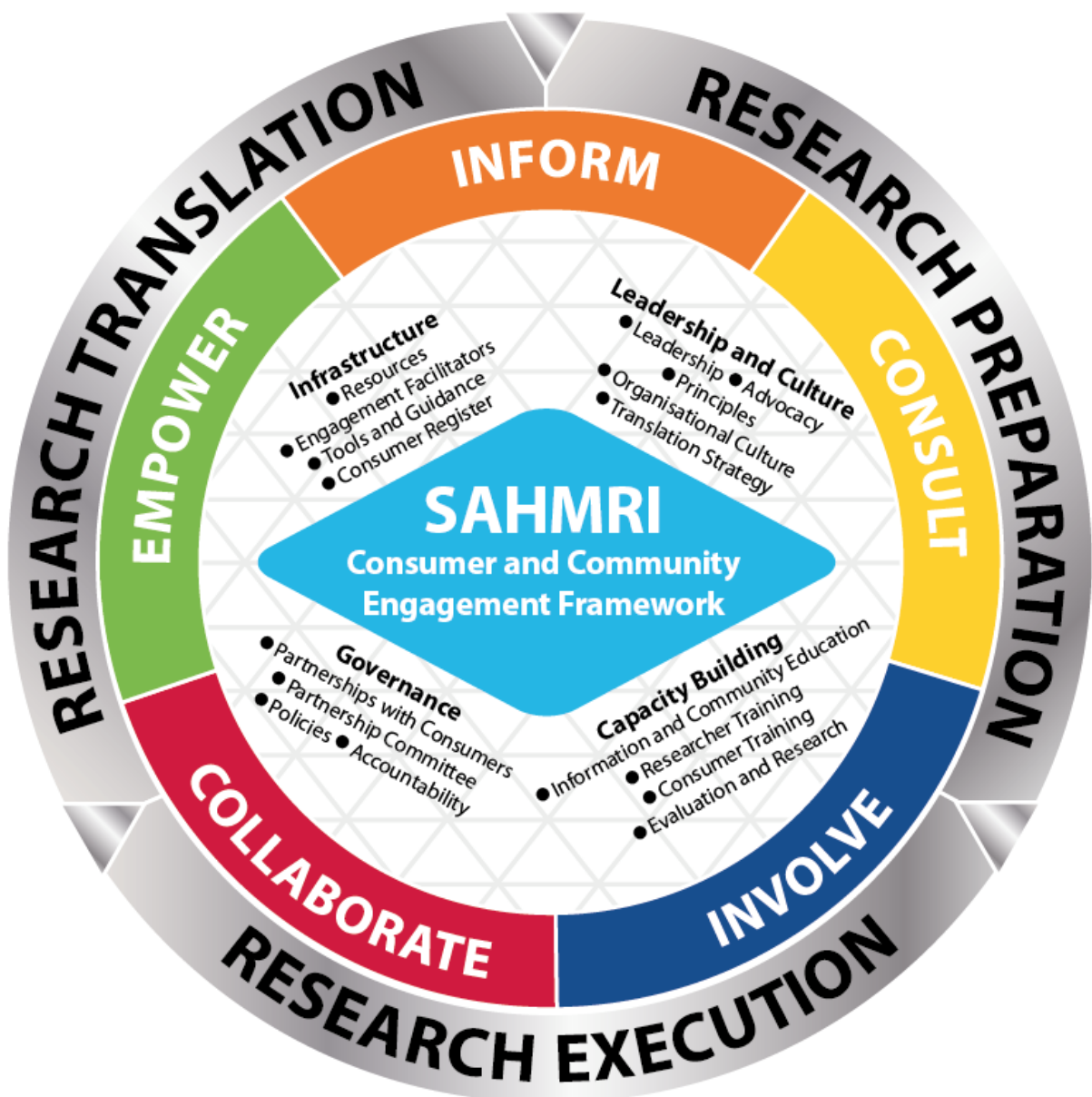hc sa
Health Consumers Alliance of SA Inc.

A Consumer and Community Engagement Framework for the South Australian Health and Medical Research Institute

Final Report
June 2014

Preface

As Executive Director of the South Australian Health and Medical Research Institute (SAHMRI), I am proud to present this Framework for Community and Consumer Engagement. SAHMRI's vision is to transform research into health. Our mission is to improve the quality of life for all people, through innovative, world-class and ground-breaking health and medical research. Consumer and community engagement is fundamental to fulfilling SAHMRI's vision and mission.

At SAHMRI, we are committed to consumer and community engagement in health and medical research. We believe consumers and the community have a right to be involved in the research that affects them. We believe that consumers can and should participate across all phases of research, and we commit to facilitating community participation in SAHMRI's research priority setting and research practice.

At SAHMRI, we value excellence and this Framework demonstrates excellence in its development, which was done as a partnership with Health Consumers Alliance (SA), health consumers, and it advocates leading-edge practice for consumer engagement. We look forward to implementing this Framework and continuing to work with Health Consumer Alliance and health consumers to increase meaningful participation of consumers in health and medical research at SAHMRI. SAHMRI is an evidence-based organisation and this Framework is based on the findings of a review of the literature of existing evidence about how best to encourage community participation in research, and the evaluation of this Framework will contribute further to the evidence base. We are publishing this Framework in the hope that other health and medical research institutes will also embrace this approach, thereby increasing meaningful consumer and community engagement in research. This engagement will enhance the relevance of research and its ability to deliver outcomes for health.

Professor Steve Wesselingh
Executive Director, SAHMRI

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Section 1: Introduction

This Framework for Consumer and Community Engagement for the South Australian Health and Medical Research Institute (SAHMRI) has been developed by the Health Consumers Alliance of SA (HCA). The Framework has been developed in partnership with SAHMRI, health consumers, and staff researchers as members of a Partnership Reference Group.   The Framework was developed throughout 2013.

The South Australian Health and Medical Research Institute (SAHMRI) was established in 2009 as South Australia's first independent health and medical research institute. It is a partnership between the South Australian Government and the University of Adelaide, the University of South Australia and Flinders University. SAHMRI's vision is to transform research into health for all South Australians.

The Health Consumers Alliance of South Australia (HCA) was established in 2002 as an independent alliance of health consumers and health consumer organisations, and is funded by the South Australian Minster for Health and Ageing. HCA is the peak body for health consumers in South Australia and its vision is to see consumers at the heart of health care.

A mixed-method qualitative study was undertaken to identify the evidence supporting and preferred models for consumer and community engagement in health and medical research. Methods included a targeted literature search and review; in-depth, semi-structured interviews with key internal (SAHMRI) and external stakeholders; and a consensus workshop held with the SAHMRI Research Executive, consumers and researchers.

Examples of strategies for the engagement of consumers in health and medical research were identified in Australia, Europe and North America. Evidence on the effectiveness of consumer engagement strategies in health and medical research is limited and this may present an opportunity for SAHMRI.   Among the key stakeholders involved in the project there is broad agreement about the importance of consumer and community engagement in health and medical research. The opportunity and need to build the evidence base in this area was also noted.

Section 2: Findings

Conclusions from the literature

There are many examples of strategies for the engagement of consumers in health and medical research, but few encompass broad and embedded frameworks for consumer and community engagement within large, independent health and medical research institutes such as the new SAHMRI. Although evidence on the effectiveness of strategies for consumer engagement in research is somewhat limited, there is sufficient evidence in the literature and examples of good practice from consumer and research organisations from around the world to develop a framework for a consumer and community engagement strategy for SAHMRI.

During the project, there were few clearly described approaches identified of systematic, integrated consumer and community engagement applied across research institutes. The

opportunity for SAHMRI to design and implement such an approach is unique. Being a young organisation, SAHMRI has the chance to develop a culture of consumer and community engagement into its research and other activities in its formative stage.

Benefits and challenges of consumer participation in research

There is evidence about the contribution that consumers make to research projects. That evidence highlights both benefits and challenges from the perspective of both parties:

Benefits for researchers

Benefits identified for researchers (and the research process) include: enhanced scientific and ethical standards; improved research outcomes and translation of research; enhanced legitimacy and authority to the research; assistance with sensitive issues; a fresh/independent perspective; strengthening of communication with consumers and the community; and an increase in work satisfaction among researchers engaging with consumers.

Benefits for consumers

In addition to the above benefits for consumers in general, benefits identified for individual consumers engaged in research include: acquisition of new skills and knowledge; personal development; support and friendship; enjoyment and satisfaction; increased research literacy; and (sometimes) financial gain.

Challenges for researchers

Challenges for researchers include: concerns about pressure to diverge from scientific methods therefore raising ethical dilemmas; new relationship dynamics; time and cost; lack of training in how to engage consumers; and limited knowledge of and skills in working with consumers.

Challenges for consumers

Challenges for consumers include: tokenism; unfamiliar research language and jargon; power imbalance and conflict; emotional burden; work overload; personal exposure through the media; and frustrations at the limitations of participation.

Building consumer engagement competence

There are some critical factors required to build consumer engagement competence in a research organisation. These factors have been shown to contribute to success in consumer engagement in health and medical research.

Governance

Appropriate structures within a research organisation are required to facilitate the engagement of consumers in health and medical research. A research organisation needs to have policies that encourage and support researchers to engage consumers in their research. Resources and funding are required to encourage and support consumer participation.

Infrastructure

A range of infrastructure is necessary to support consumer engagement including registers of people interested in advising or contributing to research projects; and quality information materials that explain the roles that consumers can play in the organisation, how their participation is supported, and how their contribution to health and medical research can make a difference.

Capacity

Activities that build the capacity and skills of both researchers and consumers are vital to the success of any approach to consumer engagement. This includes training for both researchers and consumers on how to work together. The literature suggests that partnerships are likely to work best when all parties are clear about their intentions, assumptions and limitations from the start.

Advocacy

Consumer-researcher collaborations require planning and perseverance and these partnerships are reliant on a level of human interaction between people who are not necessarily like-minded.

Persistence is required for consumer engagement to be sustained, accepted, and integrated as a natural part of the life of a research organisation. Advocacy from consumers and from researchers is essential to maintain the effort and build organisational culture, both from within the Institute and from outside.

Levels of consumer and community participation

There are a number of models that identify different levels of participation that can be applied to consumer and community engagement in health and medical research. The International Association for Public Participation (IAP2) Public Participation Spectrum has gained widespread adoption in Australia; it is therefore proposed that SAHMRI adopt this spectrum to illustrate application of different levels of participation for different situations.

IAP2's Spectrum clearly shows that different levels of participation are legitimate, depending on the goals, timeframes, resources and levels of concern or interest in the decision to be made. Most important, however, is the realisation that each participation level involves a promise made to the public. This spectrum identifies five levels of participation: inform; consult; involve; collaborate; and empower. Each level incorporates a public participation goal, promise to the public and example tools. Importantly the spectrum provides for a flexible approach to participation, enabling different participation levels to be utilised for different situations, recognising that research can be iterative in nature.

Levels of activities that support successful engagement

A key finding from the literature review is that there are two levels of activities to be looked at when considering the effectiveness of strategies for consumer engagement in research:

- the first level encompasses the conditions within research organisations that foster and support consumer and community engagement
- the second level encompasses the strategies and actions used in a research program to enable consumer and community participation.

Saunders and Girgis (2011) identify four organisational dimensions that contribute to success in consumer and community engagement: governance; infrastructure; capacity and advocacy. At the research program level Shippee et al (2013) provides a structure for understanding consumer and community participation at a research program level - the Phases and Stages Model. In this model there are three stages of health and medical research; preparation; execution and translation. The phases consist of the detailed stages common to health and medical research: agenda setting and funding; design and procedures; recruitment and participation; data collection; data analysis; dissemination; implementation; evaluation. Figure 1, which is an adaption of Shippee et al and IAP2, shows the Phases and Stages of Research integrated with the IAP2 Spectrum of Public Participation.

SAHMRI has prioritised the research it will focus on through the adoption of Research Themes which are supported by four Research Pillars. The Research Themes are: Aboriginal Health; Cancer; Heart Health; Healthy Mothers, Babies and Children; Nutrition and Metabolism; Mind and Brian; Infection and Immunity. The four pillars cover the breadth of health and medical research: Bioscience; Clinical Research, Drug and Device Development; Health Services Research; Population Health, Health and Social Policy.

For the Framework to be successful it is proposed that SAHMRI implement consumer and community engagement at the Institute level, at the SAHMRI Theme level and across all phases and stages of research, where possible. Strategic and business planning at both Institute and SAHMRI Theme level should incorporate consumer and community engagement. Such an approach allows for flexible implementation of consumer engagement, allowing for an appropriate diversity of approaches across SAHMRI's Research Themes and Pillars. It also accommodates the diversity of research, skills and capacity of staff that are present in an Institute as complex as SAHMRI.

Figure 1: Phases and stages of consumer engagement in health and medical research

	Phases and Stages of Health and Medical Research							
	Preparation	**Execution**				**Translation**		
Stages of Research / Levels of Participation	**Agenda Setting and Funding**	**Research Design and Procedures**	**Recruitment and Participation**	**Data Collection**	**Data Analysis**	**Dissemination**	**Implementation**	**Evaluation**
Inform (for example: websites, social media, newsletters, consumer guides to trials)	Consumers are informed about research priorities and funding	Consumers are informed about ethics decisions and research methods	Consumers are informed about opportunities for participation in research	Consumers are informed about data collection	Consumers are informed about data analysis	Consumers are informed about research results	Consumers are informed about research implementation	Consumers are informed about research evaluation
Consult (for example: focus groups, surveys, research subjects)	Consumers are asked to give feedback on research priorities and funding, and informed about how their input influenced the research	Consumers are asked to give feedback on ethics and research design, and informed about how their input influenced the research	Consumers are asked to give feedback on recruitment strategies and participation options, and informed about how their input influenced the research	Consumers are asked to give feedback on data collection methods, and/or are research participants, and informed about how their input influenced the research	Consumers are asked to give feedback on the results of data analysis, and informed about how their input influenced the research	Consumers are asked to give feedback on how research results are disseminated, and informed about how their input influenced the research	Consumers are asked to give feedback on how research results are implemented, and informed about how their input influenced the research	Consumers are asked to give feedback on research evaluation, and informed about how their input influenced the research
Involve (for example: workshops, forums, polling, data collectors and analysers)	Consumer concerns and aspirations are understood and directly reflected in alternatives developed for priority setting and funding	Consumer concerns and aspirations are understood and directly reflected in alternatives developed for research design	Consumer concerns and aspirations are understood and directly reflected in alternatives developed for recruitment and participation	Consumer concerns and aspirations are understood and directly reflected in alternatives developed for data collection	Consumer concerns and aspirations are understood and directly reflected in alternatives developed for data analysis	Consumer concerns and aspirations are understood and directly reflected in alternatives developed for research dissemination	Consumer concerns and aspirations are understood and directly reflected in alternatives developed for research implementation	Consumer concerns and aspirations are understood and directly reflected in alternatives developed for research evaluation

Phases and Stages of Health and Medical Research								
	Preparation	**Execution**				**Translation**		
Stages of Research / Levels of Participation	**Agenda Setting and Funding**	**Research Design and Procedures**	**Recruitment and Participation**	**Data Collection**	**Data Analysis**	**Dissemination**	**Implementation**	**Evaluation**
Collaborate (for example: committees, co-design processes, co-investigators)	Consumers are partners in research priority setting and funding	Consumers are partners in research design	Consumers are partners in recruitment and participation	Consumers are partners in data collection	Consumers are partners in data analysis	Consumers are partners in research dissemination	Consumers are partners in research implementation	Consumers are partners in research evaluation
Empower (for example: citizen juries, ballots, consumer organisation commissions and owns research)	Consumers decide research priorities and funding	Consumers decide research design and procedures	Consumers decide recruitment strategies and research participants	Consumers decide data collection methods	Consumers decide data analysis	Consumers decide research dissemination	Consumers decide research implementation	Consumers decide research evaluation

Case Studies: Consumer and community engagement across different levels of participation

Consult

HIV Futures Study – Community Reference Group

A Living with HIV Community Reference Group was established to provide advice and support for the research projects conducted by the Australian Research Centre in Sex, Health and Society. Members are drawn from state and national consumer and community organisations (People Living with HIV /AIDS groups and AIDS Councils) and representatives of professional organisations. The reference group provides advice on survey content, recruitment and interpretation of data for the HIV Futures Study.

For further information: www.latrobe.edu.au/arcshs

Involve

Influenza Research in Rural and Remote Australia

Aboriginal and Torres Strait Islander community members were employed as community researchers to investigate the impact of pandemic influenza in rural and remote Indigenous communities in Australia. The project employed, trained and strengthened the capacity of local community members in the role of community researchers. An outcome for the community researchers was the sense that they were doing important health work, not just conducting research.

For further information: www.jcu.edu.au/phtmrs

Collaborate

2013 Cancer Survivorship Conference

The inaugural Flinders Centre for Innovation in Cancer Survivorship Conference brought together cancer clinicians, researchers, policy advisors and consumers to share their insights into cancer survivorship, an emerging focus in care and research. Members of Cancer Voices SA became partners in the development and delivery of the conference: collaborating on the planning, design and delivery of the conference; co-chairing each conference session; and leading the drafting of the conference communique – the Flinders Charter of Cancer Survivorship.

For further information: www.fcic.org.au/survivorship2013

Empower

Depression and Anxiety Consumer Research Unit

The Depression & Anxiety Consumer Research Unit was established to promote greater consumer involvement in research content and practice by serving as a bridge between consumers and researchers. This unit is a world-first – it not only focuses on depression and anxiety from a consumer perspective, but is also staffed by qualified and experienced academic researchers who have personally experienced depression or anxiety disorders. One of the unit's unique strengths is that they focus on research for consumers by consumers.

For further information: www.anu.edu.au/cmhr

Section 3: Project management and methods

Project management

The project was overseen by a Steering Committee made up of senior representatives from SAHMRI and HCA. A Partnership Reference Group consisting of a mix of researchers and health consumer advocates provided review and feedback as the project progressed. All findings were taken back to the Steering Committee and Partnership Reference Group for review and validation. Appendix 2 lists the membership of these two groups.

Literature review

The search question for the literature review was developed by the steering committee: What strategies for consumer engagement in health and medical research have been effective for consumers and researchers? The literature review was conducted by Dr Anne Johnson in June and July 2013. The full literature review is available as a separate report.

Stakeholder consultations

The key informant interviews provided an opportunity to test findings from the literature review with three key informant groups: consumers and carers; academics and engagement practitioners with significant experience in the field; and SAHMRI Research Theme Leaders. The interviews provided opportunity for more nuanced conversations on the practice of consumer and community engagement in health and medical research. Importantly, there was significant encouragement and support expressed for SAHMRI's efforts in this field.

Interview procedure

Interviews were conducted at a location convenient to the participant, and for those not resident in South Australia (n=5) interviews were conducted via Skype. Interviews were typically of 45 minutes in duration and all but two interviews were recorded and transcribed (these were written up from notes by the interviewer). A thematic analysis was conducted on the interview transcripts and findings were presented to the steering committee and partnership reference group.

Semi-structured interviews were conducted with key informants, who were drawn from three groups: representatives of consumer organisations related to the SAHMRI research themes (n=9); research leaders at SAHMRI (n=8); academics and practitioners with significant experience in consumer participation in health and medical research (n=5). Interview candidates were selected by the Steering Committee and Partnership Reference Group. 27 invitations were issued by email and followed up by telephone. Reasons for not participating included: no response (n=4) unavailable during the interview period (n=3) and declined (n=1). 19 interviews were conducted within the study period with two interviews being held with multiple participants representing their organisation. The interviews were conducted by Mr Michael Cousins in July through to October 2013. Appendix 3 provides the interview guide questions. Appendix 3 lists interview participants and organisations. Following the interviews a thematic analysis was conducted and Table 3 provides a summary the identified themes.

Table 1: Themes from the key informant interviews

Leadership is essential

- Learn from and build upon the examples of leadership and good practice in Australia - Aboriginal Health, HIV/AIDS, Cancer and Mental Health.

Benefits of consumer engagement

- Engagement strengthens research relevance, research ethics, research outcomes and research translation

- Engagement supports recruitment and retention of research participants

- Engagement improves accountability, transparency and exchange with the community

Consumer participation should be appropriate

- Flexibility is required to ensure the appropriateness of roles for consumers, e.g. consumer reviewers should review consumer related criteria, not be expected to assess scientific validity

- A flexible approach is required – needs change over time – engagement needs are developmental and evolutionary

- Consider a minimum of two consumers on committees to provide for less intimidation, greater participation and success

- There are many opportunities for consumer prioritisation of research

- There are many opportunities for consumer directed research

- Consider consumers as partners in research, not as subjects

- Try not to privilege expertise over experience

Infrastructure and resourcing

- Start with some early wins

- Tools, guidelines and resources for researchers are important

- Invest in education and training for researchers, consumers and the community

- Incentives for consumer engagement are worth considering – could become a required key performance indicator

- Mandatory consumer engagement works.

Opportunities

- Consumer engagement should become mandatory like the National Safety and Quality Healthcare Standards – Standard 2: Partnering with Consumers

- Flip from investigator driven research to needs driven research

- Opportunity to connect fundraising with engagement

- Measuring consumer engagement is difficult, there is an opportunity to build the evidence base

- Non-government organisations can play a key role in facilitating research activities

- Reporting back to consumers and the community on research outcomes is important

- Access to research trials can be a life or death issue for some consumers

Diversity and the importance of addressing the communities with the greatest health needs

- Reflect the diversity of society and address inequalities in health

- Strive to overcome barriers to participation in research

- Focus on improving health outcomes

Challenges

- Attitudes can get in the way; both attitudes from researchers and consumers

- Significant difference in a biomedical view of health versus a social view of health

- Reflecting the diversity of society in research is a challenge

- Research fatigue can be an issue for some consumers

- Consider a proactive discussion with the community on animal research

- Health and medical research cannot afford to have bad press, because the community will stop funding it.

Consensus workshop

A consensus workshop was held with the SAHMRI Research Executive, consumers and researchers from the Partnership Reference Group. The workshop considered the results of the literature review, stakeholder consultations and work of the partnership reference group. Discussion included principles to inform consumer and community engagement and implementation practicalities involved for the Institute. Agreement was reached on the essential elements of an engagement framework and on principles to inform the Framework.

Section 4: Principles to support consumer and community engagement

During the implementation of this project it became clear that the Steering Committee and the Partnership Reference Group considered the importance of SAHMRI making a statement of principle about the importance of consumer and community engagement to fulfilling the organisational vision of transforming research into health. The following principles are adapted from the work of Aboriginal communities with the Wardliparingga Aboriginal Research Unit; the National Statement on Ethical Conduct in Human Research; and the International Association for Public Participation's Core Values for the Practice of Public Participation.

| Table 2: Principles to Support Consumer and Community Engagement in Health and Medical Research |
| --- |
| **Consumer and community engagement in health and medical research:** |
| • **is based on the understanding that those affected by research have a right to be involved in research** |
| • **can and should, where possible, occur across all phases and stages of research** |
| • **is based on partnerships between consumers, the community and researchers to determine research priorities** |
| • **includes the promise that consumer and community contributions will influence research** |
| • **is sustainable by recognising and communicating the needs and interests of all stakeholders** |
| • **actively facilitates involvement, practically supports participation and seeks input from research participants in designing how they participate** |
| • **communicates to participants how their input influences research** |
| • **provides opportunities for consumers, communities and community organisations to develop their capacity, abilities and skills.** |

Section 5: A Consumer and Community Engagement Framework for SAHMRI

For an engagement framework to be successful, advocacy and agenda setting from the leaders of an organisation is required. This is very evident in SAHMRI by the championing of consumer and community engagement by the Executive Director and Research Executive; by the funding of this project by the Institute; and by the striking unanimity of support for consumer engagement expressed by the Research Theme Leaders in their interviews.

Following synthesis of the literature review, interviews and workshop recommendations a Consumer and Community Engagement Framework for SAHMRI has been constructed and is composed of four organisational domains adapted from Saunders and Girgis (2011). The Framework is encircled by the IAP2 Levels of Participation, identifying the different levels of engagement that may be utilised. Finally, the three phases of health and medical research identified by Shippee et al are presented, connecting the Framework to the Phases and Stages of Research. A diagram summarising the Framework is provided in Figure 2.

Figure 2: Framework Domains and Elements
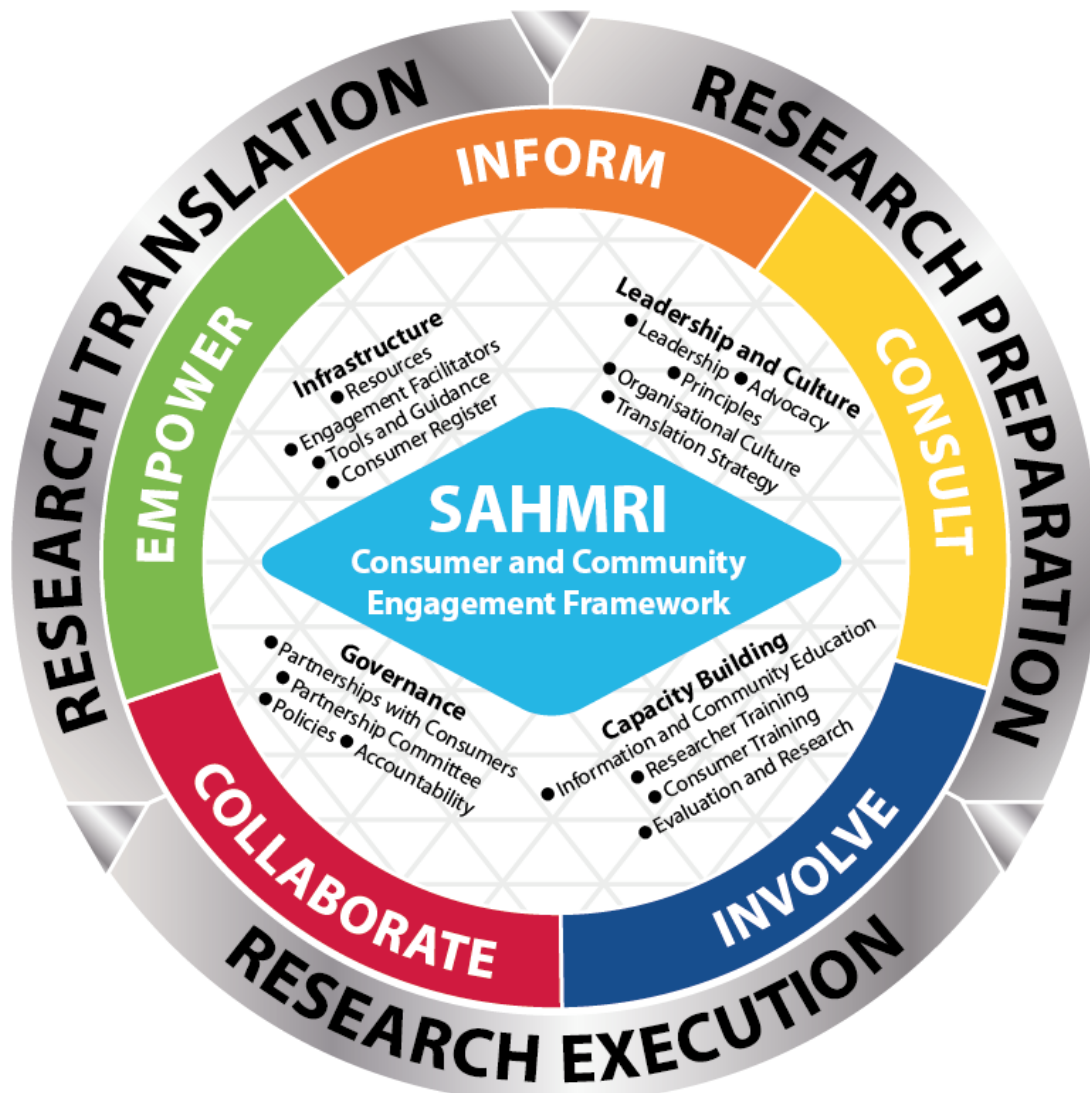
Section 6: Recommendations

For an engagement framework to be successful, advocacy and agenda setting from the leaders of an organisation is required. This is evident at SAHMRI through the funding of and strong support for this project. The following recommendations were developed for the SAHMRI Board and Research Executive from the findings of the literature review, stakeholder consultations and consensus workshop. SAHMRI is committed to the following Framework:

Table 3: Essential Elements of the Consumer and Community Engagement Framework
Leadership and Culture
Leadership – The Executive Director of SAHMRI commits to sponsor the adoption, implementation and review of the Consumer and Community Engagement Framework. The Framework will be endorsed and implemented by Management Executive, Research Executive and the Board.
Advocacy – SAHMRI commits to championing consumer and community engagement in the health and medical research sector in Australia, in partnership with HCA, leading by example. SAHMRI will formalise its partnerships, with HCA at an Institutional level, and with non-government organisations at the SAHMRI Theme level.
Principles – SAHMRI is guided by the statement of principles for consumer and community engagement within the Institute and as a commitment to the citizens of South Australia.
Organisational Culture – SAHMRI commits to embedding consumer and community engagement as a key feature of its organisational culture. Engagement will be a responsibility for all staff and incorporated into accountability processes within SAHMRI as a key performance indicator at the SAHMRI Theme level, with the aim of making engagement routine for all research projects.
Translation Strategy – SAHMRI commits to incorporating consumer and community engagement as a key element in research translation.
Capacity Building
Information and Community Education – SAHMRI is partnering with HCA to build its information and community education role with the general community to build health and research literacy. This strategy aims to educate the community on the role and value of health and medical research.
Researcher Training – SAHMRI is developing a program of learning and professional development opportunities to build the capacity of researchers to undertake consumer and community engagement.

Table 3: Essential Elements of the Consumer and Community Engagement Framework
Consumer Training – SAHMRI commits to developing a program of learning and development opportunities to build the capacity of consumers to participate in research.
Evaluation and Research – SAHMRI commits to investing in the early development of an evaluation and research strategy to measure and report on achievements in consumer and community engagement, to contribute to and build the evidence base.
Governance
Partnerships with Consumers – SAHMRI commits to ensuring there is appropriate consumer and community engagement throughout the organisation, across all aspects of operations and research. A flexible approach will be undertaken; there is no one size that fits all in consumer and community engagement for an organisation as complex as SAHMRI.
SAHMRI Consumer and Community Partnership Committee – SAHMRI commits to establishing and sustaining a Partnership Committee with a membership of consumers, community organisations and researchers. It will have strategic oversight of the Framework and report to the Research Executive.
Policies – SAHMRI is establishing policies and procedures that support consumer and community engagement throughout the organisation.
Accountability – SAHMRI is developing accountabilities and metrics to support consumer and community engagement. This will include consumer and community engagement as part of strategic and business planning at both Institute and SAHMRI Theme level.
Infrastructure
Resources – SAHMRI plans to commit resources for implementation and evaluation of the Framework over the medium term (three to five years).
Consumer and Community Engagement Facilitators – SAHMRI commits to supporting the establishment of Consumer and Community Engagement Facilitators to lead implementation of the Framework at SAHMRI and HCA.
Tools and Guidance – SAHMRI will be partnering with HCA to support researchers and consumers in the practice of consumer engagement through the provision of training, tools, guidance and support.
Consumer Register – SAHMRI commits to establishing and maintain a register of consumers interested in participating in health and medical research.

Section 7: Conclusion

Next steps and early wins

Implementation of the Framework will require designated resources and time to implement. SAHMRI and HCA will partner to apply for research funds to implement the Framework and develop a research and evaluation process. Strategic relationships with other centres of excellence in consumer and community engagement in health and medical research could be considered.

A number of early wins have been identified for 2014 and are listed for consideration. These are highly achievable in the short term and will build on the work already started.

Actions and strategies will need to be programmed over the short, medium and long term. The full report of the project provides an implementation plan for the key elements, actions and strategies of the framework, and they are programmed over a three year period.

Table 4: Early Wins 2014
☐ **Program a series of community conversations, research forums and research showcases – taking advantage of the high profile of the new SAHMRI building. One example being genetic and genomic research.**
☐ **Further develop strategic partnerships with consumer and community organisations aligned to the Research Themes.**
☐ **Develop a series of research priority setting partnerships.**
☐ **Incorporate consumer and community engagement into the organisational statement on values and culture.**
☐ **Conduct training on consumer and community engagement prior to the next round of research grants applications.**

Summary

Numerous examples of strategies for the engagement of consumers and the community in health and medical research were identified in Australia, Europe and North America. There is broad consensus about the value and importance of consumer and community engagement in health and medical research.

However, there is limited evidence that clearly identifies the most effective strategies for realising the agreed benefits. This presents an exciting opportunity for SAHMRI to develop the evidence base by adopting a comprehensive integrated Framework.

Essential elements, strategies and actions and a set of principles to inform SAHMRI's future consumer and community engagement work have been developed by the Partnership Reference Group. This Framework is presented to the SAHMRI Board as a unique opportunity to lead consumer and community engagement in health and medical research nationally and possibly internationally.

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A copy of the literature review report is available upon request from the South Australian Health and Medical Research Institute or the Health Consumers Alliance of South Australia.

Appendix 1: Glossary

Advocate

An advocate represents the broad views and experiences of a range of people affected by a health issue. This includes persons or groups of people who are unable to represent themselves. Advocacy is speaking, acting or writing, with minimum conflict of interest, on behalf of the interests of a disadvantaged person or group, to promote, protect and defend their welfare.

Carer

The Carers (Recognition) Act 2008 identifies a carer as an individual who provides, in a non-contractual and unpaid capacity, ongoing care or assistance to another person who, because of disability, frailty, chronic illness or pain, requires assistance with everyday tasks. A carer may or may not be a family member and may or may not live with the person.

Co-design

Co-design is about designers working with people in communities to develop solutions with and for them. The co in co-design stands for consumer, community or collaboration. The idea is that better understanding people's needs and aspirations and trying out new solutions with them in context, will more likely lead to innovations that engage people and enable change. Co-design is a multi-disciplinary approach that recognises that the quality of design increases if end user interests are considered in the design process.

Community

Community refers to groups of people or organisations with a common interest. While some communities may connect through a local or regional interest in health, others may share a health condition, cultural background, religion or language. Some communities may be geographically dispersed but linked through an interest in a specific health issue.

Community engagement

Community engagement refers to arrangements for individuals and communities to participate in the processes used to make good policy and to deliver programs and services. It can be a powerful vehicle for bringing about environmental and behavioural changes that may improve the health of the community through partnerships and coalitions that mobilise resources, influence systems and change relationships among partners.

Consumer engagement

Consumer engagement encompasses activities that involve consumers as participants in the planning and development of health and medical research, service planning, policy development, setting priorities and evaluating services. Terms used in the literature vary and include citizen engagement, public participation and community consultation.

Consumer representative

A consumer representative is a health consumer, including family members and carers, who is nominated by and accountable to an organisation, group or community to represent the voices, views and experiences of health consumers.

Community organisation

A community organisation is a not-for-profit, non-government, community-based body or a self-help group whose objectives include the representation of the opinions of health consumers and/or is capable of reflecting consumer and community opinions on health matters.

Consumer participation

Consumer participation is the action of involving health consumers in decision-making about health and medical research, service planning, policy development, setting priorities and evaluating services. The International Association for Public Participation (IAP2) identify consumer participation as a spectrum that includes five levels of participation: Inform, Consult, Involve, Collaborate, and Empower.

Health consumer

Health consumers are people who use, or are potential users, of health services including their family and carers. Consumers may participate as individuals, groups, organisations of consumers, consumer representatives or communities.

Appendix 2: Steering Committee and Partnership Reference Group Membership

Mary Buckskin	CEO, Aboriginal Health Council of SA
Julie Marker	Deputy Chair, Cancer Voices SA
Cathy Chong	President, Chinese Welfare Services
Helen Mikolaj	Member, SA Health and Medical Research Advisory Council
Justin Hughes	Member, HCA and carer
Geoff Vass	Member, Research Ethics Committee, Women's and Children's Health Research
Tony Lawson*	Chair, HCA
Stephanie Miller*	Executive Director, HCA
Michael Cousins*	Senior Project Officer, HCA
Daisy Miller	Project Officer, HCA
Caroline Miller*	Executive Officer, SAHMRI
Kathy Mott*	Senior Business and Relationships Manager, Aboriginal Health, SAHMRI
Amy Gathercole	Laboratory Manager, ComPath, SAHMRI
Meredith Cooney	Project Manager/Senior Clinical Research Associate, SAHMRI
Carmel Collins	Academic Leader, Child Nutrition, Women's and Children's Health Research Institute, SAHMRI
Paul Yerrell	Senior Research Fellow, Aboriginal Health, SAHMRI

* Steering Committee Member

Appendix 3: Interview guide

1. Introduce and explain project aims

2. Introduce HCA and SAHMRI when necessary

3. Identify interviewee's prior experience of consumer participation in health and medical research

4. Identify **strengths** of consumer participation in health and medical research

5. Identify desired **aspirations** for consumer participation in health and medical research

6. Identify any **challenges** with consumer participation in health and medical research

7. Identify desired **results** of consumer participation in health and medical research

8. Identify **opportunities** for consumer participation in health and medical research

9. Identify any recommended **key literature or evidence** of consumer participation in health and medical research

10. Identify any **practical examples or existing frameworks** for consumer participation in health and medical research

11. Any **other key informants** interviewee would recommend

12. Wrap up and thank you, including steps from here (consensus workshop and framework development).

Appendix 4: Key informant interview participants

Category	Person and Organisation
SAHMRI Leaders	1. Steve Wesselingh, Executive Director
	2. Neil Dear, Director of Research and Biomedical Services
	3. Charles Mulligan, Theme Leader, Cancer
	4. Alex Brown, Theme Leader, Aboriginal Health
	5. Steve Nicholls, Theme Leader, Heart Health
	6. Julio Licinio, Theme Leader, Mind and Brain
	7. Maria Makrides, Theme Leader, Healthy Mothers, Babies and Children
	8. John Hopwood, Chair Scientific Advisory Board
Other Academics and Practitioners	9. Kristina Staley, TwoCan Associates
	10. Bec Hanley, TwoCan Associates
	11. Catherine McIlwain, Cochrane Consumer Network
	12. Michelle Banfield, Centre for Mental Health Research, Australian National University
	13. Carla Saunders, South Eastern Sydney Local Health District

Consumer orientated bodies aligned to SAHMRI Research Themes	
Aboriginal Health	14. Mary Buckskin, Aboriginal Health Council of SA
Cancer	15. Julie Marker and Agnes Vitry, Cancer Voices SA
Heart Health	16. Stephanie Greene, Heart Kids SA
Infection and Immunity	17. Kerry Paterson, Tessa Opie, Deborah Warneke-Arnold, Hepatitis C Council of SA
Mind and Brain	18. Geoff Harris, Mental Health Coalition of SA
	19. Moira Deslandes, Carers SA
Invited but unable to be interviewed	
Other Academics and Practitioners	1. Paul Ward, Discipline of Public Health, Flinders University of SA
	2. Anne McKenzie, University of Western Australia/Telethon Institute for Child Health Research
	3. Jonathon Boote, School of Health and Related Research, University of Sheffield
	4. Ian Graham, University of Ottawa / Canadian Institutes of Health Research
Nutrition and Metabolism	5. Diabetes SA
Cancer	6. Cancer Council of SA
Healthy Mothers, Babies and Children	7. Maternity Coalition
	8. Miracle Babies Foundation

For more information please contact:

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A copy of the full project report is available upon request from the South Australian Health and Medical Research Institute or the Health Consumers Alliance of South Australia.