



The CARI Guidelines
Caring for Australasians with Renal Impairment
www.cari.org.au

ANNUAL REPORT
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Guidelines Office: CARI Guidelines c/o Centre for Kidney Research, Locked Bag 4001,
Westmead NSW 2145, Australia

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Report from the Chair

I took over as Chair of the CARI Steering Committee from Rowan Walker at the beginning of 2008 and would like to thank him for the enormous contribution he has made since CARI started, to the guideline development process.

Various guideline groups worked on updating their guidelines in 2008, these being the 'Acceptance onto Dialysis', 'Cardiovascular Risk Factors', 'Vascular Access' and 'Living Kidney Donor' groups. The updated guidelines are expected to be ready for publication by late 2009. A CARI guideline group was also formed to work with the Diabetes Unit, Menzies Centre for Health Policy (Sydney University) to produce a guideline titled 'The Diagnosis and Prevention of Chronic Kidney Disease in Type 2 Diabetes Mellitus' as part of a suite of four Diabetes Type II guidelines, for Diabetes Australia. The group has produced a sizeable draft document which has been sent out for peer review. We hope to make a "CARI" version of this guideline, using the CARI template and processes, once the guideline has been published. Martin Howell, a Research Officer with CARI, and a group of writers led by Steve Chadban and Jonathan Craig did the huge amount of work involved in updating an earlier version of this guideline which had not previously been finalised or published. It was also a learning curve for CARI, in that we had not previously collaborated with another organisation in the development of a guideline for which NHMRC endorsement will be sought.

A further Supplement to Nephrology was published in August 2008. The publication contained various Guideline Recommendations and Suggestions for Clinical Care relating to guidelines on 'Vascular Access', 'Renal Vasculitis' and 'Haematological Targets'. This supplement was distributed to Nephrology subscribers in Australia, New Zealand and South Asia. The Renovascular Disease guideline group (Convenor is George Mangos), working on a tight timeline and covering 5 subtopics, prepared a presentation of the draft Recommendations and Suggestions for Clinical Care for discussion at the DNT Workshop to be held in March 2009 in Lorne, Victoria. The Acceptance onto Dialysis guideline group will also present their draft Guideline Recommendations for discussion at the same meeting.

One of the biggest challenges at present for CARI is to define its relationship to KD:IGO (Kidney Disease: Improving Global Outcomes) and work out how the two organisations should best complement each other. CARI had started setting up a group to produce a guideline on the topic of 'Acute Kidney Injury' but this was abandoned when it was learned that KD:IGO had commenced work on the same topic. It is now planned that CARI will do an adaptation of the KD:IGO guideline once it has been published in 2010.

CARI has also continued its work on the implementation of guidelines with projects in the areas of anaemia and vascular access.

In 2006-07, Michelle Irving, CARI's Senior Research Officer, ran an active implementation project based on the uptake of the CARI iron guideline. Six renal units participated and were monitored for their iron, haemoglobin and epoetin management. Michelle conducted process review interviews with each of these units in 2008, to establish causes for success/non-success in the implementation of the guideline. A paper is currently being written about the findings.

Pamela Lopez-Vargas, the Project Officer for the Vascular Access Implementation group, put a lot of effort throughout 2008 into setting up a database for the participating renal units to use as part of the data collection of the project. This project began in 2007 with the aim of implementing CARI guideline recommendations on Vascular Access – those relating to 'Timing of access formation' and 'Choice of type of access'. Nine renal units in Australia and New Zealand are taking part in the

Report from the Chair cont.

study and are working with CARI to identify the barriers to access creation at each of their units and to develop strategies/ processes to improve the number of fistulas created for new haemodialysis patients. The implementation phase started in July 2008 and will finish at the end of June in 2009.

Allison Tong, a postgraduate Research Fellow with CARI, assisted with the screening of search results for the Type 2 Diabetes guidelines and has been doing other searches as required and developing evidence tables for the various guideline writers who are developing or revising guidelines. Allison has also been conducting research on consumer-oriented topics and had two papers accepted for publication in 2008, these being 'Patients' experiences and perspectives of living with CKD' and 'Patients' priorities for health research'. The data for both papers came from focus groups Allison held with patients with CKD.

I would like to thank the CARI staff, the Steering Committee, and the various guideline groups who volunteer their time in revising or creating guidelines *de novo* and contribute to making CARI an accepted and respected organisation. Our work on the implementation of guidelines, novel for a guidelines group in nephrology, has highlighted how difficult it is to bring about change in practice but also strengthens our resolve to bridge the gap between evidence and practice. While there are many barriers to practice change, the production of clearly written, evidence-based guidelines with a defined implementation plan can only help lead to improvements in the care of chronic kidney disease patients in Australia and New Zealand.



Martin Gallagher
Chair
CARI Guidelines Steering Committee

Activities 2008

In August 2008, a *Nephrology* supplement was published containing CARI Guidelines on: 'Vascular Access', 'Renal Vasculitis', and 'Biochemical and Haematological Targets'. A total of 6 subtopics were covered which included 24 guideline recommendations.

The subtopics covered in the August 2008 Supplement include:

Vascular Access

Vascular access surveillance (Nephrology 2008; 13 suppl 2: S1-S11)
Pharmacological approaches to preventing vascular access failure (Nephrology 2008; 13 suppl 2: S12-S16)

Renal Vasculitis

ANCA serology in the diagnosis and management of ANCA-associated renal vasculitis (Nephrology 2008; 13 suppl 2: S17-S23)
Induction and maintenance therapy in ANCA-associated systemic vasculitis (Nephrology 2008; 13 suppl 2: S24-S36)
Renal transplantation (Nephrology 2008; 13 suppl 2: S37-S43)

Biochemical and Haematological Targets

Haemoglobin (Nephrology 2008; 13 suppl 2: S44-S56)

New Guidelines in Development

CARI has a number of new guidelines in development – on the topics of 'Renovascular Disease', Part 2 of the 'Living Kidney Donor' guidelines, 'Cardiovascular Risk Factors', 'Nutrition in Kidney Transplant Recipients' and updates of the 'Acceptance onto Dialysis', 'Vascular Access' and 'CMV Disease and Kidney Transplantation' guidelines. In mid-2007, CARI also started working on a new set of guidelines in collaboration with Diabetes Australia on the topic 'Evidence based guidelines for the diagnosis, prevention and management of chronic kidney disease in type 2 diabetes'.

The Convenor of the Renovascular Disease group is Dr George Mangos, with the group members including Dr Karthik Kumar, Dr Murty Mantha, Dr Peter Mount, Dr Rob MacGinley and Dr Matthew Roberts. The group commenced work on this guideline in early June 2008. Drafts of the Renovascular Disease guideline will be presented for discussion at the March 2009 DNT meeting being held in Lorne, Victoria. Drafts of these will be available via the CARI website for those attending the workshop to read before the meeting.

Five subtopics are being written on the following:

- Natural history and progression of renal artery stenosis
- Endovascular treatment of renovascular disease
- Diagnosis of renal artery stenosis
- Role of distal protection devices in patients with renovascular hypertension
- Medical management of hypertension in renovascular disease.

The Convenor of the Living Kidney Donor group is Dr John Kanellis, with the group members including Emma Van Hardeveld, Allison Tong, Dr David Nicol, Dr Norma Gibbons, Dr Stephen

Activities 2008 cont.

Munn, Dr Fiona Mackie, Dr Neil Boudville, Dr Frank Ierino, Dr Nikky Isbel, Dr Shlomo Cohny and Martin Howell. The group commenced work on this guideline in May 2006. In all, 8 subtopics are being written. Documents for the first part of the guideline (6 subtopics) have been written, peer reviewed and finalised and will be published in a supplement towards the end of 2009. The second part of the guideline has been written, peer reviewed and is currently being finalised. This will be published in the same supplement to Nephrology.

Part 1 has 6 subtopics written on the following:

- Justification for living donor kidney transplantation
- Psychosocial care of living kidney donors
- Surgical techniques in living donor nephrectomy
- Assessment of donor kidney anatomy
- Donor specific transfusions.

Part 2 has 2 subtopics which cover the following:

- Donors at risk: proteinuria
- Donors at risk: haematuria
- Donors at risk: hypertension
- Donors at risk: donor obesity
- Donors at risk: impaired glucose tolerance
- Donor renal function.

The 'Cardiovascular Risk Factors' guideline group has Dr Vlado Perkovic as its Convenor. Group members include Dr Matthew Roberts, Dr Sharan Dogra, Dr Rachel Huxley, Dr Lawrie McMahon, Dr Helen Pilmore, Dr Rob Walker and Dr Toshiharu Ninomiya. The group commenced work on this guideline in mid-August 2007. A total of 5 subtopics are currently being written with one subtopic (Lipid lowering therapy) having previously been published. Documents for these subtopics have been written and need to be sent for peer review, public consultation and finalised and will be included in the supplement being published towards the end of 2009.

The 5 subtopics have been written on the following:

- Management of CAD/ revascularisation
- Management of CAD/ medication
- Hypertension
- Heart failure
- Interventions for non-traditional emerging risk factors.

The Transplant Nutrition guideline has been written by a group outside CARI, mostly based at the John Hunter Hospital. The draft documents have been put through the usual CARI peer review process and are now close to being ready for publication. The group members include Dr Steve Chadban, Maria Chan, Karen Fry, Aditi Patwardhan, Catherine Ryan, Dr Paul Trevillian and Fidy Westgarth. The group commenced working with CARI on this guideline in June 2008. In all, 9 subtopics have been written. All of these subtopics have been written, peer reviewed and are currently being finalised. They will be published in a supplement towards the end of 2009 will be

The following 9 subtopics have been researched and written:

- Food safety recommendations for adult kidney transplant recipients
- Nutritional management of diabetes mellitus in adult kidney transplant recipients
- Nutritional management of anaemia in adult kidney transplant recipients

Activities 2008 cont.

- Nutritional interventions for the prevention of bone disease in kidney transplant recipients
- Nutritional management of hypophosphataemia in adult kidney transplant recipients
- Nutritional management of overweight and obesity in adult kidney transplant recipients
- Nutritional management of hypertension in adult kidney transplant recipients
- Nutritional management of dyslipidaemia in adult kidney transplant recipients
- Protein requirement in adult kidney transplant recipients.

Updating of the 'Acceptance onto Dialysis' guideline is also underway. The Convenor of this group is Dr Grant Luxton, and group members include Dr Gad Kainer, Dr John Kelly, Melissa Stanley, Deirdre Fetherstonhaugh, Dr Eugenie Pedagogos, Dr David Harris and Dr Krishan Madhan. The group first met in mid-June 2007 and has since then written documents which have been peer reviewed and are currently being finalised for publication. These will be included in the supplement being produced towards the end of 2009. Four subtopics belonging to this guideline were previously published in October 2005.

The following subtopics have been written:

- Timing of referral of CKD patients to nephrology services
- Ethical considerations
- Comorbidities: diabetes
- Comorbidities: coronary artery and cerebrovascular disease
- Haemodialysis versus peritoneal dialysis
- Quality of life

Updating of the 'Vascular Access' guideline is also in progress. The Convenor of this group is Dr Kevan Polkinghorne, with group members including Dr Chris Russell, Dr Girish Talaulikar, Jayne Amy, Dr Ashley Irish and Dr George Chin. The group first met in early October 2007 and has since then commenced writing their draft recommendations. These need to be finalised so that they can be sent for peer review and public consultation and then finalised for publication.

The following subtopics are being written:

Placement of permanent vascular access -

- Selection of appropriate vascular access
- Pre-operative examination of the vessels
- Timing of vascular access placement
- Nursing care of the AVF/ AVG

Treatment of dysfunctional AV access -

- Treatment of AVF/ AVG stenosis: surgical vs radiological intervention
- Treatment of the thrombosed AVF/ AVG: surgical vs radiological therapy
- Other complications: treatment of vascular steal and infection

Prevention of AVF/ AVG failure -

- Vascular access surveillance for preventing AVF/ AVG failure
- Pharmacological approaches to preventing vascular access failure

Central venous catheters -

- Insertion and nursing care of catheters
- Prevention and treatment of catheter-related bacteremia
- Prevention and treatment of catheter occlusion

Activities 2008 cont.

The 'CMV Disease and Kidney Transplantation' guideline will commence their updates in 2009. The Convenor for this group is Dr Helen Pilmore, with group members being Dr Bruce Pussell and Dr David Goodman. The group plans to meet in early 2009 and has been sent the results of literature searches for their subtopics. The timeline for the group will see the revised guideline published in June 2010.

The following subtopics are going to be written:

- Diagnostic tests for CMV in renal transplantation
- Prophylaxis for CMV infection in patients following renal transplantation
- Pre-emptive treatment of CMV
- Treatment of CMV disease in renal transplant recipients

In mid- 2007, CARI started working on a new set of guidelines in collaboration with Diabetes Australia called 'Evidence based guidelines for the diagnosis, prevention and management of chronic kidney disease in type 2 diabetes'. The guideline is being prepared in collaboration with the Diabetes Unit, Menzies Centre for Health Policy at the University of Sydney, for Diabetes Australia. Funding has been received from the Department of Health and Ageing for the development of these guidelines and they are being prepared in accordance with NHMRC protocols with a view to endorsement by the NHMRC.

The joint Convenors of the guideline group are Steve Chadban and Jonathan Craig. The chronic kidney disease guideline addresses the following questions:

1. How should kidney function be assessed and how often in people with type 2 diabetes?
2. How should chronic kidney disease be prevented and/or managed in people with type 2 diabetes?
 - a. What is the role of blood glucose control?
 - b. What is the role of blood pressure control?
 - c. What is the role of blood lipid modification?
 - d. What is the role of diet modification?
 - e. What is the role of smoking cessation?
3. Is the prevention and management of chronic kidney disease in people with type 2 diabetes cost effective and what are the socioeconomic implications?

Following the publication of this guideline by Diabetes Australia, there is a plan to produce a CARI version of the guideline.

Relevant Publications

Tong A, Sainsbury P, Carter SM, Hall B, Harris DC, Walker RG, Hawley CM, Chadban S, Craig JC. Patients' priorities for health research: focus group study of patients with chronic kidney disease. *Nephrology Dialysis Transplantation* 2008; 32: 3206-3214

Irving M, McDonald S, Walker R, Frommer F, Craig J. Results of a national survey of nephrologists: opinions on the content and effects of chronic kidney disease guidelines in Australia and New Zealand. *American Journal of Kidney Diseases*, In press.

Activities 2008 cont.

CARI Guidelines Critical Appraisal Training Workshop

The Training Workshop was held in July in a meeting room at the Qantas Club, Sydney Airport. The teaching sessions were presented by Prof Jonathan Craig, Dr Martin Gallagher and Dr Angela Webster. The attendees were from four of the guideline groups whose members are currently working on guidelines – ‘Acceptance onto Dialysis’, ‘Vascular Access’, ‘Cardiovascular Risk Factors’ and ‘Renovascular Hypertension’. The Training Workshop was run over 1 day and taught basic critical appraisal skills and also outlined the process involved in writing a CARI guideline, and explained the role and responsibilities of a CARI guideline writer.

CARI Guidelines Implementation Projects

2nd Iron guideline project

An active implementation project regarding the CARI Iron guideline was conducted in 2007. Six renal units were monitored for their iron management and ferritin, haemoglobin, TSAT and epoetin use. Three units agreed to review their iron management practices with the view to implementing the CARI iron guideline. This was done through the use of an opinion leader, audit and feedback and a computerised decision support system. Two of the 3 units have shown statistically significant increases in ferritin levels after introducing new protocols in their units. The other three units, which continued to be monitored but did not introduce new protocols, did not have significant changes. Results from this project were presented at the ANZSN meeting in September 2007 in the Gold Coast and at the 4th Guidelines International Network conference in August 2007 in Toronto, Canada. The manuscript for this is being prepared for journal submission.

Vascular access guideline project

The Vascular Access implementation project is a controlled before and after study which is directed at implementing the vascular access guideline recommendations that patients starting dialysis should do so with a permanent dialysis access in situ (ideally a functioning native arteriovenous fistula, the optimum type of AV access). The CARI guidelines on ‘Timing of Access Formation’ and ‘Choice of Type of Access’ were actively implemented because both are key steps in the adequate preparation of an individual for chronic haemodialysis. Preliminary work began on the project in 2006. By the end of December 2007, the 8 units needed for the project had been chosen, the data collection form had been piloted at 2 units, the development of the Microsoft Access database to be used by the units had been started and a face to face meeting had been held for the Steering Committee to plan for the next stages of the project.

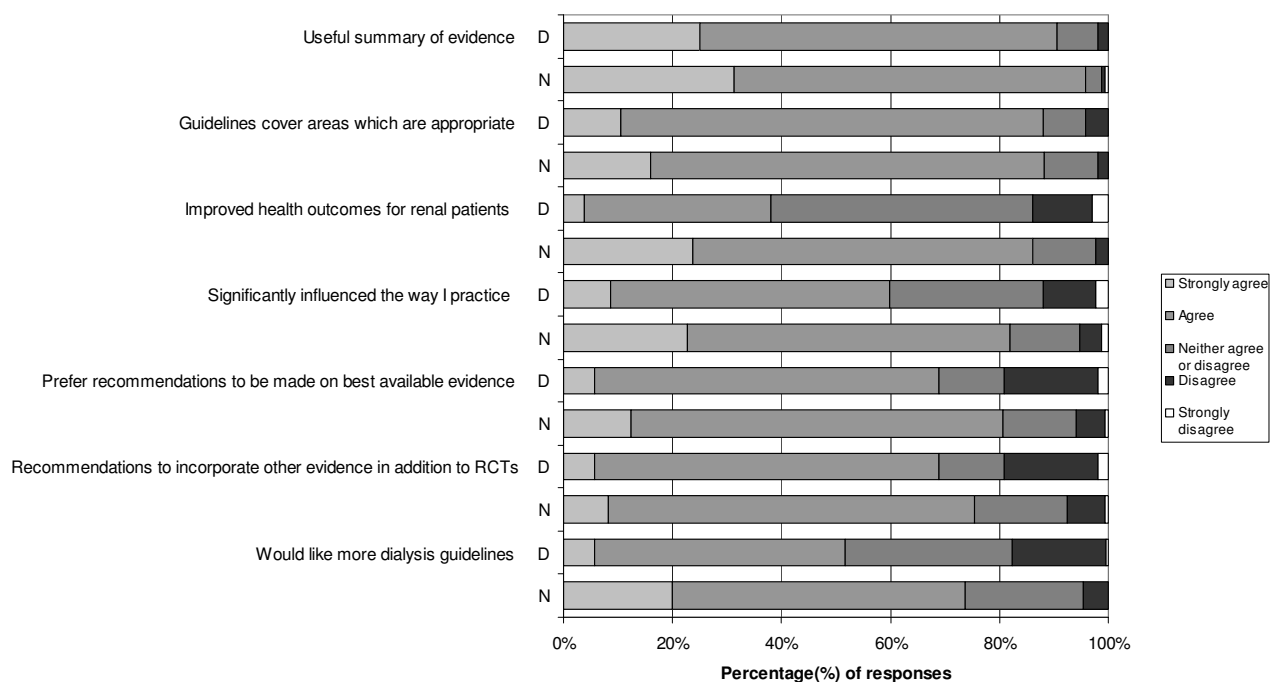
In February 2008, a face to face meeting was conducted with all participating units and the 9 Steering Committee members. During this meeting, units presented their previous year’s data on vascular access creation and use at first haemodialysis. Units were given an Access database to enter their baseline data from January to June 2008. Pamela Lopez-Vargas, the research nurse co-ordinating the project, visited the participating units during the baseline period and developed process maps for each unit. These maps were used to identify the barriers and enablers present at each site.

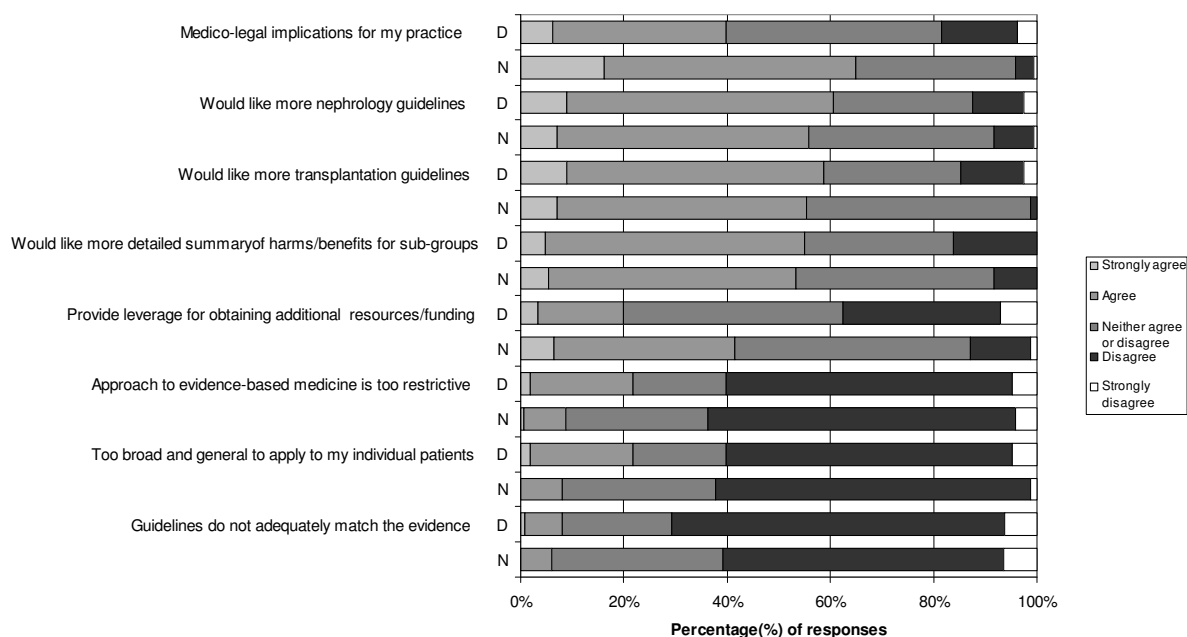
A second face to face meeting was held in July 2008 which the units’ representatives and the Steering Committee attended. All identified barriers and enablers and each unit’s baseline data were presented. Implementation strategies were discussed at this meeting. The Implementation phase of the project was begun in July 2008 and will run for 1 year. In November 2008, a third meeting was conducted to reinforce the implementation strategies and provide updated feedback of the data for all units.

Activities 2008 cont.

CARI guidelines survey of key users

Australian and New Zealand nephrologists and renal nurses were surveyed in 2006 for their opinions on the effect of the CARI guidelines, as well as content and structure of the guidelines. The response rate from nephrologists was 70% and that from renal nurses was 22%. Results show that renal nurses value the CARI Guidelines highly, use them in practice, and consider that they have led to improved patient outcomes. Over 90% of nephrologists agree that the CARI Guidelines are a useful summary of the evidence and nearly 60% report that the guidelines have significantly influenced their practice. However, only one-third believe that guidelines affect health outcomes. Overall, the results were very positive, with a large improvement in attitude toward the CARI Guidelines from the last survey done in 2002. These findings were presented at the ANZSN Annual Scientific meeting in September 2007 at the Gold Coast and at the Guidelines International Network conference held in August 2007 in Toronto, Canada. The results of the survey of nephrologists have been submitted to the *American Journal of Kidney Diseases* (Irving M, Johnson D, McDonald S, Walker R, Frommer F, Craig J. Results of a national survey of nephrologists: opinions on the content and effects of chronic kidney disease guidelines in Australia and New Zealand. *American Journal of Kidney Diseases*, In press). The results of the survey of renal nurses have been accepted for publication in *Nephrology*. Some of the results are shown below.





CARI Guidelines Research Activity

Patient priorities project

Allison Tong, the CARI Research Officer, commenced a qualitative study with the aim of identifying chronic kidney disease patients' priorities for health research. This has not been done in Australia before. The aims of the study were to: identify patients' research priorities; explore their ranking and ranking processes; and assess discrepancies between individual opinions, common priorities for research, and reasons underlying patients' opinions. Patients with chronic kidney disease from four kidney dialysis and transplant centres in 3 major Australian cities were invited to participate. Nine focus groups were held, with 3 different target patient groups (pre-dialysis, dialysis and transplant).

Results show that the research priorities preferred by the patients include: prevention of kidney disease; better access to and improvement in kidney transplantation; reduction of symptoms of CKD and complications associated with treatment; new technological therapies; psychosocial aspects of living with CKD; whole body not organ-specialised care; and improvement in dialysis and caregiver support. Five major reasons for selecting these topics were also identified. These include: normalisation of life, altruism, economic efficiency, personal needs and clinical outcomes. Unlike researchers who focus on specific interventions and questions, consumers think in terms of broad themes and quality of life outcomes. Effective methods for translating a patient-focused agenda into research priority setting and resource allocation are now needed. An oral presentation of the project was given at the Guidelines International Network conference in Toronto, Canada in August 2007. A poster of the research was presented at the ANZSN Annual Scientific Meeting in September 2007, at the Gold Coast. These findings have been published in the journal *Nephrology Dialysis and Transplantation* (2008; 23: 3206-3214).

Systematic review of implementation in CKD

Michelle Irving and co-authors undertook a systematic review on the topic of implementation of evidence-based medicine in CKD. A comprehensive search of Medline and Embase from January 1966 to June 2007 was conducted. Twenty-two studies including seven randomized controlled trials and 15 before-after studies were included in the review. Four main interventions were evaluated in more than 700 dialysis centres/hospitals or general practices.

Activities 2008 cont.

These were: audit and feedback, computerised decision support system (CDSS), opinion leader/multidisciplinary team and passive dissemination of guidelines. Due to heterogeneity, a formal meta-analysis could not be done. Results show that active and multifaceted interventions are more effective than passive dissemination and single strategy methods. Interventions need to address all barriers to implementation and provide adequate workforce assistance. In addition, specific quality indicator targets are associated with greater improvements in care.

This study has been prepared for publication but needs to be updated before it is submitted. This will occur in 2010. As a result of this study, an active multifaceted implementation approach was used in the Vascular Access implementation project. This project not only addressed barriers to implementation but took the next step of determining whether barriers were real or perceived, before addressing them.

Guideline Searches

All guideline subtopics need to have a systematic current search of the literature performed to ensure that guideline writers have all of the relevant studies, from which to write their guideline. Both Medline and the Cochrane Controlled Register of trials are searched. A comprehensive search strategy and scanning of the search results to weed out irrelevant studies is conducted by Allison Tong, CARI's part-time Research Officer. Allison uses standard Cochrane search strategies.

Searches conducted and articles obtained for writers in 2008:

GUIDELINE GROUP	NUMBER OF SEARCHES	NUMBER OF ARTICLES REQUESTED/ SENT
Cardiovascular Risk Factors	3	174
CMV Disease and Kidney Transplantation	1	29
Living Kidney Donors	3	8
Renovascular Disease	4	26
Vascular Access	6	80
Acceptance onto Dialysis	9	281
Dialysis Adequacy	2	28

Vascular Access Guideline Implementation Project

The Vascular Access implementation project is a controlled before and after study which was conducted to measure the change in the number of new haemodialysis patients starting dialysis with a functioning native arteriovenous fistula (the optimum type of AV access). The CARI guidelines on Timing of Access Formation and Choice of Type of Access were actively implemented because both are key steps in the adequate preparation of an individual for chronic haemodialysis.

Project Coordinator

Pamela Lopez-Vargas

Participating Units with Project Leaders and Access Coordinators

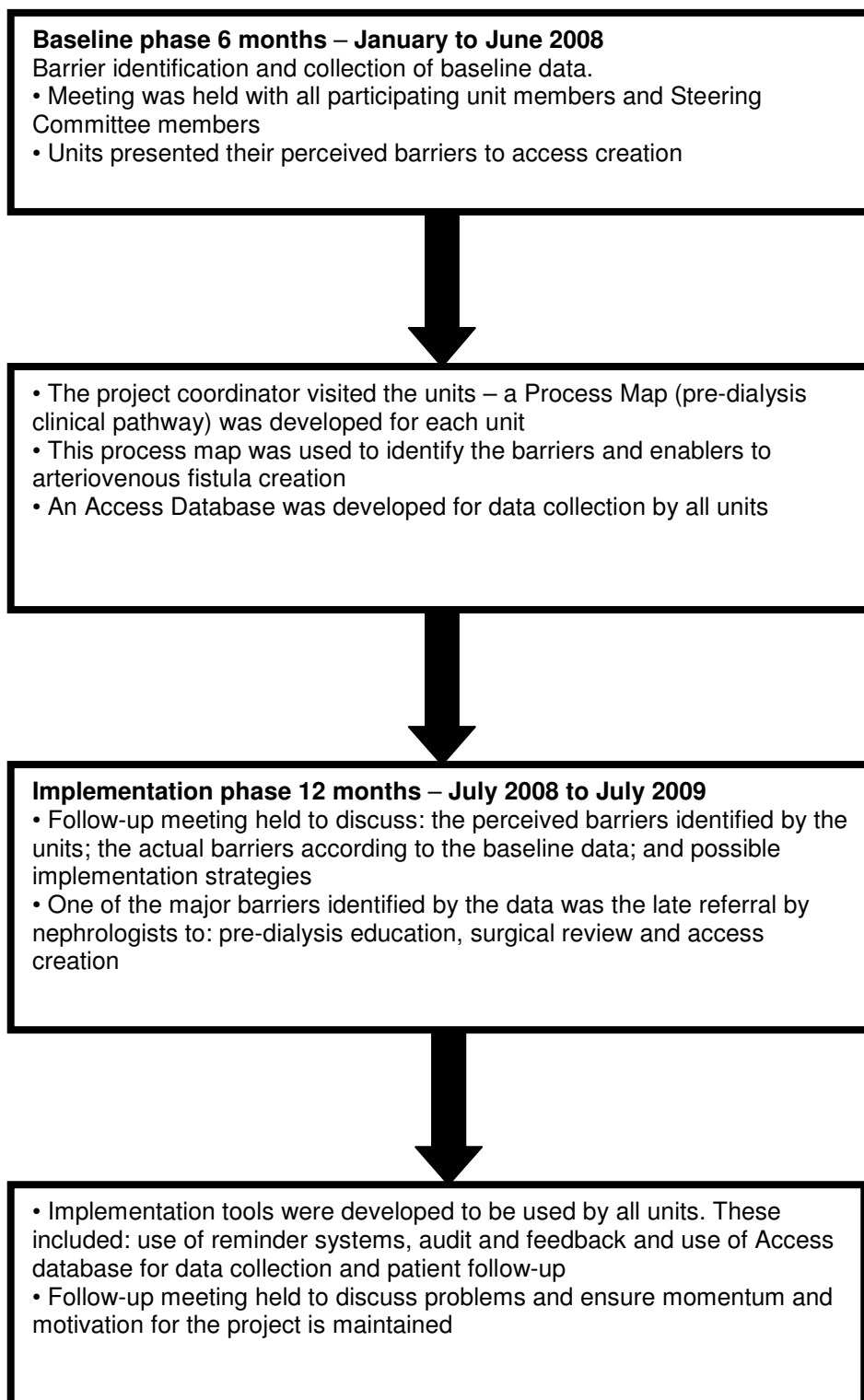
Gold Coast Hospital – Dr Murthy Divi and Dianne Du Toit
Nambour General Hospital – Dr Nicholas Gray and Sandra Glass
John Hunter Hospital – Conjoint A/Professor Alastair Gillies and Tara Csuka
Concord Repatriation and General Hospital – Dr Martin Gallagher and Catherine Stevens
Royal Prince Alfred Hospital – Dr Paul Snelling and Catherine Stevens
Liverpool Hospital – Conjoint A/Professor Michael Suranyi and Noemir Gonzalez
Monash Medical Centre – Dr Kevan Polkinghorne and Mechelle Seneviratne
Royal Melbourne Hospital – North West Dialysis Service – Assoc Professor Eugenia Pedagogos and Jayne Amy
Middlemore Hospital – Dr Hla Thein and Peta Kelly

Vascular Access Implementation Steering Committee

Professor Jonathan Craig
Dr Martin Gallagher
Dr Mark Marshall
Assoc Professor Stephen McDonald
Dr Kevan Polkinghorne
Dr Christine Russell
Assoc Professor Rowan Walker
Denise Campbell
Michelle Irving
Pamela Lopez-Vargas

Vascular Access Guideline Implementation Project cont.

Project Plan – Baseline and Implementation Phase



Vascular Access Guideline Implementation Project cont.

Baseline phase – results

There were 9 renal units who participated in this project: two units from Queensland, two from Victoria, four from New South Wales and one from New Zealand. Figure 1 shows the number of patients commencing haemodialysis in each unit during the 6-month baseline period. It should be noted that units vary in size with the smallest unit having 99 dialysis patients and the largest 703 dialysis patients.

Figure 1.
Number of Patients Commencing Haemodialysis
January - June 2008

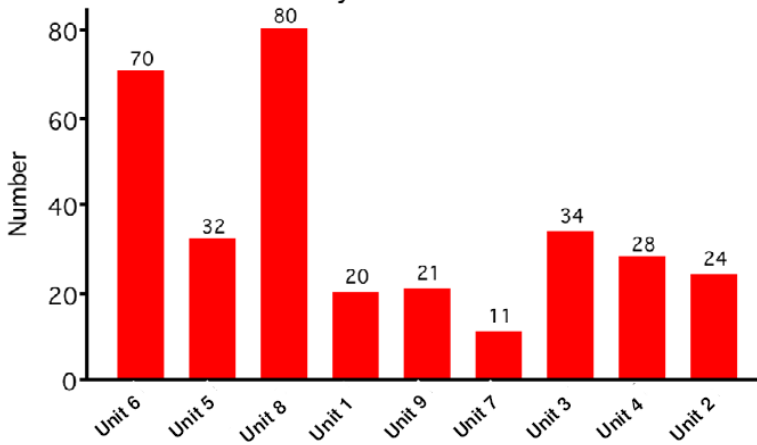
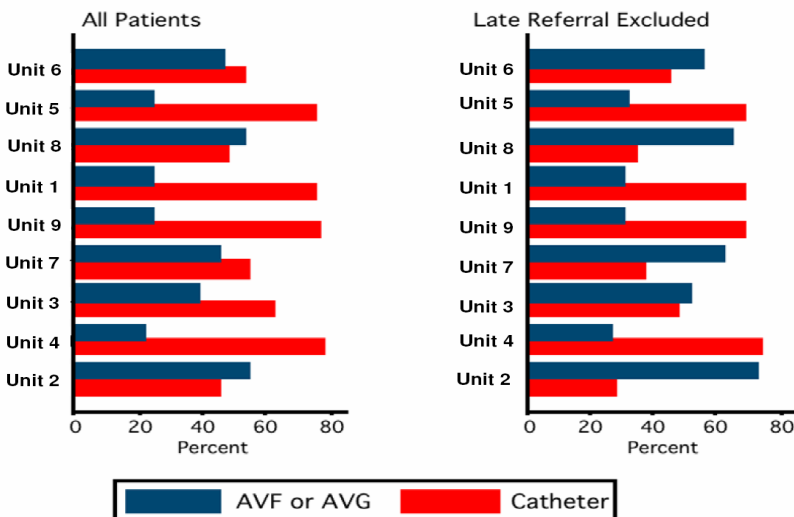


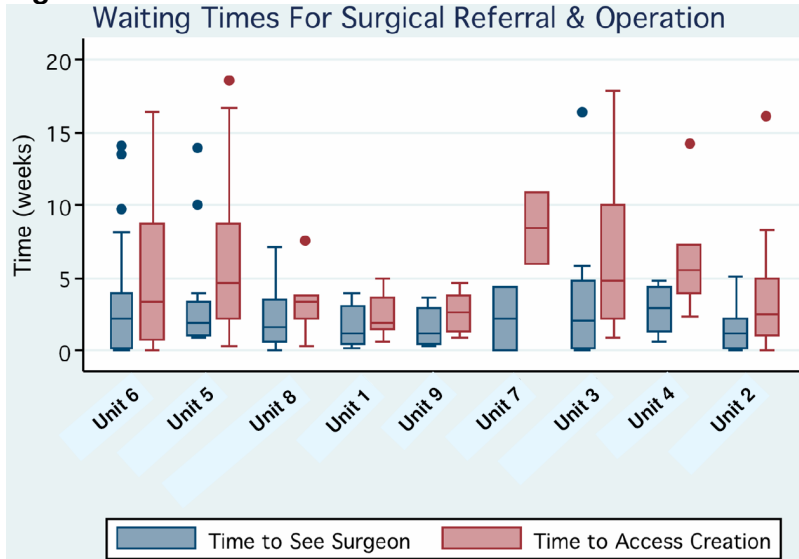
Figure 2.
Vascular Access at First Dialysis



From this graph it can be seen that the use of arteriovenous fistulas and grafts at first dialysis varies widely between the units. The lowest rate of AVF/AVG use was in unit 4 (approximately 30%) and the highest proportion was in unit 2 (about 70%).

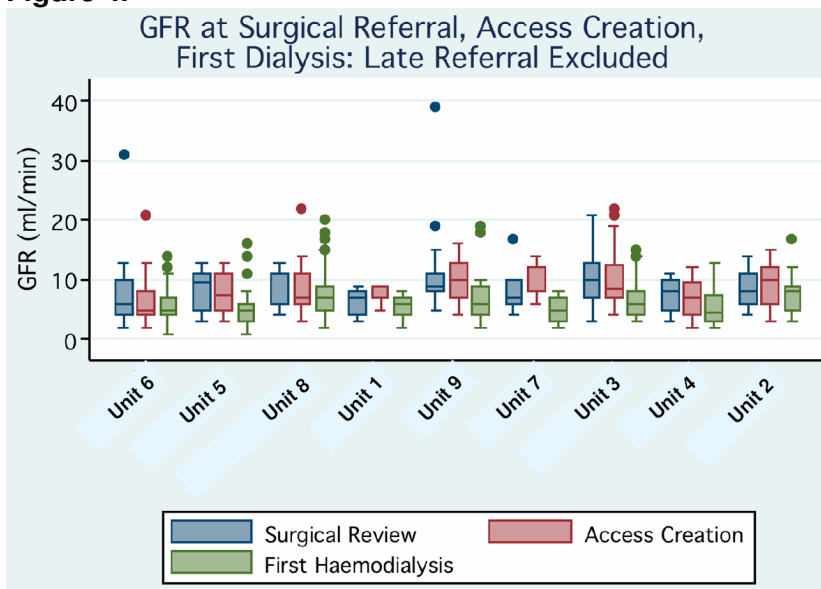
Vascular Access Guideline Implementation Project cont.

Figure 3.



This graph shows the median waiting time to see a surgeon is 2 weeks. The median waiting time to have access created after seeing the surgeon is 4 weeks. At the beginning of the project, all units had identified these waiting times to be a major barrier to vascular access creation.

Figure 4.



The average GFR values at surgical review, access creation and at first haemodialysis were: 8mL/min, 7mL/min and 6mL/min, respectively. This shows that patients are referred late to see the surgeon for access creation. The results were discussed with the participating units, during the July 2008 face to face meeting. Strategies were developed and implemented during the implementation phase of the study, which commenced after this meeting.

Meetings

National Institute of Clinical Studies (NICS) AGREE / ADAPTE Workshop, Melbourne, 13th – 14th February 2008

This workshop was held at The Royce Hotel in Melbourne. Denise Campbell, CARI's Senior Project Officer and Dr Martin Gallagher, Chair of the CARI Steering Committee, attended Day 1 of the workshop which looked at the AGREE tool and how to use it.

The workshop was led by Dr Jako Burgers, who is the Chair of the Guidelines International Network and Director of the Guidelines Program at the Dutch Institute for Healthcare Improvement (CBO). He is a respected researcher in guideline development and was a co-investigator in the international AGREE (Appraisal Guidelines Research and Evaluation) project. He is a trustee of the AGREE Research Trust, member of the ADAPTE Collaboration, which is working on guideline adaptation, and chair of SEARCH, an international working group on literature searching for guidelines.

The workshop provided an overview of the AGREE instrument for appraising guideline quality and a practical introduction to assessing guidelines using this instrument. AGREE has 6 domains, which are: scope & purpose; stakeholder involvement; rigour of development; clarity and presentation; applicability; and editorial independence. The AGREE instrument was developed to provide a systematic framework for appraising the quality of clinical guidelines and can be used by health care providers to assess guidelines before adopting recommendations into practice.

Involving People in Research Symposium, Perth, Western Australia, 5th – 6th March 2008

The University of Western Australia, School of Population Health, and the Telethon Institute for Child Health Research, presented this national symposium on consumer and community participation in health and medical research. The event was held at The University Club, University of Western Australia, and brought together some 155 researchers, 38 consumers, 32 community and non-government organisation members and 25 full time students from Australia, New Zealand and the UK.

The symposium provided an opportunity to explore barriers to participation in research, discuss how researchers and the community can work together to add value to research and to share experiences and lessons learned. Dr Allison Tong (CARI Research Fellow) presented her focus group study on 'Eliciting priorities for research from patients with chronic kidney disease'. This study was motivated by the fact that the inclusion of consumer preferences in prioritising research topics is widely advocated, but prioritisation is driven largely by professional agendas. Results from this study indicate that patients think in terms of broad themes and quality of life outcomes instead of focussing on specific interventions and questions, as researchers do. They also nominate primary and secondary prevention of CKD as a research priority.

The event was a great success. A communiqué was developed calling for the National Health and Medical Research Council to develop ways to further support consumer and community involvement in research.

Meetings cont.

Population Health Congress, Brisbane, Queensland, 6th – 9th July 2008

The Population Health Congress was held over 3 days in the Brisbane Convention and Exhibition Centre in July. This is the first time the Congress has been held and was hosted by the 4 leading public health organisations in Australia and New Zealand: the Australian Health Promotion Association, the Public Health Association of Australia, the Australasian Epidemiological Association and the Australasian Faculty of Public Health Medicine.

The congress theme was 'A Global World – Practical Action for Health and Well Being' and was attended by more than 1300 delegates. Major sub-themes of the meeting were: environment and health; social cohesion, social capital and health; and food and health. Papers were invited that "offer original research, innovative interventions and methodologies and critical or reflective comment rather than those that simply describe programs." In addition to papers on the Congress's stated sub-themes, papers were also invited on suggested areas of research.

Dr Martin Howell (Research Officer) attended this meeting and presented a paper titled 'Does the QHRA Process Adequately Address Public Health Issues? – A Contaminated Site Case Study.'

5th Guidelines International Network (G-I-N) Conference, Helsinki, Finland, 1st – 3rd October 2008

Allison Tong (CARI Research Fellow) and Michelle Irving (Senior Research Officer) attended this meeting, which brought together the producers and users of clinical practice guidelines. The theme of the conference was 'Implementation in Practice'. In total, 380 participants from 27 countries attended the conference which included 10 lectures, 68 oral presentations, 15 workshops and 96 poster presentations. The host organisations were the Current Care Guidelines and its parent organisation, the Finnish Medical Society Duodecim.

Allison Tong presented a poster titled 'An evaluation of 5 guideline programs with a new framework for assessing consumer involvement in guidelines (FACING)'. The guideline development manuals of 5 prominent guideline programs were reviewed. Results showed that although guideline programs support principles of consumer involvement, explicit and comprehensive guidelines for reporting on consumer involvement are needed to allow guideline developers and users to be more thoroughly informed when assessing consumer engagement in practice, whether consumers were appropriately and adequately involved, and to develop consumer involvement strategies.

Michelle Irving gave an oral presentation titled 'Implementation of Guidelines in Chronic Kidney Disease – a systematic review'. The review identified that well planned and executed interventions were able to improve CKD management to varying degrees. Active and multifaceted interventions which address barriers are more effective than passive dissemination and single strategy methods. Specific quality indicator targets are associated with greater improvements in care.

The major conference themes were 'Guideline implementation', 'Collaboration in guidelines production', 'Evidence in guidelines' and 'Guidelines and power'. Conference plenary topics included: Knowledge translation and guidelines; Guideline implementation research; and Guideline implementation in practice. Sessions attended covered aspects such as: changing the conceptual framework for guidelines to put greater emphasis on the end-user to promote ownership adoption and adaptation; the creation of an implementation database for all implementation attempts

Meetings cont.

worldwide; information technology – ensuring guidelines are available at the point of care; implementation projects – what has worked, what has not; the impact of patient's preferences on implementation; nurses' experiences of implementation – what do they see as the major factors in implementation; and innovative technologies to assist in implementation.

G-I-N is an international not-for-profit association of organisations and individuals involved in clinical practice guidelines. It was founded in November 2002 and currently has 54 member organisations from 27 countries. G-I-N seeks to improve the quality of healthcare by promoting the systematic development of clinical practice guidelines and their application into practice, through supporting international collaboration. CARI Guidelines is a member of G-I-N.

16th Cochrane Colloquium, Freiburg, Germany, 3rd – 7th October 2008

The Cochrane Colloquium is one of the most important conferences in evidence-based health care. The theme of the Colloquium was 'Evidence in the era of globalisation' with a focus on consumer issues and shared decision making; diagnostic test accuracy methodology; dissemination of reviews and their findings; downstream products of reviews; and much more. The plenary sessions covered topics such as: the art and science of patient involvement in evidence-based medicine; how to prioritise, partner, enhance quality and update Cochrane reviews; does evidence make a difference to health care?; and the task of globalising knowledge translation for evidence-based care. The program encompassed plenary sessions, oral and poster presentations as well as numerous workshops.

The Cochrane Colloquium offers an opportunity to interact with key players active in evidence-based health care, global knowledge management and systematic reviews. Evidence-based research is a key component in the creation of guidelines, patient information, evidence reports, and health technology assessment reports. The Cochrane Collaboration has laid the groundwork in creating a standardised international appraisal system of healthcare interventions.

Allison Tong attended this meeting and gave an oral presentation titled: 'Are Cochrane systematic reviews being used in national clinical practice guidelines for chronic kidney disease?'

The James Lind Alliance Conference, London, UK, 20th November 2008

The James Lind Alliance, which was founded in 2004, argues that addressing uncertainties about the effects of treatments should become a routine element of clinical practice, and that patients (and their representatives) should be involved in the selection, design and implementation of clinical research. The meeting was organised jointly by the James Lind Alliance, the Social Science Research Unit, Institute of Education, University of London and the Royal College of Nursing Research Institute, School of Health and Social Sciences, University of Warwick. It was held at the Institute of Education, University of London.

The Conference was centred around the theme: 'Outcomes in clinical research – whose responsibility?' and brought together some 150 academics, clinicians, policy makers, government officials, executives from patient organisations and patients themselves. The main aims were to: promote debate about the role of patients, clinicians, and researchers in determining the important outcomes to be measured in clinical research; provide examples of patient-reported outcomes and patient-important outcomes; explore how best to improve the influence of patients and the public in clinical research outcomes; and increase networking among patient groups, charities, clinicians, researchers, and other health research stakeholders.

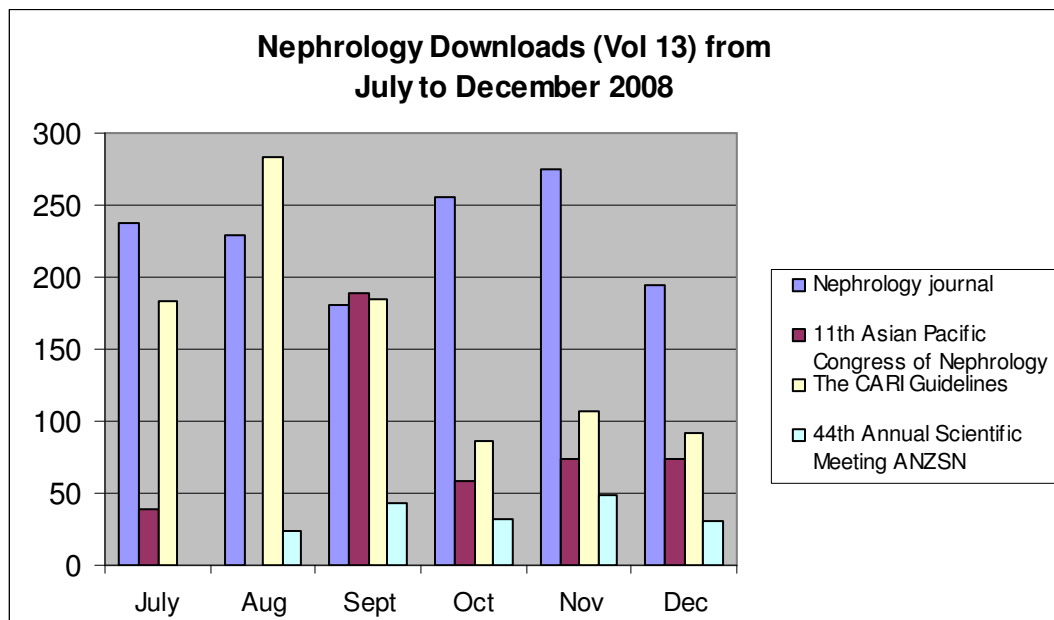
Meetings cont.

Leading experts such as Sir Iain Chalmers (Coordinator, Database of Uncertainties about the Effects of Treatment) and Professor Sandy Oliver (Professor of Public Policy, Deputy Director, Social Science Research Unit, Institute of Education, University of London) chaired and spoke at the meeting.

Dr Allison Tong attended this event and presented a poster titled: 'Patient priorities for health research: focus group study of patients with chronic kidney disease'. Results from this study indicated that patients nominate research themes not topics, and health outcomes not interventions, as researchers do. They also nominated primary and secondary prevention of CKD as a research priority. Her conclusion is that it is possible to elicit a patient-focussed agenda for CKD.

Nephrology Online Website Statistics for CARI Guidelines

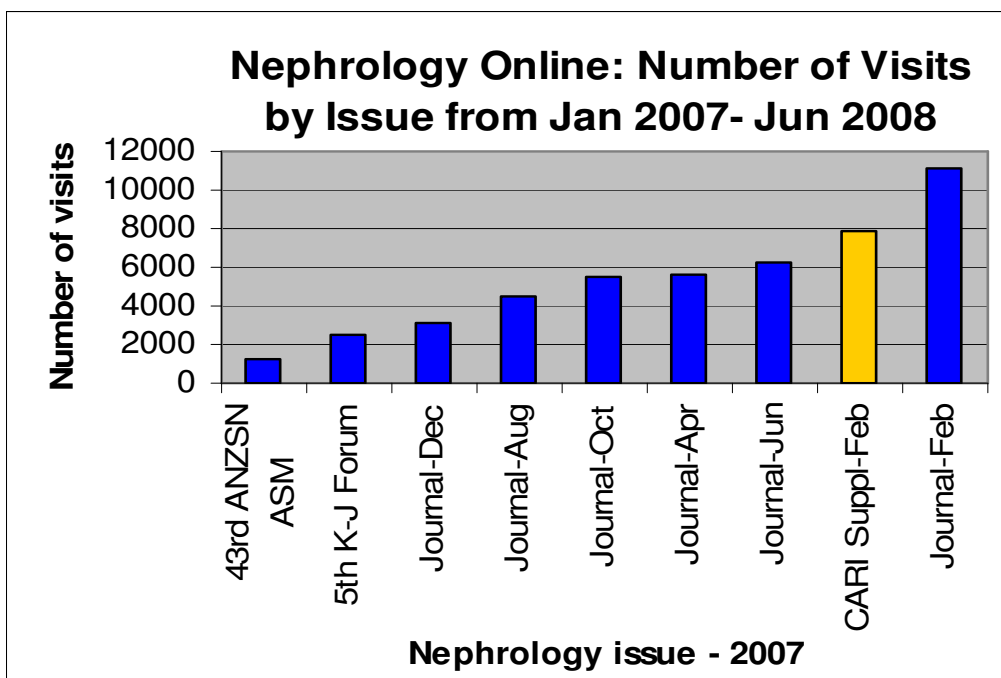
Comparison Download Accesses for a Nephrology Journal, 2 Nephrology Supplements and a CARI Supplement for July-Dec 2008*



The CARI supplement was published in August 2008 and was available online from mid-July 2008. It contained 2 subtopics on Vascular Access, 3 subtopics on Renal Vasculitis and 1 subtopic on Biochemical & Haematological Targets. Most downloads occurred in the month of print publication, the last 2 weeks of July (preceding print publication) and the month of September and were similar to the number of downloads for the *Nephrology* journal in those months. There were more downloads of the CARI supplement than the other 2 comparison supplements over the 6 months.

* Data for Jan-June 2008 is not available.

Nephrology Online Website Statistics cont.

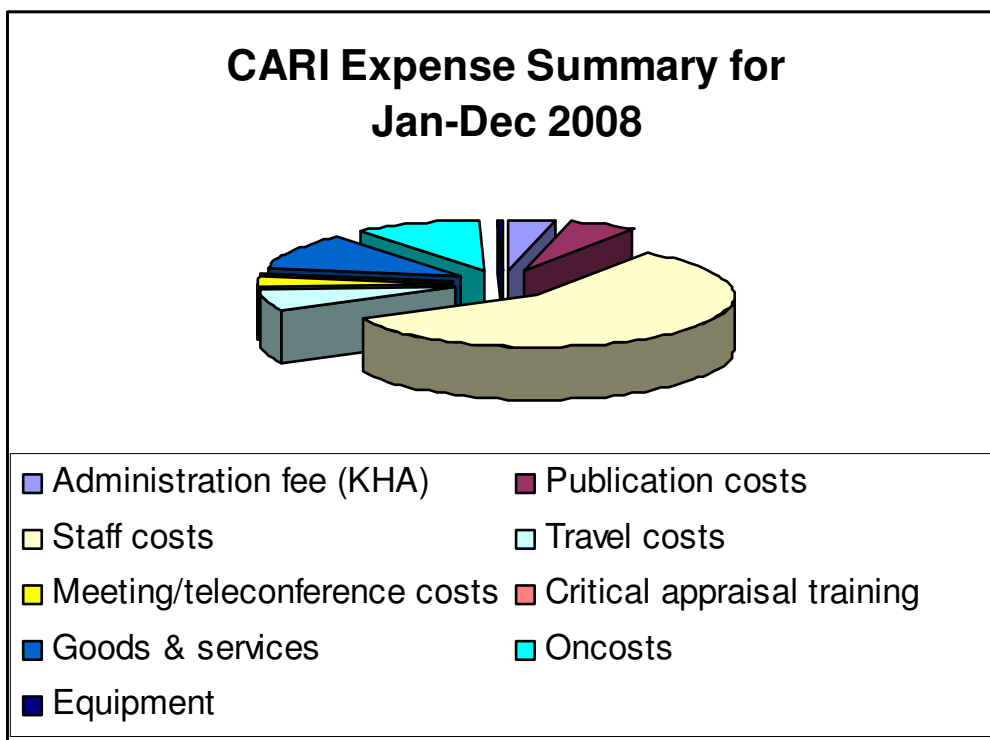


This figure shows that of the 6 Nephrology journal issues and the 3 supplements published by Blackwell-Wiley in 2007, the CARI supplement published in Feb 2007 received the second highest number of visits of all the publications, with 7922 visits over the 18 months from January 07 to June 08. This issue included guidelines on: Kidney Stones; Prevention of Progression of Kidney Disease: detection and management of patients with pre-end stage kidney disease; and Calcineurin Inhibitors in Renal Transplantation.

Finances 2008

The following is an extract of the Financial Statements received from the accountants at Kidney Health Australia.

Financial Activities: 1 Jan 2008 to 31 Dec 2008	A\$
INCOMING RESOURCES	
Income from industry sponsors	275,500
TOTAL INCOMING RESOURCES	275,500
RESOURCES EXPENDED	
Administration fee (KHA)	10,000
Publication costs (Aug 2008 suppl)	14,720
Staff costs	153,707
Travel costs	19,290
Meeting/ teleconference costs	6927
Critical Appraisal Training	1195
Goods & Services	29,426
Oncosts	27,668
Equipment	1313
TOTAL RESOURCES EXPENDED	264,246
Balance of funds	11,254
Total funds brought forward (2007)	5522
Total funds carried forward	16,776



CARI Steering Committee

- Martin Gallagher (Chair)
Concord Hospital & George Institute
Sydney, NSW
- Rowan Walker
Renal Unit
Royal Melbourne Hospital, VIC
- Tim Mathew
Kidney Health Australia
North Adelaide, SA
- Jonathan Craig
CARI Guidelines Office
Children's Hospital at Westmead,
NSW
- Fiona Brown
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Sir Charles Gairdner Hospital
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NSW
- Denise Campbell
CARI Guidelines Office
Children's Hospital at Westmead,
NSW