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RACP Foundation Research Awards

FINAL REPORT

Project / Program Title		Quantifying the burden of systemic sclerosis: from data linkage to patient reported outcomes
Name		Dr Kathleen Morrisroe
Award Received		2015 Shields Research Entry Scholarship
Report Date		1 July 2018
Chief Investigator / Supervisor		A/Prof Mandana Nikpour
Administering Institution		St Vincent's Hospital Melbourne
Funding Period	Start Date:	1 February 2015
	Finish Date:	1 February 2016

PROJECT SUMMARY

Australia has the highest reported prevalence of systemic sclerosis (SSc) worldwide (233/million cases in 1999). SSc, an autoimmune disease characterised by vasculopathy and fibrosis, is arguably the most devastating of the rheumatological diseases, with a potential to irreparably damage multiple organ systems and shorten life expectancy by an average of two decades. The true 'burden' of SSc in Australia remains unquantified, including its health service utilisation and impact on physical function, psychological wellbeing, health-related quality of life (HRQoL), employment and work ability. Such comprehensive clinical burden of disease (ccBoD) figures are essential for allocation of resources including clinical services and research funding.

PROJECT AIMS / OBJECTIVES

Hypothesis:

That the unknown burden of SSc in Australia, both to the community and affected individuals is considerable and may be quantified (i) through linkage of the ASCS clinical dataset to routinely collected datasets for health service and medication use, and (ii) through use of patient-reported outcomes such as physical function, mental wellbeing, HRQoL and work ability.

Aims:

1. To quantify hospital and emergency department utilisation (and associated costs) in SSc.
2. To quantify use of ambulatory health services in SSc, and associated costs.
3. To quantify use and costs of medications in SSc.

4. To quantify physical function and disability in patients with SSc and to determine Disability Adjusted Life Years.

5. To quantify mental wellbeing and emotional distress in patients with SSc.

6. To quantify HRQoL in patients with SSc and to determine Quality Adjusted Life Years.

7. To quantify work ability and employment in patients with SSc.

SIGNIFICANCE AND OUTCOMES

The knowledge gained from my work so far has set the scene for a number of future projects of great significance for individuals living with SSc and for the wider research community.

Firstly, I showed that combination PAH therapy improves patient survival compared with monotherapy alone. The next step is to evaluate the cost-effectiveness of combination PAH therapy versus monotherapy in the treatment of SSc-PAH. This is a project that is currently underway with my supervisor and two health economists based at the University of Melbourne. The findings of this cost-effectiveness will inform a Pharmaceutical Benefits Advisory Committee review of PAH drugs.

Secondly, by highlighting the substantial unemployment associated with SSc and its associated economic burden to policy makers, work inclusion strategies can be developed and implemented. This could be achieved by the creation of a working group composed of SSc researchers, medical professionals, policy makers, SSc patient representation and carers, in addition to patient advocate groups, to create appropriate work inclusion guidelines in order to promote and ensure the participation of SSc people with disabilities in employment.

Finally we as treating physicians need to ensure that our treatment recommendations and care are patient-centered. Collecting and evaluating patient reported outcome measures (PRO's) overtime, such as HRQoL and work ability, is vital in understanding the emotional aspect of the disease as experienced by the patient and the impact it is having on their daily activities. Taking into account the available economic resources, the knowledge derived from PROs can allow treatment to be individually tailored according to the patient's preferences, needs and values over time with the aim of not only improving the disease manifestations but more importantly the patient's disease journey.

PUBLICATIONS / PRESENTATIONS

1. **Morrisroe K** *et al.* Survival and quality of life in incident systemic sclerosis-related pulmonary arterial hypertension. Arthritis Research and Therapy 2017 Jun 2;19(1):122. PMID: 28576149
2. **Morrisroe K** *et al.* Determinants of unemployment amongst Australian systemic sclerosis patients: results from a multicentre cohort study. *Clinical & Experimental Rheumatology* 2016 Sep-Oct;34 Suppl100(5)79-84. PMID: 27463997
3. **Morrisroe K** *et al.* Risk factors for development of pulmonary arterial hypertension in Australian scleroderma patients: results from a large multicenter cohort study. *BMC Pulmonary Medicine* 2016 Sep 27;16(1):134. PMID: 27677579

Presentations

1. Research Week, St Vincent's Hospital, Melbourne, Australia August 2016 `Health-related quality of life and survival in incident systemic sclerosis related pulmonary arterial hypertension: A multicentre Australian cohort study' (Runner-up prize in the Junior Investigator Session)

2. Australian Rheumatology Association, National Conference, Darwin Australia, May 2016 `Survival in Systemic sclerosis related Pulmonary Arterial Hypertension in the Modern Treatment Era' (Selected for podium presentation in the New Investigator session)
3. SSc World Congress, Lisbon Portugal, February 2016, `Determinants of unemployment amongst Australian systemic sclerosis patients: results from a multicentre cohort study' (Selected from submitted abstracts for podium presentation)
4. PHSANZ National ASM, Sydney, Australia October 2015 `Predictors of pulmonary arterial hypertension in Australian scleroderma patients: results from a large multicentre cohort study' (Selected from submitted abstracts for podium presentation)