



Menzies Centre for  
**Health  
Policy**

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THE GEORGE INSTITUTE FOR GLOBAL HEALTH

**Serious And Continuing Illness Policy And Practice Study (SCIPPS)  
Roundtable 2**

**The economic impact of chronic disease on individuals and families**

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December 2011

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Ceramidas DM and Jan S

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## Policy context

For many patients and their families, living with chronic illness introduces the challenges of meeting out-of-pocket costs of care, loss of or reduction in employment and the additional costs associated with long-term care and self-management. This is particularly so for people with multiple or severe conditions. As a consequence, for many, the experience of illness is shaped significantly by financial stress and economic hardship. Furthermore there is emerging evidence that financial pressure/economic hardship in turn impacts adversely on peoples' health-seeking behaviours. Despite the existence of well-established health and social safety nets that we have in Australia, it is increasingly becoming apparent that there are many who currently fall through the cracks.

## Key findings

### EXPENDITURE

- > For some groups of patients and particularly for those with lower incomes, the increased expenditure associated with living with chronic illness/es can lead to economic hardship.
- > The economic impact of chronic illness can adversely affect the affordability of medicines and other aspects of ongoing care.
- > Preventive interventions can have far-reaching and long term benefits and decisions about whether to fund such interventions need to take these benefits into account.

### LEVELS OF ECONOMIC IMPACT

*"Many carers and care recipients would, if they could, get a job" (representative of a national carer's organisation).*

- > Chronic illness can affect carers, patients and households in their capacity to generate income at a time when a greater level of income is needed.
- > The risk of economic hardship is greatest during the transition to retirement and in retirement where health care costs are likely to be rising and income is likely to be falling.
- > Workforce and workplace redesign is needed to provide flexible employment options for carers and patients.
- > A 'whole of government' approach is needed to create synergies that support chronic illness policy and practice across sectors.
- > The nature of chronic illness and its sequelae need to be recognized as a community problem, much as alcohol abuse and smoking, in order for changes to be realized in policy and practice.

## Policy considerations

### OVERARCHING ISSUES

- > The issues relating to chronic illness management and self-management among Australia's rural and remote population receive inadequate attention.
- > Intervention research needs to link with existing research in the area.
- > The available data are insufficient. Chronic illness can't be researched as a single phenomenon but must encompass evidence of impact across multiple sectors.
- > There are opportunities to shape the activities and outcomes of the Medicare Locals (MLs)

- > The proposed National Disability Insurance Scheme represents a promising initiative to address the economic burden of disability on individuals and their families.
- > Eligibility for various forms of support needs to take into account the specific needs associated with different diseases and the life stage of the patient.
- > The complexity of chronic illness requires a 'whole of system' response.

## CARER ISSUES

- > Government strategies need to reflect carers' concerns. The impact of caring on the carer in terms of health, general wellbeing and economic welfare is insufficiently understood.
- > A large number of carers also have disabilities. The carer's needs should be assessed separately to and severally from the needs of the care recipient, and in a timely manner.
- > For optimum outcomes, carers need to be treated as partners in care, and given equal access to information, economic security and employment flexibility.
- > Carers need to be included in family-directed support.
- > Where children are the carers, students need to be able to combine ongoing education and other age-specific activities with their caring roles.

## RETURN TO WORK ISSUES

- > Carers and people with a disability or chronic illnesses have a right to request flexible employment.
- > Current workforce and workplace design is a barrier to employment for carers and for care recipients who frequently need part-time and flexible working arrangements.
- > Middle-aged and older carers who return to the workforce after an extended period of caring have particular needs for education and training.

## Engagement strategy

- > Identify the problems and issues that have the biggest impact and the system they belong to.
- > Determine which of these issues if changed will have the most significant impact on the system.
- > Popularise the issue/s. Information out of the academic research, if effectively disseminated, can alert the community to the problem they didn't know existed.
- > Raising the profile of the issues will put them into the public realm and start debate and provide the launching pad for action.

## 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](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	Centrelink, 'Wrap around service'
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
	<b>Chair:</b>	
1	Professor Nicholas Glasgow	Dean, ANU Medical School; SCIPPS researcher and Chief Investigator
	<b>Guest Speakers:</b>	
2	Associate Professor Stephen Jan	Senior Health Economist, Renal & Metabolic Division, The George Institute for Global Health; SCIPPS researcher and Chief Investigator)
3	Dr Dina Bowman	Principal Researcher, Research and Policy Centre at the Brotherhood of St Laurence and Honorary Fellow in the School of Social and Political Sciences at the University of Melbourne
4	Professor Bettina Cass	Social Policy Research Group, University of NSW
5	Mr John Della Bosca	National Campaign Director for the “Every Australian Counts” Campaign
	<b>Invited Guests:</b>	
6	Dr Jennifer Alexander	CEO, the Royal Australasian College of Physicians (half day)
7	Dr Anne-marie Boxall	Senior Researcher, Social Policy Section, Research Branch, Parliamentary Library
8	Ms Bev Essue	Sydney School of Public Health, The George Institute for Global Health, the University of Sydney
9	Ms Helen Hopkins	Policy Officer, National Rural Health Alliance
10	Mr David Jeffery	Anglicare Canberra Office
11	Mr Roger Killeen	Health Care Consumers Association
12	Mr Evan Mann	Policy Officer, Carers Australia
13	Dr Ian McRae	Health Economist, Australian Primary Health Care Research Institute
14	Ms Lynelle Moon	Health Group, Head of Cardiovascular, Diabetes and Kidney Unit, Australian Institute of Health and Welfare
15	Ms Eleri Morgan-Thomas	General Manager Social Advocacy and Public Affairs, Mission Australia
16	Mr Francis Sullivan	Secretary General, Australian Medical Association
17	Ms Gayle Sweaney	Aged Care Business Manager, Anglicare Canberra & Goulburn
18	Dr Jeromy Temple	Director of Research, National Seniors Australia
19	Ms Anna Wise	Senior Policy Manager, Consumers Health Forum of Australia
	<b>SCIPPS team members:</b>	
20	Dr Jim Gillespie	Deputy Director, Menzies Centre for Health Policy (Sydney); SCIPPS researcher and Chief Investigator
21	Laurann Yen	Associate Director, Menzies Centre for Health Policy (Canberra); SCIPPS senior researcher
	<b>Recorder:</b>	
22	Dr Dagmar Ceramidas	Menzies Centre for Health Policy (Canberra); SCIPPS support
	<b>Apologies:</b>	
	Dr Paul Bates	Bupa Australia
	Associate Professor Rosemary Knight	Chronic Disease Branch, Population Health Division, Department of Health and Ageing

# Appendix B

## AGENDA

### Menzies Centre for Health Policy

#### Serious and Continuing Illness Policy and Practice Study (SCIPPS)

#### Roundtable meeting 2: The economic impact of chronic disease on individuals and families

Tuesday 22<sup>nd</sup> November 2011

### Agenda

Registration

10:00 Welcome, Professor Nicholas Glasgow, Chair

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

**Speaker 1:** Associate Professor Stephen Jan, the George Institute for Global Health; and SCIPPS

**Speaker 2:** Dr Dina Bowman, the Brotherhood of St Laurence and the University of Melbourne

10:45 Discussion

11:15 Morning tea

11:30 Continue discussion

12:00 **Session 2: Policy options**

**Speaker 3:** Professor Bettina Cass, Social Policy Research Group, University of New South Wales

**Speaker 4:** Mr John Della Bosca, National Campaign Director for the “Every Australian Counts” Campaign

12:30 Lunch

1:30 Discussion

2:30 Afternoon tea

2:45 Summary of the day

3:00 Close

## Appendix C

### RECORD OF ROUNDTABLE DISCUSSION

**In attendance:** 22, plus two apologies; list of Delegates at Appendix A.

**Agenda:** At Appendix B

**Speaker 1:** Associate Professor Stephen Jan, the George Institute for Global Health; and Chief Investigator with SCIPPS (Powerpoint presentation in file)

General questions and discussion:

- > Suggestion that future research might look at the economic impact and the costs needed to prevent chronic illness. This might be done through parallel disease-specific studies.
- > Response: Could link the cost of prevention of further illness with SCIPPS

**Speaker 2:** Dr Dina Bowman, the Brotherhood of St Laurence and the University of Melbourne (Powerpoint presentation in file)

General questions and discussion:

- > Disability cannot be treated as one category because each illness has a totally different set of impacts, influences and outcomes. The common point is that disability/ illness is strongly associated with poverty and social exclusion.
- > Policy direction is not sensitive to the problems of eligibility for support; these need to be disease specific and sensitive to the economic and social consequences of disability and ill health.
- > Need also to attend to 'life stage' when considering categorisation and chronic illness
- > Transition to retirement phase is a stage where health care costs are likely to be rising and income is likely to be falling; the risk period is from ages 55 to 70 years
- > There is a tightening of eligibility requirements for Disability Support Pension which may result in an increase of people with a disability/ condition in receipt of NewStart ( with lower payments and different eligibility criteria)
- > The worry is in identifying when is work an opportunity and when is it an obligation?

Morning tea break

**Speaker 3:** Professor Bettina Cass, Social Policy Research Group, University of New South Wales (Powerpoint presentation in file)

- > Cannot create a dichotomy between having an illness and being a carer
- > Need to recognise that carers also have disabilities
- > Person-directed support
- > Family-directed support needs to be extended to carers

- > Middle-aged and older carers who return to the workforce
- > Where children are carers, students need to be able to combine ongoing education and other age-specific activities with caring roles
- > Carers are to be treated as partners in care, and given equal access to information, economic security and employment flexibility

**Speaker 4:** Mr John Della Bosca, National Campaign Director for the “Every Australian Counts” Campaign (powerpoint presentation not used)

Lunch break

General discussion

- > Carers often have to make hard choices between taking care of their own needs, and caring for their spouse
  - o There needs to be a procedure in place to receive good quality advice.
- > There is an inadequate infrastructure of services to support the recommendations of the Productivity Commission report
  - o A key policy issue, acknowledging the Carers Strategy, but there is little in the strategy and in both Productivity Commission reports to activate the policies and recommendations. The reports do not relate to the issues that carers face, or for the carer’s future.
  - o Many carers would, if they could, get a job. Work would be the first policy issue
  - o Economic hardship is only one of the hardships experienced by carers
- > Statistics highlight the high percentage of carers themselves having a disability; so what happens when carers consider they are no longer able to care and the care recipient needs to go into a care facility?
  - o Policies advocate that people remain in their own homes for as long as possible, but carer support is not provided for this to occur.
- > New Start Allowance is \$200 less per fortnight and is activity tested.
  - o Carers re-entering the workforce will need specific assistance and re-training
  - o It is not only for the well-being of the carer that they return to work, but also for the care recipient. The carer coming home from their working day and sharing the day’s stories with the care recipient enriches both peoples’ lives and maintains the care recipient’s connection with the ‘outside’ world.
- > Additional information was requested around the issue of ‘children as carers’
  - o Delegates were invited to visit the Social Policy Research Centre (UNSW) website for information regarding the issues of children as carers, <http://www.sprc.unsw.edu.au/>
  - o Great deal known
  - o 4% of children as carers in Australia (and higher in the indigenous communities) who have primary care responsibilities, especially in mental health are aged 12 years and younger.
  - o They come from and perpetuate low income households

- The children can't envisage a future of autonomy for themselves
- There is a higher rate of children as carers among the indigenous population
- Their ability to access formal services is highly restrained on two accounts:
  - Their Indigenous-ness, and
  - Inability to access services
- This is on the policy radar
- Needs to be a 'whole of school' and 'whole of health care' response
- > The Medicare Local (ML) system is about primary care sectors and links beyond
  - The ML can focus on poverty if this is one of the community needs, and MLs can be seen as possible contributors to the solutions of community problems
  - Capacity may not be there to conduct the real work of the ML
- > There are multi-layered, multi-faceted aspects of multi-morbidity.
  - It's not just the disability or the health sectors, but across all sectors
- > We have a 'boil the ocean' problem.
  - We'll never have enough heat to address everything
  - We need to find the number of things that have the biggest impact and then identify the system they are part of
  - What are the things to change that will have the most significant impact on the system, and are measurable?
- > Measurement is essential. There are too many commonalities between categories, so specifics of the change must be identified in order to be measured
- > What is the currency of change that we are looking at?
  - What measures move policy makers to change things?
  - What influences policy makers to change policy?
- > Where academic research, policy research and politics get linked:
  - The politician needs to solve problems in the community but will generally focus on those things that are popular. So we need to make the problem popular.
  - Information out of the academic research sphere can alert the community to the problem they didn't know existed.
  - This will raise the profile of the issues, put them into the public realm, start debate, and go forward from there.
- > The data 'out there' is insufficient.
  - Mission Australia is conducting some research with chronically homeless men, looking at the efficacy of a new model
  - The findings suggest that best results are realised when intensive work is done at the beginning of an intervention, when people first come into the system. Gains are greater overall, including economic gains to the system
  - The project affected the crisis end of health care
- > Anglicare support carers and also works at the crisis end of the system.
  - Need an e-health person on our SCIPPS Roundtables
- > There are actually two economic impacts:

- The cost of seeing the health professional and of receiving a service such as pharmacy, and
- How does the chronic illness affect the person's income?
  - We need to consider the impact of costs on both aspects
- > There is a need to look at opportunities to become increasingly connected.
  - There may not be a fast solution
  - Demands will increase before they lessen
  - How do we create the model that gives assistance until the problem is fixed on a broader scale, particularly for the group of people where the trajectory is a depressing one?
- > Delegates were given a description of a telehealth trial with 12 participants and conducted by a church-related organisation.
  - Results were that the wife of the care recipient was able to return to work, the GP "loved it", and the care recipient's capacity to self-manage improved
- > We can learn from the UK in terms of carer's support, especially with disability and chronic illness.
  - In the UK, carers have the same rights as the care recipient.
  - There is a statutory right for the carer's need to be assessed as person-directed care (PDC).
  - There is a quick role out of PDC assessment for the care recipient and for their carer.
  - There is an employment issue for carers and care recipients.
  - Carers have a statutory right to request flexible employment
  - In the UK, there are 'Employers for Carers' organisations under a European Union directive on carers.
  - We need to look at prevention from a policy perspective.
  - How do systems support carers?
  - Is it important that a 12 year old child is caring for their sick mother, or can another carer do this?
  - Have found very few prevention services [in the above case, 'prevention' would be that the 12 year old child is relieved of the duty of care by an adult carer]. There are several services that provide mitigation and several that provide support.
  - Being in conversation with the policy makers and with the service providers from the very conception of every project. This is the way that policy-related research needs to proceed.
- > There is a deficit with all of the discussion: one third of all Australians live outside major cities.
  - This needs to be reflected in policy
- > An opportunity exists around the level of the ML to "buy in" some providers to provide resources when the people need them.
  - This increases the capacity to engage the local area
- > The measure of chronic illness care improvement is the decrease in hospital admission rates.
- > Focus on regional / local response – address the worst first – smoking and obesity

- > The task of enjoying life is difficult for those with chronic illness, and self-management can result in increased levels of depression.
  - Discussed ‘telecross’ approach to improving connectedness for care recipients who are isolated in their own homes.
  - The results have shown (anecdotal) improved health literacy, reduced depression, and increased connectedness with the outside world
  - People with chronic illness frequently need to do more exercise. They can’t keep up with it if they are on their own, so stop all together. A carer similar to the telecross model can help a care recipient to maintain a modest exercise routine.
  - These techniques are inexpensive and can be preventive against hospital admission
- > People with chronic illness find it hard to manage their every-day expenses.
  - Need a review of levels of expenses and the level of support these are providing
- > Delegates were invited to review the Harmer Review, which gives a broader review of the tax system  
[http://www.facs.gov.au/about/publicationsarticles/corp/BudgetPAES/budget09\\_10/pension/Documents/Pension\\_Review\\_Report/PensionReviewReport.pdf](http://www.facs.gov.au/about/publicationsarticles/corp/BudgetPAES/budget09_10/pension/Documents/Pension_Review_Report/PensionReviewReport.pdf)
- > MLs have a potential role here, offering something similar to Centrelink’s ‘Wrap around’ service (Appendix D).
- > We need to look at the characteristics and inequities of the health care system that might raise the cost of chronic illness. For example, the public hospital system is equitable, but a blowout of the cost of care exists with the use of private hospitals and specialist medical services.
  - Procedures such as stenting and angioplasty, and other care are often missed out on
  - These things become preventive if done
- > The Chair provided a summary of the sense of policy considerations arising from the Roundtable.

## Appendix D

### ‘WRAP AROUND’ SERVICE

#### Service providers unite to make job seeking easier

Human Services Portfolio agencies are changing to help customers Australia wide get the services they need.

Local Connections to Work is a good example of one of the new and exciting national programs initiated by the Human Services Portfolio. Local Connections to Work is a place-based service delivery for job seekers. Service providers, in areas such as employment, health, housing, education, community welfare and many others, work jointly with job seekers to overcome barriers to employment and social inclusion. Providers co-locate in a Centrelink office on a rostered basis to give job seekers access to a **‘wrap around’** service—multiple services at once.

This **‘wrap around’** service is a collaboration between government and non-government agencies to offer targeted assistance to disadvantaged youth and those who have been unemployed for five or more years. Local Connections to Work is currently available through four Centrelink offices: Campsie in New South Wales, Frankston in Victoria, Ipswich in Queensland, and Elizabeth in South Australia.

Local Connections to Work participants have a joint interview with Centrelink and their employment services provider to identify their needs and match them with the right support. In most cases, the job seeker tells their story once to get a **‘wrap around’** service from co-located community partners.

**‘Wrap around’** service is available to other customers who would benefit—not just job seekers—from multiple services in one location.

Julian Jeyakumar, a Centrelink Multicultural Service Officer at the Campsie office works with customers from a wide range of diverse cultural and linguistic backgrounds.

‘More than 65 per cent of our customers come from a diverse cultural and linguistic background,’ Mr Jeyakumar said.

‘My role is to ensure our customers are aware of the services we offer that may be useful for them, and how to access them.’

‘This Local Connections to Work office makes it easier for our customers to access services from across the community—it saves people time as it’s all here for them in the one place.’

Additional sites will be opened in 2011.

**Source:** The Journey, No. CO315.1103, 27(Autumn), 2011. Accessed 24 November 2011.  
[www.centrelink.gov.au/internet/internet.nsf/.../co315\\_1103en.rtf](http://www.centrelink.gov.au/internet/internet.nsf/.../co315_1103en.rtf)

## Appendix E

### MEDIA OPPORTUNITIES

The following Press Release was issued through the ANU Media Office:

#### **Pills or bills: managing costs and chronic illness**

How to lessen the economic impact chronic disease has on patients and their families is the focus of a policy roundtable taking place at The Australian National University.

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.

Leading experts and stakeholders from the health, welfare, academic and government sectors around Australia will use the roundtable to determine how the link between long-term illness, and financial stress and hardship can be broken.

SCIPPS chief investigator and Dean of the ANU Medical School Professor Nicholas Glasgow said that for many patients and their families, living with chronic illness went hand-in-hand with high, out-of-pocket care-related costs. Many people leave or reduce their working hours because of illness, making it even harder to pay the bills.

“Despite the existence of well-established health and social safety nets in Australia, which we perhaps take for granted, there are many people living with long-term illness who fall between the cracks. This is particularly the case for people with lower incomes,” said Professor Glasgow.

“Our research shows that a substantial percentage of Australians with chronic illness experience economic hardship. As a consequence of these financial pressures, people with chronic illness often need to make significant sacrifices in order to manage their expenses, often at the cost of their health care.

“Of grave concern is that in some instances patients ignore recommended treatments and prescriptions in order to lessen economic hardship. We clearly need to recognise this as a reality and work out how best to deal with it.

“This roundtable will assess the current evidence and come up with innovative policy solutions for this growing problem. It will also look at how to coordinate action across numerous sectors and diverse sets of stakeholders in a way that helps the health reform process,” he said.

SCIPPS is a five-year National Health and Medical Research Council funded project. In addition to the economic impacts of chronic disease, the study has examined Indigenous health, co-morbidity, self-management of care, health literacy and informal care.

#### **Radio interviews:**

- > ABC 66FM     Laurann Yen
- > 2CC Community Radio     Associate Professor Stephen Jan

#### **Television interview:**

- > WIN News     Associate Professor Stephen Jan
- > WIN News     Mr Evan Mann, Carer's Australia

#### **Print media:**

- > Sunday Canberra Times