Identifying and integrating patient and caregiver perspectives in clinical practice guidelines for percutaneous renal biopsy

Gutman, T\textsuperscript{1,2}, Lopez-Vargas, P\textsuperscript{2}, Manera, K\textsuperscript{1,2}, Craig, J\textsuperscript{1,2}, Howell, M\textsuperscript{1,2}, Tunnicliffe, D\textsuperscript{2}, James, L\textsuperscript{1,2}, Macginley, R\textsuperscript{3}, See, E\textsuperscript{4}, Wong, J\textsuperscript{5}, Voss, D\textsuperscript{6}, Saunders, J\textsuperscript{7}, Menahem, S\textsuperscript{8}, Jesudason, S\textsuperscript{9}, Tong, A\textsuperscript{1,2}, Champion De Crespigny, P\textsuperscript{10}

\textsuperscript{1} School of Public Health, The University Of Sydney, Sydney, Australia
\textsuperscript{2} Centre for Kidney Research, The Children’s Hospital at Westmead, Sydney, Australia
\textsuperscript{3} Eastern Health Clinical School, Monash University, Melbourne, Australia
\textsuperscript{4} Department of Nephrology, Monash Health, Melbourne, Australia
\textsuperscript{5} Department of Nephrology, Liverpool Hospital, Sydney, Australia
\textsuperscript{6} Department of Renal Medicine, Counties Manukau Health, Auckland, New Zealand
\textsuperscript{7} Renal Unit, Royal Prince Alfred Hospital, Sydney, Australia
\textsuperscript{8} Department of Epidemiology and Preventive Medicine, Monash University, Melbourne, Australia
\textsuperscript{9} Central and Northern Adelaide Renal and Transplantation Service and Department of Medicine, University of Adelaide, Royal Adelaide Hospital, Adelaide, Australia
\textsuperscript{10} Department of Nephrology, The Royal Melbourne Hospital, Melbourne, Australia

Background
Percutaneous renal biopsy is often essential for providing reliable diagnostic and prognostic information for people with suspected kidney disease, however the procedure can lead to complications and concerns among patients.

Objectives
This study aims to identify and integrate patient priorities and perspectives into the Kidney Health Australia – Caring for Australasians with Renal Impairment clinical practice guidelines for renal biopsy, to ensure patient-relevance.

Method
We convened a workshop, consisting of three simultaneous focus groups and a plenary session, with ten patients who had undergone a renal biopsy and seven caregivers. Topics and outcomes prioritised by patients and their caregivers were compared to those identified by the guideline working group, which was comprised of seven nephrologists. Transcripts and flipcharts were analysed thematically to identify the reasons for participants’ choices.

Results
In total, 34 topics/outcomes were identified, 14 of which were common to the list of 28 previously identified by the guideline working group. Most of the new topics identified by patients/caregivers were related to communication and education, psychosocial support, and self-management. We identified five themes underpinning the reasons for topic and outcome selection: alleviating anxiety and unnecessary distress, minimising discomfort and disruption, supporting family and caregivers, enabling self-management, and protecting their kidney. A new topic on patient care and education was added to the guideline as a result.

Conclusions
Patient and caregiver involvement in developing guidelines on renal biopsy ensured that their concerns and needs for education, psychosocial support, and self-management were explicitly addressed; enabling a patient-centred approach to renal biopsies.