

Transforming Participation in Chronic Kidney Disease

Aim: To empower people to take greater control of their health and wellbeing in partnership, leading to better outcomes

An activated person is one who has been supported to develop the knowledge, skills and confidence to make informed choices about their health care, and who uses services appropriately to support these choices

The Problem: Between 25 and 40 per cent of the population have low levels of activation

(Hibbard and Cunningham 2008)

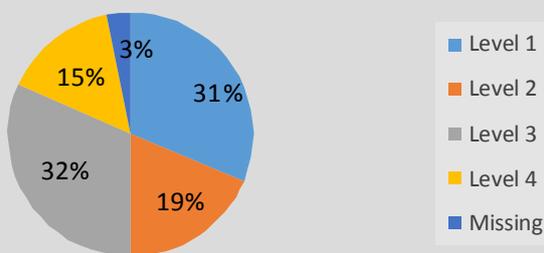
Data from the UKRR reflects a similar picture...



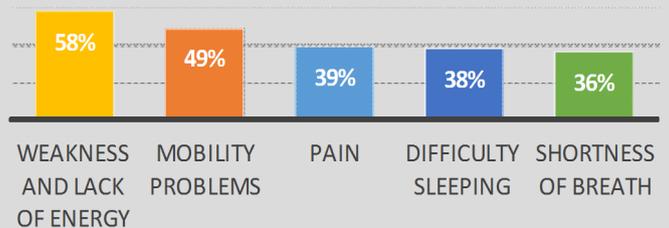
I'm a little overwhelmed, guys.

Data from the UKRR also indicates that patients suffer from a symptom burden that has the potential to impact on quality of life and activation...

Patient Activation Measures (%)



Five Most Prevalent Symptoms (Moderate to Overwhelming)



Measuring patients' activation levels means clinicians can identify those who may need additional support and target it appropriately. The score provides a guidance on the type and amount of support that is likely to be helpful to the patient...

A Developmental Scale of Patient Activation:

The PAM is calculated as a score which corresponds to a PAM level:

Level 1

Disengaged and overwhelmed.
Their perspective: my doctor is in charge of my health.

Level 2

Becoming aware but still struggling.
Their perspective: I could be doing more.

Level 3

Taking action.
Their perspective: I'm part of my health care team.

Level 4

Maintaining behaviours and pushing further.
Their perspective: I'm my own advocate.

Increasing Level of Activation

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The following is a recommended intervention identified by the TP-CKD programme for implementation with both staff and patients, to test the following question:

“Can the use of intervention tools help to improve the knowledge, skills and confidence of patients with kidney disease to enable fuller participation in the management of their own health?”

To explore other interventions identified by the programme, visit our Interventions Toolkit at:

www.thinkkidneys.nhs.uk/ckd/resources/



Peer Support

Peer Support occurs when patients are put in touch with each other for the specific purpose of giving and receiving assistance related to their common goals (Dennis 2003). Patients share their experiences all the time e.g. in clinic waiting rooms, when sharing a ward bay, whilst receiving treatment. However, formal peer support offers individuals contact with other patients who have been trained to provide such support, and has been shown to be more positively viewed than unplanned/untrained support (McCarthy 2014).

What are the benefits?

Peer support has the potential to improve experience, psycho-social outcomes, behaviour, health outcomes and service use among people with long-term physical and mental health conditions and their carers’.

Experience and evidence suggest that peer support is valued by those who take part and that it can improve how people feel and what they do. It may improve self-confidence and motivation and also enhance self-esteem in the supporter.

“I know the staff, and the nurses know about that sort of thing but it’s different when it’s the truth from a patient about how it’s affected them”

How can it be used?

- Face-to-face groups run by trained peers which focus on emotional support, sharing experiences, education and specific activities such as exercise or social activities.
- One-to-one support offered face-to-face or by telephone. This may include information provision, emotional support, befriending and conversation. This type of one-to-one support may result in reciprocal benefits for supporters and may involve volunteers rather than paid peer support facilitators.
- Online platforms such as discussion forums. These have been found to be useful for improving knowledge and reducing anxiety, though people may use them only for a limited time.

For patients

- Talking to another patient who has had similar experiences may give a patient a better understanding of their condition and help them make decisions.
- In a unit with a peer support service, a member of staff will be able to arrange a conversation with an appropriate peer supporter.

For staff

- Trained peer supporters can offer patients a level of understanding and shared experience that healthcare professionals are unable to do.
- Sharing common experience has been shown to improve experience, behaviour, and both physical and mental health outcomes.