

# Chronic disease self-management – a health management approach for patients in rural and remote communities

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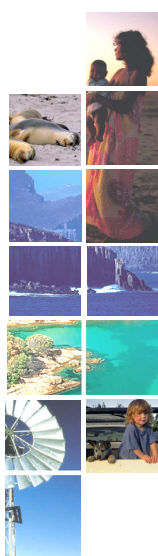
## ABSTRACT

**Objectives:** The Sharing Health Care SA project, a chronic disease self-management (CDSM) strategy for patients in rural and remote communities in South Australia, was designed to develop and demonstrate new approaches to chronic disease self-management within rural and remote communities. It also complemented and promoted the Enhanced Primary Care (EPC) program and utilisation of new Medical Benefits Schedule (MBS) item numbers for health assessment and care planning which were implemented in November 1999 following the first round of the Council of Australian Government (COAG) Co-ordinated Care Trials.

**Methods and results:** The project was established as a three-year demonstration project rather than a randomised controlled trial (RCT). The project team worked with GPs to prepare care plans for patients with chronic illness and apply goal setting and outcome measurement tools developed for the COAG co-ordinated care trial and adapt these tools and processes to support a workable CDSM model for rural and remote communities. Initial results from the co-ordinated care trial suggest that the Partners in Health and Problem and Goal approaches are effective behaviour change strategies leading to improved self-management and commensurate improvements in health and well-being for patients with chronic illness. Literature suggests that the outcomes achieved through such programs are more marked if formal goal setting and structured care planning is deployed to support behavioural change.

**Conclusions:** Initial outcomes of the SHC SA project suggest that the processes of goal setting, patient education, symptom monitoring and reporting can produce more active participation by patients with chronic conditions in the management of their health. This, in turn leads to increased uptake in appropriate preventive and primary care services and increased levels of patient empowerment and self-management skill and ability among participating patients. This may also be the basis for reduced recourse to unplanned acute care services required as a consequence of chronic illness and related improvements in health outcomes for this population.

**Implications:** CDSM is recognised as a valuable strategy for educating and supporting people with chronic conditions to improve their illness management strategies. We have detailed some elements of this approach for both remote and urban communities and this continuing work provides a model for CDSM programs generally, highlighting some effective and transferable strategies for management of chronic conditions in other contexts.



## BACKGROUND

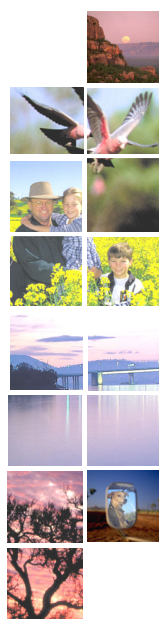
The COAG initiative in co-ordinated care enabled research into the development of systems for more effective management of chronic illness with the implicit assumption that much of the burden of chronic illness in the community can either be prevented or managed to reduce the resultant demand for acute care and improve health outcomes for patients (1). This work was based on pooling funds for preventive care as a strategy for improving health outcomes for patients with chronic conditions and reducing unplanned, preventable hospital admissions for this group (2, 3). The recently published evaluation of the co-ordinated care trials for Indigenous communities also highlights the success of these processes for Aboriginal people and suggests a way forward for chronic disease management programs within Aboriginal communities generally.

As a consequence of the COAG agenda, new item numbers were introduced to the Medical Benefits Schedule (MBS) for health assessments, care planning and a range of case conferences and service planning for patients with chronic illness in an attempt to reduce and manage the incidence of chronic disease. This has led to a steady uptake in the use of the new items in some areas and especially in rural South Australia. The uptake of the EPC items promotes integration of GP-based health assessments and care plans, allied health services and other primary care delivery systems. The Commonwealth Regional Health Service (CRHS) initiatives, in rural South Australia in particular (Eyre Region), further enhance this process through improved co-ordination of service provision for patients with chronic illness.

However, in spite of there being limited evidence of improved health outcomes resulting from co-ordinated care generally (4) or care planning in particular (5), the practice seems set to expand through the agency of the MBS system (6). What is needed now is more clarity about which strategies within the general framework of co-ordinated care and primary health care actually achieve improved outcomes for patients.

One outcome of the SA HealthPlus co-ordinated care trial was the identification of elements of the care planning and problems and goal approach that led to improved patient compliance with treatment programs and the uptake and maintenance of beneficial lifestyle options (2, 7). An additional finding was that self-management could reduce crises and improve health outcomes for some categories of patients with chronic illness (2, 8). The question arose as to which elements of the co-ordinated care process suited which patients and which patients were most likely to respond to self-management strategies.

Consequently, a number of chronic disease self-management (CDSM) programs have been established to explore the most effective ways to introduce patients to better managed systems of care and to measure the impact of self-management on patient behaviour change and resultant health outcomes. The Eyre Peninsula CDSM pilot program for Aboriginal patients, begun in 2001 in collaboration with Flinders University and the State DHS, was one such venture. This pilot aimed to develop CDSM strategies that were culturally appropriate and applicable to Aboriginal people in both urban and remote communities, and to document these approaches as possible models for other communities. A central hypothesis of this CDSM demonstration program was that a modified form of goal setting and initiation into self-management



is possible for Aboriginal people and that when implemented, such approaches could lead to improved quality of life and health outcomes for this group.

The Sharing Health Care SA (SHC SA) initiative in Whyalla and Port Augusta builds on the initial work of an Eyre Peninsula chronic illness management pilot program and encourages further integration of the CDSM initiative with existing EPC process and resources. This project is also consistent with developments elsewhere that have identified that chronic disease, much of which is preventable and/or manageable, has become the major burden upon our health systems. In the US the impact of chronic diseases such as diabetes, coronary heart disease, hypertension and asthma, for example, already account for 70% of the nation's health care costs (9, p579) and this burden is set to rise by 15% by 2010 and by an estimated 60% by 2050 (10) as our population ages.

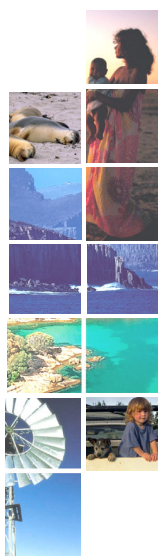
It is now clear that the effective management of such chronic conditions is a major health system challenge and that our health efforts will need to focus increasingly on illness prevention, population management and community and patient partnerships (11) as well as upon acute care delivery. The challenge is to identify and manage not only emerging chronic illness, but also to intervene at the social, economic and environmental levels to prevent much of this illness at its source (9, p586) through more population based approaches to the management of community and individual well-being.

## THE IDEOLOGY OF CDSM APPROACHES

Self-management, in the context of this study, refers to a patient's ability to understand their condition and to manage and organise their access to key elements of their care. A patient who understands their illness, how to recognise early warning signs and take appropriate action, how to manage their lifestyle for optimal health outcomes and how to work effectively with health care providers and carers is seen to be a good self-manger of their condition.

Self-management does not mean patients having to manage their illness by themselves or in isolation from mainstream services. Quite the contrary, a good self-manager knows what services to access, how and when in order to maximise their own well-being. This implies an effective partnership between patient, carer and health service provider to ensures that essential elements of care are available when needed and that the various providers involved in a patient's care are informed about key aspects of this care and are able to work together to ensure the best possible outcomes for patients.

There may be some cynicism in parts of the health care community about this philosophy where it might be seen as nothing more than an attempt to manage down irrational and ad hoc health service demand to ensure that the health system, particularly the acute sector, is not overtaxed by preventable health crises. Leaving aside the ideologically burdened proposition that CDSM approaches may be elaborate strategies for instituting demand management rather than effective methods for improving patient health outcomes specifically (12), there appears to be merit in the process for both Aboriginal and non-Aboriginal people. That is, even though CDSM might well be a construct for shifting demand away from an overtaxed acute system in crisis, in the process it may also contribute to improved health and well-being for



significant numbers of patients with chronic illness and prepare the way for the development of a more integrated preventive approach to health care generally. Whether or not these improved health outcomes can be achieved within the existing cost structures available for the care of patients with chronic illness is yet to be determined.

Whatever may be the outcome of our experiments with co-ordinated care and chronic disease self-management programs, the Australian health system appears no longer able to afford to deliver costly acute health services at the current rate of escalation. Strategies need to be found to reduce demand for acute care, especially if this demand is preventable through early intervention programs (13). The Sharing Health Care program is one such strategy designed to ensure that illness which is essentially preventable is actually prevented if possible and that unpreventable illness is managed in ways other than by resorting to unplanned end point acute intervention as a reaction to crises resulting in the main from chronic disease complications.

The Co-ordinated Care venture showed that some impact can be made on the demand for acute care by improving care co-ordination and patient approaches to self-management. These approaches can now be expanded through the wider application of new MBS item numbers for health assessment and care planning to reduce the overall burden of illness and associated health care costs upon the Australian economy.

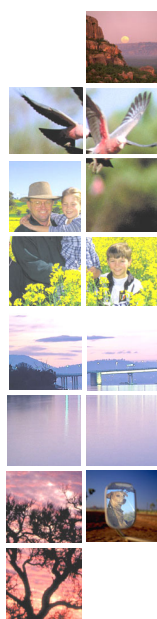
## THE SHARING HEALTH CARE SA MODEL

### Project goals and hypotheses

- Sharing Health Care will help improve health-related quality of life for people with chronic conditions, particularly those with co-morbidities.
- That Sharing Health Care will help to facilitate improvements in awareness and understanding about the benefits of self-management, as well as improving communication and collaboration between general practitioners, people with chronic conditions and their families and other health professionals.
- That the Sharing Health Care initiative will result in more appropriate use of health services.

The SHC SA project was designed to trial the application of CDSM principles with a group of patients with complex chronic conditions over a three-year period and to test the key hypotheses that suggest that these approaches will lead, over the trial time, to

- improved health outcomes for the enrolled population
- the development of improved patient knowledge about their condition and improved uptake and application of self-management and self-help skills in the enrolled population
- improved access to and use of relevant health care services for the enrolled population.



A parallel thesis is that the process of implementing the SHC program will also

- enhance the use of the new MBS item numbers for health assessment and care planning and consequently lead to the development of more effective collaboration between the various agencies involved in working with and caring for patients with chronic illness

This implies that the SHC SA project will help to enhance the uptake and application of formal care planning and service planning for patients with chronic conditions as these processes have been shown to support more effective behaviour change and lifestyle habits for patients with chronic illness (7).

## Eligible patients

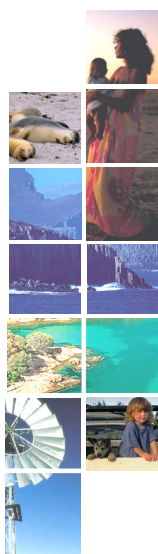
The SHC SA project targeted patients with chronic and complex health conditions in the following categories

- diabetes
- cardiac conditions
- lung conditions (asthma, COAD, COPD)
- osteoporosis
- arthritis
- with co-morbidities of depression associated with the main illness group.

Aboriginal patients 35 years and older and non-Aboriginal patients 50 years and older were recruited mainly through the standard EPC care planning process applied through GP surgeries in collaboration with allied health teams. In the Pika Wiya Aboriginal Health Service patients were recruited by Aboriginal health workers who then prepared these patients for their involvement in a subsequent formal care planning process with key health professionals in the service.

Chronic disease support initiatives and project interventions were offered to eligible patients. Interventions and supports included...

- goal setting and monitoring
- the Partners in Health (PIH) intervention at 6 month intervals
- the Stanford (Lorig) style generic CDSM course
- modified CDSM courses to suit client need
- one to one CDSM training and support
- illness specific training and education
- access to self-help and education groups
- access to resources and information through primary health care centres.



## Recruitment, sites and core data sets

Patients were offered the SHC SA project support as one of the service options available to them as a consequence of their participation in the EPC care planning process. SHC staff worked in collaboration with allied health teams, surgery staff and GPs to both assist the care planning process as health care providers and to offer additional CDSM supports to patients meeting the recruitment criteria.

Patient data were collected, at 6-month intervals, around patient access to and use of health care services, key demographic information, patient knowledge of their illness and their ability to self-manage along with other illness specific details collected through the care planning process. After due consideration of tools such as the SF12 and SF36, the modified “Stanford 2000” Health Assessment Scale was used to collect patient data for the national evaluation. The tool focuses on the degree to which chronic illness (initially arthritis in the US context) impacted upon a patient’s quality of life and ability to function effectively in the community. The final health questionnaire used in all projects also incorporated elements of the “Kessler 10 Depression Scale” and other indicators of service utilisation and patient satisfaction.

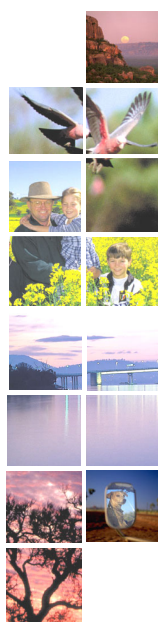
Other illness specific data were also collected at the project level and we used the “Partners in Health Scale”, developed for the COAG trials by the Flinders University Co-ordinated Care Training Unit, as both a tool for goal setting and as a measure of change in patient knowledge and skill in relation to their self-management inclination and ability. This tool is currently being refined and validated as a surrogate measure for effective changes in patient self-management ability and skill.

## Partners in health and care planning

The approach taken to introduce self-management into routine care is based on the assumption that patient behaviour change will be limited without clinician change. To bring this about, an education program for clinicians begins with a discussion about what constitutes self-management and in particular the attributes of successful self-management and the barriers to this process. The focus is then on the assessment of an individual’s self-management capacity by the clinician using the 12 questions of the Partners in Health (PIH) scale through which issues are jointly identified by the clinician and patient.

Underpinning this approach are concepts of behaviour change and motivation. Once areas for self-management improvement are identified, creating the opportunity for change, motivation is enhanced by a goal setting process (14). Behaviour change is then captured in the care plan agreed between patient and clinician, which when signed by the 2 parties becomes a symbolic contract, with shared commitment to action. Integral to this process is review of progress and goal attainment at three months, supported by the EPC care plan review item number.

Literature suggests that the outcomes achieved through such programs are more marked if formal goal setting and structured care planning is deployed to support behavioural change (7, 15, p463, 16).



## Illness specific interventions

The SHC SA team works with local allied health teams, GPs and pharmacists to provide, in addition to the generic self-management support for patients, access to a range of services through the formal referral process. By regularly reviewing patient commitment to and involvement in the management of their care, any shortfalls in service access and best practice treatments can be identified and remedied with the support of the wider team of health professionals involved in chronic illness management.

## Education and self-help

Many studies have confirmed that education alone has little impact on individual behaviour, however education targeted at the needs, education level and preferred learning style of the individual is a first step towards achieving more effective change. It is important therefore for the assessment process to result in interventions targeted to the individual. This may mean a one-to-one session with a GP, diabetic educator, a group program, information giving by pamphlet, video or web based media. This then needs to be followed by skill development. Work of Kate Lorig (17) and colleagues has demonstrated that there are a number of common problems across a range of chronic conditions and that generic skills such as stress management, problem solving, goal attainment, assertiveness and graded activity can be taught in a group program resulting in improved health outcomes and reduced hospitalisation.

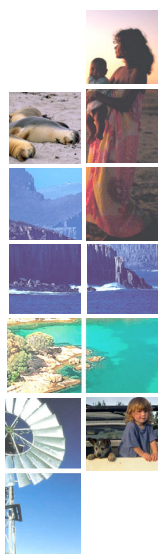
## Behaviour change

The Sharing Health Care program implies that the clinician practice patient centred care where patients have an active involvement in decision making about their illness management. Whilst this approach is espoused as being ideologically sound, its real value is in providing an environment in which the patient feels believed and listened to so that they are ready to make commitments to address change in their lives and/or in the way they manage their illness. Life factors influence chronic illness and the illness impacts on emotional, social and financial aspects of their lives. A semi-structured interview, followed by goal setting and a care plan provides a way of bringing these issues out into the open and addressing them in a step-wise manner.

Patients have chronic illness for life. Things do not have to be addressed in a hurry. Small goals achieved along a path to longer-term goals can effectively maintain behaviour change. This process also allows the clinician's concerns about issues such as smoking, diet, or weight to be recorded on the care plan and, whilst these may not be the patient's first priority, assistance with their priorities provides a negotiated environment in which both sets of goals can be addressed.

## EPC links and sustainability

A key element of the SHC SA project was the need to build sustainability beyond the project stage for successful activities such as structured support and education programs for patients with chronic conditions. One way of creating sustainability was to build as much activity as possible around existing funding and service delivery. That is, to encourage and support GPs and allied health teams to use the EPC system



for care planning and to then provide other services to support the structured care planning process such as self-management training for patients. During the project, the Partners in Health approach demonstrated alternatives to the standard “medically based” care planning process which to date has tended to alienate patients or at least not involve them actively in the process of setting goals and managing the participation in their care processes.

By the end of the project it was hoped that these elements, having been demonstrated to be possible and effective in improving patient involvement in their care, would be adopted at least in part by those continuing the approach to primary care; the GPs, allied health teams and other providers. In addition, the demonstration and experience of patient empowerment and involvement in the primary care process would also remain as a lasting legacy of how effective planning and intervention must involve patient-centred decision making and commitment to action.

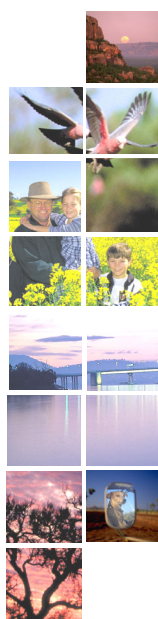
The SHC Centre was built significantly upon consumer and volunteer support so that once established and running a team of local community people, supported by health professionals, would be able to continue the patient support function of the resource and information centre. Also, local consumers were trained in the Lorig self-management format to become lay trainers in their own right and able to continue working with at risk patients into the future.

## GP and allied health collaboration

To date, limited additional collaboration between allied health and GPs has been effected. The main problem in rural and remote communities is a lack of health professionals to do the existing work so the addition of other tasks around the preparation of multi-disciplinary care plans simply created more burdens. In the longer term, perhaps, better co-ordination and collaboration might serve to reduce many of the “crisis events” being managed within the system, but in order to prevent these outcomes and to reduce ad hoc demand, additional preventive resources will be required. The GP is able to employ staff to support the care planning process with proceeds from the EPC items for health assessments and care planning, but there is, to this time, no additional funding in the system to pay for increased allied health work that may follow from this planning. The assumption is that state based funding has already been provided for these services, but most allied health teams are fully committed in terms of work demands and have little flexibility to work differently.

The interface between private GP practices and publicly funded primary health care teams is therefore problematic and success in this area still relies very much on the good will of the practitioners involved. The best collaboration is found in areas where integrated health services like Pika Wiya are incorporating a wider team approach to preventive primary care. The new commonwealth RHS structures are also well placed to work in this way as there is no distinction between the medical and community based services; all staff, GPs and allied health workers are employed by the same agency and working together with the same outcome aims for the community.

Where the private/public interface remains, this will continue to create some anxiety between GPs and public health professionals, specifically around which agency is to fund which elements of patient care. Aboriginal health services and the new RHS structures offer a sensible solution to this historical friction between agencies with



differing reasons for existing. The dual funded, public and private interface is becoming increasingly complex in Australia and, as Hall observes, cannot be addressed without much broader consideration of the essential nature of the Australian health care system (18), but such is not the scope of the present CDSM project context. The demonstration project is really only likely to illuminate possible new approaches to care and key problems and impediments to effective community level collaboration and co-operation.

## Data collection

Little patient outcome data has been analysed to date, apart from recruitment levels in the project sites and early indications, as discussed above, of the contexts in which the most effective collaboration between consumers and health service providers is possible. Patient health data is being collected at baseline, six months, twelve months and conclusion of the project and this will provide a substantial data set on the impact of self-management process on patient ability to improve their participation in and access to relevant health care services. Data will also be available on the extent to which the project has impacted upon and helped to develop patient confidence and self-management as well as providing evidence of changes in health outcomes resulting from more integrated systems of care and self-management.

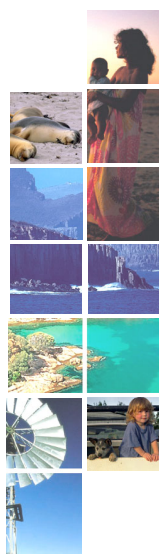
Pilot studies of the use of the PIH (0–8 score on each of 12 items) demonstrated that it was possible to show changes in patient-perceived self-management over a three-month period (19). The current SHC SA project now provides a larger sample in which to test the psychometric properties of the PIH and whether it is a reliable and valid measure of self-management. Additional analysis will determine if change in self-management score is associated with change in health outcomes and service utilisation.

## Early outcomes

Significant developments resulting from the project to date include

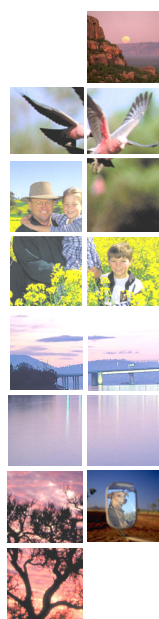
- the establishment of the SHC SA Community Information Centre
- patient recruitment in Whyalla, Pika Wiya and Port Lincoln
- the in-principle support of a range of stakeholders and service providers, including key GPs, allied health teams, Aboriginal health teams and pharmacists
- patient support is being offered (SHC SA Centre, Lorig training, consumer groups, self-help groups)
- initial qualitative data summaries (patient satisfaction) from focus groups and surveys.

The program concludes in June 2004, by which time significant numbers of eligible patients in the 3 main sites will have been involved in the CDSM intervention process. Data will be analysed locally as well as aggregate at a national level to summarise the key outcomes and achievements of the work.



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## PRESENTERS

**Peter Harvey** is currently the manager of the “Sharing Health Care SA” chronic disease self-management project established in 2001 through the University of South Australia and the South Australian Centre for Rural and Remote Health (SACRRH) in Whyalla.

Prior to working in the South Australian Health system, Peter taught literature and mathematics at secondary level and worked as a consultant for the Department of Education where he was engaged in curriculum development through community consultation and the implementation of new organisational structures for schools.

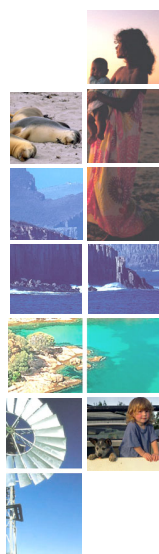
In 1996 he designed and implemented a community based Health Needs Assessment for the Eyre Regional Health Service in South Australia as part of the strategic planning process for that Region. Following the Needs Assessment project he was appointed to manage the rural component of the Council of Australian Governments (COAG), SA HealthPlus Coordinated Care Trial in South Australia. This project involved the co-ordination of primary health care services for 1300 intervention patients with chronic and complex illness in a matched controlled trial that compared intervention group health outcomes, service utilisation rates and health care costs with those of a geographical control group of 550 patients.

Peter’s PhD thesis, which was based on the COAG trial and published in 2001 through the University of WA, deals with the impact of the SA HealthPlus trial as a change leadership strategy for building a unique Regional Health Care model in the Eyre Region of South Australia. His recent work has involved implementing the Enhanced Primary Care (EPC) program and establishing Commonwealth Regional Health Services (CRHS) across four isolated and remote community clusters on Eyre Peninsula. This approach builds on much of the work initiated through the COAG co-ordinated care trial in the Eyre Region.

Peter enjoys the environment, literature and creative writing and is working on the definitive Australian “new century” novel in his spare time.

**Gary Misan** was appointed Associate Professor of the Spencer Gulf Rural Health School and Head of South Australian Centre For Rural and Remote Health (SACRRH) in July of 2002. This followed his position as SACRRH’s Director of Clinical Services and IT, which he commenced in May of 1999.

Gary’s professional career started when he graduated in Pharmacy from the South Australian Institute of Technology in 1978. My intern year at the Flinders Medical Centre was followed by a 2-year rural placement at the Gippsland Base Hospital in Sale, Victoria where he developed interests in radio-pharmacy and clinical pharmacy. Gary returned to Adelaide in 1982 to commence work at the Royal Adelaide Hospital (RAH) holding varied positions including general staff pharmacist, clinical



pharmacist, senior clinical pharmacist, Project Officer Drug Committee, specialist clinical pharmacist, and finally Director, Drug Distribution Services.

Gary developed clinical and research interests in the use of antibiotics, HIV/AIDS and drug usage evaluation as well as a growing interest in computers and computing. He completed his PhD with the University of Adelaide's Faculty of Medicine in 1997. In 1995 he was appointed Executive Editor of Australian Medicines Handbook, a position he held until early 1999. He was then appointed Senior Lecturer with the School of Pharmacy at the University of South Australia in February 1999 but left in May to join SACRRH as Director Clinical Services & IT.

