# Sustainable chronic disease management in remote Australia

John Wakerman, Elizabeth M Chalmers, John S Humphreys, Christine L Clarence, Andrew I Bell, Ann Larson, David Lyle and Dennis R Pashen


## ABSTRACT

- The Sharing Health Care Initiative (SHCI) demonstration project, which aimed to improve management of chronic diseases, was implemented in four small remote communities in the Katherine region which are serviced by the Katherine West Health Board, a remote Aboriginal-community-controlled health organisation in the Northern Territory.
- We reviewed the project proposal, final report, evaluation reports and transitional funding proposal, and supplemented these with in-depth interviews with key individuals. We determined factors critical to the sustainability of the SHCI project in relation to context, community engagement, systems flexibility and adaptability, the availability and effect of information systems, and the human nature of health care and policy.
- The project had a significant impact on community awareness of chronic disease and an improvement in clinic processes.
- We found that a number of interrelated factors promoted sustainability, including:
  - An implementation strategy sufficiently flexible to take account of local conditions;
  - A high level of community engagement;
  - Appropriate timeframes, timing and congruence between national policy and local readiness to implement a chronic disease project;
  - Effective communication between participating organisations;
  - Project champions (key individuals) in participating organisations;
  - Effective use of monitoring and evaluation data; and
  - Adequate and ongoing funding.
- The absence of a number of these factors, such as poor communication, inhibited sustainability. Other factors could both promote and inhibit. For example, the impact of key individuals was important, but could be idiosyncratic and have negative effects.

MJA 2005; 183: S64–S68


The Sharing Health Care Initiative (SHCI) is part of the Australian Government's Enhanced Primary Care Package for older Australians and people with chronic and complex health conditions. The initiative aims to improve health service management and quality of life for people with chronic diseases.[1] Between 2002 and 2004, the Australian Government Department of Health and Ageing funded eight such demonstration projects.

The Katherine West Health Board is an Aboriginal-community-controlled health organisation which trialled a model of self-care under the SCHI scheme in a context of high chronic disease prevalence among Indigenous people[2] and successful self-management approaches in other populations.[3] The project was implemented between April 2002 and June 2004 in four remote communities. The remote communities are situated between 420 km and 570 km from the town of Katherine, the regional centre (Box 1), and had a total population of 1937. The project used an "action research methodology … based on a community development model" as a response to the complex remote environment.[4,5]

The project included strategies to improve self-management by individuals and their families, and also aimed to encourage adaptive changes within existing health services. The project involved employing a male and female local Aboriginal Community Support Worker in each community; training these Support Workers and other Katherine West Health Board staff and board members in chronic disease self-management; community-based health promotion activities; and producing local resources (such as project information pamphlets and videos introducing the project and explaining self-management principles and practices) in local languages. The project included an evaluation which examined the process, impact and outcomes of the project.[6-8]

## Rationale for the research

This project provided the opportunity for an important and timely case study to examine sustainability issues as they apply to health service reform in a remote context. Too often, successful projects, pilots and trials are not sustained, while other programs continue without thorough evaluation. Here, we report an analysis which identifies factors promoting and inhibiting the sustainability of the project, which could be generalised to other settings.

## Methods

We carried out a detailed review of relevant, existing project and local evaluation documents[6-10] and supplemented these with six in-depth interviews with five key informants. The interviewees were: a member of Katherine West Health Board management, a project evaluator, and three representatives of different levels of government. Interviews were audiotaped, transcribed and thematic sorting was applied using NVivo software (version 2, 2002; QSR International, Melbourne).[11,12]


Centre for Remote Health, Flinders University and Charles Darwin University, NT.
John Wakerman, MTH, FAFPHM, FACRRM, Director;
Elizabeth M Chalmers, MPH, FAFPHM, FACRRM, Head, Katherine Unit;
Christine L Clarence, BPE, MICD, DipTeaching, Associate Lecturer, Katherine Unit.
Monash University School of Rural Health, Bendigo, VIC.
John S Humphreys, BA, Dip Ed, PhD, Professor of Rural Health Research.
Katherine West Health Board Aboriginal Corporation, Katherine, NT.
Andrew I Bell, MB BS, FAFPHM, FACRRM, Medical Director.
Combined Universities Centre for Rural Health, Geraldton, WA.
Ann Larson, BA, MA, PhD, Director.
Broken Hill University Department of Rural Health, University of Sydney, Broken Hill, NSW.
David Lyle, MB BS, FAFPHM, PhD, Head.
Mt Isa Centre for Rural and Remote Health, James Cook University, Mt Isa, QLD.
Dennis R Pashen, MPHTM, FRACGP, FACCRM, Director.
Correspondence: Associate Professor John Wakerman, Centre for Remote Health, PO Box 4066, Alice Springs, NT 0871.
john.wakerman@flinders.edu.au

The study was approved by the Top End Joint Institutional Human Research Ethics Committee.

## Findings

Through an iterative process involving repeated group discussion between the five case study research teams and staff of the Australian Primary Health Care Institute,[13] five key common themes were identified in relation to the promoters and inhibitors of program sustainability: context, community engagement, systems flexibility and adaptability, information systems and the human nature of health care and policy. For each of the five identified themes, inhibitors and facilitators of sustainability were identified from project documents and interview transcripts. These are summarised in Box 2. As would be expected from a successful project, there were more elements identified which promote sustainability than elements which detract from it.

## Discussion

Changes in health behaviour only occur when people are informed about and accept the need for change. The most striking impact of the project was the raised level of community awareness about chronic disease, and particularly about preventive activity.

> Well, it's good for my people to understand about this chronic disease and how they can be aware of it and look after themselves, because this is a major problem within our community that most people have been fighting against . . . we need to look after each other. Even our young generation need to be aware of health.

Community members were generally satisfied with the program and saw the work of Community Support Workers and activities such as videos cooperatively produced in the community as strengths of the initiative. Community members also reported the need for a whole-of-community approach, which recognised the link between the project and other community initiatives, such as responsible serving of alcohol at a club and improving the quality of food at a local store.

A clinical audit showed a trend towards improved recording and improved follow-up, but no significant changes in biochemical or other clinical markers of disease in those with diabetes and hypertension.[8] This is consistent with other studies showing that increased community awareness and improved clinical processes are prerequisites for improved clinical markers, and that modest improvements can take 3 years after an intervention to become apparent.[14,15]

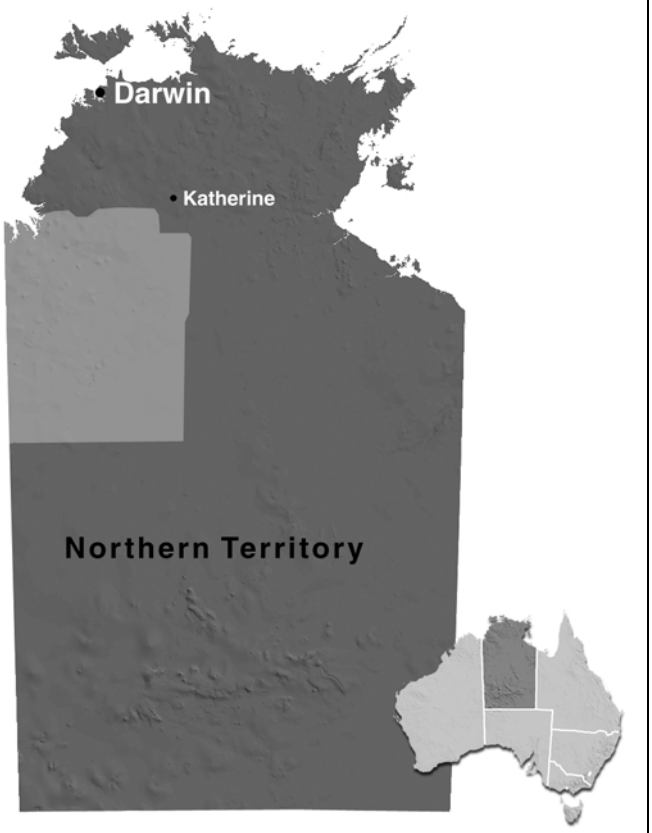
Our findings highlight the interrelated nature of sustainability factors, and paradoxically highlight how the same factors can both facilitate and inhibit sustainability. For example, key individuals can have enormous impact, either negative or positive, especially in a remote environment where "one person will have a really distinct responsibility across a fairly big area". High staff turnover can have a negative impact on programs as well as bring in fresh ideas and perspectives.

### Context

There are a number of significant dimensions of "context", including geographical, demographic, social and policy context. Implementation flexibility is critical to sustainability in this very challenging service environment. In high-need, cross-cultural settings, programs are vulnerable to individual idiosyncrasy, competition for scarce resources, limited skills and diseconomies of scale. At the same time, small, interconnected communities provide a scale which is amenable to ". . . testing some of those things . . ."

Timing is also a critical contextual factor. The triad of problem recognition, available solution and conducive political environment was realised. The problem of chronic diseases was recognised internationally and nationally, as reflected in the National Health Priorities and the efforts of national non-government organisations.[16,17] Solutions were available,[3,18] and there was political will. This triad, which makes up the "policy window" described by Kingdon in 2003, was complemented by an essential local readiness to implement such a project.[19] The congruence between national policy and local readiness was critical to sustainability.

1 Katherine West Health Board service area




### Community engagement

The high level of community engagement and ownership of both the problems and solutions was predicated on prior experience with the Coordinated Care Trial, which enabled a single integrated health service, the Katherine West Health Board, to be established for the region through pooled funds from the Northern Territory and federal governments. Engagement existed at a structural level through formal community governance, and at a community level through education and dissemination of information by Community Support Workers. In brief, the community valued the service and the community was valued by the service — an essential synergy for program sustainability. Intersectoral linkages within

the community can also contribute to sustainability. For example, despite diminished funding in one sector, activities generated by this kind of community-based project in other sectors — social club, school or store — may continue.

### Systems flexibility and adaptability

The project involved the interaction of diverse organisations with quite different cultures. These were the Department of Health and Ageing, national evaluators, local evaluators, contributing universities and educators, Katherine West Health Board management and clinic staff, the communities and program participants. Each group has its own language, priorities and world views. It takes time to develop a shared understanding.

Continuity and incremental change are important components contributing to sustainability. It took considerable time for external agents to build relationships, understanding and trust; for governance structures to be developed through the preceding Coordinated Care Trial; and for the training of staff and health professionals. Considerable time is also needed to increase knowledge, translate it into behavioural change and then measure change in health indicators.

**2 Themes identified as relating to project sustainability, and their associated promoters and inhibitors**

| Theme | Promoters | Inhibitors |
|---|---|---|
| Context | *International and national:* • Global interest in chronic disease management • Consistent with Australian National Health Priorities • National non-government organisations supportive • Ageing population • Increasing prevalence of chronic disease *Local:* • Communities small and internally cohesive • Good timing: past history of Co-ordinated Care Trial set the basis for care planning • Northern Territory already playing a leadership role in chronic disease prevention | *Local:* • Difficulties in servicing geographically isolated communities • Lack of basic infrastructure such as information technology in remote communities • Burden of acute disease overwhelms planned care • High staff turnover • Working in a culturally complex environment |
| Community engagement | • Community controlled structures and accountability systems in place • Governance training for the health board (unrelated to the project) • Project funding level was adequate and project resources (human and physical) were located in the communities • Community engagement enabled intersectoral action, which further strengthened community engagement • Community Support Workers "were respected people within the community" • The project team was very "community focused" • Evaluators took time to build relationships through consultation | • Multiple competing community priorities • Roles of Community Support Workers were not clearly understood in the community, with some confusion with the more clinic-based role of Aboriginal health workers |
| Systems flexibility and adaptability | • Flexibility in funding policy — recognition that demonstration projects in a number of small, remote, Indigenous communities should include a local evaluation only • Funder flexibility in implementation to account for local conditions (eg, redefining eligibility age from 50 to 35) • Demonstration project learnings used in national chronic disease policy development • Project has had an impact on parallel education and training systems (eg, audit of chronic disease self-management education in medical school curricula, increased postgraduate education in chronic disease self-management) • Local flexibility — health board approved change from original proposal to a more community-based and community development/heath promotion focused program • Priorities of traditional cultural obligations were accommodated despite project timelines. | • Delays because of national election • Systems at clinic level not in place • Australian Public Service organisational culture valuing rapid movement through positions along generic public sector career path ("they are about up the ladder, and they'll do that by hook or by crook") • Frequent organisational restructuring ("So who knows what is going to happen by next year? I will probably tell you we've had another three changes of personnel") • Different priorities or views within different areas of bureaucracy • High staff turnover at local health service level • Funding time limited, resulting in staff/corporate knowledge being lost while applying for and securing transitional funding |
| Information systems: availability and effect | • Regular formal communication between local and national project evaluators • Regular informal communication between the project and local Department of Health and Ageing officers • Regular informal communication between national Department of Health and Ageing officers • Community-produced videos and information pamphlets were highly valued as information source • Community Support Workers were an important source of information, providing an effective and culturally appropriate method of information delivery | • Informal communication networks vulnerable to staff turnover • Different organisational cultures and priorities limiting effective communication between the various agents and systems surrounding the project • Difficulty of maintaining communication and coordination across different branches of the Department of Health and Ageing • Insufficient formal communication (steering committee meetings) between funder and project • Unplanned opportunity costs for local health service for monitoring and reporting to project national evaluator and Department of Health and Ageing • Little interaction with Northern Territory Government health authority, which had expertise in chronic disease management |
| The human nature of health care and policy | • Key individuals in place nationally and locally • High turnover of Department of Health and Ageing staff also means "new, fresh ideas" • Community Support Workers were seen as the "face" of the program and as "the right people to see and tell us more about this chronic disease and how it can affect us in the future" | • High staff turnover, nationally and locally • Staff resistance to change • Individual, idiosyncratic behaviours • Key individuals overcommitted and unable to focus sufficiently on the project |

◆

There were a number of important inhibitors to systems adaptability. The difficulty in integrating project activities after the initial period of establishment was related to a predominant health service culture of meeting the high level of clinical need, as opposed to care planning and prevention. There are competing programs in remote communities, for which there is a final common pathway — the local health team. Reorienting health services to care planning and prevention requires adequate resources and planning to ensure successful adaptation and integration.

Adaptability is also affected by high staff turnover at both a national and local level, which contributes to and is a result of organisational culture. At a national level, high staff turnover is linked to a culture that values rapid career advancement and is subject to frequent organisational restructuring. Over 18 months within the Department of Health and Ageing, there was a new chief executive officer, four different first assistant secretaries, seven assistant secretaries and five different directors in this area. This was highlighted by the unusual longevity of a key bureaucrat who was involved with the program over an extended period.

> . . . it comes down to a sort of personal thing and whether someone is actually committed to it . . . from a policy sense as well, it is most unusual for somebody like myself to be around in the same area for 4 years, but I have.

Staff continuity is particularly important in an Indigenous context: ". . . if you know somebody, and that somebody has been there for quite a while it just works so much better."

At a local level, high staff turnover is related more to a challenging work environment characterised by isolation, high level of need, scarce resources and under-preparation of staff. A high level of turnover in both systems creates particular problems with continuity, corporate memory and the sort of incremental change over an appropriate timeframe required in chronic disease management.

### Information systems

Timely and appropriate information flow is essential to ensuring program responsiveness and sustainability. In the SHCI, there was a complex system of formal and informal information flows at different levels (local and national), within and between the different organisations involved. Access to information is empowering, and builds trust and recognition of the value of the different organisations working within a program. Informal communication, such as the "brown paper bag lunches" within the Department of Health and Ageing, can be very effective. Community involvement in producing videos and pamphlets facilitated good communication at a local level.

Importantly, the feedback of evaluation data contributed to adaptation and policy formulation. Evaluation of chronic disease self-management training was used to "convince the people higher up in the hierarchy" that there is a need to educate both consumers and health professionals. The demonstration projects thus resulted in a national audit of chronic disease self-management training education in medical school curricula and enhanced support of postgraduate education in chronic disease self-management. The demonstration projects also contributed to a national chronic disease policy.

### Human nature of health care and policy

While sustainability may entail building and strengthening robust, responsive systems, individuals can and do have an enormous impact in this context at both local and national levels. In rural and remote Australia, "at risk" or "unsustainable" systems may sometimes be sustained by individuals who just won't accept defeat. In this case study, local champions in the health service were significant. At the same time, individuals can inhibit progress through idiosyncratic behaviour or through prohibitive workload.

The non-linear and very human nature of policy development was described long ago,[20] and was well described in this case as

> ". . . not very seamless and [not] like a machine. It doesn't work that way at all. It is very haphazard, and at times you've got to pick up the vibes and hope you've picked up the right vibes. In this particular case we did pick up the right vibes.

At a national level, the Minister for Health was committed to the difficult task of improving management of chronic disease, as was a key bureaucrat, who developed and oversaw the program over an extended period.

### Conclusion

Small, poorly resourced, remote Aboriginal communities characterised by urgent health needs provide a valuable testing ground for new interventions. In this case study, we identified the interrelated factors that promoted and inhibited sustainability of the initiative. Application of this knowledge can assist in planning new initiatives and sustaining existing ones. The project was clearly successful in changing community awareness and improving a clinical process related to chronic disease management. However, despite this positive development, funding ceased at the end of the project period, and transition funding has not yet been provided. While community support, employment of local workers, appropriate time and timing, effective use of monitoring and evaluation data are all important, sustainability will ultimately depend on continued commitment to and funding of successful demonstration projects such as the Sharing Health Care Initiative.

## Acknowledgements

We are grateful to the Australian Primary Health Care Research Institute (APHRI) for funding this study, as well as facilitating an innovative process for interaction between different research groups. The Sharing Health Care Initiative and its evaluation was funded by the Australian Government Department of Health and Ageing. We acknowledge the original evaluation work carried out by the Cooperative Research Centre for Aboriginal Health, Menzies School of Health Research and PricewaterhouseCoopers. We are particularly grateful to the Katherine West Health Board for its support. Alison Stewart conducted interviews and Kerry Barber generously assisted at the drafting stage. We thank the staff of APHCRI, particularly Bev Sibthorpe, and the other research groups for their constructive comments.

## Competing interests

None identified.

## References

1 Australian Government Department of Health and Ageing 2001. Sharing Health Care Initiative (SHCI). Available at: http://www.chronicdisease.health.gov.au/sharing.htm (accessed Jun 2005).

2 Australian Institute of Health and Welfare. Australia's health 2004. Canberra: AIHW, 2004.

3 Lorig KR, Sobel DS, Stewart AL, Brown BW Jr. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. *Med Care* 1999; 37: 5-14.
4 Katherine West Health Board Aboriginal Corporation chronic disease self management demonstration project proposal. Katherine: Katherine West Health Board, 2000.
5 Kenny S. Developing communities for the future: community development in Australia. Melbourne: Thomas Nelson Australia, 1994.
6 Chalmers E, Dupont-Morris D, Angeles, G. Katherine West Health Board Aboriginal Corporation chronic disease self management program evaluation report. Katherine: Katherine West Health Board, January 2004.
7 Chalmers E, Dupont-Morris D, Angeles G. Katherine West Health Board Aboriginal Corporation chronic disease self-management program evaluation report. Katherine: Katherine West Health Board, June 2004.
8 Baillie R, Stewart A, Si D, Dowden M. Katherine West chronic disease self-management project clinical audit report. Darwin: Menzies School of Health Research for the Co-operative Research Centre for Aboriginal Health, 2004
9 Stewart A. Katherine West Health Board Aboriginal Corporation chronic disease self-management program final report. Katherine: Katherine West Health Board, 2005.
10 Stewart A. Katherine West Health Board Chronic condition and self-management program two year transitional plan: integrating self-management into organisational policy and practice. Katherine: Katherine West Health Board, 2005.
11 Pope C, Ziebland S, Mays N. Analysing qualitative data. *BMJ* 2000; 320: 114-116.
12 Rice PL, Ezzy D. Qualitative research methods — a health focus. Melbourne: Oxford University Press, 1999: 59-60.
13 Sibthorpe BM, Glasgow NJ, Wells RW. Emergent themes in the sustainability of primary health care innovation *Med J Aust* 2005; 183 (10 Suppl): S77-S80.
14 McDermott R, Tulip F, Schmidt B, Sinha A. Sustaining better diabetes care in remote Indigenous Australian communities. *BMJ* 2003; 327: 428-430.
15 Howie RJ. Formative evaluation of the Kuwinyuwardu Aboriginal Resource Unit Gascoyne healthy lifestyle program. Perth: Telethon Institute for Child Health Research, 2004. Available at: http://www.aboriginal.health.wa.gov.au/htm/publications/2004/gascoyne%5Fhealth%5Fevaluation.pdf (accessed Aug 2005).
16 Holman H, Lorig K. Patient self-management: a key to effectiveness and efficiency in care of chronic disease. *Public Health Rep* 2004; 119: 239-243.
17 Field P, Wright L. Workshop to discuss the forming of an alliance of non-government organisations to develop a chronic disease strategy for Aboriginal and Torres Strait Islander people and rural and remote populations. Available at: http://www.heartfoundation.com.au/downloads/chronic%20illness%20workshop.htm (accessed Jun 2005).
18 Weeramanthri T, Hendy S, Connors C, et al. The Northern Territory preventable chronic disease strategy — promoting an integrated and life course approach to chronic disease in Australia. *Aust Health Rev* 2003; 26: 31-42.
19 Kingdon JW. Agendas, alternatives, and public policies. 2nd ed. New York: Longman, 2003: 87-89.
20 Lindblom CE. The science of muddling through. *Public Admin Rev* 1959; Spring: 79-88.

*(Received 26 Jul 2005, accepted 31 Aug 2005)* ❑