

A WEB BASED DECISION SUPPORT TOOL AND DATABASE FOR TREATMENT AND RESEARCH INTO A RARE, CHRONIC DISEASE: THE AUSTRALIAN SCLERODERMA SCREENING PROGRAM DATABASE



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OBJECTIVES

The aims of the Australian Scleroderma Screening Program (ASSP) are

1. To provide high quality evidenced-based screening for the cardiopulmonary complications of systemic sclerosis (SSc) and mixed connective tissue disease (MCTD), and to ensure patients receive appropriate and timely treatment,
2. To create a comprehensive electronic database accessible Australia wide to assist in the application of the screening algorithm and
3. To promote research in SSc, with the goal of including as many as possible of the estimated 5000 patients in Australia with SSc.

METHOD

The dataset used in the Victorian Scleroderma database was adapted by the rheumatologists, cardiologists and respiratory physicians who had formed the Australian Scleroderma Interest Group (ASIG). Using critical data fields a screening algorithm based on current international best practice was developed as well as a screening protocol to standardise data collection.

Following this process, specifications were developed for a purpose built software program and sent to several software developers. The contract was given to a designer who had experience on a similar project in a health setting and understood the need for close liaison with the server host for both design and implementation of the database.

ASIG required a server host that could provide secure access and storage of data. St Vincent's Hospital was willing to host the database so it was designed to be compatible with the St Vincent's IT environment which uses SQL Server 2000.

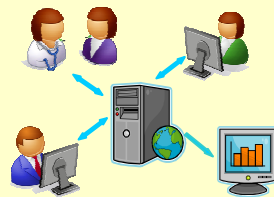
Applications for Ethics approval for sites began in March 2007. Recruitment of patients commenced at each site as approval was granted. Patients are referred by their treating rheumatologist for screening. There is no limit on the number of screening centres that can join the project.

Patient and disease-specific information is collected at baseline and then serial clinical data collected at annual reviews. Response options are tightly controlled to ensure data quality.

A key feature of the software is a clinical decision making tool for applying the screening algorithm.

When values are entered in fields that inform critical decision-making, they are compared with rules of the screening algorithm. If individual or a set combination of values fall outside the predetermined range for 'no action required' - continue standard annual screening' an email to the treating physician is automatically generated and an alert placed on the electronic record. The email indicates why the alert has been triggered and recommends a course of action.

If the physician chooses not to follow the algorithm they must specify in a text box the clinical justification for this decision.



RESULTS

The database has performed well and allows multiple users at one time to enter, view and edit data.

The database can be successfully accessed from any location around the world providing the user is on a computer that has the security software downloaded and has an assigned Remote Secure Access (RSA) token.

As at 14th July 2008, 11 sites had ethics approval and entered data on a total of 411 patients. Twenty eight of these patients have returned for a second review.

As per specifications, sites can only view and export their own data but the administrator can export de-identified aggregated data from each site. The exported data loads successfully into statistical packages for analysis and the first publication is now available¹.

The database effectively provides a live clinical record allowing access to all patient reviews conducted at any time in the past.

Physicians have found the algorithm beneficial in guiding their clinical decision making. Given that the tool identifies those patients for whom further treatment is recommended, it is planned to analyse the impact of the algorithm on treatment outcomes so that the group can contribute to best practice guidelines.

CONCLUSION

The database has performed according to the specifications and has met all security requirements. The first upgrade review is underway to improve the layout and function of the database. Data will be analysed regularly and submitted for publication and further funds will be sought to maintain the database beyond 2009.

The software has been shown to be beneficial as a decision making tool and should allow Australian researchers to contribute data to international best practice guidelines as well collaborative research studies.

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¹Mageswaran, E et al. Systemic Sclerosis in Australia: using the Australian Scleroderma Screening Programme (ASSP) database to assist in assessment of cardiopulmonary complications. Internal Medicine Journal 2008;38 (Suppl 2);A16