



CARERS VICTORIA RESEARCH AGENDA

2017–2020

Valuing Unpaid Care

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

carersvictoria.org.au



CONTENTS

ABOUT CARERS VICTORIA	3
FOREWORD	4
INTRODUCTION	5
THREE RESEARCH THEMES	6
RESEARCH THEME 1 - THE SOCIAL CONTRIBUTION OF CARE	9
RESEARCH THEME 2 - QUALITY OF LIFE FOR CARERS	11
RESEARCH THEME 3 - SUPPORTING CARER CAPABILITIES	13
CONCLUSION	15
REFERENCES	16

ABOUT CARERS VICTORIA

Carers Victoria is the state-wide peak organisation representing people who provide care. We represent more than 736,600 family carers across Victoria – people caring for someone with a disability, mental illness, chronic health issue or an age-related condition. People receiving care are parents, children, spouses/partners, grandparents, other relatives or friends.

Carers Victoria is a member of the National Network of Carers Associations, and the Victorian Carer Services Network. Carers Victoria is a non-profit association which relies on public and private sector support to fulfil its mission with and on behalf of carers.

Carers Victoria is a membership based organisation. Our members are primarily family and friend carers who play an important role in informing our work, contributing to advocacy and strategic aims and distributing information more widely to other carers.

Carers Victoria recognises that all individuals and care relationships are unique. We welcome people of diverse ages, abilities, ethnicities, cultures, sexualities and gender identities and work towards identifying and breaking down barriers to inclusion so that all people with care responsibilities, their values, beliefs and experiences are valued and respected.

Carers Victoria acknowledges the traditional owners of Victoria and pays its respects to elders past and present.

FOREWORD



Carers Victoria's vision is for an Australia that values and supports all carers.

As the peak not-for-profit agency representing over 736,600 unpaid Victorian family and friend carers, we firmly believe in research which informs and translates into carer services and supports, improving carers' quality of life and sustaining care relationships.

Over many years Carers Victoria has collaborated with universities and research institutes to support research that identifies successful interventions which address challenges faced by carers. Importantly, this research informs our policy and advocacy work and provides strategic guidance for our future work by developing new and innovative ways to respond to the needs of carers.

Carers Victoria has strong relationships and is currently working with a number of research institutions and universities. We are excited to be a founding member of the new Future Social Services Institute (FSSI) collaboration between the Victorian Government, VCOSS and RMIT University.

As a peak organisation we are keen to shape the future direction of research concerning carers, care relationships and lived experiences of caring.

This Research Agenda for 2017-2020 is based on proven experience in supporting carers in their daily lives and existing research outcomes.

Carers Victoria's Research Agenda outlines three broad research themes with the potential to significantly advance existing knowledge, inform the work of Carers Victoria, and ultimately make carers' lives better:

1. The social contribution of care
2. Quality of life for carers
3. Supporting carer capabilities.

Carers Victoria cannot do this work alone.

This Research Agenda is an invitation to the research community to contribute expertise and knowledge towards advancing the evidence base within these three research themes.

Carers Victoria recognises that research makes a real difference in the lives of carers, and research outcomes ensure our organisation delivers value to those we serve and support. We look forward to advancing our Research Agenda with you.

Annie Hayward
General Manager
Policy, Strategy and Public Affairs

INTRODUCTION

Carers Victoria is regularly approached by academic researchers to assist with the recruitment of carers to participate in research. These research projects often reflect researchers own professional and/or personal experience of caring as well as national research priorities.

Each application for carer participation is carefully evaluated to ensure the outcomes increase understanding of carer experiences, and/or promote best practice responses to the needs of people in care relationships.

Through our regular consultation with carers we understand the research which will inform carers to support and sustain their caring role. Carers tell us we need to build the capacity of caring communities as well as the capacity of individual carers.

This Research Agenda has been developed to offer some strategic direction to researchers interested in carers and care relationships and build opportunities for collaborative and co-designed research projects.

Carers Victoria's research themes are deliberately broad so they encompass the diversity of care relationships and social research approaches. Academic disciplines with an interest in carers and care relationships include health, sociology, psychology and economics.

The themes are also broad enough to be open to a range of qualitative and quantitative research methods, as well as reviews of relevant literature and evaluation of existing carer support programs.

Ultimately, the aim of this Research Agenda is to build and strengthen the evidence base to support Carers Victoria's vision for an Australia that values and supports all carers.

THREE RESEARCH THEMES

1. THE SOCIAL CONTRIBUTION OF CARE

This theme recognises interdependence in relationships between carers and people receiving care and includes research measuring the social capital produced through care relationships, as well as the social return on investment in supporting informal care.

2. QUALITY OF LIFE FOR CARERS

This theme includes research into effective interventions to improve carer wellbeing, in particular addressing loneliness and social isolation. This theme encompasses research into effective strategies to reach people who do not identify as carers or who have needs related to their membership of diverse population groups.

3. SUPPORTING CARER CAPABILITIES

This theme is focused on research into strategies to support carers having the freedom to achieve their own capabilities while caring for another person. The priority areas for this theme are: investigating the role of carers in individualised, consumer-directed care programs; assistive technology to promote independence; and innovative support for employed carers.

Carers Victoria believes these research themes will advance existing knowledge, inform the work of Carers Victoria and support the organisation's advocacy on behalf of all carers.



RESEARCH THEME 1

THE SOCIAL CONTRIBUTION OF CARE

BACKGROUND

A number of Australian and international studies^{1,2,3,4} have estimated the economic contribution of informal care. These studies predominantly estimate market wages required to be paid to replace informal care. Other studies measure 'productivity losses' and 'opportunity costs'⁵ borne by carers who are not in paid work due to their carer role. These studies often make the supposition that informal care is substitutable by formal care, highlighting contradictions in the way carers are viewed⁶ and whether formal and informal care is qualitatively different.

Governments typically limit provision of formal care; not only due to cost but because of concern that access to formal care may diminish provision of informal care; the 'crowding out' hypothesis. However, there appears to be little evidence for 'crowding out', with evidence showing formal care services supplement rather than substitute informal care. In fact, the supply of formal care may encourage the supply of informal care^{7,8}.

"We didn't choose to be carers."

WHAT THE RESEARCH TELLS US

Care takes place in the context of a relationship and measuring the outputs of care is inseparable from the people providing and receiving it⁹. While there are existing measures of the economic contribution of informal care, there is minimal research into estimates or measures of the social contribution of care.

Carers Victoria is aware of literature regarding social contribution such as social impact studies, social return on investment and social capital. Some studies have measured social return on investment in social enterprises¹⁰ and the role of volunteers in creating social capital¹¹, though a gap remains in the research literature concerning the social contribution of informal care.

Social contribution is a multi-layered and diffuse concept and there is little agreement on measuring social contribution, as opposed to economic contribution.

CARERS VICTORIA'S INTEREST IN THIS RESEARCH THEME

While existing research methods estimate the economic contribution of informal care, Carers Victoria believes the contribution of carers and care relationships cannot be expressed solely in monetary terms. There is a broader and multi-dimensional definition of care beyond the labour dimension.

Informal care builds and maintains family relationships; promotes social inclusion and supports community cohesion. Carers are the 'social glue' that binds together relationships between formal service providers; local communities; volunteers and people receiving care. While carers provide large amounts of informal care bonding the parties to the care relationship, they also bridge the boundary between informal and formal care¹² linking their relatives and friends to needed formal care services. Notably, these are all activities which produce social capital¹³.

Carers Victoria seeks to increase recognition of the important role carers play in society and research of this nature can support the wider community to better appreciate the value of care and promote greater sharing of the social costs and benefits of care among families and communities.

"As a carer you feel like you can't complain because the person you care for has it worse than you."

POTENTIAL RESEARCH APPROACHES

Carers Victoria is interested in methods that could be used to measure the social contribution of informal care in Australia. This may require investigation of suitable data sets. Research projects may also draw from existing methods used to measure social contribution such as social impact, social return on investment and existing measures of social capital.

Carers Victoria has prioritised two areas for future research:

1. Seeking the views of carers and people receiving care about similarities and differences between formal and informal care in formation of social capital; and
2. Measuring the social return on investment in supporting carers and care relationships.

RESEARCH THEME 2

QUALITY OF LIFE FOR CARERS

BACKGROUND

The impacts of caring on carer health and wellbeing and social participation are extensively documented^{14,15,16}. Direct and indirect costs incurred as a result of caring impact on carers' own standard of living¹⁷. While a number of studies and inquiries have found caring has major impacts on carers, many of their needs remain unmet.

The majority of research concerning the caring experience concentrates on the burden of caring and resulting negative impacts for carers. However, many carers identify a range of positive aspects their caring role can bring to their lives, as well as the lives of the people they care for. More research is required to discover the factors influencing these positive aspects of care.

"At first I didn't need respite – they're my parents, but ask me now and I need a break every three months."

WHAT THE RESEARCH TELLS US

Research suggests loneliness and social isolation is a significant risk to carer quality of life¹⁸ and carers can be up to 10 times more likely to be socially isolated compared to the wider community¹⁹.

The evidence for what works to support and improve carer quality of life is limited. The most studied group is carers of people with dementia and the evidence is therefore strongest for this group²⁰. There is little evidence on what interventions are most effective for carers of people with other health conditions and disabilities and in different types of care relationships; parents, partners, children, friends, resident and non-resident carers.

CARERS VICTORIA'S INTEREST IN THIS RESEARCH THEME

Carers Victoria works to assist carers to improve their health and wellbeing and social participation. We seek to meaningfully represent the diverse needs of carers and to support effective interventions to address the needs of people in care relationships.

More research is required on: effective strategies for hard-to-reach and under-represented groups; what works for those carers that do use services; and identifying the unmet and partially met needs of carers.

Well-designed evaluations of current practice in carer support would fill key gaps in the literature, especially in evaluating the effectiveness of different interventions for different types of carers.

"Know me for who I am. I have given up my life to be a carer."

POTENTIAL RESEARCH APPROACHES

Care relationships are diverse. Carers at different life stages and caring for people with different conditions have very different experiences and needs. Carers Victoria is particularly interested in research related to the specific needs and issues of carers from a variety of population groups, including but not limited to:

- Aboriginal carers
- Carers from culturally and linguistically diverse backgrounds
- Lesbian, gay, bisexual, transgender and intersex carers
- Young carers
- Ageing carers
- Carers of more than one person with care needs
- Carers in regional and rural communities
- Hidden carers – people with caring roles who do not identify as carers.

Research with diverse population groups must ensure sensitivity to and respect for carers to advance understanding of and effective responses to their needs.

Carers Victoria has prioritised two areas for further research:

1. Carer experiences of loneliness and social isolation and effective interventions to address these and improve carer quality of life; and
2. Investigation of any impact on carer quality of life of formal services and supports for people receiving care. Is there a 'respite-effect' for carers?

RESEARCH THEME 3

SUPPORTING CARER CAPABILITIES

BACKGROUND

Carers' ability to make choices about their caring role and freedom to participate in other desired activities while caring for another person is strongly linked to their quality of life. Capabilities include a range of abilities and competencies as well as individual freedom to pursue different combinations of these. While there is much emphasis in policy and service delivery on building the capacity of carers to sustain their informal caring role, there is less emphasis on supporting carers' desired range of capabilities.

The capabilities of carers and people receiving care are interdependent. Being in a care relationship can mean a carer prioritises maximising the capabilities of the person receiving care. A carer's own freedom to pursue their capabilities can be restricted by their caring role.

A focus on individual capabilities of either the carer or the person receiving care fails to recognise the impact of care relationships on whole families. A focus on the care relationship can highlight how support for a carer can benefit a person receiving care and vice versa²¹.

*"You are living a whole life, a meaningful life.
You're not just a carer."*

WHAT THE RESEARCH TELLS US

While much of the research on carers and caring is on the skills required by carers to perform the caring role, Carers Victoria is aware of literature which explores the application of Amartya Sen's capability approach to evaluating the outcomes of social care programs^{22, 23}.

The University of Birmingham has developed a range of capability measurement tools. The Carer Experience Survey (CES) has six domains including ability to influence the overall care of the person and ability to participate in activities outside of caring.

There are a range of other capability and outcome measurement tools that have been applied to people in care relationships, including the Adult Social Care Outcomes Toolkit (ASCOT)^{24,25}.

CARERS VICTORIA'S INTEREST IN THIS RESEARCH THEME

Carers Victoria seeks to shift understanding of carer needs away from relief of burden towards supporting carer strengths and capabilities. This has significant implications for future policy and program design and delivery.

Carers Victoria is interested in exploring the possibilities of the capability approach in supporting carers to achieve a range of competencies and participate in a range of activities as well as being a carer. We want and need research to translate into services and supports that make caring easier²⁶, enhance carers' sense of control over their caring role and free carers to pursue other activities of their choice.

Research to date emphasises the role of respite care in supporting carers to have a life of their own. However, as social care reforms restructure a range of programs into individualised consumer-directed packages, there is less emphasis on access to respite care by carers. On a practical level, while adequate substitute care may be necessary it is not sufficient to achieve all carers' desired outcomes²⁷.

The capabilities approach emphasis on freedom of choice links substantially to our first research theme; the recognition and valuing of informal care²⁸.

"My work is my respite."

POTENTIAL RESEARCH APPROACHES

Carers Victoria has prioritised three areas for further research:

1. Supporting carer capabilities to participate in individualised, consumer-directed care programs, including research into outcomes for carers who:
 - manage a consumer-directed package or plan on behalf of the person they care for;
 - support the person they care for to manage their own plan or package; and/or
 - manage a plan or package of support to meet their own needs.
2. Supporting carer capabilities to use technology promoting independence of people receiving care, including research into outcomes for care relationships, and carer assessment of the costs and benefits of using technology in support of caring.
3. Supporting carer capabilities to participate in paid employment and evaluating the outcomes of innovative support for employed carers.

CONCLUSION

Carers Victoria has a strong history of collaborating and supporting research concerning Victorian and Australian carers, but has limited capacity to perform or fund stand-alone research projects.

There are many under-researched areas related to carers and care relationships.

This Research Agenda identifies issues of short and long term significance to carers and care relationships.

Carers Victoria welcomes approaches by prospective research partners with research questions and project proposals which address these three themes.

We look forward to advancing our Research Agenda with you.

REFERENCES

- ¹ Arno, P., Levine, C., and Memmott, M. (1999) 'The economic value of informal caregiving', *Health Affairs*, Vol. 18, No. 2, pp 182-188.
- ² Access Economics for Carers Australia (2015) *The economic value of informal care*, Report prepared for Carers Australia, Canberra.
- ³ Diminic S, Hielscher E, Lee YY, Harris M, Schess J, Kealton J & Whiteford H. (2016) *The economic value of informal mental health caring in Australia: technical report*. The University of Queensland, Brisbane
- ⁴ <http://www.pwc.com.au/australia-in-transition/publications/understanding-the-unpaid-economy-mar17.pdf>
- ⁵ Heitmueller, A., & Inglis, K. (2007). The earnings of informal carers: Wage differentials and opportunity costs. *Journal of health economics*, 26(4), 821-841.
- ⁶ Twigg, J., & Atkin, K. (1994). *Carers perceived: policy and practice in informal care*. McGraw-Hill Education (UK).
- ⁷ Künemund, H., & Rein, M. (1999) 'There is more to receiving than needing: Theoretical arguments and empirical explorations of crowding in and crowding out', *Ageing and Society*, 19 (01), pp. 93-121.
- ⁸ Cameron, C., & Moss, P. (2007). *Care work in Europe: Current understandings and future directions*. Routledge.
- ⁹ Himmelweit, S. (2007). The prospects for caring: economic theory and policy analysis. *Cambridge Journal of Economics*, 31(4), 581-599.
- ¹⁰ Millar, R., & Hall, K. (2013). Social return on investment (SROI) and performance measurement: The opportunities and barriers for social enterprises in health and social care. *Public Management Review*, 15(6), 923-941.
- ¹¹ Onyx, J., Leonard, R., & Hayward-Brown, H. P. (2004). The special position of volunteers in the formation of social capital. *Voluntary Action*.
- ¹² Rosenthal, C. J., Martin-Matthews, A., & Keefe, J. M. (2007). Care management and care provision for older relatives amongst employed informal care-givers. *Ageing and Society*(5), 755.
- ¹³ Day, C. (2015). Young adult carers: a literature review informing the re-conceptualisation of young adult caregiving in Australia. *Journal Of Youth Studies*, 18(7), 855. doi:10.1080/13676261.2014.1001826
- ¹⁴ Australian Bureau of Statistics. (2016). *Disability, Ageing and Carers, Australia: Summary of Findings 2015*, (Vol. Cat. no. 4430.0,). Canberra.
- ¹⁵ Australian Human Rights Commission. (2013). *Investing in care: Recognising and valuing those who care*. Sydney: Australian Human Rights Commission.

REFERENCES

- ¹⁶ Edwards, B. (2008). The nature and impact of caring for family members with a disability in Australia. Melbourne: Australian Institute of Family Studies.
- ¹⁷ Hill, P., Thomson, C., & Cass, B. (2011). The costs of caring and the living standards of carers. Canberra: Department of Families, Housing, Community Services and Indigenous Affairs.
- ¹⁸ Ekwall, A. K., Sivberg, B., & Hallberg, I. R. (2005). Loneliness as a predictor of quality of life among older caregivers. *Journal of advanced nursing*, 49(1), 23-32.
- ¹⁹ Hayes, L., Hawthorne, G., Farhall, J., O'Hanlon, B., & Harvey, C. (2015) 'Quality of life and social isolation among caregivers of adults with schizophrenia: Policy and outcomes.' *Community Mental Health Journal*, 51(5), 591-597.
- ²⁰ Eagar, K., Owen, A., Williams, K., Westera, A., Marosszeky, N., England, R., & Morris, D. (2007). Effective Caring: a synthesis of the international evidence on carer needs and interventions. Centre for Health Service Development, University of Wollongong.
- ²¹ Butler, M. (2011). Good care and capabilities theory: the development of a relational framework for carers and adults with severe disability. *Sites: a journal of social anthropology and cultural studies*, 8(2), 57-76.
- ²² Coast J, Smith R, Lorgelly P. (2008) Should the capability approach be applied in health economics? *Health Economics* 17:667-670.
- ²³ Kimberley, H., Huggins, S. & Gruhn, R., (2012). Valuing capabilities in later life: the capability approach and the Brotherhood of St Laurence aged services.
- ²⁴ Jones, C., Tudor Edwards, R., & Hounsome, B. (2014). Qualitative Exploration of the Suitability of Capability Based Instruments to Measure Quality of Life in Family Carers of People with Dementia. *ISRN Otolaryngology*, 1. doi:10.1155/2014/919613
- ²⁵ Rand, S. E., Malley, J. N., Netten, A. P., & Forder, J. E. (2015). Factor structure and construct validity of the adult social care outcomes toolkit for carers (ASCOT-carer). *Quality of Life Research*, 24(11), 2601-2614.
- ²⁶ Davy, L., Adams, T., and Bridge, C. (2014) *Caring for the Carer: Home design and modification for carers of young people with disability*, for the Home Modification Information Clearinghouse, City Futures Research Centre, UNSW Australia.
- ²⁷ Francesca, C., Ana, L.-N., Jérôme, M., & Frits, T. (2011). *OECD Health Policy Studies Help Wanted? Providing and Paying for Long-Term Care: Providing and Paying for Long-Term Care (Vol. 2011)*: OECD Publishing.
- ²⁸ Lewis, J., & Giullari, S. (2005). The adult worker model family, gender equality and care: the search for new policy principles and the possibilities and problems of a capabilities approach. *Economy And Society*, (1), 76.
- ²⁹ Carers Victoria. (2017). *Final Report: Developing the Victorian Carer Statement; carer insights and feedback*.



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