at diagnosis and treatment but there is room for improvement in terms of listening and talking to the patient, to support the choices they want to make. Allowing people hope, as well as the resources for what they want to do, is fundamental to the future of the NHS.

Improved skills, knowledge and confidence can lead to a whole range of other outcomes that are important to people, like getting or maintaining a job (**Figure Two**). A sense of hope not only helps a patient's health but other areas of their life as well.

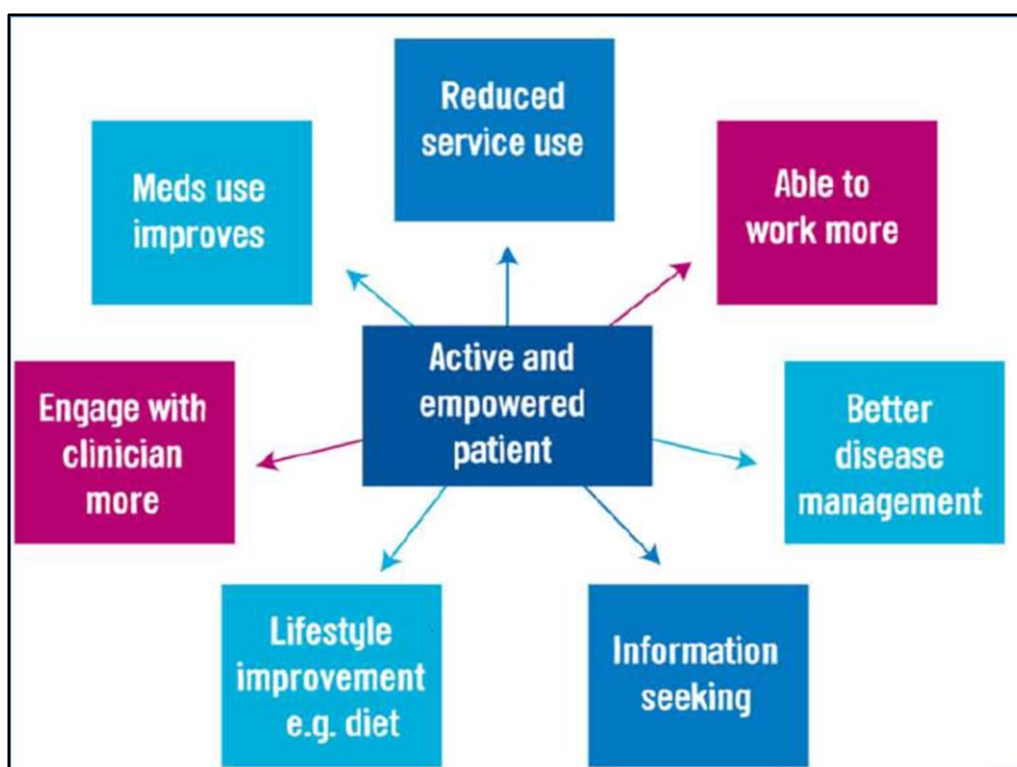


Figure Two: Potential outcomes of patient activation

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9. Conclusion

The programme is committed to working with and being accountable to patients. We commit to taking on board the feedback received from the launch event and will keep in touch to explain how these ideas will change the way we are thinking about this project

As people living with CKD we have to develop our skills knowledge and confidence and to do that we need to better understand our own existing expertise. The measure we plan to use in this work, PAM – the Patient Activation Measure; should help in this regard. Only when we know where our gaps are, in terms of skills, knowledge and confidence, will we be able to get personalised support from clinicians to help us self-manage and to know where to intervene

Jonathon Hope, patient co-chair