

Both disease and life impact are important when assessing PsA



An updated core domain set incorporates patient and physician priorities and evolving PsA research.

INTRODUCTION

Psoriatic arthritis (sometimes shortened to PsA) is a chronic inflammatory disease that affects a person's joints, and sometimes spine and tendons, causing pain and disability. The disease often causes swelling of the fingers and toes. It gets its name from the link between this type of arthritis and a skin condition called psoriasis, which causes redness and scaling.

A core domain set is the minimum set of outcomes or areas that need to be assessed in any clinical trial to see how well treatments for a disease work. The first core domain set for psoriatic arthritis was developed in 2006.

WHAT DID THE AUTHORS HOPE TO FIND?

The authors wanted to see which clinical trial outcomes are important for people with psoriatic arthritis, and which are important for their doctors. They then wanted to join the two perspectives together to be able to recommend a core domain set for psoriatic arthritis that represents both patients and doctors.

WHO WAS STUDIED?

The survey was completed by 50 people with psoriatic arthritis and 75 doctors.

HOW WAS THE STUDY CONDUCTED?

The authors made a list of domains (areas) from focus groups and previous clinical trials. People with psoriatic arthritis and doctors then voted via online surveys on the importance of each of these domains. The results of the survey were presented at a meeting of 12 patients and 12 doctors, using a technique to make sure that all opinions were considered. The patients and doctors agreed on a preliminary core domain set. A second survey was then sent out to the wider group to rank the importance of each domain that had been identified.

WHAT WERE THE MAIN FINDINGS OF THE STUDY?

The study found that the core domain set should include musculoskeletal disease activity, skin disease activity, pain, physical function, health-related quality of life, fatigue, systemic (underlying) inflammation and the patient's assessment of their disease. These domains have to be measured in every clinical trial in people with psoriatic arthritis. The definition of musculoskeletal disease activity includes not only arthritis, but also enthesitis and dactylitis (swelling of the fingers and toes) and symptoms in the back and spine. The definition of skin disease activity includes psoriasis in a person's nails as well as their skin.

Domains that are important but not required in every clinical trial are emotional well-being, structural joint damage and economic cost. Domains that require further study are independence, sleep, joint stiffness and treatment burden.

The authors concluded that disease manifestations and impact on quality of life are important for both people with psoriatic arthritis and their doctors. For people with the disease, critical life impact domains are fatigue (tiredness), participation and emotional well-being.

ARE THESE FINDINGS NEW?

These results build on the core domain set that was developed in 2006. The updated version includes the priorities of people with the disease, as well as those of their doctors. It was important to learn how patients as well as physicians think about psoriatic arthritis domains because this has not been done before.

WHAT ARE THE LIMITATIONS OF THE STUDY?

The surveys were conducted in English and French only, and group meeting was conducted in English only. However, the authors addressed this limitation by making sure that there was broad international representation in the focus groups in 7 countries over 5 continents.

WHAT DO THE AUTHORS PLAN ON DOING WITH THIS INFORMATION?

A working group has moved on to the next stage of developing a core outcome measurement set for psoriatic arthritis. This will represent health measurement instruments or tools that measure the core domain set.

WHAT DOES THIS MEAN FOR ME?

Clinical trials that measure and report the updated core domain set will provide information on how treatments for psoriatic arthritis affect the disease and its impact on quality of life. If you have psoriatic arthritis, this will help you and your doctor to compare treatments more easily and choose one that is right for you.

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