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ORIGINAL ARTICLE

## The Southern Alberta Renal Program database: a prototype for patient management and research initiatives

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### Abstract

The Southern Alberta Renal Program (SARP) database was developed to respond to an urgent need for local information on clinical outcomes, laboratory information, and health care costs, and to enable our local renal program to monitor the implementation of established clinical practice guidelines. The database captures detailed demographic, clinical, and laboratory information and is unique by also capturing comorbidity, health-related quality of life and costing information for patients with end-stage renal disease (ESRD) in southern Alberta, storing the information in one common database. By collecting information on patient comorbidity, health outcomes and costs, the SARP database has enabled many quality assurance initiatives as well as research opportunities for projects involving patients with ESRD. Due to the availability of links with other available local clinical and administrative databases, information is collected with a minimal need for manual data entry. This type of database is a method by which health programs could improve the quality of patient care. Programs caring for patients with chronic medical conditions such as ESRD should examine how computer databases could assist in clinical care and improve the efficiency with which that care is delivered to their patients.

### Résumé

La base de données du Programme rénal du sud de l'Alberta (PRSA) visait à répondre à un besoin urgent d'information locale sur les résultats cliniques, les données de laboratoire et les coûts des soins de santé et à permettre à notre programme rénal local de suivre la mise en œuvre de guides de pratique clinique établis. La base des données saisit des données démographiques, cliniques et de laboratoire détaillées et sa nature unique vient du fait qu'elle saisit aussi de l'information sur la comorbidité, la qualité de vie reliée à la santé et les coûts pour les patients atteints d'une insuffisance rénale au stade ultime (IRSU) dans le sud de l'Alberta : l'information est stockée dans une base de données commune. En recueillant de l'information sur la comorbidité chez les patients, les résultats sur la santé et les coûts, la base de données du PRSA a permis de prendre de nombreuses initiatives d'assurance qualité et offert des possibilités de recherche dans le cadre d'un projet mettant à contribution des patients atteints d'IRSU. À cause des liens avec d'autres bases de données cliniques et administratives locales disponibles, l'information recueillie exige un minimum de saisie manuelle. L'utilisation de telles bases de données permettra aux programmes de santé d'améliorer la qualité des soins aux patients. Les programmes de traitement des patients atteints d'affections

médicales chroniques comme l'IRSU devraient déterminer comment les bases de données informatisées

pourraient appuyer les soins cliniques et améliorer l'efficacité de la prestation des soins aux patients.

## Introduction

Since the 1980s, computerized data collection systems in health care have increased in popularity.<sup>1</sup> They have been used for administrative purposes,<sup>1</sup> to enhance patient care<sup>2-5</sup> and for clinical research,<sup>6</sup> usually by programs caring for patients with chronic medical conditions, such as diabetes mellitus or end-stage renal disease (ESRD). National data systems such as the United States Renal Data System (USRDS) and the Canadian Organ Replacement Registry (CORR) have provided much useful information on current trends in the management of ESRD and have served to inform many research projects.<sup>7,8</sup> For instance, clinical practice guidelines for patients with ESRD make a specific recommendation on target dialysis adequacy ( $Kt/V \geq 1.2$ ),<sup>9</sup> largely on the basis of an observational trial using USRDS information that measured baseline  $Kt/V$  and then examined subsequent patient mortality.<sup>10</sup> Data from the CORR have been used to suggest that the adjusted death rate for continuous ambulatory peritoneal dialysis (CAPD) is lower than for hemodialysis, providing support for the use of CAPD.<sup>11</sup> The USRDS database, through links with Medicare data, has even provided important data on the economic costs of ESRD.<sup>12</sup> Unfortunately, such large databases often lack accurate data on individual patient comorbidity<sup>13</sup> and do not contain information on health-related quality of life (HRQOL) and patient-specific costs. Local computerized health care databases have the potential to fill this void. To date, there has been limited experience with local computerized databases in the care of patients with ESRD.<sup>4,5</sup>

The Southern Alberta Renal Program (SARP) database is a prospective data collection initiative that began in November 1998, at a time when those involved in the SARP noted a critical lack of information on demographic and clinical information, as well as an inability to access data on clinical outcomes, laboratory information and costs. Furthermore, guidelines for the care of patients having ESRD had recently been published by the Dialysis Outcomes

and Quality Initiative (DOQI),<sup>9,14</sup> and members of the SARP were unclear how best to implement and monitor these important guidelines. The SARP database captures detailed demographic, clinical and laboratory data for all patients undergoing dialysis or renal transplantation in southern Alberta, including detailed comorbidity and costing data, storing it all in a common database. Currently, the database contains information on 2661 patients with progressive renal insufficiency (PRI) or ESRD and continues to grow by more than 300 patients per year.

The high cost of caring for patients with ESRD<sup>15-18</sup> makes it even more important than usual to have information on how resources are spent in order to justify and plan the allocation of future ESRD program budgets. The data required (patient characteristics including comorbidity, clinical outcomes, HRQOL and resource use) are available from the SARP database.

In this paper, we describe the development of the SARP database, as a prototype for programs caring for patients with ESRD or other chronic medical conditions. Since this database will serve as the basis for future academic publications, it is appropriate to describe it in terms of its structure, technical specifications and sources of information.

## Objectives of the SARP database initiative

The specific objectives of the SARP database include the following:

- to enable the smooth flow of clinical and laboratory information between medical and nursing personnel who care for patients with renal failure,
- to facilitate the performance of quality assurance initiatives regarding issues such as the appropriate management of anemia and bone disease,
- to assess the impact of various interventions (e.g., multidisciplinary predialysis clinic, the effect of dialysis adequacy) on health outcomes, HRQOL and costs,

- to assess determinants of short-term and long-term risk-adjusted clinical outcomes (i.e., death, hospital admissions) for patients starting dialysis,
- to describe the relationship between health gains and resource costs, including where current resources are spent, and to assist in determining where best to place new resources
- To foster collaborative interaction with other ESRD outcome assessment projects, both in and outside Canada.

The specific objectives include many of the original objectives for the SARP database. Soon after its inception, however, it became evident that many other objectives and research questions could be addressed using data acquired from such a database.

### Database overview

This database was designed to capture information on all patients enrolled in the SARP, including those receiving dialysis or a renal transplant in southern Alberta and those with PRI referred to the multidisciplinary PRI clinic (Fig. 1).

Owing to the nature of dialysis treatment, follow-up of enrolled patients from the initiation of dialysis to renal transplantation or death is complete. All patients in the SARP are hospitalized at a single site within the Calgary Regional Health Authority (CRHA), regardless of the medical or surgical indication. Therefore, accurate assessment of medical outcomes and patient-specific costing is possible. Outcome comparisons generated by the SARP database are thus less subject to selection bias.

### Informational domains assessed

The database is constructed around 4 basic informational domains with links to 3 other areas as depicted in Fig. 2. Some of the domains are useful to administrative personnel, others are pertinent to patient care or to advance clinical and cost-effectiveness research.

First, demographic data for all patients in the SARP are imported from TDS 7000 (Eclipsys, Atlanta), the online system for communications and records used by the CRHA. Second, to enhance patient compliance with physician and nurse visits, all scheduled patient visits are recorded in an electronic appointment book, which can be accessed from all dialysis units and patient care areas. Third, clinical information is collected on dialysis modality and site (updated as patients transfer modality or site), dialysis access, current medications (updated monthly) and patient comorbidity (assessed at the initiation of dialysis). Information is entered by unit clerks (dialysis modality and site), dialysis nurses (current medications) and by trained predialysis clinic nurses (patient comorbidity). Extra workload is minimized by eliminating paper records for these data points. Finally, information is collected on HRQOL for all patients who give consent (entered by a data entry clerk in batches).

With regard to the SARP database links, laboratory data (including all hematologic test results, routine chemistry findings, iron indices, Kt/V, parathyroid hormone levels and viral serology test results) are imported for all patients from TDS 7000 and through a link with Calgary Laboratory Services at

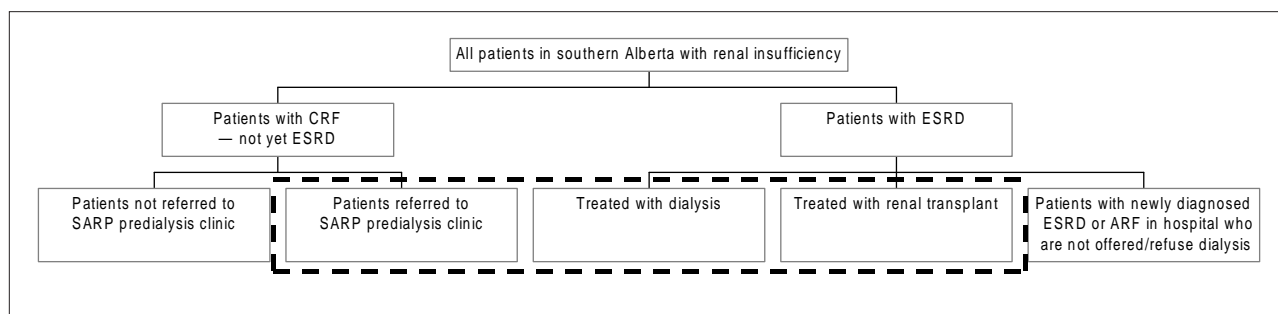


Fig. 1: The scope of the Southern Alberta Renal Program (SARP) database. The patient population within the dashed lines is captured by the database. CRF = chronic renal failure, ESRD = end-stage renal disease, ARF = acute renal failure.

no cost to the SARP. Data are also downloaded from CRHA corporate data in 2 further areas: clinical outcome data (hospital admission, surgical and radiologic procedures, and vital statistics) and the cost of every inpatient and outpatient care episode. Inpatient costing is calculated using the provincially approved methodology as set forth by the Provincial Costing Project and in accordance with the provincial and national Management Information Systems Guidelines.<sup>19,20</sup> It combines allocation and assignment of all direct and indirect costs associated with an inpatient event from the time a patient is admitted to the hospital to the time of discharge. The quality of the data reporting of costs in Alberta has been given the second highest ranking by the Canadian Institutes for Health Information.<sup>21</sup> As such, the methodologic issues associated with the collection of cost data in the United States,<sup>22</sup> in part due to the use of prices rather than costs, and for Canadian centres that cost admissions on the basis of “case-mix grouping,” should

not be an issue with the cost data considered within the SARP. The cost of outpatient dialysis care has been determined by examining actual patient resource consumption and allocated nursing contact for 166 patients treated with in-centre, satellite, home and self-care hemodialysis and peritoneal dialysis (unpublished data). Because patient-specific costing is routinely done by the CRHA (and by many other regional health authorities across Alberta and Ontario), there is no cost to the SARP for acquiring this information. Lastly, for patients who provide consent, information on physician billing is acquired in an anonymous fashion. An exhaustive list of all the data elements collected is available from the authors on request.

The SARP database was designed to introduce a minimally intrusive data collection process that draws largely on existing unit clerk and nursing staff for data entry (rather than dedicated research assistants), so data collection is sustainable financially. A

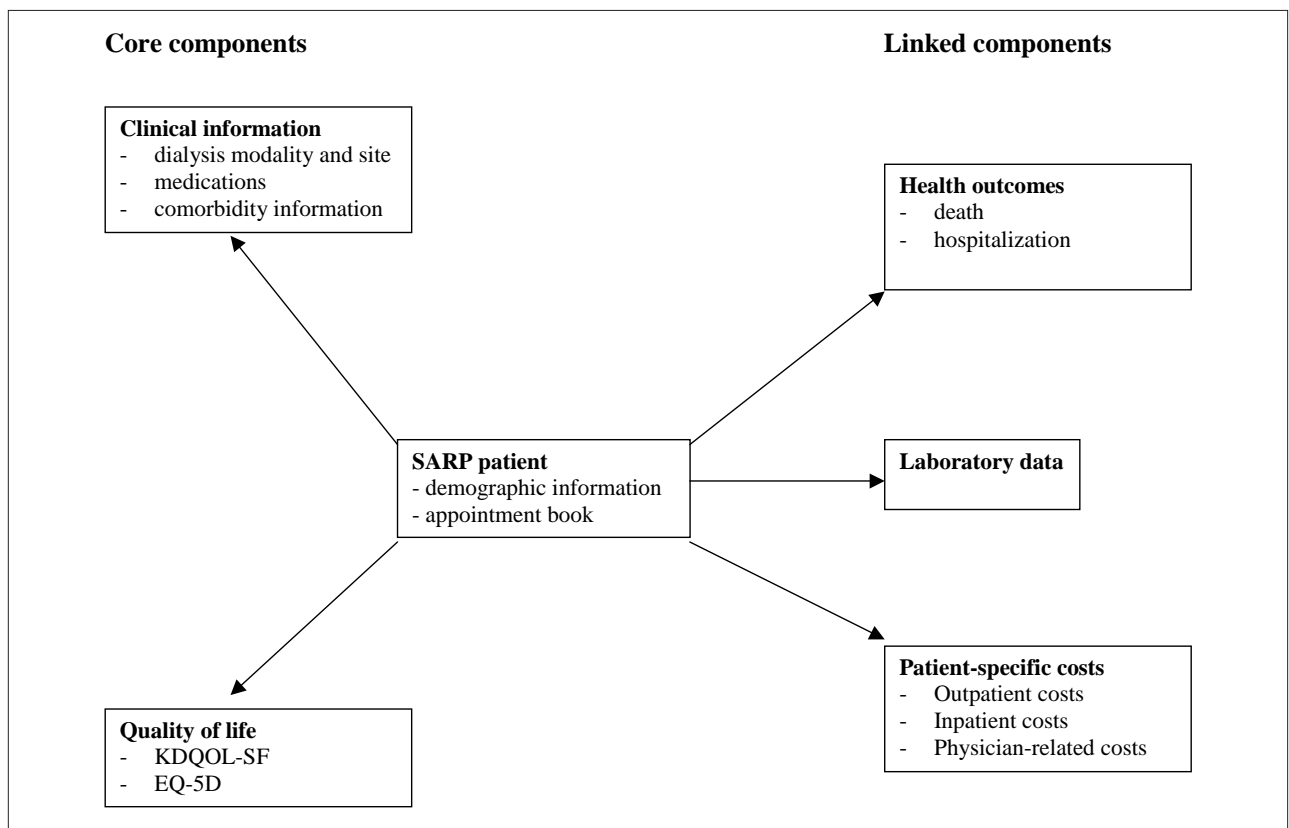


Fig. 2: The informational domains of the Southern Alberta Renal Program database. KDQOL-SF = Kidney Disease Quality of Life-Short Form, EQ-5D = EuroQol.

0.25 full-time-equivalent information technologist (paid by the SARP) is involved in data management and retrieval. The additional workload imposed on existing staff may be balanced by improvements in efficiency of care, although this hypothesis is largely untested. The workload of certain staff (i.e., dietitians) has decreased significantly since clinical and laboratory data no longer need to be abstracted on a monthly basis from every dialysis patient's chart.

The SARP database is a portable informatics system that could be transported to other geographic regions, although use of the system for quality assurance or research purposes may necessitate the availability of a multidisciplinary team (clinicians, epidemiologists, statisticians, health economists and computer system specialists) who could analyze and interpret the data. If this type of information gathering system was available in other centres, then it could be a source of valuable information that could supplement data produced by CORR.

### **Comorbidity and HRQOL assessment**

With respect to patient comorbidity, information is collected on all patients starting dialysis to enable calculation of the Charlson comorbidity index,<sup>23</sup> which has recently been validated for use in the ESRD population.<sup>24</sup> The collection of this information will not only enable calculation of risk-adjusted mortality and hospitalization rates for patients with PRI or ESRD but will also enable us to determine how well individual comorbid conditions as well as the modified Charlson index predict outcomes, including mortality, in a larger prospectively followed cohort of ESRD patients. Assessment of comorbidity is done by trained predialysis nurses who provide direct care to the patients and so have access to all physician records and the results of diagnostic imaging studies, including cardiovascular investigations.

HRQOL is assessed in all patients on their first visit to the predialysis clinic, at initiation of dialysis and yearly thereafter with the use of the Kidney Disease Quality of Life Short Form (KDQOL-SF) instrument,<sup>25-28</sup> which assesses quality-of-life aspects specific to patients with ESRD. The KDQOL-SF includes a generic quality of life scale, the Short Form-36,<sup>25,29,30</sup> enabling comparison of HRQOL for patients

with other conditions. In addition, the EuroQol (EQ-5D), a generic health index comprising a 5-part questionnaire and a visual analogue self-rating scale, is completed by patients since it has been used previously in dialysis patients<sup>31,32</sup> and provides a single global quality-of-life score that allows calculation of a quality-adjusted life-year, thus enabling cost-utility analyses. Both the EQ-5D and the KDQOL-SF are self-administered and can be completed in less than 20 minutes.

### **Technical specifications of the database**

The database used by the SARP is programmed in Microsoft Access 97. It is placed on a Windows NT server with access throughout the region of Calgary through the CRHA local area network. The data component and the copyrighted programs used for loading, displaying and reporting the information are stored separately (Meditrak Solutions, Calgary). This allows customized queries and reports to be established. There are currently 18 tables, containing over 250 data elements with over 1 million records. The system is established on approximately 50 end-user personal computers, and the SARP is in the process of extending the system to include satellite dialysis centres throughout the southern part of the province.

Data entry is automated as much as possible through the use of TDS 7000. This allows automated reporting of medical orders as well as demographic, laboratory (using HL7 protocol), and admission, discharge and transfer information. All data are stored online, allowing us to establish trends from historical data with easy download capabilities for data analysis. The data structure isolates the patient's demographic information from the ongoing collection so that confidentiality can be maintained when required.

### **Examples of academic and quality assurance projects and future prospects**

The SARP database is useful administratively, because it enhances access to demographic information and simplifies the process of routine appointments, and clinically, because it assists clinicians in day-to-

day patient care and facilitates several quality assurance initiatives. For instance, clinicians can now access blood work for outpatients online, enabling them to track trends in electrolytes, creatinine and hemoglobin levels and other important markers.

In April 1999, a local quality assurance committee was set up to monitor care of all hemodialysis patients, using the DOQI clinical practice guidelines for management of anemia,<sup>14</sup> and assessment of dialysis adequacy.<sup>9</sup> The committee has met monthly since April 1999, reviews online laboratory data and suggests therapeutic modifications at a program level to achieve therapeutic goals. The availability of online laboratory and medication data facilitates rapid identification of patients who are receiving potentially suboptimal therapy (e.g., patients with iron-deficiency anemia not on iron supplementation).

In the academic sphere, a number of research projects are using data from the SARP database. For instance, data on all patients starting dialysis are being used to investigate how patient comorbidity, choice of dialysis modality and dialysis adequacy influence health outcomes, HRQOL and costs. Whether the timing of referral for patients with PRI to a multidisciplinary predialysis clinic affects health outcomes and costs is also being investigated.

### Potential challenges for local databases

Major change does not come easily to the health care system. When the SARP database was first set up, nurses, physicians and other health care personnel were reluctant to enter and access information from the database (due to unfamiliarity with computers and because they were still required to record the same information in writing). As the computer record has replaced the need for the paper record and staff has become more familiar with the database, compliance with entering information has become virtually universal. Although the ongoing costs of the database are relatively small (0.25 full-time-equivalent information technologist, and 0.25 full-time-equivalent data entry clerk for HRQOL questionnaires), there was a significant initial expenditure on computer equipment (although many of the computers were already in place for accessing laboratory work and the hospital's online system for communi-

cations and records) and data programming. In addition, if links to local laboratory services and corporate data (for hospital records) were not available to the SARP free of charge, the expenditure on the database could be much higher.

### Conclusions

The SARP database is unique in capturing detailed demographic, clinical, laboratory and costing information for all patients with ESRD in a common database. Databases of this kind have the potential to make contributions to administrative, research and academic and clinical care spheres for programs caring for patients with chronic medical conditions.

To date, the first objective of the SARP database, enabling the smooth flow of clinical and laboratory information between medical and nursing personnel, has been met, and early indications suggest that the database is enabling treatment goals to be accomplished in a higher proportion of patients. However, the true test of an informational system is whether the benefits to patients and the health program outweigh the costs of acquiring the information. The SARP database has the potential to pass this cost-benefit test, although final judgement must await completion of the database's other objectives.

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(2001) The Southern Alberta Renal Program database: a prototype for patient management and research initiatives. *Clin Invest Med* 24: 164-170. View Article. (2009) Clinical guideline for the evaluation, management and long-term care of obstructive sleep apnea in adults. *J Clin Sleep Med* 5: 263-276. View Article. Google Scholar. 26. Mulgrew AT, Fox N, Ayas NT, Ryan CF (2007) Diagnosis and initial management of obstructive sleep apnea without polysomnography: a randomized validation study. *Ann Intern Med* 146: 157-166. View Article. Northern Alberta Renal Program and Southern Alberta Renal Program. Share best practices between transplant programs on ways to increase the use of living donor kidney transplantation. A series of presentations outlining current research, the current state of living donor kidney transplantation across Canada, and current Canadian initiatives directed at improving the rates of living kidney donation were shared with workshop participants. The speakers included two patients who provided their detailed personal accounts of the barriers and successes they experienced in their respective journeys along the pathway to kidney transplantation. Northern and Southern Alberta Renal program databases [10], as well as other databases related to program delivery such as the Chronic Disease Management database. All data is available electronically, thus there is no requirement for manual data entry. Figure 1. Manns BJ, Mortis GP, Taub KJ, McLaughlin K, Donaldson C, Ghali WA: The Southern Alberta Renal Program database: a prototype for patient management and research initiatives. *Clin Invest Med*. 2001, 24 (4): 164-170. When confronting the COVID-19 pandemic's economic consequences, elected leaders from around the world have quickly created and implemented novel and massive relief programs. Though they vary in detail, the relief strategies can broadly be classified along one key dimension: the extent to which their economic relief is given directly to workers by a government agency or channeled through a pre-existing employment relationship. Jonathan Rothwell. Nonresident Senior Fellow - Metropolitan Policy Program. Jtrothwell. Updating earlier work, this analysis examines 20 rich democracies and draws several The Southern Alberta Renal Program database: a prototype for patient management and research initiatives. *Clin Invest Med* 2001;24(4): 164-170. Google Scholar PubMed. 13. Laupland, KB, Gill, MJ, Schenk, L, Goodwin, D, Davies, HD. Outpatient parenteral antibiotic therapy: evolution of the Calgary adult home parenteral therapy program. *Clin Invest Med* 2002;25(5): 185-190. Google Scholar PubMed. 14. Altman, DG. Practical statistics for medical research. London: Chapman & Hall, 1991. Google Scholar. 15. Quan, H, Sundararajan, V, Halfon, P, et al.