Valuing Individuals - Transforming Participation in Chronic Kidney Disease
Transforming Participation in Chronic Kidney Disease (CKD)
A unique NHS programme to help people with CKD live their best life.

1 in 10 people live with CKD - that’s 6 million people in England

NHS Choices

Jonathon Hope, Patient Co-Chair

This programme will help people reclaim a day to day quality of life

NHS England 5 Year Forward View

A shared vision to place the person at the centre of their care

Richard Fluck, Clinician Co-Chair

I want to see people with CKD leading independent and fulfilling lives

About the Programme
The Transforming Participation in Chronic Kidney Disease (TP-CKD) programme will develop a person centred...
Long term conditions - facts

• Over 15m people living with an LTC in England
• Multiple LTCs are set to rise - 1.9m (2008) to 2.9m (2018)
• Consultations for patients with LTCs account for
  • 50% GP appointments
  • 64% outpatient appointment
  • 70% inpatient beds
• £7 of each £10 targets 30% population
• average exposure to health care professionals is 4 hours a year
• rest of time they self manage
Integration and smoothing transition

The chronic kidney disease continuum

- Early CKD pathway
- Preparation
- Peritoneal dialysis
- Home HD
- In centre HD
- End of life care

Vision
- Less end stage renal
- More transplantation
- Maintain and support independence

<table>
<thead>
<tr>
<th>Location</th>
<th>Dependent</th>
<th>Independent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>AAPD</td>
<td>PD</td>
</tr>
<tr>
<td></td>
<td>?AHHD</td>
<td>HHD (&gt;4x week)</td>
</tr>
<tr>
<td>In-centre</td>
<td>HD (3x week)</td>
<td>Self care HD (3-7x week)</td>
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Why person centred care?

- UK health services face big challenges
  - population increasing in size and age
  - people living longer with multiple conditions
  - severe financial constraints
- Person centred care can help to improve outcomes and reduce burden
- How can we work in partnership to support people when they are not in contact with the service?
- Ethically it’s the right thing to do – a person’s right to be involved
The Passive Patient

• Healthcare can be profoundly disempowering
• But most patients want to be treated as active participants – as co-producers of health

"When we want your opinion, we’ll give it to you"
To a person centred approach....

"I'm sorry doctor, but again I have to disagree."
Doctors’ and Patients’ Priorities

Top goals and concerns in breast cancer decisions

- **Keep breast**: 71% (Doctors) vs 7% (Patients)
- **Live as long as possible**: 96% (Doctors) vs 59% (Patients)
- **Look natural without clothes**: 80% (Doctors) vs 33% (Patients)
- **Avoid using prosthesis**: 0% (Doctors) vs 33% (Patients)

*Sepucha et al. (2008). Pt Education and Counseling. 73:504-10*
What are the questions the TP – CKD programme is asking?

- Can PAM/CS-PAM/PROM/PREM measures be collected routinely within renal units?

- Is the PAM related to PROM/PREM/Clinical Measure results?

- Can we introduce interventions that will increase a patient’s and team’s activation?

Co-production as a core value
What is ‘activation’?

An activated person has the knowledge, skill and confidence to manage their own health and care

This means

- making informed choices
- being a partner in their own care
- self management and prevention
What are the benefits of ‘activation’?

- Better health outcomes
- Improved quality of life
- Increased independence and control (decision making, informed choice, better support)
- Increased knowledge and understanding
- Understanding the impact of CKD on the other 95% of life – not just when in clinic
Low activation = problems and opportunities

The MORE ACTIVATED you are in your own health care, the BETTER HEALTH CARE you get...

<table>
<thead>
<tr>
<th>MORE ACTIVATED Patient</th>
<th>LESS ACTIVATED Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Readmitted to the hospital within 30 days of discharge</td>
<td>12.8%</td>
</tr>
<tr>
<td>Experienced a medical error</td>
<td>19.2%</td>
</tr>
<tr>
<td>Have poor care coordination between health care providers</td>
<td>12.6%</td>
</tr>
<tr>
<td>Suffer a health consequence because of poor communication among providers</td>
<td>13.2%</td>
</tr>
<tr>
<td>Lose confidence in the health care system</td>
<td>15.1%</td>
</tr>
</tbody>
</table>

Source: Adapted from AARP & You, “Beyond 50.09” Patient Survey. Published in AARP Magazine. Study population age 50+ with at least one chronic condition. More Involved=Levels 3 & 4, Less Involved=Levels 1 & 2
Patient Activation Measure - PAM

A validated 13 question survey to assess the knowledge, skills and confidence a person has in managing their own health and healthcare.

It places the patient at one of 4 levels of activation, which provide insight into a range of their health-related characteristics, including attitudes, motivators, behaviours and outcomes.

A fundamental component of person centred care.
Patient Activation Measure

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>When all is said and done, I am the person who is responsible for taking care of my health</td>
</tr>
<tr>
<td>2</td>
<td>Taking an active role in my own health care is the most important thing that affects my health</td>
</tr>
<tr>
<td>3</td>
<td>I am confident I can help prevent or reduce problems associated with my health</td>
</tr>
<tr>
<td>4</td>
<td>I know what each of my prescribe medications do</td>
</tr>
<tr>
<td>5</td>
<td>I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself</td>
</tr>
<tr>
<td>6</td>
<td>I am confident that I can tell a doctor concerns I have even when he or she does not ask</td>
</tr>
<tr>
<td>7</td>
<td>I am confident that I can follow through on medical treatments I may need to do at home</td>
</tr>
<tr>
<td>8</td>
<td>I understand my health problems and what causes them</td>
</tr>
<tr>
<td>9</td>
<td>I know what treatments are available for my health problems</td>
</tr>
<tr>
<td>10</td>
<td>I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising</td>
</tr>
<tr>
<td>11</td>
<td>I know how to prevent problems with my health</td>
</tr>
<tr>
<td>12</td>
<td>I am confident that I can figure out solutions when new problems arise with my health</td>
</tr>
<tr>
<td>13</td>
<td>I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress</td>
</tr>
</tbody>
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A developmental scale

**Level 1**

*Starting to take a role*
Patients do not yet grasp that they must play an active role in their own health. They are disposed to being passive recipients of care.

**Level 2**

*Building knowledge and confidence*
Patients lack the basic health-related facts or have not connected these facts into larger understanding of their health or recommended health regiment.

**Level 3**

*Taking action*
Patients have the key facts and are beginning to take action but may lack confidence and the skill to support their behaviors.

**Level 4**

*Maintaining behaviors*
Patients have adopted new behaviors but may not be able to maintain them in the face of stress or health crises.

Increasing Level of Activation
Medication adherence by level of activation

Use of Medications By Level of Activation

<table>
<thead>
<tr>
<th>Condition</th>
<th>Level 1 &amp; Level 2</th>
<th>Level 3</th>
<th>Level 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes</td>
<td>57%</td>
<td>62%</td>
<td>86%</td>
</tr>
<tr>
<td>High Cholesterol</td>
<td>45%</td>
<td>61%</td>
<td>72%</td>
</tr>
<tr>
<td>Heart Disease</td>
<td>44%</td>
<td>57%</td>
<td>86%</td>
</tr>
<tr>
<td>Hypertension</td>
<td>46%</td>
<td>73%</td>
<td>88%</td>
</tr>
</tbody>
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Level of activation linked to each behaviour

<table>
<thead>
<tr>
<th>Hypertension Self-care Behaviors</th>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
<th>Level 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Take Rx as recommended</td>
<td>31</td>
<td>13</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>Know what BP should be</td>
<td>55</td>
<td>17</td>
<td>16</td>
<td>9</td>
</tr>
<tr>
<td>Monitor BP weekly</td>
<td>73</td>
<td>27</td>
<td>14</td>
<td>8</td>
</tr>
<tr>
<td>Keep BP diary</td>
<td>88</td>
<td>58</td>
<td>33</td>
<td>21</td>
</tr>
</tbody>
</table>
Targeted interventions can increase patient activation

Effective interventions have -

• Utilised peer support
• Changed the social environment
• Increase patient skills
• Tailored support to the individual’s level of activation

Least activated patients make the most gains – when appropriately supported
Patient Reported Experience Measure - PREM

PREM is a measure of a patient’s experience of services -

• For example being treated with respect, the team being responsive to people’s concerns and problems, and overall experience of the service and environment

• The main purpose of the PREM is to help improve services in relation to patient needs
Two surveys which reflect a person’s perspective on their own health status and health related quality of life

- EQ-5D-5L; 5 questions to assess a person’s overall health. E.g. problems performing usual activities, self-rating their health by assessing between 0 (worst imaginable health state) and 100 (best imaginable health state)
- IPOS-Renal; 11 questions on the most common symptoms renal patients experience plus additional items, information needs, practical issues, and family anxiety.
Clinical Support for Patient Activation Measure - CSPAM

A questionnaire for clinicians to assess the views and attitudes of the renal team towards helping their patients to self-manage their condition.

The CSPAM is worked out based on clinicians’ responses to 23 questions.

The results will help renal teams to understand whether and how they could do better in terms of supporting people to take an active role in their care, to become ‘activated’.
The first cohort of Renal Unit Teams

1. **Birmingham Heartlands Hospital** (Heart of England NHS Foundation Trust)
2. **St Luke’s Hospital** (Bradford Teaching Hospitals NHS Foundation Trust)
3. **Coventry** (University Hospitals Coventry & Warwickshire NHS Trust)
4. **Derby** (Derby Teaching Hospitals NHS Foundation Trust)
5. **Hammersmith Hospital** (Imperial College Hospital NHS Trust)
6. **King’s London** (King’s College Hospital NHS Trust)
7. **Freeman Hospital** (Newcastle Upon Tyne Hospitals NHS Foundation Trust)
8. **City Hospital** (Nottingham University Hospitals NHS Trust)
9. **Derriford Hospital** (Plymouth Hospitals NHS Trust)
10. **Northern General Hospital** (Sheffield Teaching Hospitals NHS Foundation Trust)
What Have We Achieved? Phase 1 - embedding

- 1000 ‘Your Health’ surveys returned to UKRR
- 400 CS-PAM surveys returned – landscape
- Data returns to clinical teams
- Additional PV screens developed to view results alongside clinical data
- Changes in practice
CS-PAM Score by Centre

Activation score by centre

Median activation score and confidence intervals

Centre 1, Centre 2, Centre 3, Centre 4, Centre 5, Centre 6, Centre 7, Centre 8, Centre 9, Centre 10, All
CS-PAM Level by Centre

Activation level by centre

Centre1  Centre2  Centre3  Centre4  Centre5  Centre6  Centre7  Centre8  Centre9  Centre10  All

High  Moderate  Low

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Median CS-PAM score by staff profession

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## Patient Activation Levels

<table>
<thead>
<tr>
<th>PAM level</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 1</td>
<td>329</td>
<td>31.2</td>
</tr>
<tr>
<td>Level 2</td>
<td>198</td>
<td>18.8</td>
</tr>
<tr>
<td>Level 3</td>
<td>334</td>
<td>31.7</td>
</tr>
<tr>
<td>Level 4</td>
<td>160</td>
<td>15.2</td>
</tr>
<tr>
<td>Unknown</td>
<td>32</td>
<td>3.0</td>
</tr>
<tr>
<td>All</td>
<td>1,053</td>
<td>100.0</td>
</tr>
</tbody>
</table>

![Pie chart showing the distribution of patient activation levels.](chart.png)
Median PAM score by renal unit
PAM levels by renal unit
The five most prevalent symptoms are: (prevalence determined as the proportion of patients with moderate, severe or overwhelming symptoms)

58% of those surveyed experienced Weakness and lack of energy
49% of patients surveyed reported having poor mobility
39% of those surveyed experienced pain,
38% of those surveyed reported difficulty in sleeping
36% of those surveyed experienced shortness of breath.
Percentage of patients by health condition and age group with moderate, severe and extreme health conditions
37% of haemodialysis patients were at least moderately bothered by itchy skin.

18% did not report itch to any health care professional
21% used no treatment for it

70% of nephrologists underestimated the prevalence of itch among their patients.
Key Messages

From those surveyed:

Nearly 50% are level 1 & Level 2 – overwhelmed with little or no knowledge, skills and confidence to participate in health care.

Large variation in the median PAM score by renal centre ranging from 49 to 62 with the median PAM activation score 53

Patients symptom burden is significant
Phase 2 – Spread & Sustainability

- Cohort 2 – embed using lessons learned + small cycles of change
- Spread within cohort 1
- Intervention toolkit + re-survey
- Workshops - Changes in conversation and behaviours
- Innovation – challenging
- It hasn’t been done on this scale before
Contact Think Kidneys

How to find out more

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