



Terms of Reference – NACE Consumer Advisory Group (CAG)

Background

About the National Allergy Centre of Excellence (NACE)

Allergy is one of Australia's greatest public health challenges. It affects more than 20 per cent of Australians and represents an annual financial burden of more than \$10 billion to the Australian economy.

In a world-first, the Commonwealth Government has responded to this crisis by funding the creation of the National Allergy Centre of Excellence (NACE) and the National Allergy Council (NAC). These two organisations will work together to address the rising toll of allergic disease in this country.

As the country's leading allergy research body, the vision of the NACE is to accelerate allergy research in Australia to save lives, improve health and reduce the costs related to allergic disease.

The mission is to seamlessly centralise allergic disease research and the translation of evidence into practice through:

- Establishing a clinical trials network to improve access to the world's best treatments,
- Harnessing the power of big data analysis through a National Allergy Repository and Biobank,
- Leading a world-first series of live systematic reviews on allergic disease, and
- Mentoring and training the next generation of allergy experts.

In parallel, the NAC will continue its focus on the implementation and expansion of the highly valued and successful National Allergy Strategy, and the partnership between the Australasian Society of Clinical Immunology and Allergy (ASCI) and Allergy & Anaphylaxis Australia (A&AA) – the leading medical and support organisations for allergy in Australia.

The goal of government, NACE and NAC is to work together to address the rising toll of allergic disease across Australia and improve the lives of those it impacts on a daily basis.

Terms of Reference

About the NACE Consumer Advisory Group (CAG)

The NACE recognises that meaningful consumer involvement provides the opportunity for different lived experiences and perspectives to shape and inform decisions on research activities, projects and public health programs. As the beneficiaries of advances in health care, consumers have a real interest in promoting the translation of quality research into improved policy, guidelines and clinical practice.

The CAG will work to ensure the inclusion of consumer opinion across the full research and project cycle; including involvement in the setting of priorities, design, implementation, evaluation and reporting; and advocacy.

The Group will hold national representation and will be an active partnership between researchers, health professionals (i.e. clinicians, nurses, co-ordinators and allied health) and those affected by or who may benefit from research into allergic disease.

The NACE will work towards having a CAG membership that will consist of individuals from a broad age range (18 and over) and with varied lived experience and knowledge in allergy and research. Where appropriate, the NACE will establish further connections with the youth sector through NAC's Allergy 250K Project.

The NACE will also have a Consumer Engagement Register which will give select consumers the opportunity to participate in time limited or once-off research activities such as workshops, focus groups or the reviewing of information materials.

Consent will be obtained from all consumers involved with NACE to have their details maintained on a Consumer Engagement Register.



In summary, this Terms of Reference applies to the operations of the NACE CAG only. However, it is recognised that the NACE and NAC have a joint interest in the engagement of consumers in allergy and will work as a partnership as needed.

1. Role of the NACE Consumer Advisory Group

The establishment of the CAG ensures there is a formal body of members with varied experience and knowledge, who are considered capable of providing consumer oversight and opinion on activities related to allergic disease.

The responsibilities of the members are:

- To actively participate in CAG meetings, provide independent opinions and advice and contribute to decision making. This includes bringing issues of importance to the attention of the Group for wider discussion. Involvement may include the following:
 - Offering opinion on research and project priorities and the defining of research questions,
 - Providing advice on project design, planning and implementation,
 - Identifying outcomes of interest,
 - Improving the content and readability of participation information,
 - Offering viewpoints to ensure a balanced assessment of research related findings,
 - Providing advice on how to make trials more attractive to participants, and
 - Advocating the role of the CAG and the work of the NACE to promote better public awareness and understanding of our research projects and activities.
- To willingly participate in any recommended training, seminars or development activities that will increase knowledge and understanding in the conduct of research and public health programs. Ongoing education is key to supporting full and active participation in this role.
- To act in the best interests of the NACE and the health care consumers they are appointed to represent; and to perform their roles in good faith, honestly and impartially. To think broadly and be conscious of considering a diversity of consumer needs and interests that might differ or extend beyond their own.
- To respect and maintain confidentiality when reviewing documentation and on the matters discussed within the CAG.
- To make every reasonable effort to attend scheduled meetings and to have reviewed the relevant documentation or materials for discussion.
- To make timely responses to correspondence and requests for opinion, to avoid any delays on progressing priority matters for action.
- To declare any existing or new potential Conflict of Interest as soon as it arises, including any involvement with companies or political parties.
- To not use any NACE contacts for the benefit of their own personal or organisational gain without prior disclosure or discussion with the Chair.

2. Membership of the NACE Consumer Advisory Group

The CAG will be hosted by the NACE through the Murdoch Children's Research Institute and will receive its core funding from the Commonwealth Department of Health.

The CAG will have national representation and a membership that provides experience and knowledge across the four allergy streams – drug, food, insect and respiratory. Members will include those with lived experience of allergy and those that care for or about them.



The CAG will consist of:

- Up to ten consumer members and a chairperson

The role of Chair for the National CAG will be an appointed position. The Chair will be selected on agreement by the NACE Director and the Executive.

The Chair is appointed for a minimum term of two-years. The plan for replacement must commence three months prior to the end of their term.

If for any reason, the Chair is unable to meet their commitment to a two-year term, the NACE Director will action a plan to make a new appointment to the role.

If the Chair is unavailable at short notice and the meeting cannot be rescheduled, the NACE Director will step into the role. Where possible, attempts should be made to reschedule to accommodate the Chair and CAG members in such instances.

Method of appointment

Membership for the NACE CAG and Consumer Engagement Register will be advertised, and consumers invited to forward an online Expression of Interest (EOI) form. The NACE Management Office will review the online EOIs and send an Application Pack to those interested in a CAG role. This will include: a NACE CAG EOI Form (Appendix A), a Membership Position Description (Appendix B) and a Conflict of Interest Disclosure Form (Appendix D). Applications will be short-listed and approved for interview by the NACE Director.

Interviews will be conducted in a formal setting by senior representatives from the NACE Management team. The purpose of the interview will be to assess the suitability and compatibility of the consumer for the role, and to ensure they understand the responsibilities of the position and the level of commitment. Consumers will be assessed on the same standard criteria and the interview outcomes will be discussed with the NACE Director.

The NACE Director will determine the preferred candidates and then obtain approvals from the NACE Executive for their appointment.

Term of appointment

Members of the CAG will be appointed for a two-year term. Members may be re-appointed at the end of their tenure for one extra two-year term. After two terms, the member is no longer eligible for re-appointment.

Invitees

The CAG may invite other stakeholders as guests to participate in discussion.

The Chair must approve any guest attendance ahead of the CAG meeting and the agenda will need to indicate their upcoming attendance when circulated to CAG members.

The guest attendee will need to sign a Confidentiality Agreement and disclose any conflict of interest on the '*Disclosure of interests and conflict of interests*' form (Appendix D). Refer to items 3 (iii) and (iv) below.

3. Administration of the Consumer Advisory Group

i. Meetings

The CAG meetings will be held by teleconference (using MS Teams) every three months or four times a year. There may be occasions where members will be invited to attend in person, but this will be atypical and associated expenses would be covered – refer to the *Remuneration for NACE consumer members* document (Appendix E).

The CAG membership will be consulted prior to the inaugural CAG meeting to determine the meeting day (dates) and time that meets the needs of the majority. The CAG meeting schedule and invitations for the year will then be circulated.

The Chair may elect to schedule additional meetings or alter meeting dates and their frequency to address any matters that may arise and need discussion. Members are expected to make every reasonable effort to attend scheduled meetings, to be prepared having read circulated documents and to contribute to the items listed for discussion.

ii. Agendas and minutes

The NACE Management Office will hold administrative responsibilities for the CAG, including the circulation of the agenda and minutes.

Agenda items must be submitted at least two weeks (10 business days) before the scheduled CAG meeting.

The agenda, minutes (of the previous meeting) and any related documentation for discussion will be distributed to CAG members via email at least one week (five business days) prior to the meeting to ensure sufficient time for review and consideration.

Note: Given the CAG meetings will be scheduled every three months, the minutes will be circulated within two weeks post the actual meeting date so that members are aware of any items for action. When the new agenda is circulated for the next scheduled meeting (every three months), they will be provided again as a point of reference of previous discussions and actions.

iii. Confidentiality

All discussion and related meeting papers and documents from the CAG must be considered confidential. Members must respect and uphold the confidentiality requested of them by the NACE Executive and the researchers involved.

New members will sign written confidentiality agreements when appointed (Appendix C). A new agreement will need to be entered into if a member is appointed for another two-year term.

Guest attendees to CAG must also sign a confidentiality agreement.

iv. Conflict of interest

Members of the CAG (including guest attendees) must sign a '*Disclosure of interests and conflict of interests form*' (Appendix D).

A summary of conflicts of interest will be included in the meeting agenda at the start of each meeting.

Any potential new conflict that arises is to be declared at the earliest opportunity in line with the above policy.

4. Conduct of the Consumer Advisory Group

i. Quorum

A quorum for the CAG is defined as 50 per cent of members in attendance. A quorum relates to the consumer members only, and excludes the Chair, NACE representatives, researchers and guest attendees.

If the number of members present is less than a quorum, the Chair may adjourn the meeting and arrange a new date and time or elect to proceed for discussion purposes only. Any proposed decisions are to be circulated by email for consensus.

ii. Reporting

The CAG will report to the NACE Executive via the NACE Director. The NACE Management Office will have the responsibility of providing operational support to the CAG as appropriate.

iii. Evaluation

The CAG will undergo a satisfaction and evaluation process annually with its members and any guest attendees or key stakeholders. The results will be presented to the next scheduled CAG meeting and reported



to the NACE Executive via the NACE Director for their consideration. Any issues that need to be addressed will be overseen by the Chair with the support of the NACE Director.

5. Payment and support

The CAG members are entitled to sitting fees where appropriate and reimbursement for the performance of specific tasks, such as speaking engagements and documentation review. Reasonable travel and personal expenses that they may incur due to their involvement with CAG will be covered – refer to the *Remuneration for NACE consumer members* document (Appendix E).

The consumer sitting fees and hourly rate is provided in the following document: *Cost model for consumer sitting fees and hourly rate* (Appendix E).

6. Administration of the NACE Consumer Engagement Register

Consumers expressing interest in joining the NACE Consumer Engagement Register will be required to submit an online EOI Form. The NACE Management Office will review the EOI submissions and contact the consumers by phone to discuss the role. A phone script will be used that will include some standard questions to assist in identifying the types of activities and engagement that may best suit the consumer. If after a screening phone call, their involvement is agreed to be appropriate they will be listed on the Consumer Engagement Register.

Members will be approached and invited to participate in special projects and will be given sufficient notice and information about their involvement and the level of commitment. They will need to sign a '*Confidentiality Agreement*' and '*Disclosure of interests and conflict of interests*' form when first actively involved in a project. These documents will remain on file and apply to all future project participation, with the question of any change to their conflict of interests status raised prior to any new project involvement.

Members will be reimbursed for their time and any associated expenses – refer to the *NACE Cost model for consumer sitting fees and hourly rate* and *Remuneration for NACE consumer members* documents (Appendix E).

Registration on the NACE Consumer Engagement Register will be ongoing with members able to request removal at any time.

7. Review and approval of the Terms of Reference

The Terms of Reference must be approved by the NACE Executive.

The Terms of Reference will be reviewed every two years.

Version	Changes	Date approved	Next review date
1.0	Original version	17 May 2023	17 May 2025



Appendix A

Expression of Interest NACE Consumer Advisory Group (CAG)

Personal details		
Full name:		Preferred name:
Phone number:		Mobile:
Email:		Preferred contact method:
Street address:		
Suburb:	State:	Postcode:
Postal address (if different from above):		
Gender: <input type="checkbox"/> Female <input type="checkbox"/> Male <input type="checkbox"/> Non-binary <input type="checkbox"/> Prefer not to state <input type="checkbox"/> Other _____		
Age range:		
<input type="checkbox"/> 13-18 years <input type="checkbox"/> 19-24 years <input type="checkbox"/> 25-30 years <input type="checkbox"/> 31-40 years <input type="checkbox"/> 41-50 years <input type="checkbox"/> 51-60 years <input type="checkbox"/> 60+ years		
Do you identify as a member of the following groups?		
<input type="checkbox"/> Aboriginal or <input type="checkbox"/> Torres Strait Islander <input type="checkbox"/> LGBTIQ+: Lesbian, gay, bisexual, transgender, intersex, questioning or other diverse sexuality/gender		
Country of birth: <input type="checkbox"/> Australia <input type="checkbox"/> Other, please state: _____		
Do you speak and read English? <input type="checkbox"/> Yes <input type="checkbox"/> No		
Do you speak a language other than English at home? If yes, please state: _____		
Do you have any other needs or requirements that would need to be supported for you to fully participate in CAG?		
<input type="checkbox"/> Interpreter <input type="checkbox"/> TTY <input type="checkbox"/> Visual aids <input type="checkbox"/> Printing of documents <input type="checkbox"/> Other: _____		
Would you be able to participate in online meetings using MS Teams? <input type="checkbox"/> Yes <input type="checkbox"/> No		
Would you be able to travel if a meeting or event was scheduled outside your home state? Your expenses would be covered and this would be a rare event. <input type="checkbox"/> Yes <input type="checkbox"/> No		
Relationship with allergic disease		
Please indicate which group category reflects your experience with allergic disease:		
<input type="checkbox"/> Living with allergies <input type="checkbox"/> Parent/carer of person with allergy <input type="checkbox"/> Health professional <input type="checkbox"/> Researcher <input type="checkbox"/> Government <input type="checkbox"/> Other _____		
Meeting the requirements of the CAG member role		
<p>Please review the NACE Consumer Advisory Group (CAG) membership position description. It details the expectations, responsibilities and level of commitment required of the role.</p> <p>If you are interested in the role, please write a formal submission (one page) outlining your interest and suitability for joining the CAG.</p>		



You may wish to include some of the following in your submission:

- Why does joining the NACE CAG interest you?
- What is your personal experience with allergic disease?
- What knowledge, skills and experience would you bring to the CAG?
- What examples of your involvement in teams and collaboration can you share?
- How would you represent the diverse range of concerns, needs and perspectives of other consumers?
- Outline any other consumer/family/carer groups/networks that you are involved with – now or previously
- Outline any working groups or committees that you are involved with – now or previously
- Detail any other information you think relevant to this role, including any qualifications you hold and previous or current work roles (paid or volunteer)

The information provided in your EOI and written submission will be securely stored and overseen by the NACE Management team only. Unsuccessful applications will be securely destroyed.

Email or mail the application to:

E: nace@mcri.edu.au

**✉ NACE Management Office, Murdoch Children's Research Institute
The Royal Children's Hospital
Level 5/50 Flemington Road, Parkville VIC 3052**

If you are not appointed to the CAG, do you consent to your details being added to the NACE Consumer Engagement Register?

☐ Yes

☐ No – please securely destroy my information

If yes, we may contact you in the future about participation in special projects, surveys or information reviews.

If yes, you can agree or decline to participate in activities at any time and your details can be removed from the Register at your request.

Thank you

We recognise the important role of consumer involvement in providing different lived experiences and perspectives that will help shape the way the NACE oversees research activities and projects related to allergy.

Thank you for taking the time to consider joining our NACE Consumer Advisory Group.



Appendix B

Membership position description

NACE Consumer Advisory Group (CAG)

Position:	Member, NACE Consumer Advisory Group
Position type:	Consumer representative
Reports to:	Direct - CAG Chair and NACE Director Indirect - NACE Executive and Management Office
Tenure:	Two years from appointment (renewable for a further two-year term)
Key relationships:	CAG members NACE Director NACE Management Office

1. Role of the CAG

The National Allergy Centre of Excellence (NACE) recognises that meaningful consumer involvement provides the opportunity for different lived experiences and perspectives to shape and inform decisions on research activities and projects related to allergy.

The NACE Consumer Advisory Group (CAG) will ensure consumer opinion across the full research and project cycle; including involvement in the setting of priorities, design, implementation, evaluation and reporting; and advocacy.

The Group will hold national representation and will be an active partnership between researchers, health professionals (ie. clinicians, nurses, co-ordinators and allied health) and those affected by or who may benefit from research into allergic disease.

The NACE will work towards having a CAG membership that will consist of individuals from a broad age range (18 and over) and with varied lived experience and knowledge in allergy and research. Where appropriate, the NACE will establish further connections with the youth sector through the National Allergy Council's Allergy 250K Project.

2. Role of the CAG member

The Group will be a formal body of members with varied experience and knowledge, who are considered capable of providing consumer oversight and opinion on research and program activities related to allergic disease.

The responsibilities of the members are:

- To actively participate in CAG meetings, provide independent opinions and advice and contribute to decision making. This includes bringing issues of importance to the attention of the Group for wider discussion. Involvement may include the following:
 - Offering opinion on research and project priorities and the defining of research questions,
 - Providing advice on project and program design, planning and implementation,
 - Identifying outcomes of interest,
 - Improving the content and readability of participation information,
 - Offering viewpoints to ensure a balanced assessment of research related findings,
 - Providing advice on how to make trials more attractive to participants, and



- Advocating the role of CAG and the work of the NACE to promote better public awareness and understanding of our research projects and activities.
- To willingly participate in any recommended training, seminars or development activities that will increase knowledge and understanding in the conduct of research. Ongoing education is key to supporting full and active participation in this role.
- To act in the best interests of the NACE and the health care consumers they are appointed to represent; and to perform their roles in good faith, honestly and impartially. To think broadly and be conscious of considering a diversity of consumer needs and interests that might differ or extend beyond their own.
- To respect and maintain confidentiality when reviewing documentation and on the matters discussed within the CAG.
- To make every reasonable effort to attend scheduled meetings and to have reviewed the relevant documentation or materials for discussion.
- To make timely responses to correspondence and requests for opinion, to avoid delays in the progression of priority matters for action.
- To declare any existing or new potential conflicts of interest as soon it arises, including any involvement with companies or political parties.
- To not use any NACE contacts for the benefit of their own personal or organisational gain without prior disclosure or discussion with the Chair.

3. Term of appointment

Members of the CAG will be appointed for a two-year term.

Members may be re-appointed at the end of their tenure for one extra two-year term. After two terms, the member is no longer eligible for re-appointment.

A six-month review period will be in place for each appointment. At six-months post-appointment, the CAG member will meet with the Chair to discuss the role, their experience and any supports required.

4. Meetings

The CAG meetings will be held by teleconference (using MS Teams) every three months or four times a year. There may be occasions where members will be invited to attend in person, but this will be atypical and associated expenses would be covered – refer to the *Remuneration for NACE consumer members* document.

The Chair may elect to schedule additional meetings or alter meeting dates and their frequency to address any matters that may arise and need discussion.

Members are expected to make every reasonable effort to attend these scheduled meetings and to be prepared having read circulated documents. It is expected that members will be active contributors to the items listed for discussion.

5. Confidentiality

Members must respect and uphold the confidentiality requested of them by the NACE Executive, and the researchers involved.

New members must sign a written confidentiality agreement on their appointment. A new agreement must be entered into if a member is appointed for another two-year term.



6. Conflict of interest

Members of the Group will need to sign the '*Disclosure of interests and conflict of interests form*'.

Any potential new conflict that arises must be declared at the earliest opportunity.

A summary of conflicts of interest will be included in the agenda at the start of each CAG meeting.

7. Reporting

The CAG will report to the NACE Executive via the NACE Director. The NACE Management Offices will share the responsibility for providing operational support to the CAG as appropriate.

If a member needs to discuss a matter outside of the formal CAG meeting, they can consult with the Chair or members of the NACE Management Office.

8. Remuneration

Members of the Group will be entitled to sitting fees where appropriate and reimbursement for the performance of specific tasks such as speaking engagements and research/education documentation reviews. Reasonable travel and personal expenses that may be incurred due to their involvement on the CAG will be covered – refer to the *Remuneration for NACE consumer members* document.

The consumer sitting fees and hourly rate is provided in the following document: *NACE Cost model for consumer sitting fees and hourly rate*.

9. Acknowledgement

The involvement of the Group will be acknowledged where they have been consulted to offer opinions and advice. This acknowledgement may include papers, reports, media activity or as part of presentations.

I confirm that I have read and understand my role and responsibilities as an appointed member of the NACE Consumer Advisory Group.

Signature NACE CAG Member

NACE Director

Print name

Print name

Date _____

Date _____



Appendix C

Confidentiality agreement

Consumer Advisory Group and/or Consumer Engagement Register Members

As a member of the National Allergy Centre of Excellence (NACE) Consumer Advisory Group (CAG) and/or the NACE Consumer Engagement Register, I recognise that I will hear, see and have access to confidential information. This may include the personal information of researchers, patients and carers, the details of clinical research and trials, public health programs, finances and other information that is not for public disclosure.

In line with the Australian Privacy Act (1988), I understand that I must not discuss, share, copy, sell, alter or destroy any information related to activities performed with the NACE CAG or as a member of the NACE Consumer Engagement Register, unless the Director of the NACE confirms that it is acceptable and lawful to do so.

I understand that my obligations under this agreement apply when I am on the NACE CAG and/or a member of the NACE Consumer Engagement Register and are still in effect when I am no longer serving on either.

Declaration:

As part of my position on the NACE CAG and/or the NACE Consumer Engagement Register, I agree to the following:

- I **will not** discuss confidential information circulated or discussed at the CAG or at any NACE consumer related activity with anyone outside of this group, including family, friends and colleagues.
- I **will not** misuse or be careless with confidential information. I understand that all electronic (i.e. emails and document attachments) and paper-based documents containing confidential information must be securely managed to ensure that unauthorised persons do not see or gain access to them. I recognise this extends to the responsible and secure handling of my electronic devices on which I may access CAG or other documents related to my consumer role.
- I **will** comply with the Murdoch Children's Research Institute Privacy Policy and Data Breach Policy in relation to the handling of personal information and/or data in my role on the NACE CAG and/or as a member of the Consumer Engagement Register.

Signature
NACE CAG/ Consumer Engagement Register Member

Signature
NACE Director

Print name

Print name

Date _____

Date _____

The NACE confirm the personal information you have supplied as part of your appointment to the NACE CAG and/or as a member of the NACE Consumer Engagement Register will be kept secure and confidential.



Appendix D

Disclosure of interests and conflict of interests form

Disclosure of Interests & Conflict of Interests Form

Name:

Email address:

Role in NACE:

Date of submission:

Having a conflict of interest does not, in itself, imply improper motivation or individual wrongdoing. However, it is important that any conflict of interest is properly identified and managed. This form takes you through a process of Disclosing, Identifying and Managing your Conflicts of Interest.

For more information on Conflicts of interest please see the below table excerpt from the [NHMRC guide](#), or this short (3 min) [video](#) that takes you through the basics of disclosures and conflicts of interests and how to manage them. For any assistance, please contact Research Integrity: integrity@mcri.edu.au

Please submit this form to nace@mcri.edu.au

1. DISCLOSE RELEVANT INTERESTS

Please disclose all relevant interests that you have. Please note, relevant interests are not only financial in nature. Please review these examples of relevant interests [here](#). If you are unsure of whether a matter constitutes a relevant interest, please consider disclosing or contact Research Integrity: integrity@mcri.edu.au.

Relevant Employment (current or previous):

Relevant grants or funding (ie. NHMRC, philanthropic foundations):

Relevant Board Memberships (paid and unpaid) (current or previous):

Relevant fees paid for services (consultancy, expert testimony, speaking fees, panel payments):

Relevant indirect payments (funding of travel, accommodation, professional development):

Relevant patent applications, planned or pending, including for which you are a named inventor:

Relevant stock ownership or options:

Relevant royalties (current or future):

Any other relevant interests:

Personal relationships with those with the above interests:



2. MANAGE CONFLICT OF INTEREST

For each relevant interest above, think about whether they constitute a conflict of interest and outline how you intend to manage these conflicts of interests. For examples on how to manage conflicts of interest please see [here](#).

Relevant interests:

Management plan:

3. DISCLOSURE STATEMENT [OPTIONAL]

You may wish to draft a disclosure statement that you can add to publications or presentations to help you disclose your conflicts of interest.

For examples on disclosure statements please see [here](#).

4. SIGN OFF

By submitting this form, I agree to:

- *update this disclosure periodically throughout the period of my engagement with the NACE/or when new relevant interests arise to ensure they are up to date.*
- *co-operate in the formulation of a "conflict of interest management plan" as required.*
- *comply with any conditions or restrictions imposed by MCRI to manage, mitigate or eliminate any actual, potential or perceived conflict of interest and/or commitment.*

5. REVIEW BY MCRI RESEARCH, QUALITY, GOVERNANCE & INTEGRITY LEAD

I have reviewed the disclosure (and plan where applicable) on _____ and:

- ☐ *I believe that the plan outlined in form will mitigate or remove the conflict of interest but will continue to monitor the situation.*
- ☐ *The conflict of interest cannot be adequately managed with the individual concerned and recommend to the NACE Director that they consider additional management support or terminating their involvement in the NACE Leadership Group or Stream Advisory Group.*



Examples:

RELEVANT INTERESTS

These are examples of potentially relevant interests. Please note these relevant interests may not constitute a conflict of interest but it's useful to write down all relevant interests so you can identify whether these create a conflict down the track. These are indicative hypothetical examples and are not an exhaustive list but it might be useful to think about your own interests as you work down this list to help you identify your own relevant disclosures.

1. Competitive research funding (please note if you receive NIH/PHS funding specific requirements apply- please contact the grants office)
2. Consultancy work you undertake in your personal capacity either through other organisations or your own consultancy firm that relates to your work at the NACE
3. Directly providing scientific, marketing, and other consulting services to companies that relate to your work at the NACE
4. Paid and unpaid membership of boards or advisory committees that relate to your work at the NACE
5. Current or pending patent applications for which you are named an inventor or may benefit from
6. Paid speaking engagements that relate to your work at the NACE
7. Personal relationships that could relate to your work at the NACE e.g
 - Spouse runs IT consultancy business that MCRI receives a tender from.
 - Best friend is Director of a spin off device company that your project/supervisor /colleague is trialing.
 - You are asked to peer review or provide advice on a project that is being run by a Principal Investigator (PI) you have a long-standing dispute with.
8. Direct payment to you by a sponsor or funder of research
9. Shareholdings that could relate to your work at the NACE (for example, if you or your family member owns shares in a company that is supporting your research)

DEFINITIONS OF CONFLICTS OF INTERESTS

Under [the Code](#), a conflict of interest exists in a situation where an independent observer might reasonably conclude that the professional actions of a person are or may be unduly influenced by other interests. ²

Financial Conflicts of interests are the most common and easiest to identify - such as financial relationships, including direct employment, stock ownership, access to grant funding, speaking fees, stipends, etc. This type of conflict includes the financial benefits of an individual that can help him/her in the future. ³

MANAGEMENT STRATEGIES FOR CONFLICTS OF INTEREST

“Having a conflict of interest is not in itself unethical, and some are unavoidable. Full transparency is always the best course of action, and, if in doubt, disclose.” US Office for Research Integrity

Please note that simply disclosing the Col or having a contract in place may not be enough to manage a Col.

Examples of how to manage conflicts of interest are below. Please note these are indicative hypothetical examples and is not an exhaustive list:



Example of Conflict of Interest	Type of Conflict of Interest identified	Management Plan (potential options only)
<p>Fauxsponsor are sponsoring a trial that I am PI on and wrote the protocol for. I am also doing some paid consultancy work as a scientific advisor and unpaid speaking tours for the company.</p>	<p>Financial conflict of interest as you are paid directly by the company that is also funding your research.</p> <p>Perceived conflict of interest as you are providing scientific advice and doing unpaid speaking tours for a company that has now funded your research.</p> <p>Real conflict of interest- you are undertaking research that is funded by a company you have a pre-existing financial and working relationship with. This could impact the trials conduct and outcomes.</p>	<p>Disclosure of the Col to all participants and review bodies and in all publications and presentations.</p> <p>Work with MCRI Legal and Grants to put in place agreements and funding arrangements that ensure you do not <u>directly</u> benefit from the research funding e.g. the funds go into a group cost centre to cover research costs rather than to you personally.</p> <p>Take steps to minimise any unintentional bias that may have arisen due to this Col.</p> <ul style="list-style-type: none"> - Ensure you are blinded to randomisation and data analysis if feasible - Request independent peer review of the protocol be undertaken specifically to examine whether the study design has merit and integrity and is unbiased - Ensure full disclosure of the Col at every stage of the research - If it is not feasible to remove your potential influence, consider recusing yourself as PI or terminating the paid appointment with the sponsor
<p>Spouse runs IT consultancy that MCRI receives a tender from and you are on the committee discussing and ultimately approving the tenders.</p>	<p>Financial conflict of interest -as your family may benefit from the tender being successful.</p>	<ul style="list-style-type: none"> • Disclosure the Col to the committee chair/ and remind them at committee meetings when relevant. • Recuse yourself from the discussions and abstain from voting when your spouses' company is being discussed. • Consider delegating your position on the committee to



		someone else in your team entirely.
You sit on a board or government advisory committee that is making decisions that might benefit the MCRI's future endeavours.	Perceived Col- as your advice may be impacted by your paid employment at MCRI.	<ul style="list-style-type: none"> • Disclose the Col to both parties and ask the chair of the advisory committee whether any additional steps are required to manage your Col.
You are asked to peer review or provide advice on a project that is being run by a PI you have a long-standing dispute with.	Personal Conflict of interest as your dispute may bias your advice or peer review. Note that conflicts don't always have to be beneficial.	<ul style="list-style-type: none"> • Disclose and recuse yourself.

EXAMPLE DISCLOSURE STATEMENTS

John Trials declares that he has no conflict of interest.

Adam Researcher has received research grants from Drug Company A, NHMRC and the Gates Foundation.

Ibrahim Projects has received a speaker honorarium from Drug Company B and owns stock in Drug Company C.

Dr. Carolyn Doe receives research funding from XYZ, Inc., which is developing products related to the research described in this paper. In addition, Carolyn serves as a consultant/advisor to XYZ, Inc., and receives compensation for these services.

References

1. <https://ori.hhs.gov>
2. [NHMRC Disclosure of interests and management of conflicts of interest](#)
3. <https://ascholarship.com/conflict-of-interest-statement-definition-types-and-understanding/>



Appendix E

NACE Cost model for consumer sitting fees and hourly rate

This Cost model applies to members of the NACE Consumer Advisory Group and those from the Consumer Engagement Register participating in consumer related activities.

Engagement type	Remuneration type	Engagement description	Chair fee	Member fee	Activity fee
Consumer (led)	Sitting fee*	<ul style="list-style-type: none"> Consumer engagement in governance, strategy, policy and evaluation. Advocacy, leadership, evaluation and continuous improvement of consumer engagement practice. Provision of strategic advice on consumer engagement and consumer-led education and research priorities/initiatives. 	\$276 ≥ 4hrs \$138 <4hrs	\$238 ≥ 4hrs \$119 <4hrs	
Partnership	Sitting fee*	<ul style="list-style-type: none"> Represent the consumer perspective on Steering Committees, Working Groups and Interview Panels. Program and project involvement – liaison, advisor, team member, project governance. 	\$238 ≥ 4hrs \$119 <4hrs	\$206 ≥ 4hrs \$103 <4hrs	
Involving	Hourly rate	<ul style="list-style-type: none"> Speaking engagements/panel member at events. Reviewer roles in research, education, training and communications. 			\$50 p/hr
Consulting	Hourly rate	<ul style="list-style-type: none"> Participate in consultation activities such as focus groups, consultative workshops and interviews+ Storytelling to support communications, program development or delivery: interviews, writing, video-based. 			\$40 p/hr
Informing	N/A	<ul style="list-style-type: none"> Consumers who receive CAG communications and may participate as an audience member at events. 			\$0

The costings are based on the 2023 VCCC Alliance Cost Model. This resource is part of the VCCC Alliance Consumer Engagement Toolkit (v3. dated 09/03/2023).

*Sitting fees have been segmented into 4-hour blocks, with maximum payment capped at the full day rate.

+No hourly rate remuneration for participation in surveys.



Remuneration for NACE consumer members

The remuneration outline below applies to members of the NACE Consumer Advisory Group (CAG) and those from the Consumer Engagement Register participating in consumer related activities.

A. Sitting and Hourly Rate Fees

NACE CAG members and those from the Consumer Engagement Register involved in consumer related activities will be paid at an hourly rate. This payment will incorporate preparation time for the meetings or activity (where it is specifically requested).

A minimum of 2 hours sitting fee will be paid to the CAG members in the rare occurrence that a meeting may not be two hours in length.

Refer to the *NACE Cost model for consumer sitting fees and hourly rate* for further detail.

B. Remuneration for Expenses – Travel and Personal

Reasonable travel and personal expenses that may be incurred by members due to their involvement on the CAG or in a consumer engagement related activity will be covered. These include:

i. Travel

Travel arrangements will be negotiated with each member individually. The type of travel arranged will be influenced by the availability of transport in the member's normal place of residence and the distance to travel.

ii. Petrol

Where there is an alternative and more cost-effective form of transport (eg. plane), and the individual elects to drive, the reimbursement will be paid up to the value of a return economy airfare.

iii. Accommodation

The NACE Management Office will book accommodation where needed and it will be of a comfortable and reasonable standard. Accommodation will be booked where an overnight stay is required due to the inability to book transport at an appropriate time of day for arrival or departure.

iv. Meal Allowance

A Meal Allowance will be paid where an overnight absence is required for the member to fulfil their obligations.

The recommended pricing from the ATO (2022-23) is as follows:

- Breakfast: \$26.80;
- Lunch: \$30.60; and
- Dinner: \$52.75

v. Other Expenses

Members will be eligible to apply for other out of pocket expenses that occur from sitting on the CAG.

These include:

- Car parking
- Public transport
- Other items, by negotiation

Approval for 'other expenses' will need to be sought from the NACE Management Office.