

18 January 2021 – Consultation with ANZSN Members

AUSTRALIAN AND NEW ZEALAND SOCIETY OF NEPHROLOGY
ABN 87 008 505 502
145 Macquarie Street Sydney NSW 2000 AUSTRALIA
Tel. + 61 2 9241 2586 Email. anzsn@nephrology.edu.au



CONSUMER ENGAGEMENT FRAMEWORK

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1 INTRODUCTION

The Australian and New Zealand Society of Nephrology (ANZSN) is a not-for-profit organisation established to support clinicians and researchers to better prevent, diagnose, treat and cure kidney and related diseases through research, education, policy and advocacy.

The Society, by virtue of its mission, is clinician and researcher focussed and accordingly looks to include consumers directly as well as partner with consumer facing organisations to support its engagement with consumers, patients and carers.

In this way, the Society will ensure that the professional needs of its Members and that its role in shaping education, research and advocacy in Nephrology is informed by the views of those with or affected by kidney disease.¹

2 OBJECTIVE

The objective of this Framework is to scope and define the Society's role in facilitating consumer engagement having regard to its purpose, expertise and resources.

For purposes of this Framework:

- the term 'consumer' includes patients, carers, living donors and community members at risk of or affected by kidney disease; and
- the term consumer engagement includes mechanisms used to increase a consumer's awareness of, and involvement in, health related activities, with the aim of improving health experiences and outcomes.^{2 3}

3 ENGAGING WITH CONSUMERS

The ANZSN will engage with consumers through the following initiatives:

- appointment of consumers to the Society's key advisory committees;
- welcoming consumers to all sessions of the Society's scientific and policy meetings as paying registrants;
- programing a specific consumer plenary session within the main body of each of the Society's scientific and policy meeting; and
- partnering with consumer facing organisations to conduct a consumer engagement workshop at the Society's scientific and policy meetings.

3.1 Appointment of Consumers to ANZSN Committees

The ANZSN will appoint consumers to its key advisory committees. This includes the following committees, which are responsible for policy development and the planning of the Society's key scientific and policy meetings:

- the Scientific Program and Awards Committee (two positions, one from Australia and one from Aotearoa New Zealand); and
- the Policy and Quality Committee (two positions, one for Australia and one from Aotearoa New Zealand).

¹ NHMRC, Statement on Consumer and Community Involvement in Health and Medical Research, September 2016, p.2 <<https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvement-health-and-medical-research>>

² P Sarrami, J Travaglia M Eikli and J Braithwaite, Consumer and Community Engagement: A review of the literature, 2012, p 27.

³ NHMRC. op cit p 2.

The ANZSN may also, at its discretion, appoint consumer representatives to other Committees or ad hoc Working Groups on matters of interest to the Society.

Nominations for consumer representatives on ANZSN Committees will be sought from Kidney Health Australia and Kidney Health New Zealand, recognising their role as the lead consumer facing organisations in each country.

In the event that KHA or KHNZ is unable to nominate a consumer representative, the ANZSN will directly appoint a consumer to that position.

The ANZSN will support consumer representatives by:

- helping the consumer representative understand the role of the committee and provide information on key issues under consideration;
- send out the committee papers well in advance of meetings (at least one week ahead) to enable the consumer representatives time to read the material, ask any questions they may have, and feel prepared;
- introduce the consumer representative to the Chair of the committee who will also be a source of advice and guidance should the consumer representative have questions about the meeting agenda;
- contact the consumer ahead of committee meetings to ensure that they are comfortable with the matters under discussion;
- provide the consumer representative with peer support through ensuring that there are at least two consumers on each key committee and introducing the consumer representatives to each other;
- offering education and training support to help the consumer representative gain the skills they feel they need to be fully engaged in the work of the committee;
- pay sitting fees and reimbursing any pre-approved out of pocket expenses incurred by the consumer representative as a committee member; and
- where the clinical needs of the consumer representative permits, the Society will also support their attendance at face-to-face meetings of the committee and relevant policy forums. Attendance will be considered on an individual case-by-case basis.

All consumer representatives on ANZSN Committees will be remunerated and reimbursed for their time and expertise in accordance with the recommendations set out in the *Health Consumers NSW Position Statement on Remuneration and Reimbursement of Health Consumers*.⁴

In addition, the ANZSN will pay the costs (registration fees, flights, accommodation, meals and ground transport) associated with attendance (as a committee member) of the consumer representative at the relevant ANZSN scientific or policy meeting.

3.2 Opening the ANZSN Scientific and Policy Meetings to Consumers

The ANZSN will welcome consumers to all sessions of the Society's scientific and policy meetings as paying registrants.

The meetings to which consumers will be welcomed as paying registrants include:

- the Annual Scientific Meeting;
- the (biennial) Dialysis Nephrology and Transplantation Workshop; and

⁴ <https://www.hcnsw.org.au/for-health-consumer-organisations/remuneration-and-reimbursement-of-health-consumers/>

- the (biennial) Home Dialysis Conference.

All sessions will be open to consumer attendees other than where the ANZSN, at its sole discretion, determines to hold a closed session to facilitate discussion of sensitive matters.

The ANZSN will also be guided by the relevant codes in Australia and New Zealand, which may restrict consumer access to particular components of the conference, including (within Australia) the Industry exhibition hall.^{5 6}

All consumer registrants (other than those who are participants and registrants by virtue of being attendees at the consumer workshop – refer 3.4 below) will be required to pay a registration fee.

The registration fee will be set at a breakeven rate and determined by the ANZSN for each conference taking into account the costs of convening that conference.

The Society will not be able or responsible for providing any form of support – for example lay interpretations of presentations or support personnel – for consumer attendees.

3.3 Programming a Specific Consumer Plenary Session at ANZSN Scientific and Policy Meetings

The Society will include a specific consumer led plenary session in the main program of each of its conferences.

In the event that the ANZSN partners with a consumer facing organisation to hold a pre-conference workshop, the plenary session at the conference will be planned in accordance with the provision set out at section 3.4 below.

In the absence of a pre-conference workshop, the relevant program committee (the Scientific Program and Awards Committee or the Policy and Quality Committee) will be tasked with organising a consumer led plenary session at the ASM.

Regardless of how the session is planned, the plenary session will be delivered by an invited consumer speaker who will receive an honorarium to facilitate attendance (travel, accommodation, conference registration) at the conference.

3.4 Partnering with Consumer Facing Organisations to Conduct a Consumer Workshop and Consumer led Plenary Session at ANZSN Scientific and Policy Meetings

The ANZSN seeks to promote best practice consumer engagement at its scientific and policy meetings on matters aligned with the Mission of the ANZSN within the expertise and resources of the Society.

Consistent with this commitment, the ANZSN will seek to partner with a consumer facing organisation to co-host a consumer workshop prior to each conference and a consumer led plenary session at the conference proper.

The model of engagement will be based on a partnership approach with a consumer facing organisation from the renal community. Through this approach, the aim is to ensure that consumer engagement conducted at the Society's key meetings is appropriate and respectful.

⁵ Medicines Australia Code of Conduct - <https://www.medicinesaustralia.com.au/code/>

⁶ Medicines New Zealand Code of Practice - [codeofpracticeedition17publishedapril2019effectiveseptember2019.pdf](https://www.medicinesnz.org/codeofpracticeedition17publishedapril2019effectiveseptember2019.pdf) (apcc.org)

The model to be adopted by the ANZSN is set out at Table 1 and defines the roles of the Society and the partnering consumer organisation.

The Society appreciates that it may not be possible to secure a partner organisation to conduct a consumer engagement workshop and plenary session at every ANZSN conference.

In the event that a partner organisation cannot be secured, the ANZSN, at a minimum, will arrange for the conduct of a consumer led plenary session at the relevant meeting. The relevant program committee (the Scientific Program and Awards Committee or the Policy and Quality Committee) will be tasked with the organisation of this session.

A consumer representative on the relevant conference program committee (the Scientific Program and Awards Committee or the Policy and Quality Committee) will be invited to co-host the consumer plenary session at the conference along with a clinician or scientist.

Table 1: Framework to support consumer engagement at ANZSN scientific and policy meetings^{7 8 9 10}

ANZSN Consumer Engagement Framework - Partnering with Consumer Facing Organisations to Conduct a Consumer Workshop and Consumer led Plenary Session at ANZSN Scientific and Policy Meetings		
Key element	ANZSN Role	Partner Role
<p>1. Consumers are actively involved in the design and planning of the meeting</p> <p><i>ANZSN scientific and policy meetings provide an opportunity for consumer engagement in partnership with organisations with the appropriate expertise in kidney care in Australia and Aotearoa New Zealand respectively</i></p>	<p>1.1 Invite representatives from Kidney Health Australia (KHA) and Kidney Health New Zealand (KHNZ) or other relevant consumer facing organisation to sit on the relevant meeting oversight committees (minimum two consumer representatives on each committee) to ensure a consumer perspective is brought to the planning of the ANZSN Annual Scientific meeting (ASM), Dialysis Nephrology and Transplantation (DNT) Workshop and Home Dialysis Conference (HDC).</p> <p>1.2 Appoint, by invitation via KHA or KHNZ or other relevant consumer organisation, a consumer representative to the Local Organising Committee for each of the ASM, DNT Workshop and HDC to act as a point of contact for the Partner organisation on matters of importance to consumer attendees.</p>	<p>1.4 Directly engage with consumers to plan the detailed program for the consumer workshop/symposia at the ANZSN ASM, DNT Workshop and HDC.</p> <p>1.5 The consumer engagement program must align with the mission of the ANZSN and promote the objectives of the ASM, DNT Workshop or HDC as appropriate.</p>

⁷ E Duncanson et al, 'Knowledge is power': A framework for partnering with consumers in developing and delivery a scientific meeting in nephrology, *Nephrology* (2019), p 1- 5.

⁸ National Cancer Research Institute, Patients Included <<https://conference.ncri.org.uk/patients-included/>>

⁹ Canadian Pain Society

<<https://www.canadianpainsociety.ca/page/PatientsIncl18?&hhsearchterms=%22patients+and+included%22>>

¹⁰ E Duncanson et al. op cit p 3.

ANZSN Consumer Engagement Framework - Partnering with Consumer Facing Organisations to Conduct a Consumer Workshop and Consumer led Plenary Session at ANZSN Scientific and Policy Meetings		
Key element	ANZSN Role	Partner Role
	<p>1.3 Where a consumer representative is not appointed to the LOC (whose primary role is to advise on the social events of the meeting) a member of the LOC will be appointed as the consumer liaison. The consumer liaison will be required to consult with consumers to ensure their view is taken into consideration on relevant matters.</p>	
<p>2. Consumers participate in the workshop and conference plenary sessions as Co-Chairs and speakers</p> <p><i>While in person participation is desirable, technological strategies such as live streaming should be considered to enable greater participation by consumers, generally, and as a co-chair and speaker.</i></p>	<p>2.1 Include a consumer plenary session at each of its ASM, DNT Workshop and HDC to enable feedback on the outcome of the consumer engagement workshop.</p> <p>2.2 Pay an honorarium to an ANZSN invited consumer speaker to facilitate attendance (travel, accommodation, conference registration) at the research or policy meeting. This speaker will ideally be part of the consumer workshop, but if no workshop is held, the ANZSN may directly invite a consumer speaker to attend the relevant scientific and policy meetings.</p> <p>2.3 Encourage ANZSN members to support consumer engagement through volunteering their time and clinical expertise - for instance as speakers, at the consumer engagement workshop or plenary session.</p>	<p>2.4 To identify and assist the consumer co-chair and speaker to present at the workshop and the plenary session at the ASM, DNT Workshop or HDC.</p> <p>2.5 Provide the education and 'on the ground' support required to assist consumers to actively participate and contribute to the consumer engagement workshop and the relevant ANZSN meeting.</p> <p>2.6 Liaise with the Chair of the Local Organising Committee to prepare a lay version of the program for the scientific or policy program (as relevant) as part of supporting consumer engagement.</p>
<p>3. Consumers invited to participate as audience members</p> <p><i>The aim is to promote local, targeted consultation in the host city to the extent possible</i></p>	<p>3.1 Invite consumers who are attendees at the consumer engagement workshop to participate in the conference via free registration to the meeting proceedings:</p> <ul style="list-style-type: none"> • the entire ASM (invitations capped at no more than 30 consumers); and • the entire DNT Workshop and HDC (invitations capped at no more than 30 consumers). <p>3.2 Welcome all other consumers (in addition to those to invited</p>	<p>3.4 Liaise with the ANZSN about the issuing of invitations to the scientific or policy meeting and the registration process (as relevant)</p> <p>3.5 Provide a 'buddy' to support consumer attendees invited to attend all or some components of the meeting. The role of the 'buddy' is to be the 'go to' person for the consumer on practical matters relating to attendance. Buddy</p>

ANZSN Consumer Engagement Framework - Partnering with Consumer Facing Organisations to Conduct a Consumer Workshop and Consumer led Plenary Session at ANZSN Scientific and Policy Meetings		
Key element	ANZSN Role	Partner Role
	<p>to the consumer engagement framework) to attend the ASM, DNT Workshop and HDC as paying registrants. Registration options will be flexible (full day, half day) and set at a break-even rate (ie a rate sufficient to cover costs of attendance).</p> <p>3.3 The ANZSN, at its discretion, will determine that particular sessions of the ASM, DNT Workshop or the HDC will be closed to consumers. Sessions will only be closed where the matter under discussion is considered (by the ANZSN) to be sensitive. Every effort will be made to ensure that closed sessions are advised in advance on the meeting program.</p>	<p>arrangements to be no less than 1 buddy:10 consumers.</p> <p>3.6 Ensure presented material is accessible to consumer attendees through providing lay translations as required, taking responsibility for actively preparing this material prior to consumer participation at the relevant session.</p>
<p>4. Provision of travel awards to enable consumers affected by particular issues to attend</p> <p><i>The ANZSN's preferred position is that wherever possible, consumer representatives at any particular meeting are local to the host city or its surrounds</i></p>	<p>4.1 Refer invited guest speaker provisions above.</p> <p>4.2 ANZSN to allow a portion of the grant allocated to the Partner organisation to be used at their discretion for this purpose, but no other funding will be provided by the Society for consumer related travel and accommodation.</p> <p>4.3 ANZSN to record (audio and video) the consumer plenary session at the ASM, DNT Workshop and HDC (as funds permit) and make the recording available (subject to consent) to the Partner organisation for hosting on its website.</p>	<p>4.4 Responsible for funding travel awards, as relevant and appropriate, using own sourced funds, government grants or Industry sponsorship.</p> <p>4.5 Responsible for funding and applying technological solutions (e.g.. recording of sessions and/or live streaming) to ensure conferences are accessible to consumers and enable their active participation at the consumer workshop.</p>
<p>5. Conference/meeting content accessibility for consumers</p> <p><i>The ANZSN welcomes all consumers in person but notes the increasing availability of mechanisms such as live streaming to support access by greater numbers.</i></p>	<p>5.1 Promote and publicise the consumer workshop and plenary sessions on the relevant conference website</p> <p>5.2 Provide keynote speaker presentations (as determined by ANZSN and with the speaker's consent) to the Partner organisation to make publicly available (at no cost) for a period of at least two months following the meeting.</p> <p>5.3 Refer Item 3) above regarding access to the conference and breakout sessions.</p>	<p>5.7 Promote and publicise the consumer workshop and plenary sessions as appropriate.</p> <p>5.8 Ensure consumer proceedings at the workshop and ANZSN ASM or DNT Workshop or HDC plenary session are conducted with appropriate regard to culture, equity and diversity considerations and ethical guidelines on Industry engagement.</p> <p>5.9 Ensure consumer workshop and ASM, DNT Workshop,</p>

ANZSN Consumer Engagement Framework - Partnering with Consumer Facing Organisations to Conduct a Consumer Workshop and Consumer led Plenary Session at ANZSN Scientific and Policy Meetings		
Key element	ANZSN Role	Partner Role
	<p>5.4 Having regard to the Society's ethical and legal obligations in relation to direct to consumer marketing and the engagement of consumers with Industry, invite consumers to attend social functions (conference dinner, welcome drinks) as per the fees applicable to all conference registrants for such functions.</p> <p>5.5 Provide specific facilities or a designated area for consumers to gather for informal networking and refreshments and to enable ethical and legal separation from Industry sponsors and exhibitors.</p> <p>5.6 Where possible, provide specific facilities or a designated area for consumers to attend to private clinical needs such as peritoneal dialysis; injections etc.</p>	<p>HDC plenary session proceedings (subject to cost and consent) are made available on its website post event free of charge.</p> <p>5.10 Fund and apply technological solutions to ensure conferences are accessible to consumers and enable their active participation at the consumer workshop.</p>
6. Evaluation	<p>6.1 ANZSN (via the Professional Conference Organiser) to invite consumer registrants to participate in a survey which evaluates the meeting (i.e. ASM, DNT Workshop or HDC).</p> <p>6.2 ANZSN to consider and respond to consumer feedback via the relevant organising Committee (SPAC or PQC) as appropriate.</p>	<p>6.3 To conduct an evaluation of the consumer engagement workshop using a survey instrument tool.</p> <p>6.4 Invite the AZSN to review and contribute to the evaluation questions and provide a copy of the results within two months of the completion of the conference.</p>

3.4.1 ANZSN Annual Scientific Meeting (ASM)

The ASM is the premier scientific meeting of the Society providing an opportunity for members to come together to learn, share, acknowledge and network on matters relating to Nephrological research and practice in a professional and collegial setting.

The meeting is **scientific in nature** and is focussed on the specific research and educational needs of clinicians and scientists and intended to showcase the latest in discovery and translational nephrological research with the potential to shape future research priorities.

3.4.1.1 Principle

The ASM, being a scientific meeting, provides an opportunity for consumer engagement in relation to the development, conduct and communication of research outcomes in discovery and translational research, including innovation in clinical practice.¹¹

Engagement at all stages of the research process can help align research with consumer priorities, increase participant recruitment and retention, support members to engage with consumers in the research process and facilitate dissemination of results with benefits for health policy and practice.¹²

Research related consumer engagement at the ASM provides other opportunities:

- for researchers, an opportunity to benefit from a consumer perspective on how to frame, conduct and translate their research into practical outcomes; and
- for consumers, there are the added benefits:
 - those that arise from participation and the potential for structured education and training which help develop health literacy skills and the opportunities to contribute;¹³ and
 - the potential to gain insight into how basic science underpins translational research and clinical practice.

The ASM also provides a forum which brings together a broad representation of the Nephrology community, with both national and international speakers, providing an opportunity for concurrent consumer engagement meetings to leverage this expertise for the benefit of clinicians and consumers alike.

3.4.1.2 Scope of engagement

The ANZSN supports a partnership approach with consumer facing organisations to conduct consumer engagement at its ASM, where there is a clear research or clinical practice objective aligned with the mission of the Society and the focus of the conference.

Through partnering with a consumer facing organisation in conducting the workshop the aim is to ensure that engagement is appropriate and respectful.

The ANZSN will support a partnership approach to consumer engagement at its ASM based on the following form of engagement:

¹¹ NHMRC, op cit p 2.

¹² E Duncanson et al. op cit p 1.

¹³ NHMRC. Op cit. p 5.

- a one-day consumer engagement workshop for a maximum of 30 consumers (in person attendees) which is planned, delivered and evaluated by the partner organisation; and
- a consumer Co-Chaired plenary session at the ASM (90 minutes) which reflects the proceedings of the workshop, and which is planned, delivered and evaluated by the partner organisation.

The consumer engagement workshop will be held in parallel with the ASM. A specific consumer session, linked to the workshop themes, will be included in the main body of the ASM on a topic of importance to consumers, clinicians and scientists.

To support this approach, the ANZSN will provide a cash grant of AUD\$10,000 to support consumer engagement at its ASM, with this intended to cover the cost of:

- a venue for a maximum of 30 consumer attendees and appropriately trained support or 'buddy' facilitators (capped at three) from the partnering organisation;¹⁴
- basic audiovisual support; and
- catering for morning tea, lunch and afternoon tea at the consumer workshop.

In addition, the ANZSN will provide the following in-kind support valued at up to AUD\$16,250:

- free registration for up to 30 consumers (capped) from the consumer workshop to attend the entire ASM; and
- free ASM conference registration for up to three staff from the partnering organisation conducting the consumer engagement;
- promotion of the consumer workshop and plenary session as part of the Society's marketing of the ASM;
- facilitated access, through the Scientific Program and Awards Committee, to ASM speakers who may be available to contribute to the consumer engagement workshop and/or plenary session; and
- provision of or access to selected and appropriate recordings of the ASM proceedings to provide consumers with access to the latest scientific outcomes in Nephrology.

Partners for the consumer engagement sessions will be sought through a formal EOI process released up to 12 months prior to the ASM. All consumer facing organisations within the renal community will be invited to apply. A copy of the EOI application can be found at Appendix 1.

The ANZSN funding to support consumer engagement will take the form of a grant to the successful EOI applicant. The ANZSN will be responsible for managing its in-kind funding contribution.

Partner organisations will be wholly responsible for the planning and delivery of the consumer engagement, including the development of the program, organisation of speakers, venue¹⁵ and catering, any support required for attending consumers, recording of the sessions and all other matters.

¹⁴ It is assumed the 'buddy' or 'facilitator' will be appropriately trained and an employee of the partnering organisation

¹⁵ The venue for the consumer workshop will ideally be collocated with the conference facility, but the Partner organization will have discretion based on cost and other relevant considerations

Partner organisations will also be encouraged to contribute their own funding to the workshop, including through their own sources, related research grants and/or Industry sponsorship.

In return for its financial and in-kind contribution, the ANZSN will require joint badging of the workshop and plenary session at the ASM. The Society will also require input to the evaluation methodology and a copy of the evaluation results from the consumer workshop. The de-identified results must be provided by the partnering organisation within two months of the ASM.

In the event that the Society is unable to secure a partner to conduct the consumer engagement workshop at the ASM, the workshop will not be held.

3.4.2 Dialysis Nephrology and Transplantation Workshop (DNT Workshop) and Home Dialysis Conference (HDC)

The DNT Workshop and the HDC, which alternate on a biennial basis, provide an opportunity for Members to come together to discuss contemporary policy issues in Nephrology and inform the Society's advocacy activities.

3.4.2.1 Principle

The DNT Workshop and HDC provide an opportunity for consumers to be present and to actively contribute to the discussions on policy development around disease prevention and control, and the planning, delivery, funding and evaluation of health care services.¹⁶

Policy related consumer engagement at the DNT Workshop and HDC provides a number of opportunities:

- an opportunity for clinicians and researchers to benefit from a consumer perspective on how current and future policies may affect their access to, experience of, and outcomes from care; and ¹⁷
- an opportunity for consumers to benefit from in person participation and from structured education and training to improve their knowledge and ability to enhance their contribution to policy discussions.¹⁸

3.4.2.2 Scope of engagement

The ANZSN supports a partnership approach with consumer facing organisations to conduct consumer engagement at its DNT Workshop or HDC, where there is a clear policy objective aligned with the mission of the Society and the focus of the conference.

Through partnering with a consumer facing organisation in conducting the workshop the aim is to ensure that engagement is appropriate and respectful.

The ANZSN will support a partnership approach which is based on the following form of engagement:

- a one-day consumer engagement workshop for a maximum of 30 consumers (in person attendees) which is planned, delivered and evaluated by the partner organisation; and
- a consumer Co-Chaired plenary session at the DNT Workshop or HDC (60 – 90 minutes) which reflects the proceedings of the workshop and is planned, delivered and evaluated by the partner organisation.

¹⁶ P Sarrami, J Travaglia M Eikli and J Braithwaite. Op cit. p 14.

¹⁷ P Sarrami, J Travaglia M Eikli and J Braithwaite. Op cit. p 36

¹⁸ P Sarrami, J Travaglia M Eikli and J Braithwaite. Op cit. p 27

The ANZSN will provide a cash grant of AUD\$10,000 to support the consumer engagement which is intended to cover the cost of:

- a venue for a maximum of 30 consumer attendees and support ‘buddy’ facilitators (capped at three) from the partnering organisation;¹⁹
- basic audiovisual support; and
- catering for morning tea, lunch and afternoon tea at the consumer workshop.

In addition, the ANZSN will provide the following in-kind support valued at up to AUD\$14,500:

- free registration for up to 30 consumers (capped) from the consumer engagement workshop to attend the entire DNT Workshop or HDC;
- free DNT Workshop or HDC registration for up to three staff from the partnering organization conducting the consumer engagement;
- promotion of the consumer workshop and plenary session as part of the Society’s marketing of the DNT Workshop or HDC;
- provision of or access to selected and appropriate recordings of DNT or HDC proceedings to provide consumers with access to the latest scientific outcomes in Nephrology;
- facilitated access, through the relevant Committee (Scientific Program and Awards Committee or the Policy and Quality Committee), to DNT Workshop or HDC speakers who may be available to contribute to the consumer engagement workshop.

Partners for the consumer engagement workshop will be sought through a formal EOI process released up to 12 months prior to the DNT Workshop or HDC. All consumer facing organisations within the renal community will be invited to apply. A copy of the EOI application can be found at Appendix 1.

The ANZSN funding will take the form of a grant to the successful EOI applicant. The ANZSN will be responsible for managing its in-kind funding contribution.

Partner organisations will be wholly responsible for the planning and delivery of the consumer engagement, including the development of the program, organisation of speakers, venue²⁰ and catering, any support required for attending consumers, recording of the sessions and all other matters.

Partner organisations will also be encouraged to contribute their own funding to the workshop, including through their own sources, related research grants and/or Industry sponsorship.

In return for its financial and in-kind contribution, the ANZSN will require joint badging of the workshop and plenary session at the DNT Workshop or HDC. The Society will also require input to the evaluation methodology and a copy of the evaluation results from the consumer workshop. The de-identified results must be provided by the partnering organisation within two months of the DNT Workshop or HDC.

In the event that the Society is unable to secure a partner to conduct the consumer engagement workshop at the DNT Workshop or HDC, the workshop will not be held.

¹⁹ It is assumed the ‘buddy’ or ‘facilitator’ will be appropriately trained and an employee of the partnering organisation

²⁰ The venue for the consumer workshop will ideally be collocated with the conference facility, but the Partner organization will have discretion based on cost and other relevant considerations

3.5 Consumer engagement outside the ANZSN Framework

The ANZSN recognises that its scientific and policy meetings provide an opportunity for consumer engagement that a range of independent organisations may seek to leverage.

However, consumer engagement conducted outside the provisions set out in this Framework will not be funded or endorsed by the ANZSN.

4 REVIEW

In the event that a particular consumer engagement matter is not addressed within this Framework, the matter should be referred to the ANZSN Honorary Executive Officer at anzsn@nephrology.edu.au for advice.

The ANZSN's policy framework on consumer engagement at its scientific and policy meetings will be reviewed on an as needs basis.

Appendix 1 – Template for EOI

Expression of Interest - Consumer engagement at the ANZSN Annual Scientific Meeting (ASM)

Context

The ASM is the ANZSN's premier scientific conference providing opportunities for the Nephrology community to come together to learn, share, network and celebrate achievements in discovery and translational research and innovation in clinical practice.

As part of its commitment to consumer engagement, the ANZSN is offering a grant to support consumer facing organisations to plan, deliver and evaluate a consumer engagement workshop and plenary session at its 28 August – 1 September 2021 ASM.

To be successful, applicants must demonstrate how consumer engagement at the ASM aligns with the Mission of the ANZSN and will enhance the development, conduct, communication or dissemination of discovery or translational research outcomes and innovations in clinical practice in Nephrology.

Opportunity

The ANZSN is offering support to the value of up to \$26,250 including a cash grant of \$10,000 and in-kind support of up to \$16,250 for the conduct of research and clinical practice related consumer engagement at the ASM. The engagement is to include:

- a one-day consumer engagement workshop (capped at 30 consumer attendees); and
- a consumer co-chaired plenary session (60-90 minutes) at the ASM, with the plenary session to reflect and draw upon the outcomes of the consumer workshop.

Financial support

- The Society's financial contribution is intended to cover the cost of a venue suitable for the conduct of a consumer workshop, provision of catering and basic audiovisual infrastructure.
- Any surplus above the \$10K may be applied by the Partnering organisation to other purposes directly related to the conduct of the consumer engagement session, including but not limited to, additional audiovisual support (such as live streaming) or travel support for consumers to attend the workshop.

In kind support

- The ANZSN will waive registration fees (capped at 30) for consumers attending the consumer engagement plenary session at the ASM. Refreshments (appropriate to the time of day) will be provided for consumer registrants, in a discrete area separate to the Industry exhibition.
- The ANZSN will provide three (3) free ASM conference registrations for staff of the partnering organisation to facilitate the provision of 'on the ground' ('buddy') support facilitators for attending consumers.
- Publication and promotion of the consumer engagement workshop and plenary session at the ASM via the conference website and through other means, such as promotion on the ANZSN website and through its in-house publication entitled 'Weekly Update'.
- Access to selected recordings from the ASM (including the plenary consumer engagement session) for placement on the partnering organisation's website (subject to speaker consent). Any lay translations of these presentations to a format suitable for consumers will be the responsibility of the partnering organisation

Partnering organisation

The ANZSN welcomes applications from Australian and New Zealand based consumer facing organisations, including KHA and KHNZ, who are committed to facilitating consumer engagement related to the development, conduct and communication of research outcomes in discovery and translational research in Nephrology.

The ANZSN is seeking partners who have demonstrable skills, knowledge and experience and a track record of success in consumer engagement.

Expressions of Interest

Applicants are asked to submit a high level overview of how they would implement research related consumer engagement at the ASM. The application must address the following elements:²¹

- Purpose, aim and target of the consumer engagement and how this aligns with the Mission of the ANZSN and the focus of the ASM;
- Nature of the engagement – for instance, what aspect of research (design, delivery, evaluation, dissemination etc.) or innovation in clinical practice (resulting from research) will be the focus of the consumer engagement;
- The consumers to be invited to attend the Workshop and how this aligns with the purpose and aim of the engagement;
- Identification and remediation strategies to address any barriers to consumer engagement (e.g. any cultural or linguistic considerations; 'on the ground support' to assist consumers participate and contribute etc.). The mechanism for ensuring binational consumer (Australia and New Zealand) engagement will need to be demonstrated;
- Preparation of the consumer participants for the consumer engagement workshop and plenary sessions, including how consumers will be supported to make a contribution (i.e. through any education, training and information materials prepared by the partnering organisation);
- Engagement methods (plenary discussions, focus groups etc.);
- Evaluation of the consumer engagement, with a copy of the evaluation tool to be provided for review and input by the ANZSN. The ANZSN will require a copy of the (deidentified) evaluation results to be submitted to the Society within two months of the completion of the ASM; and

²¹ P Sarrami, J Travaglia M Eikli and J Braithwaite. op cit p 59 – 62.

- How the ANZSN's contribution will be formally acknowledged, noting that as a minimum this must include joint badging of the workshop and plenary session at the ASM

The partnering organisation must also submit a high level budget setting out how it will apply the grant and any additional funding it may apply to ensure success. Evidence (certificates of currency) on applicable insurance arrangements for the consumer workshop will also need to be provided to the ANZSN.

All EOIs will be evaluated by the Scientific Program and Awards Committee of the ANZSN.

Key evaluation criteria will include, but not be limited to, the following:

- alignment of the consumer engagement with the Mission of the ANZSN;
- alignment with the focus of the ASM (research and research related clinical practice innovation);
- compliance with best practice principles of consumer engagement;
- bona fides of the applicant in conducting consumer engagement;
- co-contribution and other in-kind benefits to be provided by the partnering organisation; and
- compliance with the provisions relating to equity and diversity, environmental sustainability, industry engagement and other relevant provisions set out in the ANZSN Conference Guide.

The Scientific Program and Awards Committee will make a recommendation to the ANZSN Council on the preferred consumer engagement partner. The decision of the ANZSN Council will be final.

Appendix 1: Template for EOI to partner with the ANZSN in the conduct of a pre-conference consumer workshop and consumer led plenary session at an ANZSN Scientific or Policy meeting

Expression of Interest - Consumer engagement at the ANZSN DNT Workshop and Home Dialysis Conference

Context

The DNT Workshop and the HDC are the ANZSN's premier policy meetings providing opportunities for the Nephrology community to come together to learn, share, network and contribute to policy development impacting kidney disease in Australia and New Zealand.

As part of its commitment to consumer engagement, the ANZSN is offering a grant to support like-minded organisations plan, deliver and evaluate a consumer engagement workshop and plenary session at its 28 – 29 August 2021 DNT Workshop or HDC [insert whichever is applicable].

To be successful, applicants must demonstrate how consumer engagement at the DNT Workshop or HDC aligns with the Mission of the ANZSN and will enhance policy development to better prevent, diagnose and treat kidney disease.

Opportunity

The ANZSN is offering support to the value of up to \$24,500 including a cash grant of \$10,000 and in-kind support of up to \$14,500 for the conduct of policy related consumer engagement at the DNT Workshop or HDC, specifically:

- a one-day consumer engagement workshop (capped at 30 attendees)
- a consumer co-chaired plenary session (60-90 minutes) within the DNT Workshop or HDC meeting

Financial support

- The Society's financial contribution is intended to cover the cost of a venue suitable for the conduct of a consumer workshop, provision of catering and basic audiovisual infrastructure.
- Any surplus above the \$10K may be applied by the partnering organisation to other purposes directly related to the conduct of the consumer engagement session, including but not limited to, additional audiovisual support (such as live streaming) or travel support for consumers to attend the workshop.

In kind support

- The ANZSN will waive registration fees (capped at 30) for consumers attending the DNT Workshop or HDC. Refreshments (appropriate to the time of day) will be provided for consumer registrants, in a discrete area separate to the Industry exhibition.
- The ANZSN will provide three (3) free DNT Workshop or HDC registrations for staff of the partnering organisation to facilitate the provision of 'on the ground' ('buddy') support for attending consumers.
- Publication and promotion of the consumer engagement workshop and plenary session at the DNT Workshop or HDC via the conference website and through other means, such as promotion on the ANZSN website and through its in-house publication entitled 'Weekly Update'.

- Access to selected recordings (if any) from the conference (including the plenary consumer engagement session) for placement on the partnering organisation's website (subject to speaker consent). Any lay translations of these presentations to a format suitable for consumers will be the responsibility of the partnering organisation.

Partnering organisation

The ANZSN welcomes applications from Australian and New Zealand based consumer facing organisations involved in policy development impacting the detection, prevention and treatment of kidney disease.

The ANZSN is seeking partners who have demonstrable skills, knowledge and experience and a track record of success in consumer engagement.

Expressions of Interest

Applicants are asked to submit a high level overview of how they would implement consumer engagement at the 28 – 29 August 2021 DNT Workshop or HDC [insert whichever is applicable]. The application must address the following elements:²²

- Purpose, aim and target of the consumer engagement and how this aligns with the Mission of the ANZSN and the focus of the DNT Workshop or HDC as relevant;
- Nature of the engagement – for instance, what aspect of policy in relation to kidney disease will be the focus of the consumer engagement;
- The consumers to be invited to attend the Workshop and how this aligns with the purpose and aim of the engagement;
- Identification and remediation strategies to address any barriers to consumer engagement (e.g. any cultural or linguistic considerations; 'on the ground support' to assist consumers participate and contribute etc.). The mechanism for ensuring binational consumer (Australia and New Zealand) engagement will need to be demonstrated;
- Preparation of the consumer participants for the consumer engagement workshop and plenary sessions, including how consumers will be supported to make a contribution (i.e. through any education, training and information materials prepared by the partnering organisation);
- Engagement methods (plenary discussions, focus groups etc);
- Evaluation of the consumer engagement, with a copy of the evaluation tool to be provided for review and input by the ANZSN. The ANZSN will require a copy of the (deidentified) evaluation results to be submitted to the Society within two months of the completion of the DNT Workshop or HDC; and
- How the ANZSN's contribution will be formally acknowledged, noting that as a minimum this must include joint badging of the workshop and plenary session at the DNT Workshop or HDC.

The partnering organisation must also submit a high level budget setting out how it will apply the grant and any additional funding it may apply to ensure success. Evidence (certificates of currency) on applicable insurance arrangements for the consumer workshop will also need to be provided to the ANZSN.

All EOIs will be evaluated by the Policy and Quality Committee or the Scientific Program and Awards Committee of the ANZSN as relevant. Key evaluation criteria will include, but not be limited to, the following:

²² P Sarrami, J Travaglia M Eikli and J Braithwaite. op cit p 59 – 62.

- alignment of the consumer engagement with the Mission of the ANZSN;
- alignment with the policy focus of the DNT Workshop or HDC;
- compliance with best practice principles of consumer engagement;
- bona fides of the applicant in conducting consumer engagement;
- co-contribution and other in-kind benefits to be provided by the partnering organisation;
and
- compliance with the provisions relating to equity and diversity, environmental sustainability, industry engagement and other relevant provisions set out in the ANZSN Conference Guide.

The Policy and Quality Committee or Scientific Program and Awards Committee as relevant will make a recommendation to the ANZSN Council on the preferred consumer engagement partner. The decision of the ANZSN Council will be final.

Appendix 2 - ANZSN's financial and in-kind support for consumer engagement

ANZSN Consumer Engagement - Annual Scientific Meeting

ANZSN Financial and In-kind contribution

\$10K Grant	Cost	Assumption
Venue	\$2,000.00	1 full day, 30 - 35 consumers and support staff from partnering organisation; powerpoint AV only
Catering	\$3,150.00	1 full day, 35 attendees at \$90 per head for morning tea, lunch and afternoon tea
Other	\$4,850.00	Preparation of engagement materials, contribution toward live streaming or other engagement activities, travel support
Sub total	\$10,000.00	
In kind		
Conference Registration - Staff of partnering organisation	\$3,660.00	3 Full ASM conference registrations at \$1220 per head (ASM non Member rate) - for staff of partnering organisation
Conference Registration - Full ASM	\$12,000.00	30 full conference registrations at \$400 per head (estimated break even rate, full day). PCO fee (\$150 per head + catering (\$100 per day) + venue hire costs (say \$50 per head)
Promotion of the session	\$600.00	\$20 per head, based on budget (graphic design, printing, signage, edition, website and promotion costs for 2020 full face to face ASM
Access to selected recordings	\$0.00	ASM keynote speakers (as determined by ANZSN)
Sub total	\$16,260.00	
Total	\$26,260.00	

ANZSN Consumer Engagement - DNT Workshop or HDC

\$10K Grant	Cost	Assumption
Venue	\$2,000.00	1 full day, 30 - 35 consumers and support staff from partnering organisation; powerpoint AV only
Catering	\$3,150.00	1 full day, 35 attendees at \$90 per head for morning tea, lunch and afternoon tea
Other	\$4,850.00	Preparation of engagement materials, contribution toward live streaming or other engagement activities, travel support
Sub total	\$10,000.00	
In kind		
Conference Registration - Staff of partnering organisation	\$1,860.00	3 full conference registrations at say \$620 per head including GST (2020 HDC rate) - for staff of partnering organisation
Conference Registration - Consumers registration	\$12,000.00	30 full conference registrations at \$400 per head (estimated break even rate, full day). PCO fee (\$150 per head + catering (\$100 per day) + venue hire costs (say \$50 per head)
Promotion	\$600.00	\$20 per head, based on budget (graphic design, printing, signage, edition, website and promotion costs for 2020 full face to face ASM)
Access to selected recordings	\$0.00	Keynote speakers (as determined by ANZSN)
Sub total	\$14,460.00	
Total	\$24,460.00	