



CARI

Caring for Australasians with Renal Impairment

Annual Report 2009





Contents



Report from the Chair	3
About CARI.....	5
Activities	7
Meetings	15
Website Statistics	17
Finances & Funding	19
Contributors in 2009.....	20
CARI Steering Committee & Staff.....	22

www.cari.org.au

A project of the Dialysis, Nephrology & Transplantation Subcommittee of Kidney Health Australia
& the Australian and New Zealand Society of Nephrology.

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Report from the Chair



I took over as Chair of the CARI Steering Committee from Dr Martin Gallagher in August 2009 while he was overseas on sabbatical leave.

Various guideline groups worked on developing and updating guidelines in 2009, these being new guidelines in 'Transplantation Nutrition', 'Living Kidney Donor', 'Renovascular Disease', 'Type 2 Diabetes: Kidney Disease' and also updated the guideline for 'Acceptance onto Dialysis'. These guidelines are expected to be ready for publication by early 2010. The CARI guideline group worked with the Diabetes Unit, Menzies Centre of Health Policy (Sydney University) to produce a guideline titled 'The Diagnosis and Prevention of Chronic Kidney Disease in Type 2 Diabetes Mellitus'. We have produced a CARI version of this guideline, using the CARI template and processes. Dr Martin Howell, a Research Officer with CARI, was involved in coordinating the work of the guideline group, which had 16 members. The guideline is due to be published in April 2010.

In September 2009, it was decided to commence the adaptation of 2 Kidney Disease: Improving Global Outcomes (KDIGO) renal guidelines - the KDIGO Clinical Practice Guideline for the Care of Kidney Transplant Recipients and the KDIGO Clinical Practice Guideline for the Diagnosis, Evaluation, Prevention and Treatment of CKD and Mineral and Bone Disorders for use in Australia and New Zealand. We are following the ADAPTE process and streamlining it to fit with local conditions and resources.

Dr Michelle Irving, Senior Research Officer with CARI Guidelines, and a group of writers developed an article titled 'Nephrologists' Perspectives on the Effect of Guidelines on Clinical Practice: A Semistructured Interview Study'. The article was published in the American Journal of Kidney Diseases in 2010. The conclusions of this study show that evidence-based guidelines appear to impact strongly on the clinical decision-making of Australian nephrologists, but are only one input. Improvements in the evidence that underpins guidelines and improvements in the content and formatting of guidelines are likely to make them more influential on decision-making. Trust in the guideline group's processes is a prerequisite for implementation. Dr Irving and others also did a survey of Australian and New Zealand renal nurses. This survey found that the nurses value the CARI Guidelines highly, use them in practice and consider that they lead to improved patient outcomes. Positive responses towards the guidelines increased between 2002 and 2006. This study was finalised and submitted for publication in 2009.

A Vascular Access implementation group was formed in the latter part of 2006. Ms Pamela Lopez-Vargas, a research nurse and CARI Research Officer, has managed this project from February 2007. The group commenced a before and after study of nine units, looking at barriers to arteriovenous fistula use at first dialysis in haemodialysis patients. Two CARI guidelines were actively implemented because both are key steps in the adequate preparation of an individual for chronic haemodialysis. A draft manuscript outlining the baseline results has been commenced. It is expected that this paper will be published in 2010.

CARI staff and guideline group members presented at various conferences during 2009. Presentations at the ANZSN Annual Scientific Meeting were made by Dr Kevan Polkinghorne and Dr Allison Tong. Dr Polkinghorne presented a poster titled 'Arteriovenous Fistula Creation (AVF) – perceived and actual barriers in Australian and New Zealand units'. This identified various barriers to early AVF creation and outlined some strategies to increase use of AVF at first haemodialysis. Dr Tong had an abstract titled 'Patients' experiences and perspectives of living with chronic kidney disease'.





Various abstracts were presented at Guidelines International Network (G-I-N) Conference 2009. Titles included 'Incorporating a systematic review of qualitative studies into clinical practice guidelines on kidney transplantation' by Allison Tong, 'The effect of guidelines on clinical decision-making in Nephrology practice: a qualitative study' by Michelle Irving, and 'Identification of barriers and implementation of strategies to improve timing and creation of appropriate access for new haemodialysis patients' by Pamela Lopez-Vargas.

There have been some changes to the membership of the CARI Steering Committee in 2009, with Dr Fiona Brown and Ms Melissa Darnley (consumer member) standing down. I would like to thank them both for their input. New members of the Steering Committee include Dr Nick Cross (NZ) and Dr Neil Boudville (WA).

I would like to thank the CARI staff, Steering Committee members and the various guideline group convenors and writers, peer reviewers, and consumer members who volunteer their time in revising or developing guidelines *de novo* and contribute to making the CARI guidelines an accepted, trusted and respected organisation.

I wish CARI the best for 2010 and look forward to seeing the results of its various projects.

A/Prof. Rowan Walker

Acting Chair

CARI Guidelines Steering Committee





About CARI



Background

The Caring for Australasians with Renal Impairment (CARI) Guidelines is an evidence-based project that commenced in 1999 with funding from the pharmaceutical industry. The idea came from a Dialysis, Nephrology and Transplant (DNT) subcommittee meeting towards the end of 1998. Work began in early 1999. The first set of Clinical Practice Guidelines was published in March 2000.

The two bodies that assume responsibility for the CARI Guidelines are the Council of the Australian and New Zealand Society of Nephrology (ANZSN) and the Board of Kidney Health Australia (KHA).

The aim of the CARI Guidelines is to improve the health care and outcomes of paediatric and adult patients with kidney disease by helping clinicians and health care workers to understand and adhere to evidence-based medical practice and to encourage the implementation of the guidelines in practice as often as possible. It is anticipated that the guidelines will serve as both a valuable educational resource and a means of enhancing the quality, appropriateness, consistency, and cost-effectiveness of renal health care. The guidelines are recognised as methodologically rigorous and have a high degree of credibility internationally.

The dedication and enthusiasm of the people driving the CARI program has been a critical element of this success. The guidelines were initially developed for use in Australia, however, they are now being used in New Zealand as well. One of the great strengths of the project is the widespread involvement of Australian and New Zealand nephrologists. This has meant that the guidelines are well known and accepted among nephrologists in Australia and New Zealand.

During the time the CARI project has been in existence, guidelines have become much more widely accepted and embedded in clinical practice. Nephrologists in other countries have also been producing renal guidelines and the desirability of co-ordinating the effort and reducing duplication has been recognised. There has also been an increasing recognition that guideline development of itself is insufficient; the effort involved in development is useful only to the extent that guideline recommendations are adopted in practice. CARI Guidelines has been a leader in the area of renal guideline implementation, with two implementation projects currently underway.

The CARI office is based at the Children's Hospital at Westmead and the project has enjoyed strong and continued support by unrestricted development grants from Amgen Australia, Janssen-Cilag Pty Ltd, Genzyme Corporation, Roche Products Pty Ltd, Shire Australia Pty Ltd, and Novartis Pharmaceuticals Australia Pty Ltd.

CARI Guidelines was reviewed by a DNT-appointed panel in 2009 and recommendations were made to the effect that for the CARI project to ensure ongoing relevance, its guidelines must be perceived as having an impact on the care people with chronic kidney disease receive and the outcomes they experience. With these recommendations in mind, CARI intends improving governance, identifying clear strategic directions, improving business processes with a business plan with clear sets of deliverables, and linking with other relevant groups.





Role of the CARI Office

- To support guideline writers through the guideline development and revision processes
- To organise peer and consumer review of new and revised guidelines
- To identify relevant trials in the literature for each Guideline Group
- To obtain full text copies of papers as requested by guideline writers
- To edit completed sets of guidelines and arrange for their publication as a Supplement to the journal *Nephrology*
- To maintain the CARI guidelines website
- To actively disseminate the guidelines

The CARI Guidelines

The guidelines are divided into 3 areas. Each guideline comprises various subtopics and their Recommendations and Suggestions for Clinical Care.

A complete listing of guidelines and subtopics and their current status can be found under [Guidelines](#) on the CARI website – www.cari.org.au

About 100 guideline writers have been involved in researching and writing guidelines so far. Guideline writers are invited to attend a one-day Methods Workshop run by the CARI Office to help equip them for the task of scanning the literature and writing their Clinical Practice Guidelines. This training teaches participants how to critically review and summarise the relevant literature on their topic, how to grade the quality of studies and integrate them into their guidelines, and in general, improves their critical appraisal skills. The CARI Office assists writers by conducting systematic literature searches, locating relevant trials and preparing summary Evidence Tables for each guideline subtopic.

Summary of CARI Guidelines published

Chronic Kidney Disease	92
Transplantation	15
Dialysis	37

Summary of CARI Guidelines in development

Chronic Kidney Disease	14
Transplantation	24
Dialysis	7

Guideline Development Process

The CARI Guidelines are strictly evidence-based – that is, they are drawn from the published literature, which is carefully assessed for its level of certainty. Only when the conclusions in a particular area are based on a high degree of certainty is the guideline ratified. Recommendations are based on Level I or II evidence according to the NHMRC evidence classification system.

In July 2009, it was decided by the CARI Steering Committee that the evidence base compiled for specific topics addressed by the individual guidelines should be evaluated and graded using the approach developed by the GRADE Working Group (www.gradeworkinggroup.org). By using this system, the CARI guidelines will follow a systematic approach to assessing the overall quality of the evidence that is consistent with international practice.

The CARI Office assists writers by conducting systematic literature searches, locating relevant trials and preparing summary Evidence Tables for each guideline subtopic.

Development of a guideline by the working group occurs in five stages:

- Scoping and tasking - identification of subtopics and writing allocation
- Literature searching and writing of draft by the guideline writer/s
- External peer review, consumer review and nephrology community comment
- Steering Committee approval/request for changes to revised draft
- Editing and publication of guideline in the journal *Nephrology* and uploading to the CARI and *Nephrology* websites





Activities



Guidelines being developed for publication

In 2009, various guideline groups worked on new guidelines in 'Transplantation Nutrition', 'Living Kidney Donor', 'Renovascular Disease', 'Type 2 Diabetes: Kidney Disease' and revised the 'Acceptance onto Dialysis' guideline for publication in early 2010. A total of 29 new subtopics were covered which included 14 guideline recommendations.

Transplantation Nutrition

The Transplant Nutrition guideline has been written by a group outside CARI, mostly based at the John Hunter Hospital, NSW. The draft documents have been put through the usual CARI peer review process and will be published in 2010. The group members include Prof. Steve Chadban, Ms Maria Chan, Ms Karen Fry, Ms Aditi Patwardhan, Ms Catherine Ryan, Dr Paul Trevillian and Dr Fidy Westgarth. The group commenced working with CARI on this guideline in June 2009. In all, 9 subtopics have been written. They will be published in a Nephrology supplement in early 2010.

Living Kidney Donor

The Convenor of the Living Kidney Donor group is Dr John Kanellis, with the group members including Emma Van Hardeveld, Dr Allison Tong, Dr David Nicol, Dr Norma Gibbons, Dr Stephen Munn, Dr Fiona Mackie, Dr Neil Boudville, Dr Frank Ierino, Dr Nikky Isbel, Dr Shlomo Cohny and Dr Martin Howell. The group commenced work on this guideline in May 2006. In all, 12 subtopics have been written. They will be published in a Nephrology supplement in early 2010.

Type 2 Diabetes: Kidney Disease

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 Prof. Steve Chadban and Prof. Jonathan Craig. Following the publication of this guideline by Diabetes Australia, a CARI version will be produced and published in a Nephrology supplement in early 2010:

Renovascular Disease

The Convenor of the Renovascular Disease group is Assoc Prof. 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 2009. Drafts of the Renovascular Disease guideline were presented for discussion at the March 2009 DNT meeting that was held in Lorne, Victoria. They will be published in a Nephrology supplement in early 2010.

Acceptance onto Dialysis

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, Ms Melissa Stanley, Dr Deirdre Fetherstonhaugh, Assoc Prof. Eugenie Pedagogos, Prof David Harris and Dr Krishan Madhan. The group first met in mid-June 2007. The updated guideline will be published in a Nephrology supplement in early 2010. Four subtopics belonging to this guideline were previously published in October 2005.

Vascular Access

Updating of the 'Vascular Access' guideline is currently underway. The Convenor of this group is Dr Kevan





Polkinghorne, with group members including Ms Pamela Lopez-Vargas, Dr Christine Russell, Dr Girish Talaulikar, Ms Jayne Amy and Dr George Chin. First drafts will be ready for review in May 2010.

Dialysis Adequacy [Haemodialysis]

The revision of the 'Dialysis Adequacy [Haemodialysis]' guideline subtopic 'Dialysis Membrane' started in 2009. The group convenor and author is Dr Peter Kerr. Only this subtopic is being updated.

Cardiovascular Risk Factors

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, Assoc Prof Helen Pilmore, Prof Rob Walker and Dr Toshiharu Ninomiya. The group commenced work on this guideline in mid-August 2007. A total of 6 subtopics are currently being written. Two subtopics have been written, sent for peer review and public consultation. Three subtopics are still being written and will be ready for peer review and public consultation in May 2010.

CMV Disease and Kidney Transplantation

The 'CMV Disease and Kidney Transplantation' guideline group commenced their updates in 2009. The Convenor for this group is Assoc Prof Helen Pilmore, with group members being Prof Bruce Pussell and Dr David Goodman.

The group met in early 2009. Documents for two subtopics have been written, sent for peer review and public consultation. It is expected that the updated guideline will be ready for publication by the end of 2010.

Peritonitis Treatment and Prophylaxis

The 'Evidence for Peritonitis Treatment and Prophylaxis' guideline group commenced their updates in late 2009. The Convenor for this group is Dr Amanda Walker, with group members being Assoc Prof Kym Bannister, Prof Maureen Lonergan, Assoc Prof. Josephine Chow, Assoc Prof Charles George, Dr Maha Yehia and Assoc Prof David Mudge.

New guidelines in development

CARI has two new guidelines in development on the topics of 'Recipient Assessment for Transplantation' and 'Early Chronic Kidney Disease.'

Recipient Assessment for Transplantation

The convenor of this guideline group is Dr Scott Campbell, with the group members including Assoc Prof Helen Pilmore, Assoc Prof Steven McTaggart, Dr Bill Mulley, Dr Christine Russell, Robbie Henry and Dr David Gracey.

Early Chronic Kidney Disease

The convenor of this group is Prof. David Johnson with guideline group members including Ms Maria Chan, Dr Richard Phoon, Dr Nigel Toussaint, Mr Graeme Turner, Ms Emellia Atai, Dr Kate Wiggins, Prof. Tim Usherwood and Ms Clodagh Scott.

Guideline Adaptation

Adaptation of the Kidney Disease: Improving Global Outcomes (KDIGO) Guidelines

In September 2009, it was decided to commence the adaptation of two KDIGO guidelines for use in Australia and New Zealand. We are following the ADAPTE process and streamlining it to fit with local conditions and resources. When the first guideline adaptation is completed, we will write a publication describing our experience with the process.

1. Adaptation of KDIGO CPG for the Care of Kidney Transplant Recipients

The convenor of the group is Prof. Steve Chadban, with the primary reviewers including Dr Shlomo Chohney, Assoc Prof Josette Eris, Prof Graeme Russ, Dr Scott Campbell, Assoc Prof John Kanellis, Prof Phil O'Connell, Dr Nick Cross, Dr Toby Coates, Assoc Prof Helen Pilmore, Assoc Prof Nicole Isbel, Dr Angel Webster, Dr Kate Wyburn and Assoc Prof. Rowan Walker.





2. Adaptation of KDIGO CPG for the Diagnosis, Prevention and Treatment of CKD-related Mineral and Bone Disorders

The convenor of the group is Assoc Prof Grahame Elder, with the primary reviewers including Assoc Prof Carmel Hawley, Dr Nigel Toussaint, Assoc Prof. Eugenie Pedagogos and Prof Randall Faulk.

Critical Appraisal Training Workshop

The Training Workshop was held on 28 August 2009 at the Qantas Meeting Rooms at Sydney Airport. The teaching sessions were presented by Prof. Jonathan Craig, Dr Meg Jardine and Dr Angela Webster. The attendees were from two of the guideline groups whose members are currently working on guidelines – 'Recipient Assessment for Transplantation' and 'Early Chronic Kidney Disease'. The Training Workshop was run over 1 day and taught basic critical appraisal skills, outlined the process involved in writing a CARI guideline, and explained the role and responsibilities of a CARI guideline writer.

Implementation Projects

The overall purpose of clinical guidelines is to improve health outcomes and to encourage the appropriate use of resources. Guidelines are static entities if not put into practice. It takes a motivated team to change practice and incorporate the recommendations of a guideline into daily patient care. An essential part of the guideline development process is the formulation of a dissemination and implementation strategy.

CARI Guidelines staff have been and are continuing to research the best methods for ensuring the use of guidelines in clinical practice. Implementation projects are undertaken to assess both the impact of CARI Guidelines on clinical practice as well as the barriers faced by renal units in the implementation of CARI Guidelines. As Implementation projects progress, CARI will revise the guideline development process and develop tools to assist in guideline implementation.

Criteria used to identify which recommendations should be actively implemented include:

- The presence of a strong evidence base supporting the recommendation
- Clinical importance
- Existence of a clear evidence/practice gap
- Patient burden of disease is high
- Ability to measure a change in practice
- Feasibility of development of an implementation strategy.

Implementation projects are conducted according to three steps, namely:

- Phase I. Establish current practices and protocols
- Phase II. Conduct implementation trial
- Report findings.

To date, CARI has completed implementation projects in relation to achievement of optimum iron levels, timely placement of vascular access in dialysis patients and identifying barriers to organ donation.

Results of a national survey of Nephrologists

Irving M, McDonald S, Walker R, Frommer F, Craig J. Opinions on the content and effects of clinical practice guidelines for CKD: a survey of nephrologists in Australia and New Zealand. *American Journal of Kidney Diseases*. 2009; 53 (6):1082-90.

Evidence-based clinical practice guidelines have been a major development in nephrology internationally, but it is uncertain how the nephrology community regards these guidelines. This study aimed to determine the views of nephrologists on the content and effects of their local guidelines (Caring for Australasians with Renal Impairment [CARI]). In 2006, a self-administered survey was distributed to all Australian and New Zealand nephrologists. Seven questions were repeated from a similar survey conducted in 2002. A total of 211 nephrologists (70% of practicing nephrologists) responded. More than 90% agreed that the CARI guidelines were a useful summary of evidence, and nearly 60% reported that the guidelines had significantly influenced their practice.

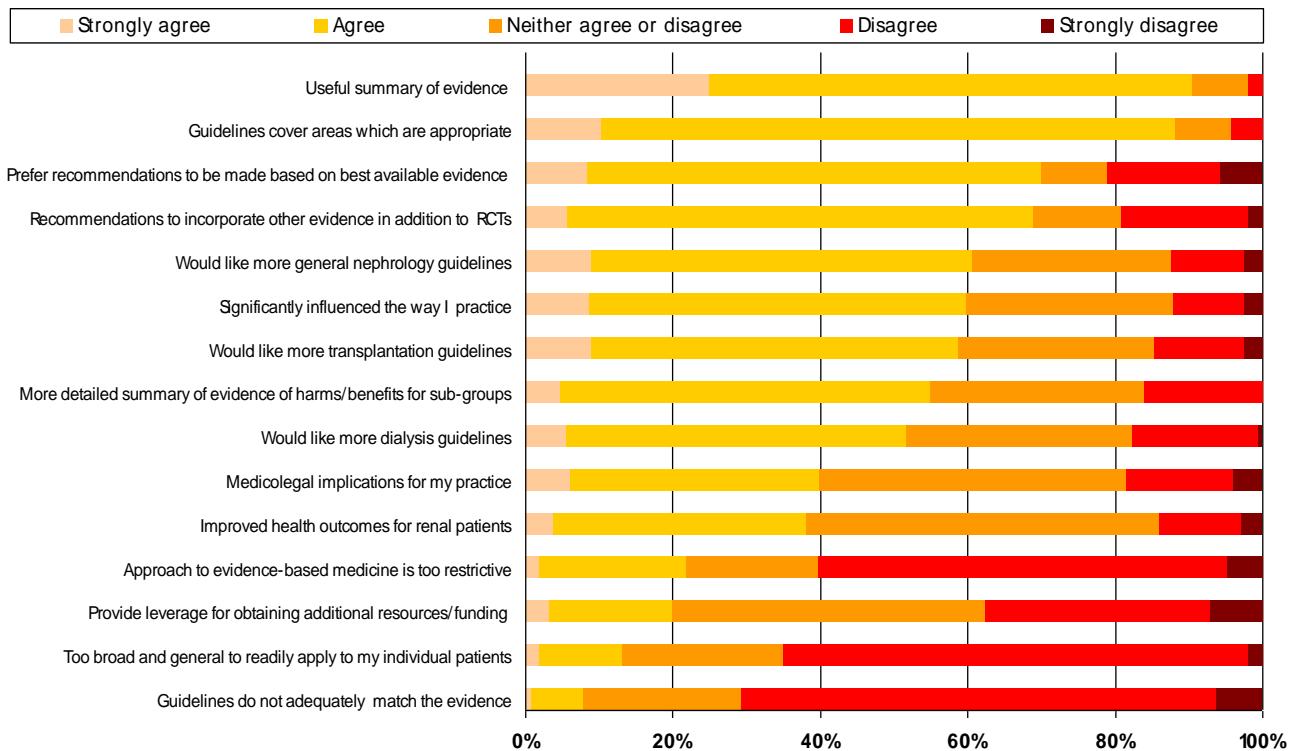




The proportion of nephrologists reporting that the guidelines had improved patient outcomes increased from 14% in 2002 to 38% in 2006. The proportion of nephrologists indicating that the guidelines did not match the best available evidence decreased from 30% in 2002 to 8% in 2006. Older age and male sex showed some associations with a less favourable response for some domains.

The CARI approach of developing rigorous evidence-based guidelines has been shown to be a successful

model of guideline production. Almost all nephrologists regarded the CARI guidelines as useful evidence summaries, although only one-third believed that the guidelines affected health outcomes. Attitudes to the guidelines have become more favourable over time; this may reflect changes in the CARI process or attitudinal changes to evidence among nephrologists. Evaluation by the end user is fundamental to ensuring the applicability of guidelines in clinical practice in the future.



Interviews with Australian Nephrologists

M.J Irving, A Tong, L Rychetnik, R.G Walker, M.S Frommer, J.C Craig. Nephrologists' perspectives on the effect of guidelines on clinical practice: a semistructured interview study. *American Journal of Kidney Diseases*. 2010; 55: 241-49.

Background

A consistent gap exists between evidence-based guideline recommendations and clinical practice across all medical disciplines, including nephrology. This study aims to explore nephrologists' perspectives on

guidelines and elicit their perspectives on the effects of guidelines on clinical decisions.

Conclusions

Evidence-based guidelines appear to impact strongly on clinical decision making of Australian nephrologists, but are only one input. Improvements in the evidence that underpins guidelines and improvements in the content and formatting of guidelines are likely to make them more influential on decision making. Trust in the guideline group's processes is a prerequisite for implementation.





Survey of Australian and New Zealand Renal Nurses

MJ Irving, DW Johnson, S McDonald, RG Walker, MS Frommer, D Fetherstonhaugh, P Deans, JC Craig. Opinions on the content and effects of the CARI Guidelines: a survey of renal nurses and comparison with the opinions of nephrologists in Australasia. *Nephrology* 2010; 15(1): 48-53.

Aim

Renal nurses in Australia and New Zealand are critical to the care of patients with chronic kidney disease (CKD), especially those on dialysis. We aimed to obtain the opinions of renal nurses in Australia and New Zealand on the Caring for Australasians with Renal Impairment (CARI) Guidelines.

Conclusions

Australian and New Zealand renal nurses valued the CARI Guidelines highly, used them in practice and considered that they led to improved patient outcomes. Positive responses towards the guidelines increased between 2002 and 2006.

2nd Stage Iron project

Implementation of the clinical practice guideline for iron management in Australian renal centres. We have undertaken an active implementation project for the CARI Iron guidelines. Six renal units are being monitored for their iron management and ferritin, haemoglobin, TSAT and epoetin use. A process review interview has been completed with each intervention unit. The manuscript has been completed and submitted for publication.

Vascular access guideline project

The Vascular Access Implementation Project is a study directed at implementing the CARI guidelines on 'Timing of vascular access formation' and 'Selection of appropriate vascular access'. These guidelines were chosen because patients starting haemodialysis should do so with a permanent dialysis access in situ (ideally a functioning arteriovenous fistula) and data shows that many patients in Australia and New Zealand do not have

a functioning AVF when they commence haemodialysis. Both of these guidelines are key steps in the adequate preparation of an individual for chronic haemodialysis. The project commenced in 2007, with the baseline phase lasting six months and the implementation phase lasting one year. The baseline manuscript has been drafted and has been sent out for review by the participating units. Work has just begun on the implementation paper.

Dissemination strategies for the CARI guidelines

Emphasis on the dissemination and promotion of the CARI guidelines will be an upcoming focus. Proposed strategies include:

E-mail updates through ANZSN:

Communications to all members of the ANZSN will be an integral part of the dissemination process. E-mails will be in a format of major summaries of focus guidelines with links for further information if required.

Targeting renal nursing staff

Renal nurses remain an untapped resource for guideline dissemination. Many nephrologists who were interviewed noted that nursing staff played a large role in monitoring patients for guideline targets and they would inform the nephrologist of major changes.

Nurses quite often do not have access to the internet and the CARI guidelines website. Many, when asked about the guidelines, would retrieve the 2000 - hard copy - guidelines folder. A hard copy of the latest guidelines or a CD-ROM of guidelines should be disseminated to renal units in Australia and New Zealand. Communications similar to the ANZSN e-mails should be published in the Renal Society of Australasia's newsletters on a regular basis. This will raise the profile of the guidelines with renal nurses as well as providing a valuable source of information.

Guideline summaries

Summaries of the guidelines will be written and disseminated in a format that is suitable for consumers,





nurses, Nephrologists and possibly, general practitioners. These will be posted on the CARI website and promoted to Nephrologists and renal nurses.

Consumer Research Projects

CARI consider that active patient involvement in the development of clinical practice guidelines is key to ensuring that important patient needs and outcomes are adequately addressed. However, most consumer involvement to date has been limited, with minimal opportunity for patients to influence the content of guidelines. To improve this, CARI commenced a pilot project of active consumer involvement whereby groups of patients, through a series of structured workshops, were asked to identify key issues and outcomes that are important to them. The outcomes of the workshops were provided to the guideline work group prior to the finalisation of subtopics. A final patient workshop was run to review the draft guidelines prepared by the writers to ensure that they had captured patient requirements. In this way, the patients were given an active role in both the scoping and reviewing of the guidelines.

In 2009, CARI commenced a new initiative of involving consumers in the development of clinical practice guidelines. Two consumer advisory panels (patient and carers) were convened to provide input into the development of guidelines on early stage chronic kidney disease. For each panel, up to 20 participants were invited to attend 3 structured peer-facilitated workshops.

By the end of 2009, the first two workshops had been completed. Consumers provided their perspectives on what topics and outcomes should be included in the guidelines. This was fed back to the guideline group during their face to face meeting. "Consumer-versions" of each guideline will be sent to all consumers who participated in the workshop for their feedback.

A third workshop is scheduled for April 2010. The project received funding from the Priscilla Kincaid-Smith Foundation.

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* 2009; 32: 3206-3214.

Irving M, McDonald S, Walker R, Frommer F, Craig J. Opinions on the content and effects of clinical practice guidelines for CKD: a survey of nephrologists in Australia and New Zealand. *American Journal of Kidney Diseases*. 2009; 53 (6):1082-90.

M.J Irving, A Tong, L Rychetnik, R.G Walker, M.S Frommer, J.C Craig. Nephrologists' perspectives on the effect of guidelines on clinical practice: a semistructured interview study. *American Journal of Kidney Diseases*. 2010; 55: 241-49.

Our Research Activities

CARI undertakes research activities that focus on key areas relevant to implementation strategies and the guideline development process. The following is a summary of recent research activities:

- Survey of ANZSN nephrologists and renal nurses to get feedback on CARI Guidelines/ usefulness (accepted for presentation at the Guidelines International Network meeting)
- Systematic review of implementation strategies used in chronic kidney disease
- Qualitative research into parent, patient & health care provider experience of chronic kidney disease and prioritisation of research topics
- Assessment of whether Cochrane systematic reviews are being used in national clinical practice guidelines for chronic kidney disease
- An evaluation of 5 guideline programs with a new Framework for Assessing Consumer Involvement in Guidelines (FACING) (accepted for presentation at the Guidelines International Network meeting)
- Patient priorities for research topics in chronic kidney disease (published in *Nephrology Dialysis Transplantation*)
- Patients' experiences and perspectives of living with CKD (accepted for presentation at ANZSN meeting)





- Incorporating a systematic review of qualitative studies into CPGs on kidney transplantation
- Research into best methods for implementation of guidelines into clinical practice
- Identification of barriers to improving timely creation of AV fistula for patients starting haemodialysis (accepted for presentation at the Guidelines International Network meeting)
- New project: Patient important outcomes in nephrology evaluation and research

Buchan was previously the CEO of the National Institute of Clinical Studies and is an experienced public health administrator and knowledgeable about the factors involved in improving clinical practice. Assoc Prof. John Collins is an experienced nephrologist who works in the Renal Unit at Auckland Hospital, New Zealand. Prof. Sally Redman is CEO of the Sax Institute (part of NSW Health) and is an experienced public health researcher with an interest in evaluating programs designed to improve health and health care.

Searches conducted and articles obtained for guideline writers in 2009

Guideline Group	No. of searches	No. of articles requested/sent
Acceptance onto Dialysis	9	241
Living Kidney Donors	4	34
Renovascular Disease	6	229
Type 2 Diabetes: Kidney Disease	12	410
CMV Disease and Kidney Transplantation	2	36
Vascular Access	5	106
Cardiovascular Risk Factors	1	33
Dialysis Adequacy	2	28

Listed below are the terms of reference of the review along with a brief statement of findings (taken from the Executive Summary):

1. Establish the standing of the body of work of the CARI Guidelines within the world literature of renal guidelines.

Finding

The CARI guidelines and guideline group are well respected nationally and internationally.

2. Comment upon the relative value for money of this body of work (including the contribution of the volunteer workforce of guidelines developers) in an international renal guidelines context.

Finding

In the time it has been operating, given the available resources, CARI has completed a remarkable number of rigorously developed new guidelines and undertaken an associated program of research into aspects of guideline development and acceptance.

3. Comment upon the feasibility of the existing CARI Guidelines work being performed by other bodies (either local or international) to a similar or higher standard using historical funding levels.

Finding

It is very unlikely that any other guideline group, local or international, could undertake the program of existing CARI guidelines work within the current funding levels.

4. Suggest future areas for investment by CARI Guidelines to ensure ongoing relevance.

Independent review of CARI Guidelines

An independent review of the CARI Guidelines program was commissioned by the Dialysis, Nephrology and Transplant Committee on behalf of its parent bodies, the Australian and New Zealand Society of Nephrology (ANZSN) and Kidney Health Australia (KHA). The review team consisted of Dr Heather Buchan (Chair), Assoc Prof. John Collins and Prof. Sally Redman. Dr





Finding

For the CARI program to ensure ongoing relevance its guidelines must be perceived as having an impact on the care people with kidney disease receive and the outcomes they experience. The Review Panel have recommendations about improving governance, identifying clear strategic directions, improving business processes with a business plan with clear sets of deliverables, and linking with other groups, including those for identifying and gathering performance indicators.

5. In light of above recommendations, to comment upon appropriate funding levels and strategies by which secure and long-term funding might be derived.

Finding

The CARI guideline program needs to move to a more assured funding position and needs to be perceived to be independent of pharmaceutical company sponsorship. There should be a clear funding agreement between CARI and its governing body that specifies the amount of funding for the CARI program and identifies what CARI will produce annually for this funding.

Other excerpts from the Review Panel's report include the following:

"The CARI guideline program has been extraordinarily successful to date. The fact that it has produced many high quality evidence-based guidelines despite a small and uncertain funding base is a remarkable achievement. The guidelines are recognised as methodologically rigorous and have a high degree of credibility internationally."

"The dedication and enthusiasm of the people driving the CARI program has been a critical element of this success. One of the other great strengths of the program is the widespread involvement of Australian and New Zealand nephrologists. This has meant that the guidelines are well known and accepted among nephrologists in Australia and New Zealand."

"There has also been an increasing recognition that guideline development of itself is insufficient – the effort involved in development is useful only to the extent that guideline recommendations are adopted in practice. The CARI program has also been a world leader in the area of renal guideline implementation, with two implementation projects complete and a third currently underway."

"The challenge for the future will be to retain the strengths of the current CARI program but to place it within a framework that will ensure long term sustainability and help increase the profile and uptake of the guidelines."



Meetings



DNT Workshop

The DNT Workshop was held in Lorne, VIC, from 1 to 4 March 2009. Part of the program for the meeting was an update on CARI activities and the presentation of new draft guidelines on Renovascular Disease, Acceptance onto Dialysis, and Diabetes Management in CKD patients. Denise Campbell, the Senior Project Officer for the CARI Guidelines and Martin Howell, Research Officer with CARI, attended the meeting. An update on CARI activities was given by Dr Martin Gallagher.

Comment by Allison

“Attendance at the Guideline International Network conference provided an opportunity to build the profile of CARI. The conference offered a variety of stimulating and useful workshops, plenaries and parallel sessions. Of note, patient involvement in guideline development and the development of patient-version guidelines are topical issues”.

6TH Guidelines International Network (G-I-N) Conference



The conference theme was 'Evidence Translation in Different Countries.' The conference was held in Lisbon, Portugal, from 1 to 4 November 2009. 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.

Michelle Irving gave an oral presentation on 2nd November in the plenary session called 'Use of guidelines'. She presented the abstract '**The effect of guidelines on clinical decision making in Nephrology practice: a qualitative study**'. MJ Irving, A Tong, L Rychetinik, RG Walker, M Frommer, JC Craig.

Comment by Michelle

“Attending the Guidelines International Network conference gave me the opportunity to present a local implementation project to an international audience. It was an opportunity to network with other researchers involved in implementation. As well as attend presentations on implementation projects being undertaken around the world and learn from these processes”.

Allison Tong submitted an abstract to the G-I-N Conference titled '**Incorporating a systematic review of qualitative studies into clinical practice guidelines on kidney transplantation**'.

Pamela Lopez-Vargas gave an oral presentation at the G-I-N Conference titled '**Identification of barriers and implementation of strategies to improve timing and creation of appropriate access for new haemodialysis patients**'. P Lopez-Vargas, M Gallagher, J Craig, R Walker, P Snelling, E Pedagogos, N Gray, M Divi, A Gillies, M Suranyi, H Thein, K Polkinghorne on behalf of the CARI Implementation Sub-Committee.

Comment by Pamela

“Attending the Guidelines International Network conference allowed me to promote the work we have done in guideline implementation. I was given the opportunity to give a talk on the Vascular Access



Implementation Project. This was a great opportunity to showcase our achievements, make contact with other guideline groups and learn from each other's experiences."

to Fellows and Trainees. The congress was attended by Dr Allison Tong and Dr Germaine Wong.

ANZSN ASM



The Australian and New Zealand Society of Nephrology's Annual Scientific Meeting was held from 7 to 9 September 2009 at the Hotel Grand Chancellor, Hobart, Tasmania.

Dr Kevan Polkinghorne presented a poster titled **'Arteriovenous Fistula Creation (AVF) – perceived and actual barriers in Australian and New Zealand units'**.

P Lopez-Vargas, M Gallagher, J Craig, R Walker, P Snelling, E Pedagogos, N Gray, M Divi, A Gillies, M Suranyi, H Thein, K Polkinghorne on behalf of the CARI Implementation Sub-committee.

Allison Tong presented an abstract titled **'Patients' experiences and perspectives of living with chronic kidney disease'**.

World Congress of Nephrology



The World Congress of Nephrology, jointly organized by ERA-EDTA and ISN, was held on 22 to 26 May 2009 in Milan, Italy. The program covered topics related to all major areas of basic, translational and clinical sciences relevant to nephrology, and also several fundamental aspects of biological sciences. There were several Special Lectures covering inter-disciplinary aspects of renal physiology and pathology relevant to various complications observed in kidney diseases.

Allison Tong submitted an abstract to WCN titled **'International Guidelines on Prevention, Detection and Management of Chronic Kidney Disease'**
A Tong, DJ Campbell, JC Craig.

RACP Congress



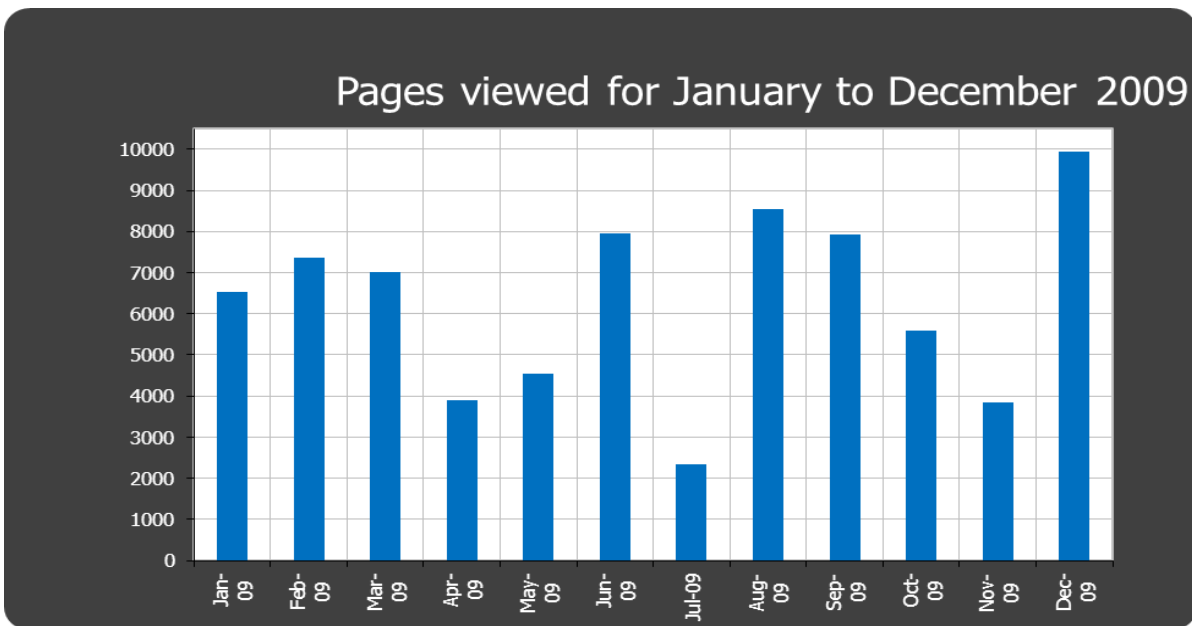
The Congress was held in Sydney, NSW, from 17 to 20 May 2009. Physicians Week incorporates the annual RACP Congress, which is the College's largest annual event. Physicians Week was adopted to reflect the diversity of the College and its multi-discipline meeting. The College's Divisions, Faculties and Chapters, in partnership with the Specialty Societies, provide professional development and networking opportunities



Web Statistics

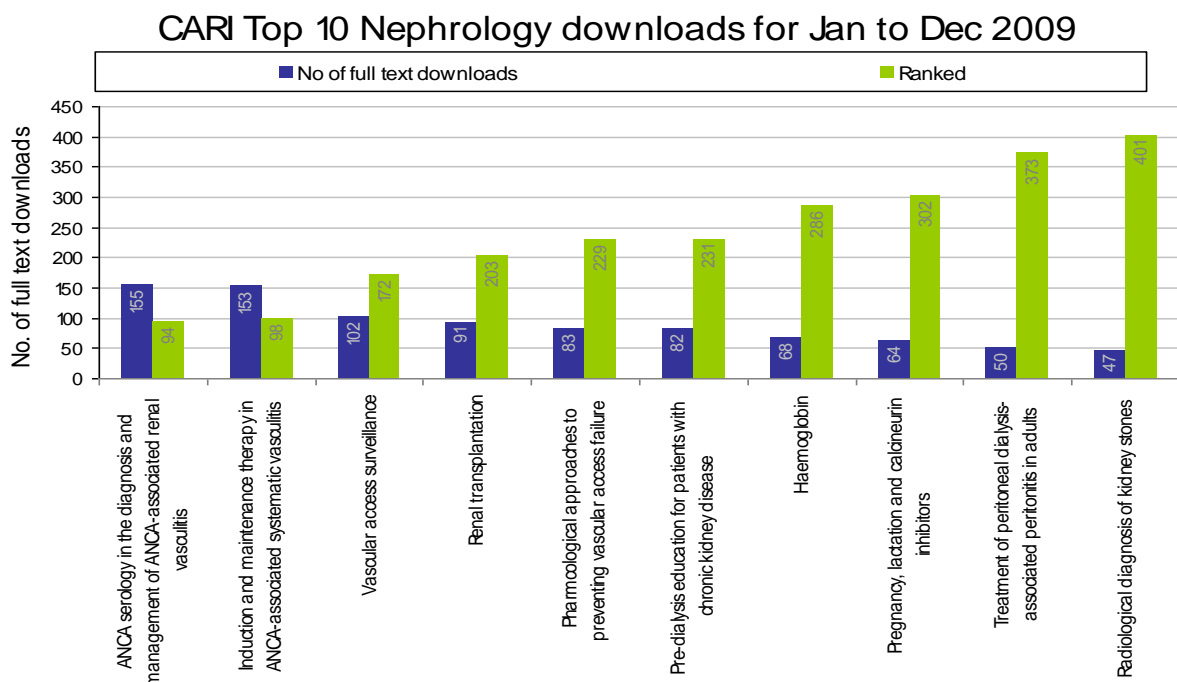
CARI Guidelines web statistics

The following figure shows the number of page views by month for the period January to December 2011. The highest number of page views were recorded for August and December. A page view represents how many pages were requested during site visits.



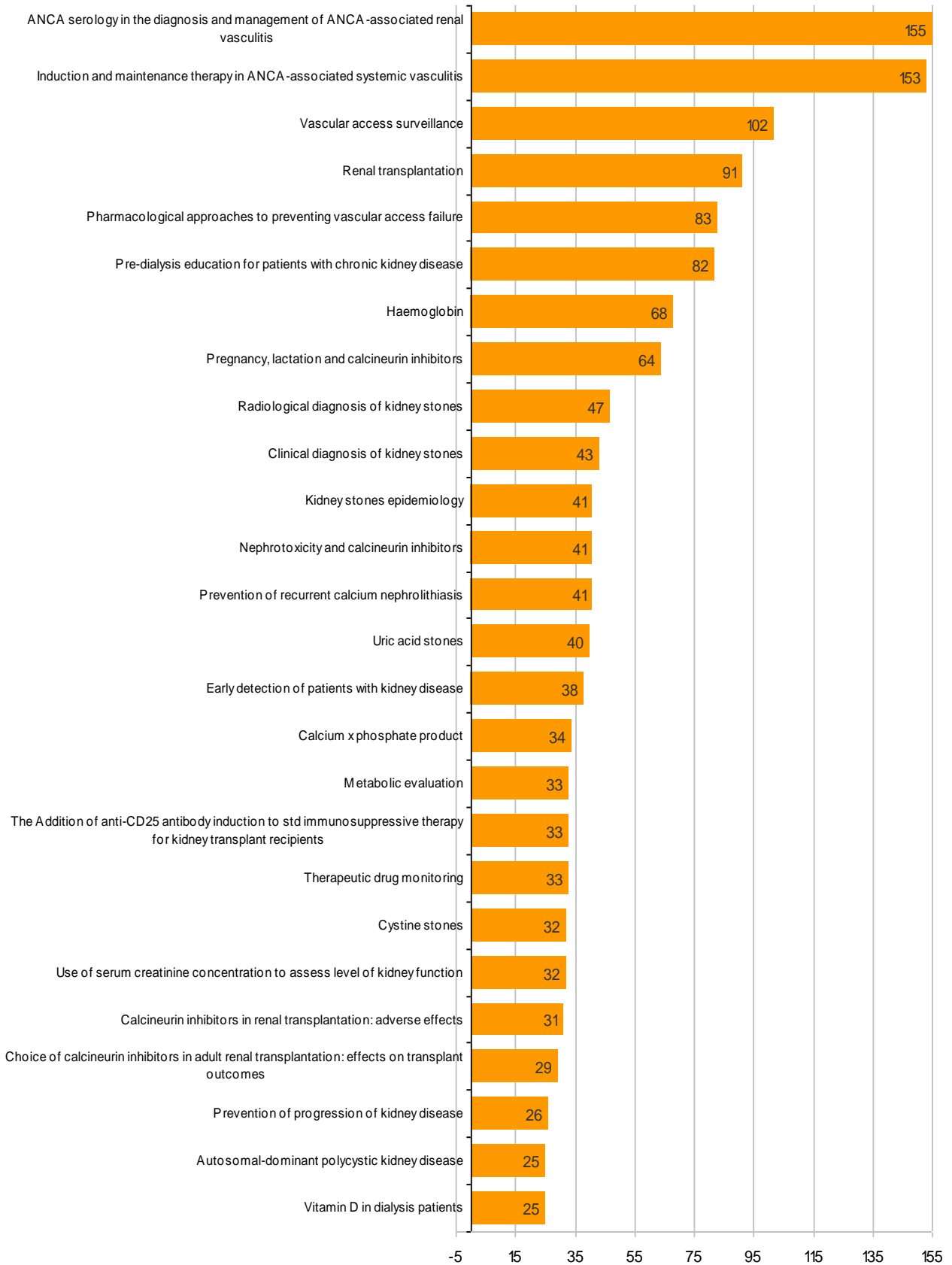
Nephrology web statistics

The following figure shows the top 10 guideline subtopics that were downloaded from the Nephrology website in 2009.





The following figure shows the top 20 articles accessed via the Nephrology website in 2009:



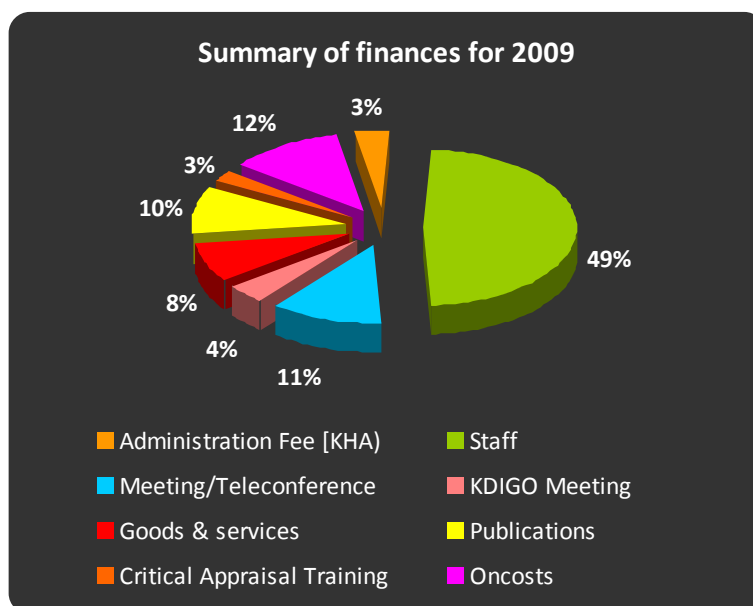
Finances & Funding



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

Financial Activities: 1 January 2009 to 31 December 2009

TOTAL INCOMING RESOURCES	A\$ 294,352.00
Income from industry sponsors	A\$ 294,352.00
TOTAL RESOURCES EXPENDED	A\$ 286,907.00
Administration fee (KHA)	A\$ 10,000.00
Staff costs	A\$ 139,406.00
Oncosts	A\$ 34,155.00
KD:IGO Meetings	A\$ 12,000.00
Critical Appraisal Training Workshop	A\$ 7,240.00
Goods & Services	A\$ 23,469.00
Meeting/ Teleconference costs	A\$ 32,710.00
Guideline Publication/ Dissemination	A\$ 27,927.00
BALANCE OF FUNDS	A\$ 7,445.00





Contributors in 2009



Contributors

Acceptance onto Dialysis

Grant Luxton, University of NSW, St George and Sutherland Hospital, Sydney, NSW
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Eugenie Pedagogos, University of Melbourne, Royal Melbourne Hospital, Melbourne, VIC
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Catherine Ryan, John Hunter Hospital, New Lambton, NSW
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Living Kidney Donor

John Kanellis, Monash University, Monash Medical Centre, Clayton VIC
Emma van Hardeveld, Royal Melbourne Hospital, Parkville, VIC
David Nicol, Princess Alexandra Hospital, Woolloongabba, QLD

Norma Gibbons, Princess Alexandra Hospital, Woolloongabba, QLD
Stephen Munn, Auckland Hospital, Auckland, NEW ZEALAND
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Type 2 Diabetes: Kidney Disease

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CARI Steering Committee

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