



## **Information for external research partners**

**2016**

## **About this information sheet**

Carers Victoria is often approached to provide input for, or be a partner of, research projects relating to carers. This may occur when the project is at planning, implementation or evaluation stages. This information sheet provides guidance on how external researchers or research institutes can work with Carers Victoria as part of their research projects.

Carers Victoria welcomes opportunities for collaboration and promotion of carer-related research. However, we carefully assess advantages, disadvantages, opportunities and risks of the project – to potential research participants who are carers, to Carers Victoria and the Carer Associations – before deciding on whether to support the project and the extent of involvement. Carers Victoria in particular wishes to support projects that explore new issues relating to carers and that add new information to the evidence base.

## **How can Carers Victoria assist with the research project?**

Carers Victoria could potentially assist with the following activities:

- reading research documentation and providing input
- modifying research project documentation (e.g. information sheet, consent form) so that it is appropriate to carers
- assisting with sourcing information and data
- promoting the research project via the Carers Victoria website, social media, mailing lists and publications (print and online)
- promoting the research project via internal networks such as the Victorian Carer Services Network (VCSN), Carer Network National Policy Working Group (NPWG), the State and Territory Carer Associations, and other affiliates
- distributing research project materials (e.g. flyers) to potential research participants
- providing feedback on the effectiveness of marketing or recruiting materials and/or helping to create them
- providing recommendations/contact details for other parties who could be involved.
- Carers Victoria staff could attend stakeholder meetings, committees, teleconferences or videoconferences to provide input
- Carers Victoria staff may agree to participate in individual interviews, focus groups, questionnaires, etc. on a voluntary basis
- Carers Victoria staff could act as co-investigators for the project and be involved with data collection and/or analysis, present at conferences and/or co-author publications, and
- suggesting certain types of training for researchers such as carer cultural awareness training.

### **What are the limits of Carers Victoria's involvement in research?**

It should not be expected that Carers Victoria will assist in the ways identified below:

- guarantee involvement of external parties (e.g. research participants and Carer Associations)
- supply carer contact lists for the purposes of the research. Carers Victoria maintains a data base of individual members and service users, and complies with all relevant privacy legislation. Costs associated with targeted communication to those carers who have agreed to be approached for research purposes will be charged to the researchers.
- guarantee more extensive involvement by staff members other than what is specified in the 'letter of support'/description of in-kind support
- provide services, programs and resources specifically to research participants – such as counselling or respite care. Carer services, programs and resources are restricted by funding body arrangements, potential waiting lists and service limits. As such, the researcher/s should provide a range of debriefing and cost reimbursement options to research participants or purchase these services out of the research budget
- Carers Victoria and the state and territory carer associations are not usually able to provide free of charge translation/interpreting services. It is recommended that researchers set funding aside for these services in order to be inclusive of culturally and linguistically diverse carers
- conduct aspects of the research (e.g. data collection and/or analysis) if the staff member and/or organisation is not listed as a co-investigator, and
- in all instances agree to provide the Carers Victoria logo and other branding for research project materials unless a prior agreement has been made.

### **Ethical considerations**

Carers Victoria is not in a position to provide ethical approval for a research project. We recommend that all research where information is sought from members of the public and this information is published should have approval from a Human Research Ethics

Committee. More than one ethics process and committee may be involved, for example an ethics application might need to be provided to a higher education institute (e.g. university), a government health service district, and/or an Aboriginal and/or Torres Strait Islander Council. The National Health and Medical Research Council are able to provide a list of organisations who offer ethics assessment services. Carers Victoria can, however, assist the researcher or

research institute to consider ethical and pragmatic issues relating to research with carers. Documents such as the National Statement on Ethical Conduct in Human Research 2007 and Guidelines for Ethical Research in Australian Indigenous Studies may provide guidance.

**Checklist for external researchers/institutes working with Carers Victoria**

<input type="checkbox"/>	<p>Carers Victoria is provided a copy of research project documentation such as the project proposal, research plan, grant application, information sheet, consent form, insurance details, provisions for ownership/use of data and intellectual property, etc. This is particularly important if Carers Victoria is explicitly listed in documentation or made mention of. Carers Victoria may request changes to documentation. A copy of documents reflecting changes requested by Carers Victoria are supplied in a timely fashion.</p>
<input type="checkbox"/>	<p>Carers Victoria has the opportunity to appraise the proposed research project against relevant standards and codes of practice and discuss any potential risks to the organisation and/or research participants.</p>
<input type="checkbox"/>	<p>Carers Victoria is contacted and asked to provide written confirmation (e.g. via e-mail or letter) of the in-kind support (e.g. staff time, attendance of meetings, review of documents, etc.) and/or financial contributions to be made towards the project – this could be outlined within a ‘letter of support’.</p>
<input type="checkbox"/>	<p>Carers Victoria is contacted and asked to provide written confirmation as to whether Carers Victoria will need additional resources or funding in order to assist with the research project.</p>
<input type="checkbox"/>	<p>Carers Victoria is contacted and asked whether Carers Victoria branding (e.g. logos) should accompany research project materials and/or whether Carers Victoria staff should be listed as investigators. If Carers Victoria staff are to be investigators there should be written confirmation of this including whether these staff are to be listed as a co-author or acknowledgement on any documentation.</p>
<input type="checkbox"/>	<p>Carers Victoria is provided a copy of ethics documentation which confirms that ethics committee approval has been granted for the research project.</p>
<input type="checkbox"/>	<p>Carers Victoria is provided with any amended research ethics documentation.</p>
<input type="checkbox"/>	<p>Carers Victoria is provided with research progress reports.</p>
<input type="checkbox"/>	<p>Carers Victoria has the opportunity to review draft copies of the research report to provide input or request changes.</p>
<input type="checkbox"/>	<p>Carers Victoria is provided with a copy of the final research project report.</p>