

# Chronic disease guidelines and the Indigenous Coordinated Care Trials

TARUN WEERAMANTHRI, CHRISTINE CONNORS,  
SHERRY O'LEARY, DAISY YARMIRR, JO WRIGHT AND  
ANDREW BELL

Tarun Weeramanthri is Community Physician at Centre for Disease Control, Territory Health Services. Christine Connors was the Medical Practitioner, Sherry O'Leary was the Nurse Practitioner and Daisy Yarmirr the Senior Aboriginal Health Worker employed by the Guidelines, Standards and Audit Team. Jo Wright is Senior District Medical Officer, Darwin Rural District, Territory Health Services and Andrew Bell was Senior District Medical Officer, Katherine District, Territory Health Services.

## Abstract

*The establishment of the NT Coordinated Care Trials in 1997 provided an opportunity for the funding and development of detailed guidelines, designed specifically for the Indigenous population, covering screening and clinical management of major chronic diseases. All guidelines were incorporated into the NT Coordinated Care Trials Information System on the Tiwi Islands and in the Katherine West region, and used to generate individual and population care plans. In contrast to what is usually written, a broad range of guidelines can be developed in a relatively short period of time utilising a dedicated multi-disciplinary team and local working groups. Having a receptive service delivery model, such as the Coordinated Care Trials, allows for a high level of uptake and use. The key features were the linking of guidelines to a computerised information system that translated them into items of service and presented them to the clinician at the time of consultation, combined with ongoing education of clinicians and clients.*

## The burden of chronic diseases and previous guideline initiatives

The burden of chronic diseases constitutes a growing public health problem for the Indigenous population in the Northern Territory (Cunningham & Condon, 1996). Prevalence rates of ischaemic heart disease, renal disease, diabetes and their underlying risk factors are all high by Australian standards, and many Indigenous people with chronic disease have one or more co-morbidities (Weeramanthri & Clark, 2001). Service delivery to Indigenous people in the NT is complicated by issues of poverty, geographical remoteness and inadequate resource allocation (Burns *et al.*, 1998).

In a bid to provide appropriate standards of care in the face of high rates of illness, disease and staff turnover, the Northern Territory (NT) has seen a series of guideline initiatives over the years. The Central Australian Rural Practitioners' Association (CARPA) standard treatment manual is the most well known example (Williams, 1993). It was first published in 1992, with subsequent editions appearing in 1994 and 1997. It is an ideal acute care handbook for the busy primary care practitioner working with Indigenous communities, and it was endorsed by Territory Health Services (THS) for use throughout the NT in 1998. Information on managing chronic diseases has grown with each edition, though it still lacks details in some parts.

THS produced a 'Bush Book' in the early 1970's and a series of Top End Standard Treatment Protocols in the early 1990's (Kennedy & Guthridge, 1997). There has also been significant NT input into national Antibiotic Guidelines (Writing Group, 1998).

## NT Coordinated Care Trials – the need for guidelines to inform care planning

In 1997, the NT was successful in tendering for two Coordinated Care Trials covering the Tiwi Islands (population 2000, 90% Indigenous) and the Katherine West area (population 3000, 85% Indigenous). The Coordinated Care Trials (CCT) were part of the process of ambulatory care reform proposed by the Council of Australian Government in 1995. One of the main goals was to improve the care and coordination of people with chronic disease. Whereas many of the other trials focused on the care of the elderly (Perkins *et al.*, 2001), both NT trials were whole population-focused in areas with predominantly Indigenous populations and high rates of chronic disease.

The trial proposals were developed and implemented in partnership with the communities involved, represented by Tiwi and Katherine West health boards. The key features of the NT Trials were *community control* through pooling of NT Government expenditure to fund-holding health boards, *increased resources* through cashing out of under-utilised MBS and PBS funds on a per capita basis, and improved *models of care* through the development of care planning processes aided by expert guidelines and a computerised CCT Information System (CCTIS).

In developing the tender, we foresaw the danger that ‘coordinated care’ could be viewed as ‘managed care’ (though any elements of gate-keeping, utilisation review and capitation were absent in the NT model). We did not want to institutionalise less than optimal care to populations already disadvantaged by historical resource constraints; hence the need to fund a new guideline development process specifically aimed at the quality management of chronic diseases.

### GSAT goals

The ‘Guidelines, Standards and Audit Team’ (GSAT) was established in March 1997 for an 18-month period. The team consisted of three full time health professionals (one medical practitioner, one nurse practitioner and one Aboriginal health worker, all with extensive clinical experience in remote NT communities). The goal for the team was to help ensure high quality care, through the rapid development of guidelines for the common chronic diseases that would complement and extend the information in the CARPA manual.

We adopted the NHMRC definition of guidelines, namely ‘systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances’ (NHMRC, 1995). All guidelines had to be completed prior to the CCT commencement in mid-1998.

The recommended NHMRC process (1995) seemed to assume an unlimited timeframe for the development of a single guideline and focused rather more on guideline development than implementation. Our task was different: to develop multiple guidelines suitable for a variety of health care professionals (medical practitioners, nurse practitioners and Aboriginal health workers) within a very limited time period. Parts of the NHMRC document proved very useful, especially the recommendations to base guidelines on multi-disciplinary input, to utilise already existing guidelines and to base them on the best available evidence. We were reassured by their emphasis on local adaptation, and the need to be mindful of resources.

### GSAT structures

We immediately set up a multidisciplinary steering committee with end-user and consumer representation. The first tasks of that committee were to establish a prioritisation process for which guidelines were most needed (based on disease burden, availability of interventions, user demand for guidelines, and potential to benefit from care coordination); to formulate a process for setting up working parties (including experts and end-users); and to then commission an expert to do literature searching for those working groups.

The steering committee met three times over the life of the project to approve and modify GSAT processes, and ratify and promote final protocols. The following adult chronic disease management guidelines were first prioritised by the steering committee and then developed: healthy lifestyle; diabetes; hyperlipidemia; hypertension; renal disease; chronic obstructive airways disease; quit smoking; hepatitis B carriers; and rheumatic heart disease.

Childhood guidelines for growth assessment and action, anaemia, scabies and chronic suppurative otitis media were also developed, as were guidelines on antenatal care. Screening guidelines for Childhood (0-3 years), School Age Kids, Adult Well Men and Well Women (for people aged 16-49 years) and Older People (for people aged 50 years and over) were also developed, and contained modules on growth and development, chronic disease, women's checks, sexually transmitted diseases and immunisations. Guidelines in the area of ischaemic heart disease were thought to be too difficult to develop in a rapid manner, with management best left to individual decision making processes.

## **GSAT processes**

We decided our search focus would first be on established guidelines and consensus statements (published in English, preferably Australian, written by credible representative groups and with possible relevance to Indigenous populations) and then on systematic reviews, including meta-analyses, rather than on original clinical trials. We were unable to assess the strength of each individual guideline and meta-analysis, because of time and resource constraints, and the lack of an agreed method for guideline evaluation. Explicit grading of evidence was therefore not possible.

It was planned that each working group would consist of 8-10 people, hold regular teleconferences, and be facilitated by a GSAT full-time staff member. Each working group member would receive focus questions (developed by the GSAT team around specific controversial topics), and a copy of the relevant literature, and then a draft new guideline would be developed by consensus. Some working groups were based on existing project groups (chronic airways disease, hepatitis B and renal disease).

Because of the difficulties of getting groups together, finding suitable times for people to teleconference, and allowing for competing work pressures on working group members, the full working group process for guideline development was followed only for the antenatal care, chronic suppurative otitis media, diabetes and screening guidelines. In practice, we used a number of shortcuts to the full process. First we used existing locally produced documents as starting points (including CARPA protocols and rheumatic heart disease and scabies papers). Second, we commissioned local experts and expert groups to produce first drafts of guidelines (quit smoking and hypertension).

## **GSAT outputs**

The guidelines were presented in A4 format, including flow charts to help decision making, and were certainly more detailed than any previously available in the NT. They included specific recommendations on what care items to deliver, how often and by whom, and some information on the rationale. Where possible, guidelines had an Indigenous cultural and family focus. All guidelines were broken down into discrete elements that were then written into the NT Coordinated Care Trials Information System (CCTIS). This was a time-consuming process requiring considerable collaborative work between the GSAT team and the computer programmers.

Consistently positive feedback has been received from primary care staff, who value the detail and layout in the documents. A few practitioners with an evidence-based medicine focus have expressed a desire to see the strength behind each recommendation. Others have commented that the resources to implement each guideline in full (eg, screening for hepatoma in hepatitis B carriers) are still not available in primary care in the NT. A small number of inconsistencies in the guidelines have also been pointed out to us, but no major deficiencies with implications for safe patient care. Given the rapidity with which the guidelines were developed, these seem acceptable flaws.

## **GSAT application within and outside Coordinated Care Trial sites**

Screening guidelines were applied to all Trial participants automatically by CCTIS (yielding population care plans specific to one's age and gender), whereas chronic disease management guidelines were specifically

activated by providers once the diagnosis had been made (yielding individual care plans). The final individual care plan could be modified within CCTIS to take into account individual patient needs and preferences (ie, specific care items could be added or deleted). CCTIS could, of course, automatically generate recall lists for community health centres. All providers in the CCT sites were oriented to the guidelines and trained in use of the information system.

Technical problems and training issues initially hindered uptake in computerised remote sites. A related issue was the large number of recall items generated on a computerised printout, which led to some staff feeling 'overloaded'. Staff working with paper-based recall systems can generally prioritise work under less 'computer pressure'.

The adult screening and management guidelines were approved for use outside the CCT sites in all THS-funded Top End community health centres in January 1999. The GSAT childhood and antenatal guidelines were withheld from wider distribution, as there was some anxiety about overloading practitioners with new guidelines. Over the last two years, 500 copies of the adult guidelines have been distributed free to all community health centres and provided on request. Two print runs have been needed. They are also available on the THS Intranet.

Ongoing support to health professionals for guideline use has been provided since 1998 by public health nurses who form the 'Total Recall' team. They help community health centre staff to do the following: compile population lists, audit charts, set up paper-based recall systems in health centres without CCTIS, utilise GSAT protocols and analyse and feedback health data. By early 2000, all eligible Top End community health centres had been included in the process.

Orientation schedules for all new THS staff going to work in remote areas now includes mandatory orientation to the GSAT guidelines. The guidelines have been consistently used as in-service training materials for health professionals and some health board members. In 1998, the GSAT guidelines were also adopted for use in Indigenous communities in the Torres Strait District of Queensland Health Service (Dr Robyn McDermott, personal communication).

## **Uptake of guidelines**

The evaluation of the CCT has provided information on the immediate uptake of the guidelines, though clearly the full impact of the guidelines and related changes will only be felt some years from now (Local Evaluation Team, 2000). The CCT evaluators based their audit instrument on the GSAT protocols. It was hypothesised that improved care coordination would lead to greater adherence to screening and clinical protocols as laid out in the guidelines (Local Evaluation Team, 2000).

Four medical record audits on the Tiwi Islands have been performed, from a baseline audit in November 1998 to the latest audit in December 2000 (Robinson *et al.*, 2000). By the time of this latest audit, 45% of sample with one or more identified health problems had been assigned a care plan, and 79% of these had been merged with a population care plan. The most frequently assigned care plans were for renal disease and diabetes. 98% of the sample of people with diabetes had a diabetes care plan, and 95% of these had been merged with a population care plan. Uptake of guideline items was variable, but generally positive. For example, 19 of 30 individual items in the diabetes care plan were being delivered more frequently on the Tiwi Islands by the time of the latest audit (Robinson *et al.*, 2000).

In both trials, there was a consistent high proportion of diabetics (over 80%) who had had their blood pressure and blood sugar levels measured at least 3 times in the prior 12 months. Other aspects of care, such as behavioural counselling and examination of diabetic feet, are still being delivered at low rates. However, periodic audit based on GSAT protocols has allowed feedback of such information to staff as part of a quality assurance process, and the effect of such feedback will be measurable.

## Discussion

Developing guidelines is easy but implementing them is hard (Hirst & Ward, 2000). If guidelines are to be implemented, they need to be 'real world', taking into account both evidence and the existing capacity of health services (Jackson & de Jong, 2001). The Coordinated Care Trials provided a unique opportunity to avoid implementation barriers, since the computerised information system needed discrete elements from which to constitute its individual and population care plans, and generate recall lists. As in other Coordinated Care Trials (Battersby *et al.*, 2001), there was a generally positive attitude on the part of health professionals and consumers to the change process. There was also a historically high acceptance of guideline use by NT health professionals. The guidelines were 'pulled into' the system. They did not need to be 'pushed onto' ambivalent practitioners.

We have shown that rapid local guideline development is possible, through a variety of mechanisms. A full NHMRC-type evidence based process was not possible, but we succeeded in including more evidence through a more explicit process than was previously possible. Finally, however, recommendations were consensus-based. There is a continuum between a fully evidence-based approach on the one hand, and a wholly consensus approach on the other. Even experts draw on evidence (however informally synthesised) when making consensus recommendations! In one sense, the limited time for development in our process was offset by the immediate implementation and widespread field testing of the guidelines. The latest revision of the NHMRC guidelines document (1999) has a greater emphasis on guideline implementation and evaluation, but is still more applicable to national guidelines on a single topic than multiple local guidelines. The future role of national bodies may be to update the evidence base (as do the Cochrane Centres), but leave the developing of guidelines and specific practice recommendations to local bodies.

These guidelines have had an impact on clinical practice because local practitioners were involved in their development, they were closely matched to local needs and implementation was immediate via the CCTIS. This is consistent with the published literature (Grimshaw & Russell, 1993). Whether and how the guidelines will lead to an improvement in intermediate health status and final health outcomes is a more difficult question to answer. Many other factors (such as level of resourcing) influence outcomes, there has been a relatively short time period over which they have been in operation, and there are methodological challenges inherent in design of such studies (Grimshaw & Russell, 1993; Worrall *et al.*, 1997).

Incorporation of the guidelines into a computerised information system offers a opportunity to easily and routinely audit key indicators (e.g. proportion of rheumatic heart disease patients receiving secondary penicillin prophylaxis, or proportion of diabetics with acceptable levels of glycaemic control), and promote healthcare integration (Jackson & de Jong, 1999). They also allow all staff (including Aboriginal Health Workers) to contribute to the delivery of service items and participate in evidence-based decision making. But utilisation of the guidelines with a paper-based recall system may be the only practical option in a situation where resources are limited. The major barriers to guideline implementation remain high rates of staff turnover and inadequate resources in the face of high acute and emergency care needs as well as a high load of chronic disease.

We have plans to revise the GSAT guidelines in 2001 and extend the variety of formats in which the content is delivered, by producing more summary sheets, wall charts and patient educational materials. This revision is taking place as part of the CARPA 4th edition revision process, with the more detailed GSAT chronic disease protocols being used as the basis for new CARPA 4th edition protocols (Dr Steven Skov, personal communication). A background reference and evidence document will be produced to complement the clinical guideline recommendations. There will then be no need for a separate ongoing GSAT process.

The potential application of evidence-based guidelines to the promotion of 'best practice' has been demonstrated in an Indigenous health setting (Couzos & Murray, 1999; McDermott *et al.*, 2001). Often, however, better practice is the first step towards best practice, and in this case study, we have demonstrated how theoretical considerations about guideline development need sometimes to be waived in favour of more pragmatic implementation aims. The key criterion was not 'are these the most perfect guidelines possible?' but 'are the final products better than what was previously available, and will they be used to shape practice?' Copies of the GSAT guidelines can be obtained by contacting the first-listed author.

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