



Valuing individuals- transforming participation in Chronic Kidney Disease co-design event - a report on the day

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Aston University, Birmingham



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Please note: the Q&A session has been reported separately and is not contained within this document.



1. Foreword

There is without doubt tremendous passion and energy from everyone here to really shape a programme of work co-produced to ensure that people are involved in their care. Our aim as co-chairs is that this programme leads to 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 and care – to improve their quality of life.

Our challenge is to create the conditions in which the work streams can support our local CCG partners and renal units to implement the measures and interventions that can make a difference to people living with chronic kidney disease and end stage renal failure.

We do not doubt the challenges ahead but from the evidence of energy, commitment and solution focused thinking on the day of the event, we are sure we can build on this platform to create a strong 'peer-to-peer' learning community.

We are truly inspired by the renal community's response, which led to an initial expression of interest to be involved in this programme by more than half the renal units in the country and by 15 CCGs.

As we move forward and confirm the units and CCGs we will work with, we look forward to continuing to share the learning and engage with you in this very important debate. This was outlined in the recently published NHS Five Year Forward View – to engage, support and empower people to manage and make decision about their own health and care.

We hope you find this report captures the energy and commitment demonstrated on the day of the co-design event. We thank you for your involvement and we look forward to working with you as this work progresses.

Jonathon Hope MBE

A light blue rectangular box containing the handwritten signature "Jonathon Hope." in black ink.

Co-Chair of the Transforming Participation
in Chronic Kidney Disease Programme and
patient representative

Richard Fluck

A handwritten signature in black ink, appearing to read "R Fluck", with a horizontal line underneath.

Co-Chair of the Transforming Participation
in Chronic Kidney Disease Programme and
National Clinical Director for Renal –
NHS England and Co-Chair

2. Introduction and context

Two of the key drivers for the Valuing Individuals programme are the NHS Mandate which commits 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*'; and the NHS outcomes framework 13/14 focus on '*enhancing quality of life for people with long term conditions*'. The commitments within the **NHS England Five Year Forward View** state 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. With the help of voluntary sector partners, we will invest significantly 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

This 'whole system' proposal to develop a patient centred pathway for chronic kidney disease is a way of meeting the mandate commitments and responding to the Five Year Forward View. It aims to build on the work delivered around shared decision making in the area of renal disease and capitalise on the commitment and existing infrastructure to take this work and learning forward to benefit both patients and their carers.

The vision for this programme is to test the effectiveness of the Patient Activation Measure as a catalyst to support people to manage their own health needs and improve their personal outcomes related to kidney disease, addressing measurement, ways of working and commissioning. The intention is to support a long term vision to provide a model of healthcare that values person centred care. The programme hopes that involving people in decision making about their services and care will become the norm for anyone with long term health needs, providing evidence, measurement and commissioning examples so people and their carers can live as full a life as possible.

This programme provides a real test bed for individual and community activation. Although it is in the context of CKD, the intention is to develop learning and demonstrate to other communities and commissioning services how it can be done.



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3. The morning sessions

Welcome and introduction - Patricia Muramatsu, Senior Strategy Advisor for the Patient Centred Care Team, NHS England

The day began with a warm welcome and introduction to the day from Patricia, who described the programme and her expectation that everyone attending would get involved, have their say and help shape the future for how the NHS can work towards developing the skills, knowledge, confidence and wellbeing of individuals with CKD.

4. Building on patient expertise

Jonathon Hope, Co-Chair of the Programme

Jonathon thanked everyone in the room for finding time to attend, recognising the challenge and pressure across the system on everyone. Jonathon said that he knows from personal experience how precious the non-dialysis days are for patients. He hoped that the huge amount of energy in the room would mean that people would enjoy working together throughout the day.

Jonathon began by talking about why we were gathered together for the day. He described how, when he heard about the 'Transforming Participation in Chronic Kidney Disease' programme, he thought it was likely to be the most important programme he would be involved in, because it is looking to tackle the 'sweet spot of care' – helping patients in the 94% of time when they are outside the system, struggling to reclaim a quality of life.



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Diagnosed with kidney disease at the age of 16 and subsequently experiencing 15 years on dialysis, three failed transplants and three years of living on hospital wards, we learned that Jonathon would be celebrating his 50th birthday in just a few days, which he described as ‘amazing’ given that at the age 16 he was told he wouldn’t reach 20.

Jonathon described how most of the care he had received had been good and sometimes outstanding. However, there was always room for improvement and that was what today was about, **to work together as equal partners in co-designing the initial draft of this project.**

Jonathon went on to say that until you have a chronic disease you really don’t know the depth of despair you face and what you really want in the face of a life limiting condition - to reclaim a day to day quality of life. He said that 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 described how it had taken him 25 years to achieve what for him was a high quality of life. He stated that no one should have to wait that long and that this project would help achieve that aim. Jonathon explained that one of the areas this project will be exploring is using a range of patient reported outcome measures that focus on the real day to day needs of those of us with CKD.

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. There is no one size fits all answer to help people achieve their own quality of life

Jonathon explained how this project would be a huge step forward for patients, many of whom feel unsupported in developing their expertise in managing their condition. There were two major gaps facing patients when they were initially diagnosed: a knowledge gap and a skills gap. This project would focus specifically on helping patients fill their skills gap.

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, 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

People living with CKD develop many new skills, but two in particular stand out:

- Clinical self-care - how to adjust and manage our life with the condition e.g. adjusting to a new diet, fluid restrictions etc.
- Holistic self-care - learning to adjust not just physically, but emotionally, mentally and spiritually to the consequences of living life with CKD.

The second of these is the most difficult to acquire. This project aims to help by trialling a new self-management programme called Hope, aimed at people with or approaching kidney failure.



As patients with CKD we go from knowing nothing about the disease to needing to become experts. It's often trial and error for us as we develop the skills we need and discovering what happens for example, if we drink or eat too much. There are currently no patient experts or disease specific self-management courses to help us understand how to manage these day to day aspects of our life. We might get lucky and bump into a fellow patient or chat with a nurse or doctor. And so step by step we learn and build our confidence, knowledge and expertise as individuals living with CKD.

In respect of mental, emotional and spiritual issues, how does the person with CKD get the right support? Often again, it's just down to trial and error. Fifteen years ago I learned a lot; for me I found meditation and it dramatically changed the way I felt about my condition

The biggest challenge of all is that there is no systematic support for us to build our skills, knowledge and confidence. We hope that this project will help to change that. Jonathon described how evidence from literature shows that increased self-care and helping people take control of their disease helps them to move to a better quality of life.

Fifteen years ago I became more holistic in my approach to my condition and as a result I reduced the number of trips I made to A&E and my GP by 75%. I also took my medical self-care to the max, I voluntarily increased my dialysis hours by 50% and this also helped me reclaim a QOL I had never dreamed of. My medication budget dropped 50%! We, as people living with CKD, become the experts when we have lived life with a condition

We commit to listen to all of the expertise in the room and to work in partnership with you to co-design this project today and in the future.

This project is about helping to support those of us with CKD to know where in our self-care and disease management journey we are. To do this we will use a new measurement tool called PAM.

Once we know where we are, our clinicians will be able to offer us support that helps us to specifically build on our own individual level of expertise.

Wouldn't it be wonderful if instead of measuring what the system and kidney care services were doing, we could measure objectively where **we**, the patients, need help in developing disease mastery? Well, in a nutshell, this is what this project is about!



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5. Long term condition management

Richard Fluck, Co-Chair of the Programme, NHS England's National Clinical Director (Renal), Consultant Nephrologist at Derby Hospitals NHS Foundation Trust and Chair of the Think Kidneys Programme

Richard began his presentation by reminding us that vision is not strategy. We need to understand the steps we need to go through to develop this work and to be quite disciplined in our approach, otherwise we will lose momentum. While we must never lose sight of the larger vision, we have to recognise that the project has boundaries and we need to delineate that to ensure success. Richard agreed with Jonathon that this programme is of great importance, not just for the renal community but for healthcare in general. It is about taking ideas that have been tried and tested and saying can we actually deliver them on an operational level? So how can ensure that what we develop from this work is self-sustaining and can be implemented?

Richard went on to describe how a significant amount of data is collected and how this builds a picture of the CKD pathway (**Figure One**). It's a continuum which the individual may experience, though they may stop at various stages.

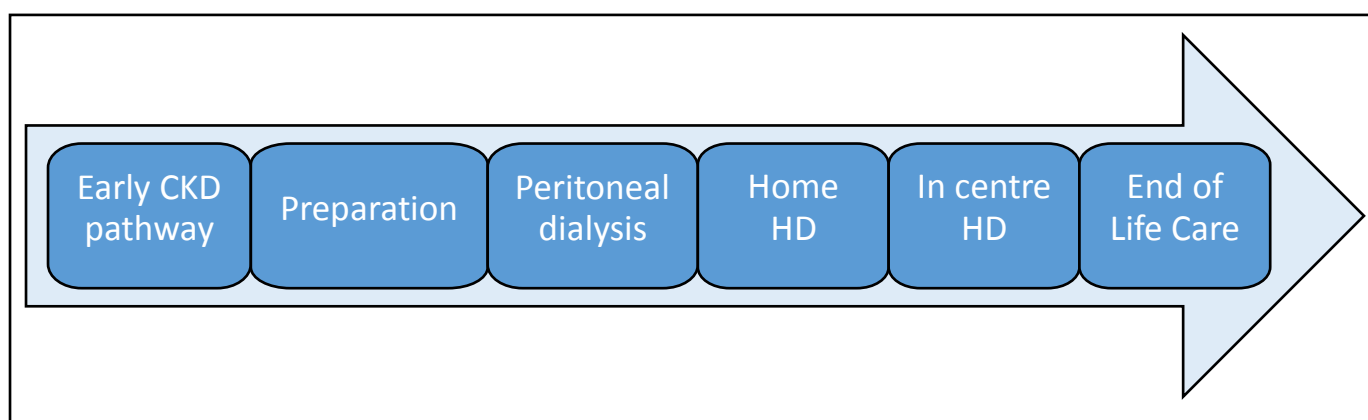


Figure One: The CKD pathway

One of the things I see as a clinician is the discontinuity in the system. People are handed on from one clinical team to another, or from commissioning system to system. The unifying element is actually the individual. If we are able to give them the knowledge they can potentially become the arbiter of what happens in their care pathway.

For me, in my role as national clinical director, I'd like to see fewer people with end stage kidney disease. I'd like to see people leading more independent and better lives, wherever they are on that pathway. That's why this programme is so important.

Richard described the **House of Care**, (Figure Two) as a framework for how we should think and work. This will lead us to a place where care is person centred and co-ordinated. To support that we need to develop practical and useful measures for the patient as well as those for clinical and commissioning outcomes, treating them with equal importance.

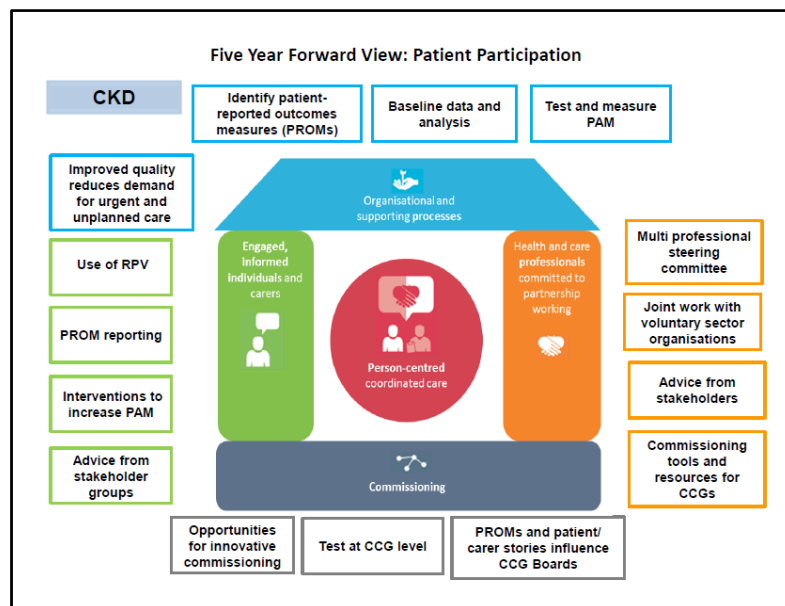


Figure Two: House of Care model for patient participation

So what do we want to do with our stakeholder groups and how do we use their expertise to shape this work?

Whilst not being enthusiastic about the term ‘activation’, Richard said that what we are really talking about is ensuring that people have the knowledge, skills and confidence to take control of their health and health care. This is at the very heart of the programme. ‘Activation’ becomes the shorthand for where the clinical team becomes the patient’s coach, enabling individuals to learn about self-management and preventative behaviours, sharing decisions with their clinical team based on informed choice and sound understanding. (Figure Three)

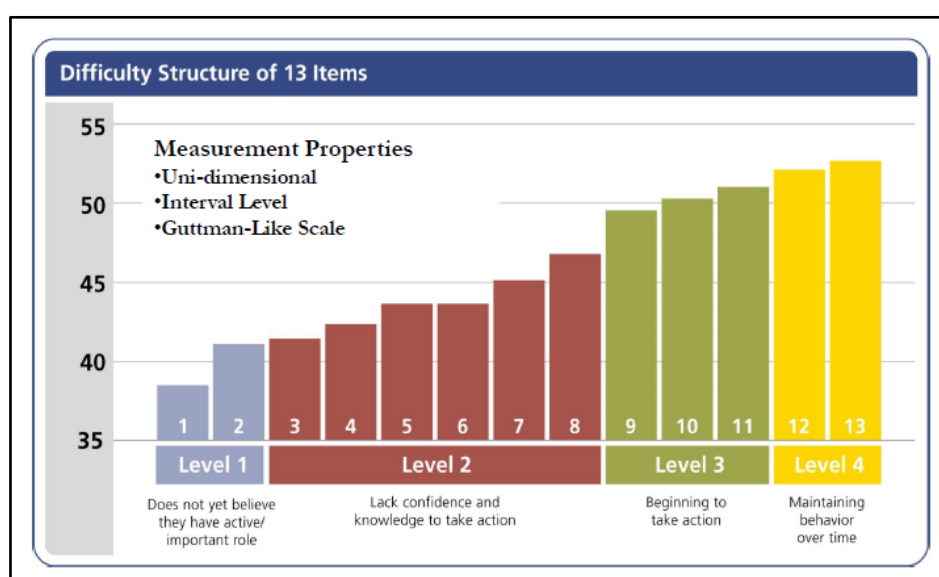


Figure Three: Patient Activation Measure (PAM)

Richard explained that levels of patient activation vary depending on the individual's circumstances, though there is surprisingly little variation due to underlying demographics. The idea is that from patient activation we can measure levels of 'non- activation' right through to 'highly activated' and allow us to develop different approaches to empowering individuals. It is important that we give people the resources they need both when they need them and when they are ready to receive them.

Research has consistently found that patients who are more activated are more engaged in:

- preventive behaviours
- healthy behaviours
- disease specific self-management behaviours
- health information seeking behaviours



Highly activated people are more engaged, involved and actively taking part in their health management. The highly engaged patient can influence their medical care. Richard discussed his experience with managing hypertension, where blood pressure results vary according to the patient's activation status (**Figure Four**). The opportunity for self-monitoring hypertension is an untapped resource. BP machines cost £35 from Boots and documenting results or keeping a diary can impact medication and health. This approach of self-management through monitoring could be used for a number of long term conditions such as heart disease or diabetes.

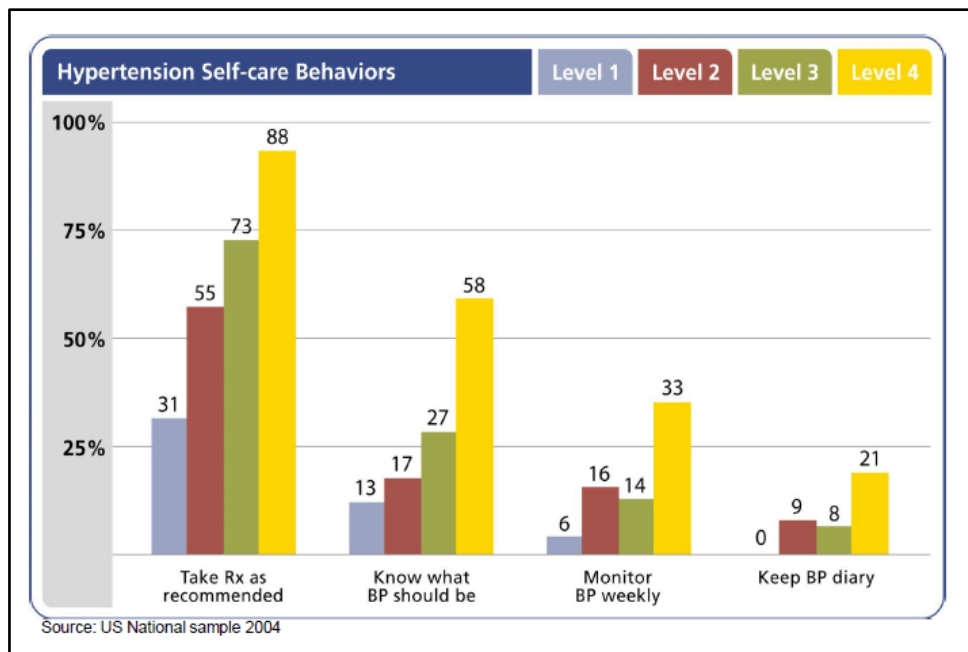


Figure Four: Hypertension self-care

This is about resource utilisation. Recently in the press there has been a lot column inches devoted to describing the stresses and strains the NHS is under during the winter, and this will increase as we approach the next general election. But as Jonathon stated, by taking control of his health by self-management, he actually reduced the healthcare services he needed to use. He felt confident that he had the skills and knowledge to know what was needed. That's activation - confidence, skills and knowledge. We know that we can change a patient's activation status. There are interventions that people can use to move people up the ladder of activation and become more self-sufficient for their both own benefit and that of the wider health system.

Richard explained that this is what the Transforming Participation programme is all about. We need to design and deliver a building block that helps us reach the grand vision of patients self-managing.



We need to understand the patient's activation status and their outcome measures. If we can connect the two and select from a range sustainable interventions in clinical situations, then we can work to increase activation status and use it in a segmented way.

Building this programme together through co-production is paramount. We have two main objectives:

1. To deliver a sustainable structure built around the house of care model
2. With this hypothesis in place, to develop the co-production ideas

Commissioning is very important and can influence and drive change. We have to develop the right tools and interventions to get clinicians engaged and involved so that patients experience better outcomes (**Figure Five**).

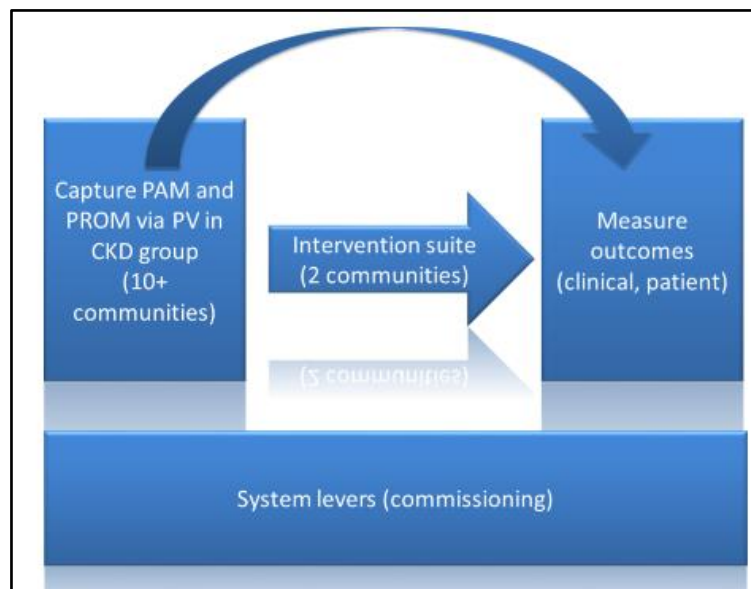


Figure Five: Commissioning model

This work is important, not just for us and our client group but also in the wider context of self-management for long term conditions. Living as long as we now do we are all likely to experience living with a long term condition. Better management of these conditions, increased self-management by the patient and improved outcomes are a central plank of the Five Year Forward View for the NHS. We need to maximise the value of the greatest resource in the NHS - the patients we serve, so that they are in the position of being able to better look after themselves.

6. Delivering excellence in kidney health

Fiona Loud Policy Director for the British Kidney Patient Association and Co- Chair of the Kidney Health Partnership Board

Copies of the [Kidney Health Report](#) had been distributed to delegates beforehand and Fiona provided background and spoke about the vision and ambition of the report.

The report covers all stages of kidney disease and is structured around the care pathway. The goal of the report was service and quality improvement and it was written by patients and professionals. It describes 16 future ambitions for kidney care from the patient's perspective and which can be supported by the whole community.

The purpose of the report was to provide:

- a framework for patient-centred kidney care for policymakers
- a view for patients of what their care should look and feel like
- an idea of what care providers should deliver



An important principle of the report was not to dictate how care should be provided but rather that it should be co-designed for the best outcome. The co-design process involved an evidence event, desk research, many conversations, community consultation, stakeholder meetings and a launch in Parliament. This approach yielded many results which identified wide variation in care and the need to drive up quality and consistency throughout the care pathway by:

- increasing public awareness of kidney disease
- improving identification of patients with kidney disease in primary care
- promoting person-centred care, including experience from the patient viewpoint and self-management
- increasing the number of transplants and delivering more equitable provision
- reducing the wide variation in access to home dialysis therapies and self-care.

Fiona went on to describe two ambitions, reflecting aspects of care:

1. Person-Centred Care where 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.
2. Self-management: All people with kidney disease are offered as much information as they would like in order to understand and manage their condition.

I've had all sorts of illness but kidney disease is the hardest to deal with because it changes your life. People need choice and to do that they need to be aware and informed – it's shared care.

Dianne Griffiths, Fresenius National Expert
Patient Board

The report contains comments from people about gaps in information about their care. Others stated that they were given information but were still confused about their treatment and care. Key findings in the report which Fiona highlighted include:

- Preparation and choice for patients so that all people approaching end-stage renal disease, or moving from one type of treatment to another, understand and are given sufficient time and support to prepare for the treatment that is right for them, chosen from the full range of options.
- Equity in regards to transplantation, ensuring that listing is based solely on clinical need and suitability and not influenced by ethnicity, socio-economic status or location.



- Support in terms of living well so that a person who receives a transplant is able to manage their transplant and is supported to achieve the greatest possible benefit and preserve that organ for as long as possible.
- With regard to dialysis, ensuring that people receive the information and education they require to enable them to engage fully in the planning and delivery of their treatment.
- Ensuring patients are supported to minimise the detrimental impact of treatment on their lifestyle and to self-care if they wish, remembering the impact of dialysis on carers and other family members.
- The importance of access to a specialist multi-professional team for everyone living with CKD.
- The importance of managing conservative care for individuals who choose non-dialytic management of their kidney disease, or who choose to discontinue dialysis treatment, to ensure that they are supported by a multi-professional team, resulting in a smooth transition to palliative and end-of-life care.



The Kidney Health Partnership Board was established in 2014. The purpose of the Board is to promote the report and its ambitions in order to:

- facilitate on-going close working between the organisations involved



- act as a catalyst for change
- work with stakeholders to help deliver the ambitions
- value individuals through patient participation, a stronger patient voice and using the Kidney Health Partnership

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Our ambitions for delivering excellence for patients with CKD are as follows:

- reduce cardiovascular risk (and get to grips with CKD)
- inform self-management
- deliver person-centred care
- measure and improve quality of life
- prevent or delay disease progression
- prevent and treat acute kidney injury
- improve outcomes from transplantation
- deliver better dialysis
- improve the care of children and young people
- treat and support people with rare diseases
- address end of life care



7. What is co-production?

Jonathon Hope, Co-Chair of the Programme

As we started to think about the first group exercise of the day, Jonathon introduced some principles of co-production and the theory behind the process. He talked about the grass roots of care, with patients working as equals with clinical partners to provide better outcomes all round, despite the complexity of CKD and its care.

Co-production invites the clinician to ask the patient ‘What is important to you?’ They can then use their experience to help shape a collaborative approach so that the important elements of care from the patient’s perspective can be achieved (**Figure Six**).

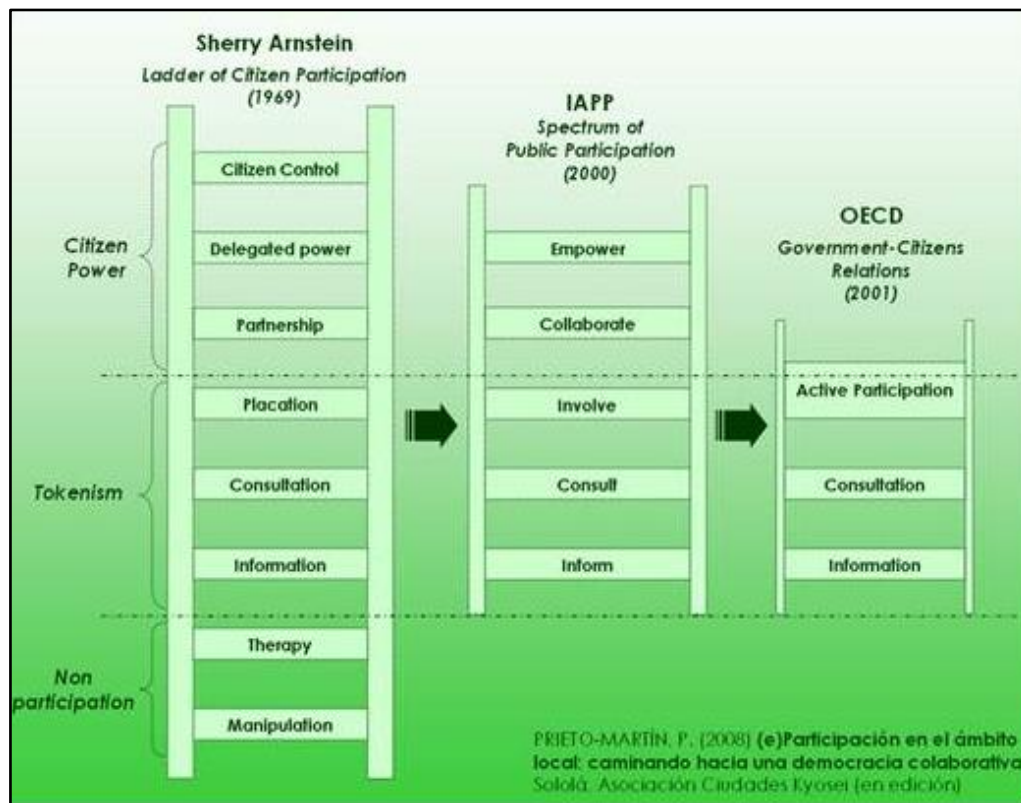


Figure Six: Co-production

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

For this first exercise delegates were asked to answer the following questions as individuals and then to discuss their thoughts in small groups.

- A. What does co-production mean to you?
- B. How do we ensure co-production is embedded in the programme?
- C. How will we know we have achieved co-production at the end of the programme?

The day was a great opportunity to share the vast expertise (which is often unspoken) from a wide range of patients and professionals. It provided a genuine challenge ... to focus on what patients see and feel to be important, rather than on what professionals think patients think is important

The responses were gathered and fed back to the room. Examples of the responses are given below, grouped by key themes for ease of reading.

A. What does co-production mean to you?

- Designing care jointly between patients, carers, professionals and commissioners, accepting that there may be boundaries
- Ensuring that the programme meets the needs of all people in the kidney care pathway - patients, professionals, commissioners etc; regardless of age, social economic group or location
- Ensuring the needs of all are met - consulting relevant stakeholders, joint working, creative process
- Looking into things that are important to patients and designing and delivering services based on that shared knowledge and information - creating something (an end product) that could not be developed without the input from all the represented groups
- Moderated shared suggestions from a wide group - patient views taken into account at all stages
- Patient access to multi-disciplinary teams including associated health professionals; repeated opportunities to ask/share/seek help/information; patients/carers truly part of the programme, not just as representatives
- Shared decision making between all parties in terms of delivery, ideas and experience. Implementation of shared vision, values and expertise. Characterised by making use of information and support; ensuring that what we design works; making sure the right stakeholders are involved; not having pre-conceived ideas about what the answers will be; positive intent
- Taking account of the views and experience of all parties using research
- Working with service users and health care practitioners from inception of the programme: directing – developing – delivering – disseminating



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

Working together

- Agree at the outset what co-production is
- Clarity of roles for programme members with patients and carers recognised as equal members and represented on all workstreams
- Patients involved at trust and CCG level
- Listening to everyone
- Create vision and goals for the programme together
- Provide training and support for patients and professionals
- No idea is a bad idea
- Prevent drift
- Understand each other's priorities
- Achieving cultural change

Values

- Prioritise co-production and ensure it is stated as a central tenet of the programme
- Decide the values for the programme (e.g. listen, respect, value, commit, communicate) then check back periodically to make sure they are being upheld
- Leadership must mean it



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

Shared ownership and delivery

- All collaborators recognise their perspective in the end process and their involvement in the final product
- Everyone's voice and contribution is evident
- Patients taking ownership of the programme and selling it
- Taking responsibility for the end product
- Outcome measures reflect patient experience
- Improvement in clinical outcomes which are reported and owned by patients and professionals

Continued involvement of everyone

- All stakeholders see the value
- Co-production is demonstrated in all patient/professional interactions
- Everyone is satisfied with what has been agreed and practiced
- Built in sustainability

Knowledge and awareness

- Testing with patients not involved in the programme
- When patients report that their outcomes have been achieved
- Patient activation increases
- Skilled staff
- Fewer complaints
- Increased patient and staff confidence

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

Feedback and evaluation, measuring results

- Feedback process throughout each stage
- Patient and carers feedback that they feel involved and empowered
- Evaluation from everyone involved in the programme's development
- Asking what has changed and achieving actual results and change, not just ideas
- Feedback from everyone and revisiting aims and goals
- Continuous feedback – qualitative and quantitative approaches

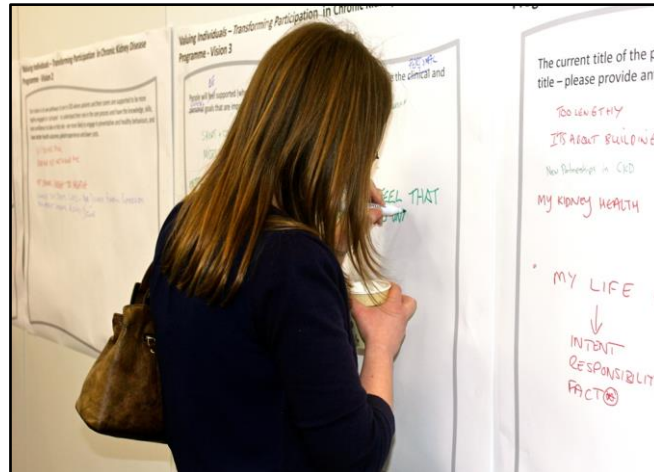
How people should feel

- Expectations have been met
- Results and relationships have improved
- Improved quality of life for patients
- Empowered

9. Group work - exercise 2 - priorities for measurement

Delegates were asked to work in facilitated groups to complete a poster with their answers to the following questions

- A. What should the programme measure?
- B. What should the priorities of the programme be?
- C. What does success look like for the programme?



A. What should the programme measure?

The responses from the groups took account of the need for qualitative and quantitative measures to demonstrate variation, improvement and standards. This will ensure that, as well as infrastructure, process and systems, the human elements of are also measured.

The responses fall into two themes:

The patient experience

Ideas for measurement included sharing information on the topics listed below – all of which can impact the quality of life for the person living with CKD.

*We need to measure
the things we can
see change in*

- Patient Activation Measures with targeted interventions - building on the UK Renal Registry's PAM learning set
- The service user's journey
- How supported, motivated and confident the patient feels to self-manage and achieve their personal goals
- Opportunities and usefulness of 1:1 peer support
- How informed the patient feels
- Wellbeing – distress/anxiety/depression scores
- The psychological dimensions of health - mental, emotional and psychological health as well as physical
- Patient centred choice and shared decision making
- Coping ability
- Expectations and personal goals

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- Carer wellbeing
- Compliance to medication
- Patient satisfaction
- Conversations and being listened to
- Ethnicity for those who don't have English as their first language and a different culture
- The readiness of the service to support self-management

Another suggestion for qualitative measurement was the use of patient stories and case studies which can be powerful to inform, provide comparison, raise expectation and motivate the individual.



Service and process measurement

- Recognising the variation in services across the NHS for patients with CKD. There is a lot of scope for measuring services for comparison and to drive up standards and improvement.
- Data to measure variation in care e.g. survival rates, hospital admissions, cost of healthcare usage such as operations and attendance at A&E. Over time, reduced use of services could also be measured.
- Service activation e.g. how the service currently supports self-management
- Staff skills measures
- IT infrastructure
- Validated tools for engagement and empowerment
- The care environment
- PAM/PROM/PREM/CSPAM

The day was a great opportunity to share the (often unspoken) vast expertise of a wide range of patients and professionals. It provided a genuine challenge to focus on what patients feel to be important, rather than on what professionals think patients think is important

B. What should the priorities of the programme be?

Responses to this question fell roughly into three main categories:

Determining and refining support for the patient and their carers

- Empower patients and carers so that variation in both service provision and standards are reduced and the patient can learn what to expect from clinical services.
- Promoting personalised care or health plans
- Priorities for the patient's health and well-being for an achievable and acceptable quality of life (where well-being is defined as involving psychological and physical aspects of care).
- Recognising the need for more psychologists, as only a few units currently have them. Improved access to social workers and more allied healthcare professionals is also an important priority.
- Develop support for patients to get the treatment they choose. Identify individuals with low activation levels so that participation can be increased and patients motivated to engage with their clinicians to develop a relationship of mutual respect. Consideration must be given to those who are disempowered and the involvement of carers.



Developing service provision from the providers and commissioners' perspective should include

- Identifying, sorting and agreeing on the measures
- Understanding outcomes for all stakeholders
- Understanding the cost and the benefit
- Understanding what should be expected from patients and professionals
- Understanding what is happening out there and working to share good practice so that no one is reinventing the wheel.
- Focusing not those who are already engaged but on those who feel disempowered

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System wide priorities

- Education for staff and service users
- Shared learning which develops the partnership for patients, carers and staff; both peer and professionally led
- Developing a process for peer support
- Identifying leadership across systems, recognising responsibility for engaging the renal community
- Making use of culture and change champions to make change happen and raise awareness of the programme



C. What does success look like for the programme?

Success from the **patient's** perspective involves:

- Increased understanding and confidence in their health goals
- More patients being actively involved in their own care
- Patient goals and wishes being included, recorded and followed up
- An increase in well-being, with better outcomes for the patient and no patient left out
- Improved clinical outcomes
- A charter for patients with CKD
- Consistent care, with real choice, based around the patient's needs

Success from the **clinician's** perspective involves:

- Cultural change in clinical care
- Standardised best practice

Success from the **commissioner's** perspective involves:

- Measurable impact. Knowing the true cost of this way of working would be a measure of success, as would a reduction in:
 - mortality
 - waste
 - admissions
 - drug costs
 - complaints
- Qualitative markers of success such as:
 - clinician and patient satisfaction
 - patients telling a consistently good story
 - increased community involvement
- Co-production being well modelled for use in future work

Success from all **stakeholders'** perspectives involves:

- Work that is on-going and sustainable beyond the programme itself
- Good management of resources for the programme
- Effective co-design

Havering CCG is committed to improving the management of Kidney Disease at patient, practice and acute levels.

For me the enormous benefit of just being aware of the condition and how powerful it is for patients to be actively managing their own health, was the single most important thing I took away from the day

Cathy Lobendhan, Senior Locality Lead,
Havering CCG

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

The Transforming Participation in CKD programme is organised into three work streams:

- Intervention
- Commissioning
- Measurement

Delegates were divided into the three workstream groups and provided with poster templates to discuss and agree their response to the following topics

- Review the workstream scope
- Identify workstream outputs
- Consider if the membership of the workstream is right
- Consider how patients feed into the workstream
- Identify what opportunities and challenges there are for the workstream
- Identify how we will know if the workstream has been successful


The results from each workstream can be found on the following pages.



Intervention workstream

Objective – The intervention workstream will consider a set of tools and approaches to support people living with chronic kidney disease/end stage renal failure to gain the skills, knowledge and confidence to manage their health and have a good quality of life. The workstream will cover approaches that support patients and clinical staff to work in a collaborative, person-centred way.

WORKSTREAM SCOPE	
<ul style="list-style-type: none"> Identify and focus on patient issues – targeting interventions at different levels Patient and carers Professionals develop skills & knowledge <ol style="list-style-type: none"> 1. Identify, consider, evaluate, recommend 2. Across the pathway 3. Patient, care & clinician activation 4. Focalised – so many potential interventions – pragmatic, evaluated input 5. Effect of psychological distress 6. Baseline PAM to focus grades integral, progressive 7. Resources and 'doability' 	
OPPORTUNITIES	CHALLENGES
What is already working well that this workstream can build on?	What are the challenges we face that this workstream needs to address?
<ul style="list-style-type: none"> Existing 'off the shelf' tools Shared decision making PDAs Peer-support Existing programmes – HOPE, RSG etc On-line courses Support for patient activation PAM as an intervention 	<ul style="list-style-type: none"> Disengaged patients On the ground resources 'Doability' Clinicians skilling up Need to engage at renal Unit level
What are the workstream priorities for the next 12 months?	
Choose the top two opportunities and top 2 challenges the workstream should be focusing on and then frame them as an action statement below.	
Action statement	What do we need to do in next 30 days to get started on this action
Audit	Work stream members use of interventions before 16 th March meeting
Survey	Units and patients – finalise format at March 16 th meeting
Evaluation phase	



Workstream: INTERVENTION

Outputs from this workstream

- Recommendations regarding toolbox of clinical interventions – found to be useful at individual patient level. The workgroup will evaluate existing tools rather than develop new ones
- Recommendations on deployment of these interventions along patient pathway
- Recommendations - regarding renal unit implementation framework - there is a need to influence unit culture
- Recommendations regarding training needs for individual clinicians in use of tools/interventions


Success Criteria how will we know if this workstream has been successful

- At national and unit level via Registry data on PAMs, PROMs and PREMS
- At patients and unit level – through local satisfaction surveys

Commissioning workstream

Objective – The commissioning workstream will primarily focus on the incentives, levers and learning and support required for commissioners and the commissioning system to co-produce patient pathways to offer more choice and control to patients living with chronic kidney disease/end stage renal failure.

WORKSTREAM SCOPE	
<ul style="list-style-type: none"> Commissioning is 'all around the house of care' not just the base. Interdependent with the other workstreams The why? - CKD earlier stage focus - CKDS in primary care - link it to QUIPP How do we look at things differently? Quality of life measures/PAM - enable patients/GPs to look at this Incentive system - basic approach around self management Co-production - a system sensitive to people's needs More self management – not an individualised approach You need to show us evidence that your pathways deliver these: measure of PAM, self management Decision making - need to think about process and what's on offer 	
OPPORTUNITIES	CHALLENGES
What is already working well that this workstream can build on?	What are the challenges we face that this workstream needs to address?
<ul style="list-style-type: none"> Build on to AKI round (lever in contracts = incentive) How we engage with primary care - key point on pathway – QUIPP? How do you push 'kidney' up the agenda through commissioning? Co-commissioning - Havering is a pilot site - CCGs/LA for primary care - build in incentives for GPs to take across whole system DES - reducing unplanned admission/care planning 	<ul style="list-style-type: none"> Quality of life – the changes from April 2015 are a challenge Explaining the 'why' to CCGs of CKD – PHE Growth estimates for CKD - recently published
What are the workstream priorities for the next 12 months?	
Circle the top two opportunities and top 2 challenges the workstream should be focusing on and then frame them as an action statement below.	
Action statement	What do we need to do in next 30 days to get started on this action
	Get CCGs on board - need them as members of this work stream
Interdependence with other workstreams	Creating the conditions for change by getting people to measure what they currently do not – SDM, self management, PAM etc.
Gap analysis	Map out what's already there - incentives - and then see what is missing/linked with what comes out of other workstreams



Workstream: COMMISSIONING


Outputs from this workstream
<ul style="list-style-type: none"> Care plan on unplanned care DES where lead professional for that person <u>is the person!</u> Gather the evidence to measure the difference Commissioning - setting out framework for person centred care - the principles Commissioning and delivering model needs to be side by side

Success Criteria how will we know if this workstream has been successful
<ul style="list-style-type: none"> Prove 'fertile ground' so local system articulates needs Engagement is important - evidence led commissioning has made a difference Better awareness of risks of CKD/CKD and ESRF

Measurement workstream

Objective – The measurement workstream will primarily focus on how the PAM will be administered and framed within the programme. How will the PROM be developed to ensure we capture the outcomes that matter to patients? How will we capture and measure patients and clinicians feeling supported to work in a person-centred way?

WORKSTREAM SCOPE	
<ul style="list-style-type: none"> Why measure – evaluation, practice validation, clinician communication, increase awareness, create evidence of what works, not for payment? PAM What to measure – validated tools, progress, patient and professional perspective, structures, measure selection How to measure? 6-12 months for benchmarking? Interviews by mentors, paper vs online test, different forms Collecting qualitative data on patient involvement from both clinician and patient side What to do with the results? Contribute to the testing programme Who will collect the data? Target population -define characteristics Evaluating different modes Clear terminology -no abbreviations Feedback direct to facilitate consultation 	
OPPORTUNITIES What is already working well that this workstream can build on?	CHALLENGES What are the challenges we face that this workstream needs to address?
<ul style="list-style-type: none"> UKRR infrastructure - RPV Research opportunities to understand culture change APM in LTC PAM learning set PAM kidney care Co-creating health (HF) SDM service evaluation renal 	<ul style="list-style-type: none"> Increase response rate on longer term Convincing clinicians to buy in - agreement on importance Patients' understanding of importance and why/what is being measured Interpretation of patient-level and centre-level patient engagement scores Manage expectations of patients and carers
What are the workstream priorities for the next 12 months? Circle the top two opportunities and top 2 challenges the workstream should be focusing on and then frame them as an action statement below.	
Action statement	What do we need to do in next 30 days to get started on this action
Selection of instruments/Design feedback	Identify available PROMS, PREMS (UK specific), (maybe) SDM - max 4 - 'vote' among workstream members
Recruiting more workstream members	Aim for 50:50 patient:clinician (MDT) representation
Define criteria for assessing tools at the end of the programme	Draft a first list of criteria and circulate among workstream



Workstream: MEASUREMENT
Outputs from this workstream
<ul style="list-style-type: none"> Qualitative evaluation of data collection and feedback as perceived by patient and clinician Selection of tools Information on tools - acceptance by patient and clinician; response rates; costs/resources; optimal modes and frequency of admission Infrastructure for how to collect data Pilot-tested methods to feedback data to patients and renal units
Success Criteria how will we know if this workstream has been successful
<ul style="list-style-type: none"> Response rates are sufficiently high at constant level Data collection and feedback implemented in routine practice

11. Authenticity of person centred care

Luke O'Shea, Head of Integrated Personal Commissioning, NHS England

Luke's session began with a quote from the **NHS England Five Year Forward View** which was published in October 2014:

There is broad consensus on what the future needs to be. It is a future that empowers patients to take much more control over their own care and treatment. It is a future that dissolves the classic divide, set almost in stone since 1948, between family doctors and hospitals, between physical and mental health, between health and social care, between prevention and treatment.

Luke told the delegates that as a nation we face some of the greatest challenges in the NHS since its creation in 1948. We face an unprecedented financial challenge, multiple safety challenges and a rise in the number of people living with multiple long term conditions. Putting people in control of health and care is a vital response to these three massive challenges. This programme is a fundamental response to that.

There are big divides in the system - between prevention and treatment, primary and secondary care, physical and mental wellbeing - all of which are very important. Intervention is a powerful response which can bring these different parts of the system together. But we need to start with the people at the centre because the patients have the greatest interest in getting things right. We often fail to harness the motivation and energy of people in addressing some of the changes and challenges that we are facing.



Valuing individuals – transforming participation in Chronic Kidney Disease co-design event – a report on the day

Luke stated that he wanted to gain a sense of the changing nature of the population, which affects every aspect of health and social care. We're seeing an explosion in the complexity of long term conditions (**Figure Seven**). The way we shape services will become increasingly important in the NHS and across health and social care, especially for CKD patients.

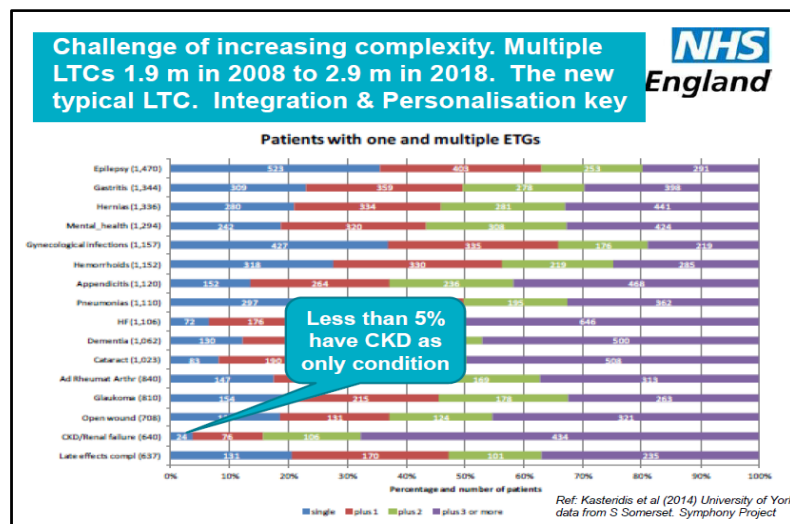


Figure Seven: Complexity of long term conditions

Luke noted that as a mental health commissioner he used to spend an immense amount of time trying to be more efficient but hardly any time communicating with patients to support them in becoming more effective in managing their own care. This is a massive missed opportunity.

Aside from the changing nature of our population and the importance of valuing the individual, there is a fundamental moral point here. There are some areas where your life is quite strongly defined by the NHS in a way that I just didn't think was conceivable. CKD is a fundamentally different proposition to many other parts of the NHS.

What the system is very good at doing is keeping people alive. In mental health you could say that you'd done really well because you'd kept a person out of hospital. But what you hadn't done for them was give them a life, to have the things that everyone considers most important – families, jobs and friends. There is a great power in giving people more control. To not only to save lives but to transform them. There is a really powerful evidence base to say that this is the thing to do.

Clinicians spend a lot of energy being very skilled at diagnosis and treatment but there is clearly 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 skills and resources for what they want to do, is really 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 Eight**). A sense of hope not only helps a patient's health but other areas of their life as well.

[Valuing individuals – transforming participation in Chronic Kidney Disease co-design event – a report on the day](#)

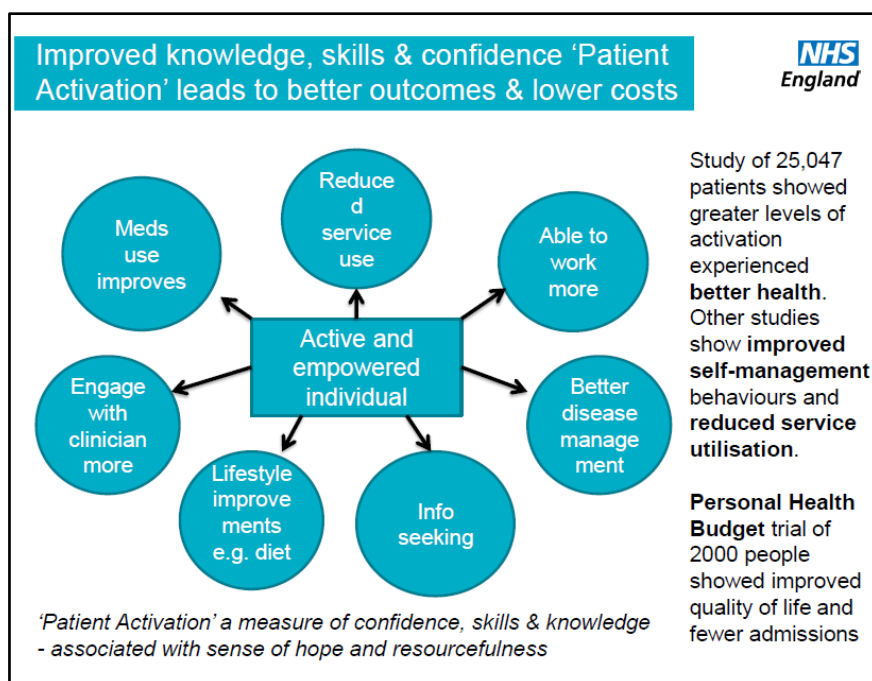


Figure Eight: Potential outcomes of patient activation

Identifying and utilising existing interventions that build patients' knowledge, skills and confidence is an important task for intervention workstream. However it is important not to underestimate the challenges of this work. There will be practical, commissioning and financial barriers and unless we deal with these we won't see the kind of change we are looking for. Luke recalls visiting a renal unit and being told by a nurse 'if we allow patients to take control of their budgets I probably won't have a job any more'. There are therefore all kinds of fears that we need to be aware of and deal with if this programme is going to be successful.



Valuing individuals – transforming participation in Chronic Kidney Disease co-design event – a report on the day

Richard started the day with the House of Care model (**Figure Nine**) and Luke felt that it was a good way to finish, helping us to think about what we need to do if we are going to be successful. The key is to start with the patient and really understand what is important to them and build out from there. As Richard said earlier, we need to really think about the measures and finances involved to enable us to remove the barriers to change and enable a much more person centred vision of care.



Figure Nine: *House of Care* model and its partnerships

What we've demonstrated today is that we need to really understand what matters to people, what they want and how to create the right conditions for change. We need to build on existing partnerships in order to make that happen. Integration is critical and unless we do that we won't see the transformation we want - hope and resourcefulness in the renal community to work our way through the challenges we face.



12. Closing remarks

Jonathon Hope, Co-Chair of the Programme

It is important that we bear in mind that this programme is committed to working with patients with every hat on to try out lots of things. The details we can work on later. Thank you to everyone – you put the smile on my face. I have a favour to ask. We have 70 people in this room. If each person goes away and tells another person about it that would be amazing. What if you told 5 people about it? What was the takeaway moment for you?

We are looking to be accountable. We commit to taking on board all your extraordinary feedback and the work we've done together today. We will keep in touch to explain how your ideas will change the way we are thinking about this project and you will recognise what's gone on here today in our work going forward.

My experience of successful programmes has taught me the importance of setting it up well and we've certainly started to do that today. Thank you everyone.

I didn't really know what to expect from this meeting. It was important to come and see how far renal care has progressed and to see what else they are doing to improve renal care

Shashi Patel – BKPA Patient Advisory Group

From the post-it boards bringing together answers to questions posed and the workgroups given a specific area to discuss, I felt a real sense of togetherness and passion. I found it to be a group of like-minded people, coming from different angles all wanting the same for Renal.

Purple Chick, Patient Voice, Advocate, Advisor, Volunteer for All

I have been a renal patient for nearly 40 years. I am very interested in anything which could improve health and quality of life for renal patients. It was interesting to see such a consensus of opinion in favour of the idea of improving patient activation, and I came away feeling very positive about the project

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