

TERMS OF REFERENCE

National Consumer Council

Introduction

Kidney Health Australia (KHA) was established in 1968 as the Australian Kidney Foundation. KHA is a national not-for-profit organisation dedicated to improving health outcomes and quality of life for people living with kidney disease, their families and carers. We do this through:

Education – encompassing all aspects of education for both health professionals looking after those with kidney disease and the community at risk of, or with kidney disease.

Advocacy – collaborating to seek solutions to the gaps in care for those with kidney disease in order to improve health outcomes.

Research – KHA Research.

Support – providing support programs for those with kidney disease.

Our mission:

To promote good kidney health through education, advocacy, research and support.

Our vision:

To save and improve the lives of those Australians affected by kidney disease.

Kidney Health Australia's National Consumer Council (NCC) was formed in 2003 (then named the National Consumer Participation Council), in recognition of the value of having a formal pathway for people living with kidney disease to provide visibility into issues and opportunities experienced by consumers; as well as providing the mechanism for feedback to the organisation on wide-ranging topics.

Consumers working together across states and territories with the support of Kidney Health Australia can provide an important role in communicating problems being experienced by Australians living with kidney disease, and in working collaboratively to help resolve these problems.

In this way The National Consumer Council works to make a positive impact on the lives of people affected by kidney disease.

Purpose

The purpose of the National Consumer Council is:

- To act as a link to the wider patient community, identifying and prioritising any unaddressed issues or changes impacting kidney patients and their carers, either negative or positive.
- To provide KHA and, where possible, the broader clinical community with an open and frank mechanism for feedback on policy, priorities, collateral and bodies of work supporting people living with kidney disease.

- To advise and support KHA in regard to consumer involvement in kidney research.
- To support KHA, where requested, in advocating for change to public health policy from the kidney patient perspective.
- To support KHA, as available, at public events that raise the profile of kidney disease.
- To work with KHA to educate about and raise the profile of kidney disease and the programs and services offered by KHA, within local communities and networks.

Values

Encouraging open and honest communication, Kidney Health Australia's elected consumer representatives and staff will work collaboratively to:

- Develop a strong, dynamic and compassionate approach to our work that is responsive to the changing needs of Australians affected by kidney disease.
- Embrace values of empathy, honesty, integrity, and professionalism in undertaking our tasks
- Respect each modality treatment and be respectful that people living with kidney disease. can have had positive or negative experiences with treatment and that both aspects are the reality of kidney disease and can be part of any conversation.

Goals

- To provide a united voice for people living with kidney disease, along with a human face to the disease and the way the current system treats it.
- To represent people affected by kidney disease at a national level.
- To maintain diversity amongst the consumers that participate in the committees, including cultural, age and modality.

Principles and Approach to Advocacy

As articulated in Kidney Health Australia's Government Relations Strategy, a key element of successful advocacy is consistency and preparation. Close engagement by the National Consumer Council with Kidney Health Australia will ensure a nationally consistent approach.

The principles outlined in Kidney Health Australia's Government Relations Strategy as it relates to advocacy include:

- **Preparation** of strong, consistent and agreed positions
- **Policy** developed and implementable by Governments
- **Strategy** that recognises the different tiers and timing of Governments
- **Communication** and responsiveness so that we are able to capitalise on opportunities
- Build, maintain and progress **relationships** across the health, medical, patient and government sectors.

It is imperative that the NCC recognise that effectively undertaking the above principles within the sensitivities of the renal and political environments is essential, but the processes required to

achieve this may provide a perception of inaction; a status that members should not consider they have the capacity to intervene in as representatives of the NCC.

If multiple messages from multiple different sources within KHA are received by a particular policymaker or influencer, it can detract rather than assist our policy agenda.

Membership

The National Consumer Council is comprised of:

- 8-10 kidney consumers drawn from various states and territories
- One or more members of Aboriginal and Torres Strait Islander communities

Ex-officio members made up from the KHA Executive, including

- Kidney Health Australia's General Manager: KHA Research (The Chair)
- Kidney Health Australia's: Clinical Director, General Manager: Clinical Directorate, General Manager: Community

Members will have a passion, commitment, the ability to articulate, understand and provide feedback on issues that affect people living with kidney disease.

It is recognised and respected that members may participate as consumers on other committees. Kidney Health Australia however requests members be respectful of any confidentiality that exist across the committees they participate in and provide visibility around and seek guidance for any conflict of interest or position.

All members should be aware that Kidney Health Australia supports all modalities of treatment and most highly values that people have informed choice. It is reiterated that all NCC members be respectful that people living with kidney disease can have had particularly positive or negative experiences with treatment and that both aspects are the reality of kidney disease and can be part of any conversation.

Meetings and Reporting

- The National Consumer Council will convene no more than four times each year by way of videoconference or teleconference.
- The Chair shall preside at all meetings when able. In the event that the Chair is unable to preside, he or she will appoint an acting Chair for the meeting.
- The Chair will:
 - Coordinate National Consumer Council meetings
 - Distribute the agenda electronically a week before each meeting
 - Ensure all discussion items end with a decision or action
 - Distribute minutes within two weeks after each meeting.
- The Chair will provide a report to the CEO and Board on request.

Secretariat support is provided by Kidney Health Australia.

Minimum numbers for decisions to be passed (a quorum) is 5 Council members.

Term

- The position of Chair of the National Consumer Council is held for a term of 12 months and this may continue at the invitation of Kidney Health Australia's CEO.
- National Consumer Council members will serve for a period of two years but this may be extended.

Other Matters

Participation is on a voluntary basis. No sitting fees or honorarium will be paid to National Consumer Council members.

All reasonable consumer expenses will be met by Kidney Health Australia in line with the "Reimbursement of Consumer Representative Expenses Policy" document.

Council members should always liaise with Kidney Health Australia before communicating on behalf of Kidney Health Australia's consumers to members of Government or senior Government (Health) officials. This position is deemed necessary to ensure consistency and preparation in strategic approach and to minimise potential negative impact.

Any correspondence drafted by Council members to Government or senior Government (Health) officials must be approved by Kidney Health Australia, with guidance sought as to appropriate signatory. Council members agree to keep confidential all information that is marked "Commercial in Confidence" or "Confidential".

Kidney Health Australia will deliver to the National Consumer Council a consistent and timely update on KHA activities at meetings.

Review

These TORs will be reviewed as necessary on the initiative of either the Chair or ex-officio Member.