

## Identifying principles and strategies for involving patients and caregivers in research in chronic kidney disease: a report of three workshops

**Gutman, T**<sup>1,2</sup>, Howell, M<sup>1,2</sup>, Dansie, K<sup>3</sup>, Hawley, C<sup>4,5,9</sup>, Craig, J<sup>1,2,6</sup>, Tong, A<sup>1,2</sup>, Jesudason, S<sup>7,10,11</sup>, Chapman, J<sup>8</sup>, Johnson, D<sup>4,9</sup>, Murphy, L<sup>10</sup>, Reidlinger, D<sup>4,5</sup>, McDonald, S<sup>3,7,11</sup>

<sup>1</sup> School of Public Health, The University of Sydney, Sydney, Australia

<sup>2</sup> Centre for Kidney Research, The Children's Hospital at Westmead, Sydney, Australia

<sup>3</sup> Australia and New Zealand Dialysis and Transplant Registry, South Australian Health and Medical Research Institute, Adelaide, Australia

<sup>4</sup> Australasian Kidney Trials Network, Brisbane, Australia

<sup>5</sup> University of Queensland, Brisbane, Australia

<sup>6</sup> College of Medicine and Public Health, Flinders University, Adelaide, Australia

<sup>7</sup> Central and Northern Adelaide Renal and Transplantation Service and Royal Adelaide Hospital, Adelaide, Australia

<sup>8</sup> Westmead Clinical School, The Westmead Institute for Medical Research, Sydney, Australia

<sup>9</sup> Department of Nephrology, Princess Alexandra Hospital, Brisbane, Australia

<sup>10</sup> Kidney Health Australia, Adelaide, Australia

<sup>11</sup> Adelaide Medical School, University of Adelaide, Adelaide, Australia

### Background

Patient involvement in research is widely advocated to ensure that their priorities are reflected in all phases of the research process, however there is limited evidence on how patients want to be engaged and involved in research.

### Objectives

To identify strategies for patient/caregiver engagement and involvement in research in chronic kidney disease.

### Method

105 patients and caregivers and 43 clinicians and researchers participated in three workshops in Sydney, Adelaide and Brisbane. In facilitated breakout groups, participants discussed principles and strategies for patient involvement in research. Transcripts were analysed thematically.

### Results

We identified five themes: fostering a consumer-centred culture (facilitating knowledge exchange and translation, providing an opportunity to give back, empowering health ownership, allaying scepticism and suspicion, building a community); respecting consumer expertise and commitment (clarifying expectations and responsibilities, equipping for meaningful involvement, valuing unique and diverse experiential knowledge, keeping 'in the loop' with results and impact); attuning to individual context (a preference based multipronged approach to engagement, reducing the burden of involvement, being sensitive to the patient journey); harnessing existing relationships and infrastructure (partnering with trusted clinicians, increasing exposure in clinical settings, mentoring patient-to-patient, extending reach through established networks); and developing a coordinated approach (power in the collective and united voice, systematic approach for equitable inclusion, streamlining access to opportunities and trustworthy information).

### Conclusions

Patients and caregivers want to be involved in research, yet are unaware and uncertain about potential opportunities for involvement. Establishing a supportive, respectful research culture may facilitate patient involvement as active partners in research.