

Research Translation and Impact of a Program of Work to Support Carers of a Person with Depressive or Anxiety Symptoms

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ABSTRACT

In 2018, Every Mind responded to a lack of research into supports for carers of a person with depressive or anxiety symptoms, by designing, piloting, and implementing an online support program targeting these carers. Previous publications have documented several benefits of this research, such as the program's feasibility, acceptability, and trends in efficacy. Although these results are promising, a deeper examination of the societal and economic significance of the research is warranted. The present study utilised the *Framework to Assess the Impact from Translational Health Research* (FAIT) and examined program documentation to retrospectively assess the benefits, costs and lessons learned from the *Minds Together* research. The results revealed that the benefits were widespread, particularly in capacity building. The economic analysis found a return on investment of over \$80,000 AUD 2022. The study also emphasised the role of research centre staff in communicating and disseminating research findings. The retrospective application of FAIT to the *Minds Together* program proved feasible and has provided valuable insights. The present study highlights the comprehensive benefits of *Minds Together* beyond the trial outcomes reported in previous studies and emphasises the advantages of using health economics methodologies to examine the impacts of research targeting informal carers.

1. Introduction

The failure of health and medical research to translate and achieve impact is a significant problem. With an estimated US\$100 billion invested in health research globally each year (Chalmers & Glasziou, 2009), it is important that research findings translate into more comprehensive benefits, policies, and practices (Macleod et al., 2014). However, evidence suggests that approximately 85% of the annual global expenditure on health research is avoidably 'wasted' (Chalmers & Glasziou, 2009). Poor decision-making across all stages of

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research, from the quality of research questions, design and methods, publications, and reporting have been identified as the main contributors to waste (Chalmers & Glasziou, 2009).

Factors identified as mitigating the risk of waste include publication of completed research and publishing sufficiently clearly, completely, and accurately for others to interpret, use, or replicate the research correctly and for new research to be designed to take systematic account of lessons and results from previous, related research (Chalmers & Glasziou, 2009). In Australia, the McKeon (2013) *Strategic Review of Health and Medical Research* highlighted the need for greater translation of research into health benefits for the Australian population.

The *Framework to Assess the Impact from Translational health research* (FAIT) is a novel assessment tool specifically developed to improve research translation and impact (Searles et al., 2016). FAIT maps a pathway from research need to impact, and is a hybrid of three existing, validated methods of impact assessment, namely: a modified Payback method, an economic analysis, and a narrative of the process by which research translates and generates impact. The FAIT framework provides a multidimensional, comprehensive view of research impact which allows the measurement and translation of research and realisation of impact to avoid research waste and guide profitable funding decisions.

Increasingly, researchers and policymakers are responding to informal carers' needs for investment in Australia (Deloitte Australia, 2020). Informal carers, such as partners, relatives and friends provide practical, physical, and emotional support to someone with whom they have an existing social relationship (Diminic et al., 2019; Neilson, 2022; Reinares et al., 2016).

The value of unpaid work by Australian carers was estimated at \$77.9 billion in 2020, highlighting the worthwhile investment of supporting carers to maintain their caring role (Deloitte Australia, 2020). Although not all carers experience adverse outcomes, studies have shown that informal care provision places carers at increased risk of adverse mental and physical health and well-being outcomes, compared to non-carers (Berglund et al., 2015, Kenny et al., 2014). Additionally, carers of a person with mental ill-health report working fewer hours in lower-paying jobs than non-carers (Diminic, Hielscher, & Harris, 2019) and carers generally experience more education and employment disadvantage than non-carers (Hill & Broady, 2019). Productivity loss is commonly experienced by carers who are employed (Kotseva et al., 2019) as well as losses resulting from work absenteeism, presenteeism, and reduced time to commit to unpaid work (e.g., volunteer work) or leisure for people who are unemployed or retired (Osnett & Jan, 1996, Zhang et al., 2010).

Targeted carer-focused psychosocial interventions have been shown to address and mitigate the potential adverse outcomes associated with the caring role. Qualitative studies have demonstrated that targeted supports can motivate carers to prioritise self-care, improve their understanding of the care-recipient's illness and help them to connect with others, which can foster feelings of hope and encouragement (Contreras et al., 2022, Whitney et al., 2012). Similarly, randomised controlled trials have indicated the capacity of targeted supports to reduce carers' perceived burden and increase their perceived quality of life and perceived ability to cope with their role, compared to control group participants (Belle et al., 2006; Schulz et al., 2009; Tawfik et al., 2021).

Depressive and anxiety symptoms are among the most significant contributors to health loss worldwide and the global pandemic has exacerbated their prevalence (Santomauro et al., 2021). Given the essential role of informal carers in supporting individuals living with mental health concerns (Diminic et al., 2019), and the many challenges that this role can encompass (Berglund et al., 2015, Kenny et al., 2014), adequate support for these carers is needed.

However, a systematic review has shown a lack of evidence on resources targeting carers of a person with depressive or anxiety symptoms specifically (Fitzgeraldson et al., 2022).

In response to this gap, a research program of work was initiated in 2018, with the goal of conceptualising, piloting, and implementing a novel support program known as ‘*Minds Together*’. This program is designed to assist individuals caring for a person experiencing depressive or anxiety symptoms. Previous publications have shown that the program is feasible, acceptable, and demonstrates preliminary trends in efficacy (e.g., Fitzgeraldson et al., 2023; Fitzgeraldson et al., in press). While the immediate results of the research have been thoroughly examined, the broader benefits and learnings remain unexplored.

In the present study, we utilise the Framework to Assess Research Translation and Impact (FAIT) to identify, measure and value the wider societal and economic benefits of the *Minds Together* research. The objective of this study is to assess the benefits of investing in this research area and to explore the feasibility of retrospectively applying FAIT. Figure 1 presents a timeline of the research activities evaluated in this paper.

2018/2019	2020	2021	2022
- Rapid literature review	- Systematic review	- Program development	- Full-scale RCT
- Community consultation		- Feasibility study	- Qualitative study
		- Social forum development and testing	

Figure 1. Timeline of Research Activities

2. Material and Methods

2.1. Setting

The co-ordinating centre for the research program was Everymind, a unit within Hunter New England Local Health District, NSW, Australia.

2.2. Participants

Participants in the impact assessment were researchers from Everymind. Oversight of the application of FAIT was undertaken by the Hunter Medical Research Institute.

2.3. Ethics and Trial Registration

Approval from the local Human Research Ethics Committees was approved at all research stages. The consultation study and pilot study have ethics approval from Hunter New England Human Research Ethics Committee of Hunter New England Local Health District, Reference (2018/ ETH00444, 2019/ ETH13205). For the RCT, ethics approval was granted by the University of Newcastle’s Human Research Ethics Committee, (Approval No. H-2021-0117).

The pilot study and RCT were registered with Australian New Zealand Clinical Trials Registry (ANZCTR: ACTRN12621001256864, ACTR: ACTRN12621001257853. Registered September 16, 2021 [retrospectively registered]).

2.4. FAIT Methods

Key components of the methods and application of the three FAIT methods are summarised below and are based on details described elsewhere (Searles et al., 2016). A modified program logic model was developed retrospectively based on available project documentation (Figure 2). In this application, ‘retrospective’ refers to the logic model being developed based on actual pathways and decision points, as opposed to ‘prospective’ which would map the intended pathway at the point where the research commences.

This logic model documents the translation pathway between the development, implementation, and evaluation of the *Minds Together* online program and its impact. Impacts are grouped within five ‘domains of benefit’: knowledge advancement, capacity strengthening, change in policy and/or practice, economic benefit, and societal benefit. The research activities were mapped to suitable published metrics as well as customised metrics that related directly to the *Minds Together* program. These additional metrics were determined by the researchers in conjunction with economists at Hunter Medical Research Institute.

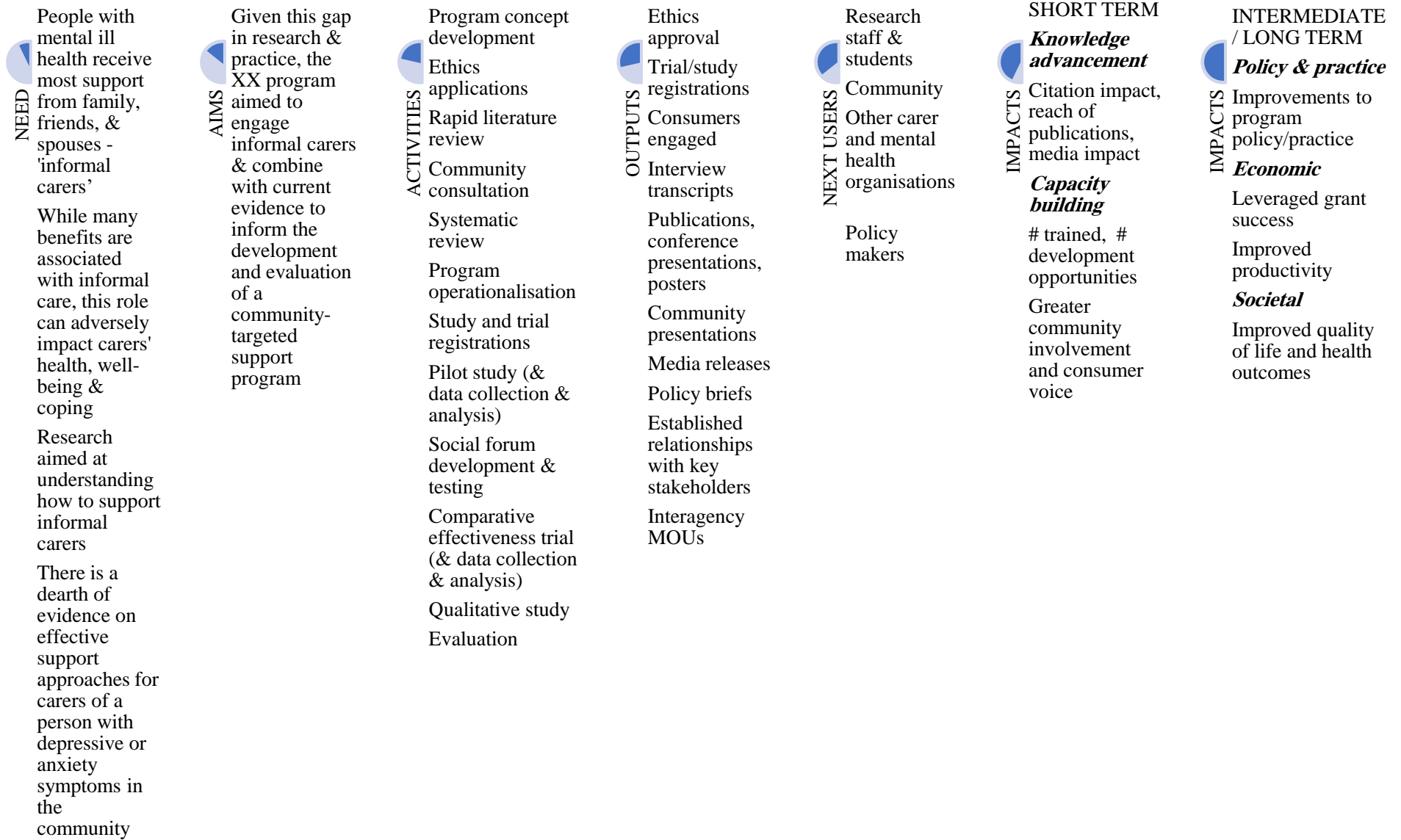


Figure 2. Program Logic Model

The next step in the assessment process involved the direct application of the three FAIT methods.

2.5. Modified Payback

The Modified Payback method assesses impact using quantitative metrics sitting across three of the five areas of benefit in the Payback framework: knowledge advancement, capacity building, policy and legislation and economic impacts (Buxton & Hanney, 2008). The areas of benefit have evolved as the application of FAIT has increased (Searles et al., 2016). Specifically, policy and legislation has developed into changes in policy and/or practice, and capacity building has been added. Societal benefits were also considered when applying this framework to the current research. Data for the impact metrics were obtained from project documentation, discussions with project researchers, and through online searches of relevant websites.

2.6. The Economics

Although a cost–benefit analysis from a societal perspective is the economic gold standard to determine return on the research investment, it was unsuitable for application to the XX program of work because: 1) there was no counterfactual, 2) many of the benefits are yet to be realised, and 3) many of the benefits could not be easily monetised.

Instead, a form of cost-consequence analysis (CCA) presenting an array of consequences and costs, was undertaken (Brazier et al., 2007). Judgement regarding overall value has been left to the reader.

2.7. Costs

Direct research costs were captured from the research centre project files, supplemented by indirect research costs, or the opportunity costs of the researchers involved using a bottom-up micro-costing method (Jones et al., 2013). Members of the research team were asked to provide calculations of the number of hours they had spent on the program from commencement to completion, defined as the point when the final randomised controlled trial results were submitted for publication. Labour time was measured in units of time and valued according to health service award pay scales. The costs associated with program development and implementation were based on invoices from website developers. An additional 30% was added to cover oncosts. All costs are reported in 2022/3 Australian Dollars.

2.8. Consequences

The direct and indirect consequences from *Minds Together* were identified using the program logic model and where possible, measured and valued based on trial outcomes and research centre project documentation.

Two specific consequences could be monetised: 1) additional research funds leveraged, and 2) productivity gains observed from the *Minds Together* RCT. The leveraging of foundational work with carers and the online pilot study findings attracted additional resources to develop and implement the program for use in additional populations (carers of a person who has made a suicide attempt and carers of paramedics).

2.8.1. Participant Outcomes

2.8.1.1. Work Productivity Activity Impairment

Given the expected baseline burden on the focus population on carers, the RCT planned for pre- and post-productivity data collection using the Work Productivity Activity Impairment (WPAI-GH) instrument (Zhang et al., 2010). The scale measures work productivity in the last week with respect to the following areas: Q1 = currently employed, Q2 = hours missed due to health problems, Q3 = hours missed other reasons Q4 = hours worked, Q5 = degree health affected productivity while working, Q6 = degree health affected regular activities.

The scale yields four types of scores: 1) Absenteeism (work time missed), 2) Presenteeism (impairment at work / reduced on-the-job effectiveness), 3) Work productivity loss (overall work impairment / absenteeism plus presenteeism), and 4) Activity Impairment (i.e., activities outside of work, such as exercise). Higher numbers were indicative of greater impairment and less productivity. The questions were adapted to ask about the caring role specifically, with the term ‘health problems’ being replaced with ‘caring role.’

2.8.1.2. Carer Quality of Life

Additionally, carer quality of life was measured using the CarerQoL instrument (Brouwer et al., 2006) which has been designed to measure quality of life in the context of informal care. The instrument measures the level of burden a person perceives from different aspects of their care situation, such as, relational problems, financial problems, and mental and physical health problems. The scale comprises five negative and two positive aspects of informal care provision which are added for a sum of scores ranging between 0-14. The higher the score the more fulfilling the care situation. The scale also includes a valuation component in the form of a visual analogue scale where a higher indication on the scale implies a higher subjective assessment of carer quality of life.

2.8.2. The Narrative

Published and unpublished findings, reports and publications from the *Minds Together* program of work were assessed for key themes to capture aspects of the research translation story from ‘the need for the research’ through to specific ‘impacts’ that were realised. Data sources included: the initial literature review (Everymind, 2018), the consultation findings and publication (Fitzgeraldson et al., in press), the systematic review publication (Fitzgeraldson et al., 2022), the pilot study publication (Fitzgeraldson et al., 2023), and the RCT findings and publication (Fitzgeraldson et al., in press).

3. Results

3.1. Payback

Table 1 summarises the results from the application of the modified Payback method of metric assessment, grouped by ‘domains of benefit’.

Table 1.
Summary of Results

Domain of benefit	Category of impact	Results
Advanced knowledge	Uptake of research outputs:	2 published in a peer-reviewed journal
	- Publications	1 article accepted
	- Abstracts	2 articles in press
	- Conference proceedings	13 Conference presentations 1 poster

Domain of benefit	Category of impact	Results
		1 keynote presentation as an invited speaker 1 panel member presentation as an invited speaker
	Grey literature	5 research protocols 2 project reports
	Media	1 news article in a national newspaper 12 radio interviews 1 podcast (6000 international listeners)
Capacity building	Collaborations	1 partnership agreement formed with the XX in Australia 20 mental health and carer organisations promoted the research 1 Member of Parliament made a promotional video 1 mental health commissioner made a promotional video
	Community engagement	Everymind co-hosted 4 community events
	Research community	2 students completed honours and PhD programs respectively, based on the research program. 5 research centre staff gained research methods skills in recruiting, delivering and evaluating online, community targeted support 2 international Professors shared insight on study design for 2 included studies 1 Australian Professor provided guidance on program and research design for 4 included studies 1 Australian Associate Professor shared guidance on research design, translation, and economic analysis for 1 included study
Policy and/or practice	Policy engagement	6 written proposals to state and federal departments of health 5 verbal discussions with key politicians which led to ongoing professional relationships. 1 submission to the inquiry into the recognition of unpaid carers.
	Practice change	Affected modified language and terminology use for communications consistent with carer/people with lived experience preferences
Economic	Value of research grants leveraged	\$771, 959
	Calculated value of lost productivity due to unmet carer needs	\$7.3 bn AUD
Societal		Evidence of trends in reduced burden and increased coping self-efficacy from the Minds Together program in the pilot study. Evidence of trends in increased quality of life from the Minds Together program and social forum in the RCT.

Using an action research approach, the *Minds Together* program has shown preliminary evidence on how to improve the care experience and coping of carers of a person with depressive or anxiety symptoms (Fitzgeraldson et al. 2023). Further, and in parallel, several positive externalities stemmed from the research, as summarised in Table 1. In particular, the

involved researchers learned about the barriers and enablers to achieving research success with respect to recruitment modes and strategies as well as the importance of context. As the research program progressed, more accessible language to reach carers in the general community, including those with low mental health literacy, was adopted. For example, the terms 'carer' and 'depressive and anxiety symptoms' were replaced with 'relatives, partners, and friends' and 'experiencing high levels of stress,' or 'a consistently low mood.'

Additionally, researchers reflected on the challenges associated with recruitment, such as carers not wanting to seek support for themselves. Recruitment material was adapted to ask carers about seeking support for care recipients rather than themselves. Researchers also took measures to diversify the participant sample from the pilot study to the RCT by engaging additional organisational stakeholders Australia-wide (e.g., the Mental Health Commissions), and advertising on additional social media platforms, such as Instagram and YouTube.

There was also the capacity building of early and mid-career researchers as they engaged with the learnings and evidence stemming from the community consultations. These learnings were also used to refine and adapt the interventions and recruitment approaches to strengthen engagement with the program. For example, throughout the research, a PhD student gained the skills and confidence to supervise an Honours student. The Honours student's research involved interviews with 14 carers from the RCT on their views about identifying as a carer which is guiding recruitment decisions for related carer programs.

The Director at Everymind met with national politicians to discuss the outcomes of the *Minds Together* program of work. These meetings led to initiating ongoing relationships with State Governments around the program. Additionally, XX has submitted recommendations to the national inquiry into the recognition of unpaid carers regarding the unique support needs of mental health carers.

Table 2 presents results from the cost consequence analysis based on achievements of the research program to date. The total research costs were measured and valued to be \$771, 959 AUD 2022/23.

Table 2.
Cost Consequence Analysis

Activity	Responsibility	Unit cost (per hour) ^a \$AUD2023	Time spent (weeks)	Component total cost	Before 30% oncosts	Total cost \$AUD2022/23
Rapid literature review	1 x Project Officer	\$37	6	\$8, 880	\$21, 320	\$27, 716
	1 x Senior Project Officer	\$43	6	\$10, 320		
	1 x Project Lead	\$53	1	\$2, 120		
Consultation	1 x Project Officer	\$37	24	\$35, 520	\$83, 680	\$108, 784
	1 x Senior Project Officer	\$43	24	\$41, 280		
	1 x Project Lead	\$53	4	\$6, 880		
Systematic review	PhD Student ^b	\$14	24	\$14, 769	\$14, 769	\$19, 199
XX program development	1 x Communications Officer	\$37	24	\$35, 520	\$155, 924	\$202, 701
	1 x Senior Project Officer	\$43	24	\$41, 280		
	1 x Project Lead	\$53	12	\$25, 440		
	1 x Program Manager	\$63	4	\$10, 080		
	Web Developers ^c	N/A	N/A	\$43, 604		
Pilot study	PhD Student	\$14	48	\$29, 538	\$114, 818	\$149, 263
	Senior Project Officer	\$43	24	\$41, 280		

Activity	Responsibility	Unit cost (per hour) ^a \$AUD2023	Time spent (weeks)	Component total cost	Before 30% oncosts	Total cost \$AUD2022/23
	Project Lead	\$53	8	\$16,960		
	Program Manager	\$63	2	\$5,040		
Program changes following feasibility study	1 x Communications Officer	\$37	8	\$15,000	\$45,360	\$58,968
	1 x Senior Project Officer	\$43	4	\$6,880		
	1 x Project Lead	\$53	4	\$8,480		
	Web Developers	N/A	N/A	\$15,000		
Social support platform development	1 x Communications Officer	\$37	2	\$2,960	\$19,940	\$25,922
	1 x Project Officer	\$37	2	\$2,960		
	1 x Senior Project Officer	\$43	4	\$6,880		
	1 x Project Lead	\$53	1	\$2,120		
	1 x Program Manager	\$63	1	\$2,520		
	Web Developers	N/A		\$2,500		
Social forum testing	1 x Senior Project Officer	\$43	2	\$3,440	\$4,630	\$6,019
	1 x PhD Student	\$14	2	\$1,230		
Qualitative study	1 x Honour's Student	\$14	24	\$14,769	\$29,609	\$38,491
	1 x PhD Student	\$14	8	\$4,760		
	1 x Program Manager	\$63	4	\$10,080		
RCT	1 x PhD Student	\$14	48	\$29,538	\$41,045	\$53,358
	1 x Program Manager	\$63	4	\$10,080		
	Web Developers			\$1,427		
TOTAL COST					\$511,466	\$690,421

^a Award wage rates for health staff in New South Wales (NSW Government, 2022). Award wage rates for health staff in New South Wales (2022), (<https://www.health.nsw.gov.au/careers/conditions/Awards/hsu-health-managers.pdf>)

^b Student labour time was included to reflect the opportunity cost of this time and valued using an hourly rate derived from an average PhD stipend of \$32,000 (The University of Newcastle, 2023).

^c Costs based on invoices paid to Web Developers.

The consequences that could be monetised included \$771,959 AUD which represents the value of grants that were leveraged. The grants included: 1) Innovation Grant (\$100,000; Suicide Prevention Australia, 2019), 2) Veterans and First Responders Mental Health Grant Program (\$0.5M; Movember and the Distinguished Gentleman's Ride, 2021), 3) series of small research grants for research related resources (\$45,161; 2019-2022), 4) travel grants to present and promote research (\$17,386; 2018-2023), 5) the expected value of a Medical Research Future Fund grant application (\$59,413)¹.

There was no discernible productivity benefit of either intervention arm based on the pre-post analysis of WPAI:GH data collected for the RCT. This was due in part to the significant amount of missing survey responses from participants in the RCT. Using multiple imputation and the last observation carried forward approach (Xu, 2009), productivity costs between the baseline and three month follow up period were calculated. Another approach taken to deal with missing data was to include only those who completed all the three WPAI:GH surveys. Each method has its own sources of bias as there is no perfect substitute for actual respondent data. The results are summarised below in Table 3.

¹ Expected value calculated as total grant value (\$540,118) multiplied by the 2022 probability of NHMRC grant success (11%)

Table 3.
Summary of Results

		Baseline	Follow Up	3 Month Follow Up	Difference
All Survey Completed	Program + Social	\$ 231.82	\$438.44	\$145.72	\$86.10
	Program	\$ 330.88	\$377.77	\$410.94	\$80.06
Last Observation Carried Forward	Program + Social	\$420.75	\$461.71	\$469.06	\$48.31
	Program	\$366.64	\$401.46	\$380.63	\$13.98
Multiple Imputation	Program + Social	\$471.64	\$563.02	\$387.26	\$84.39
	Program	373.54	\$441.54	\$433.54	\$60.00

Despite the lack of a clear productivity benefit stemming from the RCT, the data collected does provide a base estimate of the productivity costs for the carers of people with depressive or anxiety symptoms. There were 98 respondents to the first WPAI:GH survey. The cost of absenteeism per week was calculated to be \$9,263 for these individuals or an average of \$95 per respondent.

Presenteeism costs at baseline were calculated to be \$30,923, at an average cost of \$316 per participant. Based on these figures, the average total productivity costs for informal carers total \$410 per week. In 2020, there were approximately 906,000 informal carers in Australia, with roughly 37.3% of those requiring care citing psychological issues as their primary medical condition (Deloitte Australia, 2020). These figures suggest that there are 337,938 informal primary carers for individuals with mental health issues. Applying our total mean productivity cost to these 337,938 individuals amounts to a yearly societal cost \$7.3 billion AUD, 2022 (Deloitte Australia, 2020).

3.2. Carer Quality of Life

In the comparative efficacy trial, quality of life was measured using the Carer Quality of Life (CarerQoL) (Brouwer et al., 2006) instrument. As with the productivity data, the analysis was limited by large amounts of missing data. Complete case, last observation carried forward, and multiple imputation methods were employed to deal with the missing data (Little, 2012; Ross et al., 2020).

The results showing mean quality of life at the timepoints: baseline, follow up, and three month follow up for both trial arms and a pooled set, are shown in Figure 3 below.

These results show no statistically different quality of life scores at follow up between trial arms. However, they also show an uplift in quality of life from baseline to the 3 month follow up period. That is, pre and three months post the intervention. In those trial participants who completed the instrument at all time points, there is a marked difference in baseline values between trial arms, a difference which diminishes over the trial period.

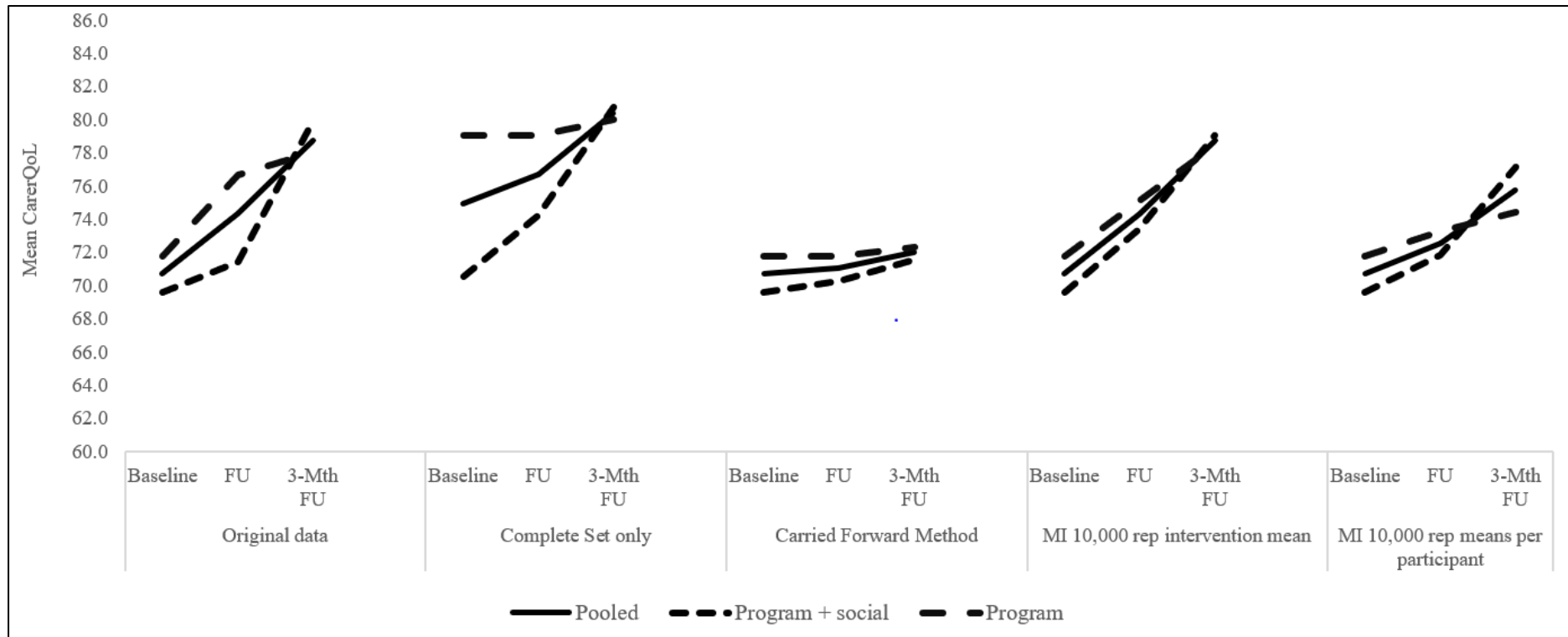


Figure 3. Mean Quality of Life over Time

3.3. The Narrative

A narrative describing the pathway from research need to impact for XX program of work is depicted in Figure 4. This approach presents a brief story of the research and incorporates the more nuanced impacts on consumers, research staff, and the mental health and carer sector.

Need

Current evidence on carers of a person supporting someone with mental ill-health is limited in Australia and typically relies on carers who are engaged with services, or who are supporting someone with a diagnosed mental illness (Diminic et al., 2019).

Interventions targeting these carers have a narrow focus typically targeting carers of a person with severe psychopathology, such as psychosis, bipolar disorder, and schizophrenia (e.g., Martín-Carrasco et al., 2016; Perlick et al., 2010; Roddy et al., 2015; Varambally et al., 2013). Although depression and anxiety are the most common mental health conditions (World Health Organisation, 2015), few studies have investigated suitable supports for these carers (Fitzgeraldson et al., 2022).

Research Response

A Series of Studies

In response to this research gap, the *Minds Together* program of work used a mixed methods approach to identify the support needs of this carer group. Carers' preferences about suitable support approaches were collected as part of community consultation through interviews and surveys (Fitzgeraldson et al., in press). Additionally, a systematic review identified and assessed available published evidence on supports targeting these carers (Fitzgeraldson et al., 2022).

Embedding Lived Experience Voices

Carers preferences in the community and the extant literature guided the development of the *Minds Together* program and decisions surrounding program implementation throughout the program of work. The *Minds Together* program of work began as four planned studies: a rapid review, a consultation study, a pilot study, and a full-scale RCT. The funding that has amounted from this program of work has led to the recruitment of a PhD student to conduct four further studies, that is: a systematic review, a pilot study, a full scale randomised controlled trial, and the current research impact study.

Working with Stakeholders

Professional stakeholders were engaged throughout this research. A working group of professionals in the mental health sector (alongside lived experience representatives), was established in initial project stages to guide decisions around community consultation and program design. Researchers and mental health professionals also contributed to podcasts that were embedded in the program. Additionally, stakeholders provided support throughout the recruitment process by promoting study collateral.

Critical Decision Points in the Research Pathway

The decision to use carers perspectives to inform the development of the *Minds Together* program was based on recommendations in the literature and current policy that consumers are best placed to understand their needs and guide effective solutions and should thus play an integral role in research decisions (Banfield & Cole, 2019; Consumers Health Forum of Australia., 2016; Rose, 2014). Additionally, evidence that peer support can encourage health promoting behaviours in illness prevention contexts (Fisher et al., 2017), and can improve carers' psychosocial outcomes (Visa & Harvey, 2019) influenced the

decision to embed lived experience videos and case studies to showcase carers voices in the program.

The decision to use an online program format was also based on a growing body of evidence for this support approach for carers. Specifically, research has supported the acceptability of this format for carers of a person with mental ill-health (Berk et al., 2013; Loi et al., 2022) and the accessibility of this format for carers generally (Dow et al., 2008; Wasilewski et al., 2017).

Challenges and Reflection

Challenges in recruiting participants to the *Minds Together* program also contributed to decisions throughout this research. Specifically, limited sample of respondents in the pilot study prompted reflection among the research team to ensure a more diverse recruitment approach for the full-scale RCT. The researchers drew on their strong relationships with sector partners to improve participant recruitment for this research because many carers do not identify as carers. However, recruitment is an ongoing significant issue. The low program engagement in the pilot also prompted researchers to develop strategies for building compliance in the main trial. Some adjustments were made to the platform, such as addressing technical issues and making phone calls to participants in the subsequent study to ensure they understood the login instructions.

Key Research Outputs

The rapid literature review report, consultation report, and systematic review publication were used to inform the design and development of the *Minds Together* program. The program was used in two national research trials to investigate its acceptability, feasibility, and efficacy.

Pilot study results were included in numerous presentations. These presentations were also used to promote the randomised controlled trial. The pilot study also identified the need for development of the social support forum. Researchers used this forum to leverage funding to test its feasibility. The forum was used in the full-scale trial. Five publications accompany each of these study phases (three are currently in press).

Key Findings

The research in this *Minds Together* program of work made a significant contribution to current knowledge. The consultation study identified formal and informal sources of support for carers of a person with depressive or anxiety symptoms and support barriers for these carers (Fitzgeraldson et al., in press). The systematic review found a gap in published evidence for supports targeting carers of a person with anxiety, and limited suitability evidence for interventions targeting carers of a person with depression (Fitzgeraldson et al., 2022). The feasibility study confirmed the feasibility and acceptability of the *Minds Together* program and identified preliminary trends in efficacy, compared to a waitlist control (Fitzgeraldson et al., 2023).

For the RCT, results showed an increase in quality-of-life scores from baseline to three-month follow-up following engagement with the *Minds Together* program (Fitzgeraldson, in press).

Impact

The *Minds Together* program of work has had an impact on (the organisation)'s status within the mental health and carers sectors. Everymind is establishing itself as a key stakeholder in the support of mental health carers. This is evidenced through requests for advice from policy makers regarding carers, and collaborations with mental health and suicide prevention organisations for the integration of *Minds Together* in the service sector. Consultation with people with lived experience has led Everymind to modify language

used for internal and external communications purposes. While not definitive, it is expected that this language change will influence other stakeholders over time.

The *Minds Together* program has also allowed Everymind staff to leverage numerous grants to expand this work for other carer groups. Everymind has secured \$600,000 to contextualise the *Minds Together* program to support partners of paramedics and family and friends of a person who had made a suicide attempt. Additionally, Everymind has established a collaborative partnership with Manna Institute in which a \$50,000 seed grant will be used to explore the support needs of carers of older Australians. Everymind staff have secured an additional \$45,000 to assist with testing, statistical analysis, and program design components (e.g., commissioning of artwork on the *Minds Together* program). Staff have also obtained more than \$17,000 in travel grants to attend conferences and present findings from this research.

In addition to the financial gains associated with *Minds Together*, the current research has led to the upskilling of two students (a PhD Candidate and Honours student). The PhD Candidate has gained experience leading a national RCT and has obtained feasibility, acceptability, and efficacy evidence for two novel online carer support interventions. This evidence has contributed to the current knowledge base and guided communications with the mental health and carer support sector. Additionally, this experience has led to five first author publications for this Candidate. Similarly, the Honours student's qualitative work has contributed to current knowledge around engaging and recruiting community-dwelling mental health carers for research and practice and has resulted in a lead author publication currently in press.

Additionally, the Candidate has secured nearly \$20,000 in small grants, presented findings at several conferences and collaborated with other researchers nationally and internationally. Similarly, the Honours student has developed skills in recruiting and engaging community members and analysing qualitative data. This work will also result in the student's first primary author publication.

Figure 4. Narrative from research need to impact

The following section briefly draws out some of the key impacts expressed qualitatively by the research program participants.

In the consultation study (Fitzgeraldson et al., in press), the need for support was clearly expressed by participants. For one participant they did not know where to seek support:

“(you feel like) you're out on a little boat in the middle of sea, trying to navigate through without any support.”

Carers also expressed the importance of accessible support. When asked what helpful support would look like, one carer said:

“knowing what website to look at or knowing a number. I think it's about knowing what's involved, so just having that information generally available. I don't know if that's through advertising or on the TV, like how do you know about it?”.

In the pilot study (Fitzgeraldson et al., 2023, p.46), it was evident that the *Minds Together* program was impactful for carers. Most carer participants (80%) reported that they could relate to lived experience content (case studies and videos) in the program.

“What emotionally shifted me... was the videos... I just related to them as real people”

Eight of the ten participants interviewed made specific comments about the impact of the *Minds Together* program on their lives. Carers said that the program helped them to value to their care role and strengthened their motivation.

“Answering questions about being a carer has made me actively think about the importance of my role and the need for self-care”

In the post-survey in the RCT (Fitzgeraldson, in press) when asked if their experience using the *Minds Together* program has impacted their life as a carer, 26 of 41 respondents said ‘yes’. When expanding on this, carers stated:

“I’m more mindful of my needs”

“Just knowing what support are available and making sure I look after myself though this process. Was also nice to know I’m not alone through this”

“It’s given me some tips and insight that has helped my role as a carer”

“It has normalised some of my feelings and made me feel less alone. It has made me think more deeply about my carer situation and how to support myself.”

“Provided me with additional skills and knowledge”

“I feel more confident in myself as I had already figured out some of the things to take care of myself. Found useful information that I can refer to in future to remind myself”

“Just knowing that what I’m doing is right - it has given me comfort during this tough time when my daughter is suicidal.”

4. Discussion

Publications documenting the *Minds Together* program of work have mainly focused on the trial outcomes (e.g., Fitzgeraldson et al., 2023; Fitzgeraldson, in press). This is the first time that an attempt has been made to understand the contribution this work made to next users, individuals, organisations, and society. The immediate next-users of this research are the research centre staff generating evidence and investment to support scale-up and the partner organisations sponsoring the online program. Downstream next-users are the carers directly engaging with program and the ultimate beneficiaries are the carers themselves who benefit in terms of their health and well-being and the individuals they support. The focus of this assessment was predominantly on the immediate next-users and given active translation is ongoing, impacts on downstream users are also considered. Hence, the application of FAIT to *Minds Together* evidenced its impact across all domains, and most strongly in capacity building.

4.1. Findings

The application of FAIT identified several impacts of *Minds Together* in this study, particularly on capacity building. The term capacity building refers to a “a process that improves the ability of a person, group, organisation, or system to meet its objectives or to perform better” (Brown et al., 2001, p.3) and is widely accepted as a multidimensional and dynamic process (Brown et al., 2001; Harsh et al., 2010). Previous studies have identified clinical and professional capacity building opportunities in research, such as evidence that involving clinicians in research can improve practice, and patient outcomes (Blevins et al., 2010; Bornmann, 2013; Misso et al., 2016), and involving professionals can improve their career opportunities and job satisfaction (Bateman et al., 2004; Crisp et al., 2000; Strout et al., 2009). The current study made similar observations around research centre staff gaining skills in research methods. Additionally, the research showed how governments, students, and other organisations in the sector can benefit from research examining early intervention mental health supports.

The return on investment identified from the cost consequence analysis was another key finding from this research. While a total of \$690, 421 AUD 2022/23 was invested into the *Minds Together* program of work, \$771, 959 AUD was gained in terms of additional grants secured. Economic evidence from mental health promotion and mental illness prevention studies typically focus on the social and economic costs of mental illness (Trautmann et al., 2016; Wittchen et al., 2011) and financial gains of support interventions (Jacka & Reavley, 2014; McDaid et al., 2019; Wolter et al., 2021). The current study has demonstrated how consumer engagement, establishing sector partnerships, and leveraging grants and funding opportunities can also contribute to economic gains in this research area.

Evidence of the approximate productivity losses associated with carers of a person with depressive or anxiety symptoms was a novel finding in this study. The productivity loss associated with mental ill health and informal care is well established in the extant literature (Evans-Lacko & Knapp, 2016; Fujihara et al., 2019; Gelfand et al., 2021). However, this is the first study to measure this outcome for carers of a person with depressive or anxiety symptoms. This finding provides tangible evidence of the importance of supporting these carers in their roles and identifying cost-effective solutions.

The narrative of the *Minds Together* program of work has showcased the noteworthy role of next users, both research staff and carer participants in research developments and translation. The study found that reflections from research staff led to improvements to recruitment and trial processes, collaboration, and research funding opportunities. Additionally, the role of researchers in embedding carer feedback in research and practice contributed to program improvements and long-term business developments, such as Everymind's adoption of language for internal and external communications. These findings demonstrate the value of collecting mixed methods data to facilitate research translation opportunities. Although the value of carers' lived experience voices is well established in the mental health and caregiving literature (e.g., Broady et al., 2017; Estradé et al., 2023; Happell et al., 2018) and Australian policy since 1992 (Australian Health Ministers, 1992; Whiteford, 1993), this study presents tangible strategies for researchers and professionals to actively translate these voices into practice.

4.2. Strengths

The main strength of this assessment is that it provides a different viewpoint, that is, one that focuses on the benefits of the research and its impact rather than on trial results. This information is useful for policy makers and funders of research who want to understand not just what the research found or did not find, but what has been the overall value in investing in the research.

Second, the mixed-methods approach of the assessment aligned well with the research approach of the *Minds Together* research program. It allowed for impacts to be described quantitatively via the metrics, qualitatively through the voices of the beneficiaries and in economic terms through a CCA.

4.3. Limitations

Some key limitations should also be acknowledged. Firstly, it should be noted that research is not linear. FAIT assumes a linear, sequential approach to research that maps a pathway from need to impact. This is not an accurate representation of how most research programs operate in practice. Translation can and did occur at different stages of the research process. To assess impact, the application of FAIT abstracts and simplifies the process. This may pose a limitation

for readers who want a clear understanding of the research program and any inherent complexities. Specific and focused *Minds Together* publications are preferable sources for this information.

The timing of this assessment (post-RCT and pre scale up) meant that it was premature to report quantitative evidence with and monetised valuation of many impacts such as improved quality of life and productivity outcomes for consumers. This limitation of impact assessment using the available evidence can be addressed to some extent by the inclusion of simulation modelling to estimate possible downstream outcomes. However, the modelling necessarily brings an element of uncertainty, deemed unsuitable in this application. Hence, the ability to fully report impact in terms of downstream effects was limited. Understanding time lags in translational research has been discussed in the literature and remains a challenge (Hanney et al., 2015; Morris et al., 2011).

4.3.1. Retrospective Versus Prospective Application

Prospective application of FAIT was not possible in this assessment. This was because the *Minds Together* research was largely complete at the start of the impact assessment. Prospective application may have identified potential benefits and costs that were not apparent in retrospect. Further, it is important that next-users' understanding of what comprises benefit is included and considered in an impact analysis. The ability to have next-users shape the research translation pathway is highly advantageous and optimises the likelihood of research realising impact. In this application, this risk was mitigated by the reflective nature of the research team. Opportunities to consult and engage with consumers and partner organisations were built into the research process, such as the use of a working group, and the use of consumer surveys and interviews embedded within all studies.

5. Conclusion

The retrospective application of FAIT to the *Minds Together* program was feasible in this study. The framework identified benefits of the research beyond trial outcomes, particularly in terms of capacity building. In estimating the productivity loss and poor quality of life of carers of a person with mental ill health, the study has highlighted the need for greater translation of research into cost effective ways to support these carers in their roles. Reflecting on this mixed methods approach to research impact also highlighted the importance of next users' in effective translation of research.

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