Giving support to disease guidelines

A commentary

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Introduction

The article by Weeramanthri *et al* (2002) provides an invaluable account of the processes, endeavours and benefits derived from the development and use of disease guidelines for Indigenous populations. It highlights several important lessons from which others with a similar interest can benefit, including the following:

- the importance of obtaining a consensus, and not just an evidence base, for guideline development
- guidelines should be judged in relation to what already exists rather than in relation to a hypothetical standard of best practice (that is, have they improved health care rather than are they perfect?)
- implementation is far more difficult than development.

The term evidence, in this context, is often used to refer to proof of benefit derived from quasi-experimental design studies. However, one should not discount the use of other forms of evidence, particularly (in the absence of evidence from studies with an adequate experimental design) experiential-based evidence.

I focus on two related matters in this commentary. The first concerns the extent to which the experiences of these two trials are similar to or contrasted by the experiences of the other Indigenous trials. The second concerns lessons learned from implementation and usage of disease guidelines as distinct from development issues which are the focus of the article by Weeramanthri and colleagues.

This commentary is based on my observations and experiences as the project director for the national evaluation of the trials. I draw heavily from the national evaluation reports (KPMG 2001) and from the reports of the local evaluators (Robinson 2000, d'Abbs 2000, Arto 2000, and Morey 2000).

Comparison with other Indigenous trials

The experiences of other Trials regarding the development and implementation of disease guidelines and the computer systems used to support health workers in the use of the guidelines are similar across the Trials. This is in spite of the fact that they sometimes used different source material to develop the guidelines, different processes to obtain consensus, and different computer systems to support care planning and execution of the guidelines. Further, disease guidelines (or care plans as they were termed during the Trials) were considered and proved to be of significant benefit to health workers and other health service providers, and improved the delivery of health care services to clients. What contrasts the Trials more relates to the following.

- Developmental support: for example, those Trials that received considerable technical and resource support from local health authorities not unexpectedly experience less difficulty during the implementation phase than those that relied almost entirely on expertise and resources within the Trial team.
- Context of the Trial: the Perth site of the WA Trial was implemented within an established and (relative to other Trials) better-resourced health service with a relatively high degree of computer literacy. Consequently, both the process of change and the uptake of disease guidelines was less of an issue (although

a still significant issue) compared to other Trials that were implementing change in less developed health services.

- Cohesion of the local health system: those Trials that operated within almost self-contained health systems had greater acceptance and uptake amongst health providers than those where there was a significant dependency on external health service providers. In some cases, there was almost total ambivalence from external providers towards the efforts of the local health service to effect change. This occurred particularly when the adoption of change by an external provider would have required that provider to maintain two standards, one for the local health service participating in the Trial and one for all other health services that it served.
- Adaptability: those Trials that initially attempted to adopt a literal and thus comprehensive approach to care assessment and care planning took much longer to reach the point of implementation than those that took a more pragmatic and more moderate view of these processes.

In summary, the use of disease guidelines, supported by a computerised system, proved one of the successful outcomes of the Trials. This was in spite of the many operational difficulties and the fact that there remains much work to be done before one could be confident of the long-term sustainability of this approach to health care. There were some notable differences across the Trials that provide lessons for others who chose to venture down a similar pathway. These are addressed in the next section.

Lessons learned

There are a number of key lessons arising from the Trials' experiences with the use of disease guidelines. These comments are a set of generalisations extracted from all Trials and thus do not always necessarily relate to the two Trials that are the subject of the article by Weeramanthri *et al* (2002). They are summarised as follows.

There is more to disease guidelines than the disease guidelines.

As much if not more effort is required to be invested in non-clinical elements of planning for the use of disease guidelines, as it is necessary to ensure both the clinical validity of the guidelines and the services required to operationalise the guidelines. The degree to which the guidelines are integrated into local clinical practices is critical to the success of care planning and care co-ordination. In some cases, there tended to be more effort expended on what I call the technical or clinical elements of disease guidelines and care planning and less effort expended on a range of other important issues such as the following.

- The impact of disease guidelines and care planning on existing practices, and the need to ensure that changes to local practices are effected or the disease guidelines moderated to fit into local practices – whichever is the more appropriate. Change management was not a formal part of the process of implementation. In some cases, this meant that the process of care planning was an added feature of existing practice rather than an integral part of a revised practice.
- The need to provide significant and continuous training and support to health workers to ensure that the processes are sustainable, and that health workers are able to capitalise on the benefits of disease guidelines.
- Disease guidelines need to be viable within given resources. The development and attempt to implement comprehensive disease guidelines can be overwhelming for health workers. It is potentially self-defeating, in part because it can raise unrealistic expectations amongst clients, health workers and community organisations.
- In some cases, care planning was seen to be a tool for those providing services rather than a mechanism to allow individual clients to commence a process of self-management. For example, some health workers expressed an interest in having the care plan in a form that could be given to clients for their own use and education.

Local control and funder-provider partnerships are essential.

The Trials were community-based and demonstrated the importance and benefits of ensuring local control and local drive to effect change. They were as much about exercising the principle of 'community control' as they were about implementation of a new way of delivering health services (coordinated care and disease pathways). Braithwaite in his discussion of the relevance of systems theory to implementation of care pathways emphasises

the importance of the 'locus of control' (Braithwaite 2001). The Trials demonstrated the locus of control must be at the point where change is required – that is, within local health services.

The Trials also demonstrated that effective partnerships between funders and local providers are essential. Strict purchaser-provider models are unlikely to be effective in Indigenous communities (this is not to suggest that they are effective in the broader community). Local community-based providers of the health services had the core role of making things happen and assuming financial responsibility for the Trial and for health services. Funders, including the State and Federal health authorities, had critical roles in supporting the Trials in various forms including technical advice, financial guidance and inter-personal support. As Hindle (2001) argues, it is not a question of whether funders should have a role, but more ensuring that they have an "intelligent" role. The Trials demonstrated that funders do have valuable roles to play and that the Trial managers welcomed such a role but one that respected the principle of community control.

The process of implementation takes time.

Stakeholders tended to under-estimate the time required to develop and implement guidelines, including the time and effort to implement the IT infrastructure required to support care planning and the time it took to train health workers to the point where they fully understood and were skilled in the use of the guidelines and the accompanying IT system. There were a number of contributing factors including the fact that the Trial timetable itself was ambitious, and that there were a number of other aspects of the Trial that required management time and resourcing to resolve that did not allow Trial managers to focus solely on the implementation of disease guidelines.

Care planning requires adequate resourcing.

There are three aspects. Firstly, the use of disease guidelines when there are few resources other than to provide a basic acute response service is unlikely to assist and could hinder, particularly if staff are overwhelmed by the raised expectations. That is, resources are required to ensure there is the capacity to deliver the services specified in disease guidelines. Secondly, care planning itself requires resourcing both in terms of ensuring that staff have the time to implement the disease guidelines and the infrastructure to do so. Thirdly, health workers require mentoring and on-going support to ensure that they are confident in their knowledge and capabilities to operate in this environment.

Disease guidelines need to be flexible not prescriptive.

Disease guidelines by the very nature present to health workers a set of largely proscriptive processes that need to be followed. Some of the computer systems allowed health workers to modify the elements of the guidelines, but others did not. Not all systems allowed guidelines for patient with multiple conditions to be merged. Even when there was technical flexibility, there was a tendency to maintain a uniform and thus comprehensive approach to application of guidelines, rather than modifying and moderating the guidelines to the individual patient circumstances and within the available resources. This may partly explain why the clinical audits identified that actual services provided were in some cases far short of those proscribed in the guidelines.

The national evaluators noted that the Trial experiences "suggest that full and comprehensive needs assessment may not be necessary or appropriate for all clients. A more selective and targeted approach may be more beneficial, enabling scarce resources to be applied to that group of clients for whom co-ordinated care will provide the greatest benefit. An appropriate mechanism for identifying target clients will need to be developed to assist in this process" (KPMG 2001a, p30).

Summary

Whether or not the co-ordinated care models are sustainable in the longer term will depend on ongoing funding and on overcoming some of the challenges described above. The use of a complete and literal model of care assessment and care planning for each individual may not be sustainable for all trials. They will require streamlining so that clients with minimal health care needs are not subjected to the same comprehensive

assessment processes as those with more complex needs.

Care co-ordination may only have a modest long-term effect, if operating problems are not overcome and if the model itself is not fully integrated into clinical practices. For this to occur, health centre staff need to drive the reform process and need to be supported during this process, otherwise the day to day clinical demands will take precedence over care planning.

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