

# The missing piece: Self-management support desires of patients with CKD

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Patients-reported  
Preferences,  
Values, & Needs

Emotional Support &  
Alleviation of Fear &  
Anxiety

Physical Comfort

Information &  
Education

## 8 Dimensions of Person-Centred Care

Continuity &  
Transition

Coordination &  
Integration of Care

Access to Care

Involvement of  
Family & Friends

Adapted from National Research Corporation, 2015

# Self-management support for people with chronic kidney disease: Patient Perspectives

Havas, Bonner & Douglas. 2016. *Journal of Renal Care*

1. Disease-specific knowledge
2. Establishing routine and planning ahead
3. Actively participating in healthcare
4. Developing and sustaining a positive attitude and caring for mental and physical wellbeing
5. Modifying lifestyle
6. Managing medications
7. Recognising and effectively responding to symptoms
8. Maintaining social and occupational roles
9. Engaging and sustaining social support
10. Building and sustaining effective relationships with HCPs



1. When (in the week) would you be able to attend sessions of a self-management program?  
(Tick as many as apply)
- During the week during the day (between the hours of 9am and 5pm)<sup>1</sup>
  - During the week in the evening (after 5pm)<sup>2</sup>
  - On weekends<sup>3</sup>
2. Where would you be willing to attend sessions of a self-management program?  
(Tick as many as apply)
- Outside your home (e.g., at the clinic)<sup>1</sup>
  - At home<sup>2</sup>
3. How would you like the face-to-face self-management program to be run?  
(Tick one option)
- Individually (one-on-one with expert)<sup>1</sup>
  - Group (with others with CKD + expert)<sup>2</sup>
  - No preference<sup>3</sup>





Kidney Health Australia

LAST CHANCE: Researchers at Queensland University of Technology (QUT) want to hear about the sorts of support that YOU would like in order to look after your kidneys.

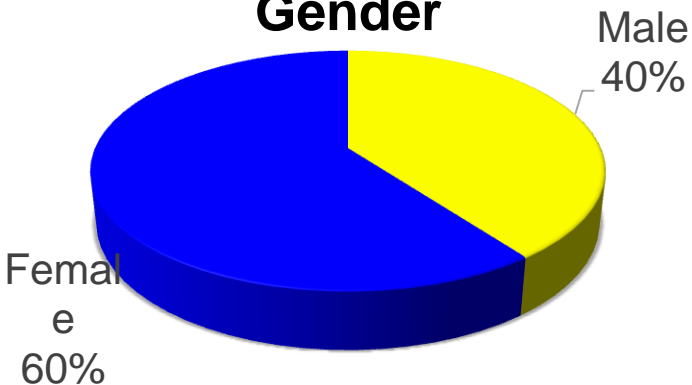
If you're living with kidney disease and would like to offer your input, complete the quick survey here: <http://bit.ly/1C4Oae5>



Have  
Your  
Say

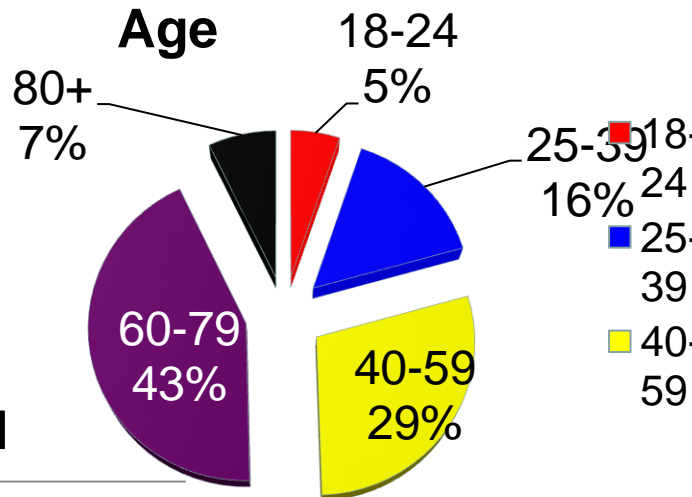
 **Kidney Health**<sup>®</sup>  
Australia

## Gender

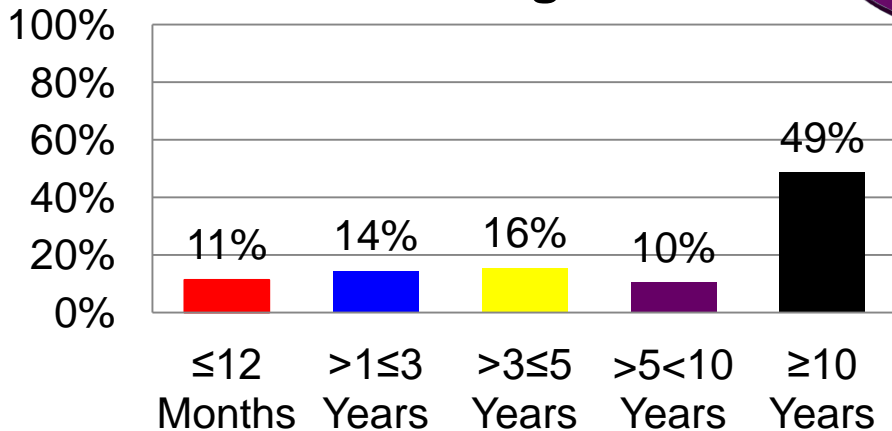


**N = 97**

## Age



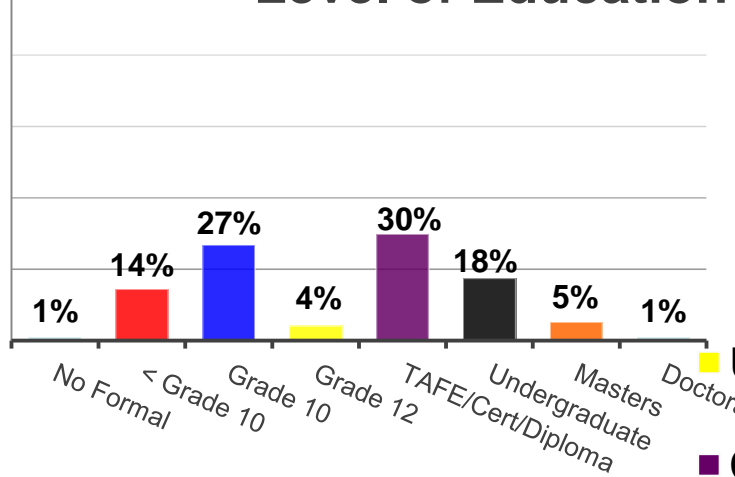
## Time since Diagnosed





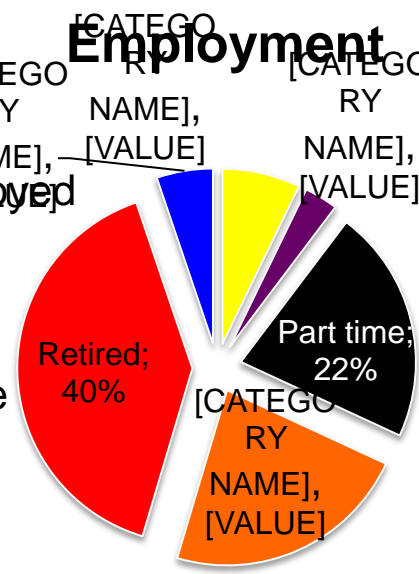
# Level of Education

100%  
80%  
60%  
40%  
20%  
0%

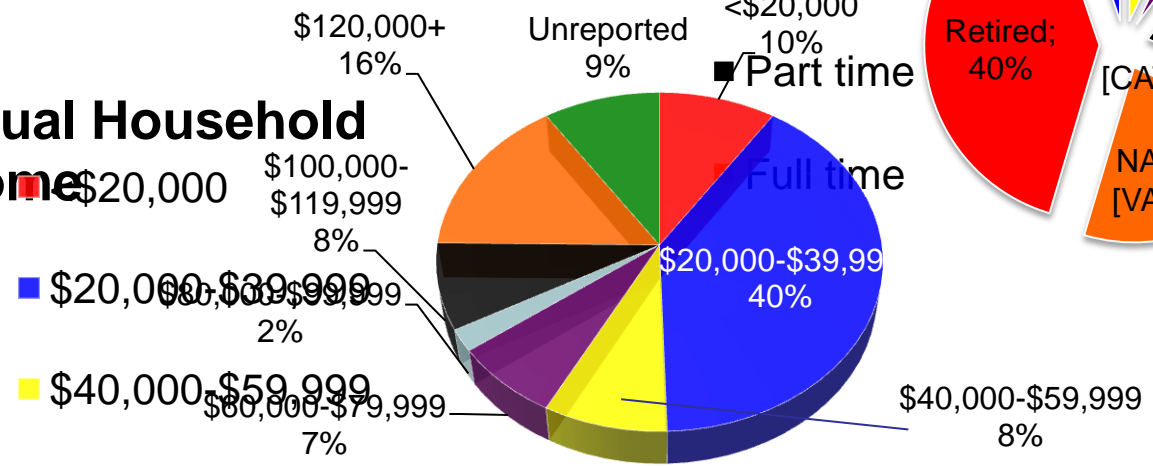


# Employment

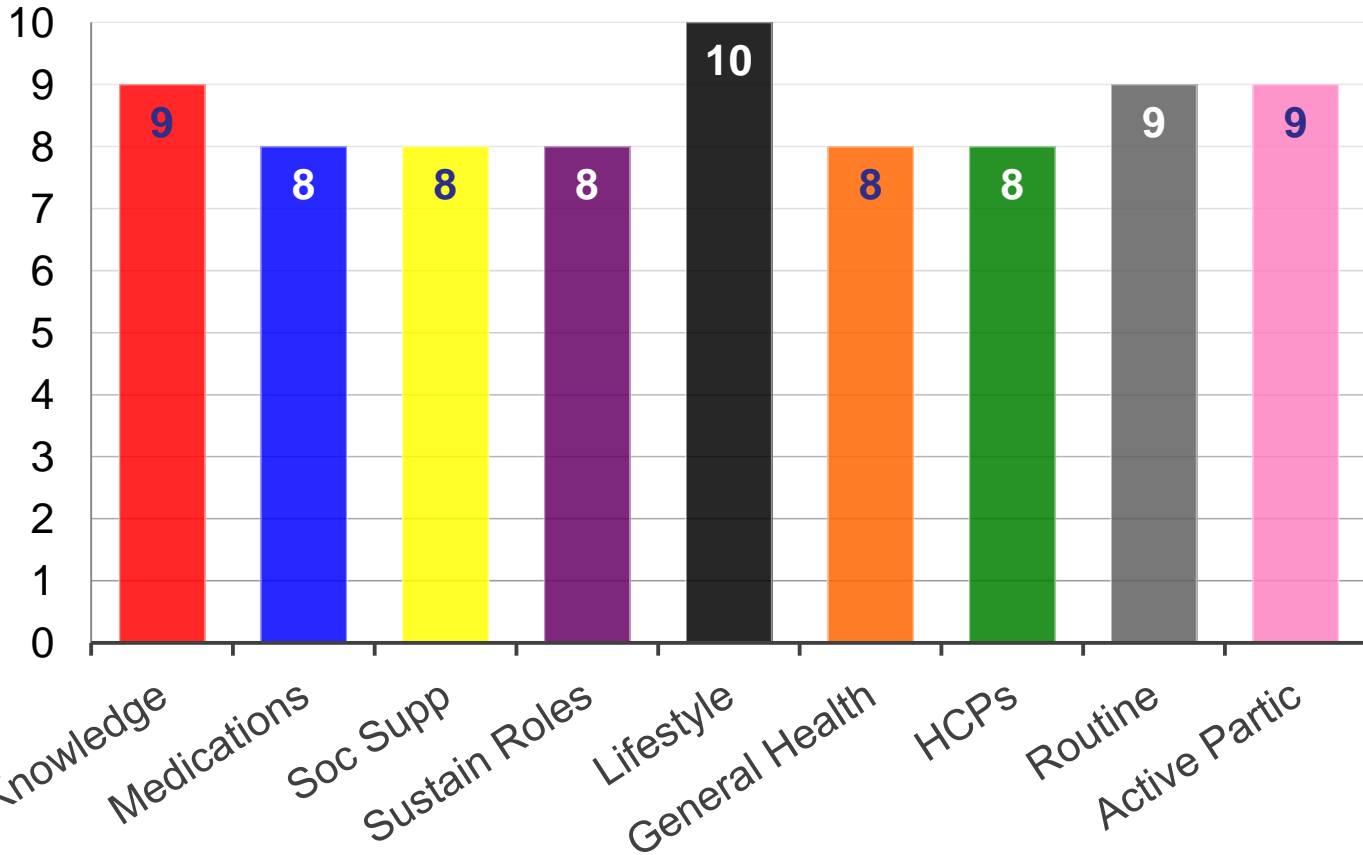
Unemployed  
Casual  
Part time  
Full time



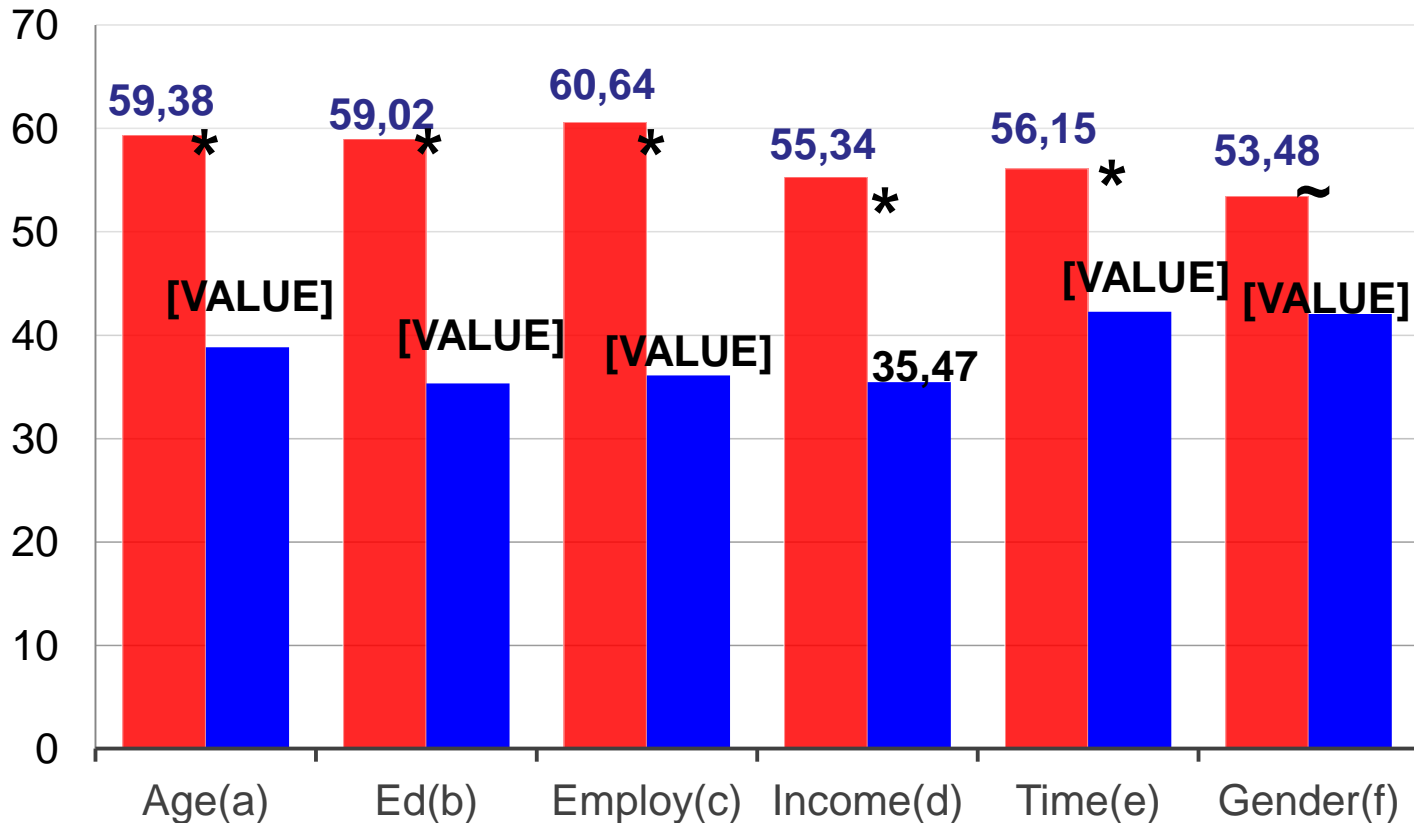
# Annual Household Income



# Desire for Additional Support



# Desire for Additional Support



\*  $p < .05$

~  $p = .05$

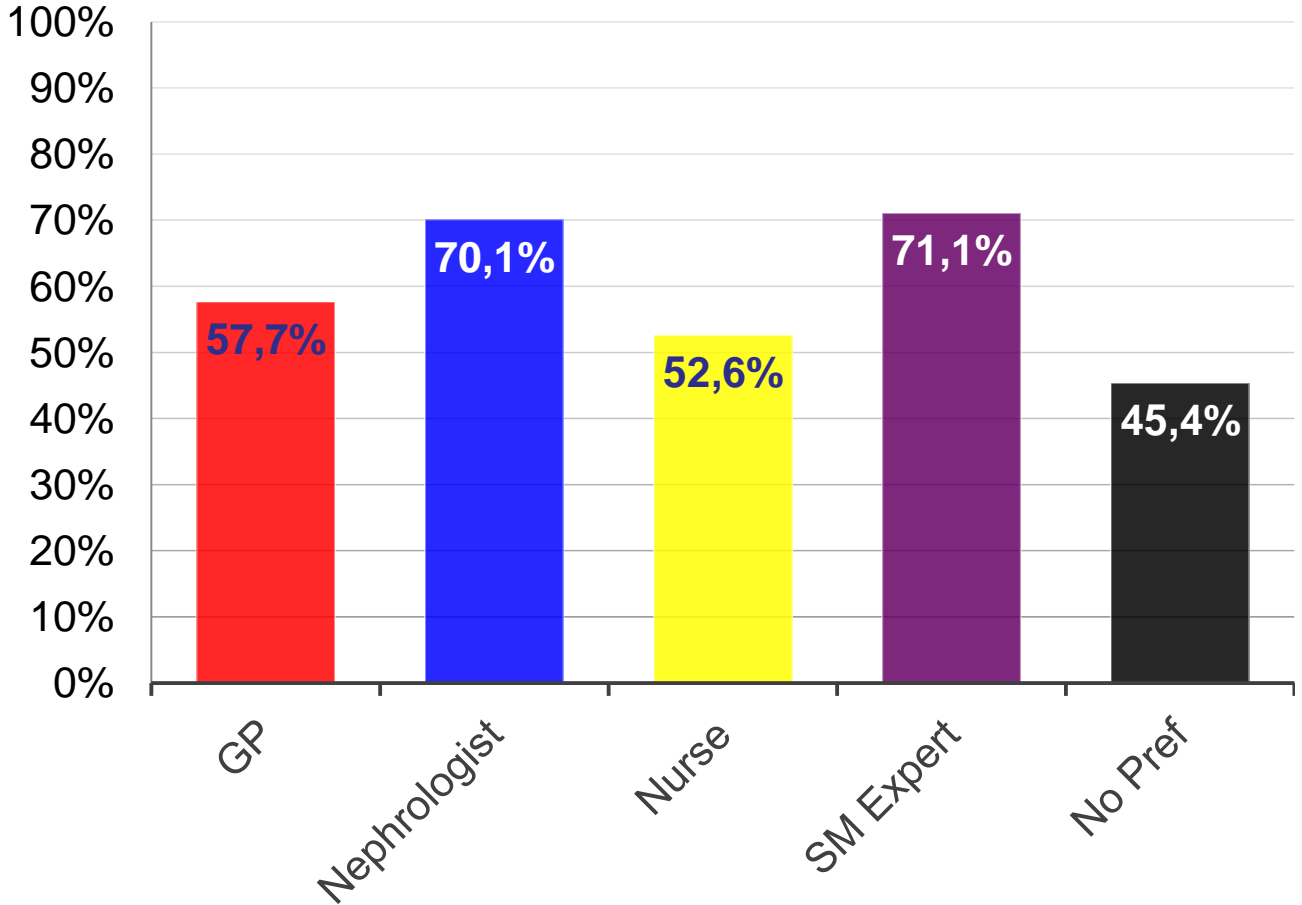
<sup>a</sup> <60 vs 60+; <sup>b</sup> >10 years vs ≤10 years; <sup>c</sup> Employed vs Not Working; <sup>d</sup> >\$40,000 vs <\$39,999;

<sup>e</sup> ≥10 years vs <10 years; <sup>f</sup> Female vs Male

# Delivery Preferences

- Overall, most (72.2%) would attend SMS sessions during business hours
  - 100% of unemployed
  - 47.1% of employed
- Most happy with clinic environment (41.7%) or no preference (45.8%)
- About half (48.5%) open to individual/group/mix
  - 24.7% group
  - 26.8% individual
- Approximately half (49.5%) would like to bring support

# Educator Preferences



# Additional Suggestions

- Only 10 participants identified online & smartphone tools as potentially helpful
- Hard copy materials (3 participants)
- Accessibility for rural patients (2 participants)
- Importance of educator being a good communicator (2 participants)
- Individualised (2 participants)
- Other suggestions:
  - Videos
  - Telephone sessions
  - Program through hospital
  - Early in disease process

# Implications

- Self-management complex & multifaceted
  - *Not* give information and instructions → patients “comply”
- Receivers vs. engagers
  - Different/more intensive strategies may be needed for receivers
- Need to empower patients early in disease process to effect change
- Multi-modal learning formats
  - Face-to-face, phone, written, internet
- Preferences for nephrologist or self-management expert to deliver

# Person-Centred Care

