

OPHELIA CVD: A Pilot Study of Optimising
Health Literacy in 'Hard to Reach' Men for
the Primary Prevention of Cardiovascular
Disease. (2016 -2018)



UNIVERSITY *of*
TASMANIA

Report prepared by Sarah Randles and Jan Radford. Finalised in collaboration with Leigh Kinsman, Manager of First Point (Nettie Burr) and Manager of the Northern Suburbs Community Centre (Denise Delphin), and the Newstead Medical general practice: 17 April 2019

Suggested citation (APA style):

Kinsman L, Radford J, Elmer S, Ogden K, Randles S, Hodson A & Gardner T. (2019) *OPHELIA CVD: A Pilot Study of Optimising Health Literacy in 'Hard to Reach' Men for the Primary Prevention of Cardiovascular Disease. (2016-2018)* Launceston: University of Tasmania

Copies of this report can be obtained from Jan Radford (J.Radford@utas.edu.au)

Table of Contents

OPHELIA CVD: A Pilot Study of Optimising Health Literacy in ‘Hard to Reach’ Men for the Primary Prevention of Cardiovascular Disease. (2016 -2018).....	1
Executive Summary.....	6
1. Key Stakeholders and Personnel.....	7
1.1 Chief Investigators	7
1.2 Other Project Personnel.....	7
1.3 Project Funding	8
2. Partnerships	9
3. Background	9
3.1 Health Inequities.....	9
3.2 Health Literacy	10
3.3 The OPHELIA approach	10
3.4 Need for Intervention in the Target Group.....	11
4. Purpose	11
4.1 Overall Aim of the Project.....	11
4.2 Objectives.....	12
4.3 Hypotheses	12
5. Intervention as initially planned	13
5.1 Design.....	13
5.2 The OPHELIA Process – A Six Step Intervention.....	13
5.2.1 Needs Assessment	14
5.2.2 Planned identification of performance objectives, determinants and change objectives..	15
5.2.3 Planned selection of new activities, methods, and strategies.....	15
5.2.4 Planned detailed design and planning of activities	15
5.2.5 Planned adoption and implementation of activities	16
5.2.6 Planned implementation trial	16
6. Implementing the OPHELIA Process – Steps Undertaken.....	16
6.1 Setting	16
6.2 Participants	16
6.3 Exclusion	16
6.4 Recruitment Methods.....	17
6.5 Engagement Strategies	17
6.6 Data Collection.....	17
6.6.1 Quantitative Data.....	17
6.6.2 Qualitative Data	18

6.7 Focus Groups.....	18
7. Research Results	19
7.1 Recruitment	19
7.2 Survey.....	19
7.2.1 The Health Literacy Questionnaire (HLQ)	19
7.2.2 General Practice Preventative Health Service Questionnaire (GP-PHSUQ).....	21
7.2.3 Assessment of Quality of Life – 8D instrument (AQoL-8D).....	22
7.3 Interviews.....	22
7.3.1 Changing Habits	23
7.3.2 A Sense of Purpose	23
7.3.3 Interactions with the Healthcare System	23
7.3.4 Mental Health Benefits of the Men’s and Community Shed	24
7.3.5 Peer Support	24
7.3.6 Helping Others	24
7.3.7 A sense of Community	24
7.4 Vignettes	25
7.5 Focus Groups.....	25
7.5.1 Ravenswood Men’s Focus Groups	25
7.5.2 GP Practice Focus Groups	25
8. Discussion of Results.....	26
8.1 Physical and Mental Health of the Target Group	26
8.2 Health Literacy and Access to Healthcare.....	27
8.3 Focus groups and Potential Interventions	27
8.4 The Role of the Men’s and Community Sheds.....	28
9. Outcomes.....	28
9.1 The Value of Community Engagement and the OPHELIA Approach	28
9.2 Implications for Future Research	29
9.3 Implications for the Community	30
9.4 Implications for Future Policy	30
9.5 Implications for Medical Students	30
Funded Projects	30
10. Conclusions and Recommendations.....	31
Realist Evaluation.....	32
11. Recommendations.....	32
References:	33
Appendices.....	35

Appendix 1.	35
Setting the scene for the OPHELIA-CVD project	35
Background – Mr Mick Goss	35
Background - Dr Kath Ogden	36
Background - Mobile And Confident: People Avoiding Chronic Conditions	36
Appendix 2. Data Collection Matrix	38
Appendix 3. Interview Framework.....	39
Appendix 4. Letter to Prospective Participants from GP	40
Appendix 5. GP Flow Chart	42
Appendix 6. Participants’ Flow Chart.....	43
Appendix 7. Study Poster	44
Appendix 8. Inclusion/Exclusion Criteria	45
Appendix 9: Interview Schedule for Use with Men Using the Ravenswood MACS.....	46
Appendix 10: Vignettes.....	47
Vignette 1: Bruce	47
Vignette 2: Wayne.....	47

Executive Summary

The aim of this project was to investigate the impact of the Optimising HEalth LIterAcy (OPHELIA) approach on a population of 'hard to reach' men from Launceston's northern suburbs who are at increased risk of cardio-vascular disease (CVD). It was hoped that the intervention would enable positive lifestyle changes in the study population, through the community organisations and general practices which care for them and deliver CVD-prevention messages or activities.

The study was based on the hypotheses that the OPHELIA approach would lead to improvements in health literacy measures in patients at risk of CVD who were disadvantaged by poorer access to health services and lower socio-economic status; and that the OPHELIA approach to health literacy would also produce targeted interventions which would have a positive effect on lifestyle behaviours, the risk of CVD, use of health services for primary prevention and care, and quality of life for this group.

The OPHELIA-CVD project recruited participants from Ravenswood through Mr Mick Goss and the Ravenswood Neighbourhood House (Starting Point). While difficulties were encountered both in recruiting the numbers of participants originally anticipated, and in retaining participants to enable the envisaged longitudinal study, underscoring the 'hard to reach' nature of the target group, the researchers adopted a pragmatic approach, using the data obtained in the initial health literacy survey and individual interviews to provide vignettes of the target group.

The vignettes distilled the issues raised by the surveys and interviews and allowed the OPHELIA approach to be used in the target audience of one general practice and Starting Point-based groups by acting as triggers to discussion. The facilitated discussions also encouraged an active role for the target audience in designing interventions to improve the health literacy and mental and physical health, including reducing risk factors for cardio-vascular disease, of 'hard to reach' men.

During the research, funding was achieved to develop first the Ravenswood and then the Rocherlea Men's Sheds, subsequently named the Ravenswood Men's and Community Sheds (MACS) and 'The Shed (Rocherlea)'. While the OPHELIA-CVD project takes no credit for these outcomes, they closely corresponded with the information obtained from the study's participants. The OPHELIA approach has led to a range of other funded projects including 'Healthy Sheds', a highly successful intervention program, which was funded by the Tasmanian State Government under the Healthy Tasmania program, in direct response to the needs identified during the OPHELIA-CVD project. The OPHELIA-CVD project also led to the granting of anticipatory care funding in 2018 to the neighbourhood houses in Ravenswood and Rocherlea to develop projects designed to improve the health of people living in Launceston's northern suburbs. A request for numeracy training by men using the Ravenswood Men's and Community Shed has also led to a grant to develop a program with them in 2019.

Working closely with the Northern suburbs community, subsequent programs will hopefully provide the basis for further research and have or will provide interventions to improve health literacy and reduce the risk of cardiovascular and other disease in this and other target groups of the initial OPHELIA-CVD project.

1. Key Stakeholders and Personnel

1.1 Chief Investigators

- Professor Leigh Kinsman, School of Health Science, University of Tasmania and, as of 2018, of the University of New Castle
- Dr Shandell (Shan) Elmer, Research Fellow, Launceston Clinical School, School of Medicine, University of Tasmania
- Associate Professor Jan Radford, A/Prof of General Practice, Launceston Clinical School, School of Medicine, University of Tasmania
- Dr Kathryn (Kath) Ogden, Launceston Clinical School, School of Medicine, University of Tasmania
- Professor Stephen Campbell, Primary Care Research, University of Canberra and University of Manchester
- Dr Toby Gardner, Lecturer in General Practitioner, Launceston Clinical School, School of Medicine, University of Tasmania
- Dr Andy Hodson, Senior Lecturer in General Practice, Launceston Clinical School, School of Medicine, University of Tasmania
- Dr Masuma Khanam, Postdoctoral Research Fellow, School of Health Sciences

1.2 Other Project Personnel

- Mr Mick Goss, convenor the Rocherlea Men's Group and long-term agitator for Men's sheds in the northern suburbs
- Ms Nettie Burr, Manager, Ravenswood Neighbourhood House (Starting Point)
- Ms Denise Delphin, Manager, Northern Suburbs Community Centre (Rocherlea, Newnham & Mayfield)
- Practice Manager and General Practitioners (GPs) Newstead Medical, Newstead
- Practice Manager and GPs of the Caledonian Medical Centre, Invermay
- Ms Martina Wyss, Masters Student, School of Health Science, University of Tasmania
- Ms Diana Taylor, Medical Student, Launceston Clinical School, School of Medicine, University of Tasmania
- Mr Suman Pillai, Medical Student, Launceston Clinical School, School of Medicine, University of Tasmania
- Mr Gak Tung, Medical Student, Launceston Clinical School, School of Medicine, University of Tasmania
- Mr Zhen Liew, Medical Student, Launceston Clinical School, School of Medicine, University of Tasmania
- Mr Zhihong Kauh, Medical Student, Launceston Clinical School, School of Medicine, University of Tasmania
- Mr George Dargaville, Medical Student, Launceston Clinical School, School of Medicine, University of Tasmania
- Mr Callum Walker, Medical Student, University of New England
- Ms Felicity Goody, Medical Student, University of New England
- Ms Camila Singhai, Medical Student, University of New England
- Prof Richard Osbourne, Prof. of Public Health, Deakin University

1.3 Project Funding

The project was initially carried out by University of Tasmania staff members and medical students. A contribution was also made by four University of New England medical students. Research support to collate data and prepare it for publication was funded by a University of Tasmania 'Better Health' grant of \$19,829 in 2018.

2. Partnerships

This research has solidified existing relationships between the University of Tasmania and the community organisations in the northern suburbs of Launceston. The research team has been working together for four years to establish a relationship with men in the Ravenswood and Rocherlea communities, and to gather preliminary data. The project has also cemented an existing alliance between UTAS and the Deakin University World Health Organisation Collaborating Centre for Health Literacy, and between the Schools of Health Sciences, Medicine and Education.

This project also relied on continuing partnerships with the Ravenswood Men's and Community Shed, the Ravenswood and Northern Suburbs Neighbourhood Houses, and two general practices, the Caledonian Medical Centre, and Newstead Medical.

3. Background

3.1 Health Inequities

Many Australians experience health inequities despite considerable policy and health service investments. Some Australian communities disadvantaged by geography and socio-economic circumstances experience 40% more deaths due to heart disease and cancer than other communities. In particular, non-metropolitan Australians are up to 30% more likely to be admitted to hospital for cardiovascular disease (CVD) than those living in major cities and are up to 40% more likely to die from CVD and develop heart failure at a younger age. (1-3)

These inequities can be attributed to four factors:

1. Poorer access to health services; (4)
2. Worse lifestyle and risk factor profiles;(5)
3. Lower socio-economic status;(6) and
4. The state of indigenous health.(7)

The combination of these factors is very relevant in the northern suburbs of Launceston, Tasmania, the site for this study.(8) Improving health literacy has great potential to help this group of non-metropolitan Australians overcome disadvantage related to health service access and socio-economic status.(9)

In addition, the team's previous research shows that primary care practitioners (GPs and nurses) in non-metropolitan settings express frustration at their lack of time and resources to engage patients with low health literacy in CVD prevention, and their consequent lack of success. This frustration affects the care given within general practices.(10)

Although 80% of Australians visit their GP at least once a year, a lower proportion of middle-aged men are seen in general practice compared to other cohorts, so opportunities for preventative healthcare are missed entirely.(11)

3.2 Health Literacy

Recent research has identified the importance of health literacy in the health of individuals and population groups.

Health literacy has been defined as ‘the ability to make sound health decisions in the context of everyday life; at home, in the community, at the workplace, the health care system and the political arena. It is a critical empowerment strategy to increase people’s control over their health, their ability to seek out information and their ability to take responsibility’.(12)

A complementary description of health literacy is ‘the ability of an individual to find, appraise and apply information to promote and maintain good health and wellbeing. It is composed of three interwoven components: the individual, the community they belong to and the healthcare environment’.(13)

The OPHELIA-CVD project focused on the health literacy of the participants as individuals within the context of their community and the specific healthcare environment.

3.3 The OPHELIA approach

The OPHELIA (OPTimising HEalth LIterAcY) process was developed by Professor Richard Osborne and his team at Deakin University. It is based on the increasingly wide understanding that improving health literacy is an important way to improve health outcomes, especially for those with long-term conditions. The OPHELIA approach recognises that improvement in individual and population health depends not just on the health literacy characteristics of the individuals, but also on the capacities and abilities of the local health systems and organisations. In a study based in Newcastle-upon-Tyne in the UK, this team showed how service improvements could be directly designed around the health literacy characteristics of people living in one of the most deprived areas of the city. This study confirmed the method as ‘practical and applicable’.(14)

The OPHELIA approach incorporates a clear set of eight principles to guide flexible implementation by stakeholders with diverse skills in different settings. These principles are that the research and its implementation should be:

- Outcomes focused,
- Equity driven,
- Driven by local wisdom,
- Sustainable,
- Responsive, and
- Systematically applied; and that it should incorporate:
 - Needs diagnosis, and
 - Co-design.

OPHELIA is a grassroots, non-expert system, based on local wisdom, and which therefore can provide an approach which overcomes organisational barriers.(14) The

OPHELIA approach combines community engagement with health literacy profiling to develop locally-driven interventions to reduce health inequities. At the centre of the OPHELIA approach are the iterative ‘Plan-Do-Study-Act’ cycles, in which the researchers work with health professionals and the client group to select activities which are based on a needs assessment, locally-generated ideas and available literature. These activities are then implemented and evaluated.

3.4 Need for Intervention in the Target Group

In 2014 Mr Mick Goss asked Dr Kath Ogden to deliver her Health-Stop check-ups to men from a group Mick convened in Rocherlea. See Appendix 1. As Mick suspected and Kath’s group found it was felt that more could be done to reach ‘hard to reach’ men from the northern suburbs to improve their heart disease risk factors. Mick had always championed Men’s Sheds as described in Appendix 1.

Prof. Leigh Kinsman then took the lead with a second survey of thirty-five participants at a BBQ (barbeque) in Ravenswood on the 19th of October 2015. While the primary purpose of this survey was not to assess the participants’ health literacy, but rather the need and support for a Ravenswood Men’s Shed, it nonetheless provided data which gave an insight into the baseline health status and health literacy of the target group. The responses to this survey showed that almost half of the respondents indicated that they were suffering from significant anxiety and depression. There was a shortfall in the capacity to find, understand and appraise health information and the lifestyle, demographic and health-related data showed indicators of ‘poor’ health: half of the respondents lived alone; most were unemployed; arthritis and pain were major issues; most regularly forgot to take medications or stopped medications if they felt better; and many had extremely poor diets. 72% of respondents supported the idea of a men’s and community shed.

This demonstrated the need for further research into the health status of this group and the potential value of an OPHELIA intervention, as well as the importance of community organisations in reaching this group of participants.

4. Purpose

4.1 Overall Aim of the Project

The purpose of the OPHELIA-CVD project was to use the OPHELIA approach as a framework for community engagement with middle-aged men in a disadvantaged community.

The project also aimed to investigate the impact of the OPHELIA approach on the health literacy of a population of ‘hard to reach’ men from Launceston’s northern suburbs who are at increased risk of cardio-vascular disease (CVD).

4.2 Objectives

The OPHELIA-CVD objectives were patient/client-centred and aimed at effecting lifestyle and behavioural change, to reduce the risk of cardiovascular disease and increase quality of life.

Specific objectives were:

- To assess the effectiveness of the OPHELIA approach in enabling effective communication with the target group of 'hard-to-reach' men.
- To measure the impact of the OPHELIA approach on health literacy and to effect a measurable change in health literacy.
- To effect lifestyle changes in the study population. The study planned to collaborate with community groups as well as local general practices to design and test ways of engaging 'hard-to-reach' men to improve their understanding of CVD and how it could be avoided.
- To identify the appropriate interventions needed for the OPHELIA approach to have a positive impact for that same population on their health literacy, lifestyle behaviours, risk of CVD, use of health services for primary preventative care and quality of life.

Additional objectives were:

- To create a baseline of data for future research and for future continuous quality improvement initiatives, including providing researchers, community organisations and general practice staff with a baseline assessment of the health measures and health literacy of the target population.
- It was also expected that the broader effects of the targeted approach of the OPHELIA-CVD pilot study might impact practise and create change at an organisational level, including systems change in the general practices which care for the study population, and in the community organisations who deliver CVD prevention messages or activities.

4.3 Hypotheses

The hypothesis for this research project was that the OPHELIA approach would improve health literacy measures in men at risk of CVD in a group which is disadvantaged by poorer access to health services and lower socio-economic status. A secondary hypothesis was that the OPHELIA approach would produce targeted interventions that had a broader positive impact on lifestyle behaviours, use of health services for primary preventative care, and quality of life for people disadvantaged by poorer access to health services and their socio-economic status.

5. Intervention as initially planned

The research used the OPHELIA approach to conduct a health literacy evaluation of the target group of middle-aged men and to gain their input into designing an intervention aimed at improving their health literacy and general health, particularly in ways relevant to reducing their risk of CVD.

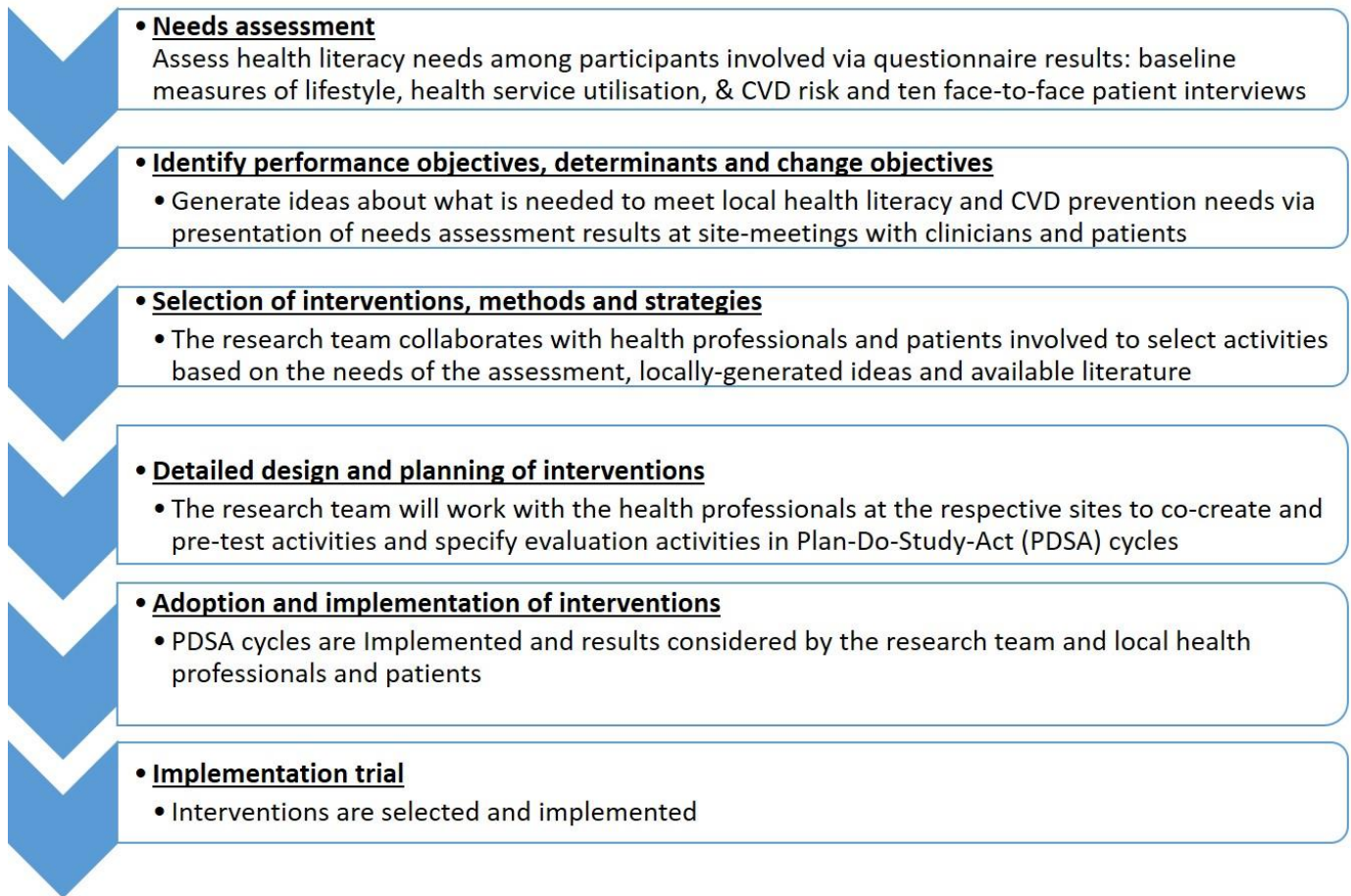
5.1 Design

The OPHELIA approach combined health literacy profiling with community engagement to work closely with men in the northern suburbs to negotiate, develop and implement their own health promotion programs. This approach was chosen to increase the participants' ownership and engagement in health promotion activities. This was a pilot study using a mixed method approach designed to investigate the impact of the OPHELIA approach on health literacy and CVD risk in a non-metropolitan, socio-economically disadvantaged population. The use of mixed methods enabled a deeper understanding of both the data and the target group.

5.2 The OPHELIA Process – A Six Step Intervention

The OPHELIA approach was implemented to apply to the primary prevention of CVD in a low socio-economic group with poor access to health service, as 'OPHELIA-CVD'. A six-step method, including a planned intervention, outlined in Figure 1, was customised for the OPHELIA CVD Project.

Figure 1: Steps in the OPHELIA-CVD intervention (15)



5.2.1 Needs Assessment

Data for the OPHELIA-CVD project came from participants recruited via the Ravenswood community centre. The data measured participants' health literacy, lifestyle, risk of CVD, and health service utilisation for preventive care and quality of life. Analysis of this baseline data was used to identify profiles and clusters of groups of individuals within the northern suburbs of Launceston. These data were then synthesised to generate vignettes (see Appendix 10) representing various health literacy levels of the typical groups of participants living in the northern suburbs. The vignettes and needs assessment data formed the basis of face-to-face meetings with the research participants, staff and volunteers at the community centres, and health professionals (General Practitioners, Practice Nurses, allied health providers and practice managers within recruited practices).

In these meetings participants were invited to consider the vignettes and identify ideas that they believed would:

1. Enhance the health literacy and healthy lifestyle of those at risk of CVD;
2. Involve the local community in social development activities with potential to improve health literacy and prevent CVD

3. Improve their organisation's response to the identified health literacy, and CVD preventive needs of these members of their community

The steps above were undertaken – the following steps were planned but not undertaken. Instead momentum for the formation and building of Men's and Community Sheds (MACS) in Ravenswood and Rocherlea meant that the community achieved success in the formation and functioning of both MACS.

5.2.2 Planned identification of performance objectives, determinants and change objectives

The research team and health professionals from the selected general practices and community groups were to be invited to participate in planning activities. The first of these would use the needs assessment data to begin construction of a program logic model to depict proposed changes and outcomes. The logic model would be a focus for decision-making about planned new activities and is a well-established science that has underpinned the use of OPHELIA in chronic disease settings.(15)

5.2.3 Planned selection of new activities, methods, and strategies

The various local providers identified new activities that they perceived would have the potential to achieve the desired organisational and client outcomes for improved health literacy and reduced risk of CVD. In other early trials of OPHELIA in chronic disease populations, these new activities have been varied and specific, ranging from the development and dissemination of information pamphlets to group exercise classes.

Initial ideas for new activities would be discussed at a workshop attended by the research team, community workers, health professionals and the research participants. The general practices, research participants and community groups involved in the recruitment of patients were given the opportunity to revise their proposed new activities based on feedback from the research team. The general practices, research participants and community groups involved would be assisted to partner with each other to develop a community of practice through shared interests, knowledge and experience in enhancing health literacy and preventing CVD in hard-to-reach populations.

5.2.4 Planned detailed design and planning of activities

This next stage of the research would involve specifying the scope and sequence of new activities and determining the required resources and materials needed to implement it, which would then be sourced within the general practices, community groups, and/or provided by the research team. The research team would work with the target group at the research sites to co-create and pre-test these activities using 'Plan-Do-Study-Act' (PDSA) cycles.

5.2.5 Planned adoption and implementation of activities

There would be an emphasis on testing the new activities and the sharing of discoveries between the implementation sites through the development of a community of practice in the OPHELIA method. The aim of the fourth and fifth steps in the OPHELIA CVD intervention was to ensure that the community groups and/or the general practices have implementable interventions in place for testing during the final stage.

5.2.6 Planned implementation trial

The interventions would be implemented according to the identified priorities of the recruited patients/clients/hard-to-reach community members at risk of CVD. Methods to measure and monitor the level of participation by these subjects would be designed based on the RE-AIM (Reach Effectiveness Adoption Implementation Maintenance) framework and an ethics amendment would be submitted at the time to clarify interventions and evaluation methods.

6. Implementing the OPHELIA Process – Steps Undertaken

6.1 Setting

The research was carried out at the Ravenswood Men's Shed and general practices located within the northern suburbs of Launceston, Tasmania.

6.2 Participants

The project aimed to recruit men between the ages of 30 and 60 living in the northern suburbs of Launceston. Participating general practices and community organisations were asked to identify male patients or clients who would be suitable participants.

6.3 Exclusion

People who were already diagnosed with CVD, a terminal illness, and/or advanced dementia were excluded from this study. CVD for these purposes was any past history of myocardial infarction, angina, peripheral vascular disease or vascular surgery. A terminal illness was defined as a treating clinician's view that the patient will die within the next six months. Advanced dementia was defined as a mini-mental exam score of 15/30 or less.

6.4 Recruitment Methods

The Neighbourhood Houses in Rocherlea and Ravenswood were approached to help recruit participants who may not access local general practices. It was hoped that these connections would provide practical assistance in accessing 'hard to reach' individuals, particularly the estimated 20% who were not connected with a general practice.

Both community group staff and the recruited participants were invited to participate in meetings to co-create interventions and in the focus group to reflect on the impact of the project.

The staff of general practices in the area were invited to participate in group meetings to co-create interventions and in a focus group to reflect on the impact of the project.

6.5 Engagement Strategies

The University of Tasmania used a range of strategies to engage with the target group of middle-aged men. By working with the northern suburbs community centres over two years, they established trust with clients of the services and developed strong working relationships with the staff of the centres.

Information was gathered via Health Literacy Questionnaires and follow up interviews conducted by the medical students. These were conducted orally to avoid potential problems to do with literacy difficulties. They were also conducted at informal BBQs held at the community centres to provide a welcoming and non-threatening approach.

6.6 Data Collection

6.6.1 Quantitative Data

Health literacy data was collected using a Health Literacy Questionnaire (HLQ). Baseline demographic information (including details such as age, gender, living arrangements, medical conditions, and measures of socio-economic and educational status) was collected at recruitment using the EPA-CVD EUROPEP questionnaire.

The 44-item HLQ covers 9 conceptually distinct areas of health literacy, in order to assess the needs and challenges of a wide range of people and organisation. It has proven to be useful in diverse participant groups, including those who are socio-economically disadvantaged, and it is sensitive to changes over 6 months (9). The following three sub-scales were selected, since they have the strongest logic towards capturing mechanisms of change that link to primary prevention of CVD:

1. Actively managing health,
2. Understanding health information well enough to know what to do, and

3. Having sufficient information to manage health.

Lifestyle measures were collected using the **EPA-CVD EUROPEP** patient survey, which was validated through a large European Study and found transferrable to the Australian context.(10, 16) It can be collected via interview when participants' literacy levels are insufficient. Measures include health perception, smoking status, quality of eating, exercise pattern & motivation to change.

Use of health services for preventative care was measured using the **General Practice Preventative Health Service Questionnaire (GP-PHSUQ)**. This questionnaire was developed to measure primary care use specifically for the purpose of primitive care.(17) The OPHELIA CVD project excluded items scoring health status perception, smoking and lifestyle that overlapped with the EUROPEP questionnaire.

Quality of life was measured using the **Assessment of Quality of Life – 8D instrument (AQoL-8D)**. This instrument is ideal for the target population as it has been tested and validated in groups with low socio-economic status, those at risk of CVD (particularly obesity, which has a high prevalence rate in the communities in this study) and has been found to be sensitive in measuring quality of life in people with mental health problems. (18, 19) Additionally, due to extensive use in Australian populations we have normative data with which to compare our sample.(20)

6.6.2 Qualitative Data

The quantitative data was supplemented with qualitative data collected via face-to-face interviews with up to ten of the respondents. Each respondent was assigned a pseudonym. The transcriptions of the interviews held with the clients/patients were analysed using reading frames to identify themes and concerns raised by the interviewees.

6.7 Focus Groups

The OPHELIA protocol was implemented to craft two clinical vignettes (see Appendix 10) based on analysis of both the qualitative and quantitative data collection. These were descriptions of fictional individuals with similar health and health literacy profiles to users of the health care systems and organisations. The vignettes were then used in focus group discussions as a basis for discussion of the findings. The focus groups were audio-recorded and notes were taken. These focus groups identified both the areas of health that the target audience felt needed improvement and the interventions needed.

7. Research Results

7.1 Recruitment

All of the participants were recruited through the BBQs held at the Ravenswood Men's Shed. Ten men completed the survey which consisted of the Health Literacy Questionnaire (HQL), the EPA-CVD EUROPEP patient survey, the General Practice Preventative Health Service Questionnaire (GP-PHSUQ), and the Assessment of Quality of Life – 8D instrument (AQoL-8D). Six men participated in face-to-face interviews.

7.2 Survey

The survey comprising the Health Literacy Questionnaire (HLQ), the EPA-CVD EUROPEP patient survey, the General Practice Preventative Health Service Questionnaire (GP-PHSUQ), and the Assessment of Quality of Life – 8D instrument (AQoL-8D) was completed by 10 participants at a barbecue held at the Ravenswood Men's and Community Shed. The survey questions were administered verbally to circumvent any literacy issues, with answers grouped on Likert scales with no midpoint. The information gained from the questionnaires provided a valuable insight into the target group, their lifestyles, health and health literacy, as well as information which would help design further research into this and similar groups.

7.2.1 The Health Literacy Questionnaire (HLQ)

Section A – Factors Relating to the Use of GPs

- The respondents identified the cost of seeing a doctor as a significant factor, with 8/10 ranking it as very or fairly important. 8 out of 10 found it very important or fairly important that the doctor bulk bill them.
- The availability of transport to the doctors was likewise important 8/10 ranking it as very or fairly important. The amount of time needed to travel was less significant with 5/10 considering it as very or fairly important.
- The relationship with an individual doctor was a significant concern, with 9/10 considering it as very or fairly important. All ten respondents ranked the amount of time spent with the doctor as very or fairly important. 8/10 ranked the time taken to get an appointment as very or fairly important.
- Less significant aspects were the number of doctors in a practice, with only 6/10 ranking it as an important factor, and only 4/10 thought the amount of waiting time at the general practice was important.

Section B – Attitudes to Doctors

- 9/10 of the respondents agreed that the care they had received from doctors in the last few years had been good, and all the participants agreed that even if a person is feeling okay, they should get a check-up every year or so. 7/10 disagreed with the statement that if you wait long enough you can get over almost every disease without seeing a doctor.

- However, there was evidence that many of the respondents were reluctant to visit doctors. 6/10 agreed that they avoided seeing a doctor whenever possible, and the same number believed that a person understands their own health better than most doctors do. 7/10 only go to a doctor if there is no other option.
- The respondents were evenly split between those who agreed and disagreed that doctors belong to a very high-status profession, that many doctors are more interested in their own income than in making sure everyone receives adequate medical care, and that it's important to choose your doctor carefully in order to get good medical care.

Section C – Social Support

- 8/10 of the respondents agreed that people didn't visit them as often as they would like, and 7/10 agreed that they often felt lonely. 6/10 felt that they often needed help from other people but couldn't get it.
- However, 6/10 respondents felt that they seemed to have a lot of friends, with the same number believing that there was always someone who could cheer them up, and 8/10 disagreed with the statement that they had no-one to lean on in times of trouble, or that they didn't have anyone they could talk to.
- All of the respondents agreed that they enjoyed spending time with the people who were important to them, and 8/10 agreed that if something was on their mind, talking about it with people they knew made them feel better.

Section D – Making Changes to Improve Health

- The majority of the men were willing to make health improvements if their doctor advised them to. All of them were likely or very likely to spend more time doing things with family or friends, 8/10 were likely or very likely to get more exercise, 7/10 likely or very likely to get more rest or sleep, and 6/10 likely or very likely to stop eating some favourite foods.
- However, 7/10 reported they were unlikely or very unlikely to cut down on the amount of work they did.

Smoking and Medication

- 4/10 of the respondents currently smoke, with 4/10 having given up more than six months ago.
- 7/10 men take regular medication.

Physical Activity

- This section produced data that was too difficult to interpret so it has been omitted.

Eating Habits

- 6/10 of the respondents reported that they usually or sometimes ate less than two servings of whole grains or high fibre starches in a day, with the same number

eating less than two servings of fruit, and less than two servings of vegetables in a day.

- 4/10 eat less than two servings of dairy in a day.
- 6/10 would sometimes eat fried food in a week, and 5/10 would sometimes eat chips, nuts etc., rather than low fat snacks in a week.
- However, only 3/10 eat more than 250g of meat or fish in a day, and 3/10 would use processed meat in a week.
- 2/10 usually or often add fats to bread, rice or potatoes, and 5/10 sometimes do.
- 5/10 sometimes or usually eat sweets in a week, while 5/10 usually or sometimes drink 500ml of sweet drinks in an average week.
- Only 2/10 sometimes or usually drink more than 1 or 2 alcoholic drinks in a day.
- All the men were willing to make changes to their eating habits.

7.2.2 General Practice Preventative Health Service Questionnaire (GP-PHSUQ)

- 9/10 of the respondents agreed or strongly agreed that they had good information about health, and 6/10 felt that they had the ability to compare health information from different sources, and the same number felt they had enough information or all the information they needed to deal with healthcare problems. However, half did not know how to find out if health information was right or wrong, 4/10 found it quite difficult to get information by themselves, and half said it was difficult to work out what is the best care and did not feel able to ask their health care provider about the quality of the information. 4/10 found it very or quite difficult to make sure that their health care provider understood their problems correctly, and 3/10 found it hard to understand what their health care providers were asking them to do. 6/10 did not check new information about health.
- 8/10 had a health care provider, 6/10 felt that their health provider knew them well, and 9/10 felt that they had at least one health care provider with whom they could discuss problems. 8/10 felt they could rely on at least one health care provider. However, 3/10 found it difficult to find information about health problems and 2/10 found it difficult to discuss health concerns with their health care provider. Half found it difficult or impossible to confidently fill in medical forms correctly.
- 6/10 felt that they did not have access to people who would support them and disagreed that they had plenty of people to rely on. The same number reported that they did not have strong support from family and friends. 7/10 felt that people did not understand what they were going through in times of illness, and 7/10 did not have at least one person to accompany them to an appointment.
- 6/10 agreed or strongly agreed that they spent a lot of time actively managing their health, and the same number made time to be healthy. 7/10 felt they did regular things to be healthy but only half agreed that they made plans to be healthy. 8/10 reported that they set their own goals for health and fitness. 4/10 found it very or quite difficult to look after their own health.

7.2.3 Assessment of Quality of Life – 8D instrument (AQoL-8D)

- 4/10 men described themselves as ‘usually tired and lacking energy’ with a further 3/10 considered themselves only ‘occasionally energetic’.
- 6/10 felt often or sometimes socially excluded or left out, 7/10 reported feeling socially isolated sometimes, often or always. 2/10 reported dissatisfying relationships with family and close friends; 6/10 reported that they enjoyed close relationships immensely or a lot and 8/10 felt generally happy in their close or intimate relationships. Half reported difficulties in communication, either in understanding others or being understood.
- Half of the respondents found at least some level of difficulty in getting around by themselves outside the house, and 4/10 had some level of difficulty with mobility, and one found self-care tasks difficult but managed by himself. 4/10 reported only being able to basic tasks slowly or not at all without help. 2/10 felt themselves a burden to others a moderate amount or a lot. 6/10 reported difficulties with vision and the same number reported difficulties with hearing. 1/10 felt their role in the community was affected by their health and half said that their health meant they could not carry out some or all of their role within their family. 6/10 often or always had trouble sleeping.
- Half the men experienced serious pain most of the time and another reported it 3 to 4 times a week. 6/10 reported that they had moderate pain, and 3/10 reported severe pain. 7/10 said that pain interfered with their usual activities sometimes, often or always.
- 3/10 reported feeling sad either usually or nearly all of the time. 6/10 felt mostly happy; the remaining 4 felt happy only sometimes. Half reported feeling agitated sometimes; one respondent described himself as usually agitated. 3/10 felt worried often or all of the time in the last seven days, with a further 5/10 feeling worried sometimes within the last week. Half of the men said they always or usually felt pressure. 7/10 sometimes felt worthless, and 6/10 sometimes felt angry. 2/10 felt they could only partly cope with life’s problems. 8/10 felt either not much enthusiasm or none at all. 2/10 felt like hurting themselves, albeit ‘rarely’. 7/10 felt depressed sometimes, often or very often, and the same number had occasionally or sometimes felt despair over the last seven days. Only 3/10 reported being mainly content with their lives; the remainder only moderately, slightly or not at all, and only half reported feeling mostly in control of their lives.

7.3 Interviews

Face to face interviews were conducted with six participants at the barbecue held in September 2017. The interviews were conducted by final year medical students from the University of New England (UNE) using a series of prompt questions for guidance (see Appendix 10). The interviews were semi-structured and focused on the participants’ experience of attending the Men’s and Community Shed (MACS), and the effects that participation might have had on their physical and mental health. The interviews were recorded with the men’s consent, transcribed and then de-identified by using pseudonyms.

Of the six men interviewed, two were retired, two were unemployed and two were employed at the MACS under the Work for the Dole Scheme. Three reported a history of mental illness. One was a carer for a family member.

The transcripts of the interviews were analysed using a reading frame. The interviews highlighted the following themes:

- Attending the MACS facilitated breaking or lessening of negative habits.
- Attending the MACS alleviated boredom and provided the men with a sense of purpose.
- Some respondents indicated their reluctance to seek conventional medical help, and negative experiences with the health system.
- Some of the men mentioned the mental health benefits of attending the MACS.
- There was a sense of support from the other men who attended the MACS.
- Several men reported that they gained fulfillment from helping others.
- Some of the interviewees alluded to a sense of belonging or welcome that they experienced at the MACS.

7.3.1 Changing Habits

A number of the interviewees mentioned that coming to the MACS had had a positive impact on negative habits, such as smoking, drinking alcohol and gambling.

‘... when I’m working I only smoke 2 a day. That’s about it. But when I’m home it’s a lot more.’ – ‘Robert’

‘I just got carried away with the smoke and a little bit of homebrew ... I haven’t had a drink for five days ...’ – ‘Daniel’

7.3.2 A Sense of Purpose

Many of the men mentioned that coming to the MACS gave them something to do, and many referred to a sense of boredom that that it helped to alleviate.

‘You can only play golf so many times a week.’ – ‘Chuck’

‘Keeps me occupied. Keeps me from sitting ‘round the house watching the bloody telly all day.’ – ‘Robert’

7.3.3 Interactions with the Healthcare System

Two of the men had been hospitalised with mental illness. One of these reported negative interactions with the healthcare system. Another reported a history of depression. One man commented on a reluctance to engage with healthcare providers.

‘I’m a bloke, we don’t go to doctors.’ – ‘Chuck’

‘I don’t like them [doctors]. That’s why I never went to one about my finger.’ – ‘Robert’

7.3.4 Mental Health Benefits of the Men's and Community Shed

Many of the respondents saw clear mental health benefits of being involved with the MACS.

'If you want to talk health and fitness, well I get a challenge and I get the satisfaction of achieving and constructing stuff. And that's good, I enjoy that.' – 'Chuck'

'I also come for my mental health.' – 'Martin'

'My wife has said I've become a bit more animated again.' – 'Stan'

'Well, I think I've got a new spark on life. Coming and meeting other people has helped me because I was in a bit of a depression state.' – 'Peter'

7.3.5 Peer Support

Several respondents mentioned the positive social interactions they had had at the MACS, and the benefits of older men being able to provide advice and mentoring to younger ones.

'It's good to be part of a group.' – 'Chuck'

'And one of the guys said, 'Well, I've been where you are. I was where you are now twenty years ago'. And so, they can help each other deal with that, you know?' – 'Stan'

7.3.6 Helping Others

Several men mentioned that the MACS provided an opportunity for helping others, which they also saw as beneficial for themselves.

'If someone rang me and said would you help with a men's shed, I'd go 'yep, I'd do it tomorrow' – 'Stan'

'Everybody is here to chip in and do a bit' – 'Chuck'

'Even though I've got all this experience that I can pass on to the others, which I do, it's also something I enjoy doing.' – 'Peter'

7.3.7 A sense of Community

Several of the respondents indicated that they felt welcomed and had found a sense of belonging at the MACS

‘The people here are pretty friendly.’ – ‘Martin’

‘It feels like home.’ – ‘Daniel’

7.4 Vignettes

Two ‘vignettes’ were developed, based on the data collected in the surveys and the interviews. See Appendix 10. These featured two fictional men called ‘Bruce’ and ‘Wayne’ who each exhibited some of the same characteristics of the men in the target group. ‘Bruce’ was characterised as 53 years old, living alone, suffering from severe anxiety, high blood pressure and back pain, who smokes but does not drink. He has a poor relationship with his GP, takes medication but stops taking them when he feels healthy. ‘Wayne’ was characterised as partnered 56-year-old, who suffers from arthritis, depression and diabetes. He has a good relationship with his GP but does not know how and where else to get health information. He is reluctant to cut down his drinking.

The two vignettes were presented to focus groups for discussion, with the staff at one of the general practices and at the Ravenswood Men’s and Community Shed.

7.5 Focus Groups

7.5.1 Ravenswood Men’s Focus Groups

The vignettes featuring ‘Wayne’ and ‘Bruce’ were presented to the Ravenswood participants at a focus group. The following issues and ideas were raised in the ensuing discussion:

- **Medications:** Educational resources needed to be accessible to the men at MACS, including printing out medication sheets.
- **Physical Activity:** Activity programs could be embedded in the MACS program.
- **Mental Health:** Measures such as mental health first aid training could be made available to members of the MACS. GPs and psychologists could recommend MACS attendance for clients with mental health problems.
- **MACS Atmosphere:** It was important for the MACS to have a welcoming environment where anyone would be free to discuss their concerns, including partners of the men. A ‘non-structured’ environment would be an important component of the MACS ‘not just feeling like work’.

7.5.2 GP Practice Focus Groups

The ‘Wayne’ and ‘Bruce’ vignettes were also presented to staff from a general practice in the region of the MACS. The following issues and ideas were raised in response:

- **Social Isolation:** Social isolation was seen as a key issue impacting health literacy, especially for men experiencing depression and anxiety. There can be a dangerous cycle where mental health conditions and unemployment can

increase social isolation and make men in the target group less likely to seek medical assistance. Social support may be as important as medical support.

- **Literacy:** There is a need to remove the stigma around poor literacy in patients. At the same time, general improvements in literacy could subsequently improve health literacy and health outcomes.
- **Lowering the Literacy Burden:** There may be benefits to using pictorial forms of information to convey health messages e.g. posters. Thought should be given to where these could be placed to best reach the target group. Suggestions included at the Men's and Community Sheds, pubs and detention facilities.
- **Peer-to-Peer Information Exchanges:** There is a need to create an environment where men can exchange personal health stories and health information, perhaps during or after other activities. At the same time, there is a risk that the information from peers may not always be reliable or a good substitute for seeing a health professional.
- **Quality of Engagement:** It is important to build trust between the men and the GPs to increase the patient's sense of connection. This may include GPs being 'male friendly', or more aware of the occupations and activities which might be compatible with the patient's lifestyle. Negative interactions with other agencies may have contributed to distrust of professional staff.
- **Clear Pathways:** The target group will need to know how to take the next step or see a clear pathway to it. There needs to be sufficient access points to health information to access the next steps to health care when they need it.
- **Crisis Management Plans:** Because the target group may not access health care until they are in a crisis situation, it could be helpful to provide crisis management plans for situations like chest pain, or severe depression. These men may only see a GP when they are really ill or if their spouse forces them.
- **Community Development Programs:** Useful lessons may be learned from models used successfully in developing countries, with community-based health workers trained to deliver specific messages.
- **Facilitating Exercise:** There is a need to make exercise more available, attractive and painless. Community involvement in exercise in a supportive environment may help to de-isolate individuals and lead to cultural shifts.
- **Community-based health improvements:** Community-based improvements can reduce the individual burden of responsibility by raising expectations and improving general health. Community-based organisations, such as the men's sheds, can be a valuable source of education and support.

8. Discussion of Results

8.1 Physical and Mental Health of the Target Group

There were a number of indicators that some of the men surveyed experienced poor physical health, with a large proportion experiencing severe pain on a regular basis, to the extent that it interfered with daily life and relationships. Many were taking regular medications. Smoking in this group was much higher than the national average, although an equal number of men had quit smoking more than six months previously. The survey showed a number of indications of poor diet, particularly with regards to low

consumption of fruit and vegetables, and other factors which might suggest better diet such as the relatively low consumption of meat, fish and alcohol may be indicative of low income rather than better health literacy.

The survey also revealed considerable evidence of loneliness and lack of social support among the respondents. Although the majority of men felt that they had a lot of friends, this did not always translate to practical support, particularly in times of need. A minority of men reported a severe lack of positive social interaction. As well as the potential impact of isolation on their mental health, the practical lack of help to access healthcare could also have a negative effect on overall health. Nonetheless, there was clear indication that friendships and social contacts were valued and could be effective in providing necessary support. There was considerable evidence of anxiety and depression among the men.

8.2 Health Literacy and Access to Healthcare

A number of factors impacted both health literacy and the access to health services. Cost and availability of transport could be significant barriers to men going to see a GP or other health practitioner, particularly for a number of men who experienced limited mobility. The relationship with an individual GP was also important and suggested that trust and communication depended on being able to see a preferred practitioner and on receiving continuity of care. Although the majority of men felt that they had received good care from GPs, a significant minority expressed distrust and the belief that visiting a GP was unnecessary or an option of last resort, a factor also borne out by the interviews. These attitudes are likely to have had a negative effect on both the quality of health care these men received and on their health literacy.

The data addressing the quality of health information available to the men was mixed and indicated that a large proportion of the respondents were not confident in their ability to obtain high-quality, reliable information. This seems to have been due in part to communication problems, based partly on lack of trust of health care professionals, but also perhaps on the lack of a common terminology for describing medical problems and giving instructions. Poor general literacy may also have played a part with reported difficulty in filling in forms, and the fact that the majority of the respondents reported hearing loss may have exacerbated the problem.

8.3 Focus groups and Potential Interventions

The participants were generally willing to make changes to improve their health, including changing their diets. Many felt that they were trying to maintain their health, although a large minority found it difficult to do. The focus group discussions based on the vignettes identified a number of potential interventions. The use of vignettes was particularly effective as a method of initiating discussion at the Men's and Community Shed, perhaps because it allowed participants to discuss issues in a way that was concrete without being personal.

8.4 The Role of the Men's and Community Sheds

The interviews highlighted the potential benefits of the Men's and Community Sheds (MACS) in combatting social isolation and providing peer support. The focus group discussion held at the MACS highlighted the potential roles of the MACS in interventions to improve health and health literacy. These roles were not limited to the social benefits that the men experienced in attending the MACS, but also suggested that the MACS could be a site for the delivery of more formal health information and education. This concept was supported by the focus group discussion at the general practice, which stressed the need for community-based health improvements.

9. Outcomes

9.1 The Value of Community Engagement and the OPHELIA Approach

The OPHELIA-CVD project amply demonstrated the value of the OPHELIA approach as a method of engaging with and investing in traditionally under-represented groups, and particularly the hard-to-reach middle-aged men at risk of cardio-vascular disease who were the subject of this study. Conducting research in place at the Men's and Community Sheds allowed for greater community involvement in the research design, embodying the principle of meeting people where they were at. The use of the vignettes and focus groups provided a platform for the target audience to be involved in the design of the interventions and invested in the outcomes.

The Healthy Shed Program

A major, direct outcome of the OPHELIA-CVD project was the 'Healthy Shed' program, funded by Healthy Tasmania for \$25,000. This was based on the background program led by Dr Shandell Elmer delivered in 2015 (see Appendix 1 for details). This was a healthy lifestyle program run for one day a week, over fourteen weeks from 1 May 2018, at the Ravenswood Men's and Community Shed, as a response to issues raised in the surveys, interviews and focus groups in the OPHELIA CVD project. Healthy Shed brought together a range of service providers and partners who attended and delivered information sessions. These included:

- City Mission,
- Cancer Council/QUIT Tasmania,
- The University of Tasmania,
- Red Cross,
- WISE Employment,
- PCYC,
- Fit 'n' Kicking,
- Relationships Australia,
- Tasmanian Health Services,
- The Active Effect,
- Terry White Chemmart, Ravenswood,
- Ravenswood Community Health Centre, and

- Healthy Tasmania.

Presentations included:

- Team work and program introduction,
- It's okay to ask (Health Literacy),
- Local Services,
- Stress, Management,
- Understanding your Medication,
- Back Pain Management,
- Food REDi (healthy eating and food safety) 1 and 2,
- Staying Alive (suicide prevention),
- Relaxation,
- Boxing,
- Quit Smoking,
- Respectful Relationships,
- Celebration (Group's Choice – Gentle Exercise).

A key outcome of the Healthy Shed program was that 100% of respondents surveyed either agreed or strongly agreed that the program encouraged them to participate in community based healthy lifestyle activities and taught them more about the services available in the community to improve their health. A video showcasing the Healthy Shed program is available at: <https://www.youtube.com/watch?v=7pPxVz6CAT4>.

9.2 Implications for Future Research

The OPHELIA-CVD pilot study was valuable in terms of the data and the information it provided which assisted in designing the Healthy Shed program. It amply demonstrated the benefits of applying the OPHELIA principles to research and interventions, and in particular the value in 'meeting people where they're at'. The project also demonstrated the benefit of removing the need for literacy in the target group through the oral administration of research tools. The surveys identified key areas in which the participants were at risk, not just for cardio vascular disease, but in terms of their general physical and mental health. They also highlighted problems with overall health literacy and engagement with health practitioners.

This study highlighted factors which have been acknowledged in recent research which also underscored the success of recruiting participants through community organisations. Rockcliffe et al. (2018) make the point that individuals who fall within the hard-to-reach category do not form a homogenous group (21). In the case of the OPHELIA CVD project, factors such as instability of accommodation, physical and mental illness, and access to transport, as well as a reluctance to engage with and lack of trust of health care providers documented in the initial survey may have contributed to unwillingness or inability to participate in the follow-up survey and interviews. So, all of the steps of the OPHELIA approach were not undertaken with the same ten men who were interviewed at the MACS to generate the vignettes. The initial ten men were lost to follow-up.

Nonetheless, this pilot study was able to capture valuable data about the nature of the target group, their health literacy and the importance of their interactions with the Men's and

Community Sheds. This data enabled observations and measures which will form a basis for further research and interventions and allow for a better understanding of the target group.

The OPHELIA-CVD project also highlighted the importance of establishing relationships between the researchers and the community over an extended period of time. This led not only to researchers' having a good understanding of the needs of the community, but also to developing trust between the two groups. This was instrumental in allowing the community to have input into the design of further research projects such as the numeracy project led by Dr Greg Oates.

The OPHELIA-CVD project has acted as a springboard for a number of other funding proposals, based on the needs expressed by the men in the focus groups, and the MACS have become a central locus for a range of programs such as gaining 'Anticipatory Care' funding for 2018–2019.

9.3 Implications for the Community

A fundamental principle of the OPHELIA approach is that it be driven by local wisdom, based on a needs assessment, and incorporate co-design and responsiveness. Creating a forum which enabled the members of the community to have input into designing an intervention based on their own needs has allowed for an effective tailored program. This means that while the outcomes of the OPHELIA-CVD project, and in particular the Healthy Shed program, were highly beneficial for the community in the northern suburbs of Launceston, this is not a program which could or should be implemented without change in another community, even one which appears superficially similar. A further benefit to the community has been the creation of a broad range of community-based partnerships with service providers and other local organisations, which will allow community members to more effectively seek health and other information in their local community.

9.4 Implications for Future Policy

This research shows that the OPHELIA approach could have benefits for future policy in health and health literacy, and in particular the advantages of involving communities in designing interventions which are tailored to particular circumstances, using the OPHELIA principles and methods.

9.5 Implications for Medical Students

Medical students who participated in this project gained valuable skills in research and community engagement. Their assistance was invaluable to the project's outcomes.

Funded Projects

- **Hall for Ravenswood Men's and Community Shed** donated by Launceston City Council
- \$80,000 funding from Relationships Australia for renovation of a former scout hall to form the Ravenswood Men's Shed.

- **The Shed (Rocherlea):** Land donated by the Launceston City Council. The fit-out of the shed was funded by State Growth/Launceston City Council, Cape Hope Foundation and the Northern Suburbs Community Centre, Neighbourhood Houses Tasmania.
- **‘Healthy Shed’ Program** - \$25,000, funded by Healthy Tasmania, in partnership with the University of Tasmania; Ravenswood Community Health Centre; the Tasmanian Health Service; Terry White Chemmart, Ravenswood; The Active Effect; Red Cross; Neighbourhood House Association of Tasmania; Fit ’n’ Kicking; PCYC; QUIT Tasmania; and Relationships Australia.
- **Black Dog Institute ‘Life Span’** suicide prevention program, focusing on men aged 40 to 64 in Launceston’s Northern Suburbs. Administered by Primary Health Tasmania.
- **Numeracy for Life Project** - \$62,455, University of Tasmania, funded by the Tasmanian Community Fund.
- **Anticipatory Care Project** - \$250,000 from the Tasmanian department to health.

10. Conclusions and Recommendations

This pilot study confirmed the difficulty of conducting research programs with this ‘hard to reach’ cohort of men. The failure of the general practices to recruit participants for the study, compared with the comparative success of the Men’s and Community Shed as a recruiting point is indicative of this group’s unwillingness to engage with the formal healthcare system. This reluctance was confirmed by the comments of the men in the interviews and in part resulted from previous negative interactions with the healthcare system in some instances, as well as from gendered societal expectations. (‘We’re men, we don’t go to the doctor.’) The general practice staff demonstrated an awareness of this issue in their focus group discussion, noting that they often only saw men like ‘Bruce’ when they were critically ill or when their female partners forced them to go to the doctor. This suggests that general practices should not be the only entry point for interventions aimed at improving health or health literacy.

In contrast, aspects of the interactions with the men at the Men’s and Community Sheds indicate that this is an effective point of contact for reaching at least some members of the target group. While the number of participants in the survey and the interviews was still not as high as had been hoped, and there was no ability to conduct a longitudinal study, nevertheless the quality of the engagement was good and the information these interactions yielded was valuable. There is potential to evaluate the effectiveness of interventions, not necessarily by conducting formal longitudinal studies, but by conducting interviews and focus groups based using the OPHELIA approach with attendees at the Men’s and Community Sheds over time.

The OPHELIA-CVD Project demonstrated both the effectiveness of the OPHELIA approach and the critical importance of the Men’s and Community Sheds as a point of contact for delivering interventions for hard to reach men. The use of the vignettes in the focus groups held at the Ravenswood MACS and the general practice provided a way to discuss details of the issues facing this cohort of men and yielded practical suggestions for interventions aimed at improving the cardiovascular, mental and general health of the target group. As well as the MACS being a more effective point of contact for recruitment of subjects for the study, the importance placed on the centres by the respondents indicated that they would be a more effective location for delivery of health programs.

While the effectiveness of the OPHELIA approach as the basis for an intervention could not be measured using longitudinal data, this pilot study demonstrated the benefits of the use of the vignettes as a method for engaging both the target group of men at risk of cardiovascular disease and the general practice staff, who would benefit from increased awareness of the needs and challenges of this group.

Realist Evaluation

A key part of the design for this research was the capacity to translate the findings of the OPHELIA intervention for preventing CVD in other disadvantaged populations. For policy makers attempting to distribute limited resources in an equitable manner, it is crucial to understand how well an intervention works, for whom, in what context. For this reason, the researchers chose to incorporate a ‘realist’ approach that focuses on identifying the mechanisms that achieve the desired outcomes in a particular context(22, 23). Because the OPHELIA-CVD project could not complete all of its planned steps a realist analysis of data to determine what mechanisms led to what outcomes could not be undertaken. The outcomes of the building of the Men’s and Community Sheds was not a result of the OPHELIA project. However, now that the Ravenswood MACS and The Shed (Rocherlea) have been built, future studies to find what works for whom (various men), why and how could be undertaken. The ‘what’ could be attendance at the Ravenswood MACS or The Shed (Rocherlea) and/or engagement in programs delivered via them. What ‘works’ could be improved mental health, better health literacy, etc. How the Ravenswood MACS or The Shed (Rocherlea) affect health could be found by talking to the men.

11. Recommendations

The potential of the Ravenswood MACS or The Shed (Rocherlea) to alleviate social isolation and provide peer support for hard-to-reach men makes them an appropriate venue for the delivery of health programs.

General practices could conduct outreach clinics in partnership with the Ravenswood MACS or The Shed (Rocherlea) in order to overcome barriers such as transport and a reluctance to attend traditional general practices. As bulk-billing such services may not be financially viable, they may need further financial support than is available via bulk-billed Medicare items.

The demonstrated benefits of the OPHELIA process, including the use of vignettes, for involving people in designing programs for their communities, supports a continuing use of this methodology in the Northern suburbs of Launceston and other areas with similar socio-economic profiles.

References:

1. AIHW. Cardiovascular disease by populations of interest. In: Welfare AIoHa, editor. Canberra: Commonwealth of Australia; 2011.
2. AIHW. Cardiovascular disease: Australian facts 2011. Cardiovascular disease series no. 35. Cat. no. CVD 53. In: Welfare AIoHa, editor. Canberra: AIHW; 2011.
3. AIHW. Australia's health 2012. Australia's health series no 13. Cat. no. AUS 156. . In: Welfare AIoHa, editor. Canberra: AIHW; 2012.
4. Clark RA, Driscoll A, Nottage J, McLennan S, Coombe DM, Bamford EJ, et al. Inequitable provision of optimal services for patients with chronic heart failure: a national geo-mapping study. *Med J Aust.* 2007;186(4):169-73.
5. ABS. Australian Health Survey: Updated Results, 2011-2012 In: Statistics ABo, editor. Canberra: ABS; 2013.
6. Council CR. Healthcare 2011-2012: Comparing performance across Australia. Report to the Council of Australian Governments. Sydney: Council of Australian Governments; 2013.
7. Begg S, Vos T, Barker B, Stevenson C, Stanley L, Lopez A. The burden of disease and injury in Australia 2003. In: Welfare AIoHa, editor. Canberra: AIHW; 2007.
8. Heart Foundation. Heart Foundation CVD Prevalence Maps – 2014 Melbourne: Heart Foundation; 2014 [Available from: https://www.heartfoundation.org.au/images/uploads/publications/2014HeatMaps_PrevCVD_TAS.pdf]
9. Beauchamp A, Dodson S, Batterham R, Buchbinder R, McPhee C, Osborne R. Ophelia: a new approach to the identification, development and testing of health literacy interventions. Boston University Health Literacy Research Conference; Boston: Boston University; 2014.
10. Kinsman L, Tham R, Symons J, Jones M, Campbell S, Allenby A. Prevention of cardiovascular disease in rural Australian primary care: an exploratory study of the 3 perspectives of clinicians and high risk men. *Australian Journal of Primary Health.* 2016.
11. Britt H, Miller G, Charles J, Henderson J, Bayram C, Pan Y, et al. General practice activity in Australia 2009-10. Canberra: AIHW; 2010.
12. Kickbusch I, Wait S, Maag D. Navigating Health: the role of health literacy. London: Alliance for Health and the Future, International Longevity Centre; 2005.
13. Nash R, Elmer S, Lee S, Jones R. HealthLit4Kids: A pilot program crossing boundaries for positive health outcomes. Hobart: University of Tasmania; 2017.
14. Eaton S, Roberts S, Beauchamp A, Osborne RH. Application of the Ophelia process in a deprived community setting in Newcastle UK: a model for local community engagement and systematic intervention development: Simon Eaton. *European Journal of Public Health.* 2015;25(suppl_3).
15. Batterham RW, Buchbinder R, Beauchamp A, Dodson S, Elsworth GR, Osborne RH. The OPTimising HEalth LIterAcy (Ophelia) process: study protocol for using health literacy profiling and community engagement to create and implement health reform. *BMC Public Health.* 2014;14:694.
16. Campbell SM, Ludt S, Van Lieshout J, Boffin N, Wensing M, Petek D, et al. Quality indicators for the prevention and management of cardiovascular disease in primary care in nine European countries. *European Journal of Cardiovascular Prevention & Rehabilitation.* 2008;15(5):509-15.
17. Zhang J, Oldenburg B, Turrell G. Measuring factors that influence the utilisation of preventive care

services provided by general practitioners in Australia. *BMC Health Services Research*. 2009;9(218):1-9.

18. Khan M, Richardson J, O'Brien P. Validating AQoL-8D in an obese population and its use to estimate weight related Burden of Disease in Australia. Economics MCfH, editor. Melbourne 2012.

19. Richardson J, Khan M, Iezzi A, Sinha K, Mihalopoulos C, Herrman H, et al. The AQoL-8D (PsyQoL) MAU Instrument: Overview September 2009. Melbourne; 2009.

20. Richardson J, Sinha K, Iezzi A, Khan M. Modelling the Utility of Health States with the Assessment of Quality of Life (AQoL) 8D Instrument: Overview and Utility Scoring Algorithm. Melbourne; 2011.

21. Rockliffe L, Chorley AJ, Marlow LAV, Forster AS. It's hard to reach the "hard-to-reach": the challenges of recruiting people who do not access preventative healthcare services into interview studies. *International Journal of Qualitative Studies on Health and Well-being*. 2018;13(1):1479582.

22. Connelly J. Evaluating complex public health interventions: theory, methods and scope of realist enquiry. *Journal of Evaluation in Clinical Practice*. 2007;13:935-41.

23. Salter KL, Kothari A. Using realist evaluation to open the black box of knowledge translation: a state-of-the-art review. *Implementation Science*. 2014;9(1):1-14.

24. Elmer S, Bridgman H, Williams A, Bird ML, Murray S, Jones RP, et al. Evaluation of a Health Literacy Program for Chronic Conditions 2017.

Appendices

Appendix 1.

Setting the scene for the OPHELIA-CVD project

Background – Mr Mick Goss

Mr Mick Goss has an amazing record of giving back to his community. In 2005 Mick started a playgroup in Invermay for dads. This led to a paid role with Relationships Australia who wanted to get the same sort of group going in Ravenswood for men caring for kids aged up to five years of age. Mick learnt things about running such groups like the role of a BBQ in giving a social focus to the group and to encourage attendance, and that guest speakers could be a daunting prospect for group members who then stayed away. Over time despite struggling with literacy he obtained a certificate 4 in community service. Working with Denise Delphin and the Northern Suburbs Neighbourhood House he was also successful in applying for small \$5,000–10,000 grants, leading onto the large grant from the state government of \$250,000 in partnership with the Launceston City Council who donated the land, that resulted in the Rocherlea Men's and Community Shed which was opened in late 2018.

The journey to getting a Men's shed goes back a long way. Mick got interested in the Men's Shed movement in 2009 when he attended a meeting in Brighton, Tasmania. At that stage there were five Men's Sheds in Tasmania. His dads' group over time came to be based at the Rocherlea Hall. He organised programs for the men such as on anger management and anxiety management. The men then wanted to learn hands-on skills. This led to collaborations with Denise Delphin to organise a group of 10 to do a TasTAFE welding skills course. They also did a small engines course. They wanted to give back to the community with their new skills as well. Over time the Rocherlea Hall and two shipping containers holding their equipment became too small for their Men's Shed. Anyway, they had always wanted their own Men's Shed.

Mick met Dr Kath Ogden of the University of Tasmania at Agfest in 2014 when Mick's group were at Agfest looking at tools for their group. He asked Kath to bring her Health-Stop to the men's group at the hall and organised the same at the local Rocherlea Footy club over two years. Health-Stop is a chance to chat to a medical or nursing student or GP about your health and have your blood pressure checked. From this relationship Mick met Leigh Kinsman who worked at the University of Tasmania too. Leigh met men from Mick's group and was introduced to others in Ravenswood who formed the group who Leigh worked with on the OPHELIA-CVD project.

So, at the end of the day the OPHELIA-CVD project is in many ways due to Mick. Thank you, Mick Goss. An amazing Launceston community member who enabled so many things including the OPHELIA-CVD project and the subsequent funding of the anticipatory care project of 2018- 2019.

Background - Dr Kath Ogden

In 2014 at Agfest, Mick Goss approached Kath at the Health-Stop tent. He explained that he ran a men's play group and was interested in running a similar health check type of intervention at the Rocherlea Football Club during a game. He was aware that many of the men (in particular) who attended the football games were less likely to attend their GP and had a high rate of health-related behaviours which put them at risk of chronic disease. Mick then introduced Kath to the president and secretary of the Rocherlea Football Club who were in the final stages of a major renovation of facilities, including a large club room/function centre and gymnasium facilities. They expressed their desire that Rocherlea Football Club become a hub for activity in the community. They talked about wanting to allow local youth to use the football field after school and that they would be happy to put the lights on in winter. They were also keen for the gym to be utilised, including by people with disabilities who were accommodated nearby. They were clearly keen to see that the facility, that they had been fortunate enough to build through government funding, contribute to the community broadly.

Kath ran the first Health-Stop session at a match in 2014. Both nursing and medical students participated. One of the nursing students was the daughter of a club legend and had grown up around the club. Having her involved, in retrospect, was key to its success. Her family link to the people at the match enabled her to have an 'in' which in the subsequent year was missed. This led to much greater acceptance and participation in the intervention in the first year. In subsequent years it was found more difficult to engage people, and Kath felt more like Health-Stop was imposing something from outside rather than within. Kath and Health-Stop also attended a community event which Mick Goss organised where there were a number of 'exhibitors' from the community, and a BBQ was arranged. This was conducted in the scout hall near the football ground.

When Prof Leigh Kinsman arrived to work at the University of Tasmania, Kath introduced him to Mick and our engagement with the northern suburbs community was then coordinated through Leigh's work.

This ongoing relationship arose because of Mick's vision to bring the University of Tasmania's Launceston Clinical School academics and their students into the community, as an alternative model for providing health-related care.

Background - Mobile And Confident: People Avoiding Chronic Conditions

Towards the end of 2015, Sandy Murray (dietician), Dr Andrew Williams (exercise physiologist), Dr Marie-Louise Bird (physiotherapist), Mara Schneiders (social worker), Michael Cheney (exercise physiologist) and Dr Heather Bridgman (psychologist) formed a multidisciplinary team led by Dr Shandell Elmer (nurse) to develop and deliver a seven-week health literacy-based program to three neighbourhood houses. The program was funded by TAZREACH.

Each of the programs was customised to the needs of the local community. While there was a key focus for each session based on the discipline/expertise of the group facilitator, the content was adapted and responsive to the needs of the participants. Starting Point Neighbourhood House at Ravenswood participated in this program. The first session focused

on physical activity, incidental exercise in particular. Each subsequent week included some aspect of physical activity tailored to the participants and guided by Michael Cheney (exercise physiologist).

Many of the participants at Starting Point had not regularly participated in programs previously and were not regular attenders at the neighbourhood house. However, the participants regularly attended the weekly sessions. The program helped the participants to achieve their own goals and work towards healthy changes. The evaluation of the program is documented in the research article: <https://eprints.utas.edu.au/27167/> (24)

Appendix 2. Data Collection Matrix

Measures	Measuring Tool	Men 30–60 at increased risk of CVD	Healthcare Professionals in Primary Care	Neighbourhood house staff & volunteers
Health literacy	Health Literacy Questionnaire (HLQ)	X		
Lifestyle & demographic details	EPA-CVD EUROPEP patient survey	X		
Primary care utilisation inclusive of (socio-demographic factors, health service utilisation & factors affecting health service utilisation)	General Practice Preventative Health Service Utilisation Questionnaire (GP-PHSUQ)	X		
Assessment of Quality of Life	8D instrument (AQoL-8D)	X		
GP Practice Medical Records	Pen-CAT Clinical Audit Tool		X	
Interviews	Qualitative analysis	X	X	X

Appendix 3. Interview Framework

Ophelia: CVD northern suburbs Launceston

Preamble:

1. Introduce self and colleague(s)
2. Reminder of research project to get local perspectives on the health of men in Ravenswood
3. Provide information sheet and ask for consent form to be signed
4. Check that it's ok for recording to commence and start recording
5. Re-introduce your-self and thank participant

Semi-structured interview for recruited men: prompt questions:

- Tell me about yourself (age, family, married, time in Ravenswood, school, work etc.)
- When did you first learn of the men's shed?
- When you heard of the shed, what prompted you to attend?
- What has it been like to attend the shed?
- Why do you attend?
- How has it influenced your daily life?
- Do you feel the shed has a positive or negative impact on your health? How?

Generally – these questions will provide plenty of information but may need prompts such as “Tell me more about...”

Is there anything else you would like to say about your health and the men's shed?

Thank you for your time and good luck.

Appendix 4. Letter to Prospective Participants from GP

Appendix 4 OPHELIA CVD northern suburbs of Launceston
Letterhead of the practice

Dear _____,

I am writing to tell you about the OPHELIA CVD (Optimising Health Literacy: cardiovascular disease) study that is being done by the University of Tasmania in our community. I feel that you may benefit from this study.

This research study hopes to:

1. Help you learn more about your general and heart health
2. Help people around you get healthier and stay healthy
3. Find good ways to share information about health

It is important to know that this letter is not to pressure you to join the study. It is your decision alone. Whether you decide to join the study or not will not have an effect on your health care as my patient.

If you are interested in knowing more, please have a look at the information sheet in this letter.

A member of the practice will phone you within the next three weeks to answer any questions you may have.

If you are interested to join the study, there is a consent form in this letter to allow the researchers to contact you. You can sign and mail it to the researchers using the envelope provided.

Sincerely,

A pilot study of optimising health literacy in “hard to reach” populations for the primary prevention of cardiovascular disease: OPHELIA CVD

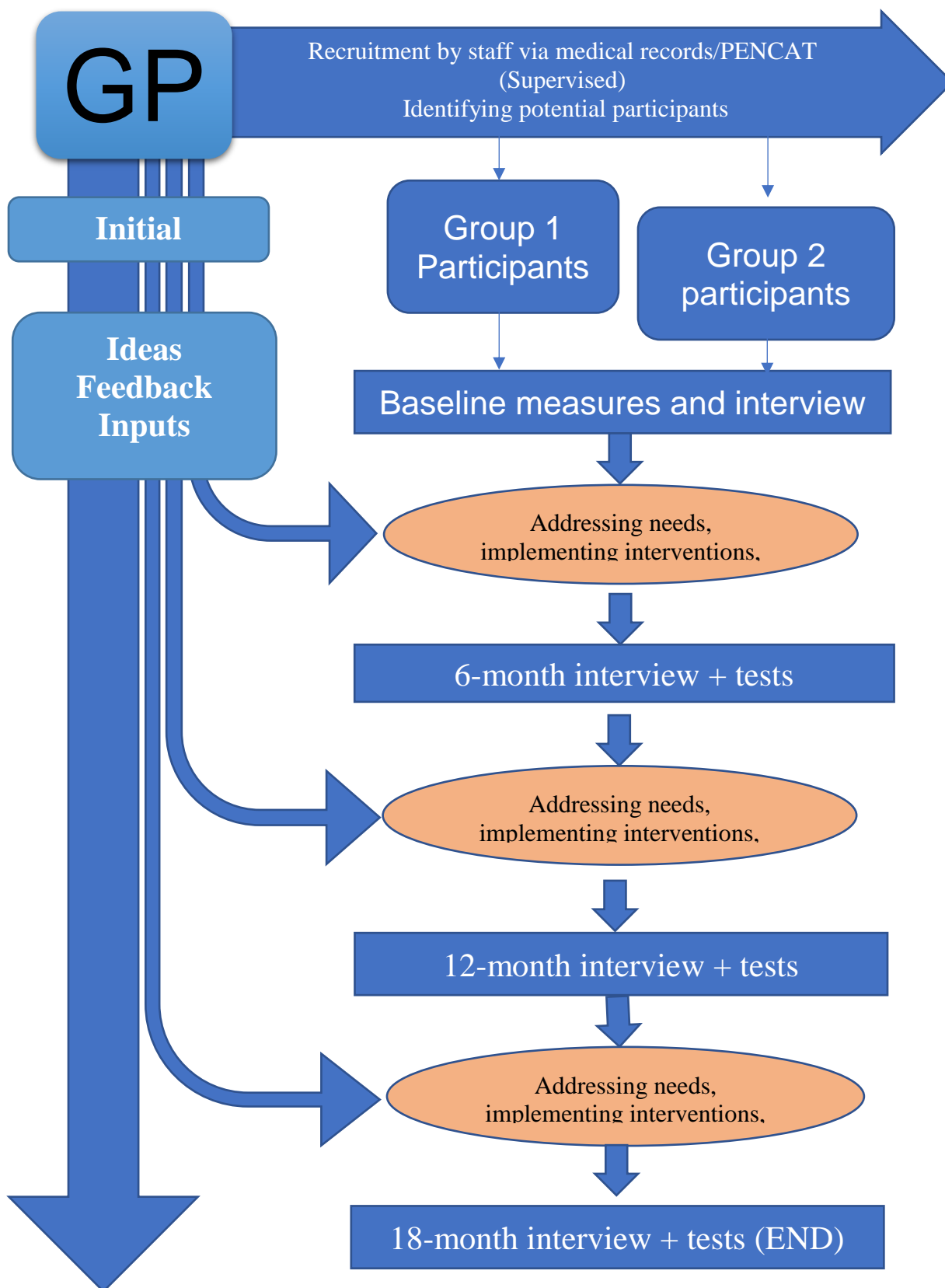
Please complete this form and return it in the pre-paid envelope provided

- I am interested in learning more about this study. Please contact me using the following information:
- Name: _____
- Telephone(s): _____
- Best time and day to call: _____
- Address: _____

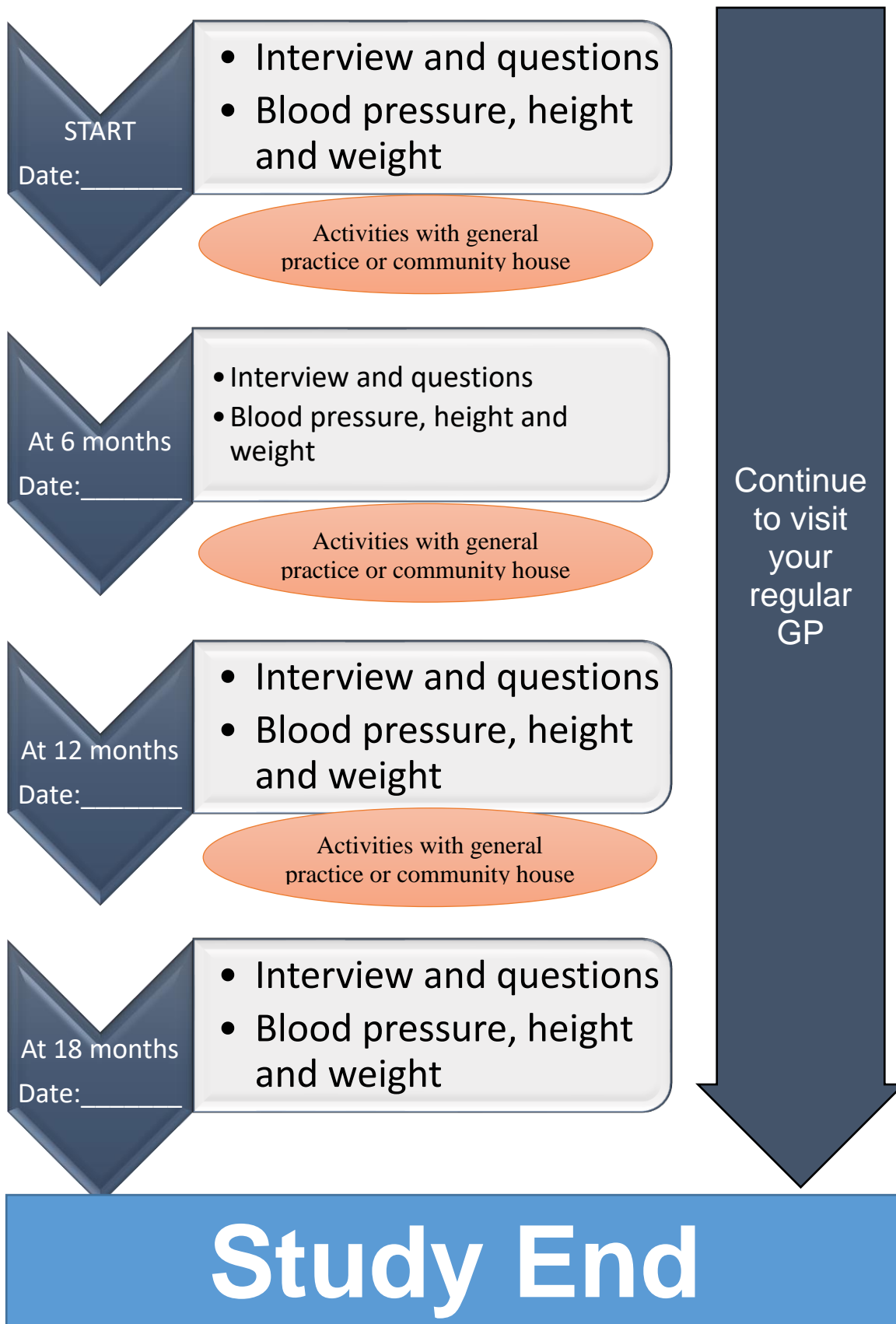
Researcher contact information:

Prof Leigh Kinsman
OPHELIA: CVD study
Launceston Clinical School
Locked Bag 1377
Launceston 7250

OPHELIA CVD GP Flow Chart

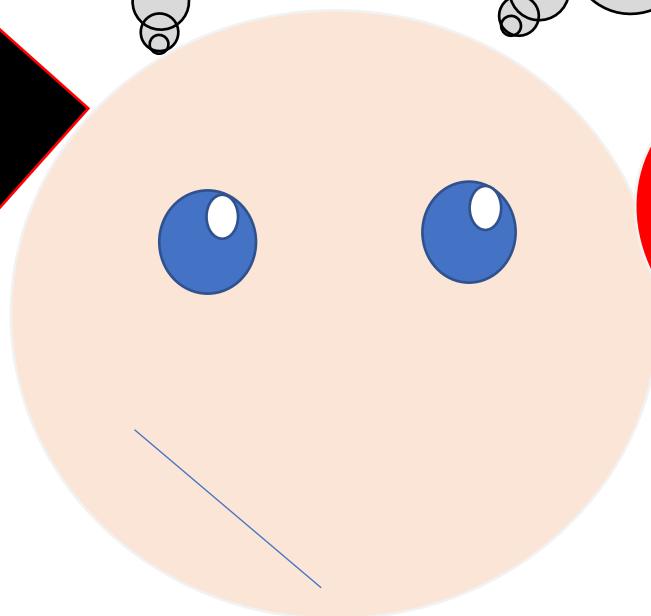
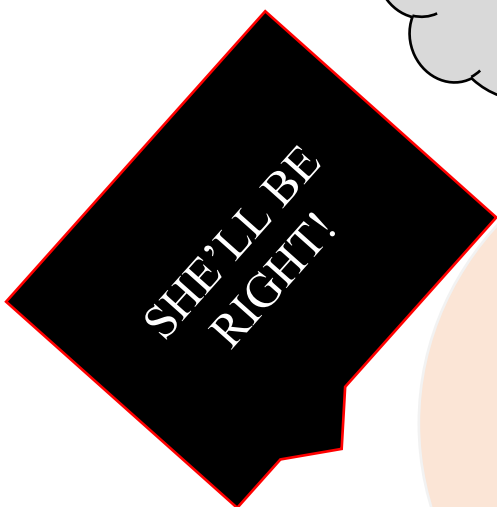
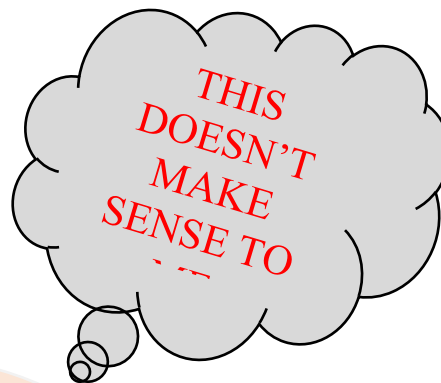
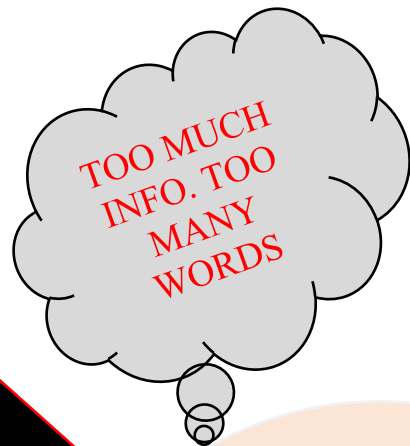


OPHELIA CVD Participants Flow Chart



HEART STUDY FOR MEN

IS THIS YOU?



YOUR HEALTH NEEDS, YOU.

WHO CAN JOIN?

- MEN
- 30 TO 60 YEARS OLD
- LIVING IN NORTHERN SUBURBS

WHY JOIN?

- KNOW YOUR HEALTH
- LEARN ABOUT YOUR HEART
- GET HEALTHY. STAY HEALTHY.
- HELP PEOPLE AROUND YOU TOO.

WHAT DO YOU DO?

- DISCUSS IDEAS
- SHARE EXPERIENCE
- GIVE FEEDBACK
- TALK HEALTH

KEEN? HOW TO JOIN?

CONTACT: RESEARCHER NAME(s)
RESEARCHER NUMBER(s) and/or
email

Appendix 8. Inclusion/Exclusion Criteria

OPHELIA CVD for consideration

Inclusion criteria:

1. Male
2. Age between 30 and 60

Exclusion criteria:

1. Terminal illness
 - Illness or disease with reasonably expected result of death within a short period of time (6 months by clinicians' view)
2. Previously diagnosed cardiovascular condition
 - Acute coronary syndrome
 - Myocardial infarction
 - Angina
 - Cardiomyopathy
 - Congenital Heart disease
 - Arrhythmia
 - Heart failure
 - Rheumatic heart disease
 - Valvular disease of the heart
 - Stroke/ Cerebrovascular disease
 - Peripheral artery disease
 - Past vascular surgery
3. Advanced (moderate to severe) Dementia
 - MMSE <15/30

Appendix 9: Interview Schedule for Use with Men Using the Ravenswood MACS

OPHELIA: CVD northern suburbs Launceston

Preamble:

6. Introduce self and colleague(s)
7. Reminder of research project to get local perspectives on the health of men in Ravenswood
8. Provide information sheet and ask for consent form to be signed
9. Check that it's ok for recording to commence and start recording
10. Re-introduce your-self and thank participant

Semi-structured interview for recruited men: prompt questions:

- Tell me about yourself (age, family, married, time in Ravenswood, school, work etc.)
- When did you first learn of the men's shed?
- When you heard of the shed, what prompted you to attend?
- What has it been like to attend the shed?
- Why do you attend?
- How has it influenced your daily life?
- Do you feel the shed has a positive or negative impact on your health? How?

Generally – these questions will provide plenty of information but may need prompts such as “Tell me more about...”

Is there anything else you would like to say about your health and the men's shed?

Thank you for your time and good luck.

Appendix 10: Vignettes

Vignette 1: Bruce

Bruce is a 53-year-old painter who lives alone. He did not complete secondary school. Since leaving school, he has changed jobs frequently. He has been painting for the past 2 years.

He suffers from severe anxiety, high blood pressure and mild back pain. When his back pain flares up, he is forced to miss work for a few days. He smokes 20 cigarettes a day but does not drink.

He tries to go to the GP at least once a year but does not like his GP and feels as though he is not understood. None of his friends go to the GP and once when he said he was going they all laughed. None of his friends know about his anxiety. He has told his GP about his back pain but feels like the GP didn't care and only tells him to lose weight, eat better and stop smoking. He doesn't know how he is meant to do these things and doesn't think it'll be possible because he is too busy with work and doesn't have any spare money.

He is on two medications but doesn't know what they are for and often when he feels healthy he doesn't take them. Bruce has a concession card in his wallet but does not know what he can use this for.

Vignette 2: Wayne

Wayne is a 56-year-old who lives at home with his partner. He did not complete secondary school. He stopped working in the local car garage 3 years ago due to increasing pain in his hands and back, caused by arthritis. He also suffers from depression and diabetes.

Wayne has a GP who he tries to see regularly. He feels like his GP understands most of his problems. Wayne also finds that the advice his GP gives is easy to understand, though sometimes he doesn't fully understand why he has to change medications and walk more, but he does it anyway as he knows that his GP is well trained.

Wayne's GP also tells him to cut down his drinking, however neither Wayne nor his partner wish to cut back. He feels bad about this as he does really like his GP and does want to do what his GP says. Other than one GP he does not know how and where to get health information. When he cannot get into his GP he will wait and hope he gets better or sometimes thinks about asking his neighbour who he knows is old and sick so might know more.