Arthritis
VICTORIA
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A novel patient-centred instrument for assessment of systemic lupus erythematosus

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Institution:	Centre for Inflammatory Diseases, Southern Clinical School, Monash University
Grant:	$20,000

Background

In August 2011 the Arthritis and Osteoporosis Victoria Board approved the funding of the research project, *A novel patient-centred instrument for assessment of SLE*, as part of our Project Grants for 2011.

The aim of the project was to use the knowledge and experience of Australian people living with systemic lupus erythematosus (SLE or lupus) to develop an Australian-relevant and patient-centred instrument to assess the state of their disease.

While the disease state of SLE can be measured using clinician tools (eg the Systemic Lupus Erythematosis Disease Activity Index – SLEDAI), they don’t necessarily capture all the information that is important to the patient.

Information collected from a ‘patient-centred instrument’ would then be compared to information that has been gathered over time using the standard clinical tools like the SLEDAI, to determine any similarities or differences between them.

Development of an Australian patient-centred tool was deemed to be important. Patient-centred tools already in use were developed in the US and Europe with people who have less severe lupus than is routinely seen in Australian clinics. A high proportion of people of Asian ethnicity - known to be associated with more severe lupus – use the Australian clinics.

What is lupus?

Systemic lupus erythematosus (SLE) is a chronic condition that results from a malfunctioning immune system. The immune system is designed to identify foreign bodies (such as bacteria and viruses) and attack them to keep us healthy. However, in the case of lupus, the immune system mistakenly attacks particular tissues including the skin, joints, kidneys and lining of the heart and lungs, causing ongoing inflammation and pain.

The project

Researchers at the Centre for Inflammatory Diseases at Monash University began this project by first reviewing the literature to understand what is currently known about the experience of lupus from the patient’s perspective and the tools used for measuring disease activity and damage.

This led to the development of a ‘patient-centred instrument’ consisting of 59 questions designed to capture information about the issues most important to Australian people living with lupus.

They then surveyed Australian patients with lupus to understand their attitudes towards their disease, asking questions relating to disease activity, damage, medications, and the social and economic impact of living with lupus. Sixty-nine people attending the Monash Lupus Clinic took part.

The new tool also included LUPUSPRO-LIT (Lupus Impact Tracker), developed to help people with lupus communicate to their doctor about their symptoms and how lupus impacted on their life.

In November 2012, information collected from the survey was collated and analysed. It was then compared with the information gathered from the use of standard clinical tools.

Findings

The researchers discovered that the existing tool LUPUSPRO-LIT was completely suitable for Australians with lupus.

Issues that patients rated most important on the patient-centred tool developed by the Monash team were closely associated with LUPUSPRO-LIT. This was an unexpected finding. Researchers had believed that because of the more severe lupus that Australians experience, that outcomes such as organ damage would be seen as more important than symptoms like fatigue. However, this wasn't the case.

During this project, researchers discovered that people with lupus were more likely to rate an issue as more important if they had personally experienced it. This has implications for future consumer information and education. Lupus is a complex and unpredictable condition. It is important that people living with lupus understand all possible outcomes, including those that they have not experienced.

Information from this project continues to be analysed, with the aim of publishing and sharing this information with the broader lupus community.

Find out more about lupus

At Arthritis and Osteoporosis Victoria, we have a range of services and programs to help you learn more about lupus. You can:

- Talk with one of our nurses if you have lupus and want to find out more about it; if you need assistance navigating the complex health, disability and social services systems; or if you need information on community resources in your area. Call 1800 263 265 weekdays, or email msk@arthritisvic.org.au.
- Enrol in one of our courses and seminars to learn practical ways to live with lupus. Visit our website for more information about upcoming events: http://www.arthritisvic.org.au/Courses-and-Events
- Check out our library and our collection of lupus books. You can access the library catalogue to see what the library has available - http://www.arthritisvic.org.au/Useful-Information/Our-Services/Library. Or contact the librarian on 03 8531 8031 (toll free for country callers on 1800 011 041).
- Join a lupus peer support group and meet with people who understand what you are going through. Go to the Arthritis Map - http://www.arthritismap.com.au - and click on Lupus Support Groups, to find the details of lupus groups in Victoria.

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