**OPUS Consumer Engagement Program:**

**Consumer Information**

Thank you for partnering with OPUS as a consumer representative!

This information pack has been designed to ensure that the experience is productive, educational and enjoyable. Consumers come from all walks of life with experience and perspectives that our researchers and students will not have been exposed to. It is invaluable to bring these perspectives into research to gain better insight into what really matters to the community and we appreciate that you have joined us as a representative.

***Once you have read through this information pack and agree to be included in our program, please sign below and return this copy to us (either by post or electronically) as affirmation that you understand the conditions of this program.***

We look forward to partnering with you and hope you enjoy the program!

***I consent to my contact details being placed on a consumer participation register for use by OPUS and the Department of Orthopaedics at St Vincent’s Hospital Melbourne.***

***By signing below, I agree to abide by the Code of Conduct as outlined in section 11 of this document.***

*Your details will not be used for any other purposes than the Consumer Engagement Program as outlined in this document, nor will it be released to any other organisation or third party.*

**OPUS Consumer Member**

Name: Name:

Signature: Signature:

Date: Date:

# **Introduction**

Consumers play an important role in medical research as they may have used or could potentially use the health services that we are looking to improve, or are caring for a patient who is using the health service. Participants bring a variety of qualities that boosts the integrity of research:

* Advocate the interests of consumers
* Present consumer views, values and concerns
* Provide balance to discussions
* Ensure the Centre considers consumer consultation wherever appropriate throughout research development

And the benefits of consumer consultation is numerous:

* Robust decisions
* Smooth implementation
* Boost consumer confidence
* Community awareness and education

# **Contributing to OPUS research**

When you completed your Expression of Interest form, you will have indicated what level of engagement you prefer and your time commitment. This informs us what kind of contribution would be suitable for you. Your Letter of Participation will confirm the Tier that you have nominated and our records will reflect this. Should you wish to change your Tier level or opt out, we highly encourage you to inform us at your earliest convenience to ensure the records are up to date.

* **Tier 1: Consumer subscriber**

This beginning level introduces participants to the nuances of research and the research conducted at OPUS. Participants will occasionally receive surveys to complete but are not required to provide feedback on documents and attend research meetings. Most communication will be completed via email and postal mail depending on participant preferences.

* **Tier 2: Document reviewer**

Often there will be times when documents of all kinds will require ‘fresh eyes’ to ensure they are appropriate for the audience intended. This can include proofing for surveys, pamphlets, information factsheets and consent forms sent to study participants, highlighting jargon and ensuring information is easily digestible. There will be little need for face-to-face meetings as most communication will be via email, postal mail or telephone.

* **Tier 3: Research buddy**

For those who wish to contribute further, a research buddy provides direct feedback on larger activities such as grant applications. Research buddies will be asked to meet with partnered researchers and students to gain a thorough understanding of projects, may be asked to sit on team meetings, review grants and work alongside researchers. This is a more time intensive, but effective way to immerse participants in research and understand how the research landscape works. Depending on participant preferences, meetings can be arranged via teleconference, video conference or direct face-to-face meetings.

* **Tier 4: Consumer Representative**

At the highest level, select consumers may wish to participate on a more strategic level by providing advice on the various OPUS programs. Those at this Tier will attend meetings in pairs and work alongside committee members, particularly in disseminating information to the community. These participants should feel confident in speaking out during meetings with health experts to provide a community perspective on research programs as well as constructive feedback. Participants in this Tier must be able to attend meetings quarterly, preferably face-to-face or via video conferencing if travel is an issue.

We will work with you to ensure that you are equipped with the information you require to provide feedback and advice on the issues that we present you with. Our training, governance and guideline documents can be found at: [www.opus-tjr.org.au/consumers/](http://www.opus-tjr.org.au/consumers/) for you to reference at any time. We are also happy to get in touch to answer your queries at: opus@opus-tjr.org.au or (03) 9231 2578.

# **Partnering with our Researchers**

There are always projects running at OPUS and we will endeavour to update our website with the latest projects to ensure you are aware of them. Should you wish to change or add your interest in another project, please contact us so we can match you to the right project for you.

Depending on the Tier, researchers can contact consumers for their opinion about small or big challenges such as:

* a participant survey that a consumer (or two!) can check over
* proofing an article for the media
* a grant application - a straightforward philanthropic grant could be proofed for comprehensibility and errors
* a one-hour meeting to explain to the consumer what your team is working on (this is great practice for students in laymen’s english)
* a review on a presentation

This requires commitment and communication to ensure that our consumers are regularly involved in the research (we propose that all partnered researchers engage quarterly at the minimum) and aren’t left hanging in the dark for months on end.

# **Expectations**

### **What are you expected to do?**

As a consumer, your role is to raise views and concerns that Committees and researchers should take into consideration in their decision-making process. Depending on the selected level of engagement, representatives are expected to:

* **Tier 1: Consumer subscriber**

Respond back to surveys and questionnaires wherever required and as relevant to you (these will take minimal effort and time), browse through our research updates and newsletters.

* **Tier 2: Document reviewer**

In addition to Tier 1 expectations, Tier 2 requests participants to review and provide feedback for documentation that can vary in complexity (we will provide guides to take consumers through the process).

* **Tier 3: Research buddy**

Research buddies are expected to attend some in person meetings with researchers and commit some personal time to read and prepare for these meetings. Consumers will be asked to provide feedback and advice on the development of research projects, directions and grants. The consumer must be confident in their opinions, but respectful of the research process.

* **Tier 4: Consumer Representative**

Consumer members at this level are expected to participate in quarterly Committee meetings either in person or via video conferencing. Membership on committees involve analysing issues, advising on the effect on consumers and ensuring that a broad consumer experience is reflected. It is essential that consumer representatives understand how to provide constructive feedback and are not afraid to ask for clarification during these meetings. OPUS acknowledges that the personal lived experiences of consumer representatives, particularly those sitting on Committees, are invaluable insights but we ask that consumers remain mindful that personal experiences should be used when appropriate and valid to aid the delivery of constructive feedback.

Occasionally, we will also invite our consumer cohort to special events such as our Consumer meet and greet morning teas, OPUS Forum (next upcoming event in 2021) where we will design sessions that specifically enables consumers to engage the scientific community and Student Research Showcases.

### **What is OPUS expected to do for you?**

For a safe and effective consumer engagement program, our role at OPUS is to ensure that all consumer participants are:

* **Tier 1:** Receiving relevant project updates and research newsletters/surveys, able to freely voice issues, comments and feedback as appropriate and ask for clarification and explanations at any time.
* **Tier 2:** Provided all information needed to conduct tasks, able to freely voice issues, comments and feedback as appropriate and ask for clarification and explanations at any time.
* **Tier 3:** Provided all information needed to prepare before meetings, able to ask for clarification and explanation at any time, able to freely voice issues, comments and feedback as appropriate.
* **Tier 4:** An equal member of the committee, heard and understood, able to ask for clarification and explanations, provided all the information needed to prepare before meetings, able to freely voice issues, comments and feedback as appropriate.

Our job is to facilitate the partnership between researchers and consumers in a safe and constructive environment, ensuring appropriate information is shared and received and creating as many opportunities for both parties to benefit.

We will provide guidance to consumers at each Tier in their role as partners. We will develop guides and info sheets on how to provide constructive feedback, what kind of feedback researchers are looking for and how your advice contributes to the research project. We encourage all participants to get in touch with us (opus@opus-tjr.org.au) if there are any queries, concerns or comments.

# **Your entitlements for contributing to OPUS**

As appreciation for your work, your contribution and time will be remunerated according to the activities requested.

All travel for face-to-face meetings with OPUS researchers will be reimbursed.

* **Tier 1:** In line with the expected time commitment at this level, Tier 1 consumers will be volunteers and therefore, do not receive compensation.
* **Tier 2:** Consumers will be compensated for the time taken to review documentation and provide feedback as we acknowledge that this is extra time invested in our research. Depending on the complexity of the documentation, reviewers will receive gift cards of varying denominations for each of their contribution.
* **Tier 3:** Face-to-face meetings with researchers and students will be remunerated on set hourly allocations and all travel expenses will be reimbursed (this includes public transport tickets, parking and distance driven at 67c/km).
* **Tier 4:** Consumers participating in committee work will be compensated for the time taken to prepare for and sit-in on meetings as well as for travel expenses will be reimbursed (this includes public transport tickets, parking and distance driven at 67¢/km).

# **Remuneration and Sitting fees**

All remuneration and sitting fees will be paid in the form of gift cards to allow easy transfer of funds.

*It is the responsibility of Committee secretaries and Group Leaders to lodge any remuneration or reimbursement on your behalf. Speak to your research contact to arrange for reimbursement.*

## **Document revision**

Compensation for participating in document revision will be set at **$20 per hour** spent reviewing documents. The researchers will estimate what the reasonable completion time would be for each case.

*For example: a consumer receives an infographic and two surveys to review which the researcher estimates will take two hours to review, the compensation will total $40.*

The documents requested will generally not require extensive background information and preparation, but researchers should provide some information to guide the feedback process. Reference guidelines will be made available on the OPUS website to guide reviewers on how to provide constructive feedback and what parts to look out for.

## **Sitting fees**

Committee and working group face-to-face meetings (found in Tiers 3 and 4) will be lodged by the Committee Chair or Group Leader to ensure accurate hours are recorded. Meeting durations will be rounded up to the nearest hour. In the case that remuneration has not been received, please follow up with the Chair or Group Leader in the first instance.

The sitting fee will be **$25 per hour** for contact meetings: this includes face-to-face, telephone or video conference participation. Hourly rate will apply to the allocated meeting time regardless if the meeting runs over or under time.

There are limitations to the level of remuneration afforded to consumer and this includes:

* Attendance to functions/events (eg. Meet and Greet morning tea, Forums and training workshops) although travel expenses will be reimbursed using the same guidelines outlined below
* Loss of income reimbursement
* Air fare costs
* Accommodation costs
* Child care reimbursement
* Respite care reimbursement

## **Reimbursement**

All travel expenses to OPUS campuses and research sites will be reimbursed in the form of gift cards or will be arranged by OPUS via Uber vouchers where appropriate. Travel expenses that may be claimed include public transport tickets, on-site parking and the distance driven at 67¢/km if using the consumers’ private (non-corporate) vehicle. A snapshot of the ticket expense/receipt incurred or a photocopy is acceptable evidence to be submitted to the Committee Chair or Group Leader.

## **Procedure for Claims**

* Please submit all receipts and evidence to the Committee secretary or Group Leader of the research team along with a completed Consumers Claim form found in the Document Repository section of the OPUS Consumers website ([www.opus-tjr.org.au/consumers](http://www.opus-tjr.org.au/consumers)).
* The Secretary or Group Leader will verify the information you have provided and approve of the claim and lodge the documentation to OPUS management (opus@opus-tjr.org.au).
* OPUS management will record the information and arrange for reimbursement directly to consumers.

# **OPUS Governance**

The Centre is governed by numerous committees that oversee various aspects of operation.

**Data Linkage Committee**

Big data drawn from organisations and research groups requires thoughtful planning to ensure information is handled and used appropriately. This committee informs OPUS of the latest progress in linking big data and how it is being used by research groups.

**Education & Training Committee**

The Centre is composed of established senior researchers as well as early career researchers and students who are just beginning their foray into research. To ensure that the new generation of researchers are exposed to wider networks, the best research training and appropriate research conduct, mentorship plays a role at all levels. The committee is dedicated to sharing knowledge and skills through various activities (ie. webinars and tutorials sessions) and support schemes (ie. scholarships and fellowships).

**Translation & Engagement Committee**

This committee is focused on developing programs that translate current knowledge gained from our research into educational tools that reach the community. A major project since inception has been the OPUS Forum, a conference that disseminates research findings, fosters collaboration and encourages dialogue between the scientific and broader community groups.

**Executive Committee**

Overseeing the strategic direction and prioritising areas of interest is the Executive Committee which comprises the heads of each research group, a PhD representative and postdoctoral representative. This committee reviews research progress every 3 months to identify challenges, potential gaps in knowledge and resolve issues. This is where selected Consumer Representatives (Tier 4) will be situated as they are well placed to raise broad issues that concern the community.

**Stakeholders Advisory Committee (SAC)**

This Committee is composed of industry representatives who have extensive experience working in osteoarthritis, from the consumer perspective to primary health and health insurance. These are stakeholders that can provide executive level views on the research project in conjunction to the Consumer experience. This group usually attends the face-to-face meeting with the Executive Committee to advise on key aspects of research progress.

**Consumers Advisory Group (CAG)**

A *Consumer Advisory Group* will be established consisting of administrative staff, researchers, students and consumer representatives, who will meet biannually. This group is designed to discuss research progress and activities within the Consumer Engagement program and provides an opportunity for all consumer participants to bring any issues or concerns to the attention of OPUS for resolution. If you have any issues that you wish to raise anonymously, please go to: [www.opus-tjr.org.au/consumers/contact-us](http://www.opus-tjr.org.au/consumers/contact-us) to submit your comments or speak to your CAG consumer representative.

# **Consumer networks**

Consumer participation at any level can be isolating and intimidating at first. As part of our responsibility and to ensure that you enjoy the program, we ask all consumer participants (without any obligation) to join a consumer networking group to share experiences, raise awareness and read more about issues that concern you. OPUS consumers will be able to keep in touch and communicate with OPUS researchers through a *Consumer Advisory Group*, which will be established shortly after recruitment. We encourage consumers to think about participating in external networks:

* Consumer Connect run by the Health Issues Centre (<https://www.healthissuescentre.org.au/consumers/getting-involved-in-health-care/consumer-connect/>)
* Subscribing to MSK Australia and get in touch with Consumer Services to learn more about joining a consumer group

(<https://www.cotavic.org.au/news/cota-connects/>)

* Subscribing to the Consumers Health Forum of Australia

(<https://chf.org.au/our-members/become-a-member>)

Please be mindful that confidentiality be exercised as appropriate in relation to sensitive research information when discussing research issues with fellow consumers.

# **Meeting Locations**

Often meetings will be conducted at St Vincent’s Hospital Melbourne in Fitzroy, VIC 3065. This is where we are headquartered, but we do have researchers based all over Melbourne (as well as interstate in SA, QLD, WA and internationally). Should you be unable to travel to our meetings, we can arrange for tele- or video- conferencing.

We are based at:

Department of Surgery | The University of Melbourne

Level 2, Clinical Sciences Building

29 Regent Street

Fitzroy, VIC 3065

There will be times where activities and events are held in other locations around Melbourne but advanced notice, contact details and location directions will be provided. All locations will be accessible for all access needs.

# **Evaluation**

Regular evaluation every 6 months will be conducted with input from yourself and our researchers to identify what activities are working and which aren’t. This program is ongoing and we are committed to an effective program that is educational for all partners.

We invite informal feedback at any time to ensure that the program continues to improve, but a formal evaluation can take various forms:

* Group discussions
* Informal feedback
* Face-to-face and telephone interviews
* Self-completed questionnaires
* Website submissions

# **Code of Conduct**

## **Behaviour**

OPUS expects all participants to behave honestly with integrity and act with due care and diligence by considering the following items in this section.

## **Conflict of Interest**

We respectfully request consumers to declare when a potential conflict of interest may arise as soon as possible to avoid compromising on the standard of research conducted at the Centre. This includes standing aside when conflict of interest exists or may be perceived as well as informing us when conflict of interest of others may arise.

## **Confidentiality**

As part of your participation in certain projects, you may come into contact with information that must be kept confidential. Any breach of confidentiality may result in termination and cessation of your consumer position. A breach includes:

* The result of inappropriate discussion,
* Access to,
* Disclosure of any matter relating to the business of the OPUS Executive Committee or any working group,
* Or sharing information by others in good faith.

When dealing with confidential information, by signing the first page of this document, you agree to abide by the Code of Conduct as outlined by the Consumers Health Forum of Australia.

By signing the first page of this pack, OPUS will not pass on the participants’ information to any third party and will not be used for purposes other than communicating osteoarthritis research. Any audio or visual recordings made while participating in the Engagement Program will require express permission prior to publication.

## **Anti Discrimination**

All consumers must show respect to all participants equally without regard for age, race, gender, sexual orientation, disability or religious views to maintain a positive work environment for all. Any discrimination or harassment based on these, or any other basis, will not be tolerated and OPUS reserves the right to terminate the partnership of any participant who breaches this policy.

## **Use of Resources**

OPUS asks all consumers to consider the use of resources sensibly and in a proper manner to ensure that our research projects consume resources in an effective and sustainable approach.

## **Publications**

For projects that require extensive consumer engagement (ie. Tier 3), it is the responsibility of individual research groups to consider the management of consumer participants in regards to publications. Appropriate acknowledgement for significant contributions to projects must be discussed between the consumer and Research Group at the beginning of the partnership. Any consumer who would like further advice on authorship in publications and acknowledgements may do so confidentially via OPUS management (opus@opus-tjr.org.au).

## **Breaches of Code of Conduct**

Any breach to the Code Conduct is expected to be examined for disciplinary action. OPUS will follow up all complaints discretely and provide complainants with updates until a resolution has been found.

## **Termination or opting out of the program**

Both parties are capable of terminating the agreed arrangement. If the consumer breaches the Code of Conduct, OPUS retains the right to terminate the consumer from the program and they will be placed on a ‘no contact list’ to avoid further correspondence – note that their details will still be retained for record-keeping purposes but under no circumstances will they be passed to any third party.

If the consumer wishes to terminate their participation in the program, OPUS will again place the consumer on the ‘no contact list’. Notification of termination must be made in writing to OPUS and sent to opus@opus-tjr.org.au.