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**The nature, burden and management of psoriatic  
arthritis-related foot problems from the  
perspective of patients and health professionals**

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Best Care for Everyone

## Outline

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- Features of psoriatic arthritis in the foot
- Gaps in our knowledge
- Patient experience of foot problems related to psoriatic arthritis
- Key take home messages

## Background

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- Previously considered a mild disease
- 50% develop progressive arthritis
- Impairment of joint function, deformity and impact on quality of life
- High levels of unemployment and long term work disability



(a) Marked bony resorption



(b) Telescoping digit

## Psoriatic arthritis

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### CLINICAL FEATURES OF PSORIATIC ARTHRITIS



Small joint  
arthritis



Enthesitis



Sausage toe



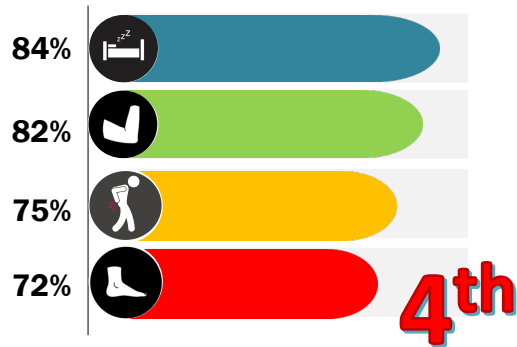
Nail psoriasis



Skin psoriasis

## Foot and ankle

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Large UK clinical study of 104 people with psoriatic arthritis found over 60% of the sample reported foot pain, 95% had deformity in the forefoot, 65% in the rearfoot, a high frequency of tendon problems, and skin and nail psoriasis was found in 8% and 13% respectively

## Patient perspective

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ARD Online First, published on September 9, 2016 as 10.1136/annrheumdis-2016-210242  
Clinical and epidemiological research



EXTENDED REPORT

International patient and physician consensus on a psoriatic arthritis core outcome set for clinical trials



The Journal of  
Rheumatology

The Journal of Rheumatology

Volume 42, no. 11

Enhanced Patient Involvement and the Need to Revise the Core Set —  
Report from the Psoriatic Arthritis Working Group at OMERACT 2014

Arthritis & Rheumatism (Arthritis Care & Research)  
Vol. 57, No. 3, April 15, 2007, pp 487–494  
DOI 10.1002/art.22695  
© 2007, American College of Rheumatology

ORIGINAL ARTICLE

Concepts Important to Patients With Psoriatic Arthritis Are Not Adequately Covered by Standard Measures of Functioning

Curr Rheumatol Rep (2014) 16:418  
DOI 10.1007/s11006-014-9418-7

PSORIATIC ARTHRITIS (O FITZGERALD AND P HELLIWELL, SECTION EDITORS)

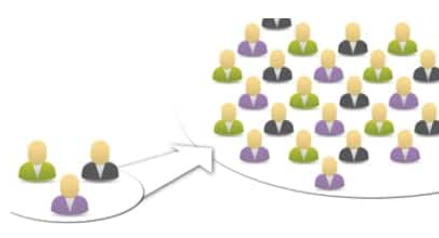
Patient Involvement in Outcome Measures for Psoriatic Arthritis

## Research design

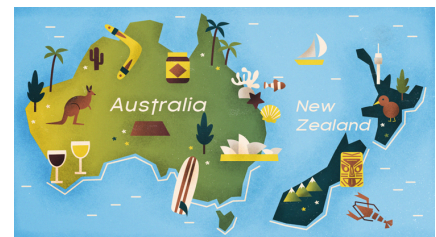
- Concepts important to people with the condition
- Health professionals understanding of the patient experience
- Locally representative data



Patient experience.

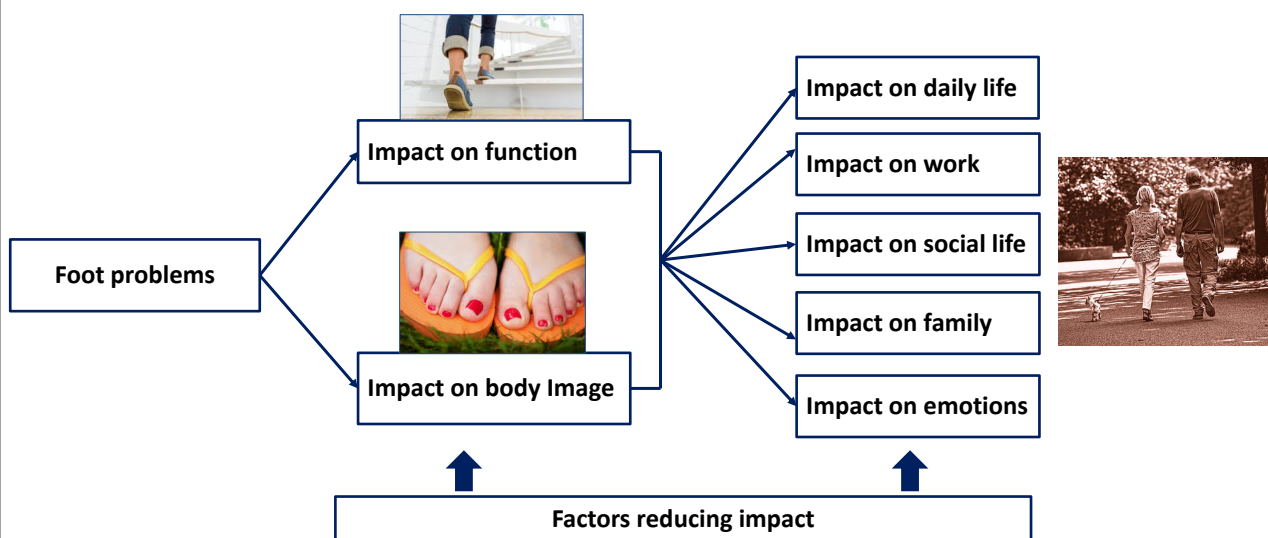


Representative group.



Local data

## Impact overview



## Signs and symptoms

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unbearable  
throb主ing  
totally random  
ridiculous  
sharp  
absolute agony  
massive  
worst pain I have ever had  
crawling on the floor with pain  
a world of pain  
killing me  
excruciating  
Pain  
severe  
sore  
hurts like hell  
constant  
burning  
makes you want to cry  
aching  
unpredictable  
persistent  
through the roof  
phenomenal  
walking on stones and pebbles  
mild  
intense  
extreme

## Impact on body image

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"I feel a bit embarrassed to walk alongside with my family members because I mean, I used to be limping"

horrible  
awful  
not normal  
ugly  
revolting  
hideous  
they look like  
little claws to me



"everybody's eyes goes there... people will be asking me 'what's wrong with your feet?' ...It doesn't feel good"



"I don't do much for the simple fact I get embarrassed"

## Impact on foot function

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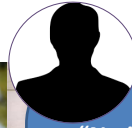
**"when I get out of bed um  
it's extremely painful"**



**"you can't walk, you can't  
run, you can't do anything  
you want to do"**



**"The most troublesome thing at  
the moment is just not being able  
to walk at a normal speed"**



**"No it's very important, the  
feet is the main thing to move  
me here and there you know.  
So when the pain is there I'm  
just locked. The other things ok  
so I don't move my hands or  
move my arms, my fingers I can  
do, but if I can't drive, can't  
walk, that's the worst thing"**

## Impact on daily life

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**" 'incapacitating', 'disturbing',  
'debilitating', 'really impossible',  
'disaster', 'distressing',  
'a nightmare', 'life is ruined' "**



**"Um ruined, like err useless. Yeah because  
some days I have to take the kids and some  
days I can't take them because of the pain I  
feel uncomfortable you know. If I can't put my  
feet down and drive the car. And I have to  
take them to the park, to walk or push the  
bike or something. It makes me sad"**



**"Um like I feel older than I am...like it makes  
me sad because I can't do things but I just  
put up with it...I just have to deal with it"**



**"I have to change my life around...I can't do  
a quarter of the stuff I used to do"**



**"I can't actually look under the sole of my foot,  
because I can't get the angle so you really  
don't know what's going on under there"**

## Impact Family, social and work life

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### Family

*"sometimes I feel bad for everything, like I'm a disappointment to my wife"*

*"I think because I've got kids it's not really the worry for myself. I don't want to miss out on stuff for them"*



### Work

*"I quit my job...because it's mostly you have to stand"*

*"you try to keep everything a secret especially people that you worked with"*

### Lack of understanding

*"Other people...they don't understand how it does affect your life with getting up, walking, just simple things"*

*"they see me like this they think I am healthy, but the pain is there"*

"you know on the odd occasion you're invited to a wedding or, like you know like, last year before I had a couple of weddings to go to and I just bought some, you know, I was just running around trying to find a pair of shoes that was um comfortable. And um I ended up buying a pair of shoes which by the time I got to the reception I was already dreading that I'd even bought them. And it was just um, you can't even enjoy yourself because you're in pain and you are just thinking - how the hell do I get out of here and I just want to go home"

## Self-management strategies

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*"And it's good, I mean it feels so good to be able to walk around and not be in pain you know what I mean. Like um or not have to shuffle around or err know confidently that you can, you know, you can go for a walk at lunch time and you're not going to, you know, be in pain by the time you get back"*

- Finding suitable footwear





*"if I was in pain I would still force myself to participate"*



*"I still have to do what I have to do. I just try and do less of it. Like I try and rest in between... but some days I can't keep pushing myself..."*



*"I'm at the point now where I wouldn't mind. In the past I wouldn't have done it."*

## Key findings

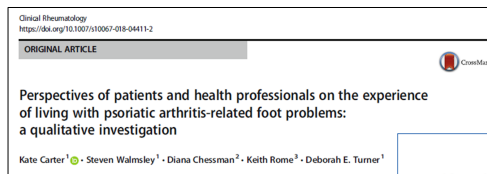
- **Patient perspectives** – insight into the wide-reaching impact, spread across all aspects of life
- **Lack of understanding** about the disease
  - by patients and their family and friends
  - by health professionals
- **Better coping with**
  - readily available social support
  - access to health care support

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## Impact and Beyond

- Dissemination
- National survey
  - Better understanding
  - Population-based data
- [www.psoriaticfootarthritis.com](http://www.psoriaticfootarthritis.com)



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**A Survey of Foot Problems Among People with Psoriatic Arthritis**

Hello, I'm Kate Carter from Western Sydney University, Australia. The aim of this survey is to find out about your foot problems related to psoriatic arthritis and how they impact on your life. This survey will be used in future work to help better treat foot problems. If you would prefer to complete this survey online, please use this link X or if you would like to learn more about this study, please visit our website [www.psoriaticfootarthritis.com](http://www.psoriaticfootarthritis.com)

To take part in this study you should:

- be aged 18 or over
- have psoriatic arthritis
- have past or present foot problems
- live in Australia or New Zealand

Participation is completely voluntary and confidential. Completing the survey indicates that you have understood the information provided and that you consent to participate. The information you provide will be used in this study and other related studies. The survey should take about 20 minutes. We hope you will be able to take part.

**About you**

1. Where do you live?

☐ Australia ☐ New Zealand (Aotearoa)

2. What is your post code? \_\_\_\_\_

**About you**

We are seeking general information about you so that we can describe who is taking part in the survey.

3. How old are you? \_\_\_\_\_ Years

4. Are you male or female? ☐ Male ☐ Female ☐ Prefer not to state

5. Approximately how tall are you?

\_\_\_\_\_ feet \_\_\_\_\_ inches **OR** \_\_\_\_\_ centimetres

6. Approximately how much do you weigh?

\_\_\_\_\_ stone \_\_\_\_\_ lbs **OR** \_\_\_\_\_ kg

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**Changes to practice. Service provision and access.  
Improvements in health care**

## Any questions?



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