



Menzies Centre for
**Health
Policy**



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**Serious And Continuing Illness Policy And Practice Study (SCIPPS)
Roundtable 3**

**Health literacy for individuals and communities to support self-
management**

December 2011

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Policy context

The National Chronic Disease Strategy promotes patient self-management of chronic illness. Effective health literacy is essential for self-management, yet two-thirds of the population have inadequate health literacy. Poor health literacy can lead to increased hospital admission rates and decreased health outcomes, fostering social disadvantage.

Health literacy is generated through interactions with the health professional, with family and with the community which people develop for themselves. This community and more specifically the family as the primary community are the most likely channels through which health literacy is converted into effective self-management. Medicare Locals face the challenge of engaging with communities to find new models of working closely with other health professionals and with community organisations to facilitate the adoption of health literacy knowledge into effective self-management.

Key findings

CONCEPTS

“Often health literacy is not about health as we try to articulate it. Often it is about the friends we have and the connections we have in the community” (representative of a national consumer organisation).

- > Health literacy is essential for effective self-management. Health literacy empowers the consumer to make effective health decisions that maximise health and well-being and quality of life.
- > Public and private health professionals and other service providers need to communicate effectively and efficiently in order to address the consumer’s overall health needs.
- > The family needs to be integrated into the caring and self-management process. Formal and informal carers need recognition in relevant policies.
- > Health literacy is gender specific and occurs most effectively where people gather naturally in the community during everyday life.

INFRASTRUCTURE

- > A national policy approach is indicated to maximise collaboration between and across sectors, particularly the public and private sectors.
- > The uptake by communities of existing successful models of health literacy can be maximised by enabling access to existing evaluation findings and data bases.
- > A co-ordinated and cohesive research agenda is needed to develop an understanding of barriers and facilitators to improving health literacy in Australian communities.
- > Standardised health literacy messages are needed to provide a consistent message to the care recipient.

Policy considerations

OVERARCHING ISSUES

- > The sharing of patient information across systems and sectors and between health and other service providers can minimise service duplication and service gaps.
- > Effective health literacy will best be achieved through collaboration between the community and health systems.
- > The quality of collaborations between Medicare Locals (MLs) and the community will influence the effectiveness of health literacy promotion.
- > Medicare Local (ML) funding needs to be sufficient to support community engagement activities.
- > Patient connectedness with the community needs to be maintained.
- > Interventions need to target at risk groups whose connectedness with the community is reduced through chronic illness.
- > Effective interventions need to be inclusive of family and others, gender specific and not illness-focused.
- > Consumer-focused approaches will enable consumers and their formal and informal carers to feel empowered, understood and heard.
- > The evidence base needs to be expanded and particularly from an illness-specific perspective.
- > A feedback loop from evidence back into policy is needed.

HEALTH LITERACY

- > Health literacy needs to become an integral component of existing policies.
- > Discussions around health literacy will raise its profile and value to Australians.
- > The language of health literacy needs to be part of the whole patient journey discourse and needs to be in terms of multi-morbidity.

SELF-MANAGEMENT ISSUES

- > Increased time spent on self-management reduces the time available for active citizenship that can lead to isolation.
- > Measures of the consumer experience of services need to drive change.
- > A policy-driven framework or definition around self-management is needed to enable consumer monitoring of changing health literacy needs.
- > A single care management plan is needed to incorporate all health requirements.
- > Consumers with multi-morbidity, rural and remote-dwelling Australians, and those over the age of 65 years are advised to have an advocate for their health care needs.

RURAL AND REMOTE COMMUNITIES

- > Opportunities for community engagement and advancement in rural and remote communities are reduced.

- > Models of care and well-being for rural and remote communities need to enable access to health services and opportunities for health literacy exchange.

Solutions

- > Interprofessional learning at graduate and at post-graduate level provides a proactive approach to promulgating health literacy and reducing the barriers between health professionals and consumers.
- > The patient care experience from the perspective of functional abilities is flagged as a national Key Performance Indicator.
- > Health literacy needs inclusion in the school curriculum from years K to 12 in order to increase its value to all Australians.

Methods

The Serious and Continuing Illness Policy and Practice Study (SCIPPS) was developed jointly by the University of Sydney and the Australian National University branches of the Menzies Centre for Health Policy. The five-year SCIPPS sought to examine the lived experience of people with chronic illness.

Following ethics approvals, SCIPPS gathered data from community-dwelling Australians with co-morbid chronic heart failure (CHF), complicated Type II Diabetes Mellitus (TTDM) and chronic obstructive pulmonary disease (COPD). The 52 participants aged between 45 and 85 years of age lived in Western Sydney or in the Canberra region. Fourteen carers also participated. Eighty-seven percent of the combined group experienced multi-morbidity, a figure exceeding the 70% of older Australians known to have multiple chronic conditions.

Ethics approvals were received from all institutions involved in the study.

Dissemination of research findings has occurred in part through publications that are available at

http://menzieshealthpolicy.edu.au/research_scipps_publications.php Translation of the study findings into policy has occurred in the final few months of SCIPPS in the form of Roundtable discussions. The Roundtables were by invitation only, with approximately 20 delegates in attendance at each discussion.

The three Roundtable discussions were:

- > 'Understanding the complexities of co-morbidity with respect to policy and practice' was conducted on Wednesday 16th November 2011 at the Darlington Conference Centre, the University of Sydney.
- > 'The economic impact of chronic disease on individuals and families all expenses' was conducted on Tuesday 22nd November 2011 at The Common Room, University House, the ANU, Canberra.
- > 'Health literacy for individuals and communities to support self-management' was conducted on Wednesday 30th November 2011 at The Drawing Room, University House, the ANU, Canberra.

This report records the proceedings and outcomes of the second Roundtable.

The final dissemination strategy will be a conference with the purpose of translating SCIPPS findings and the policy considerations that were raised within the three Roundtables into shaping practice and effecting policy development.

APPENDICES TO THIS DOCUMENT

Appendix A	List of delegates
Appendix B	Roundtable agenda
Appendix C	Record of Roundtable discussion
Appendix D	The Australian Commission on Safety and Quality in Healthcare advice on forthcoming Health Literacy Stocktake
Appendix E	Media opportunities

The Serious and Continuing Illnesses Policy and Practice Study (SCIPPS) was a five-year NHMRC funded program (no: 402793) conducted at The Australian National University and University of Sydney and administered by The Menzies Centre for Health Policy.

Appendix A

LIST OF DELEGATES

	Delegate	Organisation and role/ title
	Chair:	
1	Mr Bob Wells	Director, Menzies Centre for Health Policy (Canberra); Director APHCRI; SCIPPS researcher and Chief Investigator
	Guest Speakers:	
2	Ms Carol Bennett	Chief Executive Officer, Consumers Health Forum
3	Associate Professor Jim Gillespie	Deputy Director Menzies Centre for Health Policy , and Director, Master of Health Policy, The University of Sydney; SCIPPS researcher and Chief Investigator
4	Dr Anita Peerson	Faculty of Health, Deakin University
5	Ms Laurann Yen	Associate Director Menzies Centre for Health Policy (Canberra) and SCIPPS Senior Researcher
	Invited Guests:	
6	Dr Penny Abbott	Senior Fellow, Department of General Practice, University of Western Sydney
7	Dr Tim Adair	Director of Research, National Seniors Australia
8	Ms Sharon Appleyard	Assistant Secretary, Policy Development Branch, Primary and Ambulatory Care Division, Department of Health and Ageing
9	Ms Diana Aspinall	Consumer Reference Group for Chronic Diseases, Blue Mountains GP Network
10	Ms Erica Drew	Integration Coordinator, WentWest Medicare Local
11	Ms Helen Hopkins	Policy Officer, National Rural Health Alliance
12	Ms Dianne Lowe	Research Officer, Cochrane Consumers and Communication Review Group, Centre for Health Communication and Participation, Latrobe University
13	Dr Karen Luxford	School of Public Health, Sydney Medical School, The University of Sydney
14	Mr Evan Mann	Carers Australia
15	Mr Tim Nayton	Medibank Private Health Solutions
16	Ms Margo Saunders	Public Health Policy Researcher/Consultant
17	Adjunct A/ Prof Annette Schmiede	Menzies Centre for Health Policy
18	Ms Ros Walker	Queensland Council of Social Services (for ACOSS)
	SCIPPS team members:	
19	Dr Justin McNab	SCIPPS researcher (Sydney)
20	Tanisha Jowsey	SCIPPS researcher (Canberra)
	Recorder:	
21	Dr Dagmar Ceramidas	Menzies Centre for Health Policy (Canberra); SCIPPS support

Apologies:		
1	Dr Dina Bowman	Principal Researcher, Research and Policy Centre, School of Social & Political Sciences, University of Melbourne (representing the Brotherhood of St Laurence)
2	Dr Danielle Butler	Practicing GP, Darwin; APHCRI
3	Ms Elizabeth Harris	Director, the Centre for Health Equity Training, Research and Evaluation, UNSW
4	Professor Stephen Leeder	Director, Menzies Centre for Health Policy (Sydney); SCIPPS researcher and Chief Investigator
5	Mr Peter McInnes	Primary Health Care Research, Evaluation and Development Liaison Officer, APHCRI

Appendix B

AGENDA

Menzies Centre for Health Policy

Serious and Continuing Illness Policy and Practice Study (SCIPPS)

Roundtable meeting 2: Health literacy for individuals and communities to support self-management

Wednesday 30th November 2011

Agenda

Registration

10:00 Welcome, Mr Bob Wells, Chair

10:15 **Session 1: The nature of the problem / Context**

Speaker 1: Ms Carol Bennett, Chief Executive Officer, Consumers' Health Forum

Speaker 2: Dr Jim Gillespie, Deputy Director Menzies Centre for Health Policy (Sydney) and Director, Master of Health Policy; Sydney School of Public Health, Sydney Medical School

10:45 Discussion: The problem

11:15 Morning tea

11:30 **Session 2: Building the evidence base for policy**

Speaker 3: Dr Anita Peerson, School of Health and Social Development, Deakin University

Speaker 4: Laurann Yen, Associate Director Menzies Centre for Health Policy (Canberra) and SCIPPS Senior Researcher

11:45 Discussion: Challenges and imperatives for policy

12:30 Lunch

1:30 Discussion: **The way forward**

2:30 Afternoon tea

2:45 Summary of the day

3:00 Close

Appendix C

RECORD OF ROUNDTABLE DISCUSSION

In attendance: 21, plus FIVE apologies; list of Delegates at Appendix A.

Agenda: At Appendix B

Welcome: Mr Bob Wells welcomed delegate sand provided a broad description of SCIPPS.

- > Jim Gillespie provided the historical context for SCIPPS, and the development of the HealthOne model of primary care

Speaker 1: Ms Carol Bennett, Chief Executive Officer, Consumers' Health Forum (Powerpoint presentation was circulated to all delegates)

- > We need to look at health literacy (HL) from a health information perspective but this doesn't eliminate the accessibility problem
- > Often HL is not about health as we try to articulate it. Often it is about the friends we have and the connections we have in the community
- > HL is about prevention
- > Families are the most likely source of health information – the environment and the community in which you live
- > Time and cost are critical factors
- > Time and cost are critical factors
- > HL improves health outcomes, and decreases hospital admissions
- > HL involves navigating the system and communicating with health professionals
- > HL improved informed consent
- > 66% of the population have inadequate HL
- > Factors influencing HL:
 - o Individual
 - o Community
 - o Behaviour and skills of health professionals
- > Social disadvantage:
 - o Income
 - o Older Australians are more likely to experience poverty levels
 - o Older women especially experience long term poverty and are more likely to experience health problems
 - o There is a strong relationship between income levels and financial stress
 - o Poverty = being older and having a disability; and these are predictors of poor health status

- Over 800,000 Australians are on a disability pension and about 30% of these have mental health problems. In addition, the unemployed do not qualify for a disability pension.
- Need to ensure multiple levels of access to HL information for the different groups within the community
- HL needs to be aimed at
 1. Self-care
 2. Family care
 3. Community care
- > Our system provides 'illness treatment' and not HL
- > We can learn from Europe
- > A delegate reported findings of some recent research in the USA:
 - People are using their families as the first reference point for HL, despite website development, therefore
 - We need to be cautious about simplistic solutions that tend not to be the best use of government funding

Speaker 2: Dr Jim Gillespie, Deputy Director Menzies Centre for Health Policy , and Director, Master of Health Policy, The University of Sydney; SCIPPS researcher and Chief Investigator. (Powerpoint presentation not used)

- > Conventional models of HL
 - In the UK, medical focus on literacy, concerned with clinical communications
 - In the USA, HL is more about language because of the large Hispanic population
 - The European approach is broader and more of a 'critical literacy' approach
 1. Negotiation with the health system
 2. Empowerment
 3. The individual is a consumer
- > So, what does this mean for the elderly? How can we talk about empowerment with someone who has multiple hospital admissions and feels little sense of control?
 - We need to talk at a community level
- > Three anecdotes from service users in the Mt Druitt (Sydney west) region:
 1. Gentleman with severe COPD – was happy with care but unhappy that he didn't have enough understanding about his condition. He had no capacity for internet access to information but was dependent on his grandson in this respect.
 2. Gentleman with emphysema and decreased mobility – reported that the nursing staff was "great" but didn't understand the roles and need for other health professionals other than, "they are keeping people out of hospital".
 3. Gentleman, only had female interaction through visiting nurses and other health professionals; longed for some male interaction. Incidentally met a man on the street who introduced him to a community computer club. This community interaction provides male interaction that enabled health support for the gentleman.

- We need to ask ourselves, what's going on in the community that can provide the various types of support needed by the broad cross-section of people in the community?

Discussion:

- > In rural communities, the population ages faster. Young people move to the cities and as a whole don't remain in the rural and remote communities. Therefore the communities in rural and remote Australia become older and older, and don't have the interaction opportunities of urban and metropolitan communities with a broad age and service mix.
 - Therefore, HL is provided by the GP.
 - There is no public transport, so people have access difficulties to health services
 - Rates of avoidable hospital admissions are higher because there is less community infrastructure to support people
- > We need to take a geographical look at the assistance available in communities
 - Women living alone are often totally alone – we need to be smarter at getting to these targeted groups within the community
 - Communities have strength
 - We need committed stakeholders, but we need to allow communities to take charge and find their own champions.
- > Need to identify what is working to help people navigate the system
- > Less obvious things – the power of the word-of-mouth – are probably what we are looking for in terms of community support
- > Health professional paired with a community leader who has a chronic illness
- > What self-management styles are working?
 - Prevention across the paradigm is an important part
- > The Aboriginal Medical Services in one area conducted a life skills course – cooking etc.
 - It was emphasised that no prior knowledge or skill was required.
 - It was not an illness-focused intervention
 - The intervention was open to family members and friends to come along with the patient to share the experience.
 - They were asked what the most motivating thing was. 'Fun' - they all learned something while having fun.
- > Another successful program reported was 'Blokies Day Out' in Geelong. In the background of BBQs and activities for the family and community was a health promotion intervention targeting men and facets of their self-identity and interests rather than from a health focus.
 - A 'blokies bag' show bag was provided to each male who registered
- > 'Men in the kitchen' was reported as another successful program where men learn to cook or share their cooking skills and then share the meal with each other in a relaxed home environment.
 - This was hard to develop to attract funding and difficult to develop into policy
 - Successful programs such as these are potential for Medicare Local (ML) adoption and development
- > MLs have a big responsibility to pick up short-term initiatives that have now been de-funded.

- > (consumer) ML funding won't go that far unless these activities are supported
- > Linkages need to be made between MLs and community services that are 'out there'.
 - MLs don't know where to start
 - Chronic illness requires health care and well-being care
 - GPs can provide the health care, but not the well-being care
 - Need to make these connections across the community
 - A lot of support is out there but is untapped because of the poor linkages
- > MLs are experiencing conflicting DoHA requirements, so don't know how to translate the existing services into their own scope of activities.
 - Different parts of Australia work differently and sometimes the states are responsible and sometimes the Commonwealth is responsible. There are political tensions caused by state versus commonwealth funding and this impacts at community level
 - Concerns are felt more in rural and more isolated communities – as the local knowledge becomes more peripheral the further you are away from the centre of the ML
- > Consumers are to drive the community linkages until the ML engagement with the community gets off the ground
 - The community engagement will be very different for each ML
- > We also need measures of consumer experiences of the services and use this to drive the way forward
- > Discussion at the Chronic Illness Conference in Sydney last week was the same as the discussion around the table today
 - Reflecting the patchwork of services
 - The real problem is the national one of endemic problems
 - How little we know about what's happening in the state results in little policy learning from evaluations
 - The data bases are usually kept secret within the state in which the evaluation was conducted
- > There is a lack of sharing of experiences and therefore a lack of knowledge of what others are doing
 - How to create sustainability for some of the existing good work
 - One delegate shared that the InfoNet website shared indigenous data bases, <http://www.healthinonet.ecu.edu.au/>
- > We need a more national approach; we need to not separate services into silos, especially the public-private service delivery
- > It is critical for internet support groups to meet physically occasionally
 - The internet is critical for house-bound people with chronic illness, enabling them to connect with their peers.

Morning tea break

Speaker 3: Dr Anita Peerson, School of Health and Social Development, Deakin University
(Powerpoint presentation in file but not circulated to delegates)

- > Kickbusch approach to HL is everyday life in community settings, gender specific
- > Social marketing health promotion needs to be gendered
- > Lay people are not a blank blackboard with no information
- > What are the mediating contextual factors that move knowledge into action?
- > Evidence base on HL in Australia is very low. The policy evidence base relies on the ABS data from the 2006 OECD initial survey of HL; however, the growing Australian evidence base is ignored in Australian policy documents
- > HL is not found in current policies such as obesity, alcohol, Australian Safety and Quality Commission, Aged Care providers and carers policy
 - NHMRC shows little focus on HL
 - Chronic disease management policy revision in Northern Territory 2003 included HL and included the indigenous population
 - Victoria is starting to mention HL as an issue, but is still relying on the ABS data
 - Western Australia – there is a ‘for consultation’ draft Primary care Strategy that mentions HL
- > How can we encourage HL discussions and raise the profile?
- > Health workforce – patient-centred care, communication, but the level of HL given to patients is often poor
- > Interprofessional learning is required
- > There are training issues at graduate and at post-graduate level
- > The patient journey – quality of care – entry and exit points are ill-defined, having a negative effect on the potential HL that can be offered

Discussion:

- > Without HL, self-management can't be effective
- > The language of HL needs to be part of the whole patient journey discourse AND needs to be in terms of multi-morbidity
- > There is a need to include lay people
- > Policy levers –
 - How do you improve the patient care experience within the National Health Reform Strategy/
 - The patient care experience is flagged as a national Key Performance Indicator
 - Now coming from a diagnosis based perspective, but need to approach it from a person's functional perspective
 - Need to break the barriers between health professionals and people and the organisations
- > We are exposed to multiple literacies, all with different systems
 - Computer literacy
 - Law literacy etc

- food literacy
- > People in some geographical areas can't afford computers and the internet so have no internet access
- > Another consideration is that you need a level of HL to discern what information on the Internet is accurate and which information is to be disregarded.
- > One aspect of health literacy is navigating the health system
 - People in custody and returning into the community find this very difficult, especially aboriginal people. Even basic primary care information is not known.
- > In some geographical areas with a high ethnic population and NESB people approach the GP for assistance to complete Centrelink forms
- > HL is also needed for the front-line workers
- > Very often, HL is withheld because the government doesn't want to advertise a particular newly available service and associated payment potential

Speaker 4: Laurann Yen, Associate Director Menzies Centre for Health Policy (Canberra) and SCIPPS Senior Researcher (powerpoint presentation not used)

- > Self-management is not part of the care experience, it is what a person does when they leave the GPs room.
 - That's when people begin to unpick what is happening to them
 - The issues are personal
 - How are you going to make choices? Who will be involved in the choices? How do you know they are the right choices?
- > There is little help for people from NESB, or for people with language, reading, writing or basic mathematical skills
 - These are barriers affecting peoples' capacity to self-manage based on the findings of the SCIPPS in partnership with National Seniors Australia
- > Sometimes it is not the type of chronic disease but the number of chronic illnesses that drives the impact on finances and on outcomes of health decisions. The strength of the impact of the number of illnesses will drive and determine the impact of the diseases
- > The greater the multi-morbidity, the greater is the interaction with the health services
- > Chronic illnesses keep adding on or increasing in severity as we age
- > Each chronic illness can take one year off someone's working life when they are over 60 years of age. This might push someone out of the workforce.
- > There is a greater likelihood of being pushed out of the workforce if you are female. This increasingly creates the cohort of lonely, unemployed women with multi-morbidity, and puts them at high risk of poverty and poor health outcomes
- > Mental illness pushes people out sooner – how can this be managed? What information do people with a mental illness need that will help them?
- > For 15% of people, their income drops with chronic illness and with multi-morbidity by over \$20,000 p.a. If they have a high salary, this can be manageable, but if their salary is lower, then this can represent a substantial portion of their income.
- > Self-management takes time

- As people increase the time spent on managing their health, their time spent on other activities decreases, reducing the time people have to spend in their communities and interacting with others. This increases isolation and decreases the active capacity for citizenship.
- No-one sees them because they are at home, caring for their illness. The isolation increases as they fall off the community radar.
- These people become an invisible group who are increasingly disconnected and therefore find it increasingly harder to achieve the level of HL that they need.
- People need to compromise how they spend their time.
- > Access to services is important.
 - People living in rural and remote Australia do not have service, or the services are too far away, resulting in poorer health outcomes.
- > We have to think about the cycle of increased time spent on self-management, in that this means less time is available for HL

Discussion:

- > The approaches are often isolated, so HL falls in priority
- > We need to make HL available in the spaces where people already naturally circulate, such as supermarkets
 - We need to think laterally about ways to make HL available
- > (Consumer voice) is driven by sheer need to gain HL
 - It is extremely time consuming to gain HL
- > We need to look at the resilience level of older people. The reducing involvement of older people in the community and their increasing isolation was described as “going to seed”
 - Community services are needed just to socialise, so that isolated people have someone to talk with
- > Need co-ordination of information around self-management so that older people know where to go to get help
- > One of the private health insurance companies is known to provide HL services free to members who participate in the company’s programs
 - The company programs are based on claim behaviour, but they are expanding to others at risk
 - A number of health insurers are moving down the path of health care/coaching programs
- > Consumers need to have more knowledge of health insurer provisions
 - Need to bridge the private / public split and encourage the transfer of health information
- > Need co-ordination of service provision especially among NGOs
 - Co-morbidity and self-management brings in the need for HL
 - The issue of adult literacy is a major problem in Australia
- > People with low general literacy or dyslexia have developed compensatory mechanisms to cover their problems and difficulties, making it more difficult for the provider to discern that someone has a literacy problem

- There are issues around shame and stigma
- > Health professionals need to assess levels of literacy in teach-back techniques
- > Patient advocacy is important – every patient needs someone ‘on their side’, to listen with them, ask questions, remember what was said
 - A carer advocate needs to be empowered to say things on behalf of the care recipient, even at hospital emergency departments
 - People over the age of 65 years and with multi-morbidity need an advocate
 - There need to be brokers for older people in the choice of Residential Aged Care Facilities
- > This is occurring with some Aboriginal Health Care services. Some people have a broker or an individual case worker who goes with them, and advocates on their behalf
 - This is the lynch pin of the Aboriginal Health Services; an advocate to help people negotiate a very complex system where HL is essential
- > Also need an advocate model for rural and remote dwelling Australians
- > A large proportion of complaints management deals with the people feeling disempowered, not being understood or not being heard.
- > More quality needs to come back to the consumer
- > Health promotion perspectives – need to be in local indigenous language as well as English language options
- > The Indigenous HL base is very limited
- > Many models of Indigenous health can be applied to the general community

Lunch break

Discussion

- > Australia needs health policy to drive HL development
- > There is a compelling case for low HL and economic impact of chronic illness
- > There is a need for a champion for HL
- > We are not quite ready yet to move to policy. There is still much groundwork to be done.
- > The ABS is not releasing the 2006 data because this is owned by DoHA
- > Need to start moving towards national HL policy that ties in gender and other frameworks
- > Has there been a mapping exercise to identify what is happening in Health Promotion activities that are related to health and well-being?
- > MLs plan to do that over time and have the findings publicly available on their websites
- > MLs will need to do an analysis of their community needs – a needs analysis
 - For continued funding, they will need to show the evidence for the strategies they to put into place
 - DoHA is providing more guidance to the MLs
- > HL mapping is different to service mapping

- > A Health Initiatives stock take by the Australian Commission on Safety and Quality (Appendix D) is in progress, [http://www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/909477C6C27A1BC6CA2577AE0080816E/\\$File/Patient%20Centred%20Care%20Newsletter%20Issue%20October%202011.pdf](http://www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/909477C6C27A1BC6CA2577AE0080816E/$File/Patient%20Centred%20Care%20Newsletter%20Issue%20October%202011.pdf)
- > The scope of DoHAs activity is too narrow and may miss the needs
- > Need to provide HL information: “where people meet” rather than “where we want to inform people”
 - An example given was the smoking reduction campaign where most work has been done out of the health care sector.
 - HL is more of a community literacy issue
 - Many suburbs don’t naturally have a community
- > We need a policy that goes beyond health
- > Remote and Indigenous Service Delivery Program builds community capacity
 - Builds community education
 - Builds employment, etc
 - Is now starting to show promising results
 - We need to look outside of the health sector
- > The obstacle is the built environment
 - Behaviour change is needed
- > We need a framework or a definition around self-management, from policy down, to be spelled out better
 - Private and public need to work together
 - We need to de-mystify self-management from top policy level and filtered down to what consumers need
 - We need to build on existing self-management strategies and enhance them, but if there is no clear view of what is available, then we can’t improve
- > Perhaps the development of pathways will help the consumer identify what is a critical event and determine what to do, make an effective health decision
 - It issues come up, then consumers need to be able to reflect post-illness on their decisions and actions
- > We need a single care management plan, not one for each chronic illness
 - The points of intersection need to be identified
- > Excessive management plans lead to non-compliance
- > The same information needs to be provided at each silo
 - We need to fill out one form, once, and not many forms that provide the same information but to different people, “we get turned off”
- > I would like to see more emphasis on the family carer.
 - The family carer needs a place in the policy
 - Carers needs need to be recognised in the policy

- > There are also huge issues around splitting off couples, where one spouse is not given information or allowed into the GPs room because of privacy requirements. The spouse may be the primary carer.
- > The family needs to be integrated into the caring and self-management process
 - The Aboriginal Medical Service patients do not access HL programs but other tools work in the local community
 - These other tools need to be reinforced
- > Specific population groups have particular congregation points – we need to meet people in ‘their’ place
 - Maintain male self-identity
 - Community gardens – also address food insecurity
 - Provides better quality food
 - Men feel as though they are providing something better for their families
 - These work well particularly with migrant populations with a horticultural background
- > Need to address access more in the ML
 - How will we address the homeless?
- > How will we address needs when there are NO people to apply for funding for Men’s sheds or for community gardens?
 - The funding is usually only short-term and not done in a sustainable community way
 - There IS nobody to be the core unless we find other ways to target needs.
- > Need to get rid of funding silos and help MLs to apply for funding to identify issues and solutions.
 - DoHA recognises that the current systems only take us part of the way and we need more flexible systems
 - We need to build up trust and confidence that MLs can do this work and find the needs and develop solutions
- > Have we got enough in place now to MONITOR HL?
- > We need to build an evidence base around innovation – how do you get to this model, then enable it, and then stand back and evaluate it.
- > There are tensions between State level and NGO expectations
- > It is easy for HL to get lost in these activities
 - Community engagement needs to be involved
- > There needs to be a measurement tool to measure HL, and gather baseline measures
- > It needs the involvement of the education system
 - There needs to be cross-jurisdictional work
 - School HL
 - Cross-sector work is being done, but is in its infancy.
 - There is little support for HL
- > The social determinants of health require improved HL

- > We need to recommend that HL be included in the school curriculum from years K to 12
 - Work around HL psychology
 - We do well with the 'worried well'
 - To what extent do people WANT to be HL?
 - What would a HL person look like?
 - Is HL valued by the general person?
- > Need to look at response efficacy – people may have a low level of belief that anything they can do in their lives will make any difference; a fatalistic approach, 'que sera sera'
- > A common area is medicines.
 - We could join up our HL efforts to avoid misuse of medicines
 - This is a common factor related to multi-morbidity
- > Poly pharmacy is a treatment management area
 - It has come up in the previous Roundtable 2
 - Have health funds done work on hospital admissions due to adverse drug interactions?
 - Poly pharmacy is a consumer movement worldwide
 - Needs to consider prescription medicines as well as alternate remedies
 - It is very hard to be a consumer with multi-morbidities and be compliant!
- > Qumax model in Aboriginal Medical Services
<http://www.naccho.org.au/Files/Documents/2010NovQumaxnews1.pdf>
 - Positive effect of quality use of medicines
 - Developing a relationship with the community pharmacists
 - Fine tuning is needed for home review of medicines program
 - The program needs supportive policy
- > Suggestion that MLs have an on-call Registered Nurse or pharmacist
- > DoHA is alert to the problems with a view to ML potential
- > (Health insurer) no, but we should do.
 - Have done work on degenerative conditions of the knee and hip and on needs at community level
- > Often the causes of hip / knee is because of a fall through another condition and the orthopaedic surgeon advises only on HIS condition and not on other factors
 - The whole condition needs to be looked at
 - Specialist teams need to talk with each other
 - Needs informed consent for treatment, which requires HL
- > HL solution: the different clinical teams need to talk with each other and talk better
- > Home review of treatment, with GPs as the gatekeeper
 - Policy response needed
- > (consumer) This is already in process. Consumers are already requesting home review
- > We need a feedback loop from evidence back into policy

- > DoHA is aware that this is a problem. We have to improve on identifying the evidence and how to put this into policy
- > The Chair provided a summary of the sense of policy considerations arising from the Roundtable.

Appendix D

THE COMMISSION'S HEALTH LITERACY STOCKTAKE

Service providers unite to make job seeking easier

“The Commission will shortly be commencing work on a stocktake of health literacy initiatives, policies and programs that have been developed, implemented and/or evaluated within Australia. The Commission will source and then collate this information into a resource for national distribution and use in 2012. Further information will be provided in the next newsletter and the open request will be posted on the Commissions website in late November.”

At 7th December 2012, no additional postings had been made.

Source:

[http://www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/909477C6C27A1BC6CA2577AE0080816E/\\$File/Patient%20Centred%20Care%20Newsletter%20Issue%20October%202011.pdf](http://www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/909477C6C27A1BC6CA2577AE0080816E/$File/Patient%20Centred%20Care%20Newsletter%20Issue%20October%202011.pdf)

Appendix E

MEDIA OPPORTUNITIES

The ANU Media Office issued the following Press Release:

Understanding illness: Why health literacy matters

How individuals and communities can better deal with increasing rates of chronic illness in Australia will be the main focus of a health policy roundtable taking place at The Australian National University today.

The roundtable forms part of the Serious and Continuing Illness Policy and Practice Study (SCIPPS) run by the Menzies Centre for Health Policy – a collaboration between ANU and the University of Sydney. It will bring together leading experts from the health, welfare, academic and government sectors from around Australia to examine how health literacy and partnerships can help deal with ongoing illness in our communities.

Roundtable convener Mr Robert Wells, Director of the Australian Primary Healthcare Research Institute at ANU, said that while 40 per cent of Australians have adequate levels of health literacy, around 80 per cent of the population will experience serious or chronic illnesses in their lifetime.

“Identifying symptoms of illness and relating them to any single illness can be tricky and requires an effective level of personal health literacy. The SCIPPS study found that inadequate health literacy was a major barrier to effective self-management of chronic illness.

“The study, in common with other studies, found that many older Australians have several chronic illnesses concurrently. Some participants had up to eight chronic illnesses and about half of the Australians with chronic illnesses have five or more at the same time.

“The incidence of chronic illness increases with age and the ageing Australian population will therefore make increasing economic demands on the health system unless collaborations can be identified with community and non-government organisations.”

Mr Wells said that the roundtable will identify where and how partnerships can be developed which will improve the health outcomes for people with chronic illnesses as well as ease the pressures on the health care system.

“The advent of Medicare Locals and Local Health Networks across Australia provide a timely opportunity for the development of collaborations between the health care system and the community.

Collaborative efforts can be forged to alleviate the pressures on the health care system, and to provide the essential and ongoing services that are required by people with chronic illness. Partnerships can assist with not only the practical response to transport and other needs, but also the needs for health literacy and helping people to make effective health choices,” he said.

Radio interviews:

- > ABC radio South Australia Mr Bob Wells