

Engaging the Decision Makers: Planning With Rural and Remote Communities for the Delivery of Health Services Using Telecommunications Networks

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Abstract

A participatory action research study was conducted using a single case to describe and analyse community participation in health service planning by government for regional, rural and remote area health care and telecommunications infrastructure planning in Western Australia. The study provides an account of the state government of Western Australia's planning for the implementation of a telecommunications network infrastructure between 1998 and 2002.

The purpose of the study was to examine the process of participatory planning within the dynamic political, economic and social forces that impact on the development of regional, rural and remote area health services. Specifically, the study outlines the challenges in providing for significant local participation in projects that are centrally initiated and controlled. It examines the problems in planning for projects that incorporate local community based beliefs and needs, the requirements of collaborating multiple state and national government departments, and the private sector.

In-depth interviews and a survey was used to collect data and analysis clearly indicated consensus between all respondents that telecommunications did offer the opportunity to provide increased, improved or alternative health services. In general, participants identified a number of barriers to the planning process including; a lack of local community inclusion in planning committees, poor communication within central government, overuse of external consultants, local information being overlooked in the final implementation plan, a bias toward the medical view of health services, and a limited scope of invitation to contribute.

Analysis revealed a process for, and the outcomes of, engaging communities when planning for health and telecommunications services which involve the public and private sectors; and indicates the importance of engaging the organisational and political stakeholders who make the final decision about outcomes.

Keywords

Community participation, health care decision making, telecommunications, telehealth, action research

Introduction

New and rapidly emerging communications and information technology developments are occurring globally in health contexts facing unparalleled pressures for a reduction in costs and the increasing demand for improved patient care (Marshall 1997). Global health industry trends reveal a common need for integrated services and a continuum of care, whereby patients and clients receive continuous care in an appropriate setting from a network of multi-disciplinary providers in acute hospitals, community-based facilities and home-based care.

To achieve this, health service issues must be addressed including: escalating costs of delivering high quality care; inadequate access to primary and specialty care for segments of both rural and urban populations; duplication of expensive facilities and infrastructure; and access to current, relevant and accurate information for both providers and consumers (Marshall 1996).

This situation was recognised by staff within the government of Western Australia who identified that new opportunities were offered by telecommunications, interactive multimedia technology and information technology to transform the quality, efficiency and effectiveness of health service delivery, management and administration, and to address some of the problems of access to and equity in health services. It was decided that health related telecommunications (telehealth) applications had the potential to make a positive difference in the lives of Western Australians and improve the delivery of health care to remote and rural areas.

In the assessment of this new opportunity, for telehealth applications to integrate successfully with existing health services, a telehealth project in Western Australia needed to address three major issues. Firstly, the need for extensive community consultation; secondly, the lack of a suitable, economically costed communications infrastructure to support Telehealth; and thirdly, a tendency for telehealth to follow a medical model of health care based on the management of illness rather than the maintenance of health (Gott 1994).

Community participation in planning

The trend toward greater community involvement in health care decision-making is evident in the literature (Redden 1999) and includes widespread consensus amongst policymakers about the importance of participation in planning. As governments around the world adopt the concept of community participation in health care, it has become a principal underlying policy (Morgan 2001), ensuring that the principle of participation is merged into policy and planning at the local, national and international levels (Chambers 1995; Kahssay and Oakley 1999).

Participation in planning for health programs and services can be seen as a means to achieve a set objective or goal, or as development activity in itself (Baum et al. 2000; Legge 1990). To enable an increased opportunity for participation, Parker et al. (2003) and Ismael (2002) propose a model using

a community-based participatory action approach that recognises the value of involving intended beneficiaries such as local residents and organisational staff.

Ismael (2002) and Maloff et al. (2000) describe the relationship and the interaction of social, economic, political and environmental variables in communities as essential. Community involvement and a participatory action approach can have a positive impact on the success of project planning and implementation. However, a large number of variables and issues are relevant to success. These critical issues relating to participation include the organisation's and individual's skills in working with community groups, the extent of communication and planning with other groups serving the same community and the level of community participation in organisational planning (Parker et al. 2003). Other issues included the large number involving external funding sources, the imposition of funding agency guidelines on the communities and the amount of guidance by experts and the methods of collecting data to monitor the participatory process (Naylor et al. 2002).

Naylor et al. (2002) expand on this to include critical issues in the evaluation of participation, variations in the meaning of community and participation among participants, and the complexity of evaluating the extent and incremental progression of participation in a multi-level project. Baum et al. (2000) describe the key issues debated in the literature on participation as those regarding types, purposes and levels of participation and their measurement in a population.

Background and context of the study

Despite the rapid development nationally and internationally of health related telecommunications (telehealth) services, at the time of the study no studies were found which examined community planning processes for telehealth. By involving community members and health professionals' needs and interests in the planning process, this study aimed to determine the contribution telehealth applications could make to improving efficiencies of health services and to improving access to health services and information for people living in rural and remote areas.

The study had five interrelated goals. It was designed to gather information on the needs of community members living in four regional, rural and remote sites in Western Australia relating to health, telehealth services and the changes required to their local health service to meet these needs; reviewed how organisations (in this case, the state government) formulated strategic plans for implementation of these needs; the problems of incorporating community, government and funding expectations and needs; and the levels of community and stakeholder participation in planning for the telehealth services.

Consultation with people from the sites determined community needs, project deliverables and the scope of requirements. Continuing discussions with private telecommunications providers and the government sector were directed at meeting the identified requirements of the rural and remote communities, and delivering a communication network that was accessible by the public and private

health sector, ensuring privacy and security of confidential information, and allowing the transfer of data, video and voice in a system.

The research team completed a report of each site's requirements (Site Implementation Plan), which were summarised and produced as the overall Telehealth Project Plan. This plan was subsequently amended at government management meetings, and the Telehealth Implementation Plan was endorsed for implementation in rural and remote areas of Western Australia.

Description of the study

The study used a single case to describe and analyse community participation in health service planning for regional, rural and remote area health care and telecommunications infrastructure planning in Western Australia between 1998 and 2002. The case study provides an account of the state government of Western Australia's planning for the implementation of a telecommunications network infrastructure to provide telehealth services to remote and rural areas of Western Australia — The Telehealth Project (Health Department of Western Australia 1997). The Telehealth Project was a government-initiated development funded jointly by the state and federal governments.

In this context, the purpose of the study was to examine participatory planning within the dynamic political, economic and social forces that impacted on the development of regional, rural and remote area health services. Specifically, the study outlines the challenges in providing for significant local participation in projects that are centrally initiated and controlled. It examines the problems in planning for projects that incorporate local community based beliefs and needs, and the requirements of multiple state and federal government departments.

The study did not seek to provide an in-depth analysis of telehealth services, health service planning, telecommunications technologies or to investigate the democratic process of government. Rather, it presents an overview of planning for health and telecommunications services, illustrating the process of participation and decision-making in government projects.

Consequently, the study sought to analyse: (1) the needs of community members living in regional, rural and remote areas of Western Australia in relation to health, telehealth services and the changes required to their local health service to meet these needs; (2) how the government formulates strategic plans for implementation of telecommunications technologies (in this case, the Telehealth Project); (3) the challenges of incorporating community, government and funding expectations and needs; and (4) the levels of community and stakeholder participation in planning for the Telehealth Project. The study sought to develop a model for incorporating technology in planning.

This paper is based on part of the study, particularly focussing on improving the process of incorporating community, organisational and political requirements.

Methodology and paradigm

In order to achieve this purpose a participatory action research method was chosen. The approach enables study participants to investigate their own problems and issues, to formulate accounts of their situations, and to provide effective solutions to problems experienced (Stringer 1996). With people being engaged as active participants in the research process, the result is a practical and theoretical outcome related to their work or lives (Dick 1994; Kemmis 1988; Stringer 1996).

Participatory action research is a methodology grounded in a naturalistic paradigm (Erlandson et al. 1993; Lincoln and Guba 1985) and rests on the notion that:

“shared constructions, developed collaboratively by empowered individuals, are the basis for significant cross-cultural and interpersonal understandings.” (Erlandson et al. 1993, p. xvii).

The naturalistic paradigm “assumes numerous realities exist and admits ungeneralisable, context-specific subjectivity as a valid process of inquiry” (Twining 1999). The aim of the naturalistic paradigm is to present social reality, as it exists, as ever changing meanings embedded in a cultural context. It seeks to understand the experiences and perspectives of different types of people in the particular context studied. It focuses on people’s everyday experience and their own ways of interpreting events in their lives (Stringer 2002).

Planning for telehealth services in rural and remote Western Australia involved consultation with government agencies, local health practitioners, community and interest groups, and individuals. A participatory action research approach enabled inclusion of diverse participant experiences as a means of reviewing the problems inherent in achieving community participation when planning health services, leading those involved having greater or extended understandings, and being able to formulate actions for which they are willing to take ownership.

Data gathering

Data collection was undertaken in three stages — research design, participant engagement and evaluation of the planning process, and used an interpretive process proposed by Denzin (1989).

The sample of study participants derived from four rural and remote sites in Western Australia. The participants were community members, health professionals and public servants. Some study participants were acknowledged by the key community stakeholders to be able to represent the perspectives of a group within the community or the community as a whole. Other people involved had contact with these sites and provided contextual information for the study. They included specialist health service providers, employees of various government departments and metropolitan health professionals.

During a 19-month period, individual in-depth interviews, focus groups and committee meetings were conducted. Participants involved with the research process explored the contribution telehealth applications could make to improving health services in their own rural and remote West Australian site, the level of community participation during planning for telehealth, and acceptability of telehealth applications proposed by the state government. A follow-up survey was undertaken to determine satisfaction with planning outcomes.

The main source of data related to health, telecommunications and the related social context in the rural and remote Western Australian sites was provided by 30 rural community members, and individuals representing their own interests or those of community interest groups and local government; 84 rural and remote health professionals; 44 public servants; and 18 metropolitan health professionals (plus data from those involved in tertiary teaching hospital telehealth technology trials).

Many health professionals living and working in rural and remote areas were key community members and were considered to represent local community interests, as well as health issues. This was particularly evident in the smaller sites.

Public servants were predominantly from state government agencies responsible for health planning, telecommunications, health information technology, and hospitals. Committee meetings relating to telecommunications involved representatives from all state government departments. Discussions and meetings also involved commonwealth public servants from the Department of Communications, Information and the Arts.

Data was also collected from documentary sources. Data collection focussed on desired outcomes including: an understanding of potential telehealth applications; telecommunications requirements to deliver these applications; the political, economic and social contexts of the sites; and planning considerations. Documents identifying potential stakeholder groups and statistical records included primary sources such as health statistics, demographic and social data, and written submissions about local health service requirements.

Secondary sources such as government and telecommunications industry plans and reports included strategic plans and policies which represented the official views of the commonwealth and state governments, and reports commissioned by their agencies to address particular issues such as business plans for telehealth, telecommunications markets and funding issues. The data also included documents related to equity programs and strategies to foster broader participation by residents in rural and remote areas, women and Aboriginal and Torres Strait Islander people.

As the study progressed, participants reviewed any literature relevant to their situation as part of the data collection process. This assisted in identifying pertinent information to enhance the

understandings emerging from other sources. Other studies within the literature provided other perspectives incorporated into the process of data collection and analysis.

Study findings — Rural and remote area participants

Individuals and groups reflected on their health needs and current practices. Defining what is health from a social perspective created discussions about the kind of health problems to be addressed and the scope of the project. This enabled a broader view of the gaps in health service delivery or practice. The result was a Site Implementation Plan.

All sites identified the lack of access to services for those living a long distance from a town centre. Identified were a need for improved community education for all age groups, and access to information for the community to assist work practice, such as grain and stock pricing through the Internet, farm advice and financial counselling.

Issues surrounding clinical practice included difficulties having case conferences when staff are 'visiting' rather than based in the town; access to regular clinical services; assistance with complex clinical cases; a lack of specialist clinical information from medical and allied health specialists; and access to monthly case presentations or grand rounds from metropolitan area. Health professionals in rural and remote areas saw the opportunity to improve team work through meetings using internet technology, access to the latest clinical practice information, access to education and training opportunities locally, and overall, a more flexible delivery of education programs to include all small sites in region, thereby supporting a team approach. Other areas of opportunity included improved access to support groups, family link-ups to discuss issues, Guardianship Board assessments, interpreter access, and disabilities information.

Telecommunications issues surrounded improved bandwidth; access to more telecommunication infrastructure, particularly linking to other health services; a need for a more unified approach to telecommunications for services, rather than each clinical application planning, purchasing and evaluating their own telecommunications and equipment; security issues related to use of telecommunications network by non-health staff; and improved information.

"We need a system that we can find people without difficulty, we need a structure that is easy to follow and straight forward. We are split into our little regions and they are all autonomous, therefore we find that when we need to access these regions we don't know who there is or who is available".

In all the study sites, mental health was clearly the major issue of concern. Participants deemed telecommunications services as a method of improving and increasing access to psychiatric services, patient management advice and second opinion, case conferences, and particularly, a way to reduce patient travel and away from family. Highlighted in all sites was the need for domestic violence

counselling and victim support, and relationship counselling, to supplement the inadequate counselling available or provide counselling where none existed.

Study findings — The decision makers: organisational and political stakeholders

The resulting plan (incorporating each Site Implementation Plan) was summarised and presented to government management committee overseeing the study and project implementation. Significant changes were made to the plan, prioritising hospital based clinical requirements, over the requirements of the rural and remote area participants. No further consultation with participants was requested and the new Telehealth Implementation Plan was endorsed.

Study findings — Feedback from rural and remote area participants

In general, respondents of the survey who had been involved in the planning process expected to contribute toward improving, enhancing or making health services more accessible in their regions; and to contribute to the body of knowledge surrounding the application of telehealth to rural and remote Western Australia. A low expectation of the process was expressed due to previous experience with consultative process whereby information provided was ignored.

Overall, respondents' expectation of the contribution they were being asked to make to the telehealth planning process was not met. Whilst one health service manager indicated that personal expectations were met, "...staff seemed to be excluded from the inner circle of decision making" by regional and central government management. Another indicated that whilst expectations were "reasonably well met ... over the last 12-18 months it seems that the government have been forcing upon (site) what uses telehealth will be used for, even if this is at odds with the (site) views". Additional work was also produced for the local sites through the need to develop protocols and procedures for telehealth use.

Opportunities for input into the planning process were considered extensive and regular by regional health service management staff. However, community members and service providers considered opportunities offered to be minimal and only in the early stages of the planning process. Improvement was noted following the appointment of locally based coordinators, enabling "local ownership".

An opportunity to feedback on findings from the initial consultation process was provided for, generally reflected the issues raised and acknowledged prior experience of respondents. In contrast, minimal or no opportunity to feedback on the Site Implementation Plan was provided to community members or service providers. However, regional government management staff were provided with good opportunities to feedback through further consultation with central government staff.

Generally, respondents found the Telehealth Implementation Plan did not address the issues raised during consultation, was unacceptable and "totally inappropriate", and neither met community needs, nor provided opportunity for all sections of the community to have input. "I had input, but listening to

staff did not follow". The Plan did not reflect recommended locations, types of equipment or links to external providers or intraregional sites, and included a strong medical focus and little community health application. "The remote applications and community uses aren't being done. Only hospital/allied health related ones".

"By linking to the (intraregional) sites first this would have allowed people who have limited access to any medical consultation to have this opportunity thus reducing the problems associated with getting Aboriginal people to leave their homes for extended periods and overcoming travel problems especially in the wet season. Also this would have enabled the RANs (Remote Area Nurses) to have greater access to resources such as second opinions, education information etc. By linking to (metropolitan teaching hospital) the entire process became bogged down in lawyers and red tape. Even for education links everything had to be booked in writing one week in advance – given that workload demands frequently made it impossible to predict until the day, who could actually attend sessions – this did not work well".

The inappropriateness of the Telehealth Implementation Plan was due to "little or no consultation with would be users", and too far from an acceptable community site or cultural centre. The Plan "doesn't meet community needs – decision made externally by regional government office". "We need to get the regional centre(s) right first before we start taking the plan further; and this is way off at present". "Telehealth agenda was being forced externally".

Again, respondents at the senior health service management level had a contrasting view, noting the Telehealth Implementation Plan addressed issues raised "very well" and "adequately ... for sites in hospitals or health centres". Community respondents in one site noted that after the Plan was reviewed and adjusted "there is a far greater potential for use now that future sites are in more appropriate places and not in 'political' places".

Consensus was found between all respondents that telehealth did offer the opportunity to provide increased, improved or alternative health services. Applications included in the Site Implementation Plans would assist in avoiding long trips for staff or clients, while still allowing "face to face" contact. It would also enable increased opportunities for staff education and professional support, administration, rehabilitation services, tertiary referrals, consultation with medical staff to and from the metropolitan area, increased access to speech pathology and diabetes education, and greater continuity of care. The applications would also reduce costs and time associated with the management members attending meetings, and "helps children lose less school time, saves costs to parents for fuel".

"Fantastic means of spreading education to disadvantaged staff in smaller remote sites eg one day twelve nurses at (remote site) grouped/crowded around their computer based telepsych unit to watch and hear a visiting midwifery expert. It was the first time many of them had this type of education in years! And all reported favourably despite the limitations of the size of their screen".

However, one respondent considered the impact of the Telehealth Implementation Plan to be “very minimal because of the area in which the government told us telehealth would be used, rather than ‘using it’ in ways it could be useful”, and another stated that “If all sites are in, it will not meet the needs of many community groups”.

Community representatives and their advocates were not provided an opportunity to have input into planning in all regions. Respondents reported lessening community involvement during further consultation as the planning process progressed. Planning input was predominantly derived from the regional health services, and through local management committees, focussing on health service providers within the hospital network. Respondents describe the Telehealth Implementation Plan as having a medical focus that offers increased access to medical services. However, the strategies included in the Plan would not meet the needs of “many pastoralists, non aboriginal, and aboriginal communities would not have access”.

The lines of communication between community and central government agencies during all phases of the planning process were considered by respondents to be both transparent and ad hoc. In general, respondents determined that central government listened to regional medical and health management, whilst communication with the community was better facilitated with a locally-based regional coordinator.

“Probably ok, but they never appear to act on suggestions from community. I guess its just too hard for them. Becoming very cynical about planning processes, much talk and lip service paid to working in the community setting but the money never goes where their mouth is and it all ends up at the central medical orientated centres and never in the community. This appears to be happening again.”

Overall, regional health management staff expressed a high level of confidence and acceptance in the planning process and the Site Implementation Plan. In contrast, community and service providers considered the process to be very poor, expressing minimal confidence in both central and regional government understanding of “the real versus perceived needs of remote areas”.

Respondents identified a number of barriers to the planning process. These included a lack of local inclusion in planning committees and the subsequent Plan; initial consultation not continued — subsequent consultations conducted with regional head office only; local key committees not seeking wider community opinion; poor communication within central government; and that relevant local information not included in the Plan.

“Regardless of my input the government had a preconceived idea of what was needed ...the real needs of the region were never taken into account”.

A strong theme emerged where it was considered that the government were bringing predetermined ideas and thereby assuming that local stakeholders “did not understand the issues”. Rural and remote area participants felt that there was a bias toward the medical staff view; a limited scope of invitation to contribute; inadequate consultation with remote sites in regions; poor information transfer from central government to sites; suppression of health service provider views at remote sites by regional health management stating that they were “Scared that I will get in trouble for responding. Have already had my knuckles rapped when I gave my opinion”.

“Telehealth should be in the best place for those who need to use it”.

Discussion

The Site Implementation Plans were products of meetings to determine the social contexts, health needs and technology requirements of the participants, and demonstrated a collaboration between local health service providers, key stakeholders, local community members and local community workers. However, the Telehealth Implementation Plan was clearly not a reflection of this collaboration.

Whilst preparation for community consultation was sound the result was not. Planning for participation involved identifying issues, participants and stakeholders; choosing a suitable methodology to support the study; having access to adequate resources; having a skilled team for implementation; and reporting in a manner that was considered to be acceptable and appropriate to the relevant participants. The result was not acceptable to the rural and remote area study participants, and reflected only the interests and predetermined ideas of the organisational and political participants within the study.

Further planning with the organisational and political stakeholders was required to ensure the outcomes were acceptable to all parties and that there was a commitment to implement the outcome.

Conclusions

The study findings and analysis presented here show the opportunities lost if project plans or studies focus only on participation with those community members whose direct interests are to be met. Organisational and political stakeholders must be more clearly included as participants within a study, thereby opening channels for discussion and feedback throughout. Engaging the decision makers in a shared planning process rather than being passive recipients of participant information collected during the study, provides a greater opportunity for successful outcomes.

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