Exploring the health consumers’ perspective on the burden of chronic illness and the role of community pharmacy in chronic illness management

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Appendix 1

Advisory Panel & Reference Group Members

Advisory Panel Members
Ingrid Struzina, Department of Health
Toni Riley, The Pharmacy Guild of Australia
Gilbert Yeates, Pharmaceutical Society of Australia
Dr Anne-Marie Feyer, The George Institute of Global Health
Deon Schoombie, Australian Self-Medication Industry
Alison Marcus, Consumers Health Forum

Reference Group Members:
Alf Davis, Team Leader and Social Worker, Kummara Indigenous Family Care, Brisbane
Christopher Freeman, Consultant Pharmacist, Director Charming Institute, Brisbane
Peter Forday, Corporate and Community Consultant, Brisbane
Elise Gorman, Program Coordinator, Population Health, General Practice Queensland
Nurse Practitioner member, (name withheld)
Satish Maganlal, Pharmacist and Community Pharmacy owner, Brisbane
Rosemary Mohammed, Practice Nurse and member Australian Practice Nurses Association
Michelle Phillips, Workforce Consultant, Health and Community Services Workforce Council, Brisbane
Paul Storey, Director, Stakeholder Liaison and Strategic Communication, Pharmaceutical Benefits Scheme, Canberra

*Members who participated and who withdrew during the lifetime of the Project include: Judy Davidson (Carer Representative), Ray Moynahan (Consumer Advocate)*
Reference Group Terms of Reference

1. Introduction

The Project Reference Group will work closely with the Project team throughout the research, combining the expertise of the Project team with the practical knowledge, experience and support of non-researcher members. The specific role of the Project Reference Group will be to assist the Project team in ensuring that the theoretical, practical and operational aspects of the project are managed in a timely manner and the information gained from the research is as reliable and useful as possible and presented so it is easily understood. Reference Group members will predominantly be based in Queensland with some representation from the two other jurisdictions.

2. Functions of the Reference Group

Project Reference Group members will be required to:

- provide guidance around practicalities of the proposed research design in local settings;
- provide guidance on the communication strategy over the Project lifetime;
- provide direction in identifying documentation for review;
- assist with identifying interview participants (key stakeholders and consumers and carers);
- advise on how best to engage with research participants;
- providing guidance and assistance to engage with health consumers and carer organisations and groups in community settings;
- provide expertise and acting as local champions to support recruitment and retention of consumers, carers and health professionals throughout the project;
- providing guidance on consent processes for research participants;
- liaison with their representative professional and consumer and carer networks, collaboratives and groups at a national, state-wide and local level;
- ensuring information, summaries and reports are easily understood for people with or without health or professional backgrounds;
- assisting with preparation of media releases and identifying appropriate media outlets; and
- ensure the research remains focussed on and useful to the Funder’s needs.

3. Format and frequency of meetings

It is proposed that the Project Reference Group will meet a minimum of twice per year (either face-to-face or by teleconference) throughout the research period. Meetings are expected to be of two hours duration and there will be some reading and documentation provided for feedback outside of the regular meetings.

4. Expenses

Members will be reimbursed for any meeting related expenses (parking) and refreshments provided. Members who work in a private capacity will be reimbursed for their time ($100/meeting).
Appendix 2

Project Information

Appendix 2.1 – Project Fact Sheet

Exploring the health consumers’ perspective on the burden of chronic illness and the role of community pharmacy in chronic illness management

Project Background

With chronic illness on the rise in Australia, now is the time for health professionals to have greater insight about the impact that chronic illness(s) have on consumers, family members or their carers, to ensure that their health care needs are met. As pharmacies are frequently visited by most people who have, or are at risk of a chronic illness, pharmacies are critical stakeholders in improving the care of these consumers. However, there is little information as to how people might prefer to interact with their pharmacies as they seek to manage their health more effectively.

Project Objective

To fully explore the perspective of health consumers about the burden of chronic illness and multiple treatment regimes, their desire in terms of patient centred care and the related role of community pharmacy. This project will form the basis of recommendations for models of care for community pharmacy to assist people with chronic disease and complex treatment regimes to better manage their illness.

Method

The project will be conducted in three stages over three years, starting with interviews from key consumer and professional organisations to identify their perspective of:

- patient centred care, treatment burden and the role of community pharmacy in assisting consumers to self-manage their illness(s)
- the health care priorities and needs for the consumers that they represent or support
- recruitment strategies for consumer engagement

The second and third stage will involve consumers and health professionals in five key areas across 3 states: Logan-Beaudesert, Mt Isa and North West region (QLD), Northern Rivers region (NSW) and the greater Perth area (WA). A minimum of 108 interviews and 16 focus groups with health consumers, their family members or carers will ask for their personal accounts on their:

- chronic illness, its treatment burden and impact on them and their family
- interactions with health providers, particularly community pharmacy services
- health care priorities and perceptions of what patient centred care should be in the pharmacy
- expectations of community pharmacy in assisting them to self-manage their illness(s)
Six focus groups will also be conducted with various health professionals (e.g. pharmacists, GPs, physiotherapists, diabetes educators) across the three states. This will explore their views on patient-centred care, treatment burden and patient health care priorities to reveal any disparities with the views of the consumer. This information will provide insight into how current expectations are or are not met and will form the basis of recommendations for models of care for community pharmacies to assist consumers with chronic illness(s) and complex treatment regimes.

The final stage of the project is to survey a minimum of 600 health consumers and 200 health professionals to:

- quantify consumer preferences and the potential impact of selected pharmacy models of care
- statistically measure the burden of chronic illness
- compare the preferences of consumers and health professionals around what they expect would be important aspects of service delivery for consumers

The integration of findings from all three stages will be used to develop a meaningful set of recommendations that inform the development of model(s) of care for community pharmacy.

If you would like to take part or find out more information, please Freecall 1800 600 687 or visit www.chronicillnessproject.com.au

This project is funded by the Australian Government Department of Health as part of the Fifth Community Pharmacy Agreement Research and Development Program managed by The Pharmacy Guild of Australia. Ethics approval has been obtained from the Griffith University Human Research Ethics Committee (PHM/12/11/HREC).

The researchers involved are: Prof Amanda Wheeler, Prof Elizabeth Kendall, Dr Michelle King and Dr Fiona Kelly (Griffith University) and A/Prof Jennifer Whitty (University of Queensland).

<table>
<thead>
<tr>
<th>Stage One:</th>
<th>Stage Two:</th>
<th>Stage Three:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Literature review &amp; stakeholder interviews.</td>
<td>Semi-structured interviews with consumers and carers (n=108)</td>
<td>Survey of consumers (n=600) and health professionals (n=200)</td>
</tr>
<tr>
<td>Focus groups with consumers (16 groups including diverse minority groups) and health professionals (6 groups)</td>
<td>To explore perspectives on the burden of chronic disease, consumer healthcare priorities and perceptions of what patient-centred care should be in community pharmacy.</td>
<td>To develop measurement tools based on data collected in Stage 2 to statistically measure the burden of chronic illness and the potential impact of selected pharmacy models of care.</td>
</tr>
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Appendix 2.2 – Consumer & Carer Participation Flyer

Dealing with an ongoing health condition? Have your say

If you or a family member have an ongoing health condition then we are interested in hearing about your experiences.

Researchers from Griffith University are conducting a research project that will investigate your perspective on the impact that ongoing health (chronic and long term) conditions have on you or your family member(s), and the support that community pharmacy can provide with managing these condition(s). We are looking for adults who have a newly diagnosed or existing health condition, or who care for others who have an ongoing health condition, to help us understand their experiences and the health services that they think could assist them with managing treatment. If you live in the following areas, we would like to hear from you: Logan-Beaudesert and Mt Isa/North West regions (QLD), Northern Rivers region (NSW) and the greater Perth area (WA).

Why is this study important?

Each year more people are being diagnosed with ongoing health conditions like asthma or diabetes. We need to know more about how people with these conditions (and their family) experience them to make sure that their healthcare needs are met.

What will I have to do?

Give a short face-to-face interview, attend a focus (discussion) group and/or complete a telephone survey. We will ask what your conditions are like for you, your experiences of healthcare and what you want from health providers like pharmacists. The project will be conducted in stages over the next three years (2011-2014).

What are the benefits?

If you choose to take part, the information you provide will help us understand better how people manage their ongoing health conditions and what health care providers such as pharmacists can do to assist them. You will be provided with a small gift to compensate you for your time. We will keep your personal information confidential and any information reported or published by researchers will not have your name in it.

Who is behind this project?

This project is funded by the Australian Government Department of Health as part of the Fifth Community Pharmacy Agreement Research and Development Program managed by The Pharmacy Guild of Australia. Ethics approval has been obtained from the Griffith University Human Research Ethics Committee (PHM/12/11/HREC).

Know more. Do more.

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*Based on fields of research at the 5-digit level in the Excellence in Research for Australia 2015 National Report.
Exploring the health consumers’ perspective on the burden of chronic illness and the role of community pharmacy in chronic illness management.

Dear Participant

Griffith University is undertaking a study that will form the basis of recommendations for models of care for community pharmacies to assist patients with ongoing health (chronic and long term) conditions and complex treatment regimens to manage their illness. This project is funded by the Australian Government Department of Health and Ageing as part of the Fifth Community Pharmacy Agreement Research and Development Program managed by The Pharmacy Guild of Australia. The researchers involved in this project are: Assoc Prof Amanda Wheeler, Prof Elizabeth Kendall, Dr Jennifer Whitty, Dr Michelle King (Griffith University) and Dr Fiona Kelly (University of Auckland). The team members who will be conducting the interviews are Dr Adem Sav (Senior Research Assistant) and Sara McMillan (Pharmacy lecturer and PhD candidate).

We are seeking your consent to take part in this study as a key stakeholder in this area. In particular, we are interested in learning about your organisation’s perspective of patient-centred care, treatment burden and health care priorities for the consumers with ongoing health conditions that you represent or support or both, and the role of community pharmacy in this. We would also like to identify strategies to recruit or conduct research with health consumers and ask for your organisation’s support in promoting the study to your members or consumers.

What is involved?

1. We would like to invite two representatives from your organisation to participate in an interview (60 minutes). The information obtained will assist the project team to develop further questions for consumer interviews, ensuring that the project fully explores the perspectives of consumers and their experiences and expectations of community pharmacy in managing their ongoing health condition. Participants will be offered a small gift as a token of appreciation for their time.

2. We also seek your organisation’s support to identify consumers that have an ongoing health condition and their family members and carers, and ask if they would like to participate in the project. Your organisation will be provided with an information sheet to give to those consumers who may be interested in participating or to your members who may be interested in recruiting consumers.

Do I have to participate?
No. Participation in any research project is voluntary. If you and your organisation do not wish to take part there is no obligation to do so. If you and your organisation decide to take part and later change their mind, participants are free to withdraw from the project at any stage and the information will not be included.

**Are there any benefits to me?**  
The results of this project will potentially improve or assist the way that consumers with ongoing health (chronic and long term) conditions are managed in the community pharmacy. This project seeks your support to ensure that your member’s views and needs are represented, and we make appropriate recommendations to improve their health care.

**Are there any risks involved?**  
We do not anticipate that there would be any risks to participants as a result of participation in the project. Although the interview will be recorded, information obtained will be de-identified for analysis and only the research team will have access to this information. The personal information obtained from the expression of interest form will be used for follow-up purposes only and, as with all information, this will be stored securely at Griffith University, Logan Campus. Information you provide for this study will be retained for a period of five years post publication and then destroyed.

**Ethical Clearance**  
This project has received Griffith University Human Research Ethics Committee approval (GU Ref No: PHM/10/11/HREC). Griffith University conducts research in accordance with the National Statement on Ethical Conduct in Human Research. If you have any concerns or complaints about the ethical conduct of this research project you should contact the Manager, Research Ethics on (07) 3735 5585 or [research-ethics@griffith.edu.au](mailto:research-ethics@griffith.edu.au)  
If you would like to take part in the study, please complete and return the attached expression of interest form. If you have any further questions please contact Sara McMillan or Amanda Wheeler, the project leader (Freecall 1800 600 687) or email [chronicillness@griffith.edu.au](mailto:chronicillness@griffith.edu.au)

Thank you for your time.

Yours sincerely,

Amanda Wheeler  
BSc, BPharm, PGDip(PsyChPharm), PGCert(PubHealth), PhD

Sara McMillan  
BPharm Grad Cert HigherEd MPS
EXPRESSSION OF INTEREST FORM

Exploring the health consumers’ perspective on the burden of chronic illness and the role of community pharmacy in chronic illness management.

Our organisation would like to take part in an interview:

**Please circle yes or no:**   **Y / N**

Our organisation would like to assist in recruiting health care consumers:

**Please circle yes or no:**   **Y / N**

I hereby give permission for my name to be added to a database of key stakeholders that will be used to contact me regarding participation in the project. Only the research team will have access to this information.

Name: 

______________________________________________

Organisation Name: 

______________________________________________

Address: 

______________________________________________

_________________________ Post Code: __________________

Telephone: 

_________________________

Email: 

______________________________________________

**Privacy statement**

The conduct of this research involves the collection, access and/or use of your identified personal information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information consult the University’s Privacy Plan at [http://www.griffith.edu.au/about-griffith/plans-publications/griffith-university-privacy-plan](http://www.griffith.edu.au/about-griffith/plans-publications/griffith-university-privacy-plan) or telephone (07) 3735 5585.

**Please complete and return the attached expression of interest form to:** Chronic Illness Project, School of Human Services, Logan Campus, Griffith University, University Drive, Meadowbrook QLD 4131 Australia; or email [chronicillness@griffith.edu.au](mailto:chronicillness@griffith.edu.au) or fax +61 (0)7 3382 1210
Appendix 2.4 – Eligibility Criteria for Consumers & Carers

Chronic Illness Project Expression of Interest Form
Consumer and Carer Participants

Please note, to register for this project you must live or access medical and pharmacy services in the
Perth and surrounding areas.

1. First Name _______________________________ Family Name _______________________________

2. Please circle your gender:  Male / Female

3. What is your cultural background? Tick all that apply.
   □ Australian (Caucasian)  □ New Zealand or Pacific Islander  □ Middle eastern
   □ Aboriginal             □ Asian                     □ Torres Strait Islander
   □ European               □ African                   □ British
   □ Other: __________________________

4. Email address
   __________________________________________________________________________

6. Street Address ________________________________________________________________
   Suburb ___________________________________________ Postcode ___________________
   Phone number ___________________________ Mobile _______________________________

7. What year were you born? ______________________________________________________

8. Please tick the box that applies to you:
   □ I have one or more long term health condition
   □ I care for someone with a long term health condition
   □ Both

9. What long-term health condition impacts most on your life or the person you are caring for?
   __________________________________________________________________________

10. Do you have someone to assist you manage your condition?  □ Yes  □ No
    □ Family member    □ Home help (eg Blue Care)  □ Other ____________________________
11. Please tick the boxes below that apply to you, or the person you are caring for:

☐ I have had a long term health conditions for more than six months

☐ I have been recently diagnosed with a long term health condition within the last six months

☐ I have recently started to use pharmacy services, for example health screening, home medicine reviews, Webster packing, home delivery

☐ I take 5 or more regular medicines

☐ I take more than 12 doses of medicine each day

☐ I have experienced difficulties with or significant changes to my medicine routine in the last 3 months

☐ I use medical services (Drs, GPs and specialists) at least 12 times per year

☐ I have qualified for cheaper prescription medicines (such as the PBS safety net threshold) this year or last year

☐ I am Aboriginal or a Torres Strait Islander person and qualify for the Closing the Gap PBS co-payment
Appendix 2.5 – Stage Two Consumer & Carer Information Sheet

School of Human Services
Logan Campus, Griffith University
University Drive
Meadowbrook QLD 4131
Australia
Telephone +61 (0)7 3382 1201
Facsimile +61 (0)7 3382 1210
www.griffith.edu.au

Date

Dear Consumer,

My name is Sara McMillan and I am a PhD student involved in a study that will form the basis of recommendations for models of care for community pharmacies to assist patients with ongoing (chronic) medical conditions manage their illness and its treatment. This project is funded by the Australian Government Department of Health and Ageing as part of the Fifth Community Pharmacy Agreement Research and Development Program managed by The Pharmacy Guild of Australia. The researchers involved in this project are: Assoc Prof Amanda Wheeler, Prof Elizabeth Kendall, Dr Jennifer Whitty, Dr Michelle King (Griffith University) and Dr Fiona Kelly (University of Auckland).

I am seeking your consent to take part in a study on the role of pharmacy in assisting consumers to manage their medical conditions. In particular, we are interested in learning about your experiences and perspective of chronic illness and the health services that you think could assist you with managing treatment.

Who are we looking for?
All health consumers that have an ongoing (chronic) medical illness and their family members or carers. Once you have expressed an interest in the project, the research team will contact you with some questions to determine your eligibility for participation.

What is involved?
If you choose to participate, you may be invited to take part in three different stages of the project. Based on your availability and time commitments, this could include an interview (45 minutes), focus group (1 hour) and survey (45 minutes). Questions will ask you about your experience of chronic illness and its treatment and what you need or want from community pharmacy and other health services to help you manage your chronic illness. This could include questions on how community pharmacy can help you to manage your medicines or to self-manage your chronic illness. If you are a carer, the project team would like to hear your perspective on assisting you and your family member or patient. Some questions may be of a personal nature but you will be free to skip questions if you feel uncomfortable answering.

You do not need to participate in all stages of the study; however, as a token of appreciation for your time, participants will be offered ColesMyer vouchers to the value of $150 for participating in all three stages of the study (interview, focus group and survey), $80 for participating in two stages, $30 for the interview or $50 for the survey only. These vouchers cannot be redeemed for cash.
Do I have to participate?
No. Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage and your information will not be included. Your decision not to take part will not affect your relationship with your health professional or health service.

Are there any benefits to me?
The results of this study will potentially improve our understanding of the consumer perspective of managing chronic illness and assist the way that health consumers with chronic illness are managed in the community pharmacy.

Are there any risks involved?
We do not anticipate there will be any risks to you as a result of your participation in the project. Although the interviews and focus groups will be recorded, the information obtained from all aspects of the study will be de-identified for analysis and only the research team will have access to this information. The personal information obtained from the expression of interest forms will be used for follow-up purposes only and, as with all information, this will be stored securely at Griffith University, Logan Campus. The study includes a survey that will be administered by a third party research company on behalf of Griffith University. We may provide your name and contact details to the company undertaking the survey to enable them to invite you to participate in the survey. If we do so, your details will only be provided for the purpose of undertaking this research study. Information you provide for this study will be retained for a period of five years post publication and then destroyed.

Ethical Clearance
This project has received Griffith University Human Research Ethics Committee approval (GU Ref No: PHM/10/11/HREC). Griffith University conducts research in accordance with the National Statement on Ethical Conduct in Human Research. If you have any concerns or complaints about the ethical conduct of this research project you should contact the Manager, Research Ethics on (07) 3735 5585 or research-ethics@griffith.edu.au

If you would like to take part in the study, please complete and return the attached expression of interest form. Please note that as this project is being undertaken over a three year period (2011-2014), it may be some months before a researcher contacts you. If you have any further questions please contact myself or Amanda Wheeler, the project leader (Freecall 1800 600 687) or email chronicillness@griffith.edu.au

Thank you for your time.

Yours sincerely,

Sara McMillan
BPharm Grad Cert HigherEd
MPS

Amanda Wheeler (Project Leader)
BSc,BPharm,PGDip(PsychPharm),
PGCert(PubHealth), PhD
EXPRESSION OF INTEREST FORM

I would like to take part as a participant in the Chronic Illness – A consumer perspective research project (PHM/10/11/HREC):

Please circle yes or no: Y / N

I hereby give permission for my name to be added to a database of Health Consumers that will be used by Griffith University or by a research company acting on behalf of Griffith University to contact me regarding my participation (as indicated above):

Name: ____________________________________________

Address: ____________________________________________

____________________________________ Post Code: ____________

Contact Number: ______________________________

Email: ____________________________________________

Privacy statement

The conduct of this research involves the collection, access and/or use of your identified personal information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information consult the University’s Privacy Plan at http://www.griffith.edu.au/privacy-plan or telephone (07) 3735 5585.
Appendix 2.6 – Stage Three Consumer & Carer Recruitment Newspaper Advertisement

Does your pharmacy provide the support you need?

If you’re dealing with an ongoing health condition or caring for someone who does, we’d like to hear from you.

The Griffith Health Institute is researching the support given by local community pharmacies, in Mt Isa and the North West area, for people with ongoing health conditions. This is part of a nationwide project designed to assist in the planning of future pharmacy services.

Participants must be at least 18 years old and be:

- Living with an ongoing health condition, or
- Caring for a person with an ongoing health condition.

The study involves completing a 30-minute phone survey with participants reimbursed for their time.

To register visit chronicillnessproject.com.au or call 1800 600 687 (free of charge).

The Chronic Illness Project is funded by the Australian Government Department of Health and Ageing as part of the Fifth Pharmacy Agreement Research and Development Program managed by The Pharmacy Guild of Australia.

This project has received ethics approval from both Griffith Human Research Ethics Committee (Protocol: PHM/12/11/HREC) and Metro South Health Hospital and Health Service (HREC/13/QPAH/605).
Appendix 2.7 – Stage Three Consumer & Carer Recruitment Flyer

If you're dealing with an ongoing health condition or caring for someone who does, we'd like to hear from you.

The Griffith Health Institute is researching the support given by local community pharmacies, in Mt Isa and the North West area, for people with ongoing health conditions. This is part of a nationwide project designed to assist in the planning of future pharmacy services.

Participants must be at least 18 years old and be:

- Living with an ongoing health condition, or
- Caring for a person with an ongoing health condition.

The study involves completing a 30 minute phone survey with participants reimbursed for their time.

To register visit chronicillnessproject.com.au or call 1800 600 687 (free of charge).

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This project has received ethics approval from both Griffith Human Research Ethics Committee (GU Ref No: PHEM/12/11/HREC) and Metro South Health Hospital and Health Service HREC number HREC/13/QPAH/605.

Know more. Do more.
Richard got there on a wing and a spanner

I will just sit in my hangar, having a sandwich or a coffee and I just look at my completed plane.

Local news

In brief

Illness study

Chronic patients, carers wanted

Many of the carers we interviewed also experience chronic conditions themselves.

Local insurance for everyone

- Business including Trades
- Householders
- Landlords
- Commercial & Hobby Farms
- Private & commercial Motor

Including pay by the month at no extra cost

Elders Insurance
23 Prince Street
Grafton
026642 2333

Elders Insurance

FULL FINAL REPORT 19
Quota gets crafty to raise funds for charity

By JACOB KOSHYAKA

One of the best-known Quota clubs in the country, the Quota Int. of Lower Clarence, has been in operation for over 50 years. It was formed in 1962 and has been active in various community service projects.

In 2018, the club decided to hold a craft fair to raise funds for charity. It was a successful event, raising over $10,000.

Free hearing tests

DOCTOR: Did you know that 90% of seniors do not use hearing aids?

PATIENT: What can I do about it?

DOCTOR: You can get a free hearing test.

PATIENT: How do I schedule it?

DOCTOR: Simply call our office to set up an appointment.

FULL FINAL REPORT

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Appendix 2.9 – Stage Three Consumer & Carer Information Sheet

Chronic Illness – A Consumer Perspective.
Research project PHM/12/11/HREC

Dear Consumer/Carer,

Griffith university is currently undertaking a study that will form the basis of recommendations for models of care for community pharmacies to assist patients with ongoing health (chronic and long term) conditions manage their health condition and its treatment. The project is funded by the Australian Government Department of Health and Ageing as part of the Fifth Community Pharmacy Agreement Research and Development Program managed by The Pharmacy Guild of Australia. The project is led by researchers from Griffith University including: Prof Amanda Wheeler, Prof Elizabeth Kendall, Dr Jennifer Whitty, Dr Michelle King and Dr Fiona Kelly. The team also comprises: Dr Adem Sav (Senior Research Assistant) and Sara McMillan (Pharmacy lecturer and PhD candidate), Beth Hunter (Project Manager) and Claire Campbell (Consumer Researcher).

We are seeking your consent to take part in a study on the role of pharmacy in assisting consumers to manage their medical conditions. In particular, we are interested in learning about your experiences and perspective of your ongoing health condition and the health services that you think could assist you with managing treatment.

Who are we looking for?

All health consumers that have an ongoing health condition and their family members or carers. Once you have expressed an interest in the project, the research team will contact you with some questions to determine your eligibility for participation.

What is involved?

If you choose to participate, you may be invited to take part in the final stage of the project a phone survey (estimated duration 25-30 minutes) which will be occurring later in 2013. Questions will ask you about your experience of an ongoing health condition and its treatment and what you need or want from community pharmacy and other health services to help you manage your health condition. This could include questions on how community pharmacy can help you to manage your medicines or to self-manage your ongoing health condition. If you are a carer, the project team would like to hear your perspective on assisting you and your family member or patient. Some questions may be of a personal nature but you will be free to skip questions if you feel uncomfortable answering.

Eligible participants who participate in the phone survey will be offered Coles voucher to the value of $50 as a token of appreciation for your time. This voucher cannot be redeemed for cash.
Do I have to participate?

No. Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage and your information will not be included. Your decision not to take part will not affect your relationship with your health professional or health service.

Are there any benefits to me?

The results of this study will potentially improve our understanding of the consumer perspective of managing ongoing health conditions and assist the way that they are managed in the community pharmacy.

Are there any risks involved?

We do not anticipate there will be any risks to you as a result of your participation in the project. The information obtained from all aspects of the study will be de-identified for analysis and only the research team will have access to this information. The personal information obtained from the expression of interest forms will be used for follow-up purposes only and, as with all information, this will be stored securely at Griffith University, Logan Campus. The study includes a survey that will be administered by a third party research company on behalf of Griffith University. We may provide your name and contact details to the company undertaking the survey to enable them to invite you to participate in the survey. If we do so, your details will only be provided for the purpose of undertaking this research study. Information you provide for this study will be retained for a period of five years post publication and then destroyed.

Ethical Clearance

This project has received Griffith University Human Research Ethics Committee approval (GU Ref No: PHM/12/11/HREC). For Queensland participants, the project has also received approval from Metro South Human Research Ethics Committee HREC/13/QPAH/605.

Griffith University conducts research in accordance with the National Statement on Ethical Conduct in Human Research. If you have any concerns or complaints about the ethical conduct of this research project you should contact the Manager, Research Ethics on (07) 3735 5585 or research-ethics@griffith.edu.au

If you would like to take part in the study, please complete and return the expression of interest form on the Chronic Illness Project’s website www.chronicillnessproject.com.au If you have any further questions please contact myself or Amanda Wheeler, the project leader (Freecall 1800 600 687) or email chronicillness@griffith.edu.au

Thank you for your time.

Yours sincerely,

Beth Hunter
Project Manager

Amanda Wheeler (Project Leader)
BSc,BPharm,PGDip(PsychPharm),
PGCert(PubHealth), PhD

Privacy statement

The conduct of this research involves the collection, access and/or use of your identified personal information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information consult the University’s Privacy Plan at http://www.griffith.edu.au/about-griffith/plans-publications/griffith-university-privacy-plan or telephone (07) 3735 5585.
Appendix 2.10 – Expression of Interest Form for Health Professionals

**Chronic Illness Project** – Eligibility Contact for Health Care Professionals

*Please complete the below demographic information to the best of your ability prior to the focus group interview.*

<table>
<thead>
<tr>
<th>1. Name: ___________________________</th>
<th>Male / Female</th>
<th>Year of birth: ______</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preferred postal address:__________</td>
<td>Suburb: ______</td>
<td>P/code: ______</td>
</tr>
<tr>
<td>Name of Workplace: ________________</td>
<td>Suburb where you work: ______</td>
<td>P/code: ______</td>
</tr>
<tr>
<td>Email: __________________________</td>
<td>Ph: (H)________  Ph: (W)________</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. Do you or does someone you are caring for have one or more long term conditions?</th>
<th>Yes / No</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ I have one or more long term health condition</td>
<td></td>
</tr>
<tr>
<td>☐ I am a carer/support person for someone with one/more long term condition(s)</td>
<td></td>
</tr>
<tr>
<td>☐ Both</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3. What is your current health professional role?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Generalist medical practitioner</td>
<td>☐ Specialist medical practitioner</td>
</tr>
<tr>
<td>☐ Registered pharmacist</td>
<td>☐ Pharmacy assistant / technician</td>
</tr>
<tr>
<td>☐ Dental practitioner</td>
<td>☐ Nurse/midwife</td>
</tr>
<tr>
<td>☐ Nurse practitioner</td>
<td>☐ Allied health professional</td>
</tr>
<tr>
<td>☐ Alternative health practitioner</td>
<td>☐ Other __________________________</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4. In which country did you first receive your professional training in this role?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Australia</td>
<td>☐ New Zealand</td>
</tr>
<tr>
<td>☐ Other __________________________</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5. In which sector(s) do you work in? (Please tick all that apply)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Health policy and administration</td>
<td>☐ Non-profit organisation</td>
</tr>
<tr>
<td>☐ Education and training</td>
<td>☐ Hospital</td>
</tr>
<tr>
<td>☐ Rural and remote health</td>
<td>☐ Primary health</td>
</tr>
<tr>
<td>☐ Other __________________________</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6. How many years have you been working in your professional role?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Less than 5 years</td>
<td>☐ 6 – 10 years</td>
</tr>
<tr>
<td>☐ 11 -15 years</td>
<td>☐ 16-20 years</td>
</tr>
<tr>
<td>☐ 21-25 years</td>
<td>☐ 26 - 30 years</td>
</tr>
<tr>
<td>☐ 31 years or longer</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>7. How many hours do you work on average each week in your health professional role?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Total hours__________</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>8. What is your cultural background?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Australian (Caucasian)</td>
<td>☐ Aboriginal</td>
</tr>
<tr>
<td>☐ Torres Strait Islander</td>
<td>☐ New Zealand or Pacific Islander</td>
</tr>
<tr>
<td>☐ Middle eastern</td>
<td>☐ European</td>
</tr>
<tr>
<td>☐ African</td>
<td>☐ African</td>
</tr>
<tr>
<td>☐ Asian</td>
<td>☐ Asian</td>
</tr>
<tr>
<td>☐ Other: __________________________</td>
<td></td>
</tr>
</tbody>
</table>
9. Would you like to **participate in a short (10-15 minutes) telephone assisted** survey about this project towards the end of this year? ($30 reimbursement for participants time in the form of gift vouchers will be provided) Y / N

10. **Where do you mainly work (please circle)**: In a hospital / in the community / other _____________

11. How did you **hear about the project**? _______________________________
Appendix 2.11 – Stage Two Health Professional Information Sheet

School of Human Services
Logan Campus, Griffith University
University Drive
Meadowbrook QLD 4131
Australia
Telephone +61 (0)7 3382 1201
Facsimile +61 (0)7 3382 1210
www.griffith.edu.au

Date

Exploring the health consumers’ perspective on the burden of chronic illness and the role of community pharmacy in chronic illness management.

Dear Health Care Professional

My name is Sara McMillan and I am a PhD student involved in a study that will form the basis of recommendations for models of care for community pharmacies to assist patients with chronic conditions and complex treatment regimens to manage their illness. This project is funded by the Australian Government Department of Health and Ageing as part of the Fifth Community Pharmacy Agreement Research and Development Program managed by The Pharmacy Guild of Australia. The researchers involved in this project are: Assoc Prof Amanda Wheeler, Prof Elizabeth Kendall, Dr Jennifer Whitty, Dr Michelle King (Griffith University) and Dr Fiona Kelly (University of Auckland).

I am seeking your consent to take part in a study on the role of pharmacy in chronic illness management. In particular, we are interested in learning about your perspective of patient-centred care, treatment burden and health care priorities for consumers with chronic illness and also seek your support in recruiting suitable health consumers.

What is involved?

1. We would like to invite you to participate in a focus group (1 hour) or survey (45 minutes) or both, to identify what services you think health consumers would like community pharmacies to provide to support the management of their chronic illness(s). As a token of appreciation for your time, you will be offered ColesMyer vouchers to the value of $50 for participation in a focus group, and $30 for participation in the survey. These vouchers cannot be redeemed for cash. You will also be given a certificate of participation as evidence for your continuing education or research portfolio.

2. We also seek your support and the support of your work colleagues and staff to identify consumers with a chronic illness, or family members or carers who support people with chronic illness, and ask if they would like to participate in the project. You will be provided with a consumer information sheet to give to those who may be interested in participating.

Do I have to participate?

No. Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage and your information will not be included.
Are there any benefits to me?

This project seeks the support of all health care professionals to improve the services provided in community pharmacy, as part of the health care team. The results of this study will potentially improve or assist the way that health consumers with chronic illness(s) are managed in the community pharmacy.

Are there any risks involved?

We do not anticipate that there would be any risks to you as a result of your participation in the project. Although the focus group will be recorded, information obtained from all aspects of the project will be de-identified for analysis and only the research team will have access to this information. The personal information obtained from the expression of interest form will be used for follow-up purposes only and, as with all information, this will be stored securely at Griffith University, Logan Campus. The study includes a survey that will be administered by a third party research company on behalf of Griffith University. We may provide your name and contact details to the company undertaking the survey to enable the company to invite you to participate in the survey. If we do so, your details will only be provided for the purpose of undertaking this research study. Information you provide for this study will be retained for a period of five years post publication and then destroyed.

Ethical Clearance

This project has received Griffith Human Research Ethics Committee approval (GU Ref No: PHM/10/11/HREC). Griffith University conducts research in accordance with the National Statement on Ethical Conduct in Human Research. If you have any concerns or complaints about the ethical conduct of this research project you should contact the Manager, Research Ethics on (07) 3735 5585 or research-ethics@griffith.edu.au

If you would like to take part in the study, please complete and return the attached expression of interest form. If you have any further questions please contact myself or Amanda Wheeler, the project leader (Freecall 1800 600 687) or email chronicillness@griffith.edu.au

Thank you for your time.

Yours sincerely,

Sara McMillan
BPharm Grad Cert HigherEd MPS

Amanda Wheeler (Project Leader
BSc, BPharm, PGDip(PsychPharm),
PGCert(PubHealth), PhD

FULL FINAL REPORT 26
EXPRESSION OF INTEREST FORM

I would like to take part as a participant in the Chronic Illness project (PHM/10/11/HREC):

Please circle yes or no:  

Y / N

I would like to assist in recruiting health care consumers:

Please circle yes or no:  

Y / N

I hereby give permission for my name to be added to a database of Health Care Professionals that will be used by Griffith University or by a research company acting on behalf of Griffith University to contact me regarding my participation (as indicated above):

Name:  

__________________________________________________________

Organisation Name:  

__________________________________________________________

Address:  

__________________________________________________________Post Code: __________________

Telephone:  

________________________

Email:  

__________________________________________________________

Privacy statement

The conduct of this research involves the collection, access and/or use of your identified personal information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information consult the University’s Privacy Plan at http://www.griffith.edu.au/about-griffith/plans-publications/griffith-university-privacy-plan or telephone (07) 3735 5585.
Appendix 2.12 – Stage Three Health Professional Recruitment Example

Do you help people manage their chronic conditions?

Do you work in Logan-Beaudesert area?

We are looking for health professionals including pharmacists and pharmacy assistants, GPs, allied health professionals and community health workers to assist researchers in a study conducted by the Griffith Health Institute.

This study aims to fully explore the perspective of health consumers about the burden of chronic illness and multiple treatment regimes, their desire in terms of patient centred care and the related role of community pharmacy. Your participation will form the basis of recommendations for models of care for community pharmacy to assist people with chronic disease and complex treatment regimes to better manage their illness.

The study involves completing a 20 minute phone survey with reimbursement offered for your time.

To register visit chronicillnessproject.com.au or call 1800 600 687.

The Chronic Illness Project is funded by the Australian Government Department of Health and Ageing as part of the Fifth Community Pharmacy Agreement Research and Development Program managed by The Pharmacy Guild of Australia.

For further information about the SCPA Research and Development Program visit scpacom.au/research

This project has received ethics approval from both Griffith Human Research Ethics Committee (Protocol: PHM/12/11/HREC) and Metro South Health Hospital and Health Service (HREC/13/QPAH/605).
Appendix 2.13 – Stage Three Health Professional Recruitment Newsletter Examples

Do you help people manage their chronic conditions?

Do you work in Mt Isa and the North West area?

We are looking for health professionals including GPs, pharmacists and pharmacy assistants, allied health professionals and community health workers to assist researchers in a study conducted by the Griffith Health Institute.

This study aims to fully explore the perspective of health consumers about the burden of chronic illness and multiple treatment regimes, their desire in terms of patient centred care and the related role of community pharmacy. Your participation will form the basis of recommendations for models of care for community pharmacy to assist people with chronic disease and complex treatment regimes to better manage their illness.

The study involves completing a 20-25 minute phone survey with reimbursement offered for your time.

To register visit www.chronicillnessproject.com.au or call 1800 600 687.

The Chronic Illness Project is funded by the Australian Government Department of Health and Aged as part of the Fifth Community Pharmacy Agreement Research and Development Program managed by The Pharmacy Guild of Australia.

Andrology Aust – Male Health Education DVD

Andrology Australia’s Male Health Education DVD has been accredited by the RACGP with 4 Category 2 QI&CPD points and the ACRRM with 2 core PDP points.

The DVD provides health professionals with the knowledge and skills to initiate dialogue and engage with Aboriginal and Torres Strait Islander males about the potentially tricky topic of male reproductive health. To request a copy, email info@andrologyaustralia.org.
Does your pharmacy provide the support you need?

If you’re dealing with an ongoing health condition or caring for someone who does, we’d like to hear from you.

The Griffith Health Institute is researching the support given by local community pharmacies, in Mt Isa and the North West area, for people with ongoing health conditions. This is part of a nationwide project designed to assist in the planning of future pharmacy services.

Participants must be at least 16 years old and be:
• Living with an ongoing health condition, or
• Caring for a person with an ongoing health condition.

The study involves completing a 30 minute phone survey with participants reimbursed for their time.
To register visit chronicillnessproject.com.au or call 1800 600 687 (free of charge).

The Chronic Illness Project is funded by the Australian Government Department of Health and Ageing as part of the Fifth Pharmacy Agreement Research and Development Program managed by The Pharmacy Guild of Australia.

Mindful Eating, Psychosocial Risk factors and Coronary Heart Disease.

A review of evidence by the Heart Foundation shows that psychosocial risk factors and depression are
Recall Action Notification

**Type of Product**
Medicine

**TGA Recall Reference**
RC-2013-RN-00710-1

**Product Name/Description**
Febridol Paracetamol 500mg, 100 tablet bottle
Batch Number: ACN2134
ARTG Number: 98138

**Recall Level**
Consumer

**Recall Classification**
Class I

**Recall**
Commencement Date/Time 18/07/2013

**Responsible Entity**
Ascent Pharma Pty Ltd

**Reason / Issue**
Ascent Pharmaceuticals is recalling batch ACN2134
Febridol Paracetamol 500 mg (which is an analgesic used to treat aches, pains and feverish conditions) because of the possibility of a peach coloured triangle shaped tablet in some bottles of this batch.

**Recall Action**
Recall

**Recall Instructions**
Ascent Pharmaceuticals is advising consumers not to take any tablets from the affected batch (Batch ACN2134). Consumers are to return the product to the pharmacy where they purchased the Febridol Paracetamol 500 mg, 100 tablets bottle for a full refund.

**Contact Information**
1800 678 302 - Ascent Pharmaceuticals Customer Care

Attention: Pharmacies in Northern Rivers Area

**Have your say about future pharmacy services**
With the rise of chronic illness in Australia, researchers from the Griffith Health Institute at Griffith University are seeking to better understand the impact that these conditions have on people living with them and on those who care for them. More specifically, as community pharmacies play such a critical role in improving the care of these health consumers, we want to better understand how people might prefer to interact with their pharmacies. We also want to hear from pharmacists regarding consumer preferences as they seek to manage their health more effectively.

To date in the Northern Rivers area of NSW, we have spoken with over 100 people living with ongoing health conditions, carers and health professionals and in this final stage of the project we would like to hear from another 150 participants. At the project’s conclusion, recommendations for new model(s) of care for community pharmacy will be developed.

**What we are doing:**
We will be conducting a phone survey in October and November 2013.

**Participant categories:**
Pharmacists, allied health professionals, GPs. We are also looking to recruit people 16 years and over who have at least one chronic condition, or carers.

**Funder:**
The Chronic Illness Project is funded by the Australian Government Department of Health and Ageing as part of the Fifth Pharmacy Agreement Research and Development Program managed by The Pharmacy Guild of Australia.

**Reimbursement:**
Participants will be offered a Coles Group and Myers voucher.

**Registration:**
Via the website (www.chronicillnessproject.com.au) or call us on 1800 600 687 (free call).
Do you work in Logan-Beaudesert area?

We are looking for health professionals including GPs, pharmacists and pharmacy assistants, allied health professionals and community health workers to assist researchers in a study conducted by the Griffith Health Institute.

This study aims to fully explore the perspective of health consumers about the burden of chronic illness and multiple treatment regimes, their desire in terms of patient centred care and the related role of community pharmacy. Your participation will form the basis of recommendations for models of care for community pharmacy to assist people with chronic disease and complex treatment regimes to better manage their illness.

The study involves completing a 20–25 minute phone survey with reimbursement offered for your time.

To register visit chronicillnessproject.com.au or call 1800 600 687.

The Chronic Illness Project is funded by the Australian Government Department of Health and Ageing as part of the Fifth Community Pharmacy Agreement Research and Development Program managed by The Pharmacy Guild of Australia.

For further information about the 5CPA Research and Development Program visit 5cpa.com.au/research

This project has received ethics approval from both Griffith Human Research Ethics Committee (Protocol: PHM/12/11/HERC) and Metro South Health Hospital and Health Service (HREC/13/QPAH/605).
Appendix 2.15 – Stage Three Health Professional Information Sheet

Chronic Illness – The Health Care Professionals Perspective.
Research project PHM/12/11/HREC

Exploring the health consumers’ perspective on the burden of chronic illness and the role of community pharmacy in chronic illness management.

Dear Health Care Professional

Griffith University is undertaking a study that will form the basis of recommendations for models of care for community pharmacies to assist patients with chronic conditions and complex treatment regimens to manage their illness. This project is funded by the Australian Government Department of Health and Ageing as part of the Fifth Community Pharmacy Agreement Research and Development Program managed by The Pharmacy Guild of Australia. The researchers involved in this project are: Prof Amanda Wheeler, Prof Elizabeth Kendall, Dr Jennifer Whitty, Dr Michelle King (Griffith University) and Dr Fiona Kelly (University of Auckland). The team also comprises: Dr Adem Sav (Senior Research Assistant), Sara McMillan (Pharmacy lecturer and PhD candidate), Beth Hunter (Project Manager) and Claire Campbell (Consumer Researcher).

We are seeking your consent to take part in a study on the role of pharmacy in chronic illness management. In particular, we are interested in learning about your perspective of patient- centred care, treatment burden and health care priorities for consumers with chronic illness and also seek your support in recruiting suitable health consumers.

What is involved?
1. We would like to invite you to participate in a telephone survey (20-25 minutes), to identify what services you think health consumers would like community pharmacies to provide to support the management of their chronic illness(s). As a token of appreciation for your time, you will be offered a Coles voucher to the value of $30 for participation in the survey. This voucher cannot be redeemed for cash. You will also be given a certificate of participation as evidence for your continuing education or research portfolio.

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Are there any benefits to me?
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Are there any risks involved?
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If you would like to take part in the study, please complete and return the expression of interest form on the Chronic Illness Project’s website www.chronicillnessproject.com.au. If you have any further questions please contact Beth Hunter (Project Manager) or Amanda Wheeler, the project leader (Freecall 1800 600 687) or email chronicillness@griffith.edu.au

Thank you for your time.
Yours sincerely,
Beth Hunter  
Amanda Wheeler (Project Leader)
Project Manager  BSc.BPharm,  PGDip(PsychPharm),
PGCert(PubHealth), PhD

Privacy statement The conduct of this research involves the collection, access and/or use of your identified personal information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information consult the University’s Privacy Plan at http://www.griffith.edu.au/about-griffith/plans-publications/griffith-university-privacy-plan or telephone (07) 3735 5585.