Transforming Participation in CKD

Rachel Gair
Person Centred Care Facilitator
The Passive Patient

- Healthcare can be profoundly disempowering
- But most patients want to be treated as active participants – as co-producers of health.
To a person centred approach...
Co-producing health

Shared decision making

Working in partnership

Care planning

Supporting self management
Doctors’ and Patients’ Priorities

Top goals and concerns in breast cancer decisions

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

Sepucha et al. (2008). Pt Education and Counseling. 73:504-10
Patients’ Goals may be Different from Clinicians’ Goals

To better manage my pain relief so I don’t wake up at night
To stay in my own home as long as possible
To stop taking anti-depressants because I don’t like the side-effects
To learn how to cook healthy meals that the whole family will enjoy
To have the same person caring for me from 9am to 3pm so my parents can go to work
To receive end-of-life care at the hospice close to where my sister lives

Source: Coalition for Collaborative Care. Personalised care and support planning handbook. NHS England 2015
Day to day decision making: self management

Hours with NHS / social care professional = 5-10 in a year

Self management = 8750-55 in a year
The system should work in partnership with people with LTCs in order to support them to develop the knowledge, skills and confidence to manage their own health and healthcare.
Background

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 achieve this, the **NHS Five Year Forward View** sets out how the health services needs to place emphasis on:

- a more engaged relationship with patients and communities
- promoting well-being and preventing ill-health
- supporting people to manage their own health and care

One way of doing this is to try different approaches and find which work best. This is why the TP-CKD programme has been set up by NHS England and the UK Renal Registry.
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 teams activation?

Co-production as a core value
Patient Activation Measure

Unidimensional (ie measures a single concept)
Developmental (ie appropriate interventions can support people to progress on a *journey of activation*)
Knowledge, skills and confidence to self manage
13 items, 4 levels
Score out of 100
# Patient Activation Measure

<p>| | |</p>
<table>
<thead>
<tr>
<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>
</table>
PAM Scale

Difficulty Structure of 13 Items

- **Level 1**: Does not yet believe they have active/important role
- **Level 2**: Lack confidence and knowledge to take action
- **Level 3**: Beginning to take action
- **Level 4**: Maintaining behavior over time

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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 regimen.

**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**
People at low levels of activation tend to:

Feel overwhelmed with the task of managing their health
Have low confidence in their ability to have a positive impact on their health
Not understand their role in care processes
Have limited problem solving skills
Have had a great deal of experience with failure in trying to manage, and have become passive with regard to their health
Say they would rather not think about their health
People at higher levels of activation tend to:

‘Be engaged’
   - Come prepared
   - Ask questions
   - Make decisions
   - Have less unmet needs (*nb inequalities*)

Have improved clinical outcomes (including mental health)

Enjoy an improved quality of life

Use less healthcare resource

Feel satisfied at work

Self care behaviours and activation 2

Diabetes Self-care Behaviors

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Level 1 &amp; Level 2</th>
<th>Level 3</th>
<th>Level 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medication as directed</td>
<td>86</td>
<td>57</td>
<td>62</td>
</tr>
<tr>
<td>Test glucose 3/week</td>
<td>53</td>
<td>50</td>
<td>44</td>
</tr>
<tr>
<td>Read food labels</td>
<td>74</td>
<td>28</td>
<td>33</td>
</tr>
<tr>
<td>Check cracks in feet</td>
<td>77</td>
<td>22</td>
<td>33</td>
</tr>
<tr>
<td>Read about side effects</td>
<td>67</td>
<td>19</td>
<td>40</td>
</tr>
<tr>
<td>Keep glucose diary</td>
<td>67</td>
<td>32</td>
<td>41</td>
</tr>
<tr>
<td>Manage stress</td>
<td>12</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Exercise</td>
<td>23</td>
<td>23</td>
<td>31</td>
</tr>
<tr>
<td>Count carbs</td>
<td>37</td>
<td>19</td>
<td>19</td>
</tr>
</tbody>
</table>

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Encounters with clinicians and activation

Information Seeking Behaviors

<table>
<thead>
<tr>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
<th>Level 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Read about complications</td>
<td>36</td>
<td>43</td>
<td>52</td>
</tr>
<tr>
<td>Bring doctor a list of questions</td>
<td>29</td>
<td>24</td>
<td>45</td>
</tr>
<tr>
<td>Persistence in asking</td>
<td>8</td>
<td>10</td>
<td>22</td>
</tr>
<tr>
<td>Look up doctor's qualifications</td>
<td>10</td>
<td>6</td>
<td>16</td>
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</table>
Patients can be supported on a ‘journey of activation’ by offering tailored interventions: 1:1 or group coaching.

Thus tailored interventions improve all other ‘downstream’ indicators.
Patient Reported Outcome Measure – PROM?

• An additional 22 questions about your symptoms, how you are feeling and how you manage your everyday life.

• We want to find out about YOU as a whole person and your health and wellbeing - more than just your kidneys

• These questions will act as a prompt for you and the doctor/nurse to highlight what is important and what needs addressing – short & long term
Patient Reported Experience Measures – PREM?

- Questions and themes about your care, the service, the environment, transport etc.
- These will be anonymous and won’t be seen by the clinical team
- They will be fed back to the team to inform service improvement
Clinical Support – Patient Activation CS-PAM

• Do the renal teams and individuals support patient activation?
• Do they have the knowledge, skills and confidence to move to equal partners in care?
• Potential risk of conflict – activated patients but not clinical teams
• The results of the CS-PAM fed back to individuals but also provides a ‘heat map’ of the culture of the unit and what is required to gain a shift
• This is not about judgement but about Quality Improvement
Knowledge, Skills and Confidence Matrix

Skills, knowledge and confidence matrix

Interventions

Changing beliefs about clinician's role, leadership, skills. Training e.g. MI communication, coaching

Education, self-awareness, changing beliefs about patients role, self-management, support, skills development

High

Clinical coaches patient
Tailored coaching
Sharing decisions
Maintena role

Skills, knowledge and confidence matrix

Low

Training and practice
Readiness to change
Practicing new skills
Peer support

Interventions

Changing beliefs about clinician's role, leadership, skills. Training e.g. MI communication, coaching

Low

PAM scores (Patient activation)

High

Low

Clinician coaches patient
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Maintena role

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Low

PAM scores (Patient activation)

High
## Cohorts

<table>
<thead>
<tr>
<th>Cohort 1a</th>
<th>Cohort 1b</th>
<th>Cohort 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coventry</td>
<td>Heartlands - Birmingham</td>
<td>Royal Devon &amp; Exeter - Exeter</td>
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<td></td>
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<td>QE – Birmingham</td>
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<tr>
<td>Kings - London</td>
<td>Plymouth</td>
<td>Royal Stoke – Stoke on Trent</td>
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<td>Nottingham</td>
<td>Newcastle</td>
<td>Sunderland</td>
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<td>Imperial - London</td>
<td>Southmead – Bristol</td>
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<td>St Lukes - Bradford</td>
<td>Leeds</td>
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<td>Wolverhampton</td>
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<td>Royal Cornwall Hospitals - Truro</td>
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Challenges

- Time
- Resource
- Work force
- Skills
- Other initiatives
- Not a priority
- We are already doing it
- Engagement and leadership – whole team approach
Achievements

10 renal units in cohort 1
Co-production – working groups of MDT and patients
CS-PAM completed across all units
Health Surveys coming back to UKRR and back again via PV and Sonar
PREM – co-designed and produced – BKPA sponsored & available for all patients
Interventions – next up
Cohort 2 – April onwards (13 renal units)