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FOOT INVOLVEMENT AMONG PEOPLE WITH PSORIATIC ARTHRITIS

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Abstract

Introduction Despite recognition that hallmark features of psoriatic arthritis (PsA) are predominant and persistent in the foot and ankle, limited foot-specific research exists and there are no validated outcome measures to comprehensively assess the impact of foot involvement from the perspective of people living with PsA. Previous research has shown merit in linking to the International Classification of Functioning, Disability and Health (ICF) in order to better define and understand the impact of global disease associated with PsA, but little is known about the impact of localised disease in the foot. Current understanding of foot involvement in PsA is based on a limited number of studies with relatively small sample sizes of predominantly discrete sub-populations of PsA, which fail to adequately incorporate the perspective of those living with PsA. Therefore, foot involvement in PsA remains under-researched and poorly understood with a lack of large-scale data to provide the basis for targeted disease-specific assessments and interventions. This thesis aimed to investigate foot involvement in PsA from the patient perspective, and to develop a national Australasian-based survey in order to comprehensively describe the nature, extent and location of foot problems and their impact on the daily life of people with PsA.

Methods A qualitative study explored the perspectives of those with PsA and health professionals on the impact of PsA-related foot problems on daily life in order to gain insight into the patient experience. Concepts important and relevant to the patient experience of foot involvement in PsA, derived from the qualitative study, were used to systematically link the effect of foot problems in PsA to the ICF. The qualitative research findings and ICF linking exercise were used to generate the conceptual framework for the survey and subsequent item generation. A multi-stage survey development process followed, using best practice methods in survey design and conduct, which included; cognitive debriefing, cultural sensitivity review, survey design expert validation, subject expert validation and pilot testing. Targeted postal and online survey dissemination strategies were developed in order to optimise implementation of the national survey, which collected data for a total of 6 months.

Results Key themes on PsA-related foot involvement and its impact on daily life were revealed from the qualitative study, which comprised 1) disease manifestations in the feet and ankles, 2) foot functional impairments and visual differences that impacted on daily activities, work, social and family life, and 3) mediating factors (such as coping strategies, self-care ability, footwear, social support, access to healthcare and climate) that influenced the severity of impact from foot involvement on daily life. An important concept from people with PsA was the psychological impact of foot problems on daily life, which was poorly recognised by the health professionals. Health professionals perceived limited expertise in detecting and managing foot involvement in PsA and a lack of specialist foot health service provision in Australia and New Zealand. Concepts, obtained from the qualitative study, were subsequently linked to the ICF model and a list of over 100 distinct ICF categories were identified, which confirmed the profound impact of PsA-related foot involvement on daily functioning and comprehensively defined what should be included in the evaluation of PsA-specific foot disease burden. A novel, robust survey was developed and successful survey outcomes confirmed that extensive survey pre-testing and rigorous mechanisms for survey distribution were worthwhile. Successful survey outcomes included; a high survey response (n=649), high completion rates (83% reached the end of the survey), inconsequential item non-response (5% missing data), and achieving a broadly representative PsA-specific population-based sample. Survey results demonstrated that foot problem in PsA were common, heterogeneous in nature and caused substantial burden. Important impact domains identified were 1) site-specific impact of hallmark disease features in the foot (such as rearfoot enthesitis, dactylitis, skin and toenail psoriasis) on daily routine, social participation, footwear choice and emotional well-being, 2) reduced physical activity and exercise due to foot problems with potential impact related to obesity and falls in PsA, and 3) the importance of support and understanding about the disease from health professionals and its impact on the perceived ability to cope with foot problems among people with PsA.

Conclusion Findings highlight the importance of involving those with PsA to generate survey items, which resulted in relevant concepts being included in the survey that were not considered to be important by health professionals. This programme of work provides a comprehensive view of the wide-reaching impact of PsA foot-specific involvement from the patient perspective, which will inform the future research priorities on targeted strategies towards improving foot health and the patient experience in PsA.

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Carter K, Walmsley S, Rome K, Turner DE. Health professional views on the assessment and management of foot problems in people with psoriatic arthritis in Australia and New Zealand: a qualitative investigation. BMC Musculoskeletal Disorders. 2019;20(1):191.

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Carter K, Walmsley S, Rome K, Turner DE. Development of a national survey on foot involvement among people with psoriatic arthritis in Australia using a best practice approach: A survey development protocol. Journal of Foot and Ankle Research. 2020 [Submitted].

International presentations:

Carter K, Tannous C, Walmsley S, Rome K, Turner DE. Linking the patient experience of foot involvement related to psoriatic arthritis to the International Classification of Functioning, Disability and Health. European League Against Rheumatism (EULAR) conference, Madrid, Spain, June 2019 [**Poster presentation**].

Carter K, Walmsley S, Rome K, Turner DE. Patient and clinician perspectives used for survey development to investigate the nature, extent and impact of foot problems in people with psoriatic arthritis. European League Against Rheumatism (EULAR) conference, Madrid, Spain, June 2019 [**Poster presentation**].

National presentations:

Carter K. The nature, burden and management of psoriatic-related foot problems from the perspective of patients and health professionals. Patient Experience Symposium, Sydney, Australia, April 2019 [**Oral presentation**].

Carter K. Integration of specialist podiatry services within a rheumatology multidisciplinary team to enhance the patient experience. Patient Experience Symposium, Sydney, Australia, April 2019 [**Oral presentation**].

Carter K. Clinical-academic partnerships. Musculoskeletal Network, Agency for Clinical Innovation, Sydney, Australia, August 2019 [**Oral presentation**].

Carter K. Foot involvement in psoriatic arthritis: The importance of the patient perspective. Session: Impacts in Psoriatic Arthritis. Australian Rheumatology Association Conference, Sydney, Australia, May 2020 [Keynote speaker: **Oral presentation**].

Web-based study publications:

Website link: www.psoriaticfootarthritis.com

Facebook page link: https://www.facebook.com/footsurvey/

Video link: https://youtu.be/lZZfT2BkSXk

Animation link: https://youtu.be/db5GiXe_Ut0

Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except as acknowledged in the text), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

[redacted]

Kate Carter   Date: June 2020

Abbreviations

ABS	Australian Bureau of Statistics
ACT	Australian Capital Territory
A priori	Based on theoretical deduction rather than empirical observation
CASPAR	Classification Criteria for Psoriatic Arthritis
CHERRIES	Checklist for Reporting Results of Internet E-Surveys
CI	Confidence interval
COSMIN	Consensus-based Standards for the Selection of Health Status Measurement Instruments
COTA	Council of the Aging
CRP	C-reactive protein
DIPJs	Distal interphalangeal joints
DMARD	Disease modifying anti-rheumatic drug
EQ-5D	EuroQol five-dimensions
EQUATOR	Enhancing the Quality and Transparency of Health Research
ESR	Erythrocyte sedimentation rate
EULAR	European League Against Rheumatism
GRAPPA	Group for Research and Assessment of Psoriasis and Psoriatic Arthritis
HAQ	Health Assessment Questionnaire
IA	Intra-articular
IRSAD	Index of Relative Socio-economic Advantage and Disadvantage
ICF	International Classification of Functioning, Disability and Health
LFIS-RA	Leeds Foot Impact Scale in Rheumatoid arthritis
LFIS-IF	Leeds Foot Impact Scale, foot impairment/footwear restriction,
LFIS-AP	Leeds Foot Impact Scale, activity limitation/participation restriction
MSK	Musculoskeletal
MTPJs	Metatarsophalangeal joints
NA	Not applicable
NR	Not recorded
NRS	Numerical rating scale
NSAID	Non-steroidal anti-inflammatory drug
NSW	New South Wales
NT	Northern Territory

OMERACT	Outcome Measures in Rheumatology for use in Clinical Trials
PIPJs	Proximal interphalangeal joints
PROM	Patient-reported outcome measure
PsA	Psoriatic arthritis
PTA	Percentage total agreement
PUVA	Psoralens ultraviolet A therapy
QLD	Queensland
RA	Rheumatoid arthritis
RCTs	Randomised controlled trials
SA	South Australia
SD	Standard deviation
SLE	Systemic lupus erythematous
SPSS	Statistical Package for the Social Sciences
STROBE	Strengthening the Reporting of Observational Studies in Epidemiology
SURGE	Survey Reporting Guideline
TAS	Tasmania
US	Ultrasound
UK	United Kingdom
UVB	Ultraviolet B therapy
VAS	Visual analogue scale
VIC	Victoria
WA	Western Australia
WHO	World Health Organisation

Chapter 1

1 Introduction

This chapter provides a brief introduction and justification of the rationale, aims and objectives of the programme of work presented in this thesis. An outline of the overall thesis structure and content are also provided.

1.1 Research Justification and Rationale

It is now well recognised that psoriatic arthritis (PsA) can lead to marked musculoskeletal damage with consequent functional impairment and reduced quality of life (Gladman, et al., 1998; Gladman, 2005). Two principal themes are established throughout the literature that describe inflammatory involvement in PsA: 1) an established higher involvement of the lower limbs compared with the upper limbs, and 2) the persistence of localised disease activity in the foot independent of global disease. Localised pain and disease features in the foot have been identified in those with clinically important levels of foot-related impairment and disability in PsA (Hyslop, et al., 2010a). Despite recognition that characteristic features of PsA, such as enthesitis, dactylitis and peripheral arthritis are predominant in the foot and ankle, limited foot-specific research exists. Few previous studies that comprise small sample sizes (range n=9 to 101) have focused on distinct anatomical sites of the foot affected by PsA (such as the MTPJs, Achilles tendon, toe dactylitis) (Hyslop, et al., 2010a; Hyslop, et al., 2010b; Woodburn, et al., 2013; Turner, et al., 2014; Wilkins, et al., 2016). Involvement of other sites in the foot is less well understood and it is not known how individual features may affect other disease manifestations, with few studies providing a comprehensive description of the foot in PsA.

Whilst previous studies have contributed useful initial insights into PsA-related foot involvement, how foot problems impact on the lives of people with PsA have not been explored in detail. Incorporation of the patient perspective in the development of disease domains and outcome measures has been strongly advocated by the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) and Outcome Measures in Rheumatology for use in Clinical Trials (OMERACT) groups in PsA (Kirwan, et al., 2011a; Kirwan, et al., 2011b; de Wit, et al., 2013; Tillett, et al., 2014;

Tillett, et al., 2015a). Patient participation in qualitative studies and use of international health frameworks have improved understanding of global PsA disease impact and domain measurement (Stamm, et al., 2007b; Taylor, et al., 2010; Gudu, et al., 2017). In contrast, little is known about the patient experience of foot involvement and how this may link to recognised frameworks to capture and describe localised disease impact in PsA.

Early identification of PsA leads to better functional outcomes, mitigating disease progression and destructive joint changes. To better target and treat inflammation, validated disease-specific outcome measures to assess PsA impact domains are required. Currently, no validated foot-specific measures in PsA exist. However, prior to the future development of self-report instruments, a better understanding of the localised disease impact at a patient-level is needed in order to ensure that concepts important and relevant to people with PsA-related foot involvement are adequately covered. In addition, it is important to explore foot problems among people with PsA living in the local context of the current study, Australia and New Zealand. Foot-related functional impairments in other rheumatic conditions have been shown to be influenced by healthcare access and footwear choice associated with climate and sociocultural factors. These influencing factors are likely to be important to the experience of PsA-related foot problems and are likely to be different in different countries.

Foot involvement in PsA remains under-researched and poorly understood with a lack of large-scale data needed to provide the basis for targeted disease-specific assessments and interventions. Despite the presence of some previous studies examining the foot, a full and comprehensive description of the foot is warranted in order to understand the impact of foot involvement from the perspective of people with PsA living in Australia. Development of a national survey would provide the ideal opportunity to sample a large population over a wide geographical area across Australia and New Zealand, including different regions (rural and urban) and climate zones (temperature and humidity). The objective of this programme of work was to develop a national survey based on the views of people with PsA and health professionals on foot problems, their impact on daily life, footwear choice and foot care needs.

1.2 Aims and Objectives

The primary aim of this programme of work was to establish the nature, extent and location of foot problems and their impact on the daily lives of people with PsA living in Australia and New Zealand. The secondary aim was to determine the footwear and foot care needs of this patient group. The research focus of this programme of work was to provide a comprehensive description of the foot affected by PsA, which includes the impact of PsA on foot-specific structure and function, activity and participation, and environmental factors such as footwear and foot healthcare.

The specific objectives for this programme of work were 1) to determine the nature, severity and frequency of foot involvement in PsA, 2) to evaluate site-specific involvement in the foot, 3) to explore the impact of foot problems on functioning from the patient perspective in PsA, 4) to investigate the footwear preferences of an Antipodean and PsA-specific population, and 5) to determine the foot care needs among people with PsA in the context of foot healthcare provision in Australia and New Zealand.

1.3 Thesis Structure

This thesis investigates the foot problems in people with PsA. The thesis is structured as follows:

Chapter 2. provides a detailed review of the literature relevant to the key concepts of this work with a focus on study justification.

Chapter 3. presents a theoretical framework that summarises the existing knowledge, gaps in the literature and the resultant research focus.

Chapter 4. describes the qualitative investigation into the patient experience of foot involvement related to PsA, including the background, method, results and discussion.

Chapter 5. describes the linking of qualitative concepts to the International Classification of Functioning, Disability and Health, including the background, method, results and discussion.

Chapter 6. presents a robust survey development protocol for a national survey on PsA-related foot involvement, with a focus on best practice methods in survey design, pre-testing and implementation.

Chapter 7. provides a preface to the results that explains the rationale for undertaking a focused analysis of the survey data with a statement of intent

Chapter 8. presents a focused, mainly descriptive analysis of the survey results mapped to key domains of impact informed by the qualitative research findings and ICF linking exercise

Chapter 9. provides a focused discussion of key survey findings in the context of the literature, study limitations, contribution of knowledge, clinical implications and with suggestions for future work.

Chapter 2

2 Literature Review

This chapter will review and critically appraise the literature relating to psoriatic arthritis (PsA) with emphasis on foot involvement and its impact on foot-related functional impairment and disability. Important themes in the literature include the early identification of active disease in the foot, the lack of validated disease-specific outcome measures to assess the foot, the impact of this omission on persistent foot disease among patients in clinical remission, use of ultrasound imaging and gait analysis techniques to explore the impact of localised disease, and the clinical implications of treatment alongside the treat-to-target approach. This chapter reviews the literature relevant to this field during the PhD timeframe from March 2018 to March 2020 in order to present the most contemporary information prior to thesis submission.

2.1 Statement of Intent

The literature will be interrogated for studies with PsA-specific cohorts. In the absence of such literature, the search will be extended to spondyloarthritis and rheumatoid arthritis (RA). The rationale being that historically RA disease metrics have been applied to PsA based on the assumption of shared pathogenic and clinical features, thus some transferability exists in relation to disease evaluation. Data from published research in Australasian populations will be sought and, when not available, study data from Europe and North America will be presented. Local data is preferable because potential differences in climate-related footwear may influence foot functional impairments and future podiatry treatment decisions, but most published studies in PsA have been conducted in European countries. Previous studies on foot function and gait characteristics in PsA will be reviewed and, in the absence of PsA data, knowledge will be drawn from published studies in RA. The rationale for this approach is based on RA having been the focus of many gait analysis studies compared to other inflammatory arthropathies, and thus aspects of conceptual methods may be extrapolated to PsA.

Effective disease management requires the standardized assessment of disease activity and its impact. However, in PsA there are challenges related to disease assessment on a global and foot region-specific level. In order to gain appreciation of key issues relating to the lack of validated disease measures and the consequent gaps in knowledge and understanding, the principles of management and assessment of global and local disease in PsA will be presented in the early stages of this review.

In this thesis clinical joint damage will be defined as the presence of a limited movement that is more than 20% of range, and is not related to the presence of joint effusion, deformities or ankyloses (Gladman, et al., 1990a; Bond, et al., 2007; Cresswell, et al., 2011; Gladman, et al., 2011). A clinically active joint will be defined as either tender (presence of stress pain and/or joint line tenderness) or swollen (joint swelling with or without tenderness) (Cresswell, et al., 2011).

A narrative literature review was undertaken instead of a systematic review in light of the limited research available on foot-specific assessment and management in PsA. Historically PsA has been under-researched and to date there has been a lack of research focused on localised disease in the foot. A recently published narrative review with expert commentary on foot involvement in PsA supports the necessity for a non-systematic approach taken by podiatry-led PsA research teams (Patience, et al., 2018). Whilst the scope of the literature review may be limited by few, small-scale investigations, it highlights that the foot and ankle remains a neglected area in PsA and provides strong justification for the research planned in this thesis. The aim of the narrative literature review was to provide detailed insight into the most relevant and important aspects of PsA-specific foot involvement using the limited research available, whilst accounting for the biases associated with small-scale studies.

2.2 Background to Psoriatic Arthritis

PsA is a chronic inflammatory musculoskeletal disease associated with psoriasis (Taylor, et al., 2006) and is characterized by a wide clinical spectrum and a variable disease course (Gladman, et al., 2005). The heterogeneous clinical manifestations include axial and peripheral arthritis, enthesitis, tendinopathy, dactylitis, and psoriatic skin and nail disease. In addition, PsA is associated with a higher prevalence of cardiovascular disease (Han, et al., 2006; Tam, et al., 2008; Gladman, et al., 2009; Jamnitski, et al., 2013), obesity and type 2 diabetes than the general population (Horreau, et al., 2013; Russolillo, et al., 2013; Husni, 2015), attributed to accelerated atherosclerosis from chronic systemic inflammation (Eder, et al., 2013). Typically affecting young adults of working age between 30 to 50 (Gladman and Chandran, 2011), PsA incurs a significant socioeconomic burden with high levels of unemployment (25-50%) and work disability (16-39%) (Tillett, et al., 2012; Tillett, et al., 2015b). PsA can have a broad and profound impact on quality of life (Husted, et al., 2001; Strand, et al., 2012), comparable to that experienced in other inflammatory conditions (Husted, et al., 2001; Mease, 2009). Although the direct and indirect costs of PsA are considered to be substantial (Ackermann and Kavanaugh, 2008; Lee, et al., 2010; Cortesi, et al., 2012), no Australian or New Zealand data exist characterising the healthcare costs for PsA and limited studies from other countries have unknown applicability to the local health system context.

PsA is now recognised as a unique disease entity that is different from other forms of chronic inflammatory arthritis, in relation to clinical manifestations, pathogenesis, response to treatment and prognosis (O'Neill and Silman, 1994; Helliwell and Taylor, 2005; Olivieri, et al., 2015). There have been variable estimates of prevalence of PsA owing to historical differences in classification criteria applied (McHugh, 2015). In 2006, classification criteria for PsA (CASPAR) was developed and is now the most widely used criteria in randomised controlled trials and longitudinal observational studies (Ogdie and Weiss, 2015). Current prevalence estimates of PsA range from 0.16% to 0.35% in the general population (Gelfand, et al., 2005; Gladman, et al., 2005; Haroon, et al., 2013a; Löfvendahl, et al., 2014) and between 20% to 30% among people with psoriasis (Prey, et al., 2010), with the incidence of PsA being equal in men and women. An accurate indication of the incidence and prevalence of PsA in Australia and New Zealand from pooled data is not available (Alinaghi, et al., 2019), with one observational study from Australia reporting an 8.7% estimated prevalence of PsA among 453 people with psoriasis (Spelman, et al., 2015). Skin involvement precedes the development of arthritis in 60-80% of cases (Tillett, et al., 2017a) and around 30% of people with psoriasis will develop PsA (Mease, et al., 2013; Henes, et al., 2014). Although psoriasis affects quality of life, the presence of articular involvement produces an additional impact in PsA. People with PsA have reduced functional capacity and health-related quality of life compared to people with psoriasis alone and healthy controls (Husted, et al., 1997; Husted, et al., 2001).

The heterogeneity of clinical features and variability of the disease makes the diagnosis and management of PsA difficult (D’Angelo, et al., 2016; Coates and Helliwell, 2017; Raychaudhuri, et al., 2017). Unlike conditions such as RA, there are no diagnostic criteria or diagnostic markers for PsA. Major challenges recognised in previous studies on the management of PsA include under-diagnosis, diagnostic delays and under-treatment (Armstrong, et al., 2013; Coates, et al., 2016a; Lebwohl, et al., 2016; Garrido-Cumbrera, et al., 2017). Several studies have shown that PsA is under-diagnosed among people with psoriasis, which may be due to under-recognition of musculoskeletal symptoms and lack of effective screening tools (Ibrahim, et al., 2009; Reich, et al., 2009; Haroon, et al., 2013b; Villani, et al., 2015). An additional diagnostic challenge includes the 10-15% of people that develop arthritis prior to psoriasis, as skin involvement can help differentiate PsA from other rheumatic conditions (Coates and Helliwell, 2017).

Historically, PsA was considered a mild and rare disease (Wright, 1956), characterized by fewer long-term sequelae and unlikely to progress to permanent joint damage (Scarpa, et al., 2008). However, in the last 20 years research has shown that PsA is deforming and destructive in 40% to 60% of cases with consequent functional impairment, decreased quality of life, psychosocial disability and increased risk of death compared with the general population (Gladman, 2005; Gladman, et al., 1990; McHugh, et al., 2003; Torre Alonso, et al., 1991). Several prospective and longitudinal studies have demonstrated that joint damage appears in the first years of disease onset (Gladman, et al., 1990b; Torre Alonso, et al., 1991; Wong, et al., 1997; Kane, et al., 2003b; McHugh, et al., 2003; Lindqvist, et al., 2008; Geijer, et al., 2015), and that a 6 month diagnostic delay contributes to a poorer long-term radiographic and functional outcome (Haroon, et al., 2015). Therefore, early diagnosis and treatment are essential, with the aim of preventing irreversible joint damage (D’Angelo, et al., 2016; Raychaudhuri, et al., 2017). Treatment of PsA has vastly improved with the introduction biological therapies in the last decade (D'Angelo, et al., 2012; Perrotta, et al., 2015; Gossec, et al., 2016), which have demonstrated a reduction in disease activity and radiographic progression of joint damage (Mease, et al., 2004; Mease, et al., 2005;

Kavanaugh, et al., 2006; Gladman, et al., 2007a; van der Heijde, et al., 2007; Kavanaugh, et al., 2009; Ash, et al., 2012a; Ramiro, et al., 2016).

In summary, the relative paucity of scientific research in PsA contrasts with that of other inflammatory arthropathies due to the prior lack of 1) a validated case definition, 2) universally accepted classification criteria, 3) recognition that it is not a benign condition, and 4) available drugs to alter the disease course (Helliwell and Taylor, 2005; El Miedany, et al., 2015; Gossec, et al., 2016).

2.3 Management of Psoriatic Arthritis

The concept of treat-to-target is well established in RA (Grigor, et al., 2004; Verstappen, et al., 2007; NICE, 2009). In PsA, research evidence strongly suggests a link between inflammation and joint damage (both clinical and radiographical) (Gladman and Farewell, 1999; Bond, et al., 2007). Therefore, a target for therapy has been extended to the management of PsA, with the goal of achieving minimal disease activity or remission in order to maximise clinical improvement and minimise long term damage (Coates, et al., 2010; Schoels, et al., 2010; Smolen, et al., 2014; Coates, et al., 2015). The heterogeneity of disease manifestations and lack of validated outcome measures makes defining targets particularly challenging in PsA (Coates, et al., 2010; Coates, 2015b). Consensus exists that central to the approach of tight control for PsA should be the patient preference for their own target and the means to achieve it (Coates, et al., 2015; Mease and Coates, 2018; Van den Bosch and Coates, 2018). Widespread patient dissatisfaction in the management of PsA has been reported and associated with lack of patient and health professional disease awareness, and disparity between patient and health professional priorities for treatment goals (Armstrong, et al., 2013; Lebwohl, et al., 2016; Garrido-Cumbrera, et al., 2017). Therefore, obtaining the patient’s perspective and the clinician’s view has been recognised as critically important in the assessment and management of PsA (Betteridge, et al., 2016; Lebwohl, et al., 2016; Garrido-Cumbrera, et al., 2017; Orbai, et al., 2017a).

In summary, active disease detected early can be treated more aggressively and monitored regularly, potentially leading to better patient outcomes. Patient involvement has been strongly advocated in the management of PsA in order to identify and prioritise disease features by taking into consideration what is important and relevant to them.

2.4 Psoriatic Arthritis Core Domain Set

Treating inflammation as early as possible to minimise structural joint damage and functional disability has been shown to be effective in PsA (Chandran, et al., 2008; Coates, et al., 2015; Haroon, et al., 2015). This approach requires precise evaluation of disease activity, functioning and response to therapy through validated outcome measures (Mease, 2011). Historically, instruments developed to assess RA have been used in PsA with the knowledge of limitations which include disparities in pathophysiology, patterns of joint involvement, cutaneous manifestations, range of musculoskeletal features (Gladman, et al., 2005; Veale and Fearon, 2015; Coates, et al., 2016b), as well as differences in the impact of the diseases on health-related quality of life (Husted, et al., 2001; Strand, et al., 2012). The lack of validated clinical outcomes measures led to the development of a PsA core domain set with the purpose to standardise the assessment and reporting of outcomes in PsA (Orbai, et al., 2017b).

In 2016, the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) and the Outcome Measures in Rheumatology (OMERACT) proposed the core set of 6 domains in order to identify accurate, reliable and feasible disease activity measures for clinical trials and daily practice (Gladman, et al., 2007b; Coates, et al., 2014; Orbai, et al., 2017b) (Figure 2.1). It was updated from the initial 2006 PsA core set in order to incorporate patient involvement and advances in the field in core set development. Domains refer to what should be measured and instruments specify how the domains should be measured (Escorpizo, et al., 2011).

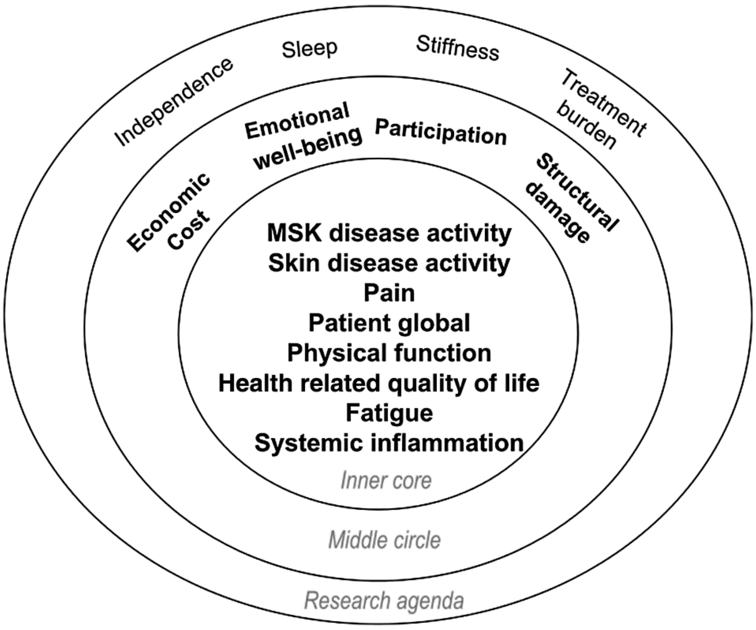


Figure 2.1. Updated 2016 PsA core domain set (Orbai, et al., 2017b).

Musculoskeletal (MSK) disease activity includes peripheral joints, enthesitis, dactylitis and spine symptoms; skin activity includes skin and nails; patient global is defined as patient-reported disease-related health status. The inner circle (core) includes domains that should be measured in PsA randomised controlled trials and longitudinal observational studies. The middle circle includes domains that are important but may not be feasible to assess in all randomised controlled trials and longitudinal observational studies. The outer circle or research agenda includes domains that may be important but need further study.

The heterogeneity of clinical features makes measuring disease activity and disease impact difficult in PsA (Mease and Armstrong, 2014). Although disease-specific instruments for PsA have been developed and validated during the last decade (McKenna, et al., 2004; Mease, 2011; Gossec, et al., 2014), there is currently no consensus on a standardised outcome measurement set for PsA (Coates, et al., 2018). Indeed, great heterogeneity of outcome measures per domain exists (Palominos, et al., 2012; Kalyoncu, et al., 2016). Whilst outcome measures commonly evaluate individual features or domains, it is recognised that the impact of the disease depends on the interaction of multiple domains (Her and Kavanaugh, 2014; Coates, 2015a). Lack of a PsA core outcome measurement set limits the optimal evaluation of domains in the core outcome set for PsA, comparability across study results and enhancement of evidence-based healthcare decisions (Boers, et al., 2014; Højgaard, et al., 2018).

Patient-reported outcomes have been increasingly recognised as critical to identifying the full burden of disease on health and daily functioning in people with PsA (McKenna, et al., 2004; Gossec, et al., 2014; Tillett, et al., 2014; Tillett, et al., 2015a). However, there has been limited incorporation of the patient perspective in the development of outcome measures and disease domains in PsA (Palominos, et al., 2012; Tillett, et al., 2014), which is essential given that discrepancies have been reported between the views of patients and health professionals (Dandorfer, et al., 2012). Consequently, few patient-reported outcome measures for PsA have evidence of quality criteria (Højgaard, et al., 2018), described by the Consensus-based Standards for the Selection of Health Status Measurement Instruments (COSMIN) as validity, reliability and responsiveness and by the OMERACT filter as truth, discrimination and feasibility (Boers, et al., 1998; Mokkink, et al., 2010b). Obtaining the patient's perspective on how they feel and function with respect to their disease provides a basis for defining what should be measured to represent comprehensively the experience of people with PsA and important domains of impact. Therefore, involvement of people with PsA in the development of outcome measures and disease domains in order to ensure patients concerns are appropriately assessed has been the focus of research led by the GRAPPA and OMERACT groups (Kirwan, et al., 2011a; Kirwan, et al., 2011b; de Wit, et al., 2013; Tillett, et al., 2014; Tillett, et al., 2015a).

In summary, key limitations to improving the understanding of PsA and effective management have been due to 1) the use of generic and RA-specific outcome measures in PsA, 2) few validated instruments developed specifically for PsA, 3) the lack of standardisation of domains and instruments used, and 4) little incorporation of the patient perspective in the development of outcome measures and disease domains in PsA.

2.5 ICF Model in Psoriatic Arthritis

To assess the impact of disease on daily functioning, the World Health Organisation (WHO) International Classification of Functioning, Disability and Health (ICF) provides a unified language and common framework that has been widely used in rheumatic conditions (Stamm, et al., 2005; Stamm and Machold, 2007; Stamm, et al., 2007a; Boonen, et al., 2010). Previous research has shown merit in linking domains of impact in PsA to the ICF to categorise the effect of global disease (Taylor, et al., 2010; Gudu, et al., 2017). The components that are addressed in the ICF framework include 1) body functions and structures, 2) activity and participation, 3) environmental factors and 4) personal factors (Figure 2.2).

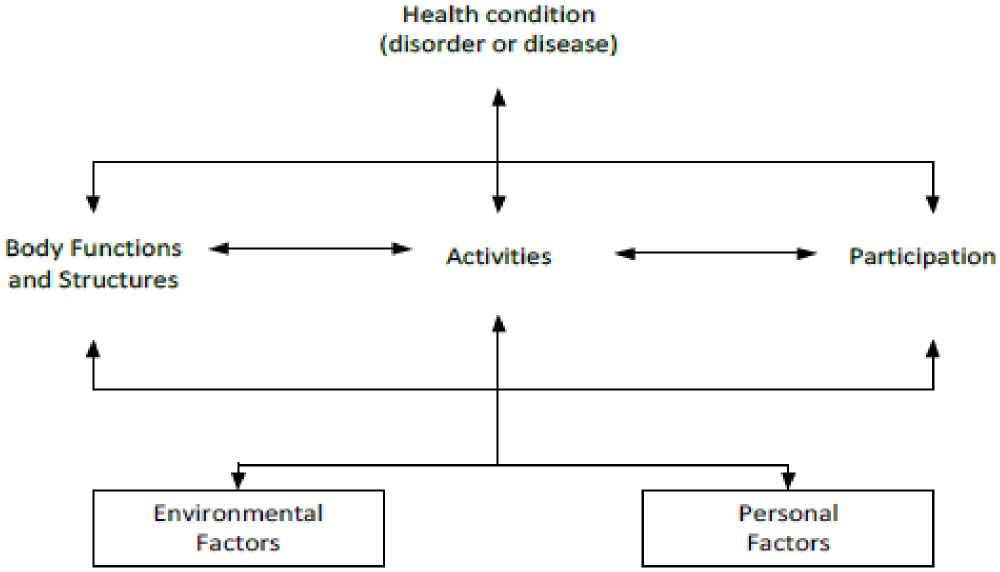


Figure 2.2. The International Classification of Functioning, Disability and Health (ICF) framework by the World Health Organisation (WHO, 2001).

As an internationally accepted conceptual model, the ICF has become the reference model for the conceptualisation of OMERACT domains addressing aspects of functioning and disability (Stucki, et al., 2007). OMERACT groups involved in the development of OMERACT Core Sets have used ICF Core Sets as a basis to specify disease domains and to appraise instruments that measure the OMERACT domains (Stucki, et al., 2007). ICF Core Sets are selections of ICF categories necessary to describe the influence of the disease on functioning and provide an overview of the effect of the disease (Boonen, et al., 2009a). An ICF Core Set integrates the perspectives of patients, clinicians and researchers as well as expert knowledge and evidence (Stucki, et al., 2007; Boonen, et al., 2009a). Qualitative methods have been used to explore the patient and clinician perspective in order to identify relevant concepts, which can be mapped to the ICF classification for integration of these perspectives in the assessment of the disease.

Whilst ICF Core Sets have been developed for other rheumatic diseases (Stucki, et al., 2004; Boonen, et al., 2010), the PsA ICF Core Set remains in an advanced stage of development (Stucki, et al., 2007; Boonen, et al., 2009a). This represents a gap in the literature concerning all relevant aspects of functioning and impact of PsA (Taylor, 2012). Furthermore, the ICF has been used in previous research to determine that concepts derived from patients in qualitative studies are not adequately covered by patient-reported outcome measures used in PsA (Stamm, et al., 2007b). Therefore, standard instruments that assess impact on functioning in PsA encompass a limited part of the full spectrum of consequences of PsA on global functioning and do not satisfy the truth component of the OMERACT filter that comprises content, face and construct validity.

In summary, the ICF has facilitated the OMERACT process of defining what to measure and how to measure, and has provided a way to study the truth component of the OMERACT filter. This work has reinforced the importance of patient and clinician involvement as a central component of research design in PsA. However, there are gaps in current knowledge on the typical impact of PsA with no established ICF Core Set.

2.6 Psoriatic Arthritis Foot-Specific Outcome Measures

The GRAPPA-OMERACT PsA core domain set has influenced recommendations for management and the use of validated disease-specific outcome measures (Figure 2.3). Whilst there are useful overarching principles for the management of PsA and broad recommendations for how to measure global disease activity and its impact, information on how best to assess foot region-specific involvement is lacking.

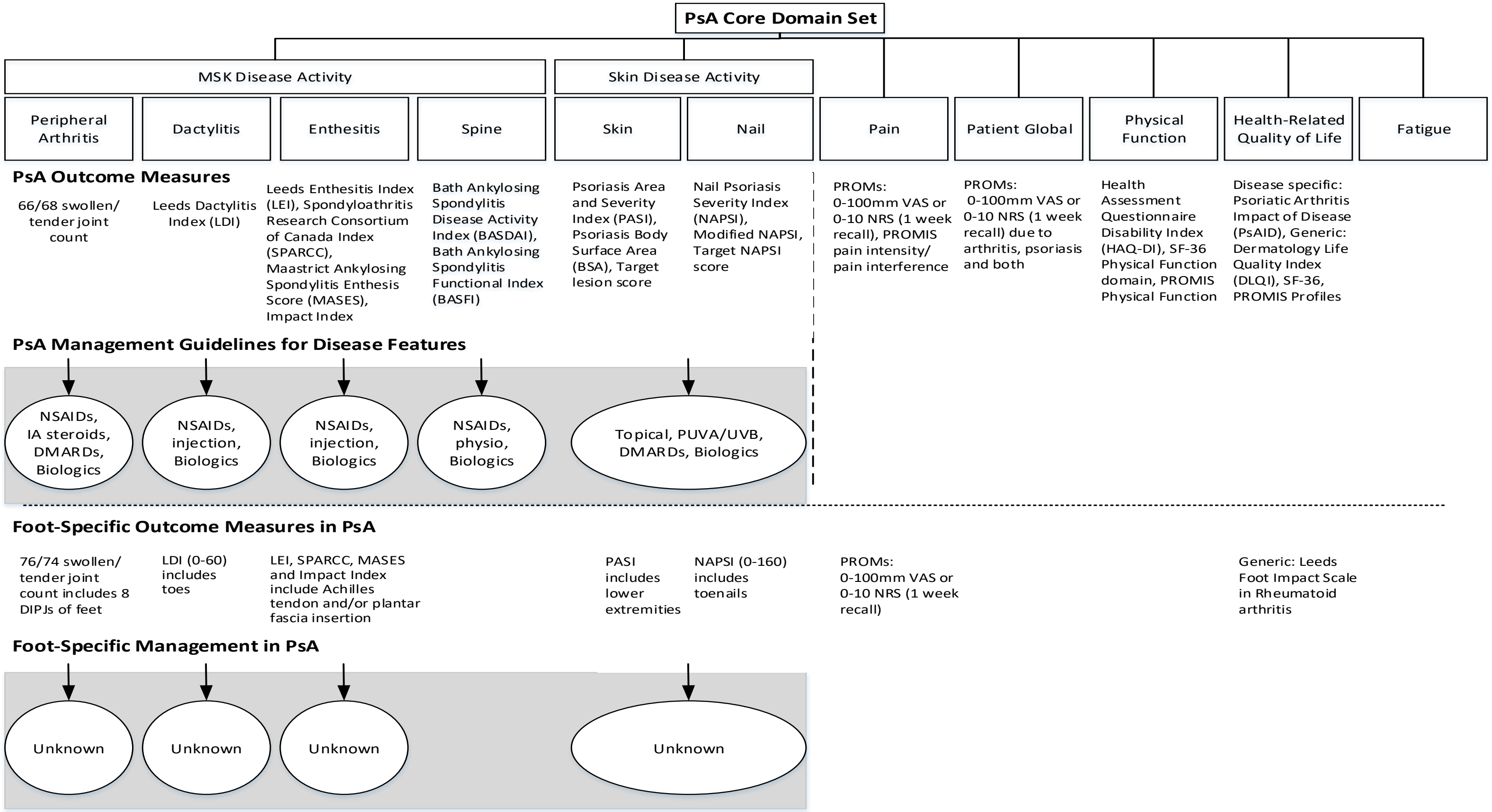


Figure 2.3. PsA core domain set aligned with the recommended outcome measures and management guidelines for global disease and localised foot disease.

Adapted from Gossec, et al., 2016 and Leung, et al., 2018. *DIPJs* Distal interphalangeal joints, *DMARDs* Disease-modifying anti-rheumatic drugs, *IA* Intra-articular injection, *NRS* Numerical rating scale, *NSAIDS* Non-steroidal anti-inflammatories, *physio* Physiotherapy, *PROMs* Patient-reported outcome measures, *PsA* Psoriatic arthritis, *PUVA* Psoralens ultraviolet A therapy, *UVB* Ultraviolet B therapy, *VAS* Visual analogue scale.

In the absence of a validated disease- and foot region-specific outcome measure to assess the impact of localised disease in the foot in PsA, the Leeds Foot Impact Scale in Rheumatoid arthritis (LFIS-RA) (Helliwell, et al., 2005a) has been used in previous foot-specific studies (Hyslop, et al., 2010a; Hyslop, et al., 2010b; Woodburn, et al., 2013; Wilkins, et al., 2016). However, the LFIS is an RA disease-specific outcome measure unlikely to capture both the musculoskeletal and dermatological impact in PsA and with limited incorporation of the patient perspective. It has been suggested that researchers and clinicians looking for instruments should first identify an outcome according to the concepts relevant to people with PsA and then select an instrument that covers the identified outcome (Stamm, et al., 2007b). However, concepts important and relevant to people with PsA-related foot involvement have not been explored in order to inform on localised disease impact and the measurement of relevant outcomes. Previous studies have assessed the perspectives of patients regarding the whole effect of PsA (Taylor, et al., 2010; Gossec, et al., 2014; Orbai, et al., 2017a), but the region-specific impact of foot involvement in PsA is still largely unknown.

The ‘window of opportunity’ paradigm in podiatry advocates the use of the LFIS-RA for localised disease monitoring with the aim of preventing irreversible joint damage in the foot affected by RA (Helliwell, et al., 2005a; Woodburn, et al., 2010). Definitive strategies to attain suppression of localised inflammation in the foot and maintain optimal functionality are limited with no validated foot-specific outcome measures to define ‘tight control’ or to determine the typical impacts of local disease on daily functioning. Currently there is limited evidence to support the management of PsA-specific foot problems (Patience, et al., 2018). Expert-led recommendations for PsA advocate the integration of podiatry within rheumatology multidisciplinary teams for rapid access to specialist foot care (Coates and Helliwell, 2017; Patience, et al., 2018). To better target and treat inflammation present in the foot it is important that the impact of local disease activity is better understood.

In summary, our understanding of the localised foot disease impact in PsA is limited because the concepts important and relevant to people with PsA-related foot involvement have not been explored. Consequently, there is no validated foot-specific outcome measure to assess the impact of foot problems in PsA on functioning and health. Further research to determine a patient-centred perspective on the burden of local foot disease and its impact on daily life in PsA is required.

2.7 Disease Pathogenesis

The pathogenesis of PsA is largely unknown (Sakkas, et al., 2013), but enthesitis (inflammation at tendon, ligament, joint capsule or fascia insertion sites to bone) is regarded as pathognomonic and a hallmark feature of PsA (Moll and Wright, 1973; Benjamin and McGonagle, 2001; Ritchlin, 2005; Aydin, et al., 2013). Not all entheses are targeted equally in PsA with the entheses typically involved being those subject to mechanical trauma (Benjamin and McGonagle, 2001). Emerging evidence from imaging, histological and genetic studies suggests that micro-damage triggered by high mechanical stress at entheses is central to the new anatomical model of disease pathogenesis in PsA (Benjamin and McGonagle, 2001; McGonagle, et al., 2001). This model supports the observation that PsA may be associated with a preceding joint injury (Scarpa, et al., 1992; Punzi, et al., 1997; Pattison, et al., 2008) and that micro-damage or trauma to the skin is known to be a factor in expression of psoriasis, an example of Koebner response phenomenon (McGonagle, et al., 2008a). Koebner responses may also contribute to nail involvement in PsA (McGonagle, et al., 2009).

Enthesitis has been proposed as the primary lesion in PsA that triggers secondary synovitis of the various structures (joint, tendon and bursa) through the release of pro-inflammatory mediators from the inflamed entheses (McGonagle, et al., 1998; McGonagle, et al., 1999a). Enthesitis has been suggested as the anatomical basis for psoriatic nail disease and dactylitis (McGonagle, et al., 1999a; Aydin, et al., 2012). The association between dactylitis and distal interphalangeal joint arthritis, as well as the direct link between the nail unit and the distal interphalangeal joint via the entheseal unit of the distal interphalangeal extensor tendon, support the link between enthesitis, dactylitis, and psoriatic nail disease (Jones, et al., 1994; Williamson, et al., 2004; Tan, et al., 2007; McGonagle, et al., 2009; Ash, et al., 2012b; Raposo and Torres, 2015; Lai, et al., 2016). Consequently, people with psoriatic nail disease should be closely monitored for the signs and symptoms of dactylitis and PsA (Kaeley, et al., 2018).

2.7.1 Enthesitis

The reported prevalence of enthesitis is between 25% to 78% of cases (Frediani, et al., 2002; Kane, et al., 2003a; Kane, et al., 2003b; Michet, et al., 2005; Helliwell, et al., 2007; Kavanaugh, et al., 2009; Gladman and Chandran, 2011; Queiro, et al., 2011; Bandinelli, et al., 2013a), with the wide variation in part explained by the use of varied definitions, different methods of clinical, radiographic and ultrasound examination, and the different populations studied (Ogdie and Weiss, 2015). Enthesitis may be painful and disabling (D'Agostino and Olivieri, 2006) or asymptomatic and only revealed by imaging techniques (Lehtinen, et al., 1994; Balint, et al., 2002). Therefore, the clinical assessment of enthesitis is challenging because these structures are not often visibly inflamed and they can be located deep within surrounding tissue making it difficult to be precise (Ritchlin, 2006). Enthesitis consists of focal destructive, microscopic inflammatory lesions that progress to fibrous scarring and new bone formation (Benjamin and McGonagle, 2007). The presence of enthesitis is an adverse prognostic factor and is associated with elevated disease activity, self-reported pain, poorer functional status and greater overall disease burden compared to those without enthesitis (Mease, et al., 2017).

Inflammation may occur at any entheses, but those of the lower extremities are involved more frequently than those of the upper limbs (D'Agostino, et al., 2003). Research evidence suggests that there are localised features associated with the classic, functional and digital entheses that may explain the predominance of inflammation in the foot in PsA (Benjamin, et al., 1995; Benjamin and Ralphs, 1997; Benjamin and McGonagle, 2001; McGonagle, 2009). The Achilles tendon insertion has been identified in the literature as the best example of a classic enthesis (Benjamin, et al., 2006). Digital entheses include those where tendons or ligaments replace a joint capsule around a synovial joint (Benjamin and McGonagle, 2001), and functional entheses occur at sites where tendons wrap closely around bony pulleys (tibialis posterior and peroneal tendons) (Benjamin and McGonagle, 2001).

The main research focus on entheseal involvement of the lower limbs has been at the Achilles tendon and plantar fascia insertion (Balint, et al., 2002; D'Agostino, et al., 2003; Mease, 2011). These entheses have been favoured not only due to the frequency of clinical involvement of PsA (D'Agostino, et al., 2003), but also because the Achilles tendon is considered the archetypical enthesis (Benjamin, et al., 2006). The relatively large size and superficial location beneath the skin of the Achilles tendon makes it most suitable for study (Balint and Sturrock, 2000; McGonagle, et al., 2008b). However, previous studies in PsA have demonstrated tenosynovitis of the tibialis posterior tendon (Galluzzo, et al., 2000; Hyslop, et al., 2010a) and peroneal tendons (Harman and Tekeoğlu, 2017) in one third of participants. Based on the fundamental principles from the work of McGonagle, Benjamin and colleagues that link localised anatomical features to disease pathogenesis, many of the entheses sites in the foot should be prime sites for disease localisation in PsA (Benjamin, et al., 1995; Benjamin and Ralphs, 1997; Benjamin and McGonagle, 2001). However, in the PsA literature the functional and digital entheses in the foot are under-reported. In addition, the omission of many anatomical sites in the foot and ankle from standard clinical enthesitis indices (Mander, et al., 1987; Heuft-Dorenbosch, et al., 2003; Healy and Helliwell, 2008; Maksymowych, et al., 2009), may lead to active disease in the foot being missed along with the opportunity to prevent progression of PsA.

In summary, whilst there is a wealth of literature on inflammatory features at the Achilles tendon and plantar fascia insertion in people with PsA, involvement of other sites in the foot are under-reported and less well understood. Few studies have examined a PsA-specific population and with limited focus on a comprehensive assessment of the foot in PsA. As a result, the prevalence and extent of enthesitis in the foot and ankle in PsA is largely unknown.

2.7.2 Predominant and Persistent Inflammation in the Foot and Lower Limb

The two main themes established throughout the literature that describe inflammatory involvement in PsA are 1) an established higher lower limb involvement, and 2) the persistence of localised disease activity that is largely independent of global disease. Inflammation of specific sites in the foot and lower limbs has been shown to be more common than in the upper limbs (Lehtinen, et al., 1994; Olivieri, et al., 1998; McGonagle, et al., 1999b; Balint, et al., 2002; D'Agostino, et al., 2003), with the Achilles tendon and plantar fascia insertion being the most frequently affected sites (Balint, et al., 2002; D'Agostino, et al., 2003). The high levels of micro-trauma at sites vulnerable to mechanical stress has been suggested to explain the greater involvement of the lower limbs (Benjamin and McGonagle, 2001).

Despite intensive pharmacological management, imaging studies have shown that inflammation is detectable in the foot in a high proportion of people with PsA (n=26, 83.9%, and n=77, 76.2% respectively) (Galluzzo, et al., 2000; Delle Sedie, et al., 2011). This has been shown to poorly correlate with systemic parameters of disease activity and to be independent of disease duration (Hyslop, et al., 2010a). As disease activity in the foot has been linked to subsequent clinical joint damage (Cresswell, et al., 2011), early identification of foot involvement in PsA is of clinical importance. Clinical joint damage is a marker of severity and is associated with, and a predictor of, loss of function and mortality (Gladman, et al., 1998; Husted, et al., 2007; Leung, et al., 2008; Ravindran, et al., 2010). Therefore, limitations to our understanding of the localised disease impact in PsA has important prognostic implications for patient outcomes.

In summary, the overarching concept from the literature to understand these findings is the indication that localised foot anatomy and biomechanics have an important role in disease pathogenesis in PsA. In order to better target and treat inflammation present in the foot, identification of the exact sites of inflammation in the foot is essential.

2.7.3 Foot Function in Psoriatic Arthritis

Few previous studies have investigated the biomechanics of the foot and ankle in PsA (Hyslop, et al., 2010b; Castro, 2013; Woodburn, et al., 2013; Turner, et al., 2014; Wilkins, et al., 2016). These studies had small sample sizes, were largely based on established disease, and focused on specific anatomical sites, including the Achilles tendon (Woodburn, et al., 2013), metatarsophalangeal joints (Turner, et al., 2014), and the toes (Wilkins, et al., 2016). Despite some existing information that demonstrates adapted gait patterns in PsA, a detailed description of the impact of foot-related functional impairment and disability is lacking.

Conversely, the gait patterns and dynamic function of the foot and ankle among people with RA have been extensively measured (Baan, et al., 2012). In RA, these insights have led to paradigmatic changes in therapeutic approaches (Woodburn, et al., 2010). The non-pharmacological management of people with RA-related foot problems is effective at reducing foot pain and improving/maintaining foot function and mobility (Farrow, et al., 2005; Gossec, et al., 2006; Woodburn, et al., 2010; Hennessy, et al., 2012). There are no guidelines or recommendations currently available on therapeutic targets or effective interventions for the foot in PsA, and with distinctly different clinical features and pathogenesis these treatment approaches are unlikely to be directly transferable. Inflammatory changes in the foot in RA have been shown to lead to altered joint mechanics and increased plantar pressure (Van Der Leeden, et al., 2010). However, two studies of PsA have shown that plantar pressures do not correlate with joint damage and pain (Turner, et al., 2014; Wilkins, et al., 2016). This suggests that a different interaction between inflammatory and mechanical factors may exist in PsA, and indicates that models of joint pain may be disease- and site-specific (Turner, et al., 2014). These inferences should be interpreted with caution as they are based on small sample sizes that increase the risk of error from inadequate power (34 and 24 participants with PsA respectively), and on cross-sectional data sets that cannot determine causal relationships (Turner, et al., 2014; Wilkins, et al., 2016). Therefore, these interpretations represent an explanatory model of peripheral joint pain in PsA, limited by the lack of research in this specific area.

In summary, our understanding of foot function in PsA is largely limited due to the lack of a comprehensive description of the impact of localised disease in the foot on functioning in PsA. Due to this, foot specific treat-to-target strategies have not yet been determined in the foot in PsA. Prior to the evaluation of interventions, a better understanding of foot-related function impairment and disability is indicated.

2.8 Foot Involvement

Despite recognition that typical features of PsA such as peripheral arthritis, dactylitis, enthesitis, tendinopathy, and skin and nail psoriasis, are predominant and persistent in the foot and ankle (Galluzzo, et al., 2000; Healy, et al., 2008; Hyslop, et al., 2010a; Delle Sedie, et al., 2011), limited research has focused on the foot. Few previous studies with small sample sizes have described the structural and functional changes in the foot affected by PsA (Galluzzo, et al., 2000; Bezza, et al., 2004; Hyslop, et al., 2010a; Hyslop, et al., 2010b; Delle Sedie, et al., 2011; Woodburn, et al., 2013; Turner, et al., 2014; Wilkins, et al., 2016; Patience, et al., 2018) (Table 2.1). Whilst these studies provide useful early insights into foot involvement in PsA, the details of how foot problems impact on the lives of people with PsA, their experiences with footwear and their foot care needs are limited.

A cross-sectional survey of subjective health complaints in people with PsA found that pain in the feet was the fourth most prevalent single complaint (71.7%, n=264.6), behind tiredness, arm pain and lower back pain (Nordbø, et al., 2017). This suggests that, for a large proportion of people with PsA, foot involvement may be the major characteristic feature of their disease. The first large study to report on the clinical manifestations of foot involvement in PsA was a single cross-sectional survey of 104 patients conducted in the UK (Hyslop, et al., 2010a). Disabling foot pain was reported in approximately two-thirds of people with PsA (62%, n=64), which is similar to that reported in RA (Hyslop, et al., 2010a). The main clinical findings showed that forefoot deformity (95%) was more frequent than rearfoot deformity (65%). Dactylitis was found in nearly one quarter of cases (24%), and skin psoriasis and nail involvement was found in 8% and 13% of cases, respectively (Hyslop, et al., 2010a). Hyslop et al (2010a) recorded a high frequency of enthesitis, most commonly found at the insertion of tibialis posterior tendon (34%), followed by the plantar fascia (26%), and the Achilles tendon (18%). Clinical examination of the peroneal, extensor and other flexor tendons were not reported in this study. Findings from this previous study may lack external validity as participants were recruited from one large teaching hospital regarded as a centre of excellence, and may not be a true representation of foot-related impairments experienced in different parts of the UK or in different countries.

Table 2.1. A summary of current knowledge from studies focusing on foot involvement in a psoriatic arthritis-specific population.

Study	Study Design	Sample Size (n)	Disease Duration (years)	Disease Activity Measures	Foot Site Studied	Method	Significance
Bezza, et al., (2004) Morocco	Retrospective cohort study	26	Not stated	-	Foot, ankle	Review of medical records between 1972 and 1999	Clinical and radiographic features of PsA-related foot involvement were common (most frequently in the rearfoot in 53% of cases) and occurred early in the course of disease
Delle Sedie, et al., (2011) Italy	Cross-sectional	101	4.5 (median) (range 0.2-23)	-	Joints: Talo-navicular, calcaneo-cuboid, navicular-cuneiform, midtarsal, MTPJ, PIPJ Tendons: Tibialis anterior, extensor halluces, extensor and flexor tendons, peroneus longus and brevis, and plantar fascia	Clinical examination and musculoskeletal US imaging (grey scale and power Doppler)	Active foot disease (synovial hypertrophy, effusion) was identified with twice the frequency of clinical examination techniques (n=77, 76.2%)
Galluzzo, et al., (2000) Italy	Cross-sectional comparative	31 PsA 9 controls	5.3 (mean) (range 0.5-16)	ESR, CRP	Joint: Ankle joint Soft tissues: Achilles tendon, retro-calcaneal bursa, calcaneal bursa, plantar fascia, tibialis posterior, flexor digitorum and peroneus longus and brevis tendons	Clinical examination, radiographic and musculoskeletal US imaging (grey scale)	Active foot disease persists in a large proportion of people with PsA (n=26, 83.9%). Clinical examination underestimates the presence of disease manifestations

Hyslop, et al., (2010a) UK	Cross-sectional	104	10 (mean)	LFIS-RA VAS Foot joint count (0-14)	Joints: Forefoot, rearfoot Soft tissue: Achilles tendon, plantar fascia and tibialis posterior tendon	Clinical examination	Clinically important levels of foot-related impairment and disability were identified in those with localised inflammatory features in the foot affected by PsA
Hyslop, et al., (2010b) UK	Experimental within- and between-day reliability study	9 PsA 9 controls	13 (mean)	LFIS-RA VAS Foot joint count (0-14)	Foot, ankle, lower leg	Temporal and spatial parameters (GAITRite system), barefoot (EMED) dynamic plantar pressure measurement, 3-D gait analysis (Qualysis Oqus), ground reaction force (Kistler)	Development of a multi-segmented foot model to assess foot function in PsA. Excellent within-day reliability was found. Between-day reliability varied depending on the segments and kinematic variables studied, suggesting those variables should not be used in the analysis of foot function in PsA
Patience, et al., (2018) UK	Narrative review	-	-	-	-	Literature review with expert commentary	Highlights the manifestations of PsA in the foot and the need for foot-specific management strategies
Turner, et al., (2014) UK	Cross-sectional comparative	34 PsA 12 controls	9.9 (mean)	Foot joint count of MTPJs	MTPJs	Clinical examination, musculoskeletal US imaging (grey scale and power Doppler) and barefoot (EMED) dynamic plantar pressure measurement	MTPJ pain in PsA was independently predicted by high BMI, female gender, the presence of local inflammation (US-proven synovitis, erosion) and structural factors (joint subluxation). No significant evidence was found linking plantar pressure and MTPJ pain, which suggests models of

							joint pain may be disease and joint specific
Wilkins, et al., (2016) UK	Cross-sectional comparative	24 PsA 12 controls	4.6 (mean) (range 1-25)	HAQ EQ-5D LFIS-RA	Toes (Most common (4th toe) and second most common (2nd toe) sites of dactylitis and corresponding MTPJs)	Temporal and spatial parameters (GAITRite system), barefoot (EMED) and in-shoe (Pedar) dynamic plantar pressure measurement	No significant evidence was found linking plantar forefoot pressures and the prevalence of toe dactylitis, suggesting that examining plantar pressure alone provides limited understanding of toe dactylitis
Woodburn, et al., (2013) UK	Cross-sectional comparative	42 PsA 29 controls	10.6 (mean)	ESR, CRP LFIS-RA VAS	Joints: Ankle joint, sub-talar joint Tendon: Achilles enthesis,	Temporal and spatial parameters (GAITRite system), 3-D gait analysis (Qualysis Oqus), ground reaction force (Kistler), musculoskeletal US imaging (grey scale and power Doppler)	Adapted gait patterns (reduced walking speed, lower Achilles tendon force) were identified among those with PsA and Achilles enthesitis, which were distinguishable from the healthy control and PsA participants without Achilles enthesitis This suggests a link between local inflammatory features in the foot and global functional adaptations

CRP C-reactive protein, *ESR* Erythrocyte sedimentation rate, *EQ-5D* EuroQol five-dimensions, *HAQ* Health Assessment Questionnaire, *LFIS-RA* Leeds Foot Impact Scale in Rheumatoid Arthritis, *MTPJs* Metatarsophalangeal joints, *PIPJs* Proximal interphalangeal joints, *PsA* Psoriatic arthritis, *US* Ultrasound, *VAS* Visual analogue scale, *3-D* Three-dimensional.

The prevalence of enthesitis in the foot varies notably across studies (Figure 2.4). Contributory factors may be the wide variability observed among studies in the definition of enthesitis, lack of standardisation of the number and location of entheses examined, and the absence of a consensus on technical parameters and methods of examination including ultrasound and clinical assessment (Gandjbakhch, et al., 2011). Some authors might designate as "inflammatory enthesitis" conditions designated "tendonitis" by others (Gandjbakhch, et al., 2011). This highlights the possible misreporting of digital and functional enthesitis as tendon rather than entheseal abnormalities. Although the concept of digital and functional entheses are well recognised in the anatomy literature, it does not seem to have transferred to rheumatology field with research focus directed towards the classic entheses.

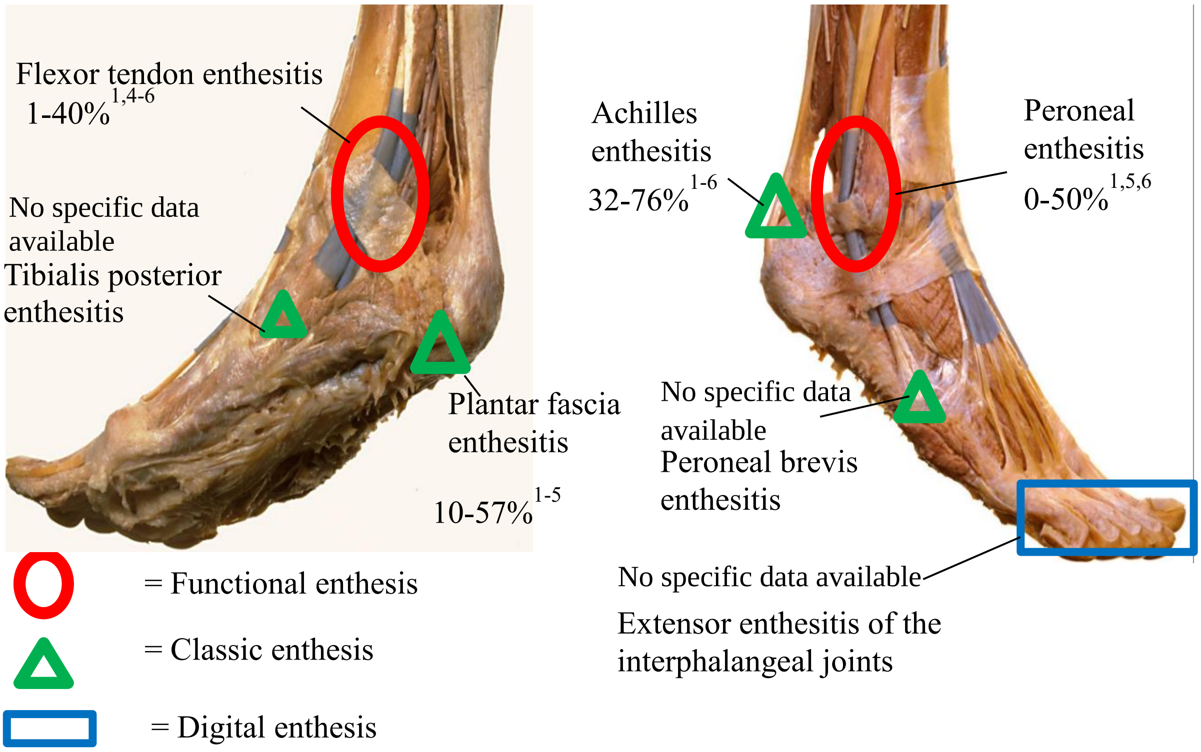


Figure 2.4. Diagram to show the prevalence of foot entheses.

[1]Galluzzo, et al. 2000; [2]Falsetti, et al. 2003; [3]D'Agostino, et al. 2003; [4]Hyslop, et al. 2010; [5]Delle Sedie, et al. 2011; [6]Harman, et al. 2017.

Figure 2.4. shows the prevalence at each site taken from published data on the specific assessment of the foot in PsA. The majority of prevalence estimates of enthesitis in the foot were derived from ultrasound imaging studies, as clinical examination has been

shown to lack the sensitivity and specificity of ultrasound to detect active disease in PsA. Lack of reliability in clinical foot examination further limits our understanding of foot involvement in PsA, which is covered in more detail in section 2.9 and 2.10.

Skin manifestations in the feet have been described in few expert review articles, with psoriatic plaques found often on the dorsum of the foot and palmoplantar psoriasis accounting for relatively few cases (3-4%) (Engin, et al., 2017; Patience, et al., 2018). Nail disease in PsA has a reported incidence of about 66% (Sandre and Rohekar, 2014), most commonly onycholysis and nail pitting, which have been found to predict the development of PsA (Wilson, et al., 2009). Nail disease is associated with pain, function loss, disfigurement and psychological distress (de Jong, et al., 1996). Despite the recognized significance of nail disease, it is often overlooked and under-treated (de Jong, et al., 1996; Williamson, et al., 2004). This is particularly the case in the feet, with most studies of nail disease omitting toenails and focusing only on fingernails (Brazzelli, et al., 2012). On clinical assessment it is difficult to differentiate fungal infections that mimic the presentation of nail psoriasis (Essayed, et al., 2015; Patience, et al., 2018), and few scoring systems used to assess the extent of nail disease have been validated in PsA (Rich and Scher, 2003). Importantly, there is a dearth of research on the extent and impact of foot-specific dermatological manifestations from the patient perspective.

Dactylitis (uniform swelling of an entire digit, also referred to as sausage digit) is a hallmark feature of PsA that can be tender or non-tender (Healy and Helliwell, 2006) and comprises tenosynovitis, synovitis and enthesitis (Bakewell, et al., 2013). Dactylitis occurs in 32-48% of people with PsA (Brockbank, et al., 2005; Gladman and Chandran, 2011; Kavanaugh and Mease, 2012; Gladman, et al., 2013), is associated with impaired function and is a marker of disease severity, with significantly greater joint damage occurring in dactylic than non-dactylic digits (Brockbank, et al., 2005; Geijer, et al., 2015). One cross-sectional study of 259 people with PsA in Canada found that toe dactylitis was more common compared with finger dactylitis (78% and 34% respectively) (Brockbank, et al., 2005), which may support the proposed mechanical pathogenesis given the load bearing function of the toes (Wilkins, et al., 2016). However, few studies have investigated the specific prevalence and impact of toe dactylitis in a PsA-specific population (Olivieri, et al., 1997; Kane, et al., 1999; Brockbank, et al., 2005; Healy, et al., 2008; Payet, et al., 2012; Wilkins, et al., 2016). Dactylitis is often the inaugural feature of PsA and is considered one of the most discriminatory PsA manifestations (Gladman and Chandran, 2011; Caso, et al., 2014). However, clinical detection of dactylitis can be difficult and is often misdiagnosed in early or mild disease (Chandran and Maharaj, 2016). The small dimensions of the structures being evaluated, clinical and pathological heterogeneity, variation in imaging technology and methodology, prior lack of a standardized definition and diverse study design preclude understanding of the natural history of dactylitis in PsA (Healy and Helliwell, 2006; Kaeley, et al., 2018).

Peripheral arthritis in PsA can be variable including oligoarticular and polyarticular disease that may be symmetric or asymmetric. Involvement of the distal and proximal interphalangeal joints in the foot is a common and distinguishing feature (Patience, et al., 2018), and synovitis of the metatarsophalangeal joints was found in 14% of people with PsA (Turner, et al., 2014). Forefoot structural damage and pain are common in people with PsA (Ghanem, et al., 2007; Delle Sedie, et al., 2011). In RA, higher levels of foot-related disability were found in people with rearfoot deformity than those with forefoot deformity, which may represent differences in the ability for functional adaptation for pain and structural impairments (Turner and Woodburn, 2008). This finding in RA should be interpreted with caution due to the study’s small sample size (28 participants with RA), lack of inferential statistical analysis and requirement for external validation of conclusions. The majority of studies reporting gait characteristics associated with inflammatory arthritis relate to RA, which will facilitate future pooling of results and meta-analyses (Carroll, et al., 2015). Conversely, the impact of region-specific foot involvement on people with PsA is not known with limited evidence of foot function relating to PsA.

In summary, there is a lack of evidence defining the nature and extent of foot involvement in a PsA-specific population. Limitations to our understanding of foot involvement in PsA are due to few studies having focused on the clinical manifestations of PsA in the feet and insights into the full impact of foot disease have not been explored from the patient perspective.

2.9 Imaging of the Foot in Psoriatic Arthritis

While plain radiographs can demonstrate established bony erosions and spurs in PsA, they provide minimal information regarding soft tissue structures, especially in the early stages of the disease (Wiell, et al., 2007). Developments in imaging techniques, such as magnetic resonance and ultrasonography have enabled detailed description of localised inflammatory features in PsA. Ultrasound is more sensitive and specific to the detection of active disease in PsA compared with clinical examination (Wiell, et al., 2007; Weiner, et al., 2008) and other imaging techniques such as radiography and magnetic resonance imaging (Kane, et al., 2003b; De Simone, et al., 2011; Coates, et al., 2012b; Bakewell, et al., 2013). It also has proven value in establishing a diagnosis, evaluating disease activity, and has been widely applied to both clinical care and research of PsA (Delle Sedie and Riente, 2015).

Despite advances in ultrasound, few studies have evaluated foot involvement in PsA using this imaging technique (Galluzzo, et al., 2000; Balint, et al., 2002; Falsetti, et al., 2003; Wiell, et al., 2007; Weiner, et al., 2008; Delle Sedie, et al., 2011). The limitations of our understanding of ultrasound-detected inflammatory features in the foot in PsA can be attributed to studies 1) not using PsA-specific populations (Kaeley, 2011), 2) using different definitions of enthesitis and different sets of examined structures (Gandjbakhch, et al., 2011; Delle Sedie and Riente, 2015), 3) using ultrasound scoring systems that have not been validated for use in PsA (Her and Kavanaugh, 2014), and 4) lacking standardisation of image acquisition and scoring (Coates, et al., 2012b).

Previous ultrasound studies assessing the foot in PsA have focused on a limited number of structures commonly targeted by inflammation, as guided by the literature. The technical difficulty in accessing relatively small structures in the foot using ultrasound has been attributed to the low prevalence of tenosynovitis and enthesitis in one study (Delle Sedie, et al., 2011), and may explain why these structures are omitted from evaluation by most studies. There is no general agreement on which joints, tendons or entheses to include in the evaluation of PsA (Poggenborg, et al., 2011).

In PsA, studies have combined the assessment of gait metrics with ultrasound imaging to detect local inflammatory disease in the foot (Hyslop, et al., 2010b; Woodburn, et al., 2013; Turner, et al., 2014). Although these previous studies are an important first step in understanding some of the biomechanical and local inflammatory features associated with foot function impairment in PsA, further research is warranted to provide a more detailed investigation into these relationships.

In summary, despite the presence of some published ultrasound studies examining the foot, there has been limited focus on a full and comprehensive ultrasound assessment of the peripheral joints, tendons and entheses in a PsA-specific population. The need exists to explore the specific distribution of foot involvement in people with PsA in order to determine site-specific involvement.

2.10 Clinical Assessment of the Foot in Psoriatic Arthritis

No guidelines exist for foot assessment in PsA. Most PsA disease activity measures are composite indices reliant upon clinical examination of inflammation in localised joints (Coates, 2015a). Previous use of the reduced 28-joint count in RA grossly underestimated the disease burden in PsA due to the omission of distal interphalangeal joint involvement shown to be characteristic of PsA (Gladman, 1998; Weishaupt, et al., 1999; Kane, et al., 2003a). Evidence-driven recommendations state that the full 66–68 joint count be used routinely to assess people with PsA, as significant proportions of active disease can be missed in the feet and hands (Coates, et al., 2013). This may explain the persistence of active inflammation in the foot and ankle, which in turn would allow undetected and unsuppressed inflammation in the foot to progress in those classified in global remission or low disease activity, who are thus prescribed less intensive pharmacological treatments.

In RA, high levels of agreement were detected between self-report and clinical examination for many foot problems, suggesting self-report can be utilised with a high degree of confidence (Wilson, et al., 2015). However, the heterogeneity of clinical symptoms in PsA is a major challenge in the assessment and evaluation of the disease (Gladman, et al., 2010), and as a result clinical examination has been shown to be unreliable (Balint, et al., 2002; D'Agostino, et al., 2003). In the foot specifically, this may be a consequence of 1) poor ability to detect different anatomical structures that are in close proximity, 2) patients reporting pain from other causes such as mechanical injury, 3) the presence of subclinical inflammation where there are no overt symptoms or signs, and 4) misinterpretation of swelling by the clinical assessor. Poor concordance between tenderness at entheseal insertions and objective evidence using imaging has also been highlighted in the PsA literature (Freeston, et al., 2014; Perrotta, et al., 2016). Previous cross-sectional studies have found normal ultrasound images in symptomatic entheses with a dissociation between sensitivity to local pressure and ultrasound findings (Freeston, et al., 2014; Perrotta, et al., 2016). The reported discrepancy may be in part due to the fact that clinical examination and ultrasound measure different findings. Ultrasound cannot demonstrate osteitis that may cause tenderness at the enthesis, other factors such as an associated higher sensitivity to pain may also explain these findings (Perrotta, et al., 2016). The accurate assessment of disease activity in PsA is challenging but fundamental to effective treatment strategies such as early detection and treat-to-target. Therefore, it is important to determine whether the common methods used to establish foot involvement in PsA can provide accurate information.

Research evidence in RA shows that feet are often neglected areas for assessment in clinical rheumatology practice (Williams and Graham, 2012). Contributory factors may include the perception that foot assessment is complicated and time-consuming (Galluzzo, et al., 2000; Cresswell, et al., 2011; Delle Sedie, et al., 2011), and the varying experience, training and confidence of rheumatologists and podiatrists in specialist foot assessments (Helliwell, 2003; Hitchen and Otter, 2010; Woodburn, et al., 2010; Hendry, et al., 2013a; Williams, et al., 2013). Although it is not known whether this is also the case in PsA, one UK-based study found that the majority of people with PsA reported foot pain but had not received professional foot care (Hyslop, et al., 2010a), which suggests that barriers to accessing care exist.

In summary, the clinical assessment of localised disease activity has been shown to be unreliable in PsA and the foot is often omitted from standard clinical indices.

2.11 Foot Involvement in Australia and New Zealand

Previous studies have shown that foot kinematics have been influenced by footwear (Woodburn, et al., 2002; Zhang, et al., 2013). Whilst altered foot function related to different footwear features has not yet been established in PsA, footwear choice is influenced by local climate and sociocultural factors that are likely to be different in different countries (Hockey, et al., 2013; Brenton-Rule, et al., 2014).

Current knowledge of the clinical manifestations in the feet is based on a few European studies that comprise small sample sizes. Research data from Europe is not likely to translate to the Australasian context due to; 1) differences in healthcare provision, with limited access to podiatry services in the public health system reported in Australia and New Zealand (Rome, et al., 2009; Hendry, et al., 2013b; Hendry, et al., 2013a), and 2) differences in climate and footwear choice that could affect the types of foot problems that occur.

UK podiatry services are well embedded within rheumatology services in the public health system with specialised podiatry roles established (Woodburn, et al., 2010). There are centres of excellence in the UK and Europe with good access to specialist services led by rheumatologists with academic research interests in PsA. Therefore, the experience of foot problems and foot healthcare in patient cohorts from European studies may not be generalisable to Australia or New Zealand, where a distinct lack of podiatry services and expertise in managing rheumatic foot problems in the public health system have been previously described (Rome, et al., 2009; Hendry, et al., 2013b; Hendry, et al., 2013a).

With research data predominantly from European countries, the need to define the foot and footwear characteristics in local rheumatology populations has been recognised in previous studies (Silvester, et al., 2010; Rome, et al., 2011; Brenton-Rule, et al., 2014; Carter, et al., 2016). Footwear characteristics are important as various shoe features have been linked to the development of foot pain, deformity and functional impairment (Barton, et al., 2009; Doi, et al., 2010; Otter, et al., 2010; Riskowski, et al., 2011). Seasonal climate variation has been reported to influence footwear choice in people with rheumatic conditions (Naidoo, et al., 2011; Hendry, et al., 2013b; Brenton-Rule, et al., 2014; Carter, et al., 2016). Therefore, the clinical characteristics and severity of foot functional impairment reported in European countries may not be a true representation of those in other countries, due to the influence of climate-related footwear. It is important to note that open-type footwear such as flip-flops (known as thongs in Australia and jandals in New Zealand) commonly worn in Australia and New Zealand (Silvester, et al., 2010) are considered to lack support, cushioning and protection. Footwear intervention has the potential to alleviate pain, increase mobility and independence (Moncur and Ward, 1990; Fransen and Edmonds, 1997; Egan, et al., 2001; Farrow, et al., 2005; Williams, et al., 2007a; Cho, et al., 2009; Dahmen, et al., 2014), and awareness of footwear problems has the potential to improve patient outcomes. To date the choice of footwear, the key factors influencing footwear choice and the associated contribution of footwear to foot impairment (pain, deformity and disability), has not been reported in people with PsA.

In summary, to the best of the authors' knowledge no study has comprehensively investigated foot involvement related to PsA in Australia and New Zealand. There is a lack of locally representative data on PsA-related foot problems and there is no local data pertaining to footwear preferences and foot care needs of this patient group.

2.12 Conclusion

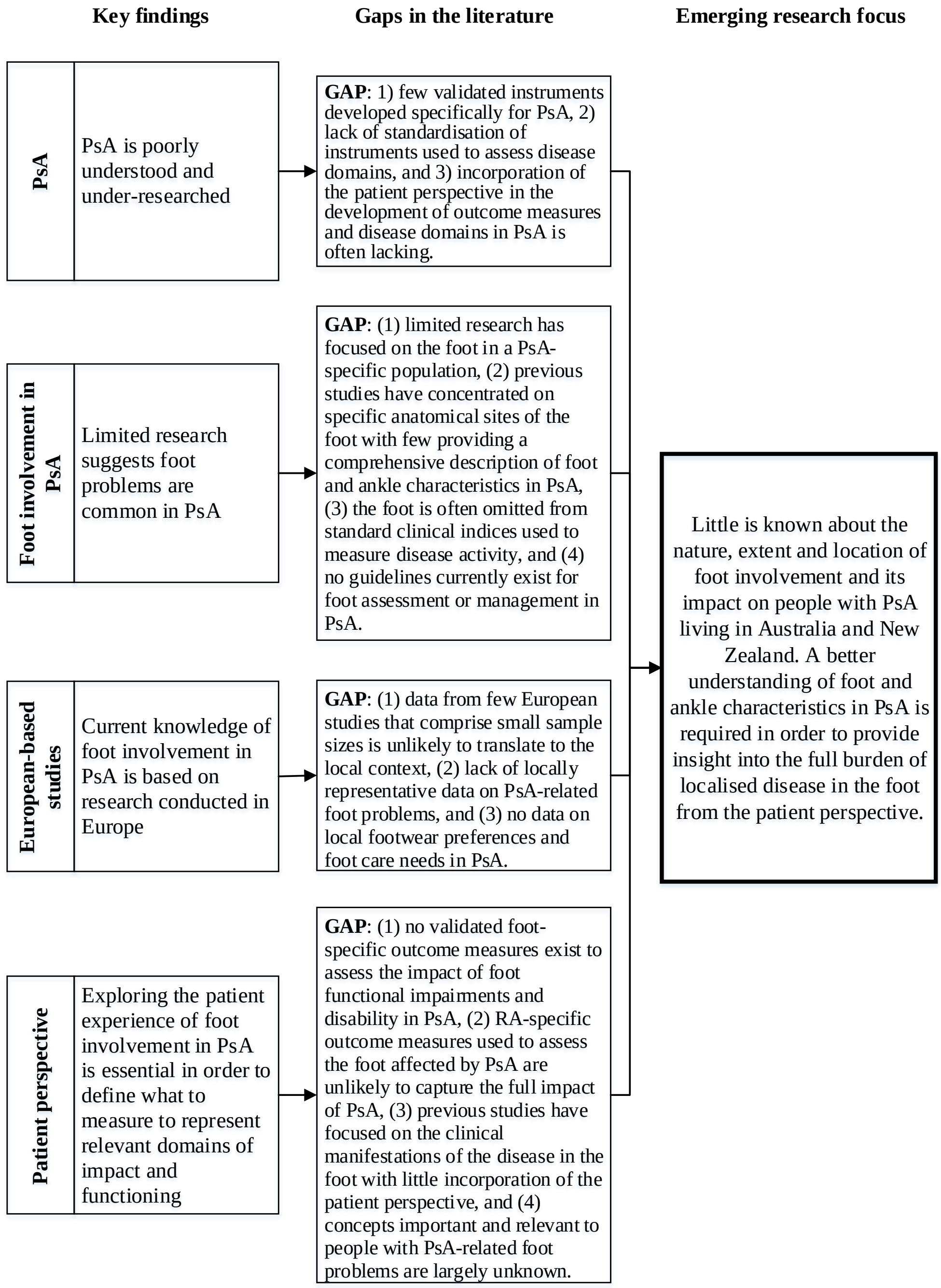
There is a known predilection for expression of persistent disease activity in the feet and lower limbs in those with PsA. Whilst it is generally recognised that foot involvement is common with PsA, there is a paucity of data to support this. Few European studies that comprise small sample sizes have focused on the clinical manifestations in the feet, but little is known about the impact of PsA on foot-specific structure and function, activity and participation, and environmental factors such as footwear and foot healthcare. To better target and treat inflammation present in the foot, a comprehensive understanding of the concepts important and relevant to people with PsA-related foot involvement is required. In line with the work undertaken by the GRAPPA and OMERACT, exploring the patient perspective should be central to the research approach, including use of the ICF classification to describe the typical impact of foot involvement in PsA and to help define what should be measured in the evaluation of foot disease burden.

The premise of this research was to gain insight into, and a comprehensive understanding of, foot involvement and the associated impact on daily life from the perspective of people with PsA. Given that footwear can contribute to foot-related functional impairments and the lack of supportive footwear typically worn in Australia and New Zealand (flip-flops), it is important to explore foot problems in the local context in order to account for local differences in healthcare access, climate and sociocultural factors that may influence footwear choice. Foot involvement in PsA remains under-researched and poorly understood with a lack of large-scale data needed to provide the basis for targeted disease-specific assessments and interventions.

Chapter 3

3 Theoretical framework and research focus

The purpose of this chapter is to outline the theoretical framework for the proposed research, including the specific research questions and phases of the research The theoretical framework highlights the existing knowledge, gaps in the literature and the focus of the research to be conducted (Figure 3.1).



PsA is poorly understood and under-researched

GAP: 1) few validated instruments developed specifically for PsA, 2) lack of standardisation of instruments used to assess disease domains, and 3) incorporation of the patient perspective in the development of outcome measures and disease domains in PsA is often lacking.

Limited research suggests foot problems are common in PsA

GAP: (1) limited research has focused on the foot in a PsA-specific population, (2) previous studies have concentrated on specific anatomical sites of the foot with few providing a comprehensive description of foot and ankle characteristics in PsA, (3) the foot is often omitted from standard clinical indices used to measure disease activity, and (4) no guidelines currently exist for foot assessment or management in PsA.

Current knowledge of foot involvement in PsA is based on research conducted in Europe

GAP: (1) data from few European studies that comprise small sample sizes is unlikely to translate to the local context, (2) lack of locally representative data on PsA-related foot problems, and (3) no data on local footwear preferences and foot care needs in PsA.

Exploring the patient experience of foot involvement in PsA is essential in order to define what to measure to represent relevant domains of impact and functioning

GAP: (1) no validated foot-specific outcome measures exist to assess the impact of foot functional impairments and disability in PsA, (2) RA-specific outcome measures used to assess the foot affected by PsA are unlikely to capture the full impact of PsA, (3) previous studies have focused on the clinical manifestations of the disease in the foot with little incorporation of the patient perspective, and (4) concepts important and relevant to people with PsA-related foot problems are largely unknown.

Little is known about the nature, extent and location of foot involvement and its impact on people with PsA living in Australia and New Zealand. A better understanding of foot and ankle characteristics in PsA is required in order to provide insight into the full burden of localised disease in the foot from the patient perspective.

Figure 3.1. Theoretical framework and research focus.

PsA Psoriatic arthritis, *RA* Rheumatoid arthritis.

The premise of this research was to provide a comprehensive description of foot involvement and its impact on daily life from the perspective of people with PsA through the development and implementation of a national survey. This provided the opportunity to sample a large population over a wide geographical area across Australia and New Zealand, including different regions (rural and urban) and climate zones (temperature and humidity). The programme of work was divided into a series of work packages that were undertaken in order to address the research questions (Table 3.1).

Table 3.1. Research questions and related work packages.

Question type		**Research question**	**Research methods**
Quantitative	Qualitative		
	X	What are the perspectives of patients and health professionals on the experience of living with foot problems related to PsA?	**Qualitative investigation** To answer this question, a qualitative study was undertaken. Semi-structured, one-to-one interviews of people with PsA about their foot problems and the impact they have on daily life were performed. Focus groups were undertaken with health professionals to explore their understanding of the patient experience of PsA-related foot problems.
	X		**Linking to the ICF** To answer this question, the ICF classification was used to categorise the impact of localised disease in the foot on daily life as obtained from the qualitative study. Linking to the ICF means to translate concepts into a common language in order to contextualise the impact of disease on daily functioning.
	X	What is the nature, extent and location of foot involvement and its impact on the daily life of people with PsA?	**Survey development protocol** To answer this question, a novel high-quality survey was developed and pre-tested using robust, best practice methods in survey design and based on the views of patients and health professionals.
X			**National survey** To answer this question, a cross-sectional national survey about foot involvement among people with PsA was implemented in Australia and New Zealand.

ICF International Classification of Functioning, Disability and Health, *PsA* Psoriatic arthritis.

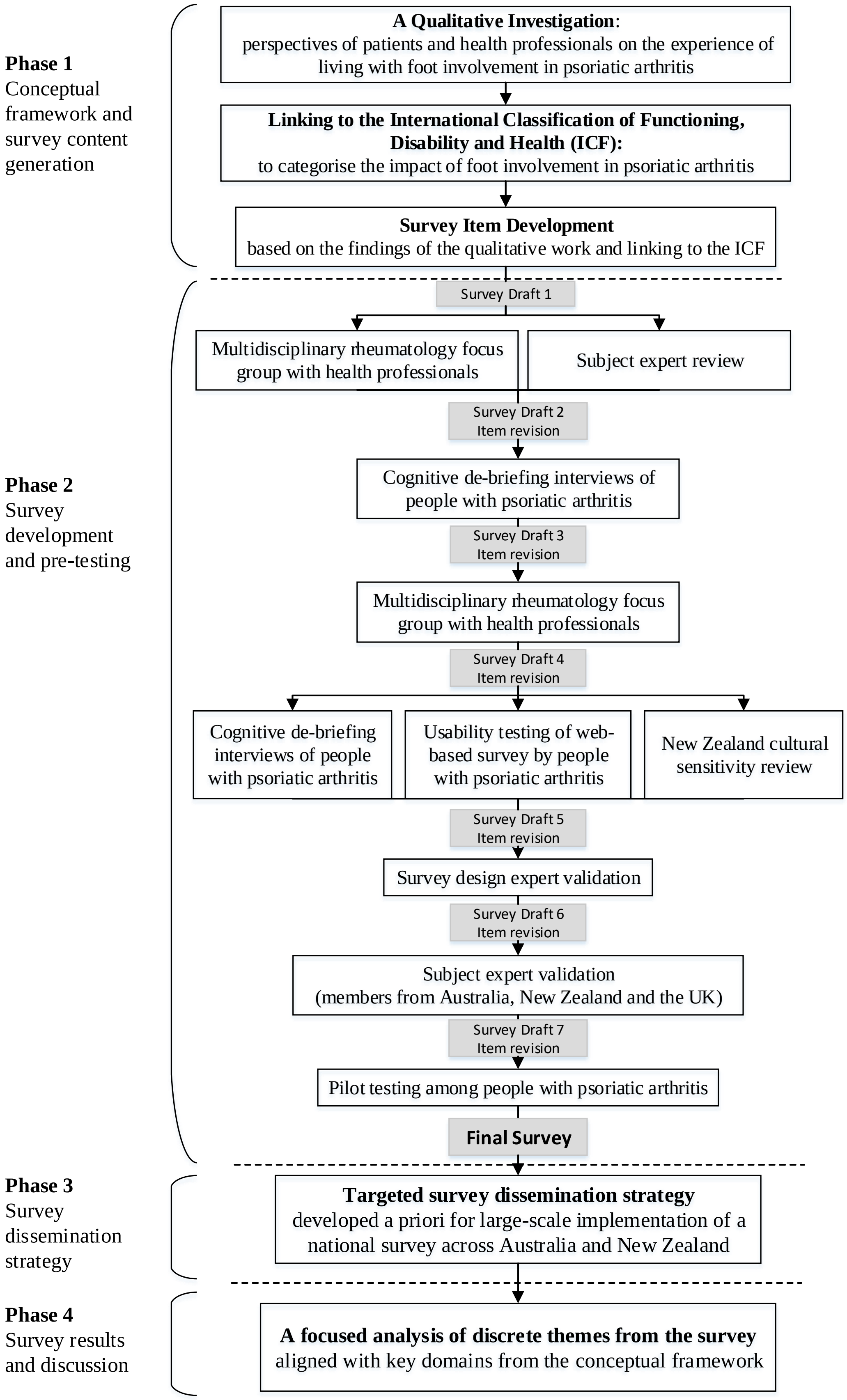


Figure 3.2. Order of proposed studies.

ICF International Classification of Functioning, Disability and Health.

The overall objective of this programme of work was to develop a national survey based on the views of people with PsA and health professionals on foot problems, their impact on daily life, footwear choice and foot care needs. The lack of standardised foot-specific clinical or image-based assessments and poor reliability of clinical examination in PsA, limited the potential value of conducting clinical-based studies. Data obtained through clinical encounters usually represent a small part of the patient experience and given the lack of specialist-led rheumatology services to target for recruitment in Australia and New Zealand, survey research was considered appropriate in order to sample a large population over a wide geographical spread of states.

Each chapter will describe the study context, aims, methods, results, discussion and conclusion for the individual work packages. A brief description of the phases of research used to achieve the objective is provided below (Figure 3.2):

3.1 Phase 1 Conceptual framework and survey content generation

A Qualitative Investigation - To explore, in-depth the perspectives of people with PsA and health professionals on their understanding of the patient experience of PsA-related foot problems a qualitative investigation was undertaken. Qualitative methods were used to obtain the level of rich and meaningful data required to gain a comprehensive understanding of the concepts important and relevant to the patient experience of foot involvement in PsA. Key themes developed from the qualitative investigation were used to inform the conceptual framework for the survey and to generate survey items.

Linking to the International Classification of Functioning, Disability and Health (ICF) - To gain a better understanding of the extent and coverage of themes identified by the qualitative work, concepts derived from the interviews were linked to the ICF in order to use common terminology to describe the impact of localised disease in the foot. Widely used by the OMERACT groups, the WHO’s ICF was chosen as an internationally accepted theoretical model to comprehensively define the impact of localised disease on daily functioning and to determine what to include in the assessment of key impact domains. The list of ICF categories generated was used to inform the conceptual framework for the survey and to generate survey content.

3.2 Phase 2 Survey development and pre-testing

To achieve a comprehensive evaluation of foot involvement in PsA and its impact at the patient-level across Australia and New Zealand, a national survey was developed using robust patient-centred methods in survey design. The survey development protocol comprised 3 stages 1) generation of the conceptual framework and survey content, 2) development of the survey and pre-testing, and 3) development of the survey dissemination strategy. Quality criteria for survey design and conduct have been developed but adoption is low with evidence that survey studies are poorly reported, which limits the validity and generalisability of survey findings. Following a rigorous, best practice approach has shown merit in the development of a survey protocol that presents a high-quality worked example of survey design and conduct.

3.3 Phase 3 Survey dissemination strategy

To optimise response rates and yield successful survey outcomes, a targeted postal and online survey dissemination strategies were developed *a priori*. With the prevalence of PsA unknown in Australasia and a lack of large databases of PsA populations to target for recruitment, the sampling strategy was to identify the major sites for dissemination and determine the response rate relative to the populations that were targeted. Robust strategies for sampling, survey dissemination and community engagement made a powerful contribution to response rates and the scale of information collected. Methods included mixed modes of survey administration, reminders sent to recruitment sites, a study website, Facebook page with weekly posts, video and animation for survey promotion.

3.4 Phase 4 Survey results and discussion

To comprehensively capture foot-specific domains of impact important and relevant to people with PsA, a national survey was implemented in Australia and New Zealand over a 6-month period. Survey research provided the opportunity to generate large-scale data from a wide range and number of participants, and to measure a broad range of constructs with sufficient granularity. To provide valuable insights into the large amount data collected, a focused analysis of discrete themes was undertaken.

3.5 Future implications

The theoretical implications of this research are a detailed understanding of the relationship between local disease, key areas of life impact and dominant concerns of people with PsA-related foot involvement. This research aims to improve current knowledge of foot involvement in PsA and provide new insights into the impact of localised disease in PsA. This may direct future work on the development of an instrument to measure the impact of foot involvement in PsA.

The clinical and practical implications of this research will be to inform future randomised controlled studies on novel assessment techniques and targeted pharmacological and non-pharmacological management of foot disease in PsA. A better knowledge of foot involvement in PsA will facilitate early detection, effective management and improve patient outcomes.

Chapter 4

4 Qualitative study

This chapter describes two separate qualitative studies. A qualitative research approach was chosen in order to identify concepts important and relevant to people with PsA and health professionals, and to be able to explore and gain an in-depth understanding of their views. Qualitative methods are used increasingly to contribute new knowledge and to provide new perspectives in healthcare (Tong, et al., 2007). Qualitative studies have found that patients may prioritise different outcomes to health professionals and may also identify additional important outcomes. Therefore, exploring the perspectives of both patients and health professionals provided the opportunity to determine any concordance or discordance between views.

The philosophical underpinning of the qualitative research was based on the principles of naturalistic inquiry, which aims to study something (the lived experience with foot problems) in its natural state (Guba and Lincoln, 1982). This approach requires the researcher to remain close to the data and provide a comprehensive descriptive summary of the experience. The naturalistic approach is further supported by the use of constant comparative thematic analysis, which focuses on an explicit account of the data to develop themes, rather than through interpretation of the data. Whilst qualitative description may not be as interpretive as other qualitative methods, there is a level of interpretation placed on the description of the data (Sandelowski, 2000; Sandelowski, 2010).

With a lack of previous research exploring the personal impact of PsA-specific foot involvement on daily life, the use of qualitative research methods was central to gaining a full understanding of the lived experience of people with PsA-related foot problems. In addition, the need to explore the participant’s experiences aligned with the holistic approach of the researcher in respect of their clinical practice having worked with people with complex, chronic diseases and with the wider multidisciplinary team, with the focus being on the person in the context of their problem rather than the problem alone. These influences led to an interpretivist approach to the process of qualitative inquiry (Koch, 1995; Dowling, 2004). Maintaining an extensive audit trail throughout the qualitative research process facilitated continuous reflection on the approach taken to data collection and interpretation, and helped to ensure the authenticity and trustworthiness of the data. In qualitative research, it is acknowledged that the researcher becomes an integral part of the process and outcome. Reflecting on the experience of conducting qualitative research, the researcher recognised the personal responsibility connected with collating participants' thoughts and feelings, the significant value of the information gathered, and the importance of involving participants in the research process. This reflection clarified the researcher's worldview of qualitative research, a naturalistic worldview was driven by limited prior knowledge or preconceived assumptions of the impact of PsA-related foot problems and the desire to represent the participant's views as authentically as possible through induction.

The first study was the original research intention, which was to explore the lived experience of foot involvement in PsA. The second study focused on a distinct qualitative theme generated from data collected as part of the first study. In the first study, focus groups with health professionals explored their understanding of the patient experience of PsA-related foot problems, which contributed qualitative data for the generation of themes in the first study. During the focus group interviews, health professionals described the challenges relating to the management of foot problems in PsA from diagnosis, to assessment and treatment. These perspectives generated the distinct overarching theme of suboptimal foot disease management that required separate presentation and dedicated description.

Study 1) Perspectives of patients and health professionals on the experience of living with psoriatic arthritis-related foot problems: A qualitative investigation.
The objective of the first study was to explore how foot problems impact on the lives of people with PsA by interviewing patients and health professionals.
Publication: Clinical Rheumatology. 2019;38(6):1605-1613.

Study 2) Health professional views on the assessment and management of foot problems in people with psoriatic arthritis in Australia and New Zealand: a qualitative investigation.
The objective of the second study was to explore the views of health professionals on the assessment and management of people with PsA-related foot involvement.

Publication: BMC Musculoskeletal Disorders. 2019;20(1):191.

This research was presented at the Patient Experience Symposium, Sydney, Australia in April 2019 (Conference abstract in Appendix 4: The nature, burden and management of psoriatic-related foot problems from the perspective of patients and health professionals).

The studies in chapter 4 are presented in the form of stand-alone published papers. In the context of the thesis they represent the exploratory phase of a programme of work towards developing a national survey to find out about how foot problems impact on the lives of people with PsA. Insights gained from this qualitative investigation will be used in sequential phases to inform the content and design of a large national survey. In the results section 4.1.3.1, exemplars, selected from the supplementary materials of the publication (Appendix 3), have been included in the chapter in order to better support the interpretations and findings of the study.

Perspectives of patients and health professionals on the experience of living with psoriatic arthritis-related foot problems: A qualitative investigation

Carter K, Walmsley S, Chessman D, Rome K, Turner DE. Perspectives of patients and health professionals on the experience of living with psoriatic arthritis-related foot problems: a qualitative investigation. Clinical Rheumatology. 2019;38(6):1605-13.

4.1 Abstract

Objective: The aim of the study was to explore how foot problems impact on the lives of people with psoriatic arthritis by interviewing patients and health professionals.

Method: Participants were recruited from outpatient rheumatology clinics in Sydney, Australia and in Auckland, New Zealand, using a convenience sampling strategy. People with psoriatic arthritis were asked questions in semi-structured interviews about their foot problems and the impact they have on daily living until qualitative data saturation. Focus groups were undertaken with health professionals to explore their understanding of the patient experience of psoriatic arthritis-related foot problems. All interviews were audio-recorded and transcribed verbatim. Constant comparative analysis was used to identify emerging themes from the data.

Results: Twenty-one people with psoriatic arthritis-related foot problems and 17 health professionals participated. Three overarching key themes were derived from patients and health professionals: 1) structural and functional foot manifestations, 2) impact on daily life leading to social withdrawal and reduced work productivity and 3) mediating factors influencing the severity of impact from foot problems on their lives such as social support, self-management strategies and experiences of healthcare.

Conclusion: Foot problems caused functional disability and altered self-concept, which lead to a cascade of social, economic and psychological consequences. People with foot problems contend with profound disruption to their functioning and life roles. Whilst health professionals recognised the functional and visual impact that foot problems have on daily life, the emotional burden may be under-appreciated. Future work to determine the scale and types of foot problems in psoriatic arthritis is required.

Key words: Psoriatic arthritis, foot, podiatry, qualitative, interviews.

4.1.1 Introduction

Psoriatic arthritis (PsA) is a chronic inflammatory musculoskeletal disease associated with psoriasis (Taylor, et al., 2006) and is characterized by a wide clinical spectrum and a variable course (Gladman, et al., 2005). Clinical features of PsA, such as peripheral arthritis, enthesitis, dactylitis and tendinopathy, as well as skin and nail psoriasis, can affect the feet (Bezza, et al., 2004; Hyslop, et al., 2010a; Delle Sedie, et al., 2011; Patience, et al., 2018). Previous studies have described the structural and functional changes in the foot affected by PsA (Bezza, et al., 2004; Hyslop, et al., 2010a; Hyslop, et al., 2010b; Delle Sedie, et al., 2011; Woodburn, et al., 2013; Turner, et al., 2014; Wilkins, et al., 2016). However, the details of how foot problems impact on the lives of people with PsA, their experiences with footwear and their foot care needs are limited.

Previous studies have assessed the perspectives of patients and clinicians regarding the whole effect of PsA, confirming that it has a demonstrated detrimental effect on health-related quality life (Taylor, et al., 2010; Gossec, et al., 2014; Orbai, et al., 2017a). One study found that pain in the feet was the fourth most prevalent single complaint, behind tiredness, arm pain and lower back pain (Nordbø, et al., 2017). This suggests that, for a large proportion of people with PsA, foot involvement may be the major characteristic feature of their disease. However, the specific consequences of PsA on foot functional impairment and disability has not been explored in detail. Obtaining the patient's perspective on how they feel and function with respect to their disease and the clinician's view has been recognised as critically important in the assessment and management of PsA (Betteridge, et al., 2016; Lebwohl, et al., 2016; Garrido-Cumbrera, et al., 2017; Orbai, et al., 2017a). The aim of this study was to explore how foot problems impact on the lives of people with PsA by interviewing patients and health professionals.

4.1.2 Methods

4.1.2.1 Participants

Participants with PsA were recruited from rheumatology outpatient clinics in Sydney, Australia and Auckland, New Zealand. Health professionals with clinical experience of managing people with PsA, including podiatrists, physiotherapists and rheumatologists, were recruited to take part in focus groups. Participating sites were selected to provide a representative sample from public and private sector, from lower and higher socioeconomic geographical areas and to provide local data from Australia and New Zealand. Ethical approval was granted by the South Western Sydney Local Health District (HREC/171/LPOOL/353), the Auckland University of Technology Ethics Committee (AUTEC 17/320) and the Waitemata District Health Board of Auckland New Zealand (RM/3907) (Appendix 1). Both participants and health professionals read the participation information sheet and provided written informed consent prior to data collection (Appendix 2).

Participants with rheumatologist-diagnosed PsA, aged over 18 years old and who had current or previous experience of foot problems were recruited by their rheumatologist in Australia and New Zealand. Those who could not read or speak English or those with cognitive impairment precluding ability to answer health-related questions accurately were excluded. Convenience sampling was used to recruit people with PsA for semi-structured interviews. Semi-structured, one-to-one interviews were used to gain a rich description of their individual experiences of foot problems and their impact. This technique was selected as participants tend to be more inclined to disclose personal information in face-to-face interviews and with the researcher being able to respond accordingly (Legard, et al., 2003).

Focus groups were selected as the method of data collection to explore the views of health professionals. Group dynamics and interactions are distinct features of this method, used to generate rich data (Thomas, et al., 1995). It was anticipated that health professionals who work together would be able to contribute freely to a group discussion. Exploring the patient experience from the perspective of health professionals facilitated further insight into the impact of foot problems reported by people with PsA. Sample size for each focus group was based on recommendations suggesting that 4-12 people will generate sufficient data (Liamputtong and Ezzy, 2005). Potential participants were recruited by response to an invitation email containing an outline of the study, screening form and contact details of the primary researcher (KC).

The interview guides (Table 4.1 and 4.2) were developed based on a review of the literature, which related to 1) PsA-specific foot involvement (Hyslop, et al., 2010a;

Hyslop, et al., 2010b; Woodburn, et al., 2013; Turner, et al., 2014; Wilkins, et al., 2016; Patience, et al., 2018), 2) foot problems in other rheumatic diseases to identify relevant foot-specific concepts (Helliwell, et al., 2005a; Otter, et al., 2010; Hendry, et al., 2013a; Brenton-Rule, et al., 2014; de Souza, et al., 2016; Otter, et al., 2016; Williams, et al., 2017; Wilson, et al., 2017b; McCulloch, et al., 2018), and 3) the PsA Core Set and outcome measures to identify key domains of impact for inclusion (Mease, 2011; Her and Kavanaugh, 2014; Orbai, et al., 2017b). The purpose of this literature appraisal was not to provide a systematic review, but to select priority areas that could be explored to gain a better understanding of foot involvement specific to PsA. The interview guides were developed by the researcher based on the review of the literature. Finally, the interview guides were scrutinised by the research team, which comprised a consultant rheumatologist, specialist podiatrists and academic researchers. The interview guides were designed to cover priority areas of interest, which included (1) foot involvement in PsA, (2) its impact on daily life, (3) experiences with footwear and (4) foot care needs. The interview guides used open-ended questions to encourage detailed descriptions. Additional probes were used to facilitate discussion and to maintain the focus on foot problems. All interviews and focus groups were conducted by the same researcher (KC), a podiatrist with 15 years of clinical experience.

Table 4.1. Semi-structured interview guide for people with psoriatic arthritis-related foot problems.

Questions	
1	Tell me about any problems you experience with your feet because of your psoriatic arthritis?
2	Can you point to the specific parts of your foot where you experience problems because of your psoriatic arthritis?
3	How do your foot problems due to psoriatic arthritis affect your daily life?
4	Do the problems you experience with your feet have any impact on your ability to work?
5	How do you manage your foot problems?
6	How do the problems in your feet due to psoriatic arthritis make you feel?

7	How important do you feel your foot problems are compared with other issues you may have related to your psoriatic arthritis?
8	Can you tell me about your experiences with footwear in light of your psoriatic arthritis?
9	Does your rheumatologist or doctor ask about your feet during consultations?
10	Have you ever seen a podiatrist about the problems in your feet?
11	Can you tell me about any problems or difficulties you experience with your nails because of your psoriatic arthritis?
12	Is there anything else that we have not already talked about that you would like to add concerning the experiences you have or have had with your feet related to your psoriatic arthritis?

Table 4.2. Focus group interview guide for health professionals with experience of managing people with psoriatic arthritis-related foot problems.

Questions	
1	What do patients with psoriatic arthritis tell you about when they report problems with their feet?
2	In your experience, have you found any differences between the reporting of foot problems and the demographic characteristics of your patients?
3	In what ways do you find that foot problems arising from psoriatic arthritis impact on your patients’ day-to-day lives?
4	In what ways, if any, do you find foot problems arising from psoriatic arthritis impact on the psychological/emotional health of your patients?
5	In your experience, what footwear difficulties (if any) do your patients report as a result of psoriatic arthritis?
6	How often do you examine the feet of patients with psoriatic arthritis?
7	Have you encountered any barriers in relation to your patients receiving appropriate foot care services?
8	Is there anything else that we have not already talked about that you would like to add concerning the experiences of your patients in relation to their foot health and care?

4.1.2.2 Procedure

Prior to interview, participant demographic information was collected including age, gender, ethnicity and occupation. Clinical characteristics were recorded including body mass index, disease duration, comorbidities, current medications, erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP). Activity limitation was measured using the Health Assessment Questionnaire (HAQ) (Fries, et al., 1980) that includes 20 tasks for which participants are asked to rate their ability to perform them over the last week (without difficulty = 0, some difficulty = 1, much difficulty = 2 or unable to do = 3). Global disease activity over the last week was measured using a 100mm Visual Analogue Scale (VAS) with the assessment of both joint and skin components, joint alone and skin alone. Global pain was also measured using a 100mm VAS.

Foot functional impairment and disability was assessed using the LFIS-RA (Helliwell, et al., 2005a). The LFIS-RA is a self-completed questionnaire comprising 51 items in total ($\text{LFIS}_{\text{TOTAL}}$), divided into two subscales: impairments/shoes (LFIS_{IF}) and activities/participation (LFIS_{AP}). LFIS_{IF} scores ≤ 6 represent mild, 7–13 moderate and ≥ 14 severe levels of foot related impairment. LFIS_{AP} scores ≤ 9 represent mild, 10–19 moderate and ≥ 20 severe levels of activity limitation (Hooper, et al., 2012). Severity of foot pain on the day and over the last week were measured using a 100mm VAS. Previous and current foot or lower leg ulceration, previous foot surgery and having previously seen a podiatrist were recorded.

Data recorded from the health professionals prior to the focus groups included demographic information, professional qualifications and number of years of clinical experience. All interviews and focus groups were audio-recorded and transcribed verbatim immediately after each session. Recruitment to the study continued until qualitative data saturation of emerging concepts was achieved (Francis, et al., 2010). Data was collected between October 2017 and March 2018.

4.1.2.3 Data analysis

All demographic and clinical data were described as mean (SD) for continuous data and n (%) for categorical data. Qualitative data were analysed using a constant comparative method (Morehouse and Maykut, 1994) and a thematic framework approach to facilitate conceptual mapping (Attride-Stirling, 2001). ATLAS-ti version 7.5.7 software (Scientific Software Development GmbH, Berlin, Germany) was used to analyse the data (www.atlas-ti.com). The researcher (KC) read each transcript several times and meaningful units within the data such as words, phrases and concepts were assigned codes, framed by the researcher's focus of inquiry. This method combines inductive category coding with a simultaneous comparison of all units of meaning obtained. The codes were continuously refined, compared and subsequently grouped with similar units of meaning and then organised into themes (Morehouse and Maykut, 1994). The emergent themes were scrutinised and agreed by the research team to increase analytical rigor. The conceptual framework of themes was verified by both participants and health professionals. This methods approach required the researcher to remain close to the data in qualitative description (Sandelowski, 2000) and naturalistic inquiry (Guba and Lincoln, 1982).

4.1.3 Results

Participant demographic and clinical data are summarised in Table 4.3. Twenty-one people with PsA and self-reported foot involvement were recruited, the majority of which were women (62%, n=13). The mean (SD) age was 53 (13) years and the mean (SD) disease duration was 11 (9) years. The HAQ found mild overall activity limitation with a mean (SD) of 1.0 (0.5). Moderate levels of global disease activity were reported for joints and skin, joints alone and skin alone. Seven participants with elevated CRP levels had global assessment scores greater than 70mm.

All participants had experienced previous foot pain (n=21, 100%) and over 80% (n=17) of participants had current foot pain (Table 4.4). The mean (SD) of the LFIS_{IF} was 12 (4) and the LFIS_{AP} was 18 (7) indicating moderate levels of foot impairment and activity limitation. Over half of participants had previously seen a podiatrist (n=11, 52%).

Table 4.3. Demographic and clinical characteristics of participants with psoriatic arthritis, (n=21).

Variables	**Value**
Ages, years	53 (13)
Women, n (%)	13 (62%)
Ethnicity, n (%)	
Caucasian	18 (86%)
Fiji-Indian	2 (10%)
Indian	1 (5%)
Body Mass Index, Kg/m^2	32.1 (7.4)
Geographic location, n (%)	
Sydney, Australia	18 (86%)
Auckland, New Zealand	3 (14%)
Employment status, n (%)	
Employed	6 (29%)
Unemployed (health reason)	8 (38%)
Unemployed (other reason: student, home-maker)	2 (10%)
Retired	5 (24%)
Disease type, n (%)	
Psoriatic arthritis with skin psoriasis	19 (90%)
Psoriatic arthritis without skin psoriasis	2 (10%)
Disease duration, years	11.2 (9.1)
Medications, n (%)	
Methotrexate	11 (52%)
Other DMARD (leflunomide, salazopyrin, hydroxychloroquine)	12 (57%)
Biologics	7 (33%)
Prednisone	1 (5%)
Other medications, n (%)	
NSAID	15 (71%)
Opioid	3 (14%)
Other pharmacological treatment	16 (76%)
Comorbidities, n (%)	
Cardiovascular conditions	14 (67%)
Musculoskeletal conditions	12 (57%)
Depression	3 (14%)
Diabetes Mellitus	9 (43%)
Cancer	4 (19%)
HAQ score	1.0 (0.5)
CRP, mg/L *[1]	7.0 (7.1)
ESR, mm/h *[2]	20.5 (15.6)
Patient global disease activity (joint and skin) VAS (VAS 0-100), mm	52 (24)
Patient global skin disease activity VAS (VAS 0-100), mm	43 (31)
Patient global joint disease activity VAS (VAS 0-100), mm	56 (28)
Patient global pain VAS (VAS 0-100), mm	49 (28)

Data presented as mean (SD) unless specified.

DMARD Disease modifying anti-rheumatic drug, *NSAID* Non-steroidal anti-inflammatory drug, *VAS* Visual analogue scale, *ESR* Erythrocyte sedimentation rate, *CRP* C-reactive protein.

Table 4.4. Foot and ankle characteristics and footwear type of participants with psoriatic arthritis (n=21).

Variables	**Value**
Previous foot pain, n (%)	21 (100%)
Presence of current foot pain, n (%)	17 (81%)
Current foot pain VAS (VAS 0-100), mm*	43 (29)
Foot pain over the last week VAS (VAS 0-100), mm*	49 (24)
Previous foot or lower leg ulceration, n (%)	3 (14%)
Current foot or lower leg ulceration, n (%)	0 (0)
Previous foot surgery, n (%)	3 (14%)
Has seen a podiatrist before, n (%)	11 (52%)
Leeds Foot Impact Scale	
$\text{LFIS}_{\text{TOTAL}}$ score	30 (10)
LFIS_{IF} subscale score	12 (4)
LFIS_{AP} subscale score	18 (7)
Type of footwear worn on the day of the interview, n (%)	
Walking shoe (lace-up shoe, sports shoe)	8 (38%)
Sandal (contoured)	3 (14%)
Sandal	2 (10%)
Sketchers (slip-on shoe)	2 (10%)
Thong	2 (10%)
Thong (contoured)	1 (5%)
Backless slipper	1 (5%)
Therapeutic sandal	1 (5%)
Other	1 (5%)

Data presented as mean (SD) unless specified.
VAS Visual analogue scale, $\mathit{LFIS}_{\mathit{TOTAL}}$ Leeds Foot Impact Score total, $\mathit{LFIS}_{\mathit{IF}}$ Leeds Foot Impact Score foot impairment/footwear restriction, $\mathit{LFIS}_{\mathit{AP}}$ Leeds Foot Impact Score activity limitation/participation restriction.
*n=20 (two participants did not fully complete the questionnaire in different sections).

The demographic characteristics of the health professionals are shown in Table 4.5. Three focus groups were undertaken and a total of 17 health professionals participated, 12 from Australia and 5 from New Zealand. The majority of focus group participants were rheumatologists (n=10, 59%), working in the public sector (n=7, 70%), with over 15 years of clinical experience managing this patient group (n=6, 35%). The other focus group members were rheumatology registrars (n=2, 12%) and allied health professionals (n=5, 29%). The mean (SD) number of years of clinical experience amongst the allied health professions was 13 (6) years. The interviews and focus groups lasted approximately 45 to 60 minutes.

Table 4.5. Demographic characteristics of the health professionals with experience of managing people with psoriatic arthritis (n=17).

Variables	**Value**
Age, years	44 (8)
Women, n (%)	9 (53%)
Ethnicity, n (%)	
Caucasian	12 (71%)
Chinese	4 (24%)
Indian	1 (6%)
Occupation, n (%)	
Rheumatologist	10 (59%)
Rheumatologist registrar	2 (12%)
Podiatrist	3 (18%)
Physiotherapist	1 (6%)
Rheumatology care coordinator	1 (6%)
Clinical experience, years	12 (8)
Qualifications, n (%)	
Bachelor of Medicine (MBBS)	11 (65%)
Fellow of the Royal Australasian College of Physicians (FRACP)	9 (53%)
Bachelor of Science (BSc)	10 (59%)
Master of Science (MSc)	2 (12%)
Doctor of Philosophy (PhD)	6 (35%)
Geographical location, n (%)	
Sydney, Australia	12 (71%)
Auckland, New Zealand	5 (29%)
Health sector, n (%)	
Public sector	13 (77%)
Private sector	4 (24%)

Data presented as mean (SD) unless specified.

4.1.3.1 **Qualitative results**

Three overarching themes emerged from the analysis of interviews of people with PsA and focus groups with health professionals (Table 4.6). The conceptual framework of themes was verified by both participants and health professionals (Figure 4.1). Exemplars from the transcripts were identified to support each of the themes (Appendix 3). People with PsA will be referred to as participants and health professionals will be identified as health professionals.

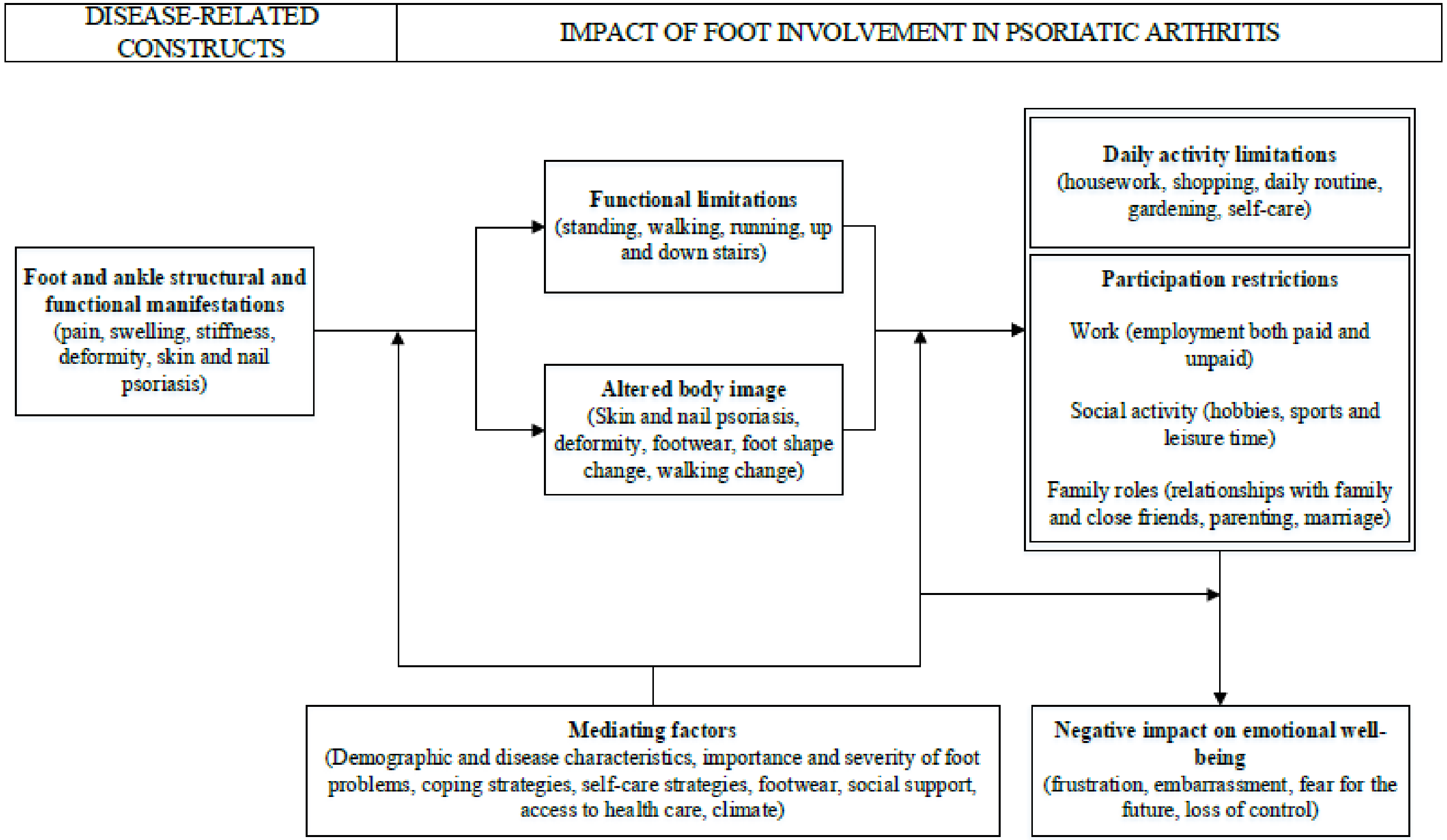


Figure 4.1. The conceptual framework of themes.

The manifestations of psoriatic arthritis in the feet and ankles (Theme 1) caused foot functional impairments and visual differences that impacted on daily activities, social participation, work productivity and family life (Theme 2). Mediating factors (Theme 3) influenced the severity of impact from foot involvement on the lives of people with psoriatic arthritis.

Table 4.6. Key themes emergent from the interviews of people with psoriatic arthritis and focus groups with health professionals.

No.	Overarching themes	Sub-themes
1.	Foot and ankle structural and functional manifestations of PsA	Foot pain, swelling, stiffness, foot cramp, numbness, hot and cold sensations, joint deformity and skin and toenail changes
2.	The impact of foot problems on the lives of people with PsA	Body image, physical function, daily activity, social, family and work life
3.	Mediating factors that influenced the severity of impact of PsA related-foot problems	Demographic and disease characteristics, importance and severity of foot problems, self-management strategies, footwear, climate and social and healthcare support

Overarching Theme 1 – Foot and ankle structural and functional manifestations of PsA.

Pain was the most commonly reported symptom and the main descriptors for the nature of foot pain were ‘persistent’ and ‘unpredictable’. The duration of current foot pain ranged from 3 months to 5 years. Foot pain severity varied according to the time of day and the level of priority given to the feet within the context of their whole experience of living with PsA. Pain was exacerbated mostly by walking and pressure from footwear, but also by changes in the weather and increased global disease activity and body weight. All participants experienced some foot pain during or following walking activity.

> *“...having a long day if I am on my feet for a long time is just you know a world of pain by the end of the day” (participant 2)*

> *“…as soon as I start walking I’m aware of it, it’s not terribly painful but I’m aware it’s there. So it never actually goes away, it’s always there and you feel it so you walk carefully because of it” (participant 21)*

Musculoskeletal involvement in the feet was reported by all participants and health professionals, which included arthritis, enthesitis (Achilles enthesitis and plantar fasciitis), tendinopathy (tibialis posterior and peroneal tendons), bursitits (retro-calcaneal and intermetatarsal) and dactylitis. Variable clinical presentations of foot pain were described by the health professionals, but the most common were deemed to be related to localised inflammation, mechanical dysfunction or a 'mixed' type presentation and were described within the context of disease duration. Toenail psoriasis was commonly reported and over a quarter of participants reported having skin psoriasis that affected their lower legs, soles of the feet, tips of the toes or in between the toes. For 2 participants plantar skin psoriasis was their most troublesome foot problem.

> *"I can't walk. It really stops me from functioning. Um to really do anything especially when the psoriasis is really really bad on my feet it, just the skin builds up so quickly, it it actually just splits and I mean real deep deep cuts into the foot. And it's like needles when you walk so it's very uncomfortable like I've been at times I've been crawling on the ground to get from A to B until I went to the hospital. Because it's really yeah, I can't explain it it's just like stepping on glass" (participant 14)*

> *"…that's about the worst for me… The only thing that does stop me is breaks in the feet…yes it does stop you doing a lot of things. But that's just the nature of it when it flares up it really is bad… you can't walk anywhere if you haven't got your feet" (participant 3)*

One third of participants reported that their feet were the first site affected by PsA and 9 participants described that their feet were the most severely affected site compared with symptoms elsewhere in the body. Self-reported foot manifestations at disease onset were dactylitis, plantar skin psoriasis, metatarsophalangeal joint synovitis, ankle joint synovitis, tibialis posterior tendinopathy, plantar fasciitis and Achilles enthesitis.

Overarching Theme 2 – The impact of foot problems on the lives of people with PsA. Six impact areas were identified as sub-themes including altered body image, functional limitations, daily activity limitations, social participation restrictions, family and work life restrictions. Health professionals described the impact of foot problems on the lives of people with PsA as ‘incapacitating’, ‘disturbing’, ‘debilitating’, ‘really impossible’, ‘disaster’, ‘psychologically distressing’ and ‘a nightmare’.

Altered body image - Change to the physical appearance of the feet and footwear restrictions, regardless of the social context, had a negative impact on body image. Participants felt demoralised and stigmatised by the appearance of their feet relating to skin and toenail changes, swelling, deformity and the visible changes to their gait. Strategies to hide the appearance of foot problems included the non-disclosure of their disease to others, closed-in footwear, clothes to cover, disuse of walking aids and limiting social participation. Increased body weight attributed to foot pain that impeded exercise revealed the far-reaching effects of PsA-related foot involvement.

> *“I mean they look hideous and I hate the way they look… I think they’re revolting. Because they’re so wide now as well… They look like little claws to me” (participant 11 - female)*

> *“…it does bother me. Yeah. Every time I don’t wear socks you know, I just wear thongs or something then everybody’s eyes goes there - you feel very bad for yourself you know” (participant 1 – male)*

> *“…I don’t like to go out because I hate wearing, I can’t wear some sort of shoes [laugh]. And so I don’t really want to go out.... It’s like affected a little bit of my life but like I just have to try and just move on you know” (participant 9)*

> *“…you can’t really dress to look good… you kind of miss that because you see all these people all dressed up nice and they’ve always got lovely shoes on you know. I try and dress nice but I have to wear these shoes you know [laugh]. I have to wear the shoes for my, that are best for my feet. Um so it gets me down a little bit” (participant 6)*

> *"...patients talk a lot about the vicious cycle. Between I have this terrible foot pain, and I know some of its because I'm overweight, but I can't exercise because of my foot pain so I can't lose the weight" (rheumatologist 6)*

Functional limitations – Foot problems had an impact on the ability to sit, stand, walk and function normally for all participants. Foot pain and stiffness was described by all participants in relation to the time of day, their activity level and with either maintaining or changing body positions. Walking disability was attributed to a variety of foot problems including pain, stiffness, swelling, plantar skin psoriasis, corns and calluses, toe deformity, ankle surgery and uncomfortable footwear. Functional limitations included being unable to walk barefoot, short or long distances and being unable to run, as well as difficulty walking on uneven ground, up-hill or down-hill and up or down stairs. Changes to the spatiotemporal parameters of gait were described as walking slower, limping, shuffling, hobbling and feeling unstable on their feet. Pain avoidance behaviour was associated with all functional limitations and dictated life choices.

> *"Well when its bad you just can't walk… I've only had one fall and that was because I was not aware that I didn't have the balance in my foot" (participant 3)*

> *"The most troublesome thing at the moment is just not being able to walk at a normal speed [exhale]… or run if I need to um yeah... and um having to [exhale] plan things out a lot more um because I can't necessarily rely on running to catch a bus or um running to the train [exhale] um so yeah having to be more conscious about that" (participant 12)*

> *"The feet is the main thing to move me here and there you know. So when the pain is there I am 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" (participant 1)*

Daily activity limitations - Most participants were limited in their ability to undertake their daily routine because of the structural and functional manifestations of PsA in the feet and ankles. Participants described how they had stopped, modified or reduced the frequency of household tasks such as shopping, cleaning, cooking, gardening and home maintenance. Sleep and driving were also reported to be affected, as maintaining or changing position increased the severity of foot symptoms. Not having the physical capacity to undertake basic foot care activities was a concern for some participants and was reported by the health professionals, which included maintaining foot hygiene, nail cutting, skin care and taking shoes/socks on and off. Comorbid diseases such as obesity, PsA related-axial involvement and of the shoulder, hips and hands also interfered with the ability to self-care.

> *"…things like mowing the lawn you don't tend to do that as much now… things like walking the dog you just don't do that… it's a big problem just walking from one end of the shopping centre to the other" (participant 16)*

Some participants explained how they felt 'stuck at home' (confined and isolated), which was associated with pain avoidance behaviour but also with stress, frustration, decreased motivation and a sense of 'losing control'. Many statements about daily activity limitations revealed negative emotions such as anxiety, bad temper, depression, embarrassment, helplessness and low self-worth. These feelings were reinforced by the perception that others do not understand and might be forming judgements about them. Existing coping strategies included accepting limitations, stoicism, pacing and planning. Most pushed themselves to undertake daily activities despite the foot pain either because of necessity or to maintain a sense of control. A limited range of coping strategies (accepting limitations and stoicism) and emotional states (frustration and fear for the future) were reported by the health professionals suggesting a potential under-appreciation of the psychological impact of foot involvement on the daily lives of people with PsA.

> *"I have to change my life around… I can't do a quarter of the stuff I used to do" (participant 4)*

> *"Well it makes me feel that I'm useless… It makes me sad" (participant 10*)

> *"I don't do much for the simple fact I get embarrassed if I've got to, in front of people because your feet are just look horrible" (participant 14)*

Social participation restrictions - The majority of participants reported difficulty socialising, maintaining friendships and taking part in leisure activities due to foot problems. Functional limitations and negative body image had a profound impact on social participation. The exacerbation of foot symptoms during and after the social activity reduced their enjoyment and motivation, which consequently led to social withdrawal. Fear of foot injury also led to a disruption of social activities involving the use of public transport, going to concerts, dancing and walking through crowds.

> *"Well as I mentioned yeah you know my social life was ruined" (participant 10)*

> *"Oh very painful yep. And I can't really go out with friends much. I really just stay at home" (participant 7)*

> *"I've constantly got a fear of somebody um stepping on my feet…it impacts where I go out, so if I go out with friends and they're going for long walks, I don't go. But if we are going out to dinner or something like that where I'm sitting down, that's where I'll tend to go. So it impacts me socially" (participant 5)*

> *"So that does impact your social activities because you don't want to go out there and feel like you're burdening people" (participant 16)*

Family life impact - Spending time with family was disrupted due to foot symptoms and functional limitations. Participants described how being pre-occupied with pain altered their mood, which led to a loss of enjoyment and negative interactions. An increased reliance on family members for physical and emotional support was identified and parents specifically talked about fearing a deterioration in their functioning and becoming a burden. Those participants who had a family member with psoriasis, PsA or other inflammatory arthropathies described a greater level of understanding about the disease by family members and felt generally better informed about their own disease. Conversely 4 participants who reported that they were the only family member with PsA associated it with a sense of isolation and fear for the future. Enduring foot pain in favour of social and family participation and hiding pain from others was frequently reported by participants, but these strategies were not recognised by the health professionals.

> *"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. Like I don't want to be you know the mum that can't go in the three legged race at school because you know she's got arthritis" (participant 13)*

> *"But I like to hide my pain. I do not like to show my pain to others. I take my pain myself… I do not like to disturb my wife. I have a pain here. I have a pain here" (participant 1)*

> *"if I go to a social function I feel a bit embarrassed to walk alongside with my family members because I mean, I used to be limping" (participant 10)*

Work life impact - Severe foot related-disability directly contributed to the loss of paid work in 4 participants. Whilst the health professionals did not identify the full impact of the disease on family and social life, they described the devastating impact of long-term work disability with most citing the provision of documentation to employers. Of the 6 participants who were in employment, all experienced some difficulty performing their job roles because of foot pain and stiffness, which related to taking longer to get to work, managing to travel to and from work sites, prolonged sitting at a desk and being slower at completing work tasks. Footwear restrictions negatively impacted on job roles (i.e. with the inability to wear smart business shoes or safety boots), walking activities and social participation including special occasions such as weddings. Difficulties with footwear were related to skin and toenail psoriasis, swelling, deformity and a wider/bigger foot shape, which triggered foot pain, discomfort and rubbing in shoes. Difficulty finding shoes that were comfortable, well fitting, supportive and nice looking were frequent experiences, which provoked feelings of dread, embarrassment, frustration and envy.

> *"I know one patient needed to wear steel toe-capped boots, I think it was in a factory or something, and that was a real problem for him because he was going to lose his job if he couldn't wear the steel capped boots" (rheumatologist 5)*

> *"I can't really work at the moment so I quit my job...because it's mostly you have to stand, serve the customer, get on the ladder… physically get down on the floor… It's very physical. I liked the job and everything but I can't do that…" (participant 7)*

> *"So standing up for long periods of time is difficult, which makes it difficult when I'm training a group of people. So I have to go between sitting and standing and it just yeah. So it impacts the way I facilitate" (participant 5)*

Overarching Theme 3 – Mediating factors that influenced the severity of impact from foot problems on the lives of people with PsA.

There was evidence of a unique combination of situations and experiences for each participant that facilitated or impeded their ability to influence the severity of impact from PsA-related foot involvement on their daily life. These mediating factors were considered to be intrinsic or extrinsic to the individual. Characteristics such as demographic (age, gender, ethnicity and socioeconomic status), disease (disease onset, duration, course and activity and morbidity), foot and ankle (perceived importance and severity of foot problems) and psychological (coping strategies and emotional well-being) were considered as intrinsic factors. Social support (availability of help from family, friends and employers), self-care strategies (effectiveness of non-pharmacological interventions including footwear), climate (influencing foot symptoms and footwear choice) and healthcare support (access to healthcare and effectiveness of medical management) were considered as extrinsic factors. The interface between these mediating factors was considered to determine the ability of the participant to decrease or minimise the impact of PsA-related foot involvement.

> *"…females in general are quite attached to their sort of um the persona they want to project in terms of dress and clothing… I think that's probably more acute for woman" (rheumatologist 5)*

> *"…younger patients say if you've got crooked toes or funny looking toes it can be quite disfiguring…" (rheumatologist 9)*

Health professionals associated younger age, female gender, lower socioeconomic status, later disease diagnosis, longer disease duration and high disease course variability with a greater severity of foot disease impact. The severity of foot problems and the level of importance attributed to them were considered to influence the participant's emotional well-being (sadness and frustration) and their ability to cope (accepting and adapting), which consequently affected the severity of impact on daily life. Effective self-management strategies included positive coping skills, the ability to self-care, readily available social support, finding suitable footwear and accessing healthcare. Stoicism was the most commonly identified coping mechanism used by participants when describing their foot disease burden. Five participants reported that they found it easier to confide in people with PsA due to a mutual understanding of the experience and one participant found it beneficial to attend a local arthritis support group. With six participants receiving regular podiatry treatment, the majority engaged in self-care activities with variable levels of effectiveness and expenditure. The ability to self-manage foot problems and reduce foot symptoms to a certain extent was associated with a sense of relief and control.

> *"…if I was in pain I would still force myself to participate" (participant 1)*

> *"I'm at the point now where I wouldn't mind. In the past I wouldn't have done it" [wearing open-toed shoes] (participant 2)*

> *"… 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 to go and do it. So yeah that's a bit hard but I manage" (participant 9)*

A mix of good and bad experiences were reported by participants and health professionals in relation to footwear. A few participants described that their footwear choice had improved their mobility and reduced foot pain. Closed-in shoes helped to hide foot problems, protected feet from injury and kept feet warm, whilst open shoes helped improve skin psoriasis, were easier to get on and off and kept feet cool. Footwear restrictions along with the resultant loss of clothes choice due to foot problems had a greater severity of impact on women, who harboured feelings of shame and judgement. Climate-related footwear difficulties increased the severity of impact of foot problems on body image, functioning and participation.

> *"… 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" (participant 2)*

> *"I've got them shoes for wearing around at day time – they are the best thing that happened to me. They're great" (participant 4)*

> *"I guess shoes are the biggest problem for me…. I need to wear closed-in shoes for work... the relief I have when I take them off is unbelievable… I struggle to get my shoes on in summer" (participant 11)*

Previous healthcare experiences and the level of satisfaction with and effectiveness of foot disease management appeared to influence all aspects of a participant's lived experience. Accessing healthcare led to empowering relationships with health professionals and improvements to foot symptoms and functioning for some participants. Improved understanding of foot manifestations and knowledge of non-pharmacological foot care interventions appeared to have a positive influence on reducing the impact of foot problems. Participants who reported disappointing experiences with healthcare services described diagnostic delay in those presenting at onset with foot problems; a lack of understanding about foot involvement by health professionals and by themselves; unmet expectations of treatment benefit; and dissatisfaction with the limited scope of podiatry care received. These concepts were consistent with comments made by the health professionals who discussed in detail their patients' experiences of suboptimal foot disease management.

> *"Other people… they don't understand how it does affect your life with getting up, walking, just simple things" (participant 14)*

> *"…thankfully my wife and my son they're quite understanding. They understood the problem and they helped me a lot" (participant 10)*

> *"I've got family members with it so I mean - that's just us [laugh] …it's what we've inherited… just got to get on with it and they've all got that same attitude" (participant 20)*

> *"…it's just hard to talk to anyone about it, like I said I must say um if they've got it themselves they understand…" (participant 14)*

4.1.4 Discussion

This is the first study to explore the impact of foot and ankle problems on people with PsA from Australia and New Zealand by interviewing patients and health professionals. PsA is associated with musculoskeletal disability (McHugh, et al., 2003), reduced health-related quality of life (Husted, et al., 2001) and incurs a high socioeconomic burden (Tillett, et al., 2015b). This study highlights the specific contribution of foot involvement to the disease burden in PsA, which can be spread across core disease domains (Orbai, et al., 2017a) such as pain, physical function, economic cost, emotional well-being and participation. The complex nature of the manifestations of PsA in the foot and ankle were subsequently mirrored in the multifaceted functional impairments and activity limitations experienced by participants. This qualitative study revealed that people with PsA experienced difficulties with foot problems from symptom onset, through to diagnosis and management. Our findings show how suffering with debilitating and uncontrollable foot symptoms can impact on the lived experience of an individual, and how important it can be to gain back control by adopting positive self-management strategies and making empowered decisions. In routine healthcare consultations people with PsA may not have the opportunity to describe in-depth the impact of foot problems on their lives. As a result, the burden may not be properly appreciated by health professionals.

This study provides preliminary insight and understanding of the impact of PsA-specific foot involvement from the perspective of people with PsA and health professionals. Previous studies have linked domains of impact in PsA from qualitative studies to the International Classification of Functioning (ICF) framework to allow the effect of PsA to be structured and categorised (Taylor, et al., 2010; Gudu, et al., 2017). Concepts relevant and important to people with PsA-related foot problems have been identified and linking them to the ICF would help to define what should be measured in the evaluation of foot disease burden. Establishing a core set of foot-specific measures would inform a standardised assessment of the foot in PsA, representing the work supported by the GRAPPA (Group for Research and Assessment of Psoriasis and Psoriatic Arthritis) (Taylor, et al., 2010). Further research will be to use the ICF classification to describe the impact of foot involvement in PsA based on the current study findings.

The impact of foot problems in PsA described in this study appear to be similar to those reported in other foot-related rheumatic conditions such as altered body image (Firth, et al., 2011; Naidoo, et al., 2011), reduced functional capacity and participation (Hendry, et al., 2013b; Williams, et al., 2017; Wilson, et al., 2017b), footwear restrictions (Naidoo, et al., 2011; Martini, et al., 2012; Hendry, et al., 2013b) and suboptimal standards of foot care (Williams and Graham, 2012; Hendry, et al., 2013b; de Souza, et al., 2016; Wilson, et al., 2017b). However, in contrast to other rheumatic conditions, foot involvement in PsA remains under-researched and poorly understood with a lack of large-scale data needed to develop targeted disease-specific interventions. Future work will be to develop a survey in order to obtain information about foot involvement from a wider range and number of people with PsA across Australia and New Zealand, which includes different regions (rural and urban) and climate zones (temperature and humidity). Improving our understanding of foot involvement in PsA and its impact will also help to inform the development of a PsA-specific outcome measure to assess foot involvement.

Limitations of this study included a convenience sampling strategy, as participants who volunteered to take part in the study may not be representative of all people with foot involvement in PsA or the health professionals who have insight into their experiences. However, both people with PsA and health professionals were invited from different socioeconomic geographical locations and healthcare settings within the study regions to ensure that a wider range of opinions were collected. The study sample was considered to reflect the epidemiology of PsA and is comparable with other PsA studies (Gladman, et al., 1987; Torre Alonso, et al., 1991). Foot problems from comorbidities such as diabetes and obesity remains a factor in determining their relative contribution to symptoms and functioning. Therefore, findings from this study may be subject to bias as confounding variables were not adjusted for. However, eliminating the impact of co-morbidities comes at the expense of external validity and loss of generalisability in a real-world context.

4.1.5 Conclusion

In conclusion, people with PsA contend with profound disruptions to their functioning and self-image due to foot problems, the effects of which are wide-reaching and spread across all aspects of life. Health professionals may underappreciate the psychological impact of living with foot problems related to PsA.

4.1.6 Significance and Innovations

- A diverse expression of PsA disease in the foot caused functional disability and altered body-image, which impacted on work, social and family life and had psychological consequences.

- Despite the region-specific focus of the current study, the impact of localised disease in the foot was profound and widespread across all aspects of life.

- Coping strategies, self-care ability, the availability of social support, finding suitable footwear and accessing healthcare were key factors that facilitated or impeded the ability of people with PsA to influence the severity of impact from foot problems on their lives.

- Discordance between the views of people with PsA and health professionals were identified. Whilst health professionals recognised the functional and visual impact that PsA-related foot problems have on daily life, the emotional burden may be underappreciated.

Health professional views on the assessment and management of foot problems in people with psoriatic arthritis in Australia and New Zealand: a qualitative investigation

Carter K, Walmsley S, Rome K, Turner DE. Health professional views on the assessment and management of foot problems in people with psoriatic arthritis in Australia and New Zealand: a qualitative investigation. BMC Musculoskeletal Disorders. 2019;20(1):191.

4.2 Abstract

Objective: Active foot disease persists in a high proportion of people with psoriatic arthritis despite the availability of pharmacological and non-pharmacological interventions to modify the course of the disease. Limited information exists on the provision of healthcare for foot disease in psoriatic arthritis. The objective of this study was to explore the views of health professionals on the assessment and management of people with psoriatic arthritis-related foot involvement.

Methods: Convenience sampling was used to recruit health professionals working in rheumatology outpatient clinics in Sydney, Australia and Auckland, New Zealand. Three focus groups were undertaken to explore the views and experiences of health professionals on the assessment and management of foot problems in people with psoriatic arthritis. All interviews were audio-recorded and transcribed verbatim. Qualitative data was analysed using a constant comparative analytic approach to identify themes.

Results: A total of seventeen health professionals participated including rheumatologists, podiatrists and a physiotherapist. Key themes derived from the focus groups suggest that health professionals perceived that people with psoriatic arthritis-related foot problems experience suboptimal management from symptom onset, to diagnosis and treatment. Frustration was expressed throughout discussions relating to lack of appropriate training and expertise required for the specialised management of foot problems typically encountered with psoriatic arthritis and poor access for patients to specialist podiatry services.

Conclusions: This study provides new insight into the perspectives of health professionals on the management of foot problems related to psoriatic arthritis. Deficiencies in the diagnosis, assessment and treatment of foot problems were revealed. To meet the foot health needs of people with psoriatic arthritis, reducing diagnostic delay, improving knowledge and awareness about the disease among people with psoriatic arthritis and health professionals, and increasing specialist podiatry service provision may be required.

Key words: Psoriatic arthritis, foot problems, health professionals, qualitative.

4.2.1 Introduction

Psoriatic arthritis (PsA) is a chronic inflammatory disease characterised by a variety of musculoskeletal and dermatological manifestations (Coates and Helliwell, 2017). The heterogeneity of clinical features makes the diagnosis and management of PsA difficult (D’Angelo, et al., 2016; Coates and Helliwell, 2017; Raychaudhuri, et al., 2017). Major challenges recognised in previous studies on the management of PsA, which include under-diagnosis, diagnostic delays and under-treatment (Armstrong, et al., 2013; Coates, et al., 2016a; Lebwohl, et al., 2016; Garrido-Cumbrera, et al., 2017), are reflected in reports of high foot disease burden associated with PsA (Hyslop, et al., 2010a). Despite intensive pharmacological management, imaging studies have shown that inflammation in the foot is detectable in a high proportion of people with PsA (Galluzzo, et al., 2000; Healy, et al., 2008; Delle Sedie, et al., 2011). Clinically important levels of foot-related impairment and disability have been identified in those with localised inflammatory features in the foot affected by PsA (Hyslop, et al., 2010a).

Despite UK podiatry services being well established in the public health system, one UK-based study found that the majority of people with PsA reported foot pain and had not received professional foot care (Hyslop, et al., 2010a). UK podiatrists have developed extended scope practices in rheumatology that include specialist training in corticosteroid injection therapy, musculoskeletal diagnostic ultrasound, gait analysis and rehabilitation (Woodburn, et al., 2010). However, it is generally perceived that Australia and New Zealand podiatrists have limited role extension and limited service provision in the public health system and therefore the severity of PsA-related foot disease reported in the UK may not represent those in other countries.

Previous studies conducted in Australia (Hendry, et al., 2013b; Hendry, et al., 2013a) and New Zealand (Rome, et al., 2009) suggest there is inadequate provision of podiatry services and significant unmet demand for foot care amongst people with rheumatoid arthritis (RA). It is possible that barriers to foot care exist for people with PsA, but the challenges specific to this patient group have not been investigated. Currently there is limited evidence to support the management of PsA specific foot problems (Patience, et al., 2018). Expert-led recommendations for PsA advocate the integration of podiatry within rheumatology multidisciplinary teams for rapid access to specialist foot care (Coates and Helliwell, 2017; Patience, et al., 2018). However, little is known about the assessment and treatment of foot problems in PsA in Australia and New Zealand. The objective of this study was to explore the views of health professionals on the assessment and management of people with PsA-related foot involvement.

4.2.2 Methods

4.2.2.1 Study design

A qualitative research approach was chosen to identify concepts important to health professionals and to be able to explore and understand their views. Focus groups were used to provide a rich and deep examination of the experiences of health professionals through semi-structured, facilitated discussion. Sample size for each focus group was based on recommendations suggesting that 4–12 people will generate sufficient data (Liamputtong and Ezzy, 2005). Questions relating to the assessment and management of foot problems specific to PsA formed the interview guide (Table 4.7). These questions were developed based on a review of relevant literature (Hendry, et al., 2013a; de Souza, et al., 2016; McCulloch, et al., 2018) and were identified as being important by the research group, which comprised clinicians and academics.

4.2.2.2 Participants

A convenience sampling strategy was used to recruit health professionals from rheumatology outpatient clinics in Sydney, Australia and Auckland, New Zealand. Participating sites were selected to include health professionals from public and private sectors in hospital and community-based services, from lower and higher socioeconomic geographical areas and to provide local data from Australia and New Zealand. Health professionals with clinical experience of managing people with PsA, working in Australia or New Zealand were eligible for inclusion (Carter, et al., 2019a). Potential participants were recruited by response to an invitation email containing an outline of the study, screening form and contact details of the primary researcher (KC). Ethical approval was granted by the South Western Sydney Local Health District (HREC/171/LPOOL/353), the Auckland University of Technology Ethics Committee (AUTEC 17/320) and the Waitemata District Health Board of Auckland New Zealand (RM/3907) (Appendix 1). Written informed consent was provided by all participants prior to data collection (Appendix 2).

4.2.2.3 **Procedure**

Prior to the focus groups, demographic data was recorded including gender, ethnicity, occupation and the number of years of clinical experience. The focus groups were conducted by the same researcher (KC) and supported by a second investigator (SW). All focus groups were audio-recorded and transcribed verbatim immediately after each session. Data was collected between October 2017 and March 2018.

4.2.2.4 **Data analysis**

Demographic data was summarised using descriptive statistics. Focus group transcripts were anonymised and imported into a data analysis software package (ATLAS-ti version 7.5.7 Scientific Software Development GmbH, Berlin, Germany, https://atlasti.com). Constant comparative analysis was used to identify themes from the data by inductive category coding and simultaneous comparison of all meaningful units (Morehouse and Maykut, 1994). Codes were generated by the first author (KC) and validated by the second author (SW). Themes and sub-themes were developed and refined by discussion between KC and SW. The full research team reviewed and agreed the final themes, which were subsequently validated by two randomly selected participants from each focus group.

Table 4.7. Focus group interview guide for health professionals with experience of assessing and managing people with psoriatic arthritis-related foot problems.

Exemplar questions		**Prompts**
1	How often do you examine the feet of patients with psoriatic arthritis?	Why do you think that is?
2	Have you encountered any barriers in relation to your patients receiving appropriate foot care?	Do patients seek help with foot problems? From whom? Have your patients reported any barriers to accessing appropriate foot care services to you? What factors do you think make it difficult for patients to access appropriate foot care?
3	Is there anything else you would like to add concerning the experiences of your patients in relation to their foot health and care?	

4.2.3 Results

Three broad themes underpinning suboptimal foot disease management were derived from the data (Table 4.8). Exemplars were identified from the transcripts to support each theme. Suboptimal foot disease management was the overarching description of the sub-themes and represents the unmet need in the screening, assessment, diagnosis and treatment of people with PsA-related foot problems. Suboptimal foot healthcare describes clinical practice that falls below recognised standards of care that promote early detection and tight control of disease in PsA.

Table 4.8. Emergent themes from the focus groups with health professionals.

Emergent themes	Sub-themes
1. Missed opportunities and diagnostic delay	Lack of recognition of foot problems by health professionals Lack of patient knowledge relating to foot problems Socioeconomic disparities in care
2. Challenges related to the management of foot problems in PsA	Varied and fluctuating clinical presentations of PsA Complexity of foot examination

	Lack of appropriate training and knowledge across professions for the management of foot health problems associated with rheumatic disease
3. Lack of specialist podiatry service provision	Lack of specialised podiatrists working within multidisciplinary rheumatology teams Lack of allied health professionals with a specialist interest and expertise in inflammatory arthritis Perceived patient dissatisfaction with limited scope of podiatry practice and high cost of ineffective treatments such as foot orthoses

Theme 1: Missed opportunities and diagnostic delay. Diagnostic delays in those presenting at disease onset with foot problems were reportedly due to patients either not seeking early medical attention or that foot problems were initially mistaken by health professionals as non-inflammatory musculoskeletal conditions. The health professionals recognised that a PsA diagnosis depends, in part, on whether a GP, allied health professional or dermatologist has the specific knowledge and skill to recognize the symptoms and promptly refer the patient to a rheumatologist. There was a general consensus amongst the rheumatologists that more information about PsA should be provided to people with psoriasis attending dermatology clinics.

> *"…they'll be sent through by musculoskeletal physicians who have been treating for tendonitis thinking that's due to injury" (rheumatologist 9)*

An earlier diagnosis was described in relation to achieving better disease outcomes and was associated with patients attending private rheumatology practice, having a higher socioeconomic status and presenting with acute inflammatory foot involvement.

> *"…the patients I see in (private practice) would be presenting much earlier because they're more likely to go and speak with their GP sooner about problems and they have the resources to get into see a specialist quickly. So they come when they're in their early inflammatory phase" (rheumatologist 6)*

The rheumatologists identified the focus of consultations to be on the medical management of PsA. Although it was recognised that some patients may not mention foot problems during rheumatology consultations, nearly all the rheumatologists agreed that they would not routinely ask about or assess the feet unless the patient reported having foot and ankle symptoms. This combined with the perceived view that many patients fail to disclose foot problems to the rheumatologists suggests that the opportunities for diagnosis of foot involvement and referral to podiatry services are being missed.

> *"…it's what's most important because they might feel like they've got 5 minutes to tell you. So they'll come in with a list of things they want to tell you…So it depends…if everything else is going really well but this is the biggest thing at the moment they might mention it" (rheumatologist 5)*

Theme 2: Challenges related to the management of foot problems in PsA. Foot pain in PsA was described in relation to global disease activity, local disease activity and/or mechanical pathology, and given this potential for diverse clinical presentations it was acknowledged to be challenging to assess and manage. Frequent reference was made to active foot disease persisting in many patients, despite achieving tight control of their disease with pharmacological treatment.

> *"The big difference with psoriatic arthritis is its periodicity and unpredictability so that people at times can do things and at other times it's really difficult" (rheumatologist 13)*

> *"But once it's established [foot involvement] it's just hard…It's probably one of the hardest things to treat" (physiotherapist 3)*

> *"…it's such a heterogeneous disease…it's a strange beast this disease" (rheumatologist 14)*

The most commonly highlighted barriers to the assessment of the foot in PsA by rheumatologists during consultations included high disease burden leading to time constraints; low priority of foot disease attributed by the patient; the complexity of foot assessments compounded by lack of training; and a lack of opportunity for onward referral. Difficulty with clinical examination of feet and ankles amongst the rheumatologists was attributed to the complex nature of the structure and function of foot anatomy and the interpretation of swelling in the presence of gravitational oedema and obesity. Further training on clinical and image-based foot examinations was deemed important in order to improve identification of pathologies that would benefit from appropriate referral and intervention.

> *"The feet I think are architecturally a bit complex and not always as straight forward as hands" (rheumatology registrar 11)*

> *"You know us rheumatologists…we are not really trained at all in terms of the functional, like the ankle or the heel and various things… like how the foot should work or take off" (rheumatologist 5)*

Health professionals reported that patients had difficulty with describing and localising foot pain, which appeared to be related to the fluctuating nature of symptoms and being unable to distinguish between joints and skin related symptoms. This further contributed to the difficulty of identifying and assessing foot problems.

> *"If you ask them to point they use their whole hand and sort of go 'Oh here' over like 80% of the surface of the foot. Even that's hard so you've often got to focally press and find where they wince or are tender and that can help narrow down" (rheumatologist 16)*

An additional barrier to the identification of local inflammatory features in the foot, reported by rheumatologists in New Zealand, was having limited access to imaging and to the expertise required to accurately interpret the findings.

> *"Here most of us don't use that… we don't use it routinely [Musculoskeletal diagnostic ultrasound]. We had a machine but it's been taken away" (rheumatologist 9 – New Zealand)*

> *"…quite often the report will come back on ultrasound inter-metatarsal bursitis, what does that mean? A bit of fluid here and there you know so it's quite non-specific" (rheumatologist 9 – New Zealand)*

> *"We don't actually really know what the normal range is that's the problem" [Musculoskeletal diagnostic ultrasound] (rheumatologist 12 – New Zealand)*

> *"I just haven't got my head around what the normal is for MRI is of the feet" (rheumatologist 13 – New Zealand)*

Theme 3. Lack of specialist podiatry service provision. One of the major barriers to rheumatologists performing foot examinations was the lack of access to specialised podiatry services in both public hospitals and private clinics.

> *"I've heard before people will say 'Why ask patients about their feet because I'll uncover something that I actually can't help with'. So why open Pandora's box effectively" (podiatrist 7)*

> *"…sometimes I wonder if we sort of give up a bit. In our hearts because yeah what's the point of assessing when we can't do anything about it…we're not the experts on feet, we are you know we're rheumatologists, but we don't necessarily have access to the experts" (rheumatologist 6)*

It was identified by health professionals in Australia and New Zealand that whilst adequate podiatry service provision had been made in the public health system for people with diabetes who have foot problems, only a few high risk foot clinics would accept people with inflammatory arthritis-related foot problems.

> *"I do find this quite bizarre that you're really much better off to have diabetes if you're going to have bad feet…I've had to watch people being shown the door with big ulcerations because they don't have diabetes, which does seem a bit potty doesn't it" (podiatrist 8)*

The lack of a multi-disciplinary team approach to preventative care, effective intervention and patient-centred management of PsA was a key topic of discussion during the focus groups, which revealed feelings of frustration. Lack of podiatrists and physiotherapists (in both public and private sectors) with specialist interest, training and knowledge in inflammatory arthritis was a problem reported by the rheumatologists signposting to professional foot care.

> *"I find it hard to find the right podiatrist… I don't know that any of them really specialise in inflammatory foot conditions. But finding someone with an interest in inflammatory arthritis is very difficult" (rheumatologist 6)*

Other barriers preventing uptake of podiatry services by people with PsA perceived by the health professionals were financial constraints and dissatisfaction with podiatry care received based on ineffective treatment and/or unfulfilled expectations due to limited scope of practice. Whilst there was awareness amongst the podiatrists of limited extended-scope practice, ineffective foot care was also linked to the limited evidence to date for non-pharmacological interventions for foot disease in PsA.

> *"Yes, a lot of podiatrists would just simply scrape some hard skin down and perhaps don't have enough insight to be able to comprehensively assess patients as well" (podiatrist 7)*

4.2.4 Discussion

This is the first study to explore the views of health professionals involved in the management of foot problems in people with PsA. The results indicate that foot health needs were not being fully met due to deficiencies in the diagnosis, assessment and treatment of foot problems related to PsA in Australia and New Zealand. A recent expert review stated that the identification and treatment of PsA were still not optimal (Coates and Helliwell, 2017), which suggests that unmet needs in the management of PsA is a much broader problem. The finding of suboptimal foot disease management in the current study may help to explain the reported persistence of active inflammation in the foot and ankle with a lack of specialist foot care for early detection and tight control of the disease. Suboptimal foot disease management was the overarching description of the sub-themes, with the term suboptimal encompassing limitations in the diagnosis and assessment of localised foot disease and inadequacies in the provision of timely and effective foot healthcare, thus identifying the need for improvement in the current management of foot health among people with PsA.

Focus group discussions identified that detecting early signs of PsA in the foot was challenging for health professionals due to a lack of awareness about the disease. This study finding supports previous reports of significant delays in PsA diagnosis (Coates, et al., 2016a; Garrido-Cumbrera, et al., 2017). Contributing factors to the under-diagnosis of PsA reported in previous studies are the failure to connect skin and joint symptoms and the difficulty in differentiating between inflammatory arthritis and mechanical joint pain (Lebwohl, et al., 2016; Coates and Helliwell, 2017).

Foot examination during routine rheumatology consultations was reported to be variable in this study, despite the recognition among health professionals of disease persistence in the feet. This finding is consistent with our knowledge of foot problems being overlooked in other rheumatic conditions (de Souza, et al., 2016; Williams, et al., 2017). Early identification of foot involvement in PsA is of clinical importance as this has been shown to be a predictor for joint damage (Cresswell, et al., 2011). Evidence-driven recommendations state that the full 66-68 joint count be used routinely to assess people with PsA, as significant proportions of active disease can be missed in the feet and hands (Coates, et al., 2013; Coates and Helliwell, 2017). No guidelines exist for foot assessment in PsA and the omission of many anatomical sites in the foot and ankle from standard clinical indices, may lead to active disease in the foot being missed along with the opportunity to prevent joint damage.

The complexity of foot examination has been acknowledged within the PsA literature and is partly due to the heterogeneity of clinical symptoms (Galluzzo, et al., 2000; Cresswell, et al., 2011; Delle Sedie, et al., 2011). This study identified the need for specialist training of podiatrists and rheumatologists to develop advanced skills for managing foot health in rheumatic disease. Inadequate podiatry service provision in the public health system reported in this study may in part explain the lack of foot care specialists in the rheumatology field because health service demand typically drives training need. Postgraduate training courses have been implemented in the UK in response to such concerns within the wider rheumatology community (Woodburn, et al., 2010). This model may need to be expanded in Australia and New Zealand to facilitate knowledge transfer between rheumatologists and allied health professionals in the absence of multidisciplinary rheumatology teams.

Establishing locally representative data on the challenges of foot disease management in PsA is an important step towards improving management approaches in the future. Limited information from European studies on the provision of healthcare for foot disease in PsA (Hyslop, et al., 2010a) may not translate to other countries, due to differences in healthcare structure, organisation and provision. Although previous research has focused on local RA foot care provision (Rome, et al., 2009; Hendry, et al., 2013b), PsA is a distinct disease entity with different challenges associated with disease management, which is supported by the current study themes.

Difficulty experienced by patients with describing and localising symptoms in the foot and ankle was recognised by the health professionals in this study. Although this issue has been previously highlighted in RA (Hitchen and Otter, 2010), it has heightened relevance in PsA with previous studies demonstrating that patients have difficulty distinguishing between the musculoskeletal and dermatological components of their disease (Cauli, et al., 2011). To facilitate foot pain self-report and localisation, foot manikins have been utilised in both clinical practice and population-based research (Garrow, et al., 2004; Roddy, et al., 2011; Otter, et al., 2016). However, it is not known how accurately pain locations are transferred on to foot manikins by people with PsA-related foot pain. Routine use of musculoskeletal diagnostic ultrasound in clinical practice would further optimise the identification of localised disease activity in the foot in PsA, and the health professionals in this study highlighted the training and development of expertise required to accurately interpret image-based findings.

Key concepts regarding foot disease management in PsA comprise reducing diagnostic delay, improving knowledge and awareness among patients and health professionals and increasing specialist podiatry service provision. A better understanding of disease persistence in the foot in PsA is required to inform the direction of future research in this area. Future work involves implementation of a survey to obtain information about foot involvement from people with PsA, generating population-based data for Australia and New Zealand. Early identification of foot and ankle problems using a screening tool or outcome measure specific to PsA may help to prevent non-disclosure of foot problems by patients and promote more timely referral and intervention. Currently there are no validated outcome measures specific to foot involvement and its impact in PsA, which limits our understanding of foot disease in PsA and impedes definitive strategies for ‘tight control’ of disease activity in the foot. Further work to validate the use of foot manikins in PsA may help to improve foot pain reporting by patients.

This study was preliminary and exploratory in nature, involving a small number of participants. As such, the findings may not be representative of health professional in other regions of Australia and New Zealand. However, the small sample size provided the opportunity for deeper exploration within a qualitative paradigm and recruitment continued until qualitative data saturation was reached. Rheumatology nurses and dermatologists were invited to take part in the study but were unable to attend, resulting in an under representation of these professional groups. The views of people with PsA-related foot problems were not sought in this current study as the focus was to explore experiences related to foot health assessment and management from the perspective of rheumatology health professionals working with this patient group. Future work on patient’s views is required.

4.2.5 Conclusions

This study has generated preliminary evidence that suggests the identification and management of PsA-related foot involvement may potentially be suboptimal in Australia and New Zealand. Further work is required to investigate the nature and extent of foot involvement and related impacts from the patient perspective, and to further examine current foot care deficiencies in PsA with a view to remediation.

4.2.6 Significance and Innovations

- Preliminary evidence suggests deficiencies in the diagnosis, assessment and treatment of foot problems related to PsA in Australia and New Zealand.

- Frustration among health professions unable to meet the needs of their patients was attributed to a lack of appropriate training in managing foot health in rheumatic disease and lack of access to specialist foot care services.

- Key priorities regarding foot disease management in PsA comprise reducing diagnostic delay, improving knowledge and awareness among patients and health professionals and increasing specialist podiatry service provision.

Chapter 5

5 Linking to the International Classification of Functioning, Disability and Health (ICF)

This chapter describes a study that linked concepts, obtained from the previous qualitative investigation on the patient experience of PsA-related foot involvement, to the International Classification of Functioning, Disability and Health (ICF). The ICF has been developed and endorsed by the World Health Organisation (WHO) as a universal framework and classification system to describe functional states associated with health conditions. To gain a better understanding of the extent and coverage of themes identified by the qualitative work in Chapter 4, concepts derived were linked to the ICF in order to 1) use common terminology to comprehensively describe the impact of localised disease in the foot on functioning and 2) to identify what should be included in the future development of foot-specific PsA assessment tools. Detailed descriptions of the preliminary work, prior to linking to the ICF, have been previously reported (Carter, et al., 2019a; Carter, et al., 2019b) (studies presented in Chapter 4).

Study 1) Linking the patient experience of foot involvement related to psoriatic arthritis to the International Classification of Functioning, Disability and Health.
The study objective was to categorise the patient experience of PsA-related foot involvement by linking it descriptive concepts from the qualitative study to the ICF.

This manuscript has been accepted for publication in the journal Rheumatology Advances in Practice and the authors include Carter K, Tannous C, Walmsley S, Rome K and Turner DE.

This research was presented at the European League Against Rheumatism (EULAR) conference, Madrid, Spain in June 2019 (Conference abstract and poster in Appendix 4: Linking the patient experience of foot involvement related to psoriatic arthritis to the International Classification of Functioning, Disability and Health).

The study in chapter 5 is presented in the form of a stand-alone published paper. In the context of the thesis it is directly linked to the initial qualitative study and therefore represents the next step in the survey development process. This subsequent study used concepts derived from the initial qualitative study that were relevant to people with PsA-related foot problems and mapped them to a recognised health framework. This mapping exercise was integral to the development of a national survey on foot involvement in PsA, since the categorisation of concepts determined what should be measured by the survey. Therefore, this study informed both the conceptual framework of the survey and survey content generation. In the results section 5.5.3 pages 102-104, additional commentary on the difficulties encountered when linking to the ICF was included in the chapter, taken from the supplementary material of the publication. In the discussion section 5.6 page 105, commentary on the current study in the context of other similar published works was included that was additional to the stand-alone publication.

Linking the patient experience of foot involvement related to psoriatic arthritis to the International Classification of Functioning, Disability and Health

5.1 Abstract

Objective. To categorise the patient experience of psoriatic arthritis (PsA)-related foot involvement by linking it to the International Classification of Functioning, Disability and Health (ICF) framework.

Methods. Concepts, obtained from a previous qualitative investigation of people with PsA and health professionals into their perspective of PsA-related foot involvement, were linked to the full version of the ICF classification. Concepts were linked to the most appropriate ICF category using established linking rules, which enable a systematic and standardised linking process. All concepts were independently linked to the ICF by 2 investigators, followed by a third investigator for adjudication. Investigator professional backgrounds included occupational therapy and podiatry.

Results. Over 100 distinct ICF categories were linked to the interview concepts. The most represented ICF category was body functions (35%), followed by environmental factors (31%), activities and participation (19%) and body structure (15%). Concepts that could not be linked to the ICF were related to coping, aspects of time and knowledge. Health professionals identified a greater proportion of body functions and fewer activity and participation categories compared with patients, indicating a possible mismatch of key concerns. Interdisciplinary group analysis demonstrated merit.

Conclusion. A list of ICF categories was generated, defining aspects of functioning important and relevant to the impact of PsA-related foot involvement. Despite the localised anatomical focus of this study, the effect of foot problems in PsA was linked to all components of the ICF, confirming the profound impact on functioning and daily life.

Key words: Psoriatic arthritis; Foot; International Classification of Functioning, Disability and Health.

5.2 Glossary of ICF-specific terms

s	Body Structure
b	Body Function
d	Activities and Participation
e	Environmental Factors
pf	Personal Factors
nc	not covered
hc	health condition
nd	not definable
nd-gh	not definable general health
nd-ph	not definable physical health
nd-qol	not definable quality of life in general

5.3 Introduction

Previous research has shown merit in linking domains of impact in psoriatic arthritis (PsA) to the International Classification of Functioning, Disability and Health (ICF) to categorise the effect of global disease (Taylor, et al., 2010; Gudu, et al., 2017; Sunkureddi, et al., 2018). Identifying ICF categories relevant to PsA provides a conceptual basis to define what should be measured in the development of outcome measures and assessment tools (Boonen, et al., 2009a; Taylor, et al., 2010; Gudu, et al., 2017). As an internationally accepted framework, the ICF has been widely used and advocated by the OMERACT (Outcome Measures in Rheumatology Clinical Trials) as a reference model to better describe the OMERACT domains relating to functioning and to evaluate health outcome measurement (Stucki, et al., 2007; Boonen, et al., 2009a). Previous studies have used the ICF to show that concepts important to people with PsA are not adequately covered by the standard self-report instruments currently used to measure functioning in PsA (Stamm, et al., 2007b; Escorpizo, et al., 2011). The main reasons for this are that existing instruments often contain items that cover different domains (for example, joints, skin, enthesitis, dactylitis, spine, pain, physical function, quality of life) due to the heterogeneity of clinical manifestations in PsA, and many of the instruments have been adapted from other rheumatic diseases with few disease-specific instruments for PsA currently available (Gladman, et al., 2004; Mease, 2011). Furthermore, incorporation of the patient perspective in the development of outcome measures and domains in PsA is often lacking (Palominos, et al., 2012; Tillett, et al., 2014), which limits the potential value of the outcome as discrepancies have been reported between the views of patients and health professionals (Dandorfer, et al., 2012).

Localised pain and disease persistence in the foot in PsA is well recognised (Galluzzo, et al., 2000; Healy, et al., 2008; Hyslop, et al., 2010a; Delle Sedie, et al., 2011; Turner, et al., 2014), but limited foot-specific research exists and there are no outcome measures to comprehensively assess foot involvement in PsA and its impact on a person’s function and participation. Previous studies have used the Leeds Foot Impact Scale (LFIS) (Helliwell, et al., 2005a) to assess foot-related disability in PsA (Hyslop, et al., 2010a; Hyslop, et al., 2010b; Woodburn, et al., 2013; Turner, et al., 2014; Wilkins, et al., 2016), which consists of sub-scales aligned to the ICF. Whilst this approach has merit in that the LFIS was robustly developed using patient perspectives in rheumatoid arthritis, it is unlikely to adequately capture the combined musculoskeletal and dermatological impact in PsA. Indeed, few qualitative studies have identified that local foot disease in PsA can cause substantial functional impairments and visual differences, which can negatively impact on emotional well-being and on all aspects of life (Carter, et al., 2019a; Carter, et al., 2019b). To date little is known about the patient experience of foot involvement and how this may link to the ICF to capture and describe disease impact. The objective of this study was to categorise the patient experience of PsA-related foot involvement by linking descriptive concepts to the ICF.

5.4 Methods

5.4.1 Concepts from previous qualitative study

A qualitative study was previously performed based on semi-structured, one-to-one interviews of people with PsA (n=21) and three multidisciplinary focus groups among health professionals (Carter, et al., 2019a). A total of 17 health professionals with clinical experience of managing this patient group participated in 3 separate focus groups (comprising groups of n=8, n=5, n=4), including podiatrists, physiotherapists and rheumatologists. The interviews and focus groups covered specific areas of interest, which included (1) foot involvement in PsA, (2) its impact on daily life, (3) experiences with footwear and (4) foot care needs. Each interview and focus group was audio-recorded, transcribed verbatim and analysed using the constant comparative method for qualitative data (Morehouse and Maykut, 1994). Meaningful concepts within the text, such as words or sentences containing relevant contextual information, were identified and used in the current study (Figure 5.1).

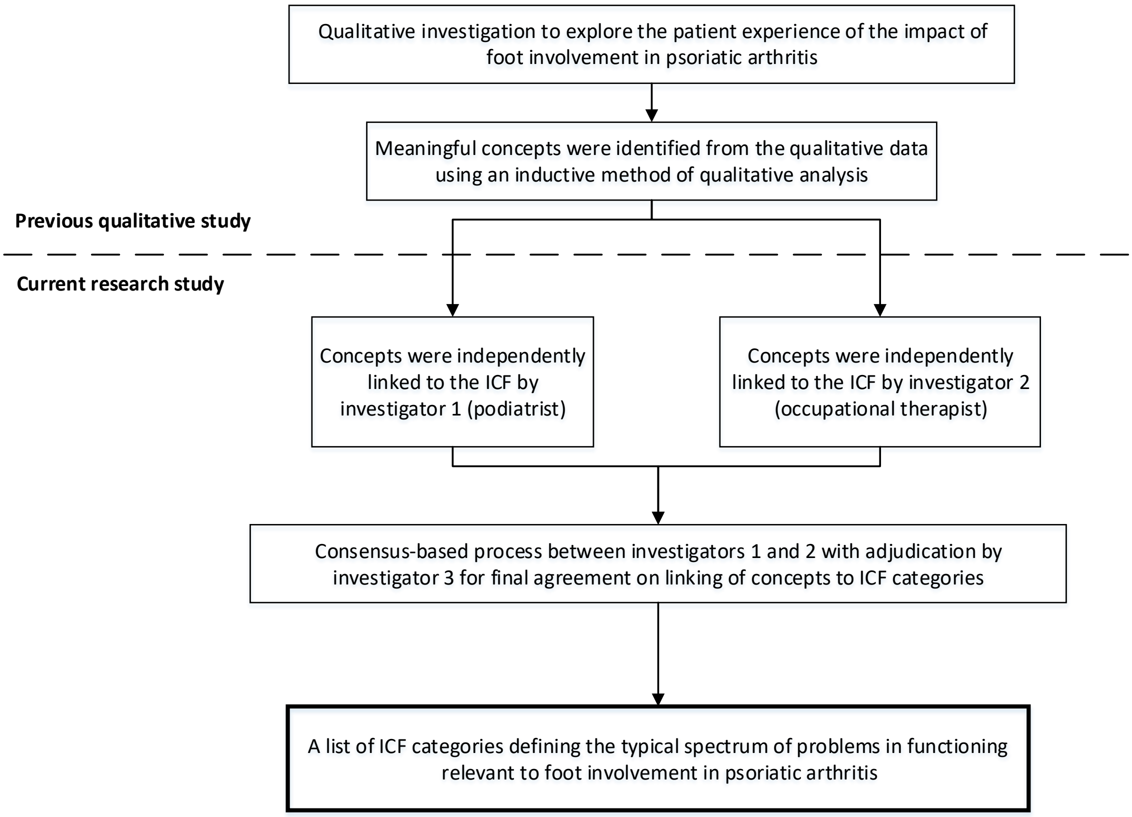


Figure 5.1. The study design process.

ICF International Classification of Functioning, Disability and Health.

Qualitative research typically uses small sample sizes with a diverse range of participants in order to obtain rich data that allows in-depth exploration and understanding of the research question (Ritchie, et al., 2009). A representative sample was sought from the public and private sector, and from lower and higher socioeconomic geographical areas in Australia and New Zealand. Recruitment to the study continued until qualitative data saturation of emerging concepts was achieved (Francis, et al., 2010). Ethical approval was granted by; the South Western Sydney Local Health District (HREC/171/LPOOL/353), the Auckland University of Technology Ethics Committee (AUTEC 17/320) and the Waitemata District Health Board of Auckland New Zealand (RM/3907) (Appendix 1), and informed consent was obtained from all participants (Appendix 2). Detailed descriptions of the preliminary work have been previously reported (Carter, et al., 2019a; Carter, et al., 2019b) (studies presented in Chapter 4).

5.4.2 Linking to the International Classification of Functioning, Disability and Health

The International Classification of Functioning, Disability and Health (ICF) has been developed and endorsed by the World Health Organisation (WHO) as a universal framework and classification system to describe functional states associated with health conditions (WHO, 2001). The ICF framework supports the biopsychosocial model of health by recognising the influence of contextual factors on functioning and disability. Based on this model, functioning is described as the complex interplay of the main health components; Body Structure, Body Functions, Activities and Participation, Environmental and Personal Factors (Figure 2.2, Chapter 2, section 2.5). By shifting the focus from health condition to functioning, the ICF places all health conditions on an equal footing, allowing them to be compared in terms of their related functioning via a common framework. The ICF provides a standard language and conceptual basis for the definition and measurement of disability (WHO, 2001). The ICF classification system comprises 1454 categories that are an exhaustive list of globally accepted descriptions of what can be relevant to people with a health condition experiencing decrements in functioning (WHO, 2001).

The structure of the ICF has two parts, part 1 covers functioning and disability that includes the components Body Structure (categories with the letter **s**), Body Functions (categories with the letter **b**), and Activities and Participation (categories with the letter **d**). Part 2 covers contextual factors that includes the components Environmental Factors (categories with the letter **e**) and Personal Factors (whole component specified with the letters **pf**). Within each component (except Personal Factors), there are multiple categories that are hierarchically grouped within chapters and denoted by unique alphanumeric codes. Within each chapter there are 2nd level, 3rd level and 4th level categories, which are the units of the classification (WHO, 2001). Within each chapter, the categories are arranged in a stem, branch, leaf scheme. Consequently, a lower-level category shares the attributes of the higher-level category to which it belongs. Hierarchically grouped, the 2nd, 3rd and 4th level categories represent increasingly more detailed frames of reference. Higher-levels of linking indicate greater specification (Figure 5.2). For example, b2 Sensory functions and pain (1st level/chapter), b280 Sensation of pain (2nd level), b2801 Pain in body part (3rd level) and b28015 Pain in lower limb (4th level).

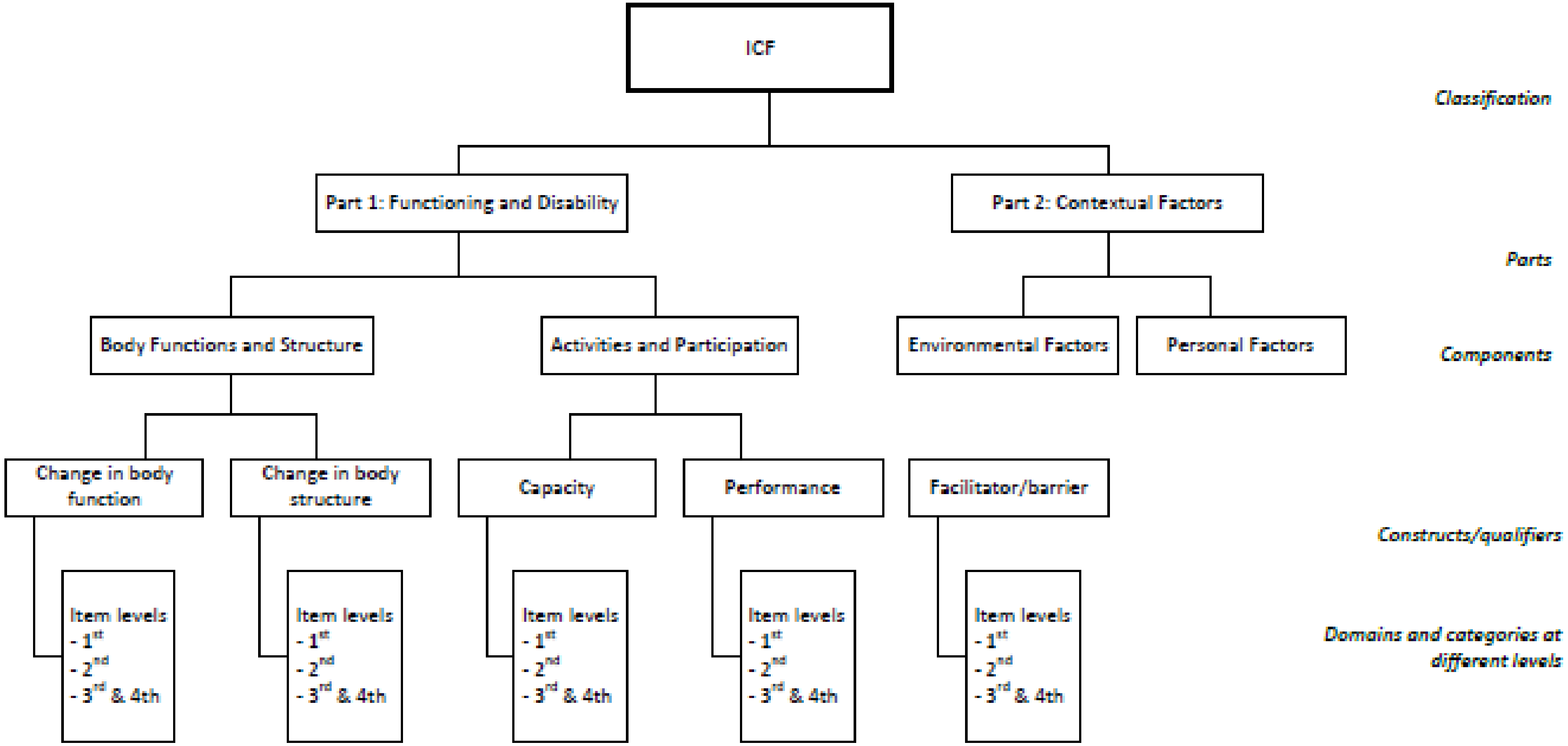


Figure 5.2. Structure of the ICF (WHO, 2001).

ICF International Classification of Functioning, Disability and Health.

Personal factors are defined in the ICF as the particular background of an individual's life and living, and comprise features of the individual that are not part of health condition. These factors include gender, race, age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background, education, profession, past and current experience, overall behaviour pattern and character style, individual psychological assets and other characteristics (WHO, 2001).

Linking refers to the procedure in which the concepts within the items of the instrument or interviews are translated into ICF language, meaning the concepts are fitted to the most related ICF category (Boonen, et al., 2009a). The number of categories should be as low as possible but as high as needed to accurately reflect functioning for the particular health condition. Linking rules have been developed to standardise the process of connecting outcome measures and qualitative data to the ICF classification (Cieza, et al., 2002; Cieza, et al., 2005; Cieza, et al., 2019).

Each concept, obtained from the previous qualitative interviews and focus groups, was linked to the most appropriate ICF category according to established linking rules (Cieza, et al., 2002) and their updates (Cieza, et al., 2005; Cieza, et al., 2019). The linking rules inform a systematic linking process and facilitate the standardised identification of the linkage between qualitative concepts and ICF categories (Cieza, et al., 2002; Cieza, et al., 2005; Cieza, et al., 2019). Using the online ICF classification tool in its full version, each concept was linked to the most precise ICF category. If a concept contained sub-concepts it was linked to more than one ICF category. For example, a statement from the qualitative data is "Due to the pain in my feet I didn't want to meet up with my friends", in which the concepts would be 'foot pain' and 'impact - meeting up with friends' and the ICF categories linked to them would be 'b28015 pain in the lower limb' and 'd9205 socialising' (more examples are provided in Appendix 5 in Supplementary Table 1).

Concepts that could not be linked to the ICF were assigned 'not covered' (**nc**), such as the concept "disease progression" in the current study. Concepts related to personal factors were linked to the ICF whole component 'personal factors' (**pf**) because this ICF component does not include separate categories. Concepts relating to health conditions other than PsA were assigned as 'health condition' (**hc**). If there was insufficient information to make a decision about which ICF category should be linked, it was assigned as not definable (**nd**), including concepts referring to general health (**nd-gh**), physical health (**nd-ph**) and quality of life in general (**nd-qol**). The ‘other specified’ and ‘unspecified’ categories at the end of each chapter were used if a concept was not explicitly specified.

5.4.2.1 **Accuracy of analysis**

All concepts were independently linked to the ICF by 2 investigators (KC, CT). After the independent linking process was complete, the investigators discussed differences in their linking in order to obtain consensus regarding a final set of categories. The third investigator (DET) assessed all categories, adjudicated cases of disagreement and determined the final category. If required, interview transcripts were reviewed to ensure that the concept had been interpreted accurately. Investigator professional backgrounds included occupational therapy and podiatry, and all three investigators undertook self-directed training in linking concepts to the ICF using the eLearning resources developed by the WHO (WHO, 2015). Full understanding of the concepts and structure of the ICF was required by the investigators prior to commencing the linking process (Cieza, et al., 2019). In addition, the three investigators had experience of qualitative research methods and 15 years of clinical practice experience.

The degree of agreement between the 2 investigators in linking concepts to the ICF was calculated using total percentage agreement and the unweighted kappa statistic (Cohen, 1960). Data were recorded for each of the 4 main components of the ICF for linking of the patient and health professional concepts individually and combined. Kappa values can range from 0 to 1, where 1 indicates perfect agreement and 0 indicates no additional agreement beyond what is expected by chance alone. When interpreting kappa statistics, published definitions were used to determine the degree of agreement (Landis and Koch, 1977). The analysis was performed using SPSS version 25 software (SPSS, Inc., Chicago, IL). Descriptive statistics were used to analyse the number and frequency of ICF categories identified.

5.5 Results

A total of 1363 relevant concepts were identified from the interviews of people with PsA and the focus groups with health professionals. The frequency with which each of these concepts were reported among all participants was 4774, of which 924 were from health professionals and 3850 were from people with PsA.

5.5.1 Frequency of ICF categories

One hundred and forty-eight distinct ICF categories were linked to the interview and focus group concepts, which related to Body Structures (n=17, 12%), Body Functions (n=48, 32%), Activities and Participation (n=55, 37%), and Environmental Factors (n=28, 19%).

The most represented ICF component was Body Functions (35%), followed by Environmental Factors (31%), Activities and Participation (19%) and Body Structure (15%) (Tables 5.1, 5.2, 5.3 and 5.4). The most frequent 3rd level categories were body image (b1801), maintaining one's health (d5702) and footwear that was linked to general products and technology for personal use in daily living (e1150). The most frequent 2nd level categories were emotional functions (b152), walking (d450), carrying out daily routine (d230) and health services, systems and policies (e580). Also cited frequently was the major life area of remunerative employment (d850), followed by the impact on family (d760) and social life (d920).

The majority of concepts reported by people with PsA were linked to 3rd level (more precise) ICF categories across all 4 components. Environmental Factors most relevant to people with PsA were footwear and assistive devices such as insoles, access to healthcare, support from family and health professionals, drugs and climate. High levels of self-care activity were reported among people with PsA, which covered maintaining and looking after one's health, and caring for skin and toenails, and these concepts were linked to healthcare access, financial assets and assistive devices. Toenail changes, relating to structure and function, were also frequently cited by people with PsA and linked to domains of body image and social relationships. Lack of understanding about the disease was a strong theme from the patient experience and was linked to the attitudes of friends, family, colleagues, strangers and health professionals, but it was difficult to link aspects of knowledge and education that did not fully represent this concept.

Body Structures that were not foot-specific were related to spine and hand involvement. Proximal issues at spine level impacted on mobility and stability at foot level, and problems with hands and fingernails were reported by way of comparison with foot and toenail problems.

Table 5.1. The frequency of ICF categories for the component Body Structure that were linked from concepts obtained from people with psoriatic arthritis and health professionals.

ICF categories Body Structure (s)	Generated from health professionals, n (%)	Generated from people with psoriatic arthritis, n (%)
s75021 Ankle joint and joints foot and toes	73 (33%)	305 (34%)
s8104 Skin of lower extremity	14 (6%)	194 (21%)
s8301 Toenails	31 (14%)	143 (16%)
s7502 Structure of ankle and foot	62 (28%)	142 (15%)
s75022 Muscles of ankle and foot	19 (9%)	53 (6%)
s75012 Muscles of lower leg	0	23 (3%)
s7302 Structure of hand	4 (2%)	13 (1.5%)
s750 Structure of lower extremity	0	8 (0.9%)
s75023 Ligaments and fasciae of ankle and foot	13 (6%)	7 (0.7%)
S7703 Extra-articular ligaments, fasciae, extramuscular aponeuroses, retinacula, septa, bursae, unspecified	3 (1.5%)	5 (0.5%)
s7501 Structure of lower leg	0	4 (0.4%)
s75011 Knee joint	0	3 (0.3%)
s8300 Fingernails	1 (0.5%)	2 (0.2%)
s7600 Structure of vertebral column	0	2 (0.2%)
s75020 Bones of ankle and foot	0	1 (0.1%)
s73021 Joints of hands and fingers	0	1 (0.1%)
s7401 Joints of pelvic region	0	1 (0.1%)
Total	220	907

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Table 5.2. The frequency of ICF categories for the component Body Function that were linked from concepts obtained from people with psoriatic arthritis and health professionals.

ICF categories Body Function (b)	Generated from health professionals, n (%)	Generated from people with psoriatic arthritis, n (%)
b28015 Pain in lower limb	166 (39.1%)	657 (29.5%)
b152 Emotional functions	48 (11.3%)	245 (11%)
b1801 Body image	44 (10.3%)	149 (6.7%)
b860 Functions of nails	20 (5%)	122 (5.5%)
b8 Functions of skin	13 (3.1%)	119 (5.4%)
b126 Temperament and personality functions	9 (2%)	114 (5.1%)
b770 Gait pattern functions	8 (1.8%)	88 (4%)
b810 Protective functions of the skin	4 (1%)	68 (3%)
b7800 Sensation of muscle stiffness	12 (2.8%)	64 (2.9%)
b2700 Sensitivity to temperature	1 (0.2%)	56 (2.5%)
b2702 Sensitivity to pressure	0	55 (2.4%)
b735 Muscle tone functions	0	45 (2%)
b710 Mobility of joint functions	15 (3.5%)	43 (1.9%)
b760 Control of voluntary movement functions	0	38 (1.7%)
b28016 Pain in joints	0	37 (1.6%)
b435 Functions of the immune system	37 (9%)	34 (1.5%)
b7801 Sensation of muscle spasm	0	30 (1.4%)
b134 Sleep functions	1 (0.2%)	29 (1.3%)
b455 Exercise tolerance functions	8 (1.8%)	26 (1.2%)
b265 Touch functions	0	26 (1.2%)
b280 Sensation of pain	0	24 (1.1%)
b530 Weight maintenance functions	19 (4.5%)	23 (1%)
b820 Repair functions of the skin	0	20 (0.9%)
b4152 Function of veins	1 (0.2%)	16 (0.8%)
b1644 Insight	1 (0.2%)	15 (0.7%)
b1645 Judgement	0	14 (0.6%)
b715 Stability of joint functions	0	9 (0.4%)

b415 Blood vessel functions	0	9 (0.4%)
b5501 Maintenance of body temperature	0	9 (0.4%)
b755 Involuntary movement reaction functions	0	6 (0.3%)
b4552 Fatigability	2 (0.5%)	5 (0.2%)
b7303 Power of muscles in lower half of the body	0	5 (0.2%)
b6601 Functions related to pregnancy	0	5 (0.2%)
b1301 Motivation	2 (0.5%)	4 (0.2%)
b1642 Time management	0	4 (0.1%)
b840 Sensation related to skin	0	4 (0.1%)
b270 Sensory function related to temperature and other stimuli (e.g. burning sensation, vibration)	1 (0.2%)	2 (0.08%)
b1142 Orientation to person	0	2 (0.08%)
b830 Other functions of the skin (e.g. sweating)	0	2 (0.08%)
b7808 Sensations related to muscles and movement functions, other specified (e.g. strain sensation)	0	2 (0.08%)
b730 Muscle power functions	0	2 (0.08%)
b7353 Tone of muscles of lower half of body	0	2 (0.08%)
b28013 Pain in back	1 (0.2%)	1 (0.04%)
b1265 Optimism	1 (0.2%)	1 (0.04%)
b1300 Energy level	1 (0.2%)	1 (0.04%)
b2800 Generalised pain	5 (1.2%)	0
b650 Menstruation functions (e.g. menopause)	2 (0.5%)	0
b114 Orientation functions	2 (0.5%)	0
Total	424	2232

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Table 5.3. The frequency of ICF categories for the component Activities and Participation that were linked from concepts obtained from people with psoriatic arthritis and health professionals.

ICF categories Activities and Participation (d)	Generated from health professionals, n (%)	Generated from people with psoriatic arthritis, n (%)
d450 Walking	22 (10%)	156 (13%)
d5702 Maintaining one's health	21 (9%)	146 (12%)
d850 Remunerative employment	76 (34%)	132 (11%)
d5200 Caring for skin	0	57 (5%)
d230 Carrying out daily routine	2 (0.9%)	57 (5%)
d570 Looking after one's health	4 (1.8%)	51 (4.3%)
d5204 Caring for toenails	8 (3.6%)	46 (3.9%)
d760 Family relationships	8 (3.6%)	45 (3.8%)
d9205 Socialising	8 (3.6%)	41 (3.4%)
d5700 Ensuring one's physical comfort	5 (2.2%)	41 (3.4%)
d920 Recreation and leisure	12 (5.4%)	31 (2.6%)
d4154 Maintaining a standing position	8 (3.6%)	30 (2.5%)
d4551 Climbing (e.g. stairs)	2 (0.9%)	27 (2.3%)
d4153 Maintaining a sitting position	3 (1.3%)	25 (2%)
d240 Handling stress and other psychological demands	0	22 (1.8%)
d4104 Standing	2 (0.9%)	21 (1.8%)
d9201 Sports	9 (4%)	19 (1.7%)
d7101 Appreciation in relationships	1 (0.4%)	17 (1.4%)
d4501 Walking long distances	3 (1.3%)	16 (1.3%)
d179 Applying knowledge, other specified and unspecified	2 (0.9%)	15 (1.3%)
d4502 Walking on different surfaces	0	14 (1.2%)
d640 Doing housework	0	13 (1.1%)
d210 Undertaking a single task	0	13 (1.1%)
d6505 Gardening	0	12 (1%)
d4602 Moving around outside the home and other buildings	0	12 (1%)

d750 Informal social relationships	7 (3%)	11 (0.9%)
d4552 Running	5 (2.2%)	11 (0.9%)
d650 Caring for household objects	0	10 (0.8%)
d4500 Walking short distances	0	10 (0.8%)
d5701 Managing diet and fitness	0	10 (0.8%)
d220 Undertaking multiple tasks	0	10 (0.8%)
d475 Driving	1 (0.4%)	9 (0.7%)
d6200 Shopping	0	9 (0.7%)
d410 Changing basic body position	4 (1.8%)	8 (0.7%)
d7600 Parent-child relationships	5 (2.2%)	5 (0.4%)
d4452 Reaching	3 (1.3%)	5 (0.4%)
d4103 Sitting	2 (0.9%)	5 (0.4%)
d5 Self-care	0	5 (0.4%)
d4600 Moving around within the home	0	4 (0.3%)
d455 Moving around	0	3 (0.25%)
d4702 Using public motorised transportation	0	3 (0.25%)
d4106 Shifting the body’s centre of gravity	1 (0.4%)	2 (0.2%)
d9204 Hobbies	0	2 (0.2%)
d5402 Putting on footwear	0	2 (0.2%)
d5100 Washing body parts	0	2 (0.2%)
d740 Formal relationships	1 (0.4%)	1 (0.08%)
d9100 Informal associations	0	1 (0.08%)
d4102 Kneeling	0	1 (0.08%)
d5203 Caring for fingernails	0	1 (0.08%)
d5403 Taking off footwear	0	1 (0.08%)
d4750 Driving human-powered transportation	0	1 (0.08%)
d177 Making decisions	0	1 (0.08%)
d7201 Terminating relationships	0	1 (0.08%)
d4105 Bending	0	1 (0.08%)
d4300 Lifting	0	1 (0.08%)
Total	225	1195

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Table 5.4. The frequency of ICF categories for the component Environmental Factors that were linked from concepts obtained from people with psoriatic arthritis and health professionals.

ICF categories Environmental Factors (e)	Generated from health professionals, n (%)	Generated from people with psoriatic arthritis, n (%)
e1150 General products and technology for personal use in daily living	150 (29%)	712 (40%)
e580 Health services, systems and policies	78 (15%)	261 (14%)
e5800 Health services	44 (8.3%)	105 (6%)
e1151 Assistive products and technology for personal use in daily living	22 (4%)	101 (5.5%)
e355 Health professionals	44 (8.3%)	89 (5%)
e225 Climate	10 (2%)	81 (4.5%)
e1101 Drugs	32 (6%)	80 (4.4%)
e445 Attitudes of strangers	5 (1%)	64 (3.5%)
e310 Immediate family	1 (0.2%)	57 (3.2%)
e425 Attitudes of colleagues	9 (1.7%)	44 (2.4%)
e1650 Financial assets	42 (8%)	32 (1.7%)
e410 Attitudes of immediate family	0	32 (1.7%)
e415 Attitudes of extended family	0	32 (1.7%)
e2450 Day/night cycles	10 (2%)	27 (1.5%)
e450 Attitudes of health professionals	15 (3%)	22 (1.2%)
e420 Attitudes of friends	0	18 (1%)
e590 Labour and employment services, system and policies	1 (0.2%)	10 (0.6%)
e1201 Assistive products and technology for personal indoor and outdoor mobility and transportation	2 (0.4%)	9 (0.5%)
e340 Personal care providers and personal assistants	0	9 (0.5%)
e245 Time-related changes	2 (0.4%)	5 (0.3%)
e510 Services, systems and policies for the production of consumer goods	1 (0.2%)	4 (0.2%)

e2250 Temperature	0	4 (0.2%)
e115 Products and technology for personal use in daily living	0	4 (0.2%)
e515 Architecture and construction services, systems and policies	2 (0.4%)	1 (0.03%)
e1651 Tangible assets	0	1 (0.02%)
e1351 Assistive products and technology for employment	2 (0.4%)	1 (0.02%)
e5850 Education and training services	44 (8.3%)	0
e215 Population	6 (1.2%)	0
Total	522	1805

ICF International Classification of Functioning, Disability and Health.

About half the number of Body Function (n=26, 57%) and Activities and Participation categories (n=27, 49%) were identified by health professionals compared with participants with PsA (n=45, 94% and n=55, 100% respectively), indicating a possible mismatch of key concerns. The majority of concepts reported by health professionals were linked to 2nd level (less precise) ICF categories from the components Body Functions and Activities and Participation. Over one-third of the ICF categories identified from the health professional focus group concepts related to Environmental Factors (n=522, 38%), with the majority being 3rd level ICF categories. This reflected key concerns about the limited access to, and provision of, specialist foot care services, which was the most frequent Environmental Factor reported by health professionals followed by concerns relating to footwear restrictions among patients and the lack of training across professionals on the management of rheumatic foot disease.

5.5.2 Levels of linking

Over half of the ICF categories identified were 3rd level categories (n=76, 51%), followed by 2nd level categories (n=60, 40%). The ICF component that had the most specific categories (higher-level) was Body Structures, with 44% of concepts being linked to seven 4th level categories (relating to the bones, joints, muscles, ligaments and fascia in the foot and ankle). This was followed by Body Functions with 76% of concepts being linked to three 4th level categories, which mainly related to ‘pain in the lower limb'. The two 1st level categories were self-care (d5) and more frequently functions of skin (b8). Psoriatic skin changes were mainly reported in relation to the physical and psychological consequences, which was reflected in the interview concept focusing on the impact of skin change and not specifically on the skin quality (b810) or sensation (b840).

5.5.3 Difficulty with linking to the ICF

Fifty-seven interview codes containing 5 concepts could not be linked to the ICF categories including the disease course (n=27, 47%) (which comprised disease variability, duration, progression, chronicity and established foot disease), comorbidity (n=24, 42%), illness knowledge (n=4, 7%), quality of life in general (such as “life is ruined”, “life is impossible”, “nightmare”) (n=1, 2%), and general physical health (such as “debilitating”, “incapacitating”) (n=1, 2%). Fifty-nine interview codes containing 7 concepts were assigned to the ICF component Personal Factors, which included coping styles (n=23, 39%), age (n=10, 17%), gender (n=10, 17%), ethnicity (n=5, 8%), family history of inflammatory arthritis (n=9, 15%), lifestyle (n=1, 2%), and concerns and priorities (n=1, 2%) (Table 5.5 and 5.6).

Table 5.5. Concepts that were linked to the ICF component personal factors.

ICF categories	Generated from health professionals, n	Generated from people with psoriatic arthritis, n
Coping styles	13	201
Family history of inflammatory arthritis	1	19
Age	10	2
Personal concerns and priorities	6	3
Gender-specific	20	0
Ethnicity-specific	9	0
Lifestyle	3	0
Total	62	225

ICF International Classification of Functioning, Disability and Health.

Table 5.6. Concepts that were not covered or were not definable by the ICF classification.

ICF categories	Generated from health professionals, n	Generated from people with psoriatic arthritis, n
nc – Illness knowledge	1	41
nc - Health condition (e.g. comorbidities)	21	40
nc - Disease course	63	19
nd-qol (e.g. life ruined)	1	7
nd-ph (e.g. debilitating)	4	5
Total	90	112

ICF International Classification of Functioning, Disability and Health, *nc* not covered, *nd-qol* not definable quality of life, *nd-ph* not definable physical health.

Concepts that could not be precisely linked to the ICF were related to coping strategies, aspects of time, knowledge of global and local disease, discomfort, rest, swelling, muscle cramp, tendon and enthesis, falls and instability, fatigue and treatment side-effects. Difficulties in linking highly specific information to categories such as sensations of pain, sensations of skin and emotional functions revealed a limitation in the ICFs ability to discriminate between various effects of the disease.

Swelling was assigned to the ICF category b435: immunological system functions to capture inflammation related to the immune response, which covered concepts such as joint and soft-tissue swelling. Swelling of body parts has previously been linked to b454: water, mineral and electrolyte balance functions (Stamm, et al., 2007a). However, the majority of concepts related to generalised, non-specific swelling in the foot, ankle and lower leg that were associated with a variety of factors, which included climate, time of day, activity levels, body position and overall change of foot shape. The swelling was unrelated to inflammation or venous insufficiency and was difficult to code in that respect.

Rest was initially assigned to the ICF category b735: muscle tone functions that refers to the tension present in resting muscles, which was later rejected in a consensus-based discussion among the investigators. Rest is seen as a body function with an activity component and has been linked to b1349: sleep function unspecified and d9209: recreation and leisure unspecified in previous studies (Stamm, et al., 2006). Other categories considered were b4552: fatigability, b455: exercises tolerance functions, b130: energy and drive functions, and pf-coping strategy. However, these categories stem from mental and cardiovascular functions that did not reflect the meaning of rest from the qualitative codes.

Enthesis and tendon disorders were linked to s75022: muscles of ankle and foot as the best-matched ICF category and in order to avoid the non-specific ‘other specified’ category. This hallmark feature of PsA is not fully represented by the structure categories available of the ankle and foot.

5.5.4 Accuracy of analysis

The overall total percentage agreement in the linking of patient and health professional concepts combined ranged from a maximum of 86.3% for Body Functions to a minimum of 72.0% for Activities and Participation. Moderate to very good levels of interrater agreement were identified across the ICF components in relation to the linking of patient and health professional concepts combined, ranging from moderate interrater reliability for Activities and Participation at 0.59 (CI 0.53, 0.64) to very good for Body Functions at 0.81 (CI 0.78, 0.85) (data on the total percentage agreement and Cohen’s kappa for interrater agreement is provided in Appendix 5 in Supplementary Tables 2 and 3).

The key difference between the raters was the perception of activity functions (d) and mental and attitudinal functions (b). For example, some aspects of coping were assigned to the ICF category handling stress and other psychological demands (d240) by the 1st rater, but were assigned to temperament and personality functions (b126) by the 2nd rater. Whilst coping style is defined as a Personal Factor present as a pre-morbid state in the linking rules, it could be attributed to a consequent impairment of the disease. This overlap in meaning of coping resulted in b126 being the 6th most frequently cited Body Function category and being the most frequent concept assigned to Personal Factors (n=214, 75%).

5.6 Discussion

To the best of our knowledge this study is the first to identify ICF categories of importance to people with PsA-related foot involvement and relevant to the health professionals involved in their care. Emergent concepts from the foot-specific qualitative-based work were linked to all components of the ICF, confirming that local disease in the foot in PsA has a broad impact on daily life with physical, psychological and societal consequences. The OMERACT and the GRAPPA (Group for Research and Assessment of Psoriasis and Psoriatic Arthritis) have endorsed work using the ICF to identify global aspects of functioning in PsA (Taylor, et al., 2010; Gudu, et al., 2017). However, with recognition that hallmark features of PsA are predominant and persistent in the foot and ankle (Galluzzo, et al., 2000; Healy, et al., 2008; Hyslop, et al., 2010a; Delle Sedie, et al., 2011; Turner, et al., 2014), this study describes the extent to which functioning is influenced by body region-specific involvement. Despite the region-specific focus of the current study, the impact of localised disease in the foot was widespread and consistent with previous studies that assessed global PsA disease (Stamm, et al., 2007b; Taylor, et al., 2010; Gudu, et al., 2017).

Similar results were reported with 136 ICF categories identified in a previous systematic review article (Gudu, et al., 2017), which used the ICF to categorise the global effect of PsA as obtained from other qualitative studies. Gudu et al (2017) found the most represented ICF component to be Activities and Participation, followed by Body Functions. However, the same study reported that the purely qualitative studies had a higher proportional representation of Body Structures and Environmental Factors than in the studies with both qualitative and quantitative phases of the methodology (Gudu, et al., 2017). This is similar to the current study findings with a higher number of ICF categories classified as Environmental Factors and supports the suggestion by Gudu et al (2017) that detailed results from qualitative studies may better assess the disease effect and patients' perspectives. Whilst previous qualitative studies have used the ICF to categorise the patient perspective of regional disease in the knee in osteoarthritis (Xie, et al., 2006a; Xie, et al., 2006b), to our knowledge there is no similar study linking qualitative work assessing the effect of localised disease in PsA to the ICF. The authors concluded that the ICF serves as a comprehensive and independent framework to identify and compare the typical patient experience, which can then be measured by specific instruments.

Using the ICF, the full spectrum of foot-specific problems in PsA and the dynamic interaction between domains of impact can be better understood. The physical domain of body structure and function was well represented, reflecting the high foot disease burden and unmet need for specialist foot care reported in other studies in PsA (Hyslop, et al., 2010a; Carter, et al., 2019b). Important concepts in the component body function were body image and emotional well-being. Dermatological problems were frequently linked to both these concepts, indicating that assessing the consequences of psoriatic skin and toenail involvement could be helpful for effective patient-centred care. Although the impact on daily activity was most pertinent to people with PsA-related foot involvement, environmental and personal factors covered an array of positive and negative aspects that may play an important role in assessing functioning. Despite the diverse expression of PsA in the foot, limited research has focused on understanding the impact of local foot disease and from the patient perspective (Carter, et al., 2019a). This study has identified the most typical and relevant aspects of functioning from the patient experience of PsA-related foot involvement using the ICF classification as a universal model and language of functioning. The translation of aspects of functioning into ICF terms enables the meaning of the patient experience to be condensed, defined and compared (Stamm and Machold, 2007; Boonen, et al., 2009a).

Whilst the benefits of early detection and tight control of active foot disease in PsA have been acknowledged (Cresswell, et al., 2011; Patience, et al., 2018), recent qualitative research revealed deficiencies in the assessment and management of foot problems related to PsA reported by patients and health professionals in Australia and New Zealand (Carter, et al., 2019a; Carter, et al., 2019b). The need for personalised, targeted assessment and management strategies focused on the manifestations and impact of foot disease in PsA has been identified in previous studies (Healy, et al., 2008; Patience, et al., 2018; Carter, et al., 2019b). Establishing what are the key concerns from the patient perspective is an important step towards identifying ‘what to measure’ in the assessment and management of PsA (Boonen, et al., 2009a; Taylor, et al., 2010). Findings from this study confirm that the views and personal importance attributed to different aspects of functioning vary between and among patients and health professionals, which supports similar published work (Hewlett, et al., 2001;

Carr, et al., 2003; Hewlett, 2003; Coenen, et al., 2005; Tillett, et al., 2014). Linking was to lower-level categories (equating to lower specificity) for concepts obtained from the health professionals, which supports the patient perception of poor understanding of the impact of the disease by health professionals. Experienced health professionals did not appear to appreciate the broader aspects of functional and emotional impact that foot problems have on daily life. Failure to recognise concepts important to people with PsA could negatively influence patient compliance with, and efficacy of, treatment strategies, which suggests a need for more education in this area. Categorising the effect of PsA-specific foot disease using the ICF framework highlights the value of this approach in identifying concepts important to both patients and health professionals.

Concepts that could not be precisely linked using the online ICF classification and the shortfalls of the ICF noted in this study were consistent with those reported in previous work in PsA (Taylor, et al., 2010; Gudu, et al., 2017), and in other rheumatic conditions (Stamm, et al., 2005; Stamm, et al., 2007a; Boonen, et al., 2009b; Campbell, et al., 2014). Given that enthesitis is a hallmark feature of PsA, the inadequate representation of the enthesis and tendon by the body structure ICF categories for the foot and ankle significantly reduces specificity in describing localised involvement. Difficulties with linking psychological concepts reflect deficiencies in the ICF and is a major limitation in defining foot disease burden. Gaps and limitations in the linking process should be taken into account in order to accurately reflect functioning with full conceptual coverage.

Interdisciplinary group analysis demonstrated merit as differences between the predominantly biomedical approach by podiatry and biopsychosocial approach by occupational therapy in clinical practice led to additional ICF categories being identified between the health professionals, which mostly related to cognitive functions. The ICF framework adheres to the biopsychosocial model of disease and recognises that function and health result from a complex interplay of the health components (Boonen, et al., 2009b). Occupational therapists have been identified to provide additional valuable perspectives that enhance the application of the ICF as a common framework, which is due to the strong conceptual connections between the ICF and occupational therapy models (Stamm, et al., 2006).

Despite the lack of evidence on the efficacy of multidisciplinary involvement in the management of people with PsA, this approach has been advocated in published expert reviews (Taylor, 2012; Coates and Helliwell, 2017; Patience, et al., 2018). Whilst it may be considered that occupational therapists do not have a strong traditional role in managing the foot in PsA, findings of this study highlight that perspectives from different health professions provides a necessary holistic view on foot functional impairment and its impact that may optimise patient outcomes.

Limitations of this study include lack of generalisability with a sample comprising participants from Australia and New Zealand. Participants in other settings and countries may experience problems with a different frequency or focus. Cross-cultural differences relating to environmental and personal factors may be revealed in other countries. Robust methods to ensure the quality of the linking process were employed in this study including the use of reliability checks, an iterative consensus-based process and multiple raters from different professional backgrounds. However, it remains unclear whether other health professionals would have applied the linking rules differently and decided on different categories, as previously identified (Coenen, et al., 2006). Lastly, this study did not report systematically problems of comorbidity and it is difficult to determine their relative contribution to problems in function. Therefore, findings from this study may be subject to bias as confounding variables were not adjusted for. However, comorbidities in PsA are common and eliminating the impact of co-morbidities comes at the expense of external validity and loss of generalisability in a real-world context.

Future work will be to use the results of this study and the ICF as a common framework to assess the extent to which existing instruments adequately cover foot-specific concepts in PsA. This definitive list of ICF categories may also be used as a starting point for new instrument development to assess foot-specific functioning for research and in clinical practice, and it provides the opportunity to compare foot-related functioning across other rheumatic diseases (Stamm, et al., 2007b; Boonen, et al., 2009a). A comprehensive understanding of foot functional impairments, limitations in activities and restriction in societal participation may provide the foundation for the development of targeted assessment and intervention strategies that are mapped to key ICF domains.

5.7 Conclusion

Despite the localised anatomical focus of this study, the effect of foot problems in PsA was linked to all components of the ICF, confirming the profound impact on functioning and daily life. These findings offer new knowledge using the perspectives of patients and health professionals that could inform the development of an instrument to measure the impact of foot involvement in PsA.

5.8 Significance and Innovations

- This study comprehensively describes the functioning of people with PsA-related foot involvement and explicitly identifies activities and participation impacted by the condition.

- The list of ICF categories generated in this study will provide a useful reference to identify what should be included when future foot-specific PsA outcome tools are developed.

- In clinical practice, the management of foot problems related to PsA should take into account the patient perspective on the impact of local disease in the foot on daily life.

- The inclusion of different health disciplines improved the categorisation process of the patient experience, highlighting the importance of a multidisciplinary team approach to PsA in future studies.

Chapter 6

6 Survey Development and Pre-Testing

This chapter describes the methods and study design for the survey development and implementation process. A multi-stage survey development protocol is presented including extensive survey pre-testing, a targeted survey dissemination strategy and a summary of the methods for survey data analysis. Study methods are described systematically in phases in order to show how each stage was deliberately designed to inform the next stage.

With limited large-scale data to date that comprehensively defines the nature, extent and impact of foot involvement in a PsA-specific population, the scale of the problem remains unclear. Survey research provided the ideal opportunity to sample a large population over a wide geographical area in Australia and New Zealand. In the absence of established empirical evidence on survey design and conduct, best practice methods in survey research were used in the current study.

Study 1) Development of a national survey on foot involvement among people with psoriatic arthritis in Australia and New Zealand using a best practice approach: A survey development protocol.
The study objective was to develop a national survey about foot involvement in people with PsA based on the views of patients and health professionals and in accordance with best practice standards for survey design, conduct and reporting.

This manuscript has been submitted for publication in the Journal of Foot and Ankle Research and the authors include Carter K, Walmsley S, Rome K and Turner DE.

This research was presented at the European League Against Rheumatism (EULAR) conference, Madrid, Spain, in June 2019 (Conference abstract and poster in Appendix 4: Patient and clinician perspectives used for survey development to investigate the nature, extent and impact of foot problems in people with psoriatic arthritis).

Development of a national survey on foot involvement among people with psoriatic arthritis in Australia and New Zealand using a best practice approach: A survey development protocol

6.1 Abstract

Background Limited research to date has defined the nature and extent of foot involvement in a psoriatic arthritis-specific population in Australia and New Zealand and the scale of the problem remains unclear. Survey research provides the ideal opportunity to sample a large population over a wide geographical area. Although quality criteria for survey research have been developed, research shows that adherence is low and that survey studies are poorly reported in peer-reviewed survey articles, which limits the ability to inform future survey design. The objective of this study was to develop a national survey about foot involvement in people with psoriatic arthritis using a best practice approach and based on the views of patients and health professionals.

Methods A systematic, multi-stage process of survey development was undertaken, which comprised 3 phases: 1) the generation of the conceptual framework and survey content; 2) the development of the survey and pre-testing and 3) development of the survey dissemination strategy. A survey best practice approach was adopted using iterative pre-testing techniques, which included; cognitive debriefing, cultural sensitivity review, survey design expert validation, subject expert validation and pilot testing. Targeted postal and online survey dissemination strategies were developed *a priori* to optimise the response rates anticipated. In the absence of known prevalence estimates of PsA in Australia and New Zealand, the target population was 6000 people with PsA based on estimates provided from the major sites for survey dissemination.

Results A 59-item survey with 8 sections was developed. Findings demonstrated a high survey response (n=649), high data completeness (83% of respondents reached the end of the survey) and low rates of missing data (below 5% for 95% of respondents). Extensive survey pre-testing among the target population, health professionals and experts improved the overall quality, content validity, functioning and representativeness of the survey instrument, which optimised potential response rates. Clear audit trails that mapped the analytical process at each stage substantiated the rigour of the survey development methods. Robust strategies for sampling, survey dissemination and community engagement were deemed to have made a powerful contribution to response rates and the scale of information collected.

Conclusions Robust patient-centred methods in survey design were used to create a novel, high-quality survey to comprehensively evaluate psoriatic arthritis-related foot involvement. Transparent and precise description of the survey design and dissemination methods provides useful information to other researchers embarking on survey design in healthcare.

Keywords Psoriatic arthritis, foot, survey research, survey protocol, patient-reported outcome

6.2 Introduction

Psoriatic arthritis (PsA) is well recognised as a distinct clinical entity with a high disease burden (Husted, et al., 2001; Helliwell and Taylor, 2005; Strand, et al., 2012; Kavanaugh, et al., 2016). Typically affecting people between 30 and 50 years old (Duarte, et al., 2012), PsA is associated with high economic and societal costs with over 25% of those at working age unemployed (Tillett, et al., 2012; Tillett, et al., 2015b). For a large proportion of people with PsA, localised disease in the foot is their single most prevalent health complaint (Nordbø, et al., 2017), which can have a profound impact on functioning and daily life (Carter, et al., 2019a). Current knowledge of foot involvement in PsA is based on a few European studies, with limited incorporation of the patient perspective (Hyslop, et al., 2010a; Woodburn, et al., 2013; Turner, et al., 2014; Wilkins, et al., 2016). Despite recognition that hallmark disease features are predominant in the foot and ankle (Galluzzo, et al., 2000; Healy, et al., 2008; Hyslop, et al., 2010a; Delle Sedie, et al., 2011), foot involvement in PsA remains under-researched and poorly understood with a lack of large-scale data to provide the basis for targeted disease-specific assessments and interventions.

Survey research provides the opportunity to sample a large population over a wide geographical area and to measure a broad range of constructs with sufficient granularity (Aday and Cornelius, 2006; Johnson, 2015). However, patient surveys have often been criticised for the lack of conceptual and methodological rigor (Bennett, et al., 2011). Poorly designed surveys and inadequate reporting can lead to inappropriate application of research findings in decision-making, healthcare, health policy and future research (Tong, et al., 2007; Bennett, et al., 2011; Turk, et al., 2018). To overcome this, quality checklists and reporting guidelines have been developed in order to promote complete and transparent reporting among researchers and to indirectly improve the comprehensiveness and credibility of survey studies (Kelley, et al., 2003; Eysenbach, 2004; Burns, et al., 2008; Draugalis, et al., 2008; Grimshaw, 2014). The checklists include the SUrvey Reporting GuidelinE (SURGE) for paper-based surveys (Grimshaw, 2014) and the CHEcklist for Reporting Results of Internet E-Surveys (CHERRIES) for web-based surveys (Eysenbach, 2004). Despite the development of guidance for reporting of surveys nearly a decade ago, previous reviews of published survey research have found that key quality criteria relating to design, conduct and results were under-reported in the majority of studies (Bennett, et al., 2011; Turk, et al., 2018). Omitting important information, such as the development of the survey, participant recruitment, survey administration, data management and ethical considerations, can compromise the transparency and reproducibility of survey research (Turk, et al., 2018). Although best practice guidelines for paper-based (Kelley, et al., 2003; Burns, et al., 2008; Draugalis, et al., 2008; Grimshaw, 2014) and web-based survey research exist (Eysenbach, 2004), there is limited empirical evidence for optimal survey design (Reynolds, et al., 1993; Edwards, 2010). Furthermore, there is no global consensus on the optimal conduct and reporting of surveys, and few medical journals provide guidance to authors regarding the reporting of survey-based studies (Bennett, et al., 2011). It is well established that the methods used in conducting health surveys can significantly affect the reliability, validity and generalisability of study findings (McColl, et al., 2001; Edwards, 2010) and that concordance with guidelines improves the quality of reporting research (Plint, et al., 2006; Smidt, et al., 2006; Nicholls, et al., 2016). However, with major discrepancies in survey reporting identified (Turk, et al., 2018), there are few high-quality worked examples of survey design and conduct to help researchers implement robust reporting practices. Therefore, the objective of this study was to develop a national survey about foot involvement in people with PsA living in Australia and New Zealand, using a best practice approach and based on the views of patients and health professionals. In the absence of established empirical evidence on survey design, the current study methods were developed in accordance with best practice standards for the development of self-administered surveys (Gehlbach, et al., 2010; Artino Jr, et al., 2014) and the subsequent description of survey conduct adhered to good reporting practices (Eysenbach, 2004; Grimshaw, 2014; Turk, et al., 2018).

6.3 Methods

A cross-sectional observational study design was used to develop a self-administered paper-based and web-based survey. Prevalence of PsA in Australia and New Zealand have not yet been established by epidemiological studies. Using worldwide prevalence estimates of PsA (Gelfand, et al., 2005; Gladman, et al., 2005; Prey, et al., 2010; Haroon, et al., 2013a; Löfvendahl, et al., 2014), it can be extrapolated that in Australia there could be approximately 40,000 to 80,000 people with PsA in the general population and in New Zealand about 7600 and 16,700 people with PsA (target population calculations are provided in Appendix 5). High variability in worldwide estimates of PsA prevalence have been due to historical differences in classification criteria applied (McHugh, 2015; Ogdie and Weiss, 2015). Therefore, with PsA prevalence in Australia and New Zealand unknown *a priori* and in the absence of national databases to determine the potential target population and estimate response rates, the study approach was to identify target estimates from the major sites for dissemination in order to establish the potential reach of survey to people with PsA.

A systematic, multi-stage process of survey development was undertaken (Figure 6.1), which comprised 3 phases: 1) the generation of the conceptual framework and survey content; 2) the development of the survey and pre-testing and 3) development of the survey dissemination strategy. Phase 1 provided the theoretical underpinning of the survey items by clearly defining and conceptualising the important and relevant constructs to be assessed. Phase 2 used recognised qualitative survey development methods for pre-testing and piloting the draft survey, which resulted in 7 iterative revisions that corrected for key features including; wording clarity, instruction comprehension, item interpretation, navigation, timescales (recall), repetition, redundancy, response options, emotiveness, overall design and responder burden (number of items, time to complete). Phase 3 encompassed the sampling strategy to identify the major sites for dissemination in order to determine the response rate relative to the populations that were targeted. The order and timing of the pre-test and pilot studies were intentionally organised to allow for analysis and revision of survey items between stages and prior to full-scale survey dissemination. The survey was developed over 18 months (phases 1 and 2 between October 2017 and April 2019) and was disseminated and open for 6 months (phase 3 between July and December 2019).

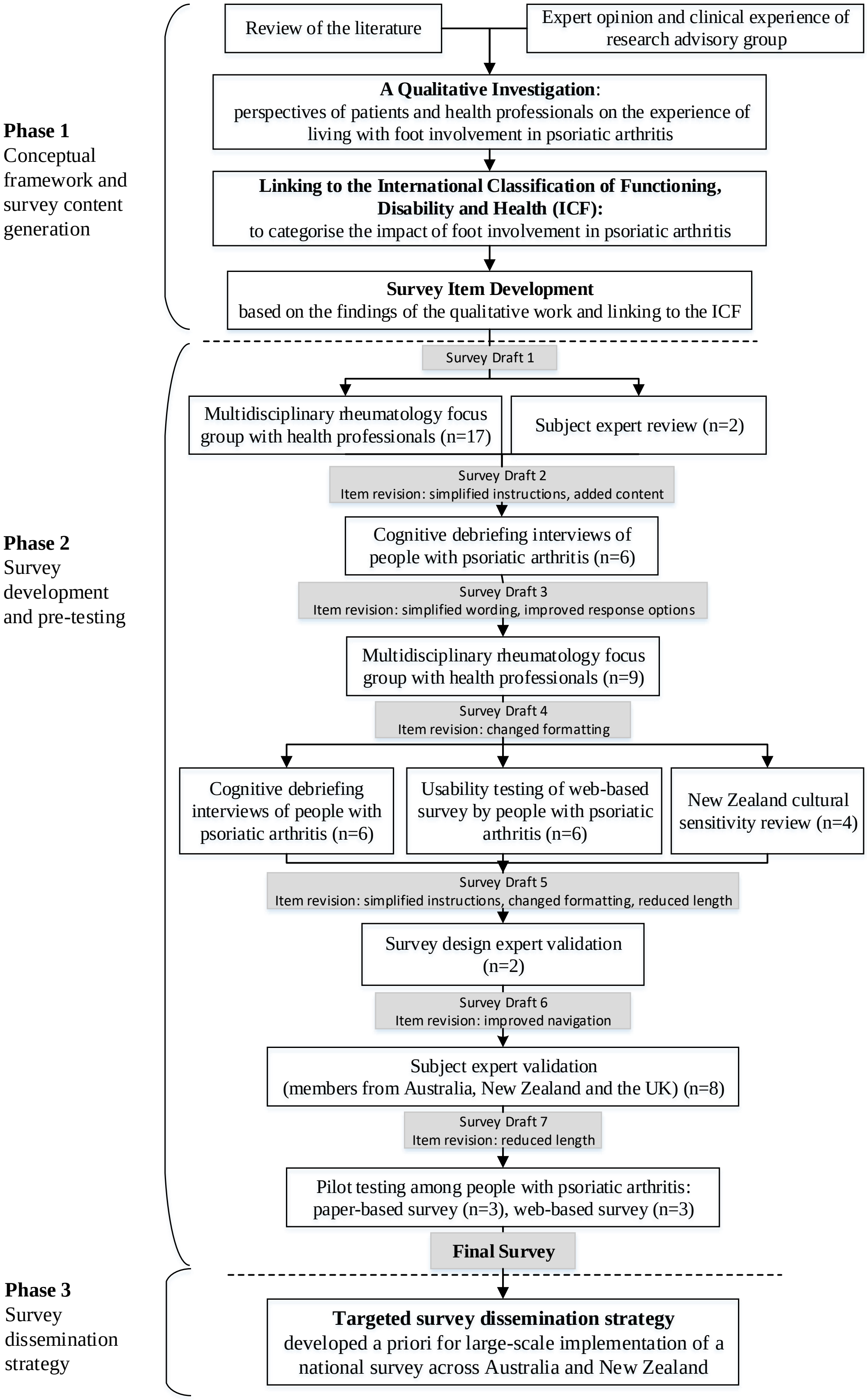


Figure 6.1. Survey development process.

ICF International Classification of Functioning, Disability and Health.

People with PsA and rheumatology health professionals involved in phases 1 and 2 were recruited using a convenient sampling technique with attention to ensuring diversity across health sectors and regions. A total of six sites across Australia and New Zealand were included, comprising three rheumatology public hospital outpatient departments, two university-based podiatry departments and a multidisciplinary rheumatology private practice with ethical approval granted for each participating site (Appendix 1 and 2). Written informed consent was provided by all participants prior to data collection.

Demographic and clinical information were collected from people with PsA for the purpose of describing the sample and have been previously reported for Phase 1 (presented in Chapter 4) and are represented in Table 6.1 for Phase 2. Key demographic and practice details were collected for the health professionals (Table 6.2). All qualitative data collection in phase 1 and 2, including the focus groups, interviews and reviews, were conducted by the principal investigator (KC) and supported by a second investigator (SW). Both investigators had experience of qualitative research methods and 15 years of clinical podiatry experience. Results were refined by discussion between the investigators (KC, SW and DET).

Table 6.1. Demographic and clinical characteristics of participants with psoriatic arthritis.

	Round 1	**Round 2**		**Round 3**	
Variables	Cognitive interviews (n=6) Paper-based	Cognitive interviews (n=6) Paper-based	Cognitive interviews (n=6) Web-based	Pilot testing (n=3) Paper-based	Pilot testing (n=3) Web-based
Ages, years	45 (15)	48 (12)	56 (14)	48 (9)	58 (12)
Women, n (%)	5 (83%)	2 (33%)	2 (33%)	2 (67%)	2 (67%)
Ethnicity, n (%)					
Australian European	6 (100%)	5 (83%)	3 (50%)	1 (34%)	1 (34%)
New Zealand European			1 (17%)		
Indian		1 (17%)	1 (17%)		
South American			1 (16%)	1 (33%)	
British				1 (33%)	1 (33%)
Bosnian					1 (33%)
Body Mass Index, Kg/m^2	34 (12)	29 (6)	30 (8)	35 (11)	26 (2)
Marital status, n (%)					
Single	1 (17%)	2 (33%)		1 (33%)	
Married	4 (66%)	4 (67%)	6 (100%)	2 (67%)	3 (100%)
Widower	1 (17%)				
Employment status, n (%)					
Employed full-time	3 (50%)	3 (50%)	3 (50%)	1 (34%)	1 (34%)

Employed part-time	1 (17%)				1 (33%)
Self-employed	1 (17%)		1 (17%)		
Unemployed (health reason)		1 (17%)	1 (17%)	1 (33%)	
Unemployed (other: student, home-maker)		1 (17%)			
Retired	1 (16%)	1 (16%)	1 (16%)	1 (33%)	1 (33%)
Education level, n (%)					
No school certificate	1 (17%)	1 (17%)		1 (34%)	1 (33%)
School certificate	1 (17%)			1 (33%)	
Higher school certificate		2 (33%)	1 (17%)		
Trade/apprenticeship		1 (17%)	3 (50%)		
Diploma	2 (33%)				
University degree or higher	2 (33%)	2 (33%)	2 (33%)	1 (33%)	2 (67%)
Disease type, n (%)					
Psoriatic arthritis with skin psoriasis	4 (67%)	6 (100%)	6 (100%)	2 (67%)	3 (100%)
Psoriatic arthritis without skin psoriasis	2 (33%)			1 (33%)	
Disease duration, years	15 (12)	15 (9)	5 (4)	14 (10)	3 (2)
Comorbidities, n (%)					
Cardiovascular conditions	3 (50%)				
Musculoskeletal conditions		1 (17%)	2 (33%)		2 (67%)
Depression	1 (17%)			1 (33%)	
Diabetes Mellitus		1 (17%)	2 (33%)	2 (67%)	
Cancer	1 (17%)	1 (17%)			
Inflammatory conditions (Crohn's, fibromyalgia)	2 (33%)	1 (17%)	1 (17%)		
Patient global assessment joint and skin (VAS 0-100), mm	74 (15)	37 (37)	40 (24)	40 (38)	50 (26)
Patient global assessment skin (VAS 0-100), mm	36 (37)	28 (29)	25 (19)	7 (6)	37 (40)
Patient global assessment joint (VAS 0-100), mm	66 (25)	37 (35)	47 (16)	40 (36)	50 (26)
Global pain (VAS 0-100), mm	69 (21)	37 (36)	53 (21)	40 (26)	47 (38)
Foot pain (VAS 0-100), mm	73 (22)	37 (37)	38 (43)	33 (6)	60 (26)
Hospital Anxiety and Depression Scale			*[2]	*[2]	*[2]
Normal (0-7)	1 (17%)	2 (34%)			
Borderline abnormal (8-10)	2 (33%)	2 (33%)			
Abnormal (11-21)	3 (50%)	2 (33%)			
Length of interview, minutes	63 (21)	60 (23)	6 (3)	*[3]	*[3]
Time to complete survey	*[1]	*[1]	29 (6)	26 (6)	22 (4)

Data presented as mean (SD) unless specified. *VAS* Visual analogue scale.

*[1] Participants were interviewed about the survey to obtain their views but did not complete it.

*[2] Not recorded for miscellaneous reasons; for example, to reduce participant burden.

*[3] Following survey completion, participants were asked if they had experienced any difficulties. There was no audio-recorded interview.

Table 6.2. Demographic characteristics of the health professionals with experience of managing people with psoriatic arthritis and subject experts.

Variables	**Round 1**		**Round 2**	**Round 3**	**Round 4**	**Round 5**
	Multidisciplinary rheumatology review (n=17)	Subject expert review (=2)	Health professional focus group review (n=9)	Cultural sensitivity review (n=4)	Survey expert review (n=2)	Subject expert review (n=8)
Women, n (%)	11 (65%)	2 (100%)	4 (44%)	3 (75%)	1 (50%)	3 (38%)
Geographic location, n (%)						
New South Wales, Australia	10 (59%)	2 (100%)	9 (100%)		1 (50%	3 (38%)
Queensland, Australia	3 (18%)					
South Australia, Australia	3 (18%)					
Northern Territory, Australia	1 (5%)					
Auckland, New Zealand				4 (100%)		1 (12%)
United Kingdom					1 (50%)	4 (50%)
Occupation, n (%)						
Rheumatologist	4 (24%)	1 (50%)	1 (11%)			3 (38%)
Podiatrist		1 (50%)	8 (89%)	3 (75%)		5 (62%)
Physiotherapist	4 (24%)					
Exercise physiologist	1 (6%)					
Nurse	6 (35%)					
Clinical researcher	1 (6%)					
Pharmacist	1 (5%)					
Maori research advisor				1 (25%)		
Survey & outcome measure specialty					2 (100%)	
Clinical experience, years	13 (13)	13.5 (9)	12 (10)	11 (10)	8 (1) *^{2}	15 (13)
Estimated experience in managing PsA, years						
0-5	9 (53%)		4 (44%)	1 (25%)		3 (38%)
6-10	6 (35%)	1 (50%)	1 (11%)	1 (25%)	2 (100%)*^{2}	1 (12%)
11-15	1 (6%)	1 (50%)	1 (11%)	1 (25%)		
16-20			1 (11%)			2 (25%)
>20	1 (6%)		2 (12%)	1 (25%)		2 (25%)

Qualifications, n (%)						
Bachelor of Medicine and Surgery (MBBS)	4 (24%)	1 (50%)	1 (11%)			3 (38%)
Fellow of the Royal Australasian College of Physicians (FRACP) or Fellow of the Royal College of Physicians (FRCP)	4 (24%)	1 (50%)	1 (11%)			3 (38%)
Bachelor of Science (BSc)	10 (59%)	1 (50%)	8 (89%)	4 (100%)	2 (100%)	6 (75%)
Master of Science (MSc)	1 (6%)		4 (44%)	1 (25%)	1 (50%)	4 50%)
Doctor of Philosophy (PhD)		2 (100%)	1 (11%)	2 (50%)	1 (50%)	7 (88%)
Health sector, n (%)				*[1]	*[3]	
Public sector	9 (53%)		5 (56%)			6 (75%)
Private sector	5 (29%)					
Mixed	3 (18%)	2 (100%)	4 (44%)			2 (25%)
Length of interview, minutes	53	45	57	66	*[4]	97

Data presented as mean (SD) unless specified. *PsA* Psoriatic arthritis.

*[1] Health professionals of the cultural sensitivity review were academic staff at Auckland University of Technology and not currently practicing in the health sector.

*[2] Not relating to clinical experience but to experience of survey development, evaluation and implementation.

*[3] The survey experts were not practicing in the health sector.

*[4] Written feedback was provided. There was no audio-recorded interview.

6.3.1 PHASE 1: Generation of the Conceptual Framework and Survey Content

Conceptual frameworks are developed to provide the theoretical underpinning for identifying what should be included when measurement tools are developed (Alam, et al., 2020). Qualitative methods provide the opportunity to explore the patient and health professional perspective in order to identify relevant and important concepts. In the current study, these perspectives informed the conceptual framework for defining ‘what should be measured’ to represent comprehensively the experience of people with PsA-related foot problems and important domains of impact. Qualitative research typically uses small sample sizes with a diverse range of participants in order to obtain the required level of rich and meaningful data (Ritchie, et al., 2009), whilst following strategies of saturation during data analysis (Francis, et al., 2010).

6.3.1.1 (1) Qualitative investigation of the patient experience of PsA-related foot involvement

A review of the literature was undertaken to develop the interview guides for the qualitative study, which related to 1) PsA-specific foot involvement (Hyslop, et al., 2010a; Woodburn, et al., 2013; Turner, et al., 2014; Wilkins, et al., 2016; Patience, et al., 2018), 2) foot problems in other rheumatic diseases to identify relevant foot-specific concepts (Helliwell, et al., 2005a; Otter, et al., 2010; Brenton-Rule, et al., 2014; Otter, et al., 2016; Williams, et al., 2017; Wilson, et al., 2017b), and 3) the PsA core set and outcome measures to identify key domains of impact for inclusion (Mease, 2011; Her and Kavanaugh, 2014; Orbai, et al., 2017b). The Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA) and Outcome Measures in Rheumatology (OMERACT) groups used qualitative research methods and an international theoretical framework to develop the core domains and outcome sets in order to integrate all perspectives into the effective and comprehensive assessment of PsA (Stucki, et al., 2007; Keeley, et al., 2016). Establishing foot-specific impact domains by similar methods to inform the development of a survey to assess the impact of localised disease, represents the work supported by the GRAPPA-OMERACT. The interview guides were reviewed for relevance and coverage by the research team and designed to cover priority areas of interest, which included (1) foot involvement in PsA, (2) its impact on daily life, (3) experiences with footwear and (4) foot care needs.

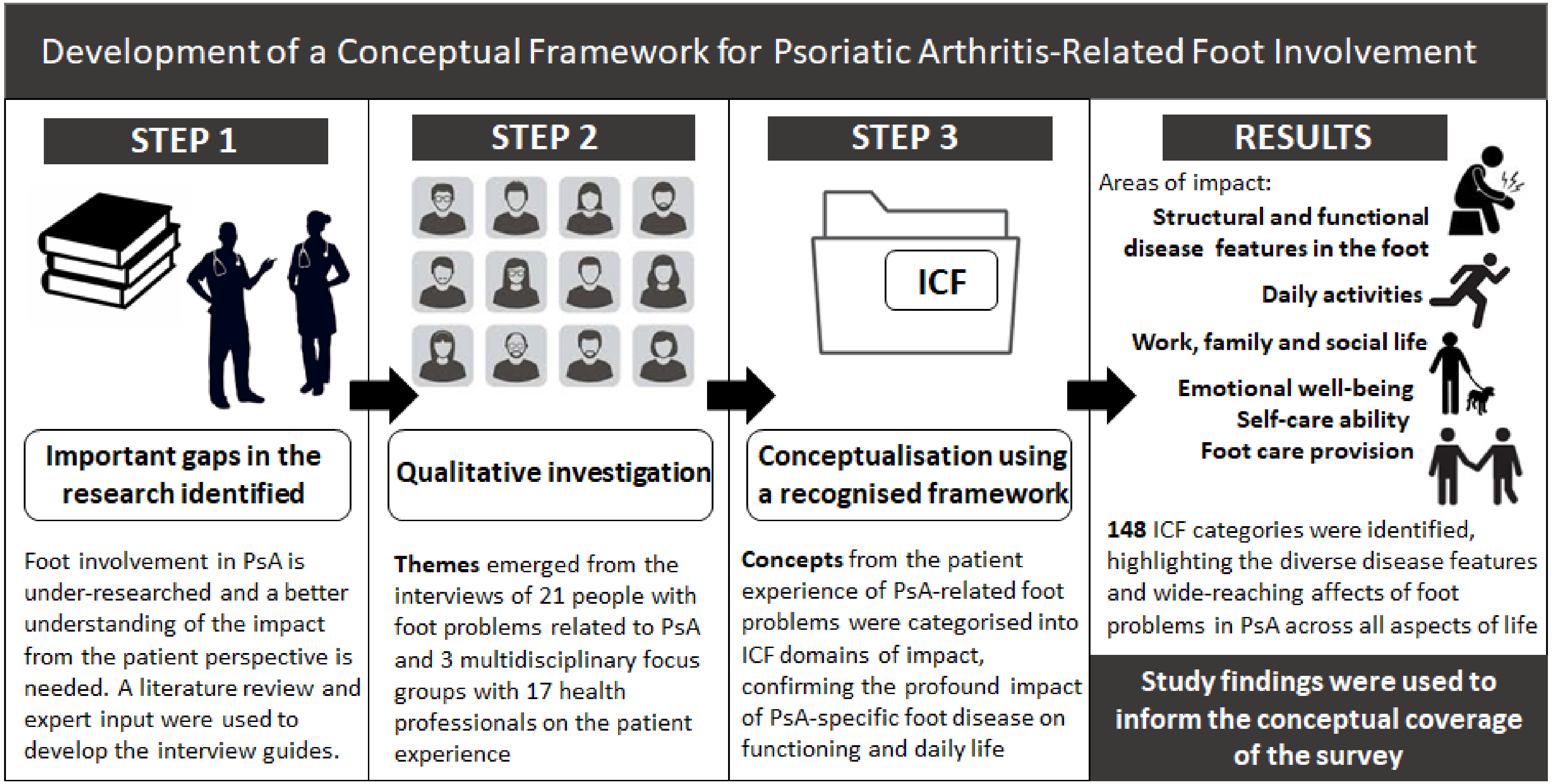
In the current study people with PsA-related foot problems (n=21) were asked questions in semi-structured, one-to-one interviews about their foot problems and the impact they have on daily life. A representative sample was sought from public and private sector, and from lower and higher socioeconomic geographical areas in Sydney, Australia (n=18) and Auckland, New Zealand (n=3). Three multidisciplinary focus groups were undertaken with health professionals on their understanding of the patient experience (n=17); two in Sydney, Australia (n=12) and one in Auckland, New Zealand (n=5). Health professionals working in rheumatology teams with different professional backgrounds were invited.

A diverse range of participants were sought by recruiting from participating sites in different health sectors and regions, and a convenience sampling strategy was used to recruit people with PsA and health professionals from the different rheumatology outpatient clinics. Recruitment to the study continued until no new relevant knowledge was being generated and qualitative data saturation of emerging concepts was achieved (Popay, et al., 1998; Francis, et al., 2010). All focus groups and interviews were audio-recorded and transcribed verbatim. Qualitative data analysis utilised the constant comparative method (Morehouse and Maykut, 1994). Themes and sub-themes were developed by discussion between KC and SW. The research team reviewed and agreed the final themes. Standards for reporting qualitative research were adhered to (O’Brien, et al., 2014), ensuring complete and transparent description of the study findings in subsequent publications (Carter, et al., 2019a; Carter, et al., 2019b).

6.3.1.2 (2) Linking the patient experience of PsA-related foot involvement to the International Classification for Functioning, Disability and Health

In order to gain a better understanding of the extent and coverage of themes identified by the qualitative work, concepts derived were linked to the World Health Organisation’s International Classification for Functioning, Disability and Health (ICF) in order to use common terminology to describe the impact of localised disease in the foot on functioning (WHO, 2001). A detailed description of the qualitative investigation and linking to the ICF in phase 1 can be found in previous studies (Carter, et al., 2019a; Carter, et al., 2019b; Carter, et al., 2020) (presented in Chapter 4 and 5). The ICF can be used as a conceptual platform to specify aspects of functioning, limitations in activities and restrictions to societal participation, whilst recognising the influence of contextual environmental factors that may act as barriers or facilitators to health and disability (WHO, 2001). A comprehensive conceptual framework was developed based on the findings from the qualitative work mapped to the ICF (Figure 6.2), which clearly defined the domains of impact to be considered in the measurement of the patient experience of localised disease impact in PsA. The qualitative exploration was a required step to better understand the patient experience. Indeed, important discrepancies between the health professionals and patient views were identified (Carter, et al., 2019a), which supports the need to define the construct from multiple perspectives. The conceptual framework provided support of content validity and served as the foundation for the subsequent stages of survey development (Figure 6.3).

Content validity is the degree to which the content of the instrument is an adequate reflection of the construct to be measured and face validity is the degree to which it looks as though it does (Mokkink, et al., 2010a). The content validity of an instrument has been asserted by an international working group in outcome measurement instruments as the most important of all the required measurement properties (Mokkink, et al., 2016). Importantly, validity and reliability are not properties of the survey instrument per se, but of the survey's development (AERA, et al., 1999). The process of validation involves the accumulation of evidence during the survey development process to build a scientifically sound and relevant measurement tool (Artino Jr, et al., 2014). Therefore, it is extremely important to include the patient perspective in survey development as personal views on outcomes vary between and among patients and health professionals. Qualitative research in the exploration and development phase of survey development allows these perspectives to be identified, clarified and included in the assessment of the disease.



Foot involvement in PsA is under-researched and a better understanding of the impact from the patient perspective is needed. A literature review and expert input were used to develop the interview guides.

Themes emerged from the interviews of 21 people with foot problems related to PsA and 3 multidisciplinary focus groups with 17 health professionals on the patient experience

Concepts from the patient experience of PsA-related foot problems were categorised into ICF domains of impact, confirming the profound impact of PsA-specific foot disease on functioning and daily life

148 ICF categories were identified, highlighting the diverse disease features and wide-reaching affects of foot problems in PsA across all aspects of life

Study findings were used to inform the conceptual coverage of the survey

Figure 6.2. Development of a conceptual framework for psoriatic arthritis-related foot involvement.

(Adapted from Alam, et al., 2020). *PsA* Psoriatic arthritis, *ICF* International Classification of Functioning, Disability and Health.

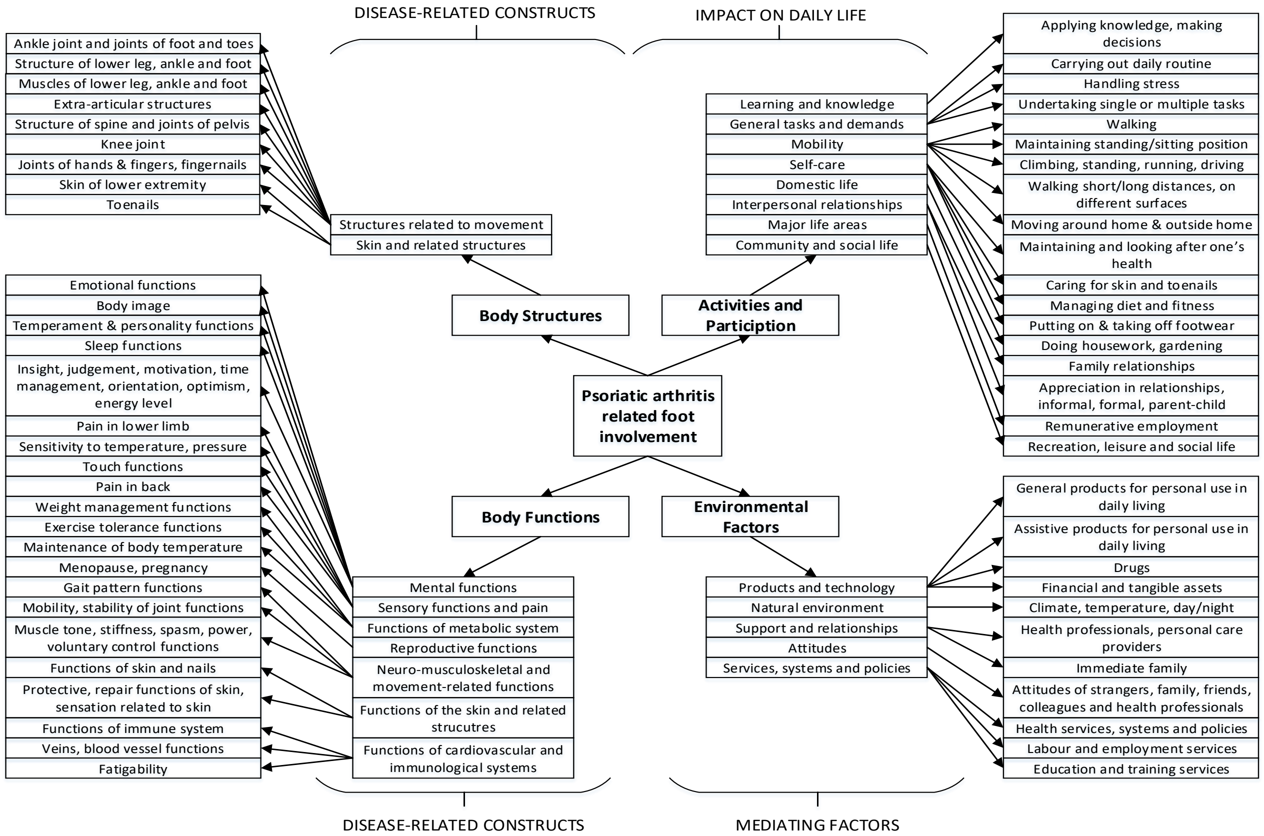


Figure 6.3. The conceptual framework of psoriatic arthritis-related foot involvement using qualitative themes and the International Classification of Functioning, Disability and Health framework.

The structure of the International Classification of Functioning, Disability and Health is divided into four main components; Body Structures, Body Functions, Activities and Participation, and Environmental Factors, which divide into chapters and then categories. The three overarching themes that emerged from the qualitative investigation are indicated in italics; 1) the disease manifestations in the feet and ankles (*disease-related constructs*), 2) foot functional impairments and visual differences that impacted on daily activities, work productivity, social and family life (*impact on daily life*), and 3) mediating factors (coping strategies, self-care ability, footwear, social support, access to healthcare, climate) that influenced the severity of impact from foot involvement on daily life (*mediating factors*).

6.3.1.3 (3) Survey item development

Use or adaptation of existing tools is often supported with the benefit that results may be comparable, whilst conserving limited healthcare resources required to develop a new tool (Boynton and Greenhalgh, 2004; Edwards, 2010; Artino Jr, et al., 2014). However, no previously validated outcome measures or surveys to assess PsA-specific foot involvement existed, which established the need to develop a new tool based on a PsA- and foot- specific conceptual framework.

Key themes from the qualitative investigation, relevant impact domains from the ICF mapping, previous PsA- and foot- specific research, and clinical experience were used to inform the conceptual coverage of the survey and to generate survey items. A review of existing outcome measures and surveys was undertaken and, where possible, a number of survey items were derived from established tools and adapted to meet the needs of the current study (including Australian-based health surveys (Up Study Collaborators, 2007), generic and disease-specific foot health questionnaires (Budiman-Mak, et al., 1991; Bennett, et al., 1998; Garrow, et al., 2000; Robinson, et al., 2001; Helliwell, et al., 2005b; Barton, et al., 2009; Otter, et al., 2010; Roddy, et al., 2011; Walmsley, et al., 2013; Otter, et al., 2016), PsA-specific quality of life instruments (Finlay and Khan, 1994; McKenna, et al., 2004; Gossec, et al., 2014), survey (Lebwohl, et al., 2014) and patient global assessment (Mease, 2011)). For example, categories of local ethnic groups, employment status, education level and physical fitness were adapted from The 45 and Up Study Questionnaire, a Government endorsed survey known to perform well in an Australian population (Up Study Collaborators, 2007). The search was conducted using PubMed, EMBASE and CINAHL electronic databases and using search terms that combine the disease and construct of interest, with useful articles identified using a common sense approach.

The qualitative study identified that whilst priorities for health professionals included the diverse expression of disease and determining the nature of foot symptoms as mechanical or inflammatory, a key theme from patients was the psychological impact of foot involvement on daily life coupled with self-management strategies (coping skills, self-care activities and social support), which was poorly recognised by the health professionals (Carter, et al., 2019a). Consequently, nearly a quarter of survey content was dedicated to those areas of impact highlighted by patients (23%).

Survey items were generated by the research advisory group using a consensus based approach, and were organised into sections measuring defined constructs. The advisory group comprised the principal investigator (KC), two subject experts (DET, DC), an experienced qualitative researcher and measurement expert (SW), an experienced researcher in podiatry rheumatology (KR), and two consultant rheumatologists (GH, MO). The purpose of the research advisory group was to assist with study progress and support the review of the pre-testing results. Consolidation of data provided a comprehensive list of survey items, reflecting how foot problems were understood and described by people with PsA using their terminology. Current best practices in survey design provided guidance on writing items, response anchors, response options, survey scales and visual design (Fowler Jr FJ and C, 2009; Artino Jr, et al., 2011; Artino Jr and Gehlbach, 2012; McCoach, et al., 2013; Dillman, et al., 2014; DeVellis, 2016). To completely and precisely assess the extent of foot involvement and its impact, survey scales were designed in order to capture frequency, severity, satisfaction, effort and level of importance. All draft survey items were included for subsequent pre-testing (n=60) to determine if items remained necessary for inclusion.

6.3.2 PHASE 2: Survey Development and Pre-testing

Pre-testing is the critical examination of the survey to determine if it will function properly as a valid and reliable research tool (Bolton, 1991; Reynolds, et al., 1993). Despite its recognised importance (Reynolds, et al., 1993), it is the stage of survey research most often restricted due to cost or time pressures (Hunt, et al., 1982). Commonly used pre-testing techniques include focus groups, cognitive debriefing, expert validation and pilot testing. Focus groups use professionals to ensure survey items capture key priorities related to the construct. In-depth cognitive debriefing interviews among the target population provide insights into how participants comprehend questions, process and recall information and decide what answers to give (Willis, 1999). Expert validation uses content experts to systematically review the survey in order to establish that each item is relevant to the construct being measured and that key items have not been omitted (Polit and Beck, 2004; Polit and Beck, 2006; Waltz, et al., 2010). Pilot testing is a ‘dry run’ of the entire survey administration; the target population completes the survey in the planned delivery mode, final versions to the survey process are made and ready for full-scale administration (Ruel, et al., 2016).

Pre-testing enables researchers to refine survey design, identify and correct errors, reduce respondent burden and determine if survey items are relevant, clearly articulated and interpreted correctly by respondents. It is an iterative process, with further pre-testing required to ensure that the changes made were desirable and that no new problems had been introduced. Sample sizes for pre-testing are typically small ranging from 5-10, but should try to cover the variety of respondents from the target population and relevant professionals (Reynolds, et al., 1993). Although there is limited empirical evidence to guide the number and type of pre-testing techniques required, there are recognised best practice methods based on expert opinion (Reynolds, et al., 1993). Researchers often use a combination of methods, as critical appraisal from multiple perspectives increases the likelihood of success for the final survey (Artino Jr, et al., 2014; Ruel, et al., 2016). Qualitative feedback from pre-testing sessions was used to make inclusion, exclusion and revision decisions for individual items, with data tabulated and examined for patterns in responses to each question (Grimm, 2010). Pre-testing is the process of collecting validity evidence to support the content validity of the final survey (Polit and Beck, 2006; Artino Jr, et al., 2014). The scope of pre-testing should include a wide range of survey features such as the appearance, layout, typeface, skip patterns and flow (Table 6.3).

In the current study, involvement of patients, health professionals and experts throughout survey development was a central component of the protocol design, which comprised 6 pre-testing techniques;

(1) focus groups with health professionals in rheumatology,
(2) cognitive debriefing interviews of people with PsA,
(3) cultural sensitivity review with New Zealand-based health professionals,
(4) survey design expert validation,
(5) content expert validation, and
(6) pilot testing among people with PsA.

A clear audit trail of survey revisions and refinements were recorded in order to ensure the comprehensive integration of responses from pre-testing sources and document the refinement of the survey (Appendix 7). The extent of survey item revision reduces in number and complexity with each subsequent stage of pre-testing.

Table 6.3. Definitions of the categories used to assign responses from the cognitive debriefing interviews, focus groups and expert reviews in order to organise decisions for survey item revision.

Categories	Description	Example(s)
Poor wording	Word changed or spelling error	Do you see any errors in wording? For example, ‘crocked’ changed to ‘crooked’, ‘ethic group’ changed to ‘ethnic group’, remove the word ‘hobble’
Comprehension and interpretation	Ability to understand the question, to accurately interpret its meaning and to follow the item instructions	What does ‘anxiety’ and ‘depression’ mean to you? Can you tell me, in your own words, what the instructions are asking you to do? Can you repeat this question in your own words?
Judgement	Ability to make considered decisions	How confident are you that you are able to mark accurately where you have or had experienced pain on the diagram? How confident are you that you can remember how many times you fell over the past 12 months?
Navigation	Navigate features of the survey and progression through the survey	Is it easy or hard to scroll to see the questions? Would you like the option to go back and review or edit your responses?
Timescales	Appropriate timescales used, acceptable recall periods	Is it easy or hard for you to remember when your symptoms first started? Do you feel that the timescale of this question is appropriate
Redundancy and repetition	Survey item is not required, no longer useful, or is too similar to another item	Do you think that any of the questions are repetitious? Is this question relevant to you?

Response options	Acceptable number and range of response options	Do you think that the answers you can choose from allow you to answer the questions in the way that you want?
Emotiveness	Triggers an unwanted emotional response	How does answering this question make you feel? For example, sad, frustrated, uncomfortable?
Responder burden	Number of survey items, time taken to complete the survey, survey length	Do you think that the respondents will have the motivation, knowledge and ability to answer the questions? Do you think the length of the survey is burdensome?
Unclear purpose	Survey items collecting data that do not appear to alignment with the research purpose	For example, collecting information about global disease is not related to the purpose of the survey about foot problems, explanation required.
Missing information	Information not already captured within the survey	Suggestion to add a question: To find out if patients access services in the public or private settings To identify the impact of proximal issues on the foot and mobility
Cultural sensitivity	Cultural factors that affect the functioning of the survey in a different country	Can you think of any problems or issues that patients in New Zealand might encounter? Do you feel that the survey has reasonable cultural sensitivity (taking into account the cultural and language differences between Australia and New Zealand) and can be adapted for people with psoriatic arthritis living in New Zealand? For example, the wording of different types of footwear will be different between countries
Face and content validity	Sufficient coverage of items, meaningful to patients	Does the survey consist of a broad range of items that are all relevant, in their coverage, to the nature, extent, location and impact of psoriatic arthritis-related foot involvement on patients' daily lives? Does the survey appear, on the face of it, to measure the problems you have with your feet and the impact it has on your life?

6.3.2.1 Conduct focus groups with health professionals (Pre-testing 1 of 6)

Multidisciplinary rheumatology focus groups systematically evaluated the survey content in order to improve the overall quality and representativeness of the items. Health professionals, such as rheumatologists, podiatrists, physiotherapists and nurses, were recruited based on *a priori* selection criteria, which included current or previous experience of managing people with PsA and working in rheumatology teams. These criteria were also dependent on the willingness and availability of the individuals being asked to participate. A total of 2 focus groups were conducted at different stages in the survey development process and the number of health professionals in each review ranged from 9 to 17, as recommended to generate consensus on proposed scale items (Rubio, et al., 2003). Health professionals in the first focus group were recruited from a national Australian rheumatology conference in 2018 with diversity of participants from different states and territories, professions and health sectors. Health professionals in the second focus group were recruited from an outpatient rheumatology and podiatry hospital department in Sydney, Australia. Open debate was encouraged and an interview guide ensured discussion on priority areas including the acceptability of each item, anticipated responder burden, relevance of items, clarity of instructions and that key items had not been omitted. All focus groups were audio-recorded, transcribed verbatim and analysed using qualitative data matrices to categorise responses (Miles and Huberman, 1994). Survey items were revised and reduced based on data from each focus group, which improved the overall functioning of the survey.

6.3.2.2 Conduct cognitive debriefing interviews (Pre-testing 2 of 6)

Cognitive debriefing interviews of people with PsA were used to identify potential sources of error and problems with the interpretation of items and response anchors by respondents (Tourangeau, et al., 2000; Willis, 2005). An interview script was designed using a standardised protocol that involved the think-aloud technique with concurrent verbal probes. Specifically, respondents were asked to provide their interpretation of each survey item, followed by a series of probe questions to elicit specific information about any parts that were unclear (Willis and Artino Jr, 2013). All participants were encouraged to speak freely and not to worry about criticising the survey. All cognitive interviews were audio-recorded, transcribed verbatim and analysed using qualitative data matrices to categorise and interpret responses (Miles and Huberman, 1994).

Three rounds of cognitive interviews of people with foot problems related to PsA were undertaken; 2 using the paper-based survey and 1 the web-based version. Each of the 3 rounds of cognitive interviews comprised 6 participants, in total involving 18 people with PsA. Convenience sampling was used to recruit participants with PsA from rheumatology and podiatry outpatient clinics, in the public and private sector, based in different socioeconomic geographical areas in Sydney, Australia. Participants with rheumatologist-diagnosed PsA, aged over 18 years old and who had current or previous experience of foot problems were recruited by their rheumatologist or podiatrist.

Paper and online formats of survey administration were developed to increase response rates and reduce selection bias. Survey content remained the same irrespective of the method of completion. Given the broad geographical spread of states and territories across Australia and New Zealand and increasing internet usage among adults in both countries (Stats Govt New Zealand, 2012; Australian Bureau of Statistics, 2016e), using a web-based survey administration was considered appropriate in order to obtain information from as wide a range and number of people as possible. The online version of the survey was developed using Qualtrics software [Qualtrics, Provo, UT, USA], a widely used platform for health-based and market survey research.

An increasing portion of survey respondents are opting to complete surveys via mobile phones or tablets (Callegaro, 2010; Millar and Dillman, 2011). With mobile response rates up to 25% and expected to grow (Bosnjak, et al., 2013; Wells, et al., 2014; Stern, et al., 2016), it is important to pre-test and adapt survey designs on small screens. Usability pre-testing of the web-based survey involved participants completing the survey on their own mobile devices (smartphone or tablet) or other electronic devices (home computer or laptop). The evaluation of the web-based survey included all the elements of the paper version, but participants were additionally asked to comment on the online layout and design of the survey items and navigation features (skip patterns, ability to scroll, click and use of the next/back button). Users experienced challenges that led to errors and frustration. For example, recommendations were made by respondents to: correct content validation errors for entry fields to allow the appropriate number or text response, increase the space between response options to avoid tapping incorrect answers, reduce the amount of text in the grid questions to improve the visual appearance on mobile screens, and clearly number questions to aid navigation. Web-based design modifications were introduced as a result in order to optimise the user experience and ensure response options would display on different types of electronic devices as intended (Geisen and Bergstrom, 2017; Olmsted-Hawala, et al., 2017).

The survey was modified and improved based on feedback from each round of cognitive debriefing, which related to wording, comprehension and interpretation, navigation, judgement, timescales (recall), content, repetition, redundancy, response options, number of items, overall survey design and responder burden. This resulted in the development of a set of items that respondents could interpret easily and respond to accurately, which was integral to the validity of the survey and reliability of resulting data. For example, instructions for completing visual analogue scales (VAS) were poorly understood by the majority of respondents on pre-testing of the paper-based survey. Although the GRAPPA recommend using a VAS to record the Patient Global Assessment in PsA (Mease, 2011), all VAS in the survey were replaced by numerical rating scales (NRS) in order to optimise user satisfaction and enable accurate completion.

In addition to the drawbacks associated with the utility of the paper-based VAS, the visual display of the web-based VAS slider bar was poorly optimised for use on smaller mobile screen sizes. Utilisation of the NRS avoided issues that had been identified in the web-based version. Previous studies comparing web-based sliding scales with numeric scales found no difference in the reliability or validity between the scales, but revealed that the sliders took significantly longer to complete than the radio button version of the scale (Cook, et al., 2001; Couper, et al., 2006). Therefore, both the research evidence of poor efficiency with slider completion and the current study findings of poor comprehension of VAS instructions, supported the use of the NRS in the paper- and web-based survey.

Body and foot pain line diagrams were used in the survey to record the location and distribution of self-reported pain among respondents. Scoring of body (Lacey, et al., 2005) and foot pain diagrams (Chatterton, et al., 2013) has been shown to be reliable and repeatable for use in survey population-based research. The current study researchers sought to determine whether foot pain line diagrams or photograph images of the feet were preferred by participants with PsA. Briefly, it was established that line diagrams were preferred to photograph images, they were able to understand the instructions for diagram completion and the recall period of one month for presence of foot pain was acceptable. Previous research has found, when compared with clinical examination of the foot, self-completed foot pain diagrams by people with inflammatory arthritis have shown reasonable accuracy (Waller, et al., 2012). Foot pain scoring grids were adapted from previous studies (Garrow, et al., 2004; Otter, et al., 2010; Chatterton, et al., 2013), based on consensus of the research team on the addition of medial and lateral scoring areas of the foot. Additional scoring areas included the medial and lateral midfoot dorsal aspect, and the medial and lateral rearfoot anterior and posterior aspects. Additional medial and lateral views of the foot were used in order to capture pain in those regions and enable the interpretation of site-specific pathology affecting different anatomical regions of the foot. Validation of the adapted scoring grids will be undertaken in future work. On the web-based survey, completion of the pain diagrams was possible using the heat map function of the Qualtrics software, which was optimised to improve comparability with the paper version. A limitation of the software restricts a maximum of 10 marks per diagram and does not permit shading. Although previous research has confirmed that pain location captured using paper and online pain diagrams are satisfactorily comparable (Jones, et al., 2013), differences in the methods of pain diagram completion between the two survey modes will be accounted for during data analysis (presented in section 8.1.4, Chapter 8).

It was important to determine the reading level of the survey and a common approach is to use the Flesch reading ease score (Winzenberg, et al., 2003; Bennett, et al., 2007). Readability of the survey was 31.7 on the Flesch reading ease score (Flesch, 1948), indicating the survey would be difficult for use by most lay people. Scores of 60 or higher indicate that the text will be easy to read by most people with short sentences and no words of more than two syllables; the lower the score, the more difficult the text is to read (Flesch, 1948). Reading ease categories include 80-89 as easy to read, 70-79 as fairly easy, 60-69 standard, 51-59 fairly difficult, 30-50 difficult and 0-29 very difficult (Farr, et al., 1951). Whilst some items were simplified and written in layman terms to account for varying levels of understanding, the majority of respondents were familiar with technical language such as plantar fasciitis, dactylitis and pitting toenails. Although the readability score was relatively low, the cognitive debriefing interviews supported the respondents' understanding of each item. Terminology complexity was a point of contrast between people with PsA and health professionals, with the majority of health professionals in the focus groups suggesting simpler alternatives to some medical terms considered to be poorly understood by potential respondents. Emphasis on patient-based testing and the discordance between their views and those of the health professionals was the reason for issues related to comprehension and interpretation continuing to be raised during survey items revisions (summaries of survey item revision included in Appendix 6).

6.3.2.3 **Conduct cultural sensitivity review (Pre-testing 3 of 6)**

For both national and international multicentre studies, cultural sensitivity reviews are required to identify and correct for any cultural differences in the interpretation of survey items, particularly if translation of the survey into other languages is involved (Edwards, 2010). Although simple translation to and back from the second language might be sufficient, further cognitive debriefing and piloting is recommended in order to establish that it measures what is intended to be measured (Edwards, 2010).

Variations in language and culture between Australia and New Zealand were considered during survey development. In Australia, pre-testing was conducted among respondents from different socioeconomic locations and healthcare settings to ensure that a wider range of opinions were collected. In New Zealand, in order to assess the usability and cultural sensitivity of the survey in the local context a focus group was conducted, which included 3 health professionals with expertise in podiatry-rheumatology research and 1 Māori research advisor. Having a Māori voice on the review panel directly informed aspects of cultural sensitivity, which led to the addition of 1) open text options for the opportunity to capture more nuanced responses, 2) contact information for a Māori advisor, and 3) wording such as 'Aotearoa' (New Zealand) in the survey to achieve better recognition of a bicultural country. The order of ethnicity response options in the survey was also changed to better recognise those indigenous to both countries. There is very little evidence showing the prevalence of

PsA among indigenous groups in Australia and New Zealand, and what details do exist suggest a low prevalence. However, using cross-cultural survey development strategies may increase the likelihood of indigenous people participating in the survey and of survey findings contributing to strategies for indigenous health advancement.

The majority of changes made to the survey related to language and footwear differences between Australia and New Zealand. For example, the term jandals, used predominantly in New Zealand and the South Pacific and known as thongs in Australia, was added; the term customised shoes was added to reflect local terminology, and the word sore was added in brackets as an alternative to wound for the same reason. A question about seasonal variation of footwear choice was removed based on comments relating to redundancy. Based on these changes, the survey was considered to have adequate cultural sensitivity in the Australian and New Zealand context.

6.3.2.4 **Conduct survey design expert validation (Pre-testing 4 of 6)**

Experts (n=2) in the development and evaluation of healthcare surveys and patient-centred outcome research reviewed the draft design of the paper- and web-based survey. Feedback was provided in the form of detailed free-text annotations on the survey and written comments to specific questions on how to optimise the look, flow and design of the survey. Consequently, survey items were re-grouped, streamlined and survey sections were numbered to improve consistency in navigation and layout between the paper and online versions of the survey. A list of the sections in the survey and their coverage was added to the survey introduction, in order to provide potential participants with a better appreciation of the study scope. Design features were added to the online survey such as forced responses. The layout of tabular matrices was changed in order to improve the on-screen view, and instructions were provided in order to optimise the user experience of functions such as save and continue later, the progress bar and back button. Valuable insights into the survey design were used to minimize responder burden and maximise survey participation and completion.

6.3.2.5 Conduct subject expert validation for final item refinement (Pre-testing 5 of 6)

An eight-member specialist panel, including 4 international leading experts in PsA-related foot involvement and 4 members of the research advisory group (DET, SW, KR, MO), reviewed the final survey items and response scales. The panel members were selected based on *a priori* criteria, which included having recent publications in PsA-specific foot involvement research, a track record of special interest in PsA and current specialised clinical practice in PsA. An innovative online collaborative platform (Google Forms included in Appendix 2) was used to design the data collection form that facilitated the instant recording of responses, while web-conferencing allowed real-time audio/visual communication between panel members across 3 countries including the UK, Australia and New Zealand. Prior to the subject expert review, a PowerPoint presentation was delivered to the panel by the principal investigator (KC) describing the survey development process, the survey item content and rationale, research aims and objectives and the purpose of the review. In addition, panel members were provided with documents showing how survey items mapped to the ICF and to the PsA core domain set, and a data analysis plan that made explicit how each variable would be analysed and categorised in order to provide relevant context. Panel members independently rated the relevance and importance of each item to its assigned construct; demographics, pain and musculoskeletal disease, skin and toenail disease, function and participation, footwear, and treatment burden and emotional well-being. For each survey item the rating options were ‘Exclude’, ‘Needs improvement’ or ‘No action’. When ‘Exclude’ or ‘Needs improvement’ were selected, panel members were asked to provide written comments about the nature of the shortcoming and how it might be addressed. The review process was moderated (SW) in order to ensure that all panel members had rated and commented on each survey construct and progressed as a group. Following independent, real-time completion of the data form, results were presented to all members for open discussion in order to reach a consensus on the final survey items. Based on this feedback, 3 survey items were excluded due to redundancy and repetition, and 4 survey items were revised by adding qualifying statements in brackets in order to help emphasise and clarify the concept under investigation (Table 6.4). To ensure face validity, the revised items were then re-reviewed by the experts to confirm that they were acceptable for inclusion. No new issues were raised. The expert panel recognised the need for all items given the heterogeneity of disease expression and potential impact. A specific line of questioning around item reduction was included, but recognition of the need to capture aspects that were deemed to be important prevented reduction of items for the specific purpose of reducing the survey length.

Table 6.4. Survey item exclusions and revision suggested by the expert validation panel.

Survey Item Exclusion		Reason from Expert Panel
Q21	When you get out of bed in the morning over the past week, do you feel stiff? If yes, how long does the stiffness generally last for? Less than 30 minutes, 30 minutes to 1 hour, 1 to 2 hours, 2 or more hours.	Redundant as the duration of morning stiffness is not a good discriminator in terms of inflammatory disease
Q39	Please indicate approximately how many toenails have been affected over the past month.	Redundant as future work would be required to explore links between toenail involvement and dactylitis for this information to be useable
Q53	Considering your foot problems overall, how much of a problem have your feet been over the past month? Numerical rating scale; 0 = no problem, 10 = severe problem	Duplication for participants with other NRS included in the survey relating to pain, trouble and coping with foot problems
Survey Item Revision		Reason from Expert panel
Q16	‘Elbow’ changed to ‘Elbows’	Wording error
Q42	Changed order of response option with ‘vigorous activity’ to follow ‘moderate activity’	For logical, clear sequence
Q46	'Work boot’ changed to ‘Work boot such as steel toe-capped'	Required clarification
Q51	‘Considering all the people around you’ changed to ‘Considering all the people around you (family, partner, friends and others)’	Required clarification

6.3.2.6 **Conduct pilot testing (Pre-testing 6 of 6)**

This work resulted in a 59-item survey with 8 sections. Whilst the number of survey items required to adequately assess the construct was considered as part of the survey design, the research priority was to assess the full complexity of the construct with a high level of granularity. Despite the substantial length of the survey, the majority of people with PsA interviewed during survey pre-testing suggested that it was acceptable. Reasons for this included 1) having a desire to share their experience of foot problems that they felt had been neglected and/or poorly understood, and 2) resonance of patient-derived statements throughout the survey, which reportedly had a positive effect on encouraging survey completion. In contrast to this finding, the majority of health professionals in the focus groups reported that the length of the survey was likely to be prohibitive to potential participants. Therefore, it was important to conduct pilot testing in order to verify that respondents would be willing and motivated to answer the survey, without input from the principal investigator (KC). Research evidence supports the hypothesis that the response rate to a survey is inversely related to its length (Edwards, et al., 2004). In health research where the option to follow-up exists, it is recommended to use shorter surveys on each occasion (Edwards, et al., 2004). However, with only one opportunity to sample response and no provision for a follow-up survey, the current survey was designed to be as short as possible whilst compromising only minimally the data collection requirements of the study.

Six prospective participants completed the survey in the planned delivery mode; 3 paper-based surveys were self-administered in a clinical setting, and 3 web-based surveys were self-administered at home. Using a retrospective approach with verbal probe questions, no problems were reported about the time and number of sections required to complete the survey. Both versions of the survey took between 20 to 25 minutes to complete. The pilot testing confirmed that respondents could complete the survey effectively, efficiently and found the survey length acceptable. Survey item reduction was not the central focus of the pre-testing methods, but it was important to consider the balance between comprehensive coverage of the construct and brevity in the final survey.

The data obtained from the pilot test was reviewed to evaluate item responses and to identify any missing data. It was noted that question 52 was missed by 3 pilot test participants (1 in the paper survey, 2 in the online version), which stated ‘how effective do you feel you have been at managing your foot problems? Extremely effective, very effective, moderately effective, mildly effective, not at all effective. Non-response or missing data may be accidental, or due to the higher cognitive burden related to recall and judgement of self-care effectiveness, or due to respondents feeling uncomfortable or frustrated when considering self-care effectiveness. Different wording or exclusion of the item was considered to avoid the potential for missing data. However, it was deemed necessary to retain it in its original form by the research team as it was anticipated that the impact would be minimal. Having established prior to the pilot test during the cognitive debriefing interviews that the question was clear and unambiguous among respondents, it was decided that altering the wording of the question could not make a meaningful difference to response levels.

The pilot test also provided the opportunity to test data entry, data processing and coding procedures (Ruel, et al., 2016). A code book was created to convert survey responses into numerical data for efficient data input and management (the code book is provided in Appendix 7). For example, no = 0, yes = 1. The pilot test confirmed the feasibility of data collection procedures and no changes to the survey administration processes were necessary. The data analysis plan was informed by the pilot test results by prompting decisions for defining and handling data and the following sub-headings describe the resultant analysis plan.

6.3.2.7 **Data analysis plan**

Statistical data analysis - Data analyses were conducted using Statistical Package for Social Sciences (SPSS) 27.0 (Inc. Chicago. Illinois). Data from the online surveys was exported from Qualtrics into Excel and then, along with the data from the paper surveys, all data was manually entered into SPSS by one researcher (KC) with accuracy checking by a second researcher (SW) by double entry of all data. Data analysis was mainly descriptive statistics for summarising survey results and comparisons between characteristics. Continuous data were expressed as means and standard deviations (SD). For categorical data, proportions were calculated and expressed as percentages. Survey reporting recommendations of SURGE and CHERRIES were applied when presenting the findings (Eysenbach, 2004; Grimshaw, 2014). Inferential statistical analyses were used to emphasise a few key relationships between the hallmark disease features in the foot, in the context of global disease and in relation to their impact on aspects of daily life. The Kruskal-Wallis test was used to determine significant relationships between variables followed by post hoc pairwise comparison of groups using Dunn’s procedure (Dunn, 1964), which incorporated a

Bonferroni correction. A Mann-Whitney U rank test was conducted to compare positions of median scores. The Chi-square test of independence and the 2-tailed Fishers exact test were used to determine any association between the frequencies of categorical variables, followed by appropriate post hoc testing.

Missing data analysis - Valid and missing data for each survey item was evaluated:

(i) Valid data refers to the number of responses from participants for each survey item.

(ii) Missing data (or item non-response) refers to an unrecorded data value which, if recorded, would be meaningful for analysis and interpretation of a study (Li, et al., 2014), thus a survey item or response option that was missed by the respondent. Missing responses may be accidental due to poor survey navigation features or intentional due to high cognitive or responder burden. Missing data below 5% is considered inconsequential for non-biasing survey results and can be reported using descriptive analysis and not imputation techniques (Li, et al., 2014; Jakobsen, et al., 2017).

(iii) Skipped data refers to an unrecorded data value due to the respondent accurately following a skip question (for example, ‘if no, skip to question 26).

(iv) Non-completions (non-responses) were defined as participants who did not progress beyond the first information page to start the survey.

(v) Partial completions were defined as participants who started the survey and the response included some missing data.

(vi) Completions of 100% were defined as participants who completed 100% of the survey with no missing data (Eysenbach, 2004; Grimshaw, 2014).

Socioeconomic data description – For planned socioeconomic evaluation the Index of Relative Socio-economic Advantage and Disadvantage (IRSAD) 2016 was selected as a measure of social deprivation to indicate health inequalities in the current study. The IRSAD 2016, produced by the Australian Bureau of Statistics (ABS), ranks areas in Australia according to relative socioeconomic advantage and disadvantage based on information from the 5-yearly census of population and housing (2016). The census collects information on individual level indicators of social deprivation (education level, income, occupation, household measures) and area level indicators (crime rates, unemployment rates, barriers to housing and services, living environment) (Grundy and Holt, 2001; Pampalon, et al., 2009). The IRSAD 2016 is a weighted sum of these variables that indicates the collective socioeconomic characteristics of the people living in an area. IRSAD scores were obtained from postcodes provided in the survey, which were converted into postal area categories using geocoding tables. The IRSAD ordinal scale ranges from 1 to 10, where category 1 represents the areas with the least deprived scores (most affluent) and 10 the areas with the most deprived scores (least affluent). The categories were an index of comparative deprivation within the population sample (Australian Bureau of Statistics, 2016c).

Numerical rating scales data analysis - The 0-10 numerical rating scales (NRS) used in the survey were for the patient global assessment (question 17, 18, 19), global pain severity (question 20), foot pain severity (question 23), how troublesome foot and ankle symptoms have been (question 27), and ability to cope with foot problems (question 47). The 0-10 NRS with a 1-week recall period are recommended in the PsA core outcome set to measure patient global assessment of disease activity and global pain intensity (Mease, 2011; Højgaard, et al., 2018). However, to the best of the authors knowledge, no studies have identified optimal cut-off points on a NRS or VAS in a PsA-specific population, with current guidance from GRAPPA-OMERACT stating that higher scores indicate worse pain or worse global health (Højgaard, et al., 2018). Division of the NRS into the categories of 0-3 for mild, 4-6 moderate and 7-10 severe for data analysis purposes and for clinical interpretation in the current study was selected based on cut-off points defined in the literature on pain-related interference with functioning (Palos, et al., 2006; Hirschfeld and Zernikow, 2013; Oldenmenger, et al., 2013; Boonstra, et al., 2014).

Early and established disease duration in PsA data analysis - With no widely accepted definition of early PsA or late PsA (long-standing or established disease), cut-off points for the duration from symptom onset and disease diagnosis of: less than 2 years (early PsA); 2 to 4 years (mid-late PsA); and more than or equal to 5 years (late PsA), were selected for data analysis purposes in the current study based on clinical studies and RCTs in PsA (Kane, et al., 2003b; Lindqvist, et al., 2008; Coates, et al., 2012a; Coates, et al., 2015; Santos, et al., 2017).

Body and foot pain diagram data analysis - For the paper surveys, pain diagrams were scored using a transparent overlay dividing the body and foot into mutually exclusive areas (Figure 6.4). The scoring was entered into Excel as ‘1’ if a template area was marked and ‘0’ if it was not marked. Scoring was undertaken by a single experienced rater (KC) who followed guidance previously described (Lacey, et al., 2005; Chatterton, et al., 2013). For the online survey, the Qualtrics software automatically scored the pain diagrams by applying the same pre-defined scoring grids to the final data set as used for the paper surveys. The scores were downloaded into Excel for analysis.

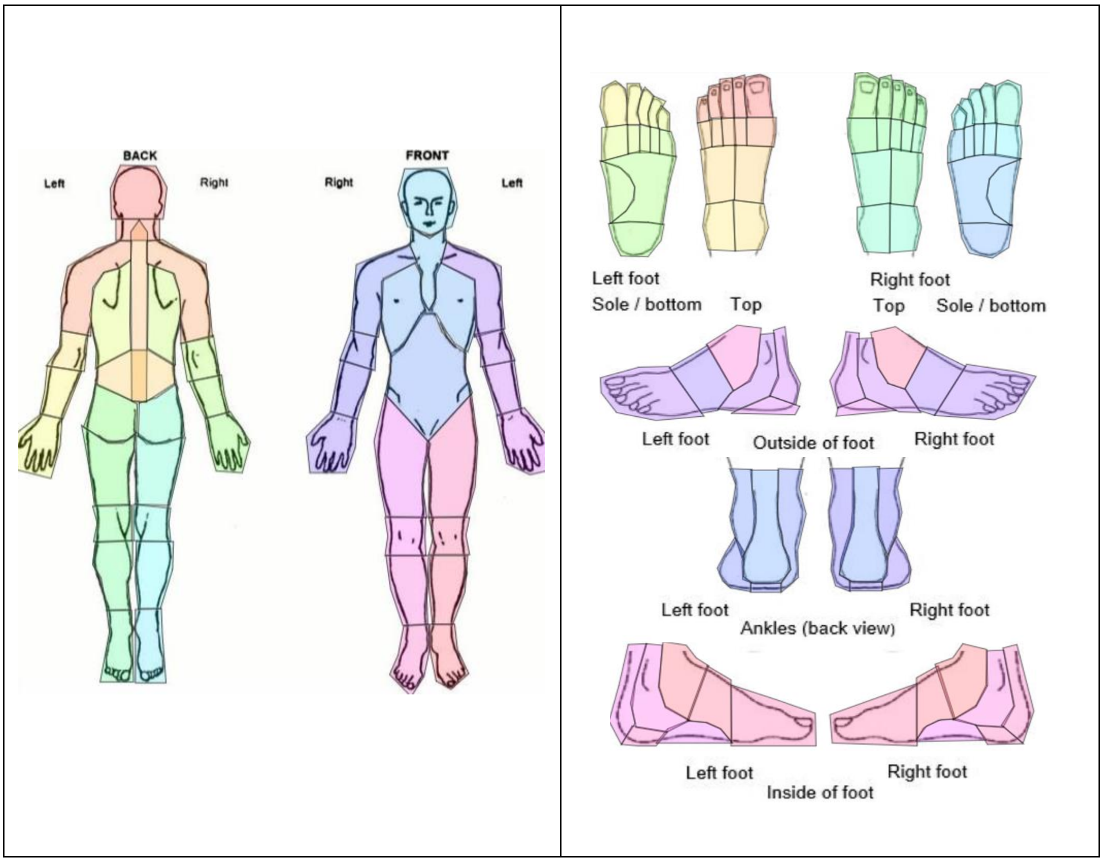


Figure 6.4. Body pain diagrams and scoring grid and foot pain diagrams and scoring grid (Garrow, et al., 2004; Lacey, et al., 2005; Otter, et al., 2010; Chatterton, et al., 2013).

Body pain diagram 1: back view, body pain diagram 2: front view; Foot pain diagram 1: left foot dorsal and plantar view, foot pain diagram 2: right foot dorsal and plantar view, foot pain diagram 3: left and right foot lateral view, foot pain diagram 4: left and right foot posterior view, foot pain diagram 5: left and right foot medial view.

Metric mapping of survey items - For a targeted approach to data analysis, survey items were mapped to key variables in order to determine associations and relationships that were formed *a priori* (Table 6.5). The data analysis strategy was informed by the conceptual framework developed in research phase 1, which was underpinned by the PsA core domain set and the ICF framework. The GRAPPA-OMERACT PsA core domain set was used to inform interview guide development for the qualitative study in research phase 1 and survey item development in research phase 2, which enabled a pre-determined core set of foot-specific variables to be established (Figure 6.5). Furthermore, linking concepts derived from the qualitative study on the impact of foot involvement in PsA to the ICF model, highlighted important patient-focused areas such as coping, self-care, footwear, support and understanding, which ensured that information central to the patient experience relating to Environmental and Personal Factors was included in the survey metrics (Figure 6.6). Mapping survey items served to highlight the commonality across key domains for a focused presentation of key insights.

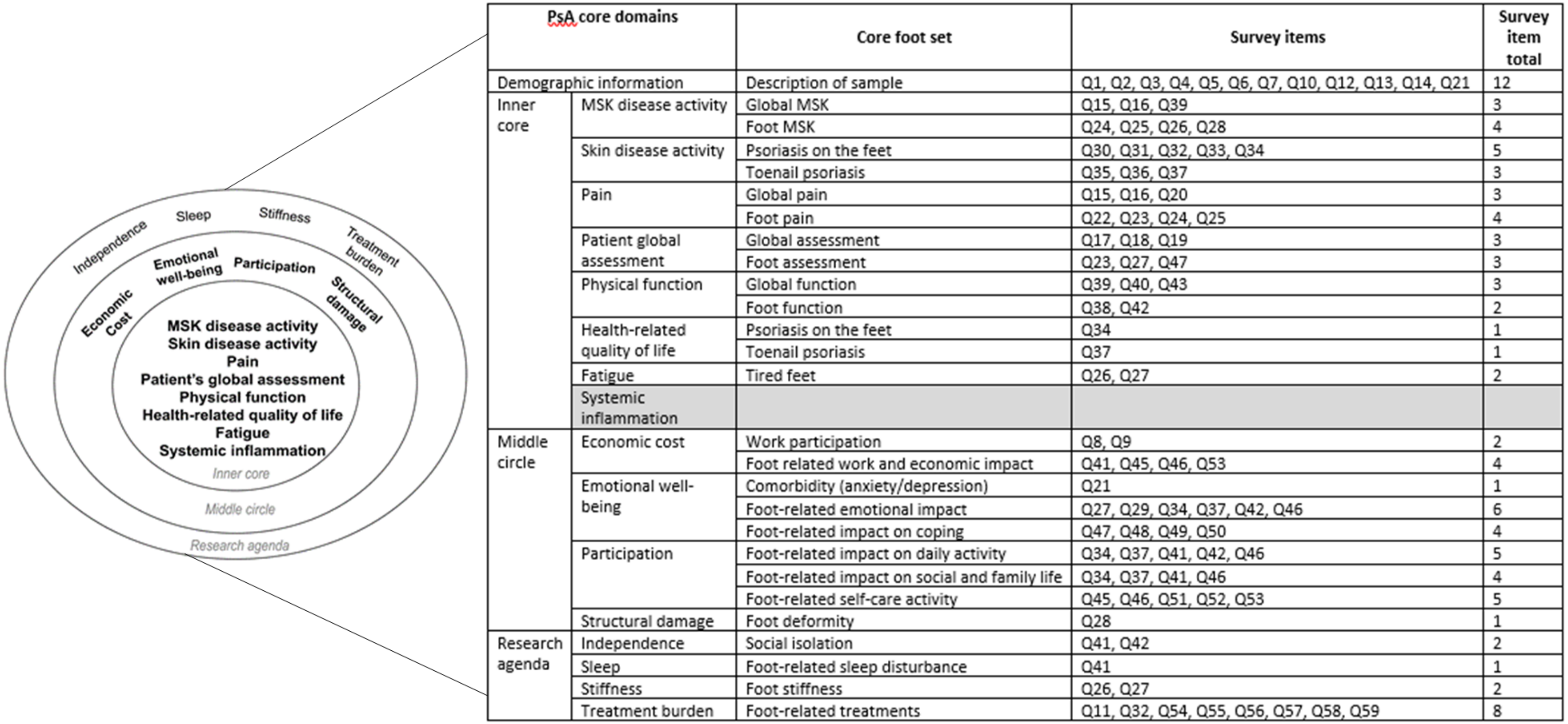
Foot-specific impact domains framed by the ICF included:

1) Body Structure; musculoskeletal and dermatology involvement of foot structures including location, extent and frequency

2) Body Functions; Foot pain, nature of foot symptoms and their impact on body image, coping, physical function and gait changes

3) Activity and Participation; impact of foot problems on walking, self-care activity and life areas such as daily routine, work, social and family life

4) Environmental; footwear restrictions and difficulties, and access to healthcare



PsA core domains		Core foot set	Survey items	Survey item total
Demographic information		Description of sample	Q1, Q2, Q3, Q4, Q5, Q6, Q7, Q10, Q12, Q13, Q14, Q21	12
Inner core	MSK disease activity	Global MSK	Q15, Q16, Q39	3
		Foot MSK	Q24, Q25, Q26, Q28	4
	Skin disease activity	Psoriasis on the feet	Q30, Q31, Q32, Q33, Q34	5
		Toenail psoriasis	Q35, Q36, Q37	3
	Pain	Global pain	Q15, Q16, Q20	3
		Foot pain	Q22, Q23, Q24, Q25	4
	Patient global assessment	Global assessment	Q17, Q18, Q19	3
		Foot assessment	Q23, Q27, Q47	3
	Physical function	Global function	Q39, Q40, Q43	3
		Foot function	Q38, Q42	2
	Health-related quality of life	Psoriasis on the feet	Q34	1
		Toenail psoriasis	Q37	1
	Fatigue	Tired feet	Q26, Q27	2
	Systemic inflammation			
Middle circle	Economic cost	Work participation	Q8, Q9	2
		Foot related work and economic impact	Q41, Q45, Q46, Q53	4
	Emotional well-being	Comorbidity (anxiety/depression)	Q21	1
		Foot-related emotional impact	Q27, Q29, Q34, Q37, Q42, Q46	6
		Foot-related impact on coping	Q47, Q48, Q49, Q50	4
	Participation	Foot-related impact on daily activity	Q34, Q37, Q41, Q42, Q46	5
		Foot-related impact on social and family life	Q34, Q37, Q41, Q46	4
		Foot-related self-care activity	Q45, Q46, Q51, Q52, Q53	5
	Structural damage	Foot deformity	Q28	1
Research agenda	Independence	Social isolation	Q41, Q42	2
	Sleep	Foot-related sleep disturbance	Q41	1
	Stiffness	Foot stiffness	Q26, Q27	2
	Treatment burden	Foot-related treatments	Q11, Q32, Q54, Q55, Q56, Q57, Q58, Q59	8

Figure 6.5. Survey items mapped to the psoriatic arthritis core domain set and establishing a core set of foot-specific impact domains.

MSK Musculoskeletal, *PsA* Psoriatic arthritis.

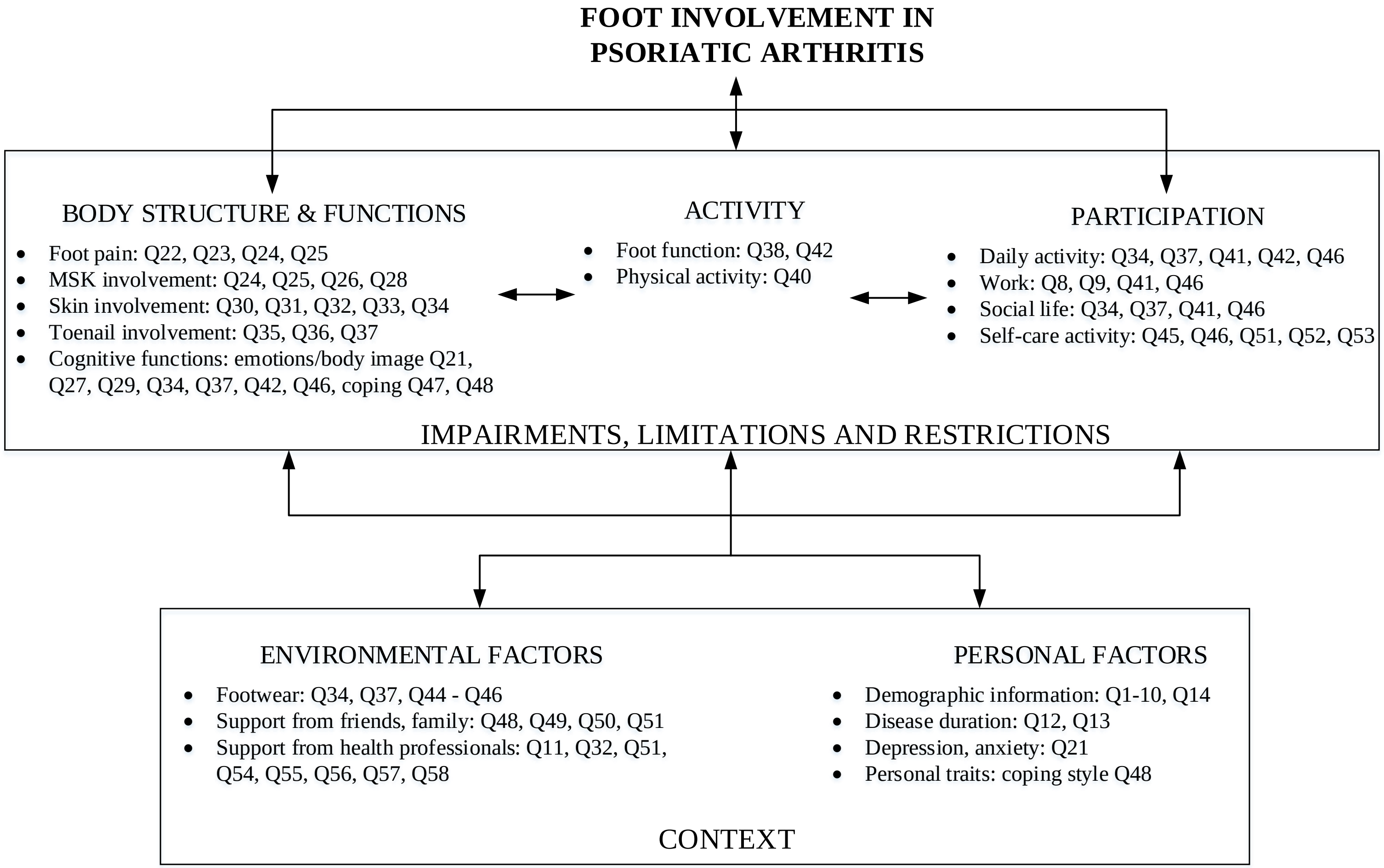


Figure 6.6. Survey items mapped to the International Classification of Functioning, Disability and Health.

MSK Musculoskeletal.

Table 6.5. Data analysis strategy for descriptive statistics of survey data.

Data categories	**Question number**	**Data collected**	**Type of data**	**Data analysis strategy** Highlighted variables were independent in analyses
A) Population demographic descriptors	1	**Where do you live**	Nominal	Description of sample, comparable sample, link between socioeconomic status, health literacy and health seeking behaviour, age-related differences, gender-related differences, ability to target specific ethnic groups
	2	**Postcode – location**	Nominal	
	3	**Age**	Ratio	
	4	**Gender**	Nominal	
	5	**Height**	Ratio	
	6	**Weight**	Ratio	
	7	**Ethnicity**	Nominal	
	8	Work status	Nominal	
B) Global PsA presentation/description	9	Work status change due to PsA	Nominal	Work participation, health economic impact comparisons with other chronic disease groups
A) Population demographic descriptors	10	Highest qualification	Ordinal	Health literacy, health seeking behaviour, ability to target specific groups
C) Healthcare professional access, support and quality of care – general and foot specific	11	Currently see a Rheumatologist for management of PsA	Nominal	Description of sample, health seeking behaviour, disease management
B) Global PsA presentation/description	12	Onset of symptoms	Ratio	Description of sample, comparable sample, mean diagnostic delay, global and local foot disease severity comparison
	13	Duration of diagnosis	Ratio	
	14	Medication management for PsA	Nominal	
	15	Location of ache/pain due to PsA – past month	Nominal	
	16	Area of body most painful/sore - past month	Nominal	Global and local foot pain comparison, determine potential sample bias or study limitations related to

Data categories	**Question number**	**Data collected**	**Type of data**	**Data analysis strategy** Highlighted variables were independent in analyses
	17	Global rating of arthritis impact – past week	Interval	severity/importance attributed to foot problems and presence of comorbidities
	18	Global rating of psoriasis impact – past week	Interval	
	19	Global rating of psoriasis and arthritis impact – past week	Interval	
	20	Global rating of pain from PsA impact – past week	Interval	
	21	Comorbidity presence	Nominal	
D) Foot symptomology potentially due to PsA involvement	22	Pain presence in feet/ankles for one month or longer – past month	Nominal	Comprehensive description of foot and ankle characteristics in psoriatic arthritis; current foot pain prevalence, site-specific foot involvement, nature of foot pain, sub-group analysis of different patterns of foot involvement with associated impacts
	23	Severity of pain in feet/ankles – past month	Interval	
	24	Location of pain in feet/ankles – past month	Nominal	
E) Foot involvement in PsA - impact	25	Impact of symptoms in feet/ankles on a typical day	Ordinal	Nature of foot pain, foot-specific impact domains
D) Foot symptomology potentially due to PsA involvement	26	Frequency of other symptoms in feet/ankles	Ordinal	Nature of foot pain, foot-specific impact domains
E) Foot involvement in PsA - impact	27	Troublesome symptoms in feet/ankles	Ordinal	Description of the key foot-specific impact domains
D) Foot symptomology potentially due to PsA involvement	28	Current/past problems affecting feet	Nominal	Comprehensive description of foot and ankle characteristics in psoriatic arthritis, site-specific foot involvement

Data categories	**Question number**	**Data collected**	**Type of data**	**Data analysis strategy** Highlighted variables were independent in analyses
E) Foot involvement in PsA - impact	29	Embarrassment/self-conscious about foot problems	Nominal	Description of the key foot-specific impact domains
F) Psoriasis – presentation/frequency	30	Presence of psoriasis - foot	Nominal	Description of sample
	31	Presence of psoriasis – ankle to knee	Nominal	
C) Healthcare professional access, support and quality of care – general and foot specific	32	Currently see a dermatologist for management of psoriasis	Nominal	Description of sample, health seeking behaviour, disease management
G) Psoriasis involvement - impact	33	Problems with skin on feet/ankles – past month	Nominal	Comprehensive description of foot and ankle characteristics in psoriatic arthritis and key foot-specific impact domains
	34	Impact of skin problems on feet/ankles - past month	Ordinal	
H) Toenail psoriasis – presentation/frequency	35	Presence of toenail psoriasis	Nominal	Description of sample Comprehensive description of foot and ankle characteristics in psoriatic arthritis and key foot-specific impact domains
	36	Problems with toenail psoriasis – past month	Nominal	
I) Toenail psoriasis involvement - impact	37	Impact of toenail psoriasis – past month	Ordinal	
J) Foot problems - impact	38	Mobility difficulties due to foot problems	Ordinal	Description of the sample, identify potential barriers and facilitators related to physical activity, links with global and foot-specific impact domains
	39	Mobility problems due to other areas of body involvement	Nominal	

Data categories	**Question number**	**Data collected**	**Type of data**	**Data analysis strategy** Highlighted variables were independent in analyses
	40	Frequency of physical activities of varying degrees of intensity – past week	Ordinal	
	41	Impact of foot problems on various activities of daily living	Ordinal	
	42	Impact of mobility difficulties due to foot problems	Ordinal	
	43	Frequency of falls	Ratio	
K) Footwear worn, selection factors and difficulties/impact	44	Type of footwear worn most during a typical week	Nominal	Description of most commonly worn footwear, sub-group analysis of site-specific foot involvement, key foot-specific impact domains associated with pathological features and self-management strategies
	45	Top 5 most important factors when choosing footwear	Nominal	
	46	Degree of difficulties experienced with footwear	Ordinal	
L) Coping strategies with foot problems	47	Ability to cope with foot problems - past month	Interval	Description of self-management strategies and key foot-specific impact domains, impact triad (severity, importance, coping)
	48	Ways used to cope with foot problems	Nominal	
M) Social support for foot problems	49	Perceived lack of understanding and/or support from friends, family and others	Nominal	Description of self-management, health literacy, identify potential barriers and facilitators related to self-management
	50	Belong to a patient support group	Nominal	
N) Coping strategies with foot problems	51	Assistance required to take care of feet properly	Nominal	Description of foot healthcare need, links with health seeking behaviour and health literacy, health

Data categories	**Question number**	**Data collected**	**Type of data**	**Data analysis strategy** Highlighted variables were independent in analyses
	52	Effectiveness of self-management of foot problems	Nominal and ordinal, respectively	economic impact comparisons, cost/benefit evaluation
	53	Out-of-pocket expenditure on caring for feet – past 12 months	Ratio	
C) Healthcare professional access, support and quality of care – general and foot specific	54	Health professionals and non-professionals seen about foot problems AND Effectiveness of help received by health professionals AND Confidence in health professionals to understand condition	Nominal AND Ordinal AND Ordinal	Description of foot healthcare need, health seeking behaviour, awareness of foot involvement in psoriatic arthritis, identify potential barriers and facilitators related to access to care, cost/benefit evaluation
	55	Rheumatologist asked about feet	Nominal	
	56	Rheumatologist examined feet	Nominal	
	57	Seen a podiatrist	Nominal	
	58	Received regular podiatry treatment	Nominal	
	59	Received foot/ankle surgery AND Improvement seen after surgery	Nominal AND Nominal	

PsA Psoriatic arthritis.

6.3.3 PHASE 3: Survey Implementation

Survey researchers typically seek a representative population-based sample. Throughout the process of recruiting research subjects and distributing surveys, bias can occur if a specific population is targeted without proper randomisation. Ambiguity relating to bias can be resolved by comprehensively reporting the recruitment process and the sample frame, characteristics, representativeness and sample size calculations (Turk, et al., 2018). The reporting of survey implementation and dissemination is crucial in order to determine the generalisability of study results.

6.3.3.1 Large-scale survey dissemination

Sample size requirements for the study were difficult to estimate as the prevalence of PsA in Australia and New Zealand were unknown *a priori*. In the absence of large databases to target established PsA populations, the sampling strategy was to identify the major sites for dissemination and determine the response rate relative to the populations that were targeted.

Targeted sites and organisations for dissemination of the survey were pre-identified including; patient community groups, patient support organisations (PsA, psoriasis, spondyloarthritis, arthritis, rheumatology, autoimmune, musculoskeletal), online patient support groups (Facebook, Reddit), professional associations (rheumatology, podiatry, dermatology, clinical immunology and allergy), specialist clinical services (PsA, rheumatology, podiatry), and research centres (clinical innovation, musculoskeletal) (Figure 6.7). Both the web-based and paper-based versions of the survey were run concurrently to optimise data collection. In the event that online survey completion was not possible, the paper survey would be provided with a stamped addressed envelope on request. Consent was implicit by the return/submission of the completed survey and participants were informed of this at the start of the paper and online survey.

In total, 900 paper surveys were posted to the targeted patient community groups and specialist clinical services in Australia (n=650) and New Zealand (n=250), as well as 2000 flyers and 300 posters. Paper survey packs sent to the targeted sites comprised an introductory letter, posters, flyers, copies of the survey with attached stamped addressed envelope and participation information sheet (survey promotion materials are included in Appendix 8). Clinical services were asked to provide an estimate of the number of their patients with PsA, those with available figures indicated that the potential reach of the survey could be 2740 in Australia and no estimates were provided in New Zealand (Table 6.6). For dissemination of the online survey, all 13 patient support organisations and 5 out of the 26 social media groups agreed to promote the survey to their membership via their monthly newsletters, website and/or Facebook page, with a potential reach of the survey to approximately 3260 people with PsA across Australia and New Zealand. This targeted approach to survey dissemination was followed by snowballing and crowdsourcing sampling techniques, where participants informed other potential participants of the research by liking posts and sharing links about the survey. Monthly email reminders were sent to all target sites and organisations to request for continued promotion of the survey during the study period (6-months).

The estimated total target population identified from the major sites for dissemination was 6000 people with PsA in Australia and unknown in New Zealand. The total target population in Australia comprised PsA sample estimates from the online organisations (n=195), social media groups (n=3065) and specialist clinical services (n=2740) in Australia, and no estimates were provided from sites or services targeted in New Zealand.

Table 6.6. Summary of sites targeted for online and paper survey promotion.

No	Online patient support groups targeted	Number of people with psoriatic arthritis
Online survey promotion		
Arthritis support organisations		
13	Arthritis Australia	X
	Arthritis & Osteoporosis New South Wales	X
	Arthritis Australian Capital Territory	122
	Arthritis South Australia	X
	Australia & Osteoporosis Northern Territory	X
	Australia Queensland	X
	Australia & Osteoporosis Western Australia	X
	Australia & Osteoporosis Tasmania	X
	Musculoskeletal Australia	73
	Arthritis New Zealand	X
	Dragon Claw, Australia	X
	Creakyjoints, Australia	X
	Psoriasis Australia	X
Social media groups		
5	Young Women’s Arthritis Support Group, Australia	X
	Reddit Psoriatic Arthritis, worldwide	X
	Spondyloarthropathy support group, Australia	X
	Psoriasis and Psoriatic Arthritis in Australia, Australia	2272
	Psoriatic Arthritis Support Group, Australia	793
7	Professional organisations (n=6 Australia, n=1 New Zealand) *1	NA
2	Research centres (n=2 Australia)	NA
Paper survey promotional packs sent to individual sites		
6	Specialist psoriatic arthritis clinical services (n=6 Australia)	455
44	General rheumatology clinical services (public) (n=22 Australia, n=22 New Zealand)	X
21	Rheumatologists with a special interest in psoriatic arthritis, Australia	2285
78	Rheumatology private practices (n=68 Australia, n=10 New Zealand)	X
8	University podiatry clinics (n=7 Australia, n=1 New Zealand)	X
	TOTAL	**6000**

X = unknown number of members or patients with psoriatic arthritis.
NA = not applicable as there is no patient membership, only health professionals.
*1 Physiotherapy and Occupational Therapy professional associations required a charge to advertise to their membership, so the survey was not promoted to these professional groups.

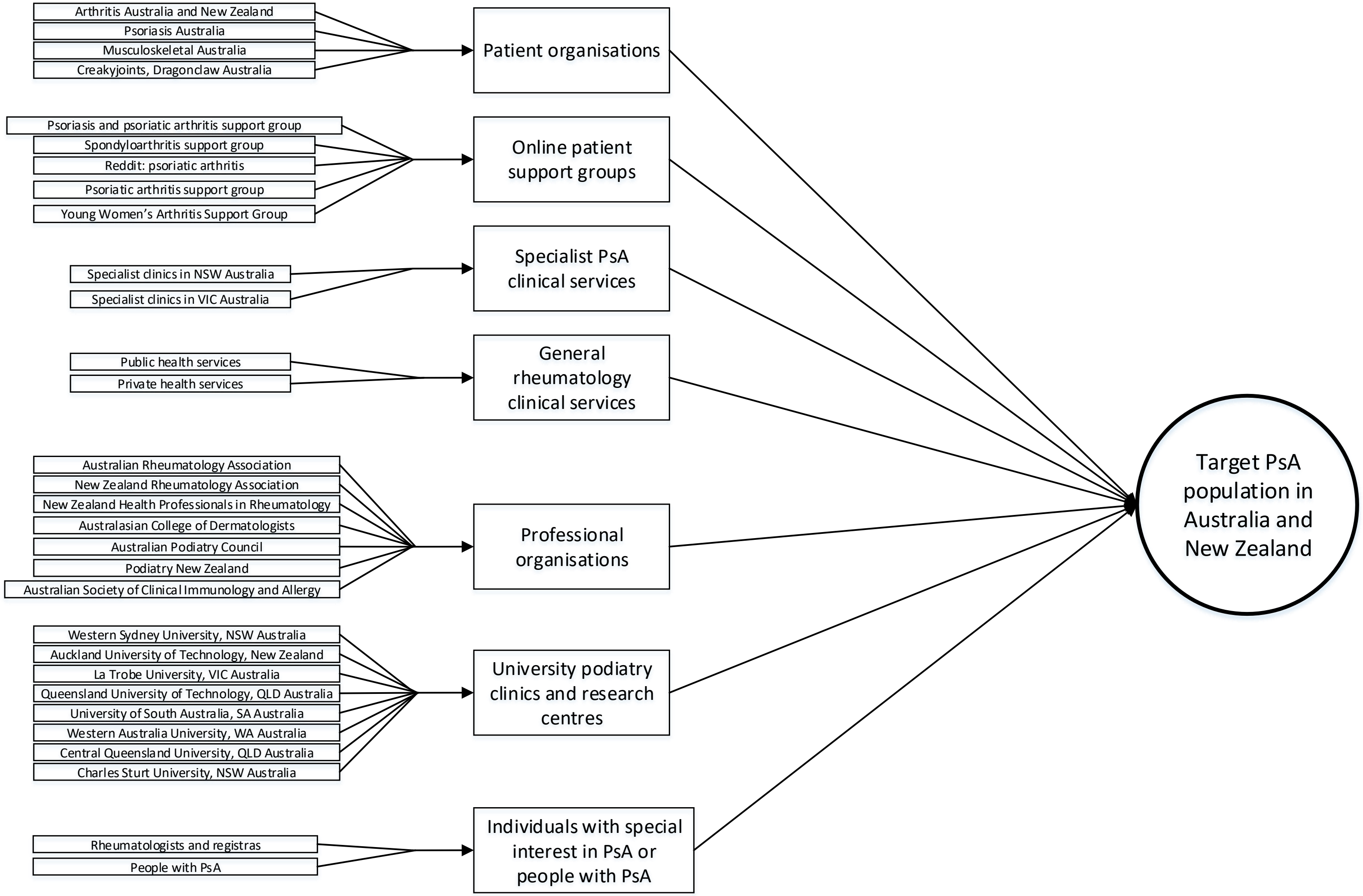
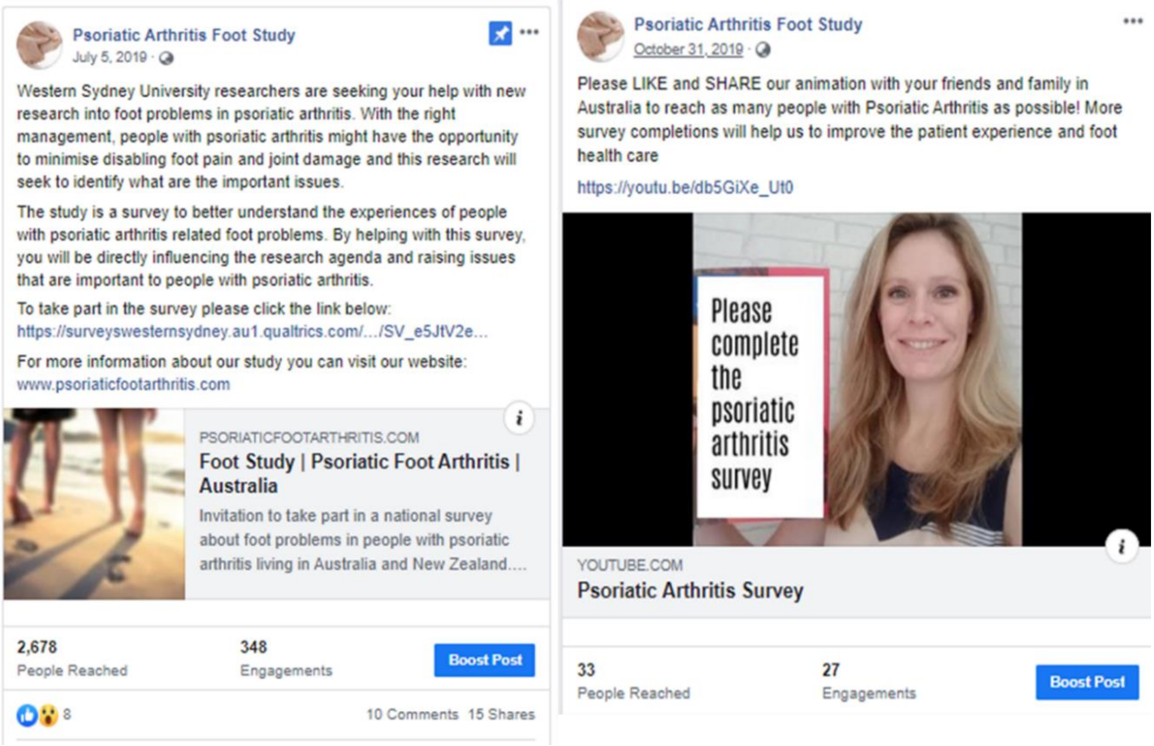


Figure 6.7. Targeted sites and individuals for survey dissemination in Australia and New Zealand.

PsA Psoriatic arthritis, *NSW* New South Wales, *QLD* Queensland, *SA* South Australia, *VIC* Victoria, *WA* Western Australia.

A study website [www.psoriaticfootarthritis.com] and Facebook page [fb.me/footsurvey, psoriatic arthritis foot study] were created to generate research interest through online health social networks and communities (Figure 6.8 and 6.9). It also provided the opportunity to engage with interested respondents over an extended period by providing regular updates on the study progress and relevant information about the disease and its impact. Over the 6-month data collection period, the website had 109 views and the Facebook page had 83 followers, received 78 post likes and had a page research (an estimated metric for the number of people who saw a specific post or any content from the page) of 2678 people (Figure 6.10). There was a total of 41 enquiries via the website, 6 people were sent the paper survey as requested, 28 people were sent the electronic survey link, 4 enquiries were from non-Australasian residents expressing interest in the study, and 3 were from people without a PsA diagnosis. Valuing the contribution of participants was key to developing a community-academic partnership, with the shared goal to move forward this area of research and to increase awareness about the disease and foot involvement. Robust strategies for sampling, survey dissemination and community engagement made a powerful contribution to response rates and the scale of information collected.

During data collection, a poor response from male participants and people living in the Northern Territory (NT) state of Australia was noted. Potential male respondents were subsequently targeted in a Facebook page post and in the animation video in order to encourage participation. Despite having established online survey promotion with Arthritis and Osteoporosis NT, two additional organisations agreed to promote the survey online to their networks; Council of the Aging (COTA) NT and NT PHN health workforce agency. Such targeted dissemination was considered to increase the likelihood of collecting data from a representative sample.



Psoriatic Arthritis Foot Study
July 5, 2019 ·

Western Sydney University researchers are seeking your help with new research into foot problems in psoriatic arthritis. With the right management, people with psoriatic arthritis might have the opportunity to minimise disabling foot pain and joint damage and this research will seek to identify what are the important issues.

The study is a survey to better understand the experiences of people with psoriatic arthritis related foot problems. By helping with this survey, you will be directly influencing the research agenda and raising issues that are important to people with psoriatic arthritis.

To take part in the survey please click the link below:
https://surveyswesternsydney.au1.qualtrics.com/.../SV_e5JtV2e...

For more information about our study you can visit our website:
www.psoriaticfootarthritis.com

PSORIATICFOOTARTHRITIS.COM
Foot Study | Psoriatic Foot Arthritis | Australia
Invitation to take part in a national survey about foot problems in people with psoriatic arthritis living in Australia and New Zealand....

2,678 People Reached
348 Engagements

8
10 Comments 15 Shares

Psoriatic Arthritis Foot Study
October 31, 2019 ·

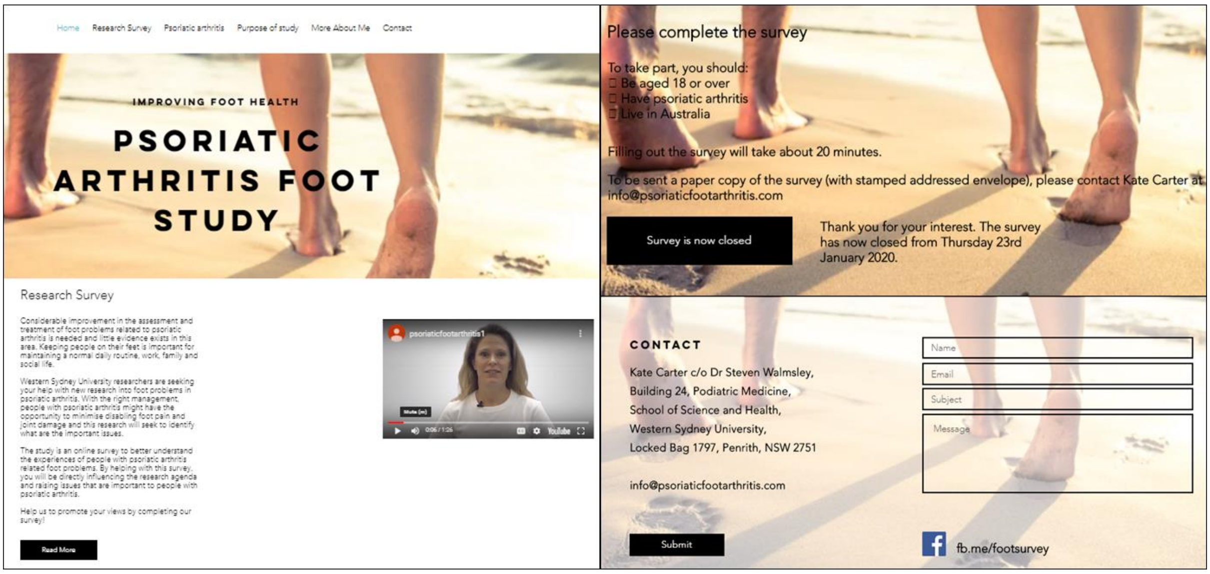
Please LIKE and SHARE our animation with your friends and family in Australia to reach as many people with Psoriatic Arthritis as possible! More survey completions will help us to improve the patient experience and foot health care

https://youtu.be/db5GiXe_Ut0

YOUTUBE.COM
Psoriatic Arthritis Survey

33 People Reached
27 Engagements

Figure 6.8. Facebook page and posts about the survey and issues relating to foot problems among people with psoriatic arthritis, including a video animation to further promote the survey.



IMPROVING FOOT HEALTH

PSORIATIC ARTHRITIS FOOT STUDY

Research Survey

Considerable improvement in the assessment and treatment of foot problems related to psoriatic arthritis is needed and little evidence exists in this area. Keeping people on their feet is important for maintaining a normal daily routine, work, family and social life.

Western Sydney University researchers are seeking your help with new research into foot problems in psoriatic arthritis. With the right management, people with psoriatic arthritis might have the opportunity to minimise disabling foot pain and joint damage and this research will seek to identify what are the important issues.

The study is an online survey to better understand the experiences of people with psoriatic arthritis related foot problems. By helping with this survey, you will be directly influencing the research agenda and raising issues that are important to people with psoriatic arthritis.

Help us to promote your views by completing our survey!

Please complete the survey

To take part, you should:
☐ Be aged 18 or over
☐ Have psoriatic arthritis
☐ Live in Australia

Filling out the survey will take about 20 minutes.

To be sent a paper copy of the survey (with stamped addressed envelope), please contact Kate Carter at info@psoriaticfootarthritis.com

Thank you for your interest. The survey has now closed from Thursday 23rd January 2020.

CONTACT

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Figure 6.9. Website page to promote the survey.

This included information about the survey, psoriatic arthritis, foot involvement, study outcomes to date, professional background of the principle investigator (KC), contact and enquiry details. A video of the principle investigator describing the purpose of the survey, background context, what participation involves and how to participant was also included for potential respondents to watch.

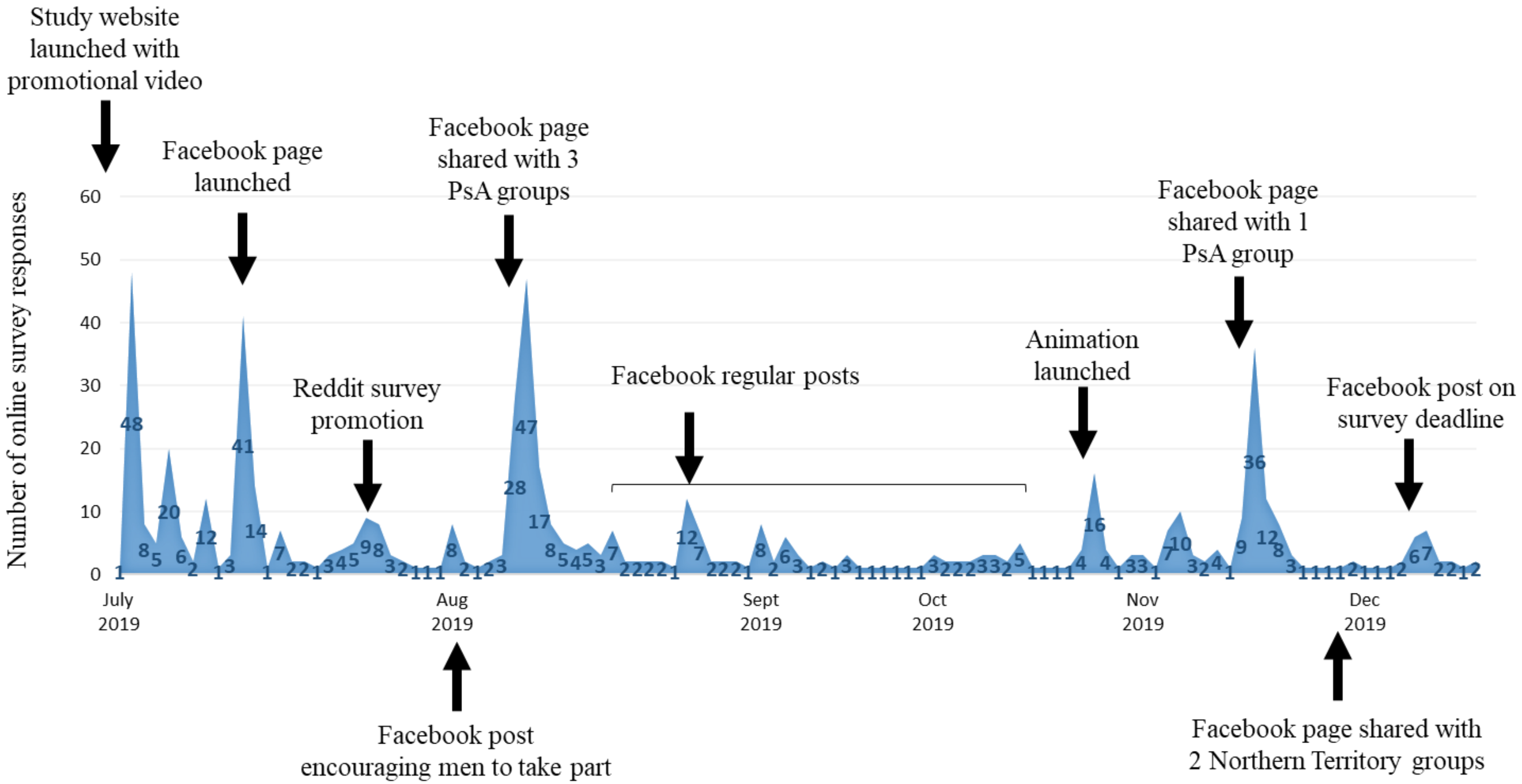

Figure 6.10. Time line for online survey responses over the 6-month recruitment period showing incremental changes in responses related to study promotional activity. There was a total of 62 Facebook posts during the study period about the survey and relevant information about the disease and foot problems.

PsA Psoriatic arthritis.

Evidence for methods to increase survey response rates (postal and electronic modes of administration) in a range of health and non-health settings have been presented in a Cochrane systemic review (Edwards, et al., 2009). Strategies adopted to increase response rates by the current study included; using a personalised approach in the survey introduction, assuring confidentiality, indicating that the survey originates from a University (rather than a government department or commercial organisation), using the non-monetary incentive of offering study results, providing stamped return envelopes for the paper survey (rather than pre-paid envelopes), offering the option of online response, putting easier questions first, and stating on the study Facebook page that others had responded, stressing the importance of responding and giving a deadline (Edwards, et al., 2009). In addition, reminders to respond were posted on Facebook and were sent to organisations who agreed to promote the survey (Nakash, et al., 2006). Strategies adopted to increase data completeness by the current study were to make the survey user friendly and to include interesting and salient questions (Edwards, et al., 2009). A strategy not adopted was to offer monetary incentives for survey completion, which can be unacceptable to some ethics committees when deemed likely to exert pressure on individuals to participate (McColl, 2007).

Handling of missing data is a difficult and complex task (Jakobsen, et al., 2017), and is frequently underreported in survey research (Turk, et al., 2018). The impact of missing data on study results was reduced by using pairwise deletion to analyse all available data (Kenward and Carpenter, 2007). In addition, transparent reporting of missing data is the recommended standard of good practice when rates are considered negligible, such as in the current study at below 5% (Li, et al., 2014; Jakobsen, et al., 2017). Therefore, both complete and partially completed surveys were analysed, with missing data provided. The survey development protocol was carefully designed and implemented in order to prospectively prevent and minimise missing data occurrence, which is supported as the best practice approach in the literature on handling missing data (Little, et al., 2012; O'Neill and Temple, 2012; Kang, 2013; Li, et al., 2014; Jakobsen, et al., 2017).

Reporting guidelines for survey research were reviewed using the EQUATOR network (Enhancing the QUAlity and Transparency Of health Research) (Equator Network, 2020). Best suited to the current study design was the SUrvey Reporting GuidelinE

(SURGE) for paper-based surveys (Grimshaw, 2014) and the CHEcklist for Reporting Results of Internet E-Surveys (CHERRIES) for web-based surveys (Eysenbach, 2004). Although the EQUATOR network recommends the STROBE (STrengthening the Reporting of Observational studies in Epidemiology) for observational studies, it does not include specific methodological characteristics that are unique to survey research (Bennett, et al., 2011; Turk, et al., 2018). Survey development, administration and data management were described using these reporting checklists.

Whilst local lead investigators to support survey dissemination in New Zealand were established, it should be noted that there can be significant challenges to conducting research in different countries. These challenges include, but are not limited to, ethical requirements, logistical management and maintaining effective communication. In New Zealand, ethical approval processes did not fit within the time restrictions of the project and were postponed. Planned dissemination of the survey in New Zealand will constitute future post-doctoral work. Therefore, the results presented pertain to Australia survey dissemination and response only.

6.4 Results

The final 59-item self-administered survey was developed based on feedback from each of the stages involving people with PsA, health professionals and experts. Key survey domains included demographic (10%) and socioeconomic data (10%), global disease information (18%), foot and ankle characteristics (18%), and the impact of foot problems on daily life including daily routine, footwear choice, family life, work and accessing healthcare (44%). The percentage coverage of items directly reflects the dominant concerns of people with PsA-related foot problems and health professionals in rheumatology. The full survey instrument and advertising text are provided in the Appendix 8 and 9.

Measures of outcome or success of survey research include those of quantity (survey and item response rates) and quality (non-response bias, validity, reliability and distribution of responses), as well as resource implications (McColl, et al., 2001). Quantity-related success outcomes in the current study included a total of 649 survey responses that comprised 602 (93%) unique online survey views and 47 (7%)

completed paper surveys (Figure 6.11). The majority of respondents progressed through 100% of the survey to reach the end (83%), with 7% of participants (n=43) not progressing beyond the first information page to enter the survey. In Australia, there was a 10% total survey response rate based on the estimated PsA sample of 6000 identified from the major sites for dissemination. The paper survey had a response rate of 7% (n=47), with 650 paper surveys distributed in Australia. The online survey full completion rate was 84%, with 559 respondents starting the first page and 468 reaching the last page of the survey. Valid and missing data for each survey item was evaluated in order to determine data completeness. With the 43 participants who did not start the survey removed from analysis, the missing data for online and paper survey completions was below 5% for the majority of respondents (95%). Time taken to complete the online survey was a mean (SD) 21 (8) minutes, with cut-off points of less than 10 minutes and more than 1 hour used to exclude survey entries with excessively short or long completion times, chosen for practical reasons to aid analysis (Eysenbach, 2004). The majority of survey respondents (82%) indicated that they would like to be contacted again about future studies related to this research, which suggests high levels of engagement and an overall positive survey experience.

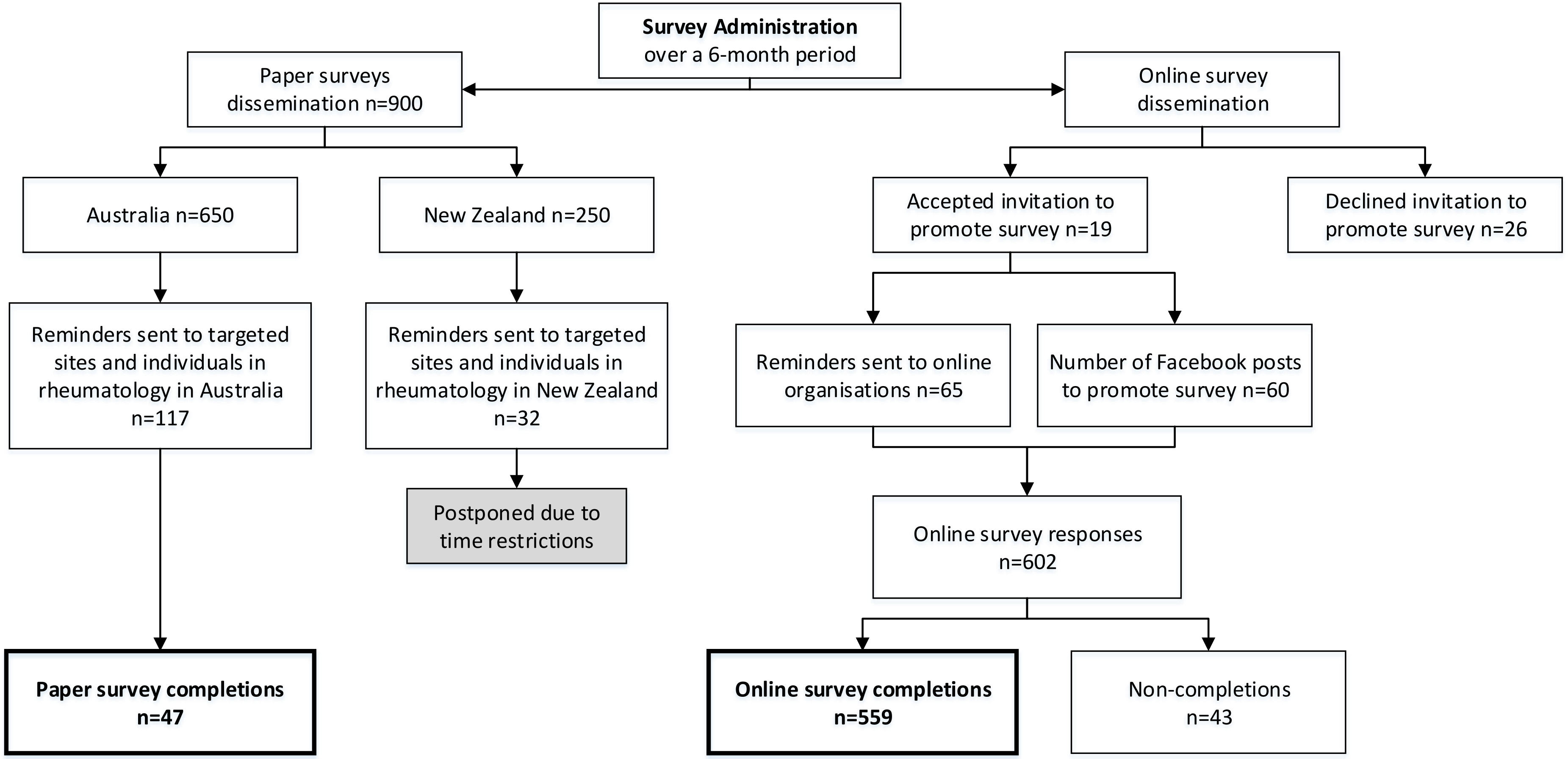

Figure 6.11. Flow diagram of survey dissemination.

Quality-related success outcomes in the current study included evidence from multiple iterations of pre-testing using different target samples, which confirmed that the instrument performed as intended in the target population. The comprehensive audit trail established that survey items were relevant to; foot involvement in the context of PsA, the target population in Australasia and the purpose of the survey, and that all items together comprehensively reflected the construct to be measured. Engaging people with PsA, health professionals and experts in the survey development methods ensured that content and face validity were achieved. Extensive pre-testing confirmed that the survey possessed sufficiently high cognitive and usability standards for potential respondents to effectively engage with and successfully complete the survey. In terms of sample representativeness, there were low reporting levels from male participants (11%), from those living in the Northern Territory state of Australia (0%) and nearly half the sample reported membership with a patient support group (41%). The results of the survey development, administration and data management were described using the SURGE and CHERRIES reporting checklists (Table 6.7 and 6.8).

Table 6.7. Summary of paper-based survey design, conduct and results using the SURGE checklist.

Checklist item	Explanation
Title and Abstract	
Design of study	A survey of foot problems among people with PsA National survey conducted in Australia and New Zealand Cross-sectional observational study design
Introduction	
Background	Considerable improvement in the assessment and treatment of foot problems related to PsA is needed, but limited evidence exists in this area. With the right management, people with PsA might have the opportunity to minimise disabling foot pain and joint damage. Most of our knowledge comes from a few studies conducted in European countries. To better target and treat localised disease in the foot, a better understanding of the foot problems and the impact they have on daily life, footwear choice and the foot care needs of people with PsA is required.
Purpose/aim of study	The aim of the survey was to find out about the foot problems experienced by people with PsA and how they impact on daily life.
Methods **Research Tool**	
Description of the survey	59-item self-administered survey There were 8 sections to the survey: Section 1 About you Section 2 About your psoriatic arthritis Section 3 About your foot and ankle Section 4 About your psoriasis Section 5 About your toenails

	Section 6 About your feet and your daily life Section 7 About your footwear Section 8 About how you manage your feet Key survey domains included demographic (10%) and socioeconomic data (10%), global disease information (18%), foot and ankle characteristics (18%), and the impact of foot problems on daily life (44%) Types of survey response options included: Text entry (n=7) Yes, or No (n=18) Two or three response options (n=3) Multiple choice (n=13) 4-point Likert scales (n=3) 5-point Likert scales (n=9) 11-point numerical rating scales (n=7) Body pain diagram; back, front (n=1) Foot pain diagram; dorsal, plantar, medial, lateral, posterior (n=1) Total number of potential skips, n=5 In total there were 27 pages of the paper-based survey Participation information sheet was attached separately (1 page) On the first page, participants were provided with the aim of the survey, inclusion criteria and an outline of the survey structure On the final page, participants willing to be contacted in the future about studies related to this research had the option to provide their name and contact information On the final page, participants wishing to find out the results from the survey were provided with the study website address and the contact information of the study investigators The full survey instrument will be provided in supplementary materials of future publications
Existing tool, psychometric properties	There were no existing tools to assess PsA-specific foot involvement
Existing tool, references to original work	
New tool, procedures to develop and pre-test	Survey items were generated by the research team based on previous work to develop a conceptual framework, a review of the related literature and clinical experience Survey items were pre-tested using methods that comprised; 1) cognitive debriefing of people with PsA, 2) focus groups with health professionals in rheumatology, 3) expert review panels of subject and survey design experts, 4) cultural sensitivity assessment and 5) pilot testing among people with PsA Best practice methods in qualitative survey design were used that resulted in 7 iterations of the survey draft Convenience sampling was used to recruit all participants involved in the development and pre-testing of the survey Ethics approval was granted and written informed consent was provided by all participants prior to data collection of demographic information
New tool, reliability and validity	Pre-testing results suggested good face and content validity, and that cognitive and usability standards were achieved
Scoring procedures	Scoring procedures for survey responses and scales were provided as examples and in the full code book
Sample selection	

Survey population	Target population included those with PsA, aged 18 or over, with current or previous foot problems, living in Australia and New Zealand
Sample frame	Adults with current foot problems, with previous without foot problems, with no experience of foot problems, with self-reported PsA, without self-reported PsA including other inflammatory or non-inflammatory arthritis condition, living in Australia and New Zealand, not living in Australia and New Zealand. - Clinic based sample; rheumatology and podiatry outpatient clinics, specialist PsA clinics - Non-clinic based sample; arthritis community groups, online patient support groups and organisations, social media groups, self-selecting participant
Sample representativeness	Potential for bias and poor representativeness included: - Participants with foot problems were more likely to take part - Reliability of self-reported PsA - Members of patient support organisations or community groups - Those receiving podiatry or rheumatology healthcare - Reach to rural areas limited - English language survey requiring a certain level of English and literacy
Sample size calculation, rationale or justification	Sample size requirements for the study were difficult to estimate as the prevalence of PsA in Australia and New Zealand were unknown a *priori*. Estimates were provided based on 1) previous Australasian-based survey research in podiatry rheumatology, 2) calculations of global percentage estimates extrapolated to the local population, and 3) target sample estimates provided by the major sites for survey dissemination
Survey administration	
Mode of administration	Mixed simultaneous mode of administration included; - Paper-based survey mailed to selected clinical services or to individuals requesting a paper copy - Web-based survey advertised (see CHERRIES checklist)
Type and number of contacts	1. Arthritis patient organisations, n=13 2. Online patient support groups, n=26 3. Specialist PsA clinic services, n=6 4. General rheumatology clinic services (public), n=22 in Australia, n=22 in New Zealand 5. Private rheumatology practice, n=68 in Australia, n=10 in New Zealand 6. Rheumatologists with special interest in PsA, n=21 in Australia 7. Health professional associations, n=7 8. Research centres, n=2 9. University podiatry clinic, n=8
Financial incentives	No financial incentives were provided
Description of who approach potential participants	- Treating rheumatologist or podiatrist - Self-selecting participants (advertising posters and flyers sent to selected clinical services, online via study website and Facebook page) - Patient support organisations (advertising at community groups, on websites, on social media groups)
Analysis	
Method of data analysis	Descriptive statistical analysis

Method for analysis of non-response error	Characterisation of respondents in order to determine non-response bias
Method for calculating response rate	With population prevalence unknown *a priori* and in the absence of national databases of PsA populations in order to estimate target population and response rates, the sampling strategy was to calculate the potential reach of the survey by samples of people with PsA identified by the major recruitment sites.
Definition of complete completion	Valid data was defined and reported n= 285 complete 100% for the online survey n= 5 complete 100% for the paper survey
Definition of partial completion	Both completed and partially completed surveys were analysed n= 274 partial completions for the online survey n= 42 partial completions for the paper survey
Methods for handling item missing data	Missing data was defined and reported. Pairwise deletion was used to analyse all available data
Results	
Response rate reported	7% response rate for the paper survey 10% response rate of the online and paper survey based on the 6000 people with PsA identified from the major sites targeted for survey dissemination
All respondents accounted for	n = 47 total number of paper survey respondents n = 559 total number of online survey respondents n= 43 total number of non-completions of the online survey (did not progression beyond the first information page)
Information on how non-respondents differ from respondents	Sample representativeness was described; Low response from: males and people from the Northern Territory High response from: Australian European/British and people with foot pain, accessing healthcare
Results clearly presented	Yes
Results address objective	Yes
Discussion	
Results summarised referencing study objectives	Yes
Strengths of the study	Yes
Limitations of the study	Yes
Generalisability of results	Information provided
Ethical quality indicators	
Study funding	There was no funding source for the study
Research Ethics Board review	Ethical approval was granted by South Western Sydney Local Health District (HREC/171/LPOOL/353) including site specific agreements for Liverpool Hospital (SSA/17/LPOOL/407), the BJC Health rheumatology clinic (SSA/17/LPOOL/407), Royal North Shore Hospital in North Sydney Local Health District (SSA/18/HAWKE/78, RESP/19/066); Western Sydney University Human Research Ethics Committee (H12973), Auckland University of Technology Ethics Committee (AUTEC 17/320), and Waitemata District Health Board of Auckland, New Zealand (RM/3907)
Subject consent procedures	Survey development: Written informed consent was provided by all participants prior to data collection. Survey administration: Consent was implied, participation information sheet was provided.

PsA Psoriatic arthritis

Table 6.8. Summary of web-based survey design, conduct and results using the CHERRIES checklist.

Checklist item	Explanation
Design	
Survey design	A survey of foot problems among people with PsA National survey conducted in Australia and New Zealand Cross-sectional observational study design
Target population	Adults with PsA, with past or present foot problems, living in Australia or New Zealand
Sample frame	- Clinic based sample; rheumatology and podiatry outpatient clinics, specialist PsA clinics - Non-clinic based sample; arthritis community groups, online patient support groups and organisations, social media groups, self-selecting participant
Convenience sample type	Yes
Institutional Review Board approval and informed consent process	
Institutional Review Board approval	Yes Western Sydney University Human Research Ethics Committee (H12973)
Informed consent process	Implied
- how long the survey will take	20 to 30 minutes
- data stored, where and how long	Data electronically compiled from the paper- and web-based survey was stored in a password-protected file, on a password-protected computer at Western Sydney University. Data will be kept for 5 years and then it will be destroyed
- study investigators	Miss Kate Carter, Dr Steven Walmsley, Professor Keith Rome, Professor Deborah Turner
- purpose of the study	The aim of the survey was to find out about the foot problems experienced by people with PsA and how they impact on daily life
Data protection	
- personal information collected	Name and telephone number or email address (optional)
- personal information stored	Participants had the option to take part in potential future studies by providing their contact details (name and telephone number or email address). For the web-based survey responses, the participant contact information was downloaded from Qualtrics and stored separately from the main survey data in a password protected file, on a password protected computer that could only be accessed by the research team. Each participant was allocated a unique identifying number under which all data was recorded
- mechanism to protect unauthorised access to personal information	Password protection
Development and pre-testing	
Procedures to develop and pre-test	The web-based survey was developed with testing the usability and technical functionality of the electronic survey by people with PsA and by a survey design expert
Recruitment process and description of the sample with access to survey	
Type of survey	Open type of survey to each visitor of the survey web-link, website and Facebook page
Contact mode	Initial contact with potential participants was through: - internet (website, Facebook page) - e-mail (providing survey web-link on request)

	- poster and flyer with survey web-link posted to sites/clinics
Advertising of survey	Mixed advertising methods included: - online patient organisation website and Facebook page - health professional associations website and Facebook page - e-newsletters of patient organisations - social media (website, Facebook page, online support groups) - poster and flyer posted to sites/clinics with survey web-link - study website and Facebook page
Wording of the advertisement	Provided in supplementary materials
Survey administration	
Web or e-mail based survey	Web-based survey only, with link to web-based survey
Data entry	Automatic web-based entry, no manual entry required
Context	Websites on which the survey was posted:
- Describe the websites	- Arthritis patient organisations, n=13
Visitors to websites, purpose of visit	Charitable, not-for-profit organisations, provides support and information to people with arthritis. Visitors may be seeking information or support, wanting to share information, donate or fundraise, or to take part in research - Online patient support groups, n=26 Open or closed groups, promotes awareness of the challenges facing people with arthritis across the community, provides support and shares information. Visitors may be seeking information or support, wanting to share information, donate or fundraise, or to take part in research - Health professional associations, n=7 Closed group of health professionals. Visitor may be seeking information on training, governance and job opportunities, to provide information, or to seek updates on current work practices and research projects - Study website and Facebook page, n=109 views, n=80 followers People with PsA and/or people with foot problems. Visitors may be seeking to take part in the survey or wanting to find out more information about the study There is a high degree to which the content of the websites could pre-select the sample or influence results. Selection bias cannot be ruled out
Mandatory or voluntary	Voluntary
Incentives	No incentives were provided
Timeframe for data collection	July 2019 – December 2019, 6 months
Randomisation of survey items	Not randomised or alternated
Adaptive questioning	Adaptive questioning was used to reduce number and complexity of the questions. Certain questions and sections were displayed based on responses to other items. Adaptive view of survey (if no, automatic skip): - Information sheet (page 2) - Items 23-25 (page 14-16) - Items 31-34 (page 20) - Items 36-37 (page 22)
Number of items per page	Number of question items per page: **Page** **Items per page** Page 1 Introduction

	Page 2 Information sheet Page 3 2 Page 4 1 Page 5 3 Page 6 1 Page 7 3 Page 8 3 Page 9 1 Page 10 2 Page 11 4 Page 12 1 Page 13 1 Page 14 1 Page 15 1 Page 16 1 Page 17 2 Page 18 2 Page 19 1 Page 20 4 Page 21 1 Page 22 2 Page 23 2 Page 24 1 Page 25 3 Page 26 3 Page 27 4 Page 28 2 Page 29 1 Page 30 1 Page 31 5 Page 32 Willing to be contacted Page 33 Study investigator contact Page 34 Review responses Page 35 Thank you for taking part
Number of screens/pages	A total of 35 screens could be viewed and the minimum due to adaptive questioning is 29 screens.
Completeness check	Completeness checks were done after the questionnaire was submitted. Forced response items related to inclusion criteria only including: - Item 1 Where do you live? - Item 3 How old are you? Mandatory selection of one response options was not enforced.
A non-response option	A non-response option was provided on 4 occasions including ‘prefer not to state’, ‘not relevant’, ‘not sure’ and ‘neither of these’
Review step	Respondents were able to review and change their answer through a back button and review step that displays a summary of the responses to check prior to submission
Response rates	
Unique site visitor	The number of unique site visitors was 602
View rate	The number of visitors to the first page of the online survey, n=602
Participation/recruitment rate	The number of people who filled in the first page of the online survey n=559, 93%
Completion rate	The number of people who submitted the last page of the online survey (n=468, 78%) divided by the number who agreed to participant (started the first page of the online survey) (n=559, 93%). Completion rate = 84%

Preventing multiple entry from the same individual	
Cookies used	Cookies were not used to prevent users from accessing the survey twice.
IP check	IP addresses were not used to prevent users from accessing the survey twice. IP address were used to identify duplicated entries from the same user. Duplicates were reviewed and eliminated before analysis. The first or last entry was selected based on completeness
Log file analysis	No other techniques were used to analyse the log file for identification of multiple entries
Registration	It was an open survey, IP addresses were used to identify duplications for later elimination before analysis
Analysis	
Handling of incomplete surveys	Both complete and partially completed surveys were analysed
Survey submitted with an atypical timestamp	Mean (SD) time taken to complete the survey was 21 (8) minutes Cut-off points were used to exclude survey entries with excessively short or long completion times, less than 10 minutes (n=87, 14%) and more than 1 hour (n=29, 5%)
Statistical correction	Methods to adjust for the non-representative sample were weighting of items/propensity scores

PsA Psoriatic arthritis.

6.5 Discussion

To the best of our knowledge this is the first time a survey has been developed on foot involvement in PsA based on best practice methods in survey design. Extensive pre-testing among key relevant stakeholder groups improved the overall quality, functioning and representativeness of the survey instrument. Although there is limited empirical evidence and few universal best practice recommendations for survey design and conduct (Reynolds, et al., 1993; McColl, et al., 2001; Edwards, 2010), comprehensive and transparent descriptions of survey design methods can allow clearer review of the usefulness and validity of the survey research (Turk, et al., 2018). This study presents a high-quality worked example of survey design and conduct, which can be used as a template by other research teams for broader application. The robust survey development protocol and pre-defined dissemination strategy positively influenced response rates and data completeness.

Whilst the sampling strategy was to gain an appreciation of the potential survey reach and response relative to reach, the resultant 10% response rate does not meet the acceptable target response rates reported between 30% and 50% for survey research (Sue and Ritter, 2007; Nulty, 2008). Similar New Zealand-based podiatry surveys reported sample sizes of 197 and 131 participants from a target sample of 400, with response rates of 49% and 32% respectively (Brenton-Rule, et al., 2014; Otter, et al., 2016). Brenton-Rule, et al., (2014) surveyed across all groups of inflammatory arthritis using a web-survey promoted by Arthritis New Zealand. Based on these existing published sample sizes, the current study survey response of 606 PsA-specific participants was a very good response rate. The full survey completion rate from participants that attempted the survey was 91.95%, which is evidence of a successfully developed survey with few partial completions.

Of the 43 participants who did not progress beyond the first information page to enter the survey, a proportion may have been other researchers, health professionals and administrators promoting the study that previewed the online survey and inadvertently contributed to the number of non-completions. A screening question to identify the difference between genuine non-responders with PsA and those interested in viewing the survey without PsA could have been included in order to better define non-completion information. Nearly half of the respondents were members of a patient support group (41%), which could be a potential source of bias in the sample. However, with no national databases to target for recruitment there was no alternative approach other than to target the membership of patient support organisations and clinic-based samples. Despite attempts to target certain groups on social media, the underrepresentation from males and those in the Northern Territory reduced the representativeness of the sample, which should be considered in the interpretation of the results and requires further work to determine the foot health needs of non-responders. In the pilot test prior to survey dissemination the poor completion of question 52 relating to self-care effectiveness was identified but not changed, which translated through to its poor completion in the final survey with 24% of missing data for that question. Exclusion or survey item revision to reduce difficulties related to recall, judgment and emotiveness may have prevented loss of data, which highlights the effectiveness of pilot testing in pre-identifying poor item performance issues.

Patient self-report is increasingly used to assess the impact of PsA, to gain insight into the patient experience and to formulate new questions for investigation (Taylor, et al., 2010; Tillett, et al., 2014; Orbai, et al., 2017a). The GRAPPA-OMERACT study groups have used qualitative self-reported information and the ICF model in the preliminary stages of defining what to include in the measurement of disease impact domains and in the development of outcome measures (Stamm, et al., 2007b; Gudu, et al., 2017; Orbai, et al., 2017b). In accordance with the international working groups in PsA, this large national survey has incorporated the patient's voice in the measurement of PsA by engaging patients in research activity throughout survey development protocol. Discordance between the views of people with PsA and health professionals were identified in phase 2 of survey development, which related to the use of technical language and the overall length of the survey with both issues being acceptable to patients but unacceptable to health professionals. These findings were consistent with similar research that found differences in the patient's and the health professional's perspective of disease in PsA (Dandorfer, et al., 2012), and emphasises the importance of embedding the patient perspective in the development of measures in PsA.

A major strength of this study was the rigorous evidence-based approach used to develop the survey and the involvement of patients, health professionals and experts as a central component of survey research. The conceptual framework provided the basis for targeting the concerns and needs of patients in the measurement of PsA-related foot involvement. The ICF provided a standardised approach to identify and describe relevant domains of impact on functioning that were used to inform the survey development, and enables the conceptual framework to be widely understood. Consequently, all components of the ICF framework were mapped to the survey, substantially improving the overall quality and relevance of the survey. By incorporating the views of those with the disease and of health professionals into the survey development process, good conceptual coverage of items important to both patients and health professionals was achieved and supports face and content validity. Their real-world experience provided insight into PsA symptoms and the associated impact that resonated with survey respondents and allowed them to describe their experience in a meaningful manner, which is likely to encourage higher response rates and fuller survey completions.

The web-based survey was acceptable among respondents with PsA, was easy to complete and took no longer than the paper version, findings that are in concordance with previous studies in PsA (Chandran, et al., 2007; MacKenzie, et al., 2011; Magrey, et al., 2019). The current study employed an adaptive design to ensure the web-version performed exactly as intended on different devices to collect equivalent data to the paper-version, and research evidence indicates that there is good comparability of data collected by paper and web-based surveys in PsA (MacKenzie, et al., 2011). Web-based surveys are increasingly used to obtain patient data and this study highlights the significant value of usability pre-testing among patients and survey experts in the preliminary stages of survey design.

Despite the widespread use of surveys in podiatry rheumatology research (Graham, et al., 2017; Brenton-Rule, et al., 2019; Stevens, et al., 2019), few studies have used rigorous methodologies or 'best practices' for high-quality survey design. Consequently, many surveys may lack the sound measurement properties required to collect reliable and valid data, which may be further demonstrated by limited research impact. Allied health research frameworks highlight the importance of research impact through engagement with patient communities and clinical networks, and through improvements that can be objectively measured and translate to clinical practice (NHMRC, 2020; NIHR, 2020; Victorian Allied Health Research Framework, 2020). Future work is planned to conduct a systematic review of existing surveys developed to research rheumatic foot conditions in order to 1) appraise explicit methodologies, 2) determine survey content validity, and 3) establish the usefulness of this approach in yielding deliverable research impact. It is acknowledged that the survey design methodology utilised in the current study does not represent the only way to develop a high-quality survey. However, it highlights important, evidence-based approaches to survey design that may be used in future podiatry survey-based research.

Limitations of the survey development process (phase 1 and 2) include a potential sampling bias with all research participants chosen by convenience sampling. Therefore, participants who volunteered to take part in the survey development may not be representative of all people with foot involvement in PsA or the health professionals who manage this patient group. However, participants were recruited from multiple sites in order to achieve a diverse cross-section of the sample and recruitment continued until qualitative data saturation was reached. Although participants were recruited using convenience sampling based on our research collaboration network in Sydney, Australia and Auckland, New Zealand, it is possible for purposive sampling to recruit heterogeneous maximum variation samples (Patton, 2002). To ensure the survey captured differences related to socioeconomic and geographic contexts, the research advisory group pre-defined key variables relating to health economic data, which were included as part of the survey item development. A limitation to the study generalisability is that the multiple iterations of pre-testing and pilot testing required to develop a high-quality survey are resource and time intensive, which may be prohibitive for some research teams.

6.6 Conclusion

This study describes a robust survey development protocol using best practice methods in survey design and conduct, with the intent that this could be utilised as a framework for survey development in other areas of clinical practice. Involvement of people with PsA, health professionals and experts throughout the survey development process was a central component that ensured the survey functioned properly and yielded successful survey outcomes. Focus on high-standards of reporting survey research permits wider application of the protocol beyond the intended target population of the survey. Findings from the survey will provide useful data to inform clinical decision making and targeted research strategies.

6.7 Significance and Innovation

- This survey protocol presents a high-quality worked example of survey design and conduct, which can be used as a template by other healthcare researchers for broader application.

- Involvement of patients throughout the survey development process was essential in order to ensure that survey items assessed constructs important and relevant to them, and that the survey functioned properly as a content-valid and usable research tool.

- Systematic application of qualitative research methods used to design and develop a self-administered survey demonstrated merit in yielding successful survey outcomes determined by high response rates and data completeness, which were likely to have been driven by high levels of motivation among respondents to complete the survey related to strong personal resonance with life impact areas.

- This study highlights the use of best practice guidelines in order to achieve high-standards of reporting survey research, which was supported by a clear audit trail and robust survey development methods.

Chapter 7

7 Preface to Results

The results and discussion section of this thesis present a focused, mainly descriptive analysis of outcomes related to the success of the survey and on the impact of foot involvement on daily life in people with PsA. Survey development activities formed a large component of the PhD structure and an *a priori* determination was made that a full in-depth discussion of the survey results would be beyond the scope of this PhD. Any inferential statistical analysis is restricted to the key pathological features of PsA in the foot, in the context of global disease and in relation to their impact on daily activities, ability to cope and foot care needs. The intention is that in-depth analysis will form the basis of a program of work at post-doc level and will include advanced statistical modelling to investigate complex relationships between domains of functioning and disease impact (see section 9.9.1 in Chapter 9).

7.1 Context

The intent of this PhD was to gain a better understanding of the nature, extent and location of foot involvement and its impact on the lives of people with PsA, which was driven by the sparsity of foot-specific research in PsA. Furthermore, to the best of the authors knowledge, no previous studies have explored the impact of PsA-related foot involvement from the patient perspective. From the initial phase of the qualitative study and International Classification of Functioning, Disability and Health (ICF) mapping, key concepts relevant and important to people with PsA-related foot problems were identified. A central component of this work was the development of a robust conceptual framework, which took into consideration the methodological recommendations of the GRAPPA-OMERACT to generate patient and clinician-relevant domains using qualitative techniques and integration of the ICF (Boonen, et al., 2009a; Orbai, et al., 2017a). From a survey analysis perspective, the qualitative and ICF work provided valuable insight into important cognitive functions that mapped across different impact domains incorporated in the survey, which included coping strategies, emotional burden, and the perceived lack of understanding about the disease by people with PsA. The conceptual framework subsequently informed the content, design and implementation of a large-scale survey. Whilst the focus for the

PhD was to develop a comprehensive survey, the supervisory team recognised that implementation of a national survey (the first of its kind) presented a unique opportunity to collect important data beyond the initial scope of the PhD. This was an intentional approach to fully exploit the implementation of the first survey on foot involvement in PsA, with recognition that future surveys of this targeted group may not yield the same uptake. To avoid an extensive but superficial description of the substantial quantity of survey data collected, a focused data analysis plan with the *a priori* declaration was established.

7.2 Statement of intent

The main elements of the survey results will be summarised in order to determine the nature, extent and location of foot involvement in PsA, with a focus on key discrete areas of the survey relating to impact directed by the conceptual framework. Rationale for a focused approach to data analysis was 1) based on the recognised value of preceding methods in highlighting important concepts and 2) to gain a more in-depth description of the key impact areas with clinically relevant interpretations (for example, site-specific foot involvement and their impact on activities of daily living, emotional well-being related to embarrassment and frustration, ability to cope, footwear, perceived understanding and support related to foot care). Whilst it is acknowledged that these complex and multifaceted concepts require more advanced statistical analysis, a focused descriptive analysis with selected inferential analyses to facilitate clinical interpretation will provide useful preliminary insights into the determinants of impact from localised disease in the foot in PsA, and will direct the future research agenda beyond the study of disease features alone. Comprehensive exploration of the survey results will form significant post-doctoral investigation.

Significant time and resources were invested in the robust survey development protocol and dissemination strategies in order to increase the likelihood of high survey response rates and the collection of valid and unbiased data from a representative sample. Evaluation of outcomes that indicate survey success were implemented in order to align with best practice and help validate the rigorous approach taken. The results chapter 8 will present the main survey findings in a similar manner to the structure of the survey with emphasis on the impact of localised disease on daily life, footwear and foot care needs using the following sub-headings:

(1) Sample response and data completeness
(2) Survey results
    i) Demographic information and clinical characteristics
    ii) Foot and ankle characteristics
    iii) Activity and participation
    iv) Footwear
    v) Self-management
    vi) Healthcare service access and support

Chapter 8

8 Results

8.1 Sample response and data completeness

8.1.1 Sample size and response rates

Of the 649 survey responses, 602 (93%) were online and 47 (7%) were paper responses. A total of 650 paper surveys were sent to target sites and 47 were returned (7% response rate). Of the 602 unique online views of the survey, 43 participants did not start the survey or submit any data and so were removed from subsequent analysis. For the online survey 559 respondents started the first page of the survey and 468 reached the last page (84% full data completion rate).

8.1.2 Missing data

The majority of respondents progressed through 100% of the survey to reach the end (83%). Missing data for online and paper survey completions was below 5% for the majority of respondents (95%). There were more partial completions of the paper survey compared with the online version, 89% and 46% respectively. There was gradual attrition of valid data through progression to the end of the paper and online survey. Time taken to complete the online survey was a mean (SD) 21 (8) minutes.

Survey items with the highest amount of missing data (paper and online) was question 53 (text entry of dollars for out-of-pocket expenditure on foot health self-care) (n=113, 21%), question 52 (5-point Likert scale on the effectiveness of self-caring for foot problems) (n=103, 19%), and question 54 (5-point Likert scale on the level of confidence in the understanding of health professionals of PsA-related foot problems) (n=79, 13%).

Pairwise deletion was used to handle the missing data and descriptive analysis was used for the transparent reporting of missing data for each survey item. Pairwise deletion is an approach to handling missing survey data that allows more of the data to be used in comparison with other methods for handling missing data such as listwise deletion. In order to preserve more information from the survey results this method was selected (Kang, 2013). A potential problem with the use of pairwise deletion is that it can be unclear what sample size is used for tests of statistical significance, because the sample sizes for each survey item typically vary with different pairwise corrections. Therefore, explicit reporting of missing data is critical to allow interpretation of results with recognition of the implications of the procedures for handling missing data. In future post-doctoral work, advanced analysis of the missing data analysis will include analysis of patterns of missing data and multiple imputation, which replaces missing values with a set of predicted values based on the existing data from other variables and creates a full and statistically rigorous imputed data set.

8.1.3 Comparison of paper survey response with the online response

Differences between the paper survey sample and online sample were related to age, ethnic group, work status and education level. Those who completed the paper survey were older with a mean (SD) age of 56 (13) years compared with the online sample of 51 (12) years. Whilst the largest ethnic groups were Australian European and British in both the paper and online samples, a greater proportion of other ethnicities completed the paper survey at 26% (n=12) compared with 15% (n=80) online. In addition, the majority of people who completed the paper survey were retired (n=18, 38%), whereas most of the online sample were in full time or part time employment (30% and 21% respectively) with 12% who were retired (n=67). No differences were found between the paper and online samples related to social deprivation (postcode) or clinical characteristics (disease duration, symptom onset, current medications, presence of foot pain, severity of global pain and foot pain).

The majority (n=40, 85%) of paper surveys were completed by participants from New South Wales (NSW). Of the 650 paper surveys that were distributed, 56% were sent to rheumatology clinical services in NSW (n=362). Therefore, the increased response was a result of the higher proportion of paper surveys distributed in NSW compared with other states, which was due to the local networks of the research team based in NSW and connections with specialist PsA services that are distinct in NSW.

8.1.4 Body and foot pain diagram data analysis

A limitation of the Qualtrics software was that it restricted each online survey participant to a maximum of 10 marks per pain diagram. The paper version allowed unlimited marks. In addition, the online version of the survey did not permit shading in, whereas the paper version did. These differences between the paper and online survey versions were analysed (Table 8.1).

Table 8.1. Comparing pain prevalence reported using the paper and online pain diagrams.

	Body pain diagram 1	Body pain diagram 2	Foot pain diagram 1	Foot pain diagram 2	Foot pain diagram 3	Foot pain diagram 4	Foot pain diagram 5
Paper survey, valid data	47	47	47	38	38	38	38
Number of painful sites, mean	7 (7)	7 (6)	8 (8)	7 (8)	3 (4)	2 (3)	3 (4)
Number of painful sites, range (n)	0 - 24	0 – 21	0 - 27	0 - 27	0 - 12	0 - 10	0 - 13
Number of painful sites >10 marks, n (%)	12 (25%)	13 (28%)	13 (34%)	13 (34%)	2 (5%)	0	2 (5%)
Online survey, valid data	577	576	524	524	525	524	523
Number of painful sites, mean	7 (3)	6 (3)	5 (3)	5 (3)	3 (2)	3 (2)	3 (2)
Number of painful sites, range (n)	0 - 10	0 - 10	0 – 10	0 - 10	0 - 10	0 - 10	0 - 10
Number of painful sites >10 marks, n (%)	100 (17%)	41 (7%)	35 (7%)	23 (4%)	4 (1%)	0	3 (1%)

Data presented as mean (SD) unless specified. Body pain diagram 1: back view, body pain diagram 2: front view; Foot pain diagram 1: left foot dorsal and plantar view, foot pain diagram 2: right foot dorsal and plantar view, foot pain diagram 3: left and right foot lateral view, foot pain diagram 4: left and right foot posterior view, foot pain diagram 5: left and right foot medial view.

Online survey results show that 100 people (17%) placed the maximum of 10 marks on body pain diagram 1 and 41 people (7%) on body pain diagram 2, indicating a potential underrepresentation of body pain in those individuals. For the online foot pain diagrams 1 to 5; there were 35 (7%), 23 (4%), 4 (1%), 0 and 3 (1%) people who placed the maximum of 10 marks per diagram respectively, indicating that there were possibly more painful sites than could be recorded for up to 7% of the online sample. It is unknown from the online pain diagrams with 10 marks, whether a total of 10 were applied or if the participant intended to apply more than 10 marks.

In the paper survey sample where there were no limits to the number of marks that could be recorded, a mean (SD) of 7 (6) marks were applied to each body diagram with a range of 0-24 for diagram 1 and 0-21 for diagram 2. A total of 12 participants placed more than 10 marks on body pain diagram 1 (25%) and 13 participants (28%) on body pain diagram 2. For foot pain diagrams 1 to 5 in the paper sample, the mean (SD) number of marks were 8 (8), 7 (8), 3 (4), 2 (3) and 3 (4) respectively, with between 5% and 34% (n=2 to 13) of the sample placing over 10 marks per foot pain diagram.

Whilst the software limitation may have created a difference in data collection between the paper and online survey in the frequencies of pain location, it was reasonable to consider that the affect was minimal with the majority of paper survey respondent's marking less than 10 painful sites on the body (72%) and foot (66%) pain diagrams, and a maximum of 17% and 7% of online survey respondents placing a total of 10 marks on the body (n=100) and foot (n=35) pain diagrams respectively.

8.2 Survey results

8.2.1 Demographic information and clinical characteristics

The demographic and clinical characteristics are summarised in Table 8.2. Survey respondents were predominately women of European descent, aged between 40 and 60 years old, from the Eastern states of Australia (Figure 8.1). The majority of participants were in full time employment (30%), with a diploma or university degree education level (75%), living in relatively affluent socioeconomic areas (50%). Nearly half (n=266, 45%) reported that their work status had changed due to their PsA, with 15% unemployed or disabled and too sick to work.

Participants reported having established disease (more than or equal to 5 years) with a mean (SD) disease duration of 8.5 (10) years. There was a mean (SD) diagnostic delay from symptom onset to diagnosis of 5.5 (2) years. A wide range of disease duration was reported from 1 month to 60 years. Nearly half (43%) of respondents were currently taking a biologic, 14% were taking methotrexate as a single line therapy, and 36% were taking more than one category of disease modifying anti-rheumatic drug (DMARD). A total of 237 (41%) reported having depression, 39% had anxiety, 30% had osteoarthritis, 20% had fibromyalgia, with diabetes being the least reported comorbidity (10%). Over half (n=325, 56%) of respondents were obese (>30 kg/m2). Underrepresented groups in the study sample included low reporting levels from male participants (n=69, 11%), from those living in the Northern Territory of Australia (0%), and those with non-European ethnic backgrounds (7%).

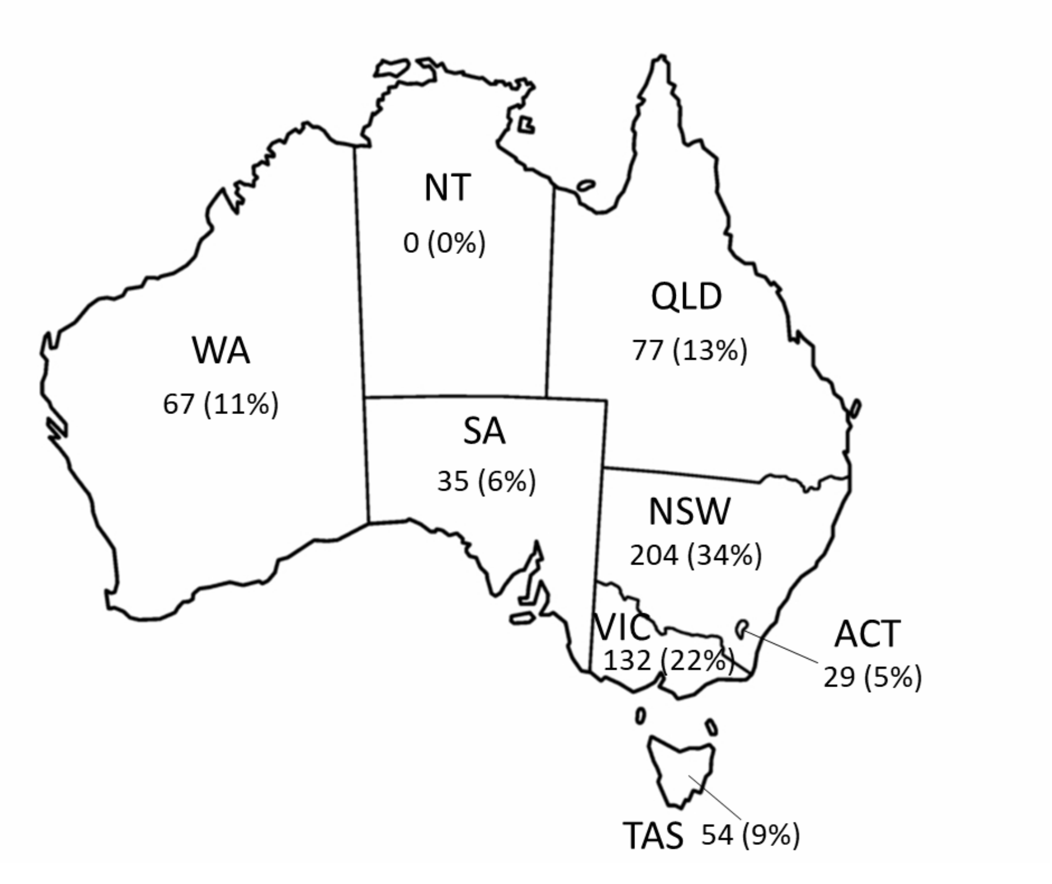

Figure 8.1. Distribution of survey responses across the states and territories in Australia, n (%).

ACT Australian Capital Territory, *NSW* New South Wales, *NT* Northern Territory, *QLD* Queensland, *SA* South Australia, *TAS* Tasmania, *VIC* Victoria, *WA* Western Australia. (Valid data = 598. Missing data = 8).

Table 8.2. Demographic information and clinical characteristics of participant with psoriatic arthritis in Australia.

Variables	Value	Valid data	Missing data
Ages, years	51 (12)	604	2
Women, n (%)	532 (89%)	601	5
Body Mass Index, Kg/m^2	31.3 (7)	589	17
Ethnicity, n (%)		598	8
Australian European	459 (77%)		
British	84 (14%)		
European	15 (2%)		
Aboriginal	6 (1%)		
Other	34 (6%)		
Socioeconomic representation, n (%)		594	12
1 – 3 Most deprived	131 (23%)		
4 – 6	165 (27%)		
7 – 10 Least deprived	298 (50%)		
Work status, n (%)		588	18
Full time paid work	177 (30%)		
Part time paid work	116 (20%)		
Completely retired	85 (14.5%)		
Looking after home/family	85 (14.5%)		
Disabled or too sick to work	84 (14%)		
Self-employed	46 (8%)		
Casual or contracted paid work	41 (7%)		
Studying	32 (5%)		
Unpaid work	20 (3%)		
Partially retired	16 (3%)		
Unemployed	5 (0.8%)		
Other (full time carer)	2 (0.2%)		
Education level, n (%)		595	11
University degree or higher	243 (41%)		
Certificate/diploma	206 (35%)		
School or intermediate certificate	45 (8%)		
Higher school or leaving certificate	44 (7%)		
Trade/apprenticeship	32 (5%)		
No qualifications	25 (4%)		
Disease onset (from symptom onset), years	14 (12)	577	72
Less than 2 years (early disease)	42 (7%)		
2 to 4 years	95 (17%)		
5 years and more (established disease)	440 (76%)		
Disease duration (from diagnosis), years	8.5 (10)	581	68
Less than 2 years (early disease)	135 (23%)		
2 to 4 years	140 (24%)		
5 years and more (established disease)	360 (53%)		
Current medications, n (%)		580	26
Methotrexate	259 (45%)		
Other DMARD (leflunomide, salazopyrin, hydroxychloroquine,	449 (77%)		

cyclosporine)			
Biologics	249 (43%)		
Prednisone	103 (18%)		
NSAIDs	256 (44%)		
Alternative or complementary medicines	79 (14%)		
Other medications for PsA not listed	93 (16%)		
No medications for PsA	43 (7%)		
Comorbidities, n (%)		573	33
Depression	237 (41%)		
Anxiety	221 (39%)		
Osteoarthritis	173 (30%)		
Fibromyalgia	112 (20%)		
Diabetes Mellitus	56 (10%)		

Data presented as mean (SD) unless specified. *DMARDs* Disease modifying anti-rheumatic drugs, *NSAID* Non-steroidal anti-inflammatory drugs, *PsA* Psoriatic arthritis.

In the context of PsA global disease characteristics, the mean (SD) patient global assessment scores rated on a numerical rating scale (NRS) for over the past week were; 6 (2) for arthritis alone, 4 (3) for psoriasis alone, 6 (2) for arthritis and psoriasis together, and 6 (2) for global pain (Table 8.3). Despite current disease management, half the participants reported severe levels of global disease activity over the last week (n=287, 50%) and local foot and ankle pain over the past month (n=246, 47%). A significant relationship was identified between greater levels of foot and ankle pain severity over the past month and increased levels of global pain severity in PsA over the past week, as determined using the Kruskal-Wallis test (Figure 8.2). In relation to foot and ankle pain and global pain, the median foot and ankle pain scores were significantly different between groups, $\chi2(2)=180.887$, p=<0.0001. The median foot and ankle pain score was significantly higher for severe global pain (7) compared with mild global pain (4) (p=<0.0001), significantly higher for moderate global pain (6) compared with mild global pain (p=<0.0001) and significantly higher for severe global pain compared with moderate global pain (p=<0.0001).

Table 8.3. Patient global assessment scores and global pain rating by people with psoriatic arthritis.

Patient global assessment over the past week, NRS (0-10)	Arthritis^{*1} n (%)	Psoriasis^{*2} n (%)	Arthritis and psoriasis^{*3} n (%)	Global pain^{*4} n (%)
0 to 3, mild	92 (16%)	294 (52%)	89 (16%)	90 (16%)
4 to 6, moderate	197 (34%)	148 (26%)	193 (34%)	235 (41%)
7 to 10, severe	283 (50%)	122 (22%)	287 (50%)	248 (43%)

Valid data = 572^{*1}, 564^{*2}, 569^{*3}, 573^{*4}. Missing data = 77^{*1}, 85^{*2}, 80^{*3},76^{*4}
NRS Numerical rating scale.

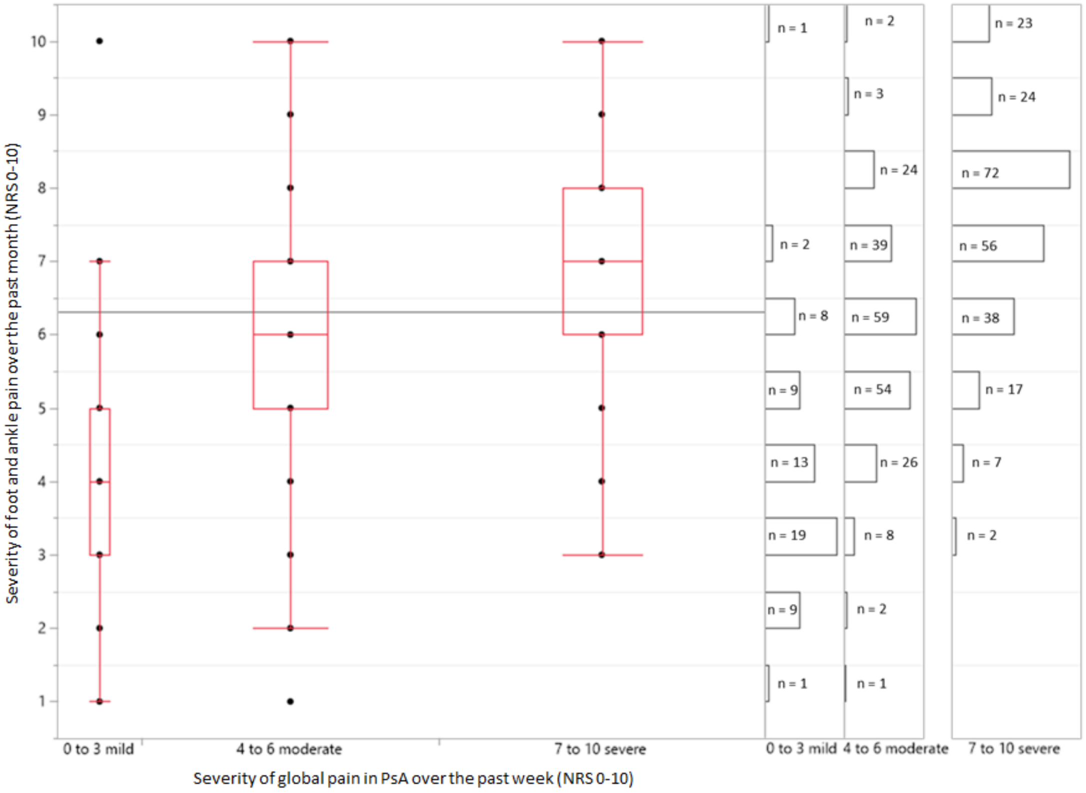

Figure 8.2. Box plot and histogram to illustrate the distribution of foot and ankle pain scores over the past month in accordance with global PsA pain over the past week, which shows that there is a greater severity of foot and ankle pain with a greater severity of global pain in PsA. The histogram is counting the numbers from the box plot, where n indicates the number of respondents. The line across the box plot is the mean severity of foot and ankle pain across all groups.

PsA Psoriatic arthritis. *NRS* Numerical rating scale, with 0 being no pain and 10 being the worst pain ever.

The distribution of commonly symptomatic (ache/pain) areas affected by PsA were the feet/toes, hands/fingers and spine (Figure 8.3). Only one respondent reported that they had experienced no pain in any part of the body over the past month (Table 8.4). There were 30 (5%) respondents who indicated that were unable to determine the single most painful part of their body, which was due to being unsure or to attributing equal pain severity to more than one body part.

Table 8.4. Global pain location of the most painful or sore part of the body over the past month reported by people with psoriatic arthritis.

Variables	**Value**	**Valid data**	**Missing data**
Most painful or sore part of the body over the past month, n (%)		577	29
Feet and toes	209 (36%)		
Hands and fingers	67 (12%)		
Back	66 (11%)		
Hips	53 (9%)		
Ankles	44 (8%)		
Knees	39 (7%)		
Shoulders	23 (4%)		
Head and neck	22 (4%)		
Wrists	12 (2%)		
Elbows	11 (1.9%)		
Not sure	11 (1.9%)		
No pain	1 (0.2%)		
Unable to select only one	19 (3%)		

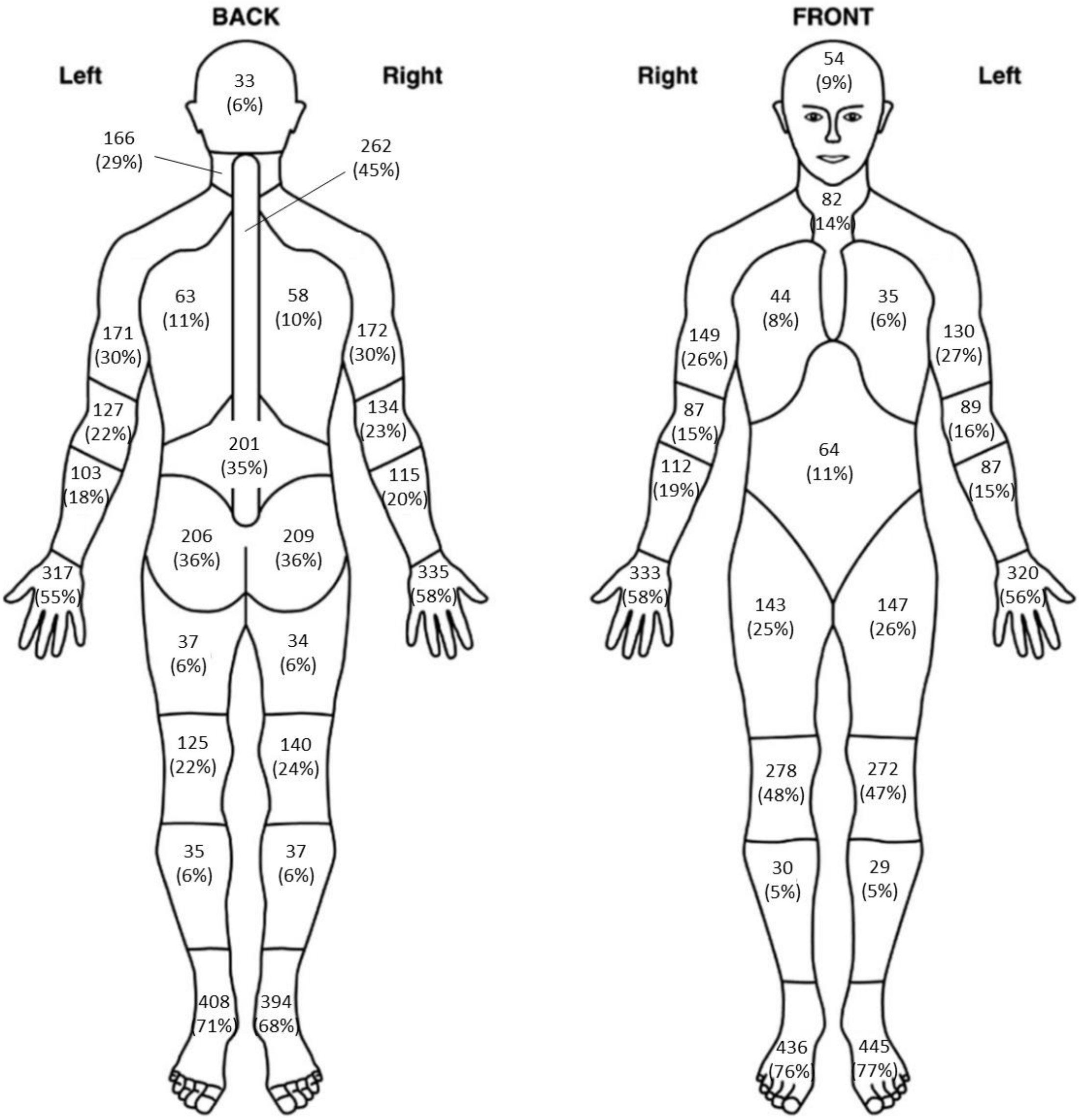

Figure 8.3. Location of global pain due psoriatic arthritis that lasted for one day or longer over the past month marked on a body pain diagram, n (%).

(Valid data = 577^{diagram1}, 576^{diagram2}. Missing data = 29^{diagram1}, 30^{diagram2}).

8.3 Foot and ankle characteristics

8.3.1 Foot pain and other foot symptoms

Ninety-two percent (n=519) of participants self-reported having experienced moderate to severe foot pain that lasted for one day or longer over the past month, with a mean (SD) numerical rating scale (NRS) score of 6 (2) (Table 8.5). Foot pain severity was relatively similar for those with early, mid and late PsA disease durations (Table 8.6). The location of foot pain experienced over the past month was most frequently reported at the rearfoot (heel and ankle) (n=3797, 40%), followed by the forefoot (n=2358, 25%), toes (n=1750, 19%) and midfoot (n=1518, 16%), with similar levels of involvement between the medial and lateral aspects of the foot and ankle (Figure 8.4). Of those with foot pain, 90% (n=473) had bilateral foot pain and 10% (n=51) had unilateral foot pain.

Table 8.5. Presence and severity of foot pain reported by participants with psoriatic arthritis that lasted for one day or longer over the past month.

Variables	Value	Valid data	Missing data
Foot pain over the past month, n (%)	519 (92%)	562	44
Foot pain severity, NRS (0-10)		519	44
0 to 3, mild	42 (8%)		
4 to 6, moderate	231 (45%)		
7 to 10, severe	246 (47%)		

NRS Numerical Rating Scale

Table 8.6. Foot pain severity over the past month reported by participants with early, mid and late disease durations of psoriatic arthritis.

Foot pain severity, NRS (0-10)	Less than 2 years disease duration (early PsA)	2 to 4 years disease duration (mid)	5 years or more disease duration (late PsA)
0 to 3, mild	6 (5%)	12 (10%)	24 (9%)
4 to 6, moderate	60 (50%)	54 (46%)	116 (42%)
7 to 10, severe	55 (45%)	52 (44%)	134 (49%)

NRS Numerical Rating Scale, *PsA* Psoriatic arthritis.

During a typical day, most participants reported that their foot pain and discomfort was there all day (71%). For 68% of respondents (n=346) foot pain was worse at the end of the day, and 67% had foot pain that randomly changed from day to day. However, a lower proportion of the sample had symptoms that were better with activity (23%).

Heterogeneity in foot and ankle symptoms were reported. Frequent symptoms included; tired feet and ankles (90%), stiffness (86%), swelling (68%), and numbness, burning and tingling sensations (63%). Nearly two thirds of participants found these symptoms extremely troublesome (64%). Whilst the qualitative concepts linked to the ICF model identified other foot and ankle symptoms such as hot feet, cold feet and cramping sensations, these domains were reported less frequently by the survey sample (50%, 51% and 51% respectively).

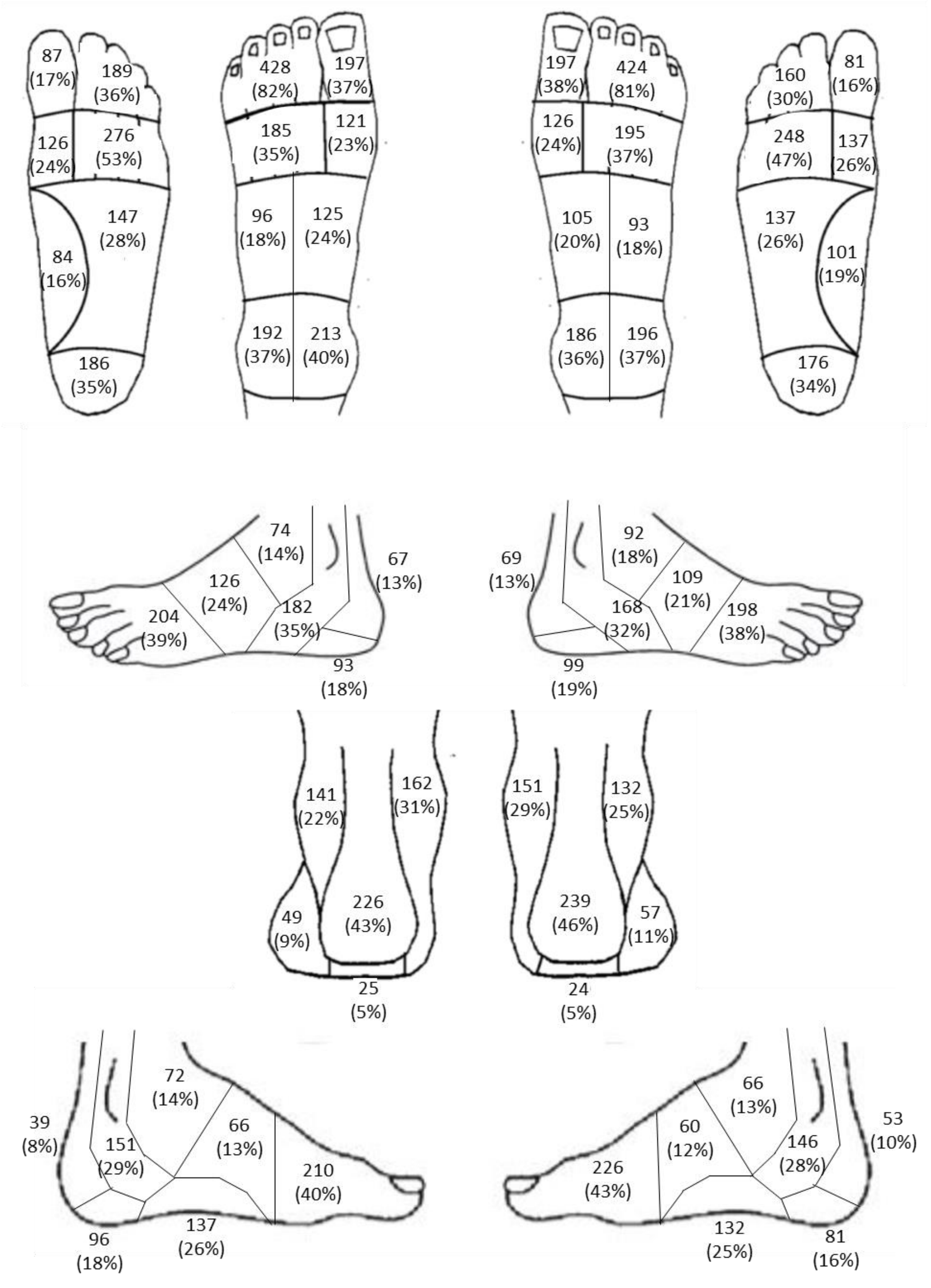

Figure 8.4. Location of foot pain due to psoriatic arthritis that lasted for one day or longer over the past month marked on a foot pain diagram, n (%).

(Valid data = 524^1, 524^2, 525^3, 524^4, 523^5. Missing data = 39^1, 39^2, 38^3, 39^4, 40^5).

8.3.2 Musculoskeletal manifestations in the feet

The full spectrum of disease features affecting the feet and ankles were reported, which included enthesitis (n=534, 95%), joint deformity (n=507, 91%), skin and toenail psoriasis (n=482, 86%), and dactylitis (n=223, 40%). The majority of responders (98%) reported the presence of one or more foot problems, and over half reported 4 or more foot problems (55%). The most common foot problem reported by almost two thirds of people with PsA was plantar fasciitis (57%), followed by dry cracked heels (49%) and toe deformities (45%) (Table 8.7). Although the type, frequency and severity of foot pain in men and women were relatively similar, more prevalent for women than men were bunions (30% and 16% respectively), the change in size of feet (40% and 25% respectively) and dry cracked heels (51% and 34% respectively). Over half of all respondents felt embarrassed or self-conscious about their foot problems (55%) and 80% felt frustrated by their foot problems.

Table 8.7. Foot and ankle characteristics of participants with psoriatic arthritis.

Variables	Value	Valid data	Missing data
Previous or current foot problems, n (%)		560	46
Plantar fasciitis	321 (57%)		
Dry cracked heels	275 (49%)		
Toe deformity	254 (45%)		
Dactylitis	223 (40%)		
Size of feet (changes in length/width)	214 (38%)		
Achilles enthesitis	213 (38%)		
Hard skin or corns	209 (37%)		
Bunions	160 (29%)		
Flat feet	157 (28%)		
Rearfoot deformity	49 (9%)		
Ulceration	48 (9%)		
Forefoot deformity (excluding toes)	46 (8%)		
Troublesome foot and ankle symptoms, NRS (0-10)		559	47
0 to 3, Not troublesome at all	54 (10%)		
4 to 6	147 (26%)		
7 to 10, Extremely troublesome	358 (64%)		
Embarrassed about foot problems, n (%)	309 (55%)	560	46
Frustrated by foot problems, n (%)	440 (80%)	550	56

NRS Numerical Rating Scale

8.3.2.1 **Enthesitis**

For the purposes of this study enthesitis was defined as self-reported problems with the ‘plantar fascia (under the heel or arch)’ and ‘Achilles tendon (back of the heel)’. High levels of rearfoot enthesitis (95%) were reported, which more frequently impacted on foot-related functional impairments and disability than forefoot pathologies. Achilles enthesitis were more disabling than plantar fasciitis, with more frequent impact on standing for 5 minutes (55% and 52% respectively), walking for 5 minutes (49% and 44% respectively) and stair walking (66% and 62% respectively). In addition, 75% of people with Achilles tendon problems reported walking slower than others (n=156) compared with 71% of people plantar fasciitis (n=223). A total of 238 (43%) participants felt embarrassed about the way that they walk and 46% of those had Achilles enthesitis (n=109) and changes to foot size (n=109). Nearly a third of participants reported staying indoors most of the day due to foot problems (n=158, 29%) and one of the most frequent causes of staying indoors was a history of Achilles enthesitis (n=76, 48%). A 2-tailed Fisher’s exact test was used to evaluate whether there was a gender difference in the presence of Achilles enthesitis or plantar fasciitis. Although there was no statistically significant association between gender and the presence of Achilles enthesitis (p=0.041), plantar fasciitis was found to be significantly more common in women (n=294, 92%) than men (n=27, 8%) (p=0.011) (Figure 8.5). Plantar fasciitis was found to be most frequently associated with foot symptoms that were worse with prolonged standing (n=208, 65%), worse in the morning (n=168, 52%) and after rest (n=151, 47%), and with obesity (n=184, 57%). There was also a trend towards the presence of plantar fasciitis and reporting moderate (n=139, 43%) to severe global pain, and reporting moderate (n=116, 36%) to severe (n=171, 53%) global PsA disease activity (as determined by the patient global assessment scores).

Rearfoot enthesitis (both Achilles enthesitis and plantar fasciitis) greatly impacted on daily life and most frequently interfered with sleep (n=411, 77%), followed by social activities (n=405, 76%), daily routine such as shopping and housework (n=397, 74%) and exercise participation (n=360, 67%). There was a trend between the presence of rearfoot enthesitis and greater levels of foot pain severity and a reduced ability to cope with foot problems, with severe foot pain reported in 47% of those with Achilles enthesitis and plantar fasciitis (n=101 and n=150 respectively) and with moderate to coping very poorly with foot problems reported in 62% of those with Achilles enthesitis and plantar fasciitis (n=131 and n=200 respectively).

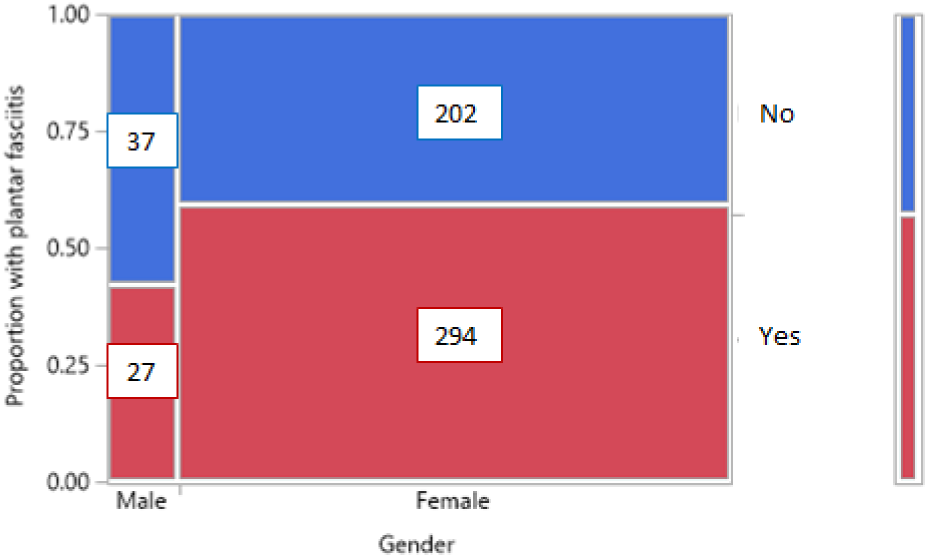

Figure 8.5. Mosaic plot representing the proportions of males and females with (yes) and without (no) plantar fasciitis, with the vertical axis indicating counts in relation to the proportions of the overall sample and the width of horizontal axis bars indicating the relative gender proportions. Plantar fasciitis was found to be significantly more common in women (n=294) than men (n=27).

8.3.2.2 **Dactylitis**

A high proportion of those with dactylitis reported having difficulty with stairs (n=143, 64%) and walking barefoot (n=129, 58%), and it interfered with driving (n=108, 48%). Dactylitis most frequently impacted on body image with nearly two thirds of participants feeling embarrassed or self-conscious about their feet (n=150, 67%).

8.3.2.3 **Peripheral arthritis**

Whilst high levels of forefoot and rearfoot pain were reported, self-perceived levels of forefoot deformity (8%, excluding toes) and rearfoot deformity (9%) were relatively minimal. However, the impact from both types of deformity was high, with higher frequencies of foot functional impairment reported by those with rearfoot deformity than forefoot. Foot-related functional impairments relate to difficulties with standing, walking and climbing stairs due to foot pain and/or problems. Rearfoot deformity most frequently caused difficulties with stairs (n=36, 73%), standing for 5 minutes (n=32, 65%) and walking for 5 minutes (n=28, 57%), and forefoot deformity most frequently affected barefoot walking (n=29, 63%). Changes to global gait patterns were most frequently reported by people with rearfoot deformity (86%), changes to foot size (81%) and forefoot deformity (80%), which were also the most common foot problems in those with an established disease duration. Whilst embarrassment about gait changes was most frequently reported by people with forefoot deformity (n=27, 59%), frustration with gait changes was most frequently reported by those with rearfoot deformity (n=47, 96%).

8.3.3 Dermatological manifestations in the feet

Common features of skin psoriasis on the feet were scaling (76%) and itching (69%), and common toenail features were thickened (84%), discoloured nails (75%) with ridges (67%). Toenail psoriasis (n=320, 57%) was more prevalent than skin psoriasis affecting the feet and ankles (n=161, 29%). A significant association was identified between the co-occurrence of psoriatic nail and skin involvement on the foot at p=<0.0001, using a 2-tail Fisher's exact test (Figure 8.6). Whilst dermatological symptoms (soreness, tenderness and pain) were commonly reported to be mild or not present and the interference from symptoms on daily activity minimal, the emotional burden and impact on footwear choice was high. Of those participants with skin and toenail psoriasis, the vast majority felt embarrassed by the dermatological features affecting their feet (74% and 80% respectively) and reported that they greatly influenced their footwear choice (85% and 84% respectively). Problems with footwear caused frustration among the majority of people with skin and toenails psoriasis (67% and 69%). The emotional impact from dermatological involvement of the feet was similar for both men and women, with relatively even proportions of those feeling embarrassed about their skin and toenail problems between genders (men: 73% and 71%, women: 74% and 80% respectively). Emotional well-being/impact is reported in relation to feeling embarrassed or self-conscious and/or frustrated, which may be in regards to foot pathologies, footwear and/or walking changes.

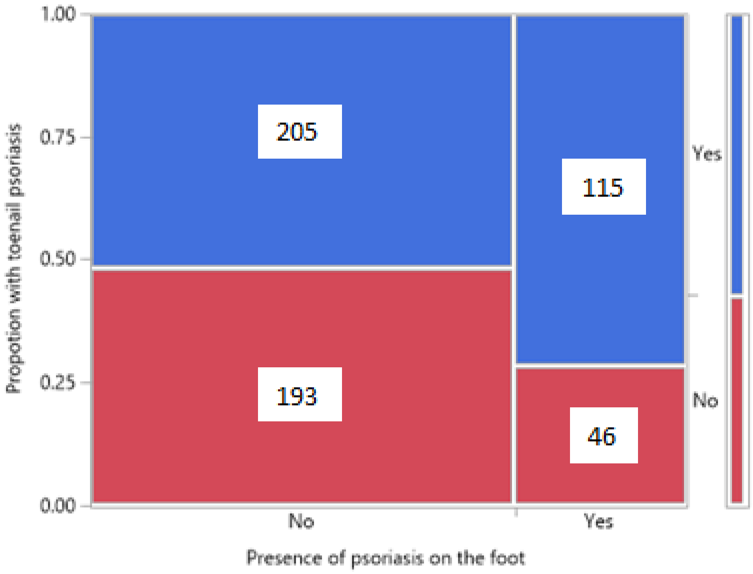

Figure 8.6. Mosaic plot representing the proportions of respondents with toenail psoriasis relative to those with (yes) and without (no) psoriasis on the foot, with the vertical axis indicating the proportion of respondents with and without toenail psoriasis and the width of the horizontal bars indicating the relative proportions of those with and without psoriasis on the foot. Toenail psoriasis was significantly more common in those with skin psoriasis affecting the feet than in those without skin psoriasis.

8.4 Activity and participation

The majority of respondents reported that they were not participating in the nationally recommended weekly amount of moderate (68%) and vigorous (93%) physical exercise. Over 80% of participants reported that foot problems had interfered with their ability to exercise over the past month, with the most frequently affected having flat feet (89%) and rearfoot enthesitis (88%).

Going up and down stairs was moderately to very difficult due to foot problems for a greater proportion of respondents (58%), compared with walking barefoot (52%), standing for 5 minutes (45%) and walking for 5 minutes (39%). Nearly half of the respondents who had difficulty with stairs confirmed that problems in other parts of the body had contributed to limitations in such activities (n=264, 48%), which were predominantly in the back, hips and knees. Indeed, 74% of respondents had difficulties with standing and walking activities due to problems in other parts of the body (n=410). Rearfoot deformity (n=36, 73%) and forefoot deformity (n=32, 70%) were the most frequent foot pathologies in those having problems with stairs. Walking barefoot was difficult for participants with forefoot pathologies (toe deformity n=143, 56%; dactylitis n=85, 53%; bunions n=129, 58%) and rearfoot pathologies (Achilles enthesitis n=128, 60%; plantar fasciitis n=190, 59%; rearfoot deformity n=28, 57%), with similar reported frequencies.

Daily life in general was adversely affected with two thirds of participants reporting that foot problems had interfered with their social and leisure activities (71%), and daily routine (66%) (Table 8.8). The extent to which foot problems affected family time, being a parent, driving and work life varied considerably between participants. High impact from foot involvement was reported by respondents where foot problems had prevented sleep (n=413, 75%) and had negatively affected their emotional well-being (n=440, 80%). For nearly a third of participants the impact from foot problems had resulted in staying indoors for most of the day (social isolation) (n=158, 29%). Skin psoriasis on the feet and ankles more commonly interfered with daily routine and social activities (n=74, 46%) than toenail psoriasis (n=88, 28%). The most frequent musculoskeletal pathologies to impact on daily and social activities were rearfoot deformity (86%) and forefoot deformity (82%).

Table 8.8. Extent to which foot problems had interfered with daily activities of participants with psoriatic arthritis over the past month.

	Yes interfered a lot, n (%)	**Yes interfered a little, n (%)**	**No not at all interfered, n (%)**	**Not relevant, n (%)**
Going to the shops[*1]	134 (24%)	236 (42%)	171 (31%)	15 (3%)
Looking after the home[*2]	147 (26.5%)	220 (40%)	174 (31%)	14 (2.5%)
Leisure or social activities[*3]	154 (28%)	236 (43%)	144 (26%)	20 (3%)
Being a parent or carer[*4]	61 (11%)	137 (25%)	171 (31%)	184 (33%)
Spending time with family[*5]	62 (11%)	149 (27%)	279 (51%)	63 (11%)
Exercise[*6]	244 (44%)	213 (39%)	66 (12%)	28 (5%)
Sleep[*7]	154 (28%)	259 (47%)	132 (24%)	9 (1%)
Driving[*8]	54 (10%)	160 (29%)	294 (53%)	46 (8%)
Work[*9]	100 (18%)	153 (28%)	135 (25%)	160 (29%)

Valid data = 556[*1], 555[*2], 554[*3], 553[*4], 553[*5], 551[*6], 554[*7], 554[*8], 548[*9].

Missing data = 50[*1], 51[*2], 52[*3], 53[*4], 53[*5], 55[*6], 52[*7], 52[*8], 58[*9].

Walking was adversely affected for over half of the respondents (66%). In total 238 individuals with PsA felt embarrassed or self-conscious about the way that they walked (43%). Changes to global gait patterns were common with 70% walking slower and 62% with a limp or unstable gait, and nearly half the survey sample had fallen in the past 12 months (49%) with a mean (SD) number of falls at 1 (1). A fall was defined in the current study as having ‘fallen to the floor or ground’ using a lay perspective as recommended in previous consensus guidelines for collecting falls data (Lamb, et al., 2005). The total number of self-reported falls over the past 12 months was 560 and the total number of individual fallers was 268 (49%), with a mean (SD) age of 52 (12) years and mean (SD) disease duration of 8 (9) years. A significant relationship between the extent of foot and ankle trouble scores in relation to fall frequency was identified using the Kruskall-Wallis test (Figure 8.7). The foot and ankle trouble scores refer to respondents indicating on a NRS to what extent the symptoms in their feet and ankles have been troublesome (cause trouble, annoyance or difficulty), with 0 being not troublesome at all and 10 being extremely troublesome. Distributions of the foot and ankle trouble scores and the number of falls were assessed using box plots, including 0 falls (n=277), 1 fall (n=99), 2 falls (n=87), 3 falls (n=41) and 4 or more falls (n=41). The mean rank of foot and ankle trouble scores was significantly different between the groups, $\chi^2(4)=25.031$, p=< 0.0001. Post hoc pairwise comparison of all groups identified that the foot and ankle trouble scores were significantly higher for 2 falls compared with 0 falls (p=0.001) and for 3 falls compared with 0 falls (p=0.012).

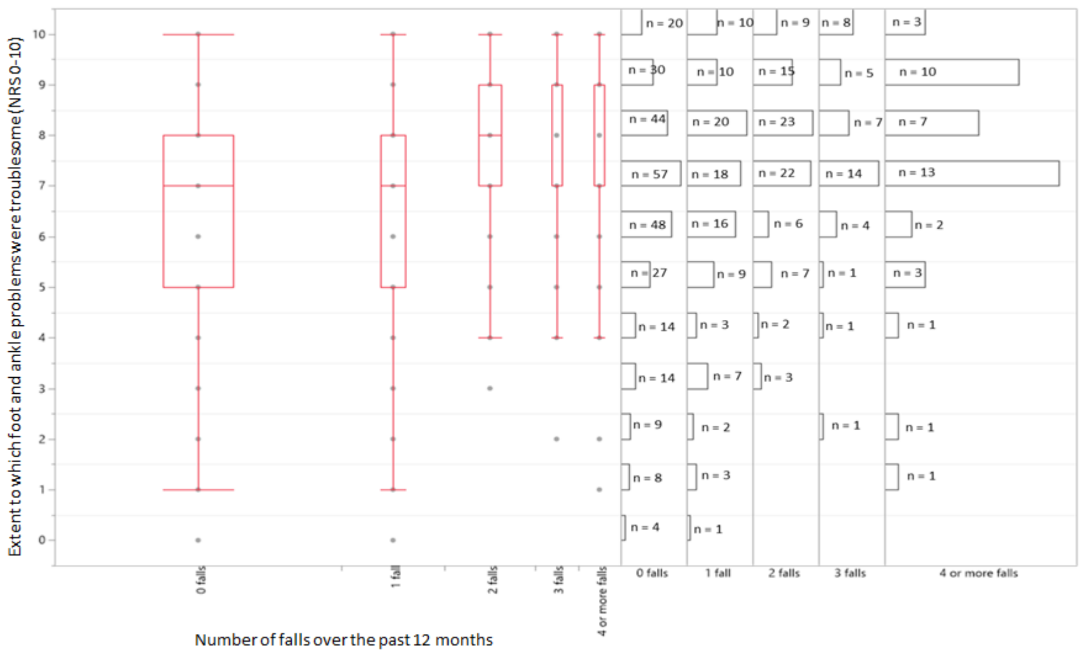

Figure 8.7. Box plot and histogram to illustrate the distribution of the foot and ankle trouble scores in accordance with the number of falls reported by respondents over the past 12 months, which shows that the number of falls increases with the extent to which foot problems are troublesome. The histogram is counting the numbers from the box plot, where n indicates the number of respondents.

NRS Numerical rating scale, with 0 being not troublesome at all and 10 being extremely troublesome.

8.5 Footwear

Walking shoes (lace-up and slip-on) (67%) and sports shoes (24%) were the most frequently worn footwear type, followed closely by being barefoot or in socks/slippers (36%) most often. The most commonly worn footwear types were similar between men and women. However, a greater proportion of women than men wore supportive style sandals and prescribed footwear, and a greater proportion of men than women wore thongs (flip-flops) and work boots. Although widely regarded to be popular in Australian culture, thongs (flip-flops) accounted for 17% (n=92) of the footwear worn by the study sample. Of the total number of respondents that wore prescribed shoes (n=76, 14%), the majority had forefoot deformity (n=13, 28%), rearfoot deformity (n=12, 24%) and foot ulceration (n=10, 21%). In total, 173 people felt embarrassed about the footwear they wore (32%).

Table 8.9. Extent of agreement with the following statements about difficulties with footwear experienced by participants with psoriatic arthritis.

	Strongly agree	**Agree**	**Neither agree or disagree**	**Disagree**	**Strongly disagree**
It is hard to find footwear that do not hurt my feet ^{*1}	185 (33%)	205 (37%)	93 (17%)	54 (10%)	15 (3%)
I have difficulty in finding footwear that fits my feet ^{*2}	128 (23%)	167 (31%)	134 (25%)	100 (18%)	19 (3%)
I am limited in the number of shoes I can wear ^{*3}	214 (39%)	219 (40%)	54 (10%)	51 (9%)	11 (2%)
I have difficulty with daily activities due to discomfort from my footwear ^{*4}	69 (13%)	153 (28%)	160 (29%)	138 (25%)	26 (5%)
I am limited in the kind of work I can do due to difficulties with my footwear ^{*5}	55 (10%)	76 (14%)	179 (33%)	173 (31%)	65 (12%)
I have difficulty finding footwear appropriate for a special occasion ^{*6}	234 (43%)	183 (33%)	64 (12%)	56 (10%)	13 (2%)
I feel frustrated about the problems I have with footwear ^{*7}	179 (33%)	167 (30%)	107 (20%)	71 (13%)	22 (4%)
I feel embarrassed about the footwear I wear ^{*8}	79 (14%)	94 (17%)	156 (29%)	175 (32%)	43 (8%)
I find that I am restricted to the same type of footwear all year round ^{*9}	149 (27%)	184 (33%)	91 (17%)	101 (18%)	26 (5%)

Valid data = 552^{*1}, 548^{*2}, 549^{*3}, 546^{*4}, 548^{*5}, 550^{*6}, 546^{*7}, 547^{*8}, 551^{*9}.
Missing data = 97^{*1}, 101^{*2}, 100^{*3}, 103^{*4}, 101^{*5}, 99^{*6}, 103^{*7}, 102^{*8}, 98^{*9}.

Cushioning sole (61%), support (55%), wider fit (51%), toe-box fit (44%) and ease of getting shoes on/off (42%) were the top 5 most frequently reported important footwear features. These top footwear features were important for all participants regardless of the type or location of the foot problem. The need to accommodate a supportive insole was a key consideration in footwear choice for 41% of participants. Whilst closed-in (13%) and open-toed (5%) footwear features were key concerns identified by people with PsA as part of Environmental Factors in the ICF model, they were not rated highly as an important factor when choosing shoes by the survey sample. However, closed-in style shoes were more frequently rated as important compared with open-toed shoes by participants with both dermatological and musculoskeletal foot pathologies, and with either forefoot, midfoot or rearfoot involvement.

Difficulties with footwear were experienced by the majority of respondents, which had a negative effect on coping ability (89%) and on emotions in relation to feeling frustrated about problems with footwear (63%). Key footwear difficulties included; 79% reported being limited in the number of shoes they could wear, 76% reported having difficulty finding footwear appropriate for a special occasion, and 71% found it hard to find footwear that did not hurt their feet (Table 8.9). These key footwear difficulties were reported by those with dermatology and musculoskeletal involvement. Footwear difficulties were female predominant, with a proportionally higher strength of agreement for all statements about footwear problems, limitations and impact. Despite high proportions of people with PsA indicating limitations in footwear choice, the impact from footwear difficulties on daily activities (41%) and work life (24%) was less frequently reported. Although the 6-month study period traversed 3 weather seasons; winter (July and August), spring (September to November) and summer (December), 60% of participants reported that they were restricted to the same type of footwear all year round.

Important footwear features most frequently reported by people with Achilles enthesitis were light-weight (n=59, 28%), a soft heel counter (n=54, 26%) and heel height (n=47, 23%), whereas the most frequently reported by people with plantar fasciitis was arch support (n=163, 51%). Dorsal toe pain (80%) and toe deformities including bunions (74%) were key features for the majority of participants, with subsequent impact on footwear choice distinctly related to the importance of a cushioning sole (65%) and adequate toe-box fit (52%). Thongs and supportive sandals were more frequently worn by people with bunions, toe deformities and dry cracked heels. Most frequently worn footwear by people with skin and nail psoriasis affecting the feet were; lace-up sneakers (42%) and being barefoot or with socks or slippers (34%). In addition, slip-on sneakers were frequently worn by people with skin psoriasis (n=43, 27%) and supportive style sandals by people with toenail psoriasis (n=76, 24%).

8.6 Self-management

In total, 309 people with PsA felt that they were not coping well (moderately to severely) with their foot problems (57%) (Table 8.10). Relevant domains of impact for those not coping with PsA-related foot involvement included severity of global pain (75%) and foot pain (82%), interference with daily life (92%) and emotional well-being (61%), and difficulties with footwear (89%). Although social support was considered important to coping well with PsA-related foot involvement (32%), half of all respondents felt there was a lack of support for people with PsA from friends, family and health professionals.

A significant relationship was identified between the severity of foot and ankle pain over the past month and ability to cope with foot problems, including 0 to 3 coped very well (n=235), 4 to 6 moderate (n=220) and 7 to 10 coped very poorly (n=89) over the past month, when compared using the Kruskal-Wallis test. Distributions of the foot and ankle pain severity scores were not equal for each of the groups as assessed by visual inspection of the box plots, meaning that it was only possible to determine whether the scores for each of the groups were significantly higher or lower than each other. The mean rank scores for foot and ankle pain severity were significantly different from each other in relation to the coping groups, $\chi^2(2)=114.355$, p=<0.0001. Post hoc pairwise comparison identified that foot and ankle pain severity scores were significantly higher for 7 to 10 severe when compared with 0 to 3 mild (p=<0.0001), 4 to 6 moderate when compared with 0 to 3 mild (p=<0.0001) and 7 to 10 severe when compared with 4 to 6 moderate (p=<0.0001). A significant relationship was also identified between the ability of respondents to cope with foot problems over the past month in relation to whether they identified that there was a lack of support for people with the disease from friends, family and/or health professionals (n=270) compared with those who did not (n=279). A Mann-Whitney U rank test was conducted to compare the scores relating to the ability to cope with foot problems between both groups. The median score for coping with foot problems for respondents who indicated a perceived lack of support for people with the disease (5) was significantly higher (less able to cope) than those who did not (4), z=3.517, p=0.0004.

A variety of coping strategies were used by participants to cope with their foot problems, with the most common being to ‘get on with it, despite the problem’ (74%) and to ‘accept limitations’ (68%) and the least common at 3% reporting that coping mechanisms were not utilised (Table 8.10). The Chi-square test of independence was conducted to examine whether there was any relationship between the frequency of different coping strategies used in relation to PsA disease duration, including less than 2 years, 2 to 4 years, and 5 years or more. All expected cell frequencies were greater than 5. A statistically significant relationship was identified between disease duration and the coping strategies; to ‘pace and plan’ ($\chi^2(2)=6.134$, p=0.047) and ‘try to keep in control of the problem’ ($\chi^2(2)=17.956$, p=<0.0001). A pairwise post hoc z-test analysis in relation to ‘try to keep in control of the problem’ revealed that this coping strategy was used to a significantly higher degree by participants of 5 years or more disease duration (52.5%), when compared with 2 to 4 years (39.8%) and less than 2 years disease duration (31%) at $p\leq 0.05$.

Table 8.10. Coping and support with foot problems in participants with psoriatic arthritis.

Variables	**Value**	**Valid data**	**Missing data**
Coping with foot problems, NRS (0-10)	4 (2)	544	62
Coping with foot problems, NRS (0-10)		544	62
0 to 3, Coped very well	235 (43%)		
4 to 6	220 (40%)		
7 to 10, Coped very poorly	89 (17%)		
Typical ways in which you cope with your foot problems, n (%)		550	52
Get on with it, despite the problem	408 (74%)		
Accept limitations	378 (68%)		
Try to keep in control of the problem	242 (44%)		
Pace and plan	241 (44%)		
Get support from family, friends and/or health professionals	176 (32%)		
Hide the problem from others	131 (24%)		
Do not think about the problem	106 (19%)		
None, I do not use coping strategies	18 (3%)		
Lack of understanding about the disease, n (%)	432 (79%)	549	53
Lack of support for people with the disease, n (%)	270 (49%)	549	53
Neither of these, n (%)	92 (17%)	549	53
Need assistance to help take care of feet, n (%)	228 (42%)	545	61
Self-manage foot problems, n (%)	488 (90%)	545	61
Belong to a patient support group, n (%)	225 (41%)	549	57

NRS Numerical Rating Scale

A total of 228 respondents (42%) indicated that they required assistance with undertaking basic foot care, and a similar proportion of participants reported membership to a patient support group for their PsA (n=225, 41%). Self-care in respect of foot problems was undertaken by the majority of participants (90%), and the mean (SD) out-of-pocket expenditure on foot care over the past 12 months was estimated to be $600 (669) with a range of $0 to $8000. Perceived effectiveness of self-care activities for foot problems was most frequently reported to be mild or moderate (n=328, 74%). Of the 64 respondents who reported having had foot and ankle surgery (12%), the mean (SD) cost of their foot care over the past 12 months was $680 (639) with a range of $80 to $3000.

8.7 Healthcare service access and support

The majority of respondents received current rheumatology services for their PsA (84%) and nearly two thirds (62%) reported having received podiatric care (Table 8.11). Of the 518 respondents who had sought foot healthcare, 81% had accessed rheumatology services, 73% the GP and 53% podiatry, with 87% having accessed two or more health services (median 4.5, range 0 to 8 health services accessed). The majority of respondents (78%) reported having had a foot examination by their rheumatologist.

Table 8.11. Access to healthcare by participants with psoriatic arthritis-related foot problems.

Variables	**Value**	**Valid data**	**Missing data**
Currently see a rheumatologist for PsA, n (%)	495 (84%)	589	17
Currently see a podiatrist for your feet, n (%)	130 (24%)	541	65
Ever seen a podiatrist for your feet, n (%)	337 (62%)	540	66
Had any foot or ankle surgery, n (%)	64 (12%)	541	65
Foot problem improved with surgery, n (%)	38 (59%)	64	65
Rheumatologist asks about feet, n (%)	438 (82%)	538	68
Rheumatologist examines feet, n (%)	420 (78%)	538	68
Who have you seen about your foot problems?, n (%)		537	71
Rheumatologist	434 (81%)		
GP/Doctor	394 (73%)		
Podiatrist	284 (53%)		
Physiotherapist	176 (33%)		
Foot massage or reflexologist	106 (20%)		
Dermatologist	88 (16%)		
Pedicurist	77 (14%)		
Surgeon	37 (7%)		
Traditional Chinese medicine	31 (6%)		
Nurse	15 (3%)		
Occupational therapist	14 (3%)		
No one	19 (3%)		
Other (immunologist, exercise physiologist, neurologist, osteopath, chiropractor, pain management specialist, radiologist, sports medicine specialist, myotherapist, orthotist, aromatherapist, retail footwear shop)	33 (6%)		

GP General practitioner, *PsA* Psoriatic arthritis

Variations in current access to rheumatology services for the management of PsA were observed across the Australian states and territories (Figure 8.8), with the highest level of access being in the Australian Capital Territory (n=26, 93%) and the lowest being in the state of Victoria (n=95, 74%). A Chi-square test of independence was conducted between participants having seen and not seen a rheumatologist about their PsA relative to the states and territories of Australia (n=598). All expected cell frequencies were greater than 5. There was a statistically significant association between seeing/not seeing a rheumatologist across Australian states and territories, $\chi^2(6)=17.095$, $p=0.008$. A pairwise z-test post hoc analysis with Bonferroni correction revealed that the proportion of respondents who had not seen a rheumatologist about their PsA was significantly higher in Western Australia (93%) than in all of the other Australian states and territories at $p=0.05$. Furthermore, the proportion of respondents who reported that they had seen a rheumatologist was significantly higher in Victoria (26%) compared with the other Australian states and territories at $p \leq 0.05$. The Northern Territory was excluded from the analysis due to no responses.

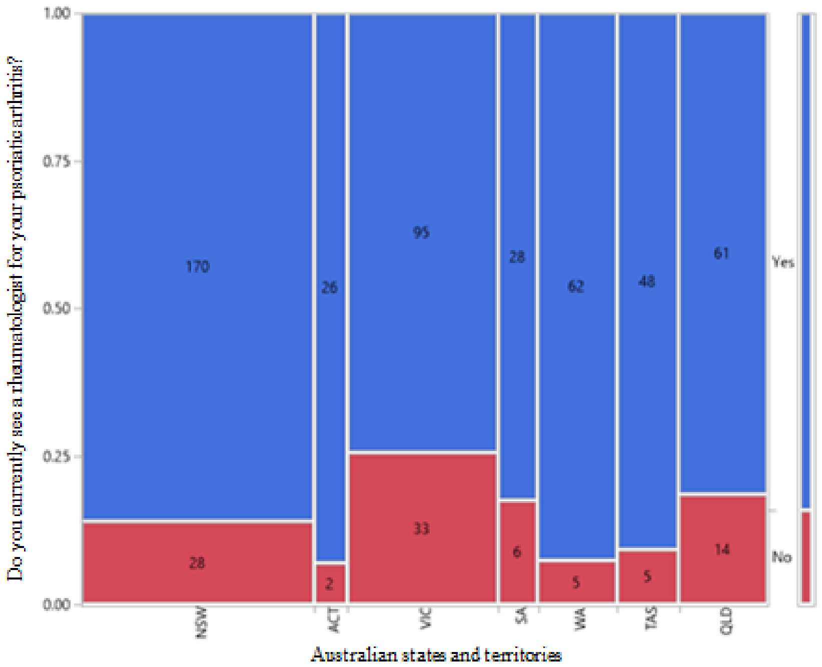

Figure 8.8. Mosaic plot to show the variation in current access to rheumatology services for management of PsA across the different Australian states and territories, with the vertical axis indicating the proportion of those who currently see or do not see a rheumatologist for their PsA and the width of the horizontal axis bars indicating the relative number of respondents from the Australian states and territories.

ACT Australian Capital Territory, *NSW* New South Wales, *QLD* Queensland, *SA* South Australia, *TAS* Tasmania, *VIC* Victoria, *WA* Western Australia.

In total, 32% of participants reported that the professional foot care they had received was ineffective (n=167) and 32% were not confident that the health professionals had a good understanding of how PsA affected their feet (n=162). The relationship between the respondents' perceptions of the effectiveness of foot healthcare they had received and their confidence in the health professionals' understanding of how PsA affects the feet in relation to each type of health professional seen was examined using the Chi-square test of independence. All expected cell frequencies were greater than 5 with regards to the rheumatologist, GP, physiotherapist and podiatrist, which were the most frequently seen health professionals for foot problems in PsA. A significant relationship was identified between the respondents' perception of effectiveness of foot healthcare and having received rheumatology ($\chi^2(4)=9.629$, $p=0.0472$), GP ($\chi^2(4)=19.022$, $p=0.0008$), physiotherapy ($\chi^2(4)=14.479$, $p=0.0059$) and podiatry services ($\chi^2(4)=20.308$, $p=0.0004$). In relation to rheumatologists, pairwise testing revealed that there was a significant difference between the respondents who rated the effectiveness of the foot healthcare they had received as 'moderately effective' and 'very effective' at $p\leq0.05$. In relation to having seen the GP for foot problems, foot healthcare rated 'not at all effective' (89%) and 'mildly effective' (83%) were significantly higher in proportion to all the other ratings of effectiveness at $p\leq0.05$. In relation to those who saw a physiotherapist, foot healthcare rated as 'moderately effective' was significantly higher in proportion to all the other ratings of effectiveness at $p\leq0.05$. With respect to podiatry, there was a significant difference between the respondents who rated the effectiveness of their foot healthcare as 'mildly effective' compared with all the other ratings of effectiveness at $p\leq0.05$.

Significant relationships were identified in the respondents' confidence that their PsA-related foot problems had been understood by the GP ($\chi^2(4)=20.549$, $p=0.0004$) and the rheumatologist ($\chi^2(4)=29.429$, $p=<0.0001$). However, no significant associations were found in the respondents' confidence in the podiatrists' understanding of foot problems in PsA ($\chi^2(4)=3.688$, $p=0.449$). Significantly greater proportions of respondents who indicated that they saw a GP for their foot problems rated their confidence in the health professionals understanding of PsA-related foot problems as 'mildly confident' (89%), followed by 'not confident at all' (85%) and then all the other ratings of confidence jointly ($p\leq0.05$). Respondents who saw a rheumatologist rated their confidence in the health professionals understanding of PsA-related foot problems as ‘very confident’ to a significantly greater degree (92%), followed by both ‘extremely confident’ (90%) and ‘moderately confident’ (84%) and then the remaining categories ($p \leq 0.05$).

Chapter 9

9 Discussion and Conclusion

This chapter discusses the findings of the survey in the context of the available literature. Key results are presented with emphasis on clinical implications for the management of the foot and ankle in people with PsA. Limitations of the survey and future research directions are outlined and discussed.

The results of each of the three interlinked phases of research presented in this thesis were discussed at the end of each relevant chapter. The findings from each research phase contributed to the next, which culminated in the cross-sectional survey among people with PsA-related foot involvement. Major components of work were; 1) the generation of the conceptual framework to inform survey content and 2) the robust processes of survey pre-testing and dissemination, which provided a best practice template for other researchers. A strategic and holistic approach was taken to the task of survey development, establishing the sampling frame, the survey dissemination plan and programme of activities for survey promotion including the study website, Facebook page, video and animation. Therefore, the discussion will focus on the survey results with emphasis on the conceptual and methodological rigor of the preceding survey design and conduct.

9.1 Context

Two principal themes were identified in the literature that describe foot involvement in PsA: 1) an established higher involvement of the hallmark features of disease (such as peripheral arthritis, enthesitis and dactylitis) in the lower limbs compared with the upper limbs, and 2) the persistence of localised disease activity in the foot independent of global disease. As disease persistence in PsA has been shown to severely impact on functional outcomes and quality of life (Husted, et al., 2001; Husted, et al., 2007; Cresswell, et al., 2011), it is important to better understand foot involvement and its impact in order to inform future targeted disease-specific assessments and interventions. Limitations in previous research on foot involvement in PsA include; few PsA-specific cohorts, use of small sample sizes, findings from predominantly European countries with no local data for Australia where health service provision and footwear habits are different, discrete site-specific focus on anatomical structures with no comprehensive and integrated description of foot involvement, and no exploration of the full impact of localised disease in the foot from the patient perspective. To improve understanding of foot involvement in PsA, the main objective of this thesis was to provide a comprehensive description of the nature, extent and location of foot problems and the impact they have on daily life from the perspective of people with PsA. To achieve this, a national survey to obtain large-scale data on foot involvement in people with PsA living in Australia was conducted. To the best of the authors knowledge, this is the largest survey of people with PsA-related foot problems and the first to examine the impact of foot involvement in PsA from the patient perspective. Key findings will be discussed in this chapter in two main stages; 1) the representativeness of the sample and success outcomes of the survey and 2) foot involvement and its impact on people with PsA.

9.2 Sample representativeness and distribution

In total, there were 606 survey completions (10% response rate) in the current study. Sample size requirements of this study were difficult to estimate in the absence of national patient databases and with unknown PsA prevalence in Australia or New Zealand. The total target population was estimated from the major sites for dissemination to be 6000 people with PsA in Australia, which, in light of these contextual challenges, was considered the best approach in order to gain an appreciation of the potential survey reach and response relative to reach. Similar New Zealand-based foot surveys received 197 web-survey completions from people with inflammatory arthritis (49% response rate, n=400 target sample) (Brenton-Rule, et al., 2014) and 131 postal survey completions (32% response rate, n=400 target sample) were received from people with systemic lupus erythematous (SLE) (Otter, et al., 2016). Although New Zealand has a smaller general population than Australia, approximately 295,000 New Zealanders are living with at least one type of inflammatory arthritis (Arthritis New Zealand, 2018) and indicates that previous approaches may not have identified the full target population to estimate response rates. However, based on these existing published sample sizes (Brenton-Rule, et al., 2014; Otter, et al., 2016), the current study survey response of PsA-specific participants was a very good response rate. The full survey completion rate from participants that attempted the survey was 91.95% overall due to partial completion, which is evidence of a successfully developed survey.

It is difficult to measure the success of the survey response due to the lack of comparable surveys. In the UK, sample sizes in previous foot-specific surveys of people with RA range from 413 to 883 (Firth, et al., 2008; Otter, et al., 2010; Graham, et al., 2017; Wilson, et al., 2017a), with the time frame for data collection poorly reported across studies. Higher response rates would be expected from previous UK-based studies given that the majority had recruited from established NHS (National Health Service) hospital patient databases and/or major NHS teaching hospitals with rheumatology outpatient departments that have embedded specialist podiatry services. Furthermore, comparison with RA populations may not be appropriate given the higher prevalence of RA when compared with other discrete sub-groups of rheumatic conditions such as PsA. Therefore, the high survey completion numbers in the current study were encouraging.

High completion rates suggest that the survey had sufficient reach to the target population and that the target sample was willing and able to complete the survey. Therefore, successful survey response in the current study may be attributed to the rigorous process of survey development and dissemination using best practice methods in survey research. The survey had a strong conceptual framework generated by the in-depth exploration of the patient experience that was linked to the ICF, which achieved good conceptual coverage of items important and relevant to both patients and health professionals. Extensive rounds of survey pre-testing among the target population, health professionals and experts further optimised potential response rates by improving the overall quality, functioning and representativeness of the survey instrument. A targeted dissemination strategy increased survey reach by utilising mixed modes of administration (paper and online), a range of promotional materials (posters, flyers, emails with reminders, study website, study Facebook page, study video and animation), and a range of dissemination sites (clinic-based services, online support organisations and social media groups), followed by snowballing and crowdsourcing sampling techniques. Robust strategies for survey development, sampling and genuine community engagement made a powerful contribution to response rates and the scale of information collected. Despite the substantial length of the survey, there were high survey completion rates and low rates of missing data (95% of respondents with less than 5% missing data).

High levels of data completeness suggest that people with PsA had a strong desire to share their experience of foot problems, and that the incorporation of insightful and meaningful concepts, generated by those with the disease, resonated with survey respondents and had a positive effect on fuller survey completion. Therefore, high response rates with minimal missing data demonstrates the value of embedding the patient perspective in research activity and in the development of measures in PsA, which aligns with the GRAPPA-OMERACT recommendations (Tillett, et al., 2015a; Orbai, et al., 2017a). Significant time and resource investment into robust survey development and dissemination strategies was considered worthwhile and there is limited reporting on this aspect of survey design in other foot-specific research, making it difficult to determine if this occurred.

The risk of bias associated with observational study designs such as cross-sectional surveys is relatively high (Galea and Tracy, 2007). Survey research provided the opportunity to sample a wide geographical area not restricted to a particular region, health service or clinic-based sample. A strength of the current study was the population-based sample of people with PsA-related foot problems living in Australia, the sample size was large and similarities were noted in sample characteristics between the current study and previous clinic-based samples of adults with PsA described in the literature including: age, disease duration, patient global assessment and global pain (Gladman, et al., 1987; Kane, et al., 2003b; Gelfand, et al., 2005; Gladman, et al., 2005; Husted, et al., 2007; Lindqvist, et al., 2008; Gladman and Chandran, 2011; Rahman, et al., 2017). The representative nature of the sample could not be ensured due, in part, to the sampling strategy used, which is accounted for in chapter 9 section 9.8 limitations pages 244-246. Characteristics of the current survey sample were interpreted favourably in the context of these previous PsA-specific studies, with the age-groups of the survey participants reflecting that of the target population and with proportional responses across ethnicities and geographical regions in Australia.

Non-response in survey research is an important concern as it can lead to bias if respondents and non-respondents differ systematically, which can adversely affect the results of the study and limit generalisability of findings (Groves, et al., 1992; Barriball and While, 1999). Recruitment of respondents was based on self-selection, which means that it is completely left to individuals to select themselves for the survey (Bethlehem, 2010). Whilst it is acknowledged in the literature that survey samples will never be exactly equal to the population characteristics they intend to estimate (Greenacre, 2016), strategies to reduce non-response bias were incorporated into the research processes of the current study with careful planning and management of sample selection, recruitment and data collection. Additional analyses are ongoing to determine the extent of bias with respect to key demographic and clinical characteristics in order to quantify the impact of non-response on study results and increase insight into these data. Deficiencies in the study sample will be accounted for in the interpretation and generalisability of results and will inform the direction of future work. Sample representation will be discussed in respect of 1) online survey response, 2) gender, 3) Australian states and territories, 4) ethnic groups, 5) health socioeconomics and 6) comorbidities.

9.2.1 Online response

Online survey response accounted for 93% of all responses in the current study. Mixed modes of administration were used in order to increase potential response rates and reduce selection bias. Although paper surveys were distribution to targeted rheumatology services in every state and territory across Australia (n=650) and were sent to potential participants on request (n=6), the online survey was substantially more successful. These findings are in concordance with previous studies that have shown respondents with PsA prefer web-based surveys over paper versions and find them easier to complete (Chandran, et al., 2007; MacKenzie, et al., 2011; Magrey, et al., 2019). PsA typically affects the age-group that has one of the highest proportions of internet users and who access the internet every day in Australia (Australian Bureau of Statistics, 2016e). In 2016, 80% of all households had internet access Australia-wide and mobile devices were used by 91% of connected households, with access and use reported to be steadily increasing (Australian Bureau of Statistics, 2016e). Therefore, it was not unexpected that most survey responses were received online. Nonetheless, access is not universal and participation in online surveys can be influenced by gender and social deprivation (Fricker and Schonlau, 2002). Indeed, the majority of participants in the current study were women (89%), in full time employment (30%), with higher education levels (75%) and from higher socioeconomic areas (43%), which is consistent with the demographic characteristics reported to influence response rates to online health surveys (Fricker and Schonlau, 2002; Turrell, et al., 2003; Bethlehem, 2010). In addition, those who completed the paper survey were slightly older, more were retired and had a lower level of education compared with the online sample, which is consistent with previous studies on postal survey respondents (Siemiatycki and Campbell, 1984; Macera, et al., 1990; Etter and Perneger, 1997).

Data collection relied in principle on the online arm of the study, which could be criticised for bias towards those who use technology and engage well with online resources. In contrast to the UK where leading centres have large early arthritis registers that could be targeted for recruitment, this does not exist in Australia and the current method of sampling was the only way to capture this type of data.

9.2.2 Gender

PsA has no gender preference with an incidence ratio close to 1:1 (Gladman, 1998) and there have been no reported gender-related differences in disease expression of peripheral features (Gladman, et al., 1992; Gladman, et al., 1993). Therefore, near equal survey completions between males and females would be expected, but low male response rates (n=68, 11%) were found in the current study. Previous foot-specific studies have identified gender-related differences in foot healthcare-seeking behaviour, which include the under-reporting of foot problems in men (Munro and Steele, 1998; Hjelm, et al., 2002; Graham, et al., 2017), and that fewer men access care in relation to their foot health (Wilson, et al., 2017a). Although foot problems have been described as more prevalent in women in the general population (Dunn, et al., 2004; Thomas, et al., 2011), prevalence differences could, in part, be explained by higher levels of reporting in women than men. Indeed, health survey research indicates that women show a greater propensity for responding than men (Etter and Perneger, 1997; Fricker and Schonlau, 2002) and previous PsA-specific research further supports lower engagement with health information in men (Drăgoi, et al., 2013; Kavanaugh, et al., 2016). Therefore, low male responses rates were most likely due to lower motivation for health engagement compared with women. Whilst this was not an unexpected result in the current study, caution should be taken with the interpretation and generalisability of the gender influenced concepts such as with reported frequencies of comorbidities known to be more common in women and with footwear components where gender-specific differences have been identified. Future work should include finding mechanisms to specifically target males in order to determine PsA-specific foot health concerns, priorities and impacts in men living in Australia.

9.2.3 Australian states and territories

Poor sample representation from the Northern Territory was identified during the survey dissemination phase and targeted survey promotion did not increase local response rates (including 3 online local health networks and 2 rheumatology services at regional localities). The Northern Territory has a distinct demography in comparison with other Australian states and territories. The Northern Territory population represents 1% of the total population of Australia and with a median age of residents of 32 years it has the youngest population in Australia, six years younger than the national median age (Australian Bureau of Statistics, 2016d). In addition, the Northern Territory has the largest group of overseas-born residents (31%) with a high proportion (53%) from non-English speaking countries (Philippines and India), and it has a large indigenous community comprising nearly a third (30%) of the Northern Territory population (Australian Bureau of Statistics, 2016a). Therefore, having fewer people, a higher proportion of young people (outside the peak age of PsA onset (Duarte, et al., 2012)), and a higher proportion of groups affected by health inequalities in the Northern Territory (McConville, et al., 2013), correlated with the lower survey response received.

Despite online survey administration that can be accessed remotely, slower internet speeds and less reliable connectivity may have contributed to the limited reach of the survey to rural and remote regions such as in the Northern Territory. An alternative approach could have been to identify the sampling frame through GP practices and hospital units across Australia. However, lower rates of utilisation and access to primary health services have been shown to relate to rurality and indigenous status (Schofield, et al., 2008; Butler, et al., 2010). Therefore, this previous evidence suggests that stronger resource investment to access the target population through clinical services may not have made much difference to the survey sample representation, with a high chance that those target groups would still not respond. Furthermore, there is very limited evidence showing what percentage of indigenous Australians have PsA and what details do exist suggest it to have low prevalence (Minaur, et al., 2004). Although gaps in the survey sample provide initial insight into factors that may influence foot health in PsA, in recognition that survey findings may not be generalisable to the whole of Australia further work into mechanisms that target specific groups is required in order to capture important perspectives from difficult-to-reach people.

9.2.4 Ethnic groups

The different ethnic groups represented in the survey sample were relatively proportional to those reported in the Australian population (Australian Bureau of Statistics, 2016b). The majority of survey respondents were Australian European and British (91%). Whilst it was an English language survey that required a certain level of English and health literacy, extensive survey pre-testing confirmed that the survey was understandable and easy to fill-out by people with no school certificate and by people from different ethnic backgrounds. Previous studies on non-response in health surveys have indicated that foreigners participate less than nationals (Bergstrand, et al., 1983). However, other studies have found that racial and ethnic minorities are as willing as other groups to participate in health research (Wendler, et al., 2005). Therefore, poorer sample representation from different ethnic groups in the current study could, in part, be due to healthcare barriers related to cultural and language differences. Hence, efforts to increase minority participation in health research should focus on culturally sensitive practices and data collection methods to specifically target and engage those from different ethnic backgrounds (Sullivan, et al., 1995; Butler, et al., 2013; Brady, et al., 2018). Whilst non-respondents can be defined from the survey sample, further work to determine the foot health needs of non-respondents is required.

9.2.5 Health socioeconomics

Under a quarter of the survey respondents were living in a relatively deprived socioeconomic area (23%), as determined by the Index of Relative Socio-economic Advantage and Disadvantage (IRSAD) scores obtained from postcodes. Non-respondents to health survey research are more likely to be from socially deprived areas (Urwin, et al., 1998). Therefore, health surveys tend to underestimate the effects of low socioeconomic status on health status due to selection bias, with lower participation from the lower educated, not working individuals with a poor health status (Lorant, et al., 2007). Although the majority of strategies to improve survey participation were adopted from the literature on survey research where possible (Edwards, et al., 2009), the use of monetary incentives or lotteries suggested to elicit higher response from economically disadvantaged groups were not employed due to lack of funding (Etter and Perneger, 1997; Lorant, et al., 2007; Edwards, 2010). The influence of social deprivation (referring to low income, inadequate housing, unemployment, ill health), on foot involvement and access to foot healthcare in PsA populations has not been established. Information about social determinants of health could be used to inform future decisions on healthcare resource allocation and service provision in order to reduce health inequalities (Marmot, 2006; Butler, et al., 2010; Butler, et al., 2013). The survey was constructed to capture postcodes, the IP addresses of online respondents and healthcare access information in order to identify the regional location of specialist services and allow state-specific differences to be explored in future analysis. PsA population access to foot care may be variable and potentially influenced by different patterns of foot care service provision, how these data reflect the situation in different geographical areas will be the focus of further investigation.

9.2.6 Comorbidities

Comorbidities are common and represent an important contextual factor in PsA (Leung and Thumboo, 2016). Similar to previous research, nearly half (43%) of people with PsA in the current study had more than one comorbidity (Husted, et al., 2013; Sanchez-Carazo, et al., 2014). Comorbidities in PsA often contribute additional disease burden with worse patient-reported disease activity scores, disability, pain and worse quality of life than in people with PsA alone (Kotsis, et al., 2012; Husted, et al., 2013; Magrey, et al., 2013; Husni, 2015; McGonagle, et al., 2015; McHugh, 2015; Brikman, et al., 2016). Therefore, comorbidity in PsA may have contributed to higher foot pain scores, greater activity limitation and reduced ability to cope with foot problems in the current study sample. In addition, foot problems from comorbidities such as diabetes, obesity, osteoarthritis and fibromyalgia remains a factor in determining their relative contribution to symptoms and functioning, which may have led to under or over-reporting of PsA symptoms. Therefore, findings from this study may be subject to bias as confounding variables were not adjusted for. However, eliminating the impact of comorbidities comes at the expense of external validity and loss of generalisability in a real-world context. Recognition of the common comorbidities in PsA that have a direct or indirect effect on foot involvement may have important clinical implications for the potential increase in perception and reporting of foot pain, and influence on patient-reported outcome measures.

Consistent with the current study findings, previous studies have shown that the majority of people with PsA were overweight or obese (Soltani-Arabshahi, et al., 2010; Bhole, et al., 2012; Jamnitski, et al., 2013; Bostoen, et al., 2014; Haroon, et al., 2014; Labitigan, et al., 2014; Eder, et al., 2015; Puig, et al., 2015). Obesity in PsA and its potential impact on foot pain, physical activity and exercise participation are addressed in section 9.4.2. Diabetes was reported in 10% of the survey sample, which is similar to the 12%-19% prevalence observed among people with PsA in a previous population-based cross-sectional study (Dreiher, et al., 2013). Depression, anxiety and fibromyalgia had higher self-reported frequencies in the current study (41%, 39% and 20% respectively) compared with previous prevalence estimates based on clinical indices and patient-reported outcome scores (22%, 36% and 18% respectively) (McDonough, et al., 2014; Brikman, et al., 2016). Female gender has been associated with a higher prevalence of depression, anxiety (Freire, et al., 2011; Bandinelli, et al., 2013b; McDonough, et al., 2014) and fibromyalgia in PsA (Salaffi, et al., 2014; Brikman, et al., 2016), which may explain higher self-reported frequencies of these comorbidities in the current study with a higher proportion of female survey respondents (89%). Future analysis using multivariate analysis techniques is planned in order to better understand the associations and relative contribution of impact from foot problems.

Comorbidities in PsA are known to influence treatment adherence, health behaviours and perceived health status (Carroll, et al., 2004; Betteridge, et al., 2016; Brikman, et al., 2016), and their influence should be taken into consideration by health professionals in the assessment and treatment of PsA at a global and local level. With increasing recognition that communication among health professionals is critical when comorbidities in PsA are present (Ogdie, et al., 2015), perhaps the role of the podiatrist should include appropriate discussions with patients regarding depression, anxiety and/or obesity with emphasis on early recognition and referral, which supports a multidisciplinary approach for both the psychological and physical consequences of psoriatic disease.

9.3 Foot involvement and its impact on people with PsA

To the best of the authors knowledge, the current survey was the largest national survey of foot problems among people with PsA and one of the first studies to comprehensively describe PsA-related foot involvement in a large population-based sample. Findings of the present study indicate that foot involvement and foot-related functional impairment and disability are common among people with PsA and that the severity appears to be largely independent of disease duration. Furthermore, survey results demonstrated heterogeneity of disease features present in the foot and ankle that varied substantially between individuals. Novel findings in this study are the trends between site-specific foot involvement and their impact on the lives of people with PsA, their experiences with footwear and their foot care needs, which have not been previously captured in clinical or image-based studies.

PsA is associated with a high disease burden that reduces functional capacity and quality of life compared with healthy controls and those with psoriasis alone (Husted, et al., 1997; Zachariae, et al., 2002). Whilst global disease severity and impact have been demonstrated, this study contributes new knowledge by identifying the body region-specific impact of localised disease in the foot in a large PsA sample. A diverse range of foot problems were reported, the majority of respondents had several foot pathologies with pain affecting multiple regions of the foot. Extensive foot involvement suggests that a high level of active foot disease and/or structural changes may have been missed or undertreated with clinical relevance for foot-related functional impairment and disability. Whilst foot pain and deformities may occur irrespective of inflammatory processes among older adults in the general population (Roddy, et al., 2007; Thomas, et al., 2011), the site-specific involvement of disease-related factors such as enthesitis, dactylitis, skin and nail psoriasis, as recognised in the current study, provides important information about impact on foot-related disability in PsA. The broad distribution and heterogeneity of foot problems found in the current study supports the need for early and comprehensive foot assessments and foot care that is coordinated and tailored (specialist and targeted) to individual needs in order to improve outcomes for people with PsA.

The proportion of self-reported foot pain and local disease manifestations in the current study were considerably higher than an earlier clinic-based study using a smaller sample size from a single centre (Hyslop, et al., 2010a) (Table provided in Appendix 11). Variations between the study findings are likely to be explained by the differences in sampling. The previous study used a convenience sample recruited from a single hospital site with embedded podiatry services compared with the current self-report survey that was conducted without the bias of a specific clinic or geographical region. By obtaining data from a larger sample size the current study attempted to reduce potential errors inherent in smaller samples. Future comparative study using a similar survey approach to sampling a large PsA population across the UK and other countries is warranted.

9.3.1 Enthesitis

Enthesitis was defined as self-reported problems with the ‘plantar fascia (under the heel or arch)’ and ‘Achilles tendon (back of the heel)’. Enthesitis was the most common disease feature at the plantar fascia (57%) followed by the Achilles tendon (38%) reported by the current survey sample. These findings were broadly consistent with previous PsA-specific ultrasound-based studies that reported prevalence rates of 10%-57% and 32%-76% respectively (D'Agostino, et al., 2003; Falsetti, et al., 2003; Delle Sedie, et al., 2011; Woodburn, et al., 2013; Harman and Tekeoğlu, 2017). Foot symptoms in PsA can be due to inflammatory or biomechanical processes or both. The current survey captures the presence of symptoms resembling disease features at the location of these structures, which provides a clinically relevant description of site-specific foot involvement in PsA. The novel finding of this study is that there was a trend towards greater levels of foot-related disability reported by people with symptoms of enthesitis at the rearfoot than with other foot pathologies (as indicated by difficulties with standing, walking and climbing stairs and by walking slower than others).

High impact associated with rearfoot involvement related to reduced mobility and interference with daily routine, social activities, exercise and sleep, which were all reported in higher frequencies by those with Achilles tendon problems compared with plantar fasciitis. Decreased biomechanical loading of the Achilles tendon with slower walking velocity has been demonstrated when the entheses and adjacent structures are inflamed (Woodburn, et al., 2013). Therefore, study findings could suggest that whilst avoidance of load transfer to parts of the forefoot may be possible, off-loading the rearfoot during gait is likely to be more difficult with severe functional consequences. This may also explain persistence of rearfoot involvement since load bearing is carried through inflamed and/or deformed musculoskeletal structures. These inferences are largely hypothesised and merit further investigation using combined inflammatory and biomechanical analysis of PsA sub-groups with a site-specific focus, which may also direct management strategies that attempt to off-load high stress areas with the aim of reducing foot pain in people with PsA.

Plantar fasciitis was significantly more common in women than men in the current study. This is similar to findings reported in non-inflammatory arthritis groups (Urse, 2012; Moustafa, et al., 2015; Reb, et al., 2015) and was associated with risk factors related to mechanical overloading (obesity, prolonged standing), which suggests the important role of mechanics in the aetiology of plantar fasciitis in PsA. Conversely, the trend between increased global disease activity and self-reported plantar fasciitis would suggest an inflammatory role with plantar fasciitis being a localised manifestation of global disease. However, the majority of the survey sample were under the care of rheumatology and taking DMARDs, which would normally indicate tight control of active inflammation. Whilst plantar fasciitis is one of the classic hallmark features of PsA (D'Agostino and Olivieri, 2006), it can be of mechanical origin unrelated to systemic disease (Furey, 1975; Wearing, et al., 2006) and a common clinical challenge in PsA can be determining the relative contribution of inflammatory and/or pathomechanical features. With no gender-related differences in PsA-specific disease features reported in the literature, this study result indicates that plantar fasciitis may be associated with mechanical features than a result of inflammatory disease, which progresses current understanding of disease manifestations in PsA having not been previously reported. In addition, it may be important to consider the influence of comorbidities such as diabetes and fibromyalgia in this context, which are associated with an increased enthesitis prevalence (Fernandez-Suerio, 2012) and increased plantar fascial thickness (Giacomozzi, et al., 2005). Therefore, the importance of mechanical or inflammatory mechanisms driving plantar fasciitis is not clear and suggests that this is multifaceted, complex and warrants further investigation.

Emotional impact of region-specific foot involvement on people with PsA was revealed in the survey, with a trend towards impaired physical function from rearfoot enthesitis being associated with greater levels of frustration compared with other foot pathologies. In addition, there was a trend towards sleep disturbance being associated with rearfoot enthesitis compared with other foot pathologies. This is consistent with a previous study that found enthesitis was associated with poor sleep quality in PsA by using the Maastricht Ankylosing Spondylitis Enthesitis Score (MASES), which tests 13 entheses sites with local pressure and includes the insertion of the Achilles tendons (Gezer, et al., 2014). Whilst it is known that people with PsA commonly suffer from sleep disorders and that they have a considerable impact on emotional health and quality of life (Duffin, et al., 2009; Gezer, et al., 2014; Gossec, et al., 2014), the current study reveals the foot-specific impact. Lack of sleep has been attributed to worse pain ratings (Finan, et al., 2013), withdrawal from favoured activities and fatigue that may lead to reduced physical fitness (Betteridge, et al., 2016). There was a trend between Achilles enthesitis and plantar fasciitis in the current study both being associated with greater foot pain severity and poorer coping. High foot disease burden in those with rearfoot enthesitis suggests that treatments in early disease should be directed towards prevention of rearfoot involvement. Survey respondents with rearfoot enthesitis preferred lace-up sneakers or being barefoot or in socks/slippers, and important footwear features were cushioning, light-weight, soft heel counter and arch support, which identifies aspects of care to focus on for podiatrists in clinical practice. Prospective studies are needed in order to fully explore the relationship between rearfoot enthesitis, foot pain, footwear and quality of life.

It should be acknowledged that involvement of the functional entheses such as the peroneal and tibialis posterior tendons around the ankle will be interpreted in future analysis of the foot pain diagrams. However, currently it is not possible to determine the precision of the anatomical localisation of site-specific pathology mapped to the foot pain diagrams, and it may require future validation with combined clinical and image-based assessment.

9.3.2 Dactylitis and forefoot involvement

Dactylitis was reported by 40% of the survey sample, which is consistent with previous clinical PsA cohort studies (Brockbank, et al., 2005; Gladman and Chandran, 2011; Kavanaugh and Mease, 2012; Gladman, et al., 2013). Although dactylitis is regarded as a marker of disease severity associated with clinical joint damage and impaired function (Brockbank, et al., 2005; Geijer, et al., 2015), limited research to date has defined the specific impact of toe dactylitis in a PsA population beyond associated mechanical factors (Wilkins, et al., 2016). Key domains of impact for respondents with dactylitis and lesser toe deformities were associated with footwear and body image. A greater proportion of people with toe involvement reported feeling embarrassed or self-conscious about their toes (67%) and footwear choice (38%) compared with other foot pathologies. Despite the load bearing function of the toes having some impact on physical function (walking barefoot, climbing stairs and driving), footwear discomfort and restrictions had greater impact by diminishing the ability to cope with foot problems. Although embarrassed by the appearance of their toes, open-type footwear was worn by most people with toe involvement with consequent important footwear features including a wider fit, having plenty of toe room, cushioning and support. Whilst it can be considered that footwear is a key modifiable contextual factor for those with toe involvement in PsA, the emotional burden related to self-management should not be neglected during clinical consultation. With current joint damage predictive of future damage (Gladman and Farewell, 1999), these study findings may support vulnerability for further progression of toe deformity. It remains unclear if a window of opportunity to actively treat those people with toe involvement has been missed, and possibly even missed at the point of diagnosis given the considerable diagnostic delay. Biomechanical factors, localised anatomy and increased functional demands require further investigation.

In contrast to previous studies (Ghanem, et al., 2007; Hyslop, et al., 2010a; Delle Sedie, et al., 2011; Turner, et al., 2014), low levels of MTPJ deformity were reported in the current study. It is highly likely that this difference can be explained by foot deformity being clinician assigned rather than self-reported, with previous studies having used image-based measures of metatarsal head prominence. It is unlikely that the current study cohort was free from metatarsal head deformity, but self-perceived deformity was low. This is consistent with previous podiatry survey research where a clinician may record the presence of mild deformity previously unrecognised by the respondent (Garrow, et al., 2004). Lack of deformity perceived by people with PsA could have important clinical implications for foot health education and management initiatives. An alternative approach in future survey research would be to consider using diagrams of foot pathologies such as the hallux valgus diagrams used in previous research (Roddy, et al., 2007). However, most participants during survey pre-testing felt confident with self-reporting foot problems finding additional diagrams unnecessary. Another way to compare the reliability of clinician-diagnosed foot deformity with self-report would be to allow respondents to upload foot photographs to the survey with instructions on the particular foot views required, which could form part of future research among those respondents who indicated an interest to participate in further study. Lesser toe deformities, one of the most common foot problems (45%) reported in the current study, have been associated with MTPJ subluxation and altered mechanical loading patterns in previous foot-specific research in PsA (Turner, et al., 2014). However, previous research found no relationship between MTPJ pain and functional changes in PsA (Turner, et al., 2014), which may be due to the impact of possible inflammatory features at the rearfoot not having been taken into account. Given the high frequency of rearfoot involvement reported in the current study, future research using metrics of global foot function such as velocity of centre of pressure may have value in elucidating relationships between foot-related pain, function and disability. Another explanation may be that early functional adaptation to local disease activity at the MTPJs may have occurred, which accounts for lower levels of foot-related functional impairments compared with other region-specific pathologies in the midfoot and/or rearfoot. Further biomechanical research is warranted to understand the mechanisms for pain and localised disease activity.

9.3.3 Dermatological manifestations

Toenail psoriasis (57%) was the most commonly reported dermatological feature (above dry cracked heels, hard skin and corns) and skin psoriasis affecting the feet and ankles was the least common (29%). Occurrence rates of clinical features of psoriasis (skin and nail) vary considerably in the literature and are often not foot-specific. Although dermatological symptoms (soreness, tenderness and pain) were reported as mild or not present, the emotional burden and impact on footwear choice was high. This suggests that whilst key clinical indicators of pain and impaired function may not be reported, health professionals should have a line of direct questioning to determine the extent of impact and clinical importance attributed to skin and toenail features as disease burden may be high. Emotional well-being, that can have a direct or indirect effect on PsA-related foot involvement and self-management, has been consistently rated as a key impact domain by people with PsA and represents an important contextual factor in the assessment of localised PsA disease activity in the foot.

Identification of toenail psoriasis as an important contributor to the impact of disease in a large PsA data set represents a measure of survey success. This finding links back to the earlier qualitative insights relating to concerns raised by patients about toenail involvement that were poorly recognised by health professionals. The importance and relevance of nail disease to people with PsA followed through to the survey design, capturing the impact of dermatological features affecting the feet and confirming it on a larger scale. This further demonstrates the value of the rigorous approach to survey design, which has also informed the interpretation of the data by having in-depth understanding of the connections between impact domains. The major intent of this research was to move beyond a simple description of disease features and to comprehensively define the localised impact and disease burden, which may inform future clinical management. Findings should highlight to health professionals to look beyond pain and function, and to perhaps find out how patients feel about the impact of localised disease. Small-scale qualitative cohort findings have been supported in the large-scale survey, but had a more basic approach been taken to producing a survey this important information on psychological aspects (emotions, coping, understanding) would have been missed.

Current study results confirm the profound burden of concurrent psoriasis in PsA that has been previously reported in global disease (Boehncke and Menter, 2013), and highlights the body-region specific impact of dermatological manifestations affecting the feet. In previous studies that have used the Leeds Foot Impact Scale in Rheumatoid Arthritis (LFIS-RA) to determine the impact of localised disease in PsA (Hyslop, et al., 2010a; Woodburn, et al., 2013; Turner, et al., 2014; Wilkins, et al., 2016), the authors acknowledged that the tool would not adequately capture dermatological involvement. This study confirms those concerns with high disease burden specifically attributed to dermatological involvement and highlights the need for disease-specific measures. Rheumatology and podiatry health professionals may under-appreciate the major psychosocial impact from dermatological involvement of the feet in PsA and that the impact may be similar for both men and women. This study identifies the urgent need to raise awareness of the specific ways in which the dermatological manifestations can impact people with PsA in order to improve understanding and support for those suffering with these features and their families.

Skin psoriasis affecting the feet and ankles was significantly associated with psoriatic toenail involvement. Whilst this association has been previously suggested (Langley, et al., 2005), foot-specific information is limited. This association has important clinical relevance when traumatic nail conditions and fungal nail infections complicate the clinical picture. Clinical uncertainty in differentiating psoriatic nail disease from other nail conditions is common (Patience, et al., 2018). Although future clinical verification of these findings are required, this association provides clinically useful information that suggests nail involvement is more likely to be psoriatic when skin psoriasis is present in the feet. Whilst there is wide recognition in the PsA literature that plantar psoriasis negatively effects quality of life measures (Farley, et al., 2009; Chung, et al., 2014; Engin, et al., 2017), the impact from toenail psoriasis on daily life and ability to cope with PsA-related foot involvement may be poorly recognised with limited research to determine its specific impact. Health professionals should seek to identify the concomitance of skin and toenail psoriasis and awareness of this possible association may also help with potential PsA diagnosis.

9.4 Activity and participation impact

9.4.1 Exercise participation

Physical exercise was limited by foot problems in the majority of participants (83%), with few achieving the recommended amounts of moderate and vigorous intensity of exercise each week outlined in Australian Government public health guidelines for adults (Australian Government Department of Health, 2020). Insufficient physical exercise is one of the leading risk factors for cardiovascular disease and is strongly associated with poor general health status (WHO, 2018). Cardiovascular disease is more prevalent among people with PsA (such as myocardial infarction and stroke) than the general population (Horreau, et al., 2013; Jamnitski, et al., 2013) and those with psoriasis alone (Eder, et al., 2013). The increased risk has been attributed to a higher prevalence of traditional risk factors (hypertension, obesity, diabetes mellitus), as a result of chronic systemic inflammation and decreased physical activity due to reduced functional capacity (Husted, et al., 2011; Dreiher, et al., 2013; Husted, et al., 2013; Beinsberger, et al., 2014; Khraishi, et al., 2014; Radner, et al., 2016). With foot pain, foot-related functional impairments and proximal involvement identified as major barriers to exercise participation, these findings highlight the significant impact of foot involvement on PsA-specific global health and functioning and identifies the need for effective evidence-based interventions for reducing foot pain and improving function among this patient group.

Localised disease impact on the ability to exercise and maintain fitness as well as the unwanted consequence of weight gain were key concerns raised in the earlier qualitative work, which are supported by the survey results. Despite limited evidence showing the benefits of regular exercise in PsA, it is recommended to improve functional capacity and quality of life (Lubrano, et al., 2009; Roger-Silva, et al., 2018; Thomsen, et al., 2018). Health professionals have an important role in encouraging regular and adequate levels of health-enhancing physical activity among people with PsA. However, the high impact of the disease on body image and the perceived lack of social support by people with PsA identified in the present study may contribute to an increased susceptibility to adopt negative health behaviours. Integral to engaging in exercise is the confidence and trust that people with PsA have in health professionals in terms of exercise knowledge and understanding the disease (Chimenti, et al., 2014). This suggests that disease-specific understanding may improve compliance and uptake of physical activity in PsA. This would need to be shown in further research, but highlights the importance of social support and the lack of understanding about the disease among health professionals perceived by patients that was identified as a concern in the qualitative work. Shown in this large PsA cohort are the themes revealed in the qualitative interviews, which allows a more sophisticated appreciation of the richness of the data set and shows the strength of this research. Survey data was collected on physical exercise in order to undertake future work to determine the foot-specific contribution to reduction in physical activity as well as the integration of information related to global disease, comorbidities and coping. Addressing concerns about exercise, approached in a way that instils confidence and that demonstrates understanding of the individual patient journey, may have important implications in clinical management with a focus on building positive relationships, providing emotional support and increasing motivation.

9.4.2 Obesity

In recognition that over half the study sample were obese (56%) and had foot pain (92%), it is important to understand the mechanisms that may contribute to the association of symptoms and impact. It is well established that foot pain is commonly associated with obesity among adults in the general population (both men and women) (Butterworth, et al., 2013; Butterworth, et al., 2015a; Mickle and Steele, 2015; Dufour, et al., 2017). Whilst obesity in PsA has been associated with decreased levels of patient-reported physical health (Husted, et al., 2013), there are limited data on the added burden of comorbidity on foot health outcomes in PsA and impact from the patient perspective is lacking. Mechanisms that may contribute to the impact include the link between obesity, high plantar pressures and increased mechanical load on musculoskeletal structures (Butterworth, et al., 2015b; Dufour, et al., 2017); and the increased inflammatory burden related to the metabolic activity of adipose tissue (Russolillo, et al., 2013; Di Minno, et al., 2014). However, specific to PsA is the link between micro-damage triggered by high mechanical stress at key anatomical sites in the lower limbs and disease pathogenesis (Benjamin and McGonagle, 2001; McGonagle, et al., 2001).

Several studies have suggested that obesity may be a risk factor for the development of PsA (Soltani-Arabshahi, et al., 2010; Love, et al., 2012), may impact on disease activity and reduce the likelihood of achieving minimal disease activity during treatment with traditional or biologic DMARDs (Russolillo, et al., 2013; Versini, et al., 2014; Lupoli, et al., 2016). Therefore, those with obesity in the current survey sample may have had a reduced response to therapy with increased disease severity at a global and foot level. Whilst it is not known if foot pain predisposed the obesity or visa-versa in the current study, foot pain and/or problems reportedly reduced physical activity and were a potential deterrent to participation in exercise. People with PsA who are overweight or obese are often encouraged to lose weight, not only for potential increased benefit from therapy but also for decreased risk of other comorbidities associated with obesity such as diabetes and cardiovascular disease (Husni, 2015).

Therefore, foot problems may be contributing to a major health issue for people with PsA, regarding the increased cardiovascular risk and inability to exercise for its protective effect. Planned future regression analysis to identify the important contributing factors to reduced physical activity and exercise participation will permit more detailed exploration of these concepts.

Current evidence in the general population suggests that reducing body mass can lead to a reduction in foot pain in overweight and obese adults (McGoey, et al., 1990; Hooper, et al., 2007). However, the influence of weight loss on foot involvement in a PsA population is not known, and key challenges highlighted in the survey data relate to the vicious cycle of foot pain and related-disability, physical exercise and body weight. Alternative strategies suggested when foot pain is inhibiting ambulation include recommending non-weight bearing exercise to aid with weight loss (Mickle and Steele, 2015). Given that mechanical stress is one of the triggers of local inflammation in PsA (Tönük, et al., 2016), further investigation into such strategies in order to determine the role of physical activity and biomechanical factors that might influence PsA-related foot involvement will be important. The degree to which obesity and biomechanical–related factors are modifiable, if at all, may also have important clinical implications for the management of PsA-foot involvement, which require further study. These findings suggest that future PsA foot-specific clinical trials for developing interventions should consider data stratification by body weight, and should focus on the importance of exercise ability and weight reduction as interventional strategies alongside local mechanical based approaches for the prevention and early treatment of obesity.

9.4.3 Participation in activities of daily living

Impact from foot involvement was considerable on ability to undertake physical activity with most participants reporting that foot problems had interfered with activities of daily living. Whilst musculoskeletal and dermatological manifestations in the feet had limited daily routine and social/leisure activities, impact from foot problems on work or family life were less frequently reported. Although 45% of the survey reported that their work status had changed due to PsA, the majority (70%) were in remunerative employment or engaged in work-related activity. These results suggest that foot problems and footwear difficulties have a minimal impact on work-related disability in PsA. An explanation could be that participation is a balancing process where people with PsA, who are typically at working age, may prioritise work productivity and make adjustments elsewhere in order to fulfil normal life roles. Balancing and redefining normal life has been previously identified as critical to the process of coping with rheumatic disease (Grønning, et al., 2011). This explanation would need further research and may also be related to the high use of biologics reported in the survey sample, which has been shown to improve work productivity and reduce absenteeism (Tillett, et al., 2017b). This current study provides new insights into the specific and substantial impact of foot problems on foot-related functional impairments and disability in PsA. Key domains of impact identified in this study were mobility, social/leisure activities, exercise, emotional well-being, coping and footwear.

9.4.4 Falls

Adults with PsA-related foot problems have an increased number of reported falls. Limited research evidence exists to suggest that falls are common in PsA. With falls not previously reported in the PsA literature or by health professionals and expert groups, this unique study finding was captured in the survey directly as a result of the robust design process. Falls were identified by people with PsA-related foot involvement in the qualitative interviews (n=5, 24% with a mean (SD) age of 63 (8) years) and that resulted in its inclusion as a survey item, it was then retained by patients during survey pre-testing and by majority expert consensus as a relevant concept, which has subsequently demonstrated falls on a large-scale in this patient group. This highlights the importance of gaining an in-depth understanding about relevant concepts from people with the disease as part of a rigorous survey development process. However, in the context of how the data was collected (retrospective recall and cross-sectional design) and with the associated limitations of this approach being acknowledged, this result should be interpreted with caution. Falls recall can lead to under-reporting of falls incidence due to forgetting a fall and particularly those without injury (Cummings, et al., 1988; Hale, et al., 1993; Peel, 2000). However, previous studies on falls recall have focused predominantly on the elderly aged 70 years and over (Ganz, et al., 2005), which may not reflect the accuracy of recall in young and middle-aged groups more typical in PsA. Given that comorbid conditions and psychotropic medication use is a significant risk factor for falls (Lamb, et al., 2005;

Stanmore, et al., 2013), it is noted that 41% and 39% of the survey sample reported having depression and anxiety respectively, which could be a contributory factor to increasing falls risk. Comorbidities in PsA are common and eliminating the impact of comorbidity may reduce external validity and generalisability. Whilst it is recognised that there may be some controversy related to the potential for error in determining falls through retrospective recall and in determining the relative contribution of comorbidities to problems in function, the data shows a significant relationship between those with foot problems and those who reported a fall. Despite these limitations, the current study findings suggest that future prospective studies are warranted in order to provide definitive conclusions regarding causes of falls in people with PsA.

Falls in PsA identified by the current study represents new knowledge contribution in this field of research that has not been previously reported in the large longitudinal and prospective PsA data sets. This unique finding in a PsA-specific population is consistent with previous research in RA that found self-reported foot-related functional impairments were associated with a greater risk of falls (Brenton-Rule, et al., 2016). However, a major difference is the younger age of those reporting falls with the majority aged between 40 and 59 years compared with those typically aged over 60 years in RA populations (Armstrong, et al., 2005; Hayashibara, et al., 2010; Stanmore, et al., 2013) and older adults aged over 65 years in the community (Deandrea, et al., 2010). Whilst several previous studies have investigated the contribution of foot and lower limb characteristics to falls risk in RA populations (Jamison, et al., 2003; Armstrong, et al., 2005; Smulders, et al., 2009; Hayashibara, et al., 2010; Levinger, et al., 2012; Stanmore, et al., 2013; Brenton-Rule, et al., 2016) and healthy older adults (Menz and Lord, 2001; Menz, et al., 2005; Menz, et al., 2006; Chaiwanichsiri, et al., 2009; Mickle, et al., 2009; Mickle, et al., 2010), there is limited falls research in PsA. With falls generally associated with elderly adults (Deandrea, et al., 2010), it is possible that health professionals may not identify the potential falls risk in younger people with PsA at working age, who consequently do not receive tailored appropriate treatment that addresses potential falls risk. Falls are associated with a significant burden of morbidity and mortality such as serious injuries, hospital admission or admission to care homes, fear of falling, decreased independence and reduced quality of life (Lamb, et al., 2005; Stanmore, et al., 2013). Therefore, falls in

PsA can have potentially devastating consequences and an awareness of the risk factors associated with falls in PsA may help health professionals to identify and better manage younger people with increased falls risk. Falls in PsA warrants future prospective investigation and highlights the potential role of podiatric interventions in foot-specific falls prevention strategies.

9.5 Contextual factors

9.5.1 Footwear impact

Footwear has been perceived as an external expression of disease by people with RA, which negatively impacts on self-identify, self-esteem and lifestyle (Williams, et al., 2007a). Whilst several qualitative studies have explored perceptions of footwear in RA (Williams and Nester, 2006; Williams, et al., 2007b; Williams, et al., 2010; Williams and Graham, 2012), limited research exists on footwear experiences in PsA (Carter, et al., 2019a). Significant patient involvement and the qualitative approach taken in the current study revealed a richness of data relating to important footwear issues and related disease impact in PsA, which guided parts of the survey development and design. Although climate and weather is known to drive footwear choice (Brenton-Rule, et al., 2014), there is a paucity of research on footwear worn in Australia. One previous Australian-based study found footwear difficulties in RA that related to comfort, aesthetics and seasonal variation (Hendry, et al., 2013b). However, PsA is a distinct disease entity with specific disease features such as Achilles enthesitis and dactylitis and hence footwear preferences and problems cannot be extrapolated from other groups, highlighting the necessity for the current survey research.

The most commonly worn footwear type was walking shoes (lace-up and slip-on sneakers) followed by sports shoes and supportive sandals in a large representative sample of people with PsA. Previous studies have also found these footwear types to be popular amongst those with inflammatory arthritis (Silvester, et al., 2010; Brenton-Rule, et al., 2014; Carter, et al., 2016; Stewart, et al., 2018; Brenton-Rule, et al., 2019). Although comparisons with previous studies are difficult due to methodological variations, there appears to be consistency in the preferred footwear categories of diverse arthritic-populations (Barwick, et al., 2018). Footwear types worn the most were those with desirable features that have been associated with improved foot health outcomes among people with RA (Hennessy, et al., 2007) and gout (Rome, et al., 2013). For example, sports shoes commonly have both cushioning and supportive properties. However, footwear construction and condition can vary significantly (Dufour, et al., 2009) and self-reported footwear choice may not represent actual footwear habits. Given the reported popularity of wearing walking shoes, sports shoes and supportive sandals, further research to evaluate the evidence for the clinical effectiveness of commercially available footwear interventions for foot pain and foot-related functional impairment and disability in people with PsA may be warranted.

No shoes (barefoot) or wearing socks/slippers was reportedly common during a typical week (36%). Nearly a quarter (27%) of the study sample reported wearing poor footwear (fashion sandals, moccasins and thongs/flip-flops), which implies a shoe design that lacks support and shock absorption. These findings are similar to previous studies reporting footwear with poor structural characteristics in people with different types of inflammatory arthritis (Silvester, et al., 2010; Brenton-Rule, et al., 2014; Brenton-Rule, et al., 2019). It has been previously suggested that wearing poor footwear may be due to financial restrictions or a lack of awareness of the importance of good quality footwear in reducing foot pain and foot-related disability (Rome, et al., 2011; Brenton-Rule, et al., 2019). In addition, whilst wearing open-type, minimal footwear may reflect difficulties in finding footwear that fits and does not hurt, it may also be related to sociocultural and climate factors in Australia. Previous studies conducted in the UK (Naidoo, et al., 2011), Australia (Hendry, et al., 2013b), New Zealand (Silvester, et al., 2010; Brenton-Rule, et al., 2014) and Singapore (Carter, et al., 2016) acknowledge that temperature, humidity and rainfall can play a key role in influencing footwear habits. Future planned analysis beyond the scope of this thesis will be to examine possible associations between sociodemographic factors, geographical locations in Australia (including tropical and temperate climates as well as remote, regional and urban areas) and different types of footwear worn, footwear preferences and difficulties with footwear. Footwear differences identified across Australia will be clinically useful for management decisions and will inform the direction of future intervention studies. Future research will also include comparisons with large population-based PsA-specific samples in other countries in order to explore differences in footwear choice driven by culture and climate.

Despite thongs/flip-flops being a popular choice of footwear among the general population in Australia and with the study period conducted over both spring and summer months, lower than anticipated frequencies of those wearing thongs/flip-flops were reported in the current study (17%). These study findings were consistent with similar New Zealand-based studies that reported thongs/flip-flops were worn by 10% to 16% of people with inflammatory arthritis (Brenton-Rule, et al., 2014), RA (Silvester, et al., 2010), SLE (Stewart, et al., 2018) and gout (Rome, et al., 2011; Brenton-Rule, et al., 2019). However, in recognition that the Australian continent has several different climate zones compared with New Zealand, thongs/flip-flops are commonly worn throughout the year in the warmer climates in Australia (Finnis and Walton, 2008). Current study findings suggest that people with PsA presenting with different inflammatory features may have different footwear needs. Greater intrinsic foot muscle strength and peak ankle joint dorsiflexion moments are required during gait in thongs/flip-flops compared with barefoot or in other footwear types (Zhang, et al., 2013; Price, et al., 2014). Additional biomechanical demands observed when wearing thongs/flip-flops may make them a less popular footwear choice among people with PsA with predominant rearfoot involvement of the entheses around the ankle reported in the survey sample. Limited gait research on foot function in PsA has identified the impact on footwear restrictions from higher LFIS-RA sub-scale scores (Hyslop, et al., 2010b; Woodburn, et al., 2013; Turner, et al., 2014; Wilkins, et al., 2016), but these findings did not inform on optimal footwear characteristics. Therefore, gaining an appreciation of what people with PsA have self-selected and consider important in regards to footwear may provide early insights. Given the heterogeneity of presentation in PsA, further analysis to understand how disease manifestations in the feet affects footwear choice may help to determine the role of footwear interventions in the management of this patient group. Study findings have direct relevance for the management of foot involvement in PsA given the effects of footwear properties on gait parameters and plantar pressures known to influence foot pain and foot-related functional impairment and disability. Further research is needed to investigate potential changes to gait parameters associated with footwear and associated improvements to patient-reported outcomes in a PsA population.

Cushioning, support and fit were the most important features when choosing footwear in the current study, which is consistent with previous studies in people with RA

(Williams and Nester, 2006; Silvester, et al., 2010), gout (Rome, et al., 2011) and inflammatory arthritis (Brenton-Rule, et al., 2014). These findings may suggest that people with inflammatory arthritis prioritise these features due to disease-related foot problems. The convenience of taking shoes on/off easily was also important and may reflect difficulties related to hand and/or spine involvement typical in PsA, with most respondents (74%) having reported reduced mobility due to other parts of their body.

Whilst there was no difference in the most commonly worn footwear types between men and women in the current study, a higher proportion of women agreed with all statements relating to difficulties experienced with footwear (discomfort, limitations, impact). Although these results should be interpreted with caution as the survey sample was under-representative of male respondents, current findings were consistent with the literature on footwear differences between sexes. Previous research on footwear in older people has reported marked gender differences relating to footwear choice, fit and comfort (Menz and Morris, 2005; Dufour, et al., 2009). Women compared with men are more likely to; suffer foot pain (Munro and Steele, 1998; Menz and Lord, 2001), report footwear difficulties (Sullivan, et al., 2015), suffer more foot pain when wearing footwear (de Castro, et al., 2010), and to choose footwear with characteristics not recommended to promote mobility and foot health (Hockey, et al., 2013). With sociocultural factors more likely to influence female footwear choice than factors relating to medical or foot conditions (Hockey, et al., 2013), gender associations with footwear among people with PsA living in Australia requires further study using a balanced sample.

This is the first study to report the PsA-specific impact of footwear on daily life. Difficulties with footwear due to both musculoskeletal and dermatological disease features of PsA in the feet were a major contributing factor to negative emotional well-being and self-perceived inability to cope with foot problems. Survey results suggest that the inability to find comfortable footwear and restrictions in the number and type of footwear worn had a substantial impact on emotional health and quality of life in PsA. Difficulties with footwear had greater impact on special occasions than on daily routine and work activities for both men and women. Current study findings provide initial insight into understanding the role of footwear in both limiting and facilitating activity and self-management. The qualitative methods used in this study that enabled researchers to gain a true understanding of patient experiences and linking to the ICF has influenced the way in which data may be interpreted. Footwear, healthcare systems and psychological status (emotions, coping) were important contextual factors linked to the ICF, which have been shown to influence foot-related functional impairments and disability in PsA. Contextual factors (environmental and personal) have been consistently rated as important by people with PsA. Footwear represents a key domain of impact and an important contextual factor in the assessment of PsA-related foot involvement. Survey results further improve understanding of the critical role contextual factors play as barriers or facilitators in self-management of foot involvement in PsA. Further directed work on footwear is required to determine the effect of contextual factors in outcome measurement, as well as longitudinal prospective studies and randomised controlled trials (RCTs) that may help to determine the clinical effectiveness of footwear among people with PsA.

9.5.2 Self-management and coping strategies

The impact triad of rheumatic diseases previously proposed that the personal impact of rheumatic conditions may be influenced by the patient's ability to cope with symptoms, the perceived severity and personal importance (Sanderson, et al., 2011). Consistent with the proposed theory of the impact triad, the majority of participants reported moderate to severe global and local pain, moderate to severe difficulty coping with localised disease, and moderate to extreme perceived importance of foot problems (as determined by the extent to which respondents rated their foot problems as troublesome). Survey data supports the impact triad in people with PsA-related foot involvement and emphasises the importance of incorporating the patient perspective into the assessment of disease and personal impact. Coping was mostly influenced by foot pain severity, experiences with footwear and the availability of social support from friends, family and/or health professionals. Coping represents an important component of impact that was revealed by people with PsA in the qualitative interviews, but was poorly recognised by health professionals. Linking to the ICF highlighted key differences between aspects of coping as an activity and cognitive function that were integrated into the survey design (for example, the coping strategies included in the survey mapped to a range of 'b', 'd' and 'pf' ICF categories; handling stress and other psychological demands, temperament and personality functions, experience of self and time functions, thought functions, adapting to changes in daily routine, looking after one's health, managing one's own activity level and personal factors). It was the strength of the survey development methods that ensured insights into the psychological burden (embarrassment, frustration and ability to cope) from patient interviews were captured on a larger scale by the survey. Interpretation of survey findings and connections in the data have been informed by these valuable insights into the patient experience and from having had the opportunity to gain an in-depth understanding of key concepts (for example, the influence of social support on coping ability and the emotional burden relating to feelings of embarrassment and/or frustration). Knowledge of the patient perception of coping may be important for health professionals in order to better interpret the extent of impact from foot involvement in PsA, but future analysis of these issues is required to inform targeted self-management interventions. Both disease duration and activity were relevant to coping with foot problems, with global pain severity reducing coping ability and with the coping strategy to 'try to keep in control of the problem' being most commonly used by those with an established PsA disease duration (5years or more). Consistent with previous research (Grønning, et al., 2011), it might be expected that people with longer disease duration are more familiar with the coping process than those newly diagnosed and thus make better adjustments and accept changes more easily during the disease course. Further data analysis is required to determine the complex barriers and facilitators to coping with foot problems in order to identify those that are most important, effective and/or potentially modifiable.

9.6 Healthcare access and support

9.6.1 Healthcare access

Access to podiatry services was higher in the survey sample (current access at 24%, past access at 62%) compared with access previously reported in a UK-based clinical study (21%) (Hyslop, et al., 2010a). One explanation may be that respondents to health surveys have been shown to demonstrate greater interest in managing their disease, higher healthcare utilisation, better health status and more positive health-related behaviours than non-respondents (Macera, et al., 1990; Paganini-Hill, et al., 1993; Grotzinger, et al., 1994; Lamers, 1997; Reijneveld and Stronks, 1999). However, despite higher access rates to podiatry services, the majority of participants reported having severe foot pain and a diverse range of disease-related foot problems. These findings may suggest that PsA-related foot health needs have not been fully met by podiatry and/or rheumatology health professionals and raises questions regarding the effectiveness and/or continuity of foot care received. Inadequate standards of rheumatic foot care provision have been previously reported in Australia, with a lack of foot care specialists in the rheumatology field and dedicated services (Hendry, et al., 2013a). There have been no PsA-specific podiatry intervention studies to date and the different disease manifestations between RA and PsA suggest that it should not be assumed that interventions will translate across disease spectrums. This study has shown that despite high uptake of podiatry services, foot care seems to have been ineffective and with a lack of any evidence base for practice this result is probably not unexpected. Integration of podiatry within expert-led rheumatology teams may lead to improvements in foot health outcomes for people with PsA. Whilst provision of effective, timely and targeted care is recommended for the appropriate management of rheumatic foot disease, PsA-specific research into beneficial strategies that address the localised inflammatory and/or biomechanical features that may be responsible for the persistence of foot involvement is warranted.

Different levels of access to rheumatology services for management of PsA were observed across Australian states and territories, which may indicate potential national variations in healthcare access linked to unmet need in PsA. However, data from this study does not necessarily represent actual access to healthcare and effectiveness, but rather perceptions of foot care that may be subject to response and recall bias. Planned future investigation of study data in relation to rural and urban areas in Australia will help to identify socioeconomic and geographical factors linked to unmet need in PsA.

A wide range and high number of professional and non-professional health services were accessed by participants with associated out-of-pocket expenditure on foot healthcare, indicating a significant treatment and financial impact. Survey results suggest an under-treatment of PsA-related foot involvement that may be associated with financial burden related to seeking appropriate care, which is similar to previous survey findings related to global disease burden in PsA (Kavanaugh, et al., 2016). In the PsA core domain set, treatment burden is in the outer circle on the PsA research agenda, which comprises financial hardship and time commitment related to the impact of treatment (Orbai, et al., 2017a; Orbai, et al., 2017b). Although the survey data may be subject to response and recall bias, the results suggest that there is unmet need for effective treatment of foot pain and/or problems, with 96% (n=518) of participants having accessed healthcare for their feet and nearly a third reporting that the care was ineffective (32%). Whilst it is recognised that the survey made no attempt to undertake any formal health service access evaluation, these early insights suggest that future studies should investigate issues related to access, provision, cost and utilisation of foot care services in order to inform the organisation and delivery of healthcare to people with PsA.

9.6.2 Diagnostic delay

Diagnostic delay from symptom onset to diagnosis was a mean (SD) 5.5 (2) years reported in the current study, which supports concerns in recent articles on the considerable diagnostic delay that remains in PsA (Coates and Helliwell, 2017; Holland, et al., 2017; Van den Bosch and Coates, 2018). Diagnostic delay was a key concern and source of frustration for participants in the qualitative investigation of the current study, which contributed to reduced confidence in health professionals and the perceived lack of understanding about the disease by patients (Carter, et al., 2019a). Results from the current survey confirm that challenges related to the screening and diagnosis of PsA are a wider problem across different regions and health services in Australia. Delays in diagnosis of more than 6 months to 2 years have been associated with an increased prevalence of clinical joint damage, poorer function and quality of life in cross-sectional studies (Gladman, et al., 2011; Haroon, et al., 2015) as well as in longitudinal cohort studies (Tillett, et al., 2013). With the majority (n=440, 76%) of survey respondents reporting that symptoms were present for 5 years or more prior to diagnosis, this could explain the high proportion of peripheral joint deformity in the toes and consequent impact on functioning reported in the current study (45%). Despite wide recognition of the importance of early diagnosis to prevent long-term structural damage, disability and the associated socioeconomic consequences, PsA still represents a considerable diagnostic and therapeutic challenge for health professionals (Van den Bosch and Coates, 2018).

PsA-related foot problems can often be poorly recognised by patients and misdiagnosed by health professionals (Carter, et al., 2019b). Hallmark features of PsA such as Achilles enthesitis and plantar fasciitis are common in community-dwelling adults (Menz, et al., 2010) and psoriatic nail disease can often be mistaken for fungal nail infections (Patience, et al., 2018). In addition, there is limited emphasis on rheumatology in undergraduate podiatry curriculums in Australia, which may explain poor recognition of PsA carried through into clinical practice (based on an informal review of university podiatry unit outlines that indicated a percentage coverage of rheumatology between 3% and 12% of the entire programme). Foot examinations are also often omitted from standard clinical indices for the assessment of disease activity in PsA and insufficient musculoskeletal expertise among GPs, rheumatologists and dermatologists has been suggested as a reason for the poor identification of PsA (Van den Bosch and Coates, 2018; Carter, et al., 2019b). This concept emerged in the qualitative study with rheumatologists reporting their reluctance to identify foot problems with few options for onward referral due to the lack of provision and access to specialised podiatry services in both public hospitals and private clinics. With foot involvement predominant and persistent in PsA, further work to increase awareness and understanding about the disease among patients and health professionals is required in order to reduce delays in initial presentation to health services, time to referral to rheumatology clinics and time to diagnosis. Current study findings will be used in future work to highlight important manifestations of the disease in the feet and ankles in order to prompt health professionals to use the full clinical picture of an individual patient to make effective management decisions.

9.6.3 Global disease management in the context of local disease

Biologic agents were taken by a relatively high proportion of the survey cohort (43%) in comparison with 12% use reported by Hyslop, et al., (2010) in a previous foot-specific study in PsA, which was conducted in a leading UK-based specialist rheumatology service. Currently, there are no differences between Australian and UK pharmacological prescribing guidelines for PsA, but there may have been limited access to biologics with sparse evidence of their efficacy and safety 10 years ago when the Hyslop, et al., (2010) study was undertaken. Based on PsA pharmacological treatment algorithms (Gottlieb, et al., 2008; Ritchlin, et al., 2009; Gossec, et al., 2016), it could be inferred that 55% (n=319) of the current survey cohort have experienced failure of conventional DMARDs with subsequent targeted escalation to combined therapy (12%) or biologic treatment (43%). Despite tight control of systemic disease with aggressive pharmacological treatment approaches indicated by biologic intervention, a high level of disease features in the feet were reported among survey respondents. Definitive strategies to attain suppression of localised inflammation in the foot and maintain optimal function are limited with no validated foot-specific outcome measures to define ‘tight control’ of local disease. Current study findings provide initial insight into pharmacological treatment regimes in PsA that may not be efficacious in lowering active disease levels in the foot, with local anatomical and biomechanical factors potentially responsible for disease persistence. These findings suggest that frequent foot screening and comprehensive foot assessments for people with PsA may be warranted. However, with no clinical or image-based assessments in the current study, no conclusions regarding disease suppression can be drawn. Given that nearly half of the participants were on biologic therapy, this provides the opportunity to explore in future research any correlation between global disease activity in those on biologic therapy, foot pain severity and patterns of hallmark disease features in the foot such as dactylitis, enthesitis and toe deformity.

9.6.4 Healthcare understanding and effectiveness

In the current study 68% of people with PsA reported that their health professional had a good understanding of how PsA affected their feet. However, in the Survey of Health Care conducted by the Australian Bureau of Statistics in 2016 on experiences with health professionals (GPs, specialist doctors, health professionals) of those aged 45 years and over in the general population, the majority (91%) of people reported that their health professional had a good understanding of their health, healthcare needs and preferences (n=35495, 29% response rate). GP and rheumatologist knowledge and understanding of foot examination and PsA presentation in the foot is critical for timely and targeted treatment of localised disease, with survey results indicating that the majority of participants had accessed GP and rheumatology services for their foot problems (73% and 81% respectively). Despite the majority of respondents having recalled undergoing a foot examination by their rheumatologist, foot health outcomes seem to be poor given the high impact of localised disease reported in the survey. The accuracy of recall can be questioned, but nonetheless it suggests that people with PsA perceived that foot examinations were undertaken. A wider focus on disease features affecting the feet is required in order to incorporate a comprehensive foot examination as standard, instead of the current limited focus on peripheral joint counts by rheumatologists. Health professionals require sufficient training to provide optimal foot healthcare and outcomes for people with PsA, in the absence of national PsA-specific foot health guidelines.

The qualitative interviews identified that experiences with healthcare seemed to mediate the severity of localised disease impact for people with PsA, and that engagement with foot healthcare was influenced by their perception of confidence in the health professional and their understanding about the disease. This major theme was also recognised by the health professionals who reported service deficiencies leading to suboptimal foot disease management. These key insights relating to lack of confidence and understanding were carried through into the survey development process and have been shown to be important for people with PsA on a large-scale by the survey data, which demonstrates the merit of the meticulous survey design process. Survey results suggest that compared with the rheumatologist and physiotherapist, podiatry treatment was reported to be less effective. In total 53% of participants had seen a podiatrist about their foot problems compared with 81% who had seen the rheumatologist and 33% the physiotherapist. Higher frequency of interactions with rheumatologists may be a factor in developing a rapport and supportive relationship, as well as the typical regular reviews or intensive treatment periods for patients receiving physiotherapy. Whereas in podiatry, whilst dermatological manifestations may require regular routine treatment, musculoskeletal manifestations are likely to represent much shorter episodes of care, which may have resulted in the patient perception of poor personal interaction and service dissatisfaction. Alternatively this finding may, in part, be explained by the distinct lack of specialist podiatry rheumatology services in the public health system in Australia (Hendry, et al., 2013b; Hendry, et al., 2013a). Using professional registration as a metric for clinical interest, there are only 57 allied health professional members of the Australian Rheumatology Association (Australian Rheumatology Association, 2020), which is considerably lower in comparison with equivalent European associations with more than 800 allied health members (such as the European League Against Rheumatism - EULAR). Previous qualitative research in RA concluded that timely and individualised management of foot health by empathic and knowledgeable practitioners was pivotal to ensuring that the known benefits of foot-specific interventions were realised (Williams and Graham, 2012). Despite the fact that evidence for the efficacy of podiatry interventions in the management of people with PsA is required (Patience, et al., 2018), this study finding identifies the need for specialist training of podiatrists, which could help to drive specialist service provision in Australia. Further work to explore the podiatry undergraduate curriculum rheumatology content, postgraduate training provision and career opportunities for podiatrists in the rheumatology field in Australia will help to inform future educational initiatives.

The lack of specialist podiatry services within the public health setting in Australia presents an opportunity to define service structure and provision. Current survey findings provide valuable insight into the impact of PsA-related foot involvement, but prior to seeking to influence connected care provision it may be important to consider the evidence base for various aspects of care. Survey findings could inform future RCT development that may be used for podiatry service recommendations. Therefore, the absence of established services represents a distinct advantage for Australia as a possible site for future RCT research as there would be no obstruction to the withdrawal of services, since they do not exist. This is in contrast to the UK, for example, where there are established models of care for rheumatic foot disease that would require research studies to withhold existing services and treatment, which are currently provided regardless of the lack of an evidence base in PsA. This suggests when developing future studies for interventions that Australia would be considered a prime site for research in this area.

9.7 Contribution of Knowledge

This programme of research addresses the knowledge gap by providing new insights into the patient perspective on the impact of foot involvement in PsA:

Qualitative investigation into the patient experience of foot involvement in PsA revealed new information on the impact of localised disease in the foot, which was profound and widespread across all aspects of life. Discordance between the views of people with PsA and health professionals was revealed, which indicated that health professionals may underappreciate the psychological burden associated with foot involvement. This qualitative study also provided new PsA-specific knowledge related to health service deficiencies in foot disease management in Australia and New Zealand.

Linking to the ICF is a relatively new approach to defining disease impact in the rheumatology field and this study was innovative in using this framework to define region-specific impact on functioning. The list of ICF categories generated in this study represents concepts translated into a universal language that comprehensively describes the functioning of people with PsA-related foot involvement, provides the starting point for future foot-specific outcome development, and an opportunity to compare foot-related functioning across other rheumatic diseases. Inclusion of an occupational therapy perspective in the interpretation of impact highlighted the importance of a multidisciplinary team approach to PsA for future studies.

The survey development protocol provides a significant methods contribution to standard survey research protocols and can be used as a template by other healthcare researchers for broader application. Survey development was heavily compliant with best practices and guidelines for survey conduct and reporting. Merit of the methodological approach and the value of embedding the patient perspective in research activity were supported by subsequent successful survey outcomes, which yielded a high survey response and completion rates despite the survey length. With poor adherence to quality criteria in previous health survey research widely acknowledged, this survey protocol presents a novel high-quality worked example of survey design and conduct in podiatry-led research.

The survey findings strengthen and build on existing literature that indicates foot problems are common in PsA and new knowledge is added on the impact of disease features affecting the feet in PsA from a large and relatively representative population-based sample. This study provides the broadest description of foot involvement and foot-related functional impairments and disability reported in people with PsA to date. With previous data on PsA-specific foot involvement predominantly generated from European studies, this national survey conducted in Australia provides locally representative data and a unique account of foot problems and their impact on daily life, footwear choice and foot care needs. The survey results provide a rich data set and a sound theoretical basis for future analyses and research.

Appropriate management of foot involvement in PsA is poorly understood and indications for referral to rheumatology and/or for specialist podiatry services are not clearly defined, which is compounded by diagnostic challenges related to disease heterogeneity. The assessment of the foot health needs of this patient group is the first step in planning and providing appropriate services, which should be based on an understanding of foot involvement within the community and an appreciation of the most important areas of impact on daily life. This programme of research provides a better understanding of patient perspectives on the impact of foot involvement on daily life, which should be used to assist in decisions regarding the clinical management of foot problems in PsA. Research findings from this PhD provide a strong conceptual foundation for further study that should aim to improve the patient experience and generate effective assessment and treatment strategies for improving foot health outcomes.

9.8 Limitations

Limitations to the other programs of work have been covered in the relevant chapters. The survey findings should be interpreted in the context of limitations inherent in health surveys including selection bias, accuracy of self-report and sample representation. First, it is possible that people with foot problems were more likely to respond to the survey, which potentially introduces selection bias. Although the sample was not restricted to those with foot problems, previous studies on survey non-response found that respondents were more likely to have experienced the topic of interest (Sica, 2006). Therefore, survey results may overestimate the severity and extent of PsA-related foot involvement. Whilst 92% of the sample had experienced foot pain over the past month, over half of the sample (55%) did not consider their foot pain to be the most painful part of their body and approximately half the sample reported mild to moderate levels foot pain (n=273, 53%), which could indicate a relatively balanced sample. Although sources of response bias were reduced by not limiting recruitment to specific clinics or geographical regions and by using mixed modes of survey administration (paper and online), it is possible that participants who volunteered to take part in survey research may not be representative of the general patient population and further non-response analysis is required.

Second, this study relied on information collected by self-report relating to the diagnosis of PsA and foot pathologies. Survey results depend on accurate recognition and appropriate reporting by respondents and self-report may have under or overestimated the PsA-related foot involvement. Previous studies have indicated that patients' self-report of chronic medical conditions is reasonably accurate (Martin, et al., 2000) and self-report of common foot problems has been shown to be reliable in RA (Wilson, et al., 2015). Whilst reliability of reporting was not formally tested in the current study, rigorous survey pre-testing demonstrated high levels of accuracy in the interpretation of survey items including identification of foot conditions. Therefore, survey pre-testing provided a high degree of confidence for accurate and appropriate self-reporting and for the acceptability of one-month recall periods among people with PsA. Nonetheless survey research can be subject to self-report errors and recall bias, which may have influenced the results and should be accounted for in the interpretation of study findings.

Finally, survey data was specific to the Australian context, which may not be representative of PsA populations in different countries. A major objective of the survey was to obtain locally representative data due to limited research on relevant sociocultural, climate and healthcare system factors that may influence foot involvement in Australia. Survey results should be interpreted relative to the context of Australia and inherent aspects including climate, footwear and health service provision, which may not be generalisable to other groups with different contextual factors. Cross-cultural adaptation of the current survey in different countries to analyse between-country differences has been planned (Europe and Singapore), which will increase insight into these data. Despite extensive mechanisms to obtain a broad representative sample, there remained a small number of discrepancies within the sample (gender, regional, ethnicity, online response, item non-response) that hampered interpretation of results and generalisability of findings. In addition, the 10% survey response rate may have created item non-response bias leading to potential sources of error in reporting of the survey findings (Groves, 2006; Davern, 2013; Lewis, et al., 2013). Although gaps in the survey sample provide initial insight into factors that may influence foot health in PsA, further work into mechanisms that target specific groups is required in order to capture important perspectives from difficult-to-reach people.

Cross-sectional surveys are vulnerable to influence from the high variability in PsA disease course as the survey data represents a snapshot in time. Although the heterogeneity of disease features among the survey sample reflects the varied nature of PsA, future longitudinal studies are required to determine change over time and causal relationships. This study provides the most comprehensive description of nature, extent and impact of foot problems reported in people with PsA to date, which demonstrates the importance of performing population-based studies that are broadly representative of people with PsA.

9.9 Future Work

The programme of work for this PhD was intended to provide a large comprehensive data set in order to permit detailed analyses to be undertaken at a post-doctoral level. Areas for future work and more in-depth exploration of the data have been purposefully integrated throughout the chapters. Survey results will be used to inform a programme of future research with the aim of developing targeted disease-specific assessments and management strategies in order to improve foot health outcomes in people with PsA. Key areas of planned future work are described as follows:

9.9.1 Advanced statistical modelling of survey data

The comprehensive and potentially related data included in the survey will require advanced statistical modelling in order to fully appreciate the level of impact and complex relationships between factors that were alluded to by people with PsA in the earlier qualitative work. The linking exercise to the ICF will permit a greater understanding of where data sits within the understanding of disease impact and will provide the basis for preliminary work towards the development of a PsA foot-specific outcome tool. Furthermore, gaps in the survey sample will be addressed in this future work in order to gain better representation from specific non-respondents such as men, those from the Northern Territory, rural and remote regions, different ethnic groups and socioeconomic backgrounds.

9.9.2 Dissemination of survey findings to people with PsA

One of the most important next steps will be to close-the-loop by informing the target population of the survey findings, which adheres to good practices for reporting survey data in health research and aligns with important concepts from the current study about increasing support and understanding. In addition, survey findings will be published on the study website and Facebook page. Dissemination of study findings serves an important role in bridging the gap between health professionals, researchers and consumers of health information, and contributes to research impact in the PsA community beyond the academic setting.

9.9.3 Multi-national adaptation and implementation of the survey

Cross-cultural adaptation of the current survey will be undertaken in order to examine the prevalence, nature and impact of PsA in the foot for implementation in different countries. The research team have undertaken preliminary work to identify potential participating sites through clinical networks in other countries, which include New Zealand, Singapore, Spain and the UK. Survey data collection in a number of different countries worldwide will identify important differences in climate, culture and healthcare delivery that may alter the patient experience of foot problems in PsA. Cross-cultural research involving survey data collection requires specific methodological practices to ensure that the instrument maintains the meaning and intent of the original items, while also being culturally relevant and comprehensible to participants in the target country population. Successful data collection in other countries will provide a comparable data set to determine key factors influencing foot health and daily functioning, and will build a bank of international survey data on the foot in PsA.

9.9.4 Development of a PsA foot-specific patient-reported outcome measure

Development and validation of a PsA-specific patient-reported outcome measure to assess foot involvement will allow the clinical measurement of site-specific disease impact and evaluation of the efficacy of foot care interventions in PsA. A core-set of foot-specific domains will be established from the current conceptual framework and survey data to inform instrument development. Future work may be to develop an online application software programme (App) for the patient-reported foot-specific outcome measure in PsA where certain responses would trigger recommendations for a consult and assessment with a rheumatologist and/or podiatrist.

9.9.5 Integrated assessment of PsA-related foot involvement with combined clinical examination, ultrasound imaging of local inflammatory features and biomechanical analysis of foot function

Clinical validation of proposed statistical models using objective measures will be warranted. To better understand the underlying inflammatory and biomechanical mechanisms that influence disease persistence in the foot in PsA, an integrated approach to assessment is required. Future studies will combine the assessment of clinical and gait metrics with ultrasound imaging to detect local inflammatory disease in the foot. A core-set of reliable foot-specific measures will need to be established in order to inform the standardised assessment of the foot in PsA. The relative contribution of site-specific involvement will be determined by categorising people with PsA according to clinical disease sub-groups, with focus on functional entheses as prime targets for localised disease in the foot. Whilst such investigations have led to paradigmatic changes to therapeutic approaches to foot disease management in RA, these future studies represent unique strategies applied in PsA. Findings will help to inform future prospective studies and targeted PsA-specific intervention research for foot involvement.

9.10 Conclusion

The qualitative research provided in-depth insight into foot involvement in PsA from the patient perspective and revealed its profound and far-reaching impact on daily life, which was translated into the universal language of the ICF. Combined with health professional and expert opinion this formed the basis to robustly develop a national survey, the implementation of which provided a detailed description of PsA in the foot and a rich data set to support ongoing research at a post-doctoral level. The survey protocol presents a robust template that could be used in other diseases or anatomical region-specific studies. Survey findings will form the basis for future intervention-based studies and outcome measure development in order to improve the patient experience and health outcomes for people with PsA in the future.

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Uncategorized References

List of Appendices

Appendix 1: Ethical and locality approvals

Ethical approval was granted by; South Western Sydney Local Health District (HREC/171/LPOOL/353, HREC/15/LPOOL/560), which included site specific agreements for Liverpool Hospital (SSA/17/LPOOL/407), BJC Health rheumatology clinic (SSA/17/LPOOL/407) and Royal North Shore Hospital in North Sydney Local Health District (SSA/18/HAWKE/78, access request RESP/19/066); Western Sydney University Human Research Ethics Committee (H12973, H10299); Auckland University of Technology Ethics Committee (AUTEC 17/320); and Waitemata District Health Board of Auckland, New Zealand (RM/3907). Written informed consent was provided by all participants prior to data collection.

Health
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Locked Bag 7103, LIVERPOOL BC, NSW, 1871
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http://www.sswahs.nsw.gov.au/swslhd/ethics/default.html

South Western Sydney Local Health District acknowledges the traditional owners of this land.

21 September 2017

Miss Kate Carter
School of Health and Science
Western Sydney University

*****THIS LETTER CONSTITUTES ETHICAL APPROVAL ONLY. THIS RESEARCH PROJECT MUST NOT COMMENCE AT A SITE UNTIL SEPARATE AUTHORISATION FROM THE CHIEF EXECUTIVE OR DELEGATE OF THAT SITE HAS BEEN OBTAINED. ******

Dear Miss Carter,

Project Title: **The nature, extent and localisation of foot problems in people with psoriatic arthritis.**
HREC Reference: **HREC/17/LPOOL/353**
Local Project Number: **HE17/191**

Thank you for your response dated 20 September 2017 to our request for further information dated 18 September 2017. This Human Research Ethics Committee is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Research Involving Humans* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.

I am pleased to advise that the Committee has granted ethical approval of the above project.

The following documentation has been reviewed and approved:

Document	**Version**	**Date**
National Ethics Application Form	AU/1/291038	21.08.2017
Protocol	1.0	10.08.2017
MASTER Participant Information Sheet – Focus Group	1.0	24.07.2017
MASTER Participant Information Sheet – Semi-structured Interviews	1.0	24.07.2017
MASTER Consent Form – Focus Group	1.0	24.07.2017
MASTER Consent Form – Semi-structured Interviews	1.0	24.07.2017
MASTER Invitation Email – Focus Group	1.0	24.07.2017
Interview Guide – Focus Group	1.0	24.07.2017
Interview Guide – Semi-structured Interviews	1.0	24.07.2017
Data Collection Form – Focus Group	1.0	24.07.2017
Data Collection Form – Semi-structured Interviews	1.0	24.07.2017
Clinical Protocol – Semi-structured Interviews	1.0	24.07.2017
De-Identification Codes – Focus Group	1.0	24.07.2017
De-Identification Codes – Semi-structured Interviews	1.0	24.07.2017
Questionnaire – Semi-structured Interviews	1.0	24.07.2017
Screening Form – Semi-structured Interviews	1.0	24.07.2017
Confirmation of Candidature email from Western Sydney University	N/A	11 August

Please ensure for all future documents submitted for review include a document version number, document date and page numbering.

Monitoring Requirements:
(National Statement Chapters 2.1 and 5.5)

- The Committee has classified this project as:

  Low Risk

- Monitoring required for this study will be:
  - Submission of Annual Progress Reports with the first report due **21 September 2018 and annually thereafter for the duration of the approval period**

Approval has been granted for the following site(s):

- Liverpool Hospital

Please note the following conditions of approval:

1. The Principal Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including:
   - any serious or unexpected adverse events; and
   - unforeseen events that might affect continued ethical acceptability of the project.

2. The Principal Investigator will report proposed changes to the research protocol, conduct of the research, or length of HREC approval to the HREC in the specified format, for review. For multi-centre studies, the Chief Investigator should submit to the Lead HREC and then send the amendment approval letter to the investigators at each sites so that they can notify their Research Governance Officer.

3. The Principal Investigator will inform the HREC, giving reasons, if the project is discontinued before the expected date of completion.

4. The Principal Investigator will provide an annual report to the HREC and at completion of the study in the specified format.

5. The Principal Investigator must reassure participants about confidentiality of the data.

6. Proposed changes to the personnel involved in the study are submitted to the HREC accompanied by a CV where applicable.

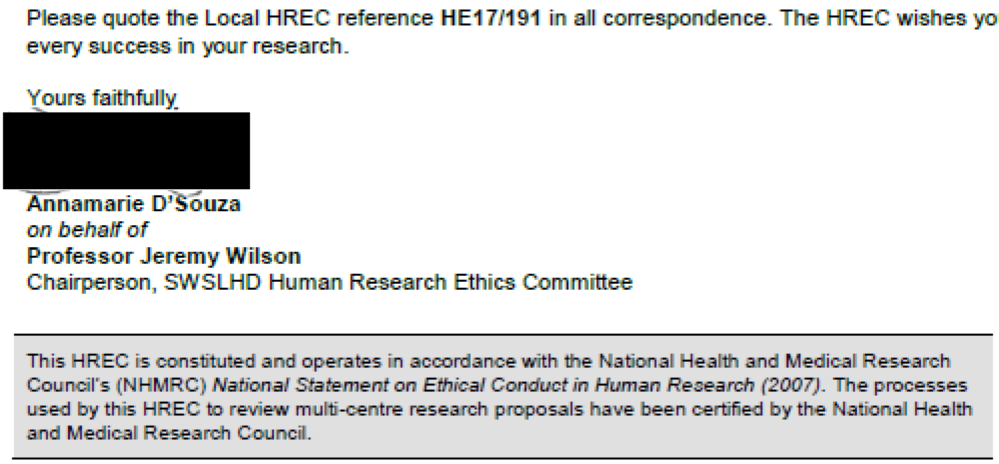
7. The Principal Investigator is responsible for ensuring the research project is conducted in line with relevant NSW Health, South Western Sydney Local Health District and Hospital policies available from: http://www.sswahs.nsw.gov.au/swslhd/ethics/policies.html

HREC approval is valid for (5) years. If the study is ongoing at the conclusion of the five year approval period, a full resubmission may be required. Ethics approval will continue during the re-approval process.

The South Western Sydney Local Health District Human Research Ethics Committee has been accredited by the NSW Ministry of Health to provide single ethical and scientific review of research proposals conducted within the NSW public health system and Victorian and Queensland Public Health Organisations participating in the Mutual Acceptance Scheme.

You are reminded that this letter constitutes ethical approval only. This research project must not commence at a site until separate authorisation from the Chief Executive or delegate of that site has been obtained. It is your responsibility to forward a copy of this letter together with any approved documents as enumerated above, to all site investigators for submission to the site's Research Governance Officer.

Should you have any queries about your project please contact **Annamarie D'Souza** on the telephone number listed above. The HREC Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the SWSLHD website: *http://www.sswahs.nsw.gov.au/swslhd/ethics/default.html*



Please quote the Local HREC reference **HE17/191** in all correspondence. The HREC wishes you every success in your research.

Yours faithfully

[redacted]

Annamarie D'Souza
on behalf of
Professor Jeremy Wilson
Chairperson, SWSLHD Human Research Ethics Committee

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research (2007)*. The processes used by this HREC to review multi-centre research proposals have been certified by the National Health and Medical Research Council.

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South Western Sydney Local Health District acknowledges the traditional owners of this land.

12 October 2017

Miss Kate Carter
804/300 Macquarie St
LIVERPOOL NSW 2170

Dear Miss Carter,

Project Title: **The nature, extent and localisation of foot problems in people with psoriatic arthritis.**
HREC Reference: **HREC/17/LPOOL/353**
SSA Reference: **SSA/17/LPOOL/407**
Local Project Number: **HE17/191**

SITE SPECIFIC AUTHORISATION

Thank you for your correspondence received 9 October 2017 in response to our request for further information dated 5 October 2017.

I am pleased to inform you that the Chief Executive has granted authorisation for this study to take place at the following site(s):

- Liverpool Hospital

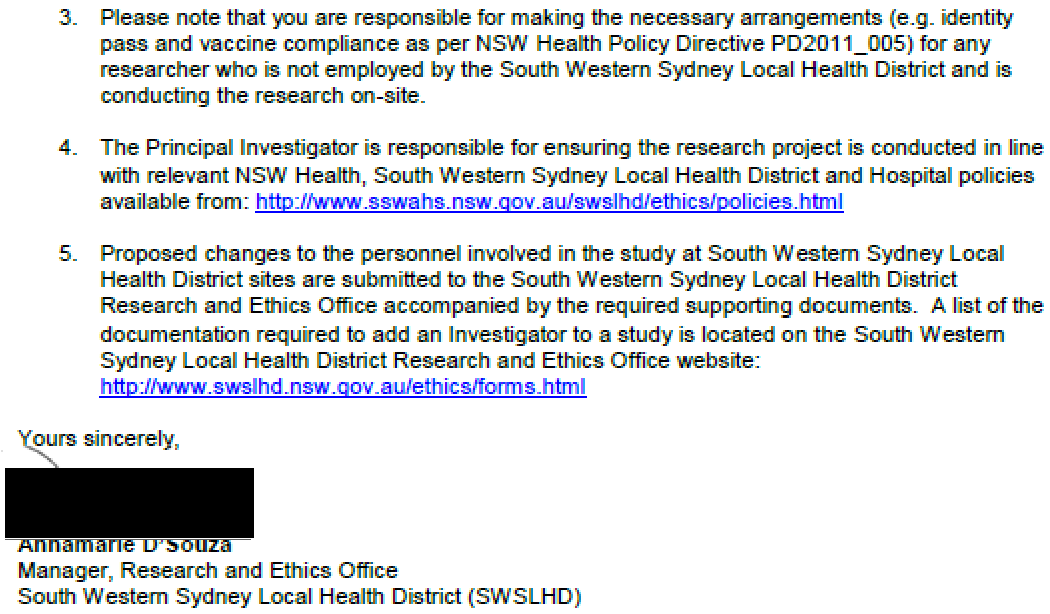
The following are authorised for use at the **Liverpool Hospital** site:

	Master		**Site Specific**	
Document	**Version**	**Date**	**Version**	**Date**
Participant Information Sheet – Focus Group	1.0	24.07.2017	1.0	22.09.2017
Participant Information Sheet – Semi-structured Interviews	1.0	24.07.2017	1.0	22.09.2017
Consent Form – Focus Group	1.0	24.07.2017	1.0	22.09.2017
Consent Form – Semi-structured Interviews	1.0	24.07.2017	1.0	22.09.2017
Interview Guide – Focus Group	1.0	24.07.2017	1.0	22.09.2017
Interview Guide – Semi-structured Interviews	1.0	24.07.2017	1.0	22.09.2017
Data Collection Form – Focus Group	1.0	24.07.2017	1.0	22.09.2017
Data Collection Form – Semi-structured Interviews	1.0	24.07.2017	1.0	22.09.2017
De-identification Codes – Focus Group	1.0	24.07.2017	1.0	22.09.2017
De-identification Codes - Semi-structured Interviews	1.0	24.07.2017	1.0	22.09.2017
Invitation Email – Focus Group	1.0	24.07.2017	1.0	22.09.2017
Clinical Protocol – Semi-structured Interviews	1.0	24.07.2017	1.0	22.09.2017
Questionnaire – Semi-structured Interviews	1.0	27.07.2017	1.0	22.09.2017
Screening Form – Semi-structured Interviews	1.0	24.07.2017	1.0	22.09.2017

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, are copied to this office.

2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, are to be submitted to this office.



3. Please note that you are responsible for making the necessary arrangements (e.g. identity pass and vaccine compliance as per NSW Health Policy Directive PD2011_005) for any researcher who is not employed by the South Western Sydney Local Health District and is conducting the research on-site.

4. The Principal Investigator is responsible for ensuring the research project is conducted in line with relevant NSW Health, South Western Sydney Local Health District and Hospital policies available from: http://www.sswahs.nsw.gov.au/swslhd/ethics/policies.html

5. Proposed changes to the personnel involved in the study at South Western Sydney Local Health District sites are submitted to the South Western Sydney Local Health District Research and Ethics Office accompanied by the required supporting documents. A list of the documentation required to add an Investigator to a study is located on the South Western Sydney Local Health District Research and Ethics Office website: http://www.swslhd.nsw.gov.au/ethics/forms.html

Yours sincerely,

[redacted]

Annamarie D'Souza
Manager, Research and Ethics Office
South Western Sydney Local Health District (SWSLHD)

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South Western Sydney Local Health District acknowledges the traditional owners of this land.

11 January 2018

Miss Kate Carter
804/300 Macquarie St
Liverpool NSW 2170

THIS LETTER CONSTITUTES ETHICAL APPROVAL ONLY. THIS RESEARCH PROJECT MUST NOT COMMENCE AT A SITE UNTIL SEPARATE AUTHORISATION FROM THE CHIEF EXECUTIVE OR DELEGATE OF THAT SITE HAS BEEN OBTAINED. *

Dear Miss Carter,

Project Title:	**The nature, extent and localisation of foot problems in people with psoriatic arthritis.**
HREC Reference:	**HREC/17/LPOOL/353**
SSA reference Number:	**SSA/17/LPOOL/407**
Local Project Number:	**HE17/191 (Liverpool Hospital)**

Thank you for your Summary Sheet for an Amendment to an Approved Protocol dated 08 December 2017, requesting approval from the *South Western Sydney Local Health District Human Research Ethics Committee*. I am pleased to inform you that the following documents are approved for the above-mentioned study:

Document	Date
Summary Sheet for an Amendment to an Approved Protocol	08/12/2017

Approval has been granted for the following site(s):

- BJC Health Rheumatology Clinic – Parramatta.

Enclosed for noting:

2 x External Entity Agreements – one copy remains on file in this office.

Conditions of approval:

1. The Principal Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including:
    - any serious or unexpected adverse events; and
    - unforeseen events that might affect continued ethical acceptability of the project.

2. The Principal Investigator will report proposed changes to the research protocol, conduct of the research, or length of HREC approval to the HREC in the specified format, for review. For multi-centre studies, the Chief Investigator should submit to the Lead HREC and then send the amendment approval letter to the investigators at each sites so that they can notify their Research Governance Officer.

3. The Principal Investigator will inform the HREC, giving reasons, if the project is discontinued before the expected date of completion.

4. The Principal Investigator will provide an annual report to the HREC and at completion of the study in the specified format.

5. The Principal Investigator must reassure participants about confidentiality of the data.

6. Proposed changes to the personnel involved in the study are submitted to the HREC accompanied by a CV where applicable.

Yours faithfully,

[redacted]

Annamarie D'Souza
Manager, Research and Ethics Office
South Western Sydney Local Health District

Research Office
Kolling Building, Level 13
Royal North Shore Hospital
St Leonards NSW 2065
Tel (02) 9926 4590 Fax (02) 9926 6179

Health
Northern Sydney
Local Health District

12 June 2018

Ms Kate Carter
804/300 Macquarie St.,
Liverpool NSW 2170

Dear Kate

NSLHD reference: RESP/18/56
Title: The nature, extent and localisation of foot problems in people with psoriatic arthritis
HREC reference: HREC/17/LPOOL/353
SSA reference: SSA/18/HAWKE/78

Thank you for submitting an application for authorisation of this project. I am pleased to advise that the delegate of the Chief Executive for Northern Sydney Local Health District on **12 June 2018** has granted authorisation for the above project to commence at **Royal North Shore Hospital**.

The version of the SSA reviewed by NSLHD RGO was: **AU/19/C0E3312**.

Ethical approval for this study was granted by the **South Western Sydney Local Health District HREC** at a meeting of the Executive Committee held on **21 September 2017.**

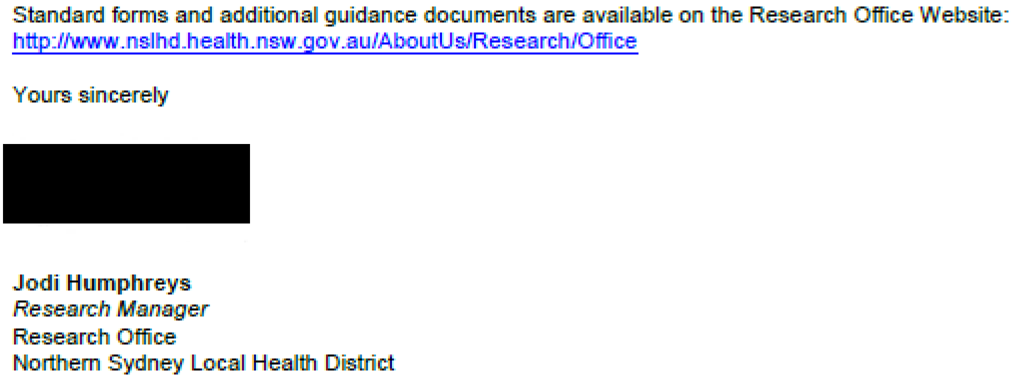
The documents authorised for use at this site are:

Document	Version	Date
Study Protocol	1.0	21 August 2017
RNSH Participant Information Sheet– Focus Group	2.0	08 January 2018
RNSH Consent Form – Focus Group	2.0	08 January 2018
RNSH Focus Group Interview Guide	2.0	08 January 2018
RNSH Focus Group Invitation Email	2.0	08 January 2018
RNSH Focus Group De-identification	2.0	08 January 2018
Focus Group Data Collection form	2.0	08 January 2018

Site authorisation will cease on the date of HREC expiry **21 September 2022**

You are reminded that, in order to comply with the Guidelines for Good Clinical Research Practice (GCRP) in Australia, and in accordance with additional requirements of NSLHD, the Chief Investigator is responsible for ensuring the following:

1. The HREC is notified of anything that might warrant review of the ethical approval of the project, including unforeseen events that might affect the ethical acceptability of the project.
2. The HREC is notified of all Serious Adverse Events (SAEs) or Serious Unexpected Suspected Adverse Reactions (SUSARs) in accordance with the Serious Adverse Event Reporting Guidelines.
3. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and are submitted to the lead HREC for review, are copied to the Research Governance Officer.
4. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project are to be submitted to the Research Governance Officer.
5. The Institutional annual report for all Human Research is due to the NSLHD Research Office on the 30 August. In addition, annual report acknowledgment from the Lead HREC should be submitted to the Research Governance Officer.



Standard forms and additional guidance documents are available on the Research Office Website:
http://www.nslhd.health.nsw.gov.au/AboutUs/Research/Office

Yours sincerely

[redacted]

Jodi Humphreys
Research Manager
Research Office
Northern Sydney Local Health District

Health
South Western Sydney
Local Health District

Research and Ethics Office
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South Western Sydney Local Health District acknowledges the traditional owners of this land.

09 January 2018

Miss Kate Carter
804/300 Macquarie St
Liverpool NSW 2170

THIS LETTER CONSTITUTES ETHICAL APPROVAL ONLY. THIS RESEARCH PROJECT MUST NOT COMMENCE AT A SITE UNTIL SEPARATE AUTHORISATION FROM THE CHIEF EXECUTIVE OR DELEGATE OF THAT SITE HAS BEEN OBTAINED. *

Dear Miss Carter,

Project Title:	**The nature, extent and localisation of foot problems in people with psoriatic arthritis.**
HREC Reference:	**HREC/17/LPOOL/353**
SSA reference Number:	**SSA/17/LPOOL/407**
Local Project Number:	**HE17/191 (Liverpool Hospital)**

Thank you for your Summary Sheet for an Amendment to an Approved Protocol dated 08 January 2018, requesting approval from the *South Western Sydney Local Health District Human Research Ethics Committee*. I am pleased to inform you that the following documents are approved for the above-mentioned study:

Document	**Date**
Summary Sheet for an Amendment to an Approved Protocol	08/01/2018

Approval has been granted for the following site(s):

- Royal North Shore Hospital.

Conditions of approval:

1. The Principal Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including:
    - any serious or unexpected adverse events; and
    - unforeseen events that might affect continued ethical acceptability of the project.

2. The Principal Investigator will report proposed changes to the research protocol, conduct of the research, or length of HREC approval to the HREC in the specified format, for review. For multi-centre studies, the Chief Investigator should submit to the Lead HREC and then send the amendment approval letter to the investigators at each sites so that they can notify their Research Governance Officer.

3. The Principal Investigator will inform the HREC, giving reasons, if the project is discontinued before the expected date of completion.

4. The Principal Investigator will provide an annual report to the HREC and at completion of the study in the specified format.

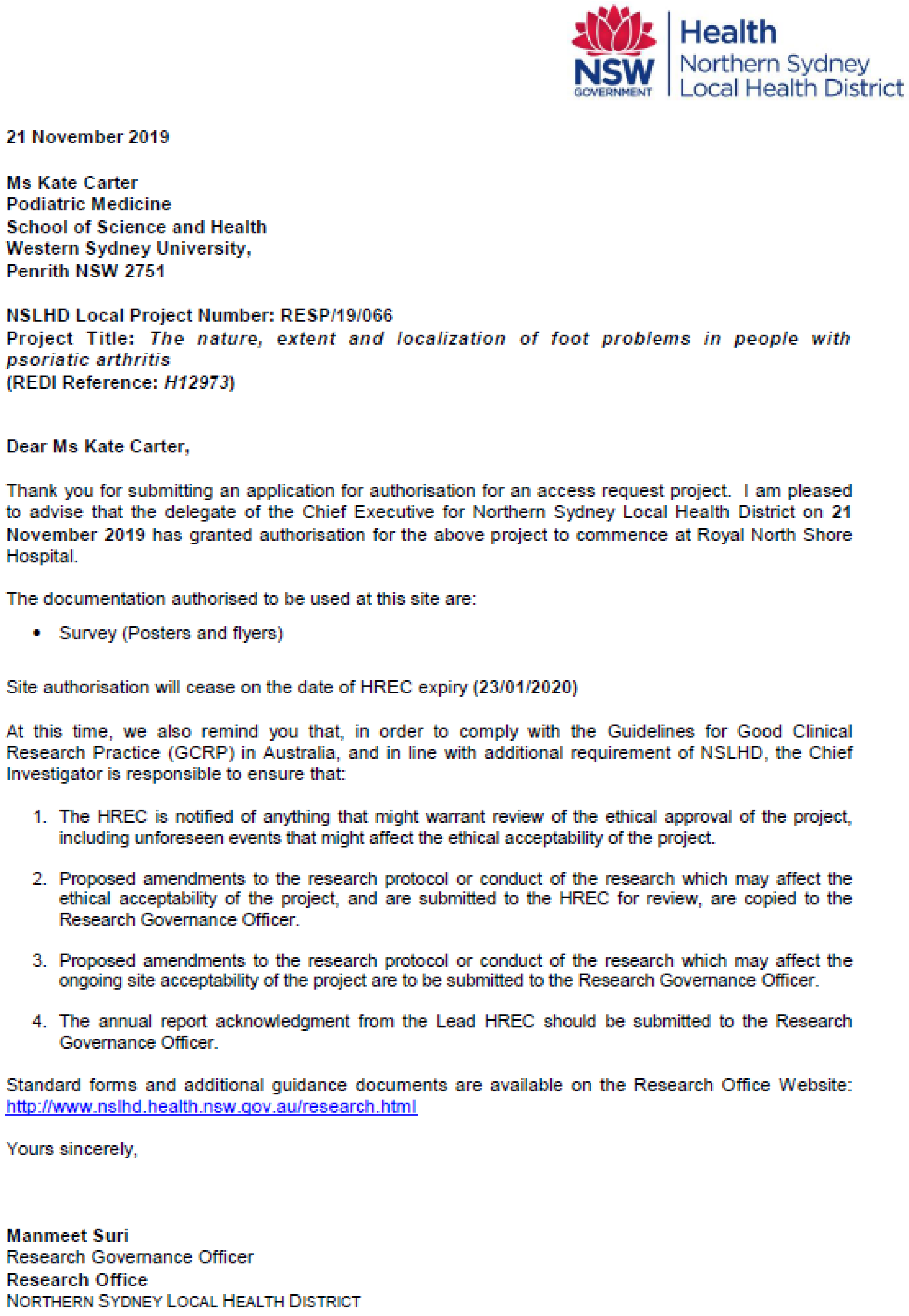
5. The Principal Investigator must reassure participants about confidentiality of the data.

6. Proposed changes to the personnel involved in the study are submitted to the HREC accompanied by a CV where applicable.

Yours faithfully,

[redacted]

Annamarie D'Souza
Manager, Research and Ethics Office
South Western Sydney Local Health District



NSW GOVERNMENT
Health
Northern Sydney
Local Health District

21 November 2019

Ms Kate Carter
Podiatric Medicine
School of Science and Health
Western Sydney University,
Penrith NSW 2751

NSLHD Local Project Number: RESP/19/066
Project Title: ***The nature, extent and localization of foot problems in people with psoriatic arthritis***
(REDI Reference: ***H12973*****)**

Dear Ms Kate Carter,

Thank you for submitting an application for authorisation for an access request project. I am pleased to advise that the delegate of the Chief Executive for Northern Sydney Local Health District on **21 November 2019** has granted authorisation for the above project to commence at Royal North Shore Hospital.

The documentation authorised to be used at this site are:

- Survey (Posters and flyers)

Site authorisation will cease on the date of HREC expiry (23/01/2020)

At this time, we also remind you that, in order to comply with the Guidelines for Good Clinical Research Practice (GCRP) in Australia, and in line with additional requirement of NSLHD, the Chief Investigator is responsible to ensure that:

1. The HREC is notified of anything that might warrant review of the ethical approval of the project, including unforeseen events that might affect the ethical acceptability of the project.
2. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and are submitted to the HREC for review, are copied to the Research Governance Officer.
3. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project are to be submitted to the Research Governance Officer.
4. The annual report acknowledgment from the Lead HREC should be submitted to the Research Governance Officer.

Standard forms and additional guidance documents are available on the Research Office Website: http://www.nslhd.health.nsw.gov.au/research.html

Yours sincerely,

Manmeet Suri
Research Governance Officer
Research Office
NORTHERN SYDNEY LOCAL HEALTH DISTRICT

AUCKLAND
DISTRICT HEALTH BOARD
Te Toka Tumai

Waitemata
District Health Board
Best Care for Everyone

He Kamaka Waiora
Waitematā and Auckland DHB
Level 2, 15 Shea Terrace,
Auckland 0740,
New Zealand
Private Bag: 93-503

---

30 October 2017

Keith Rome
Professor of Podiatry
Head of Research, School of Clinical Sciences
Auckland University of Technology

Re: The nature, extent and localization of foot problems in people with psoriatic arthritis.

Thank you for meeting with me to discuss the international psoriatic arthritis study. I understand the main issue is that the researcher will only be in Aotearoa New Zealand for a short period of time and therefore will not be able to comply with the legislative requirements of consultation. However, I understand the researcher is being supervised by yourself and while here will be supported by you.

I note the Matauranga Maori Committee at Auckland University of Technology have reviewed the study and highlighted some issues that were addressed during the meeting, in particular recruiting Maori participants and analysing the information gathered from Maori participants. I understand Maori will be purposefully selected for the study and that Maori students may be employed to help with the analysis of the data. I support the other comments made by the Matauranga Māori Committee.

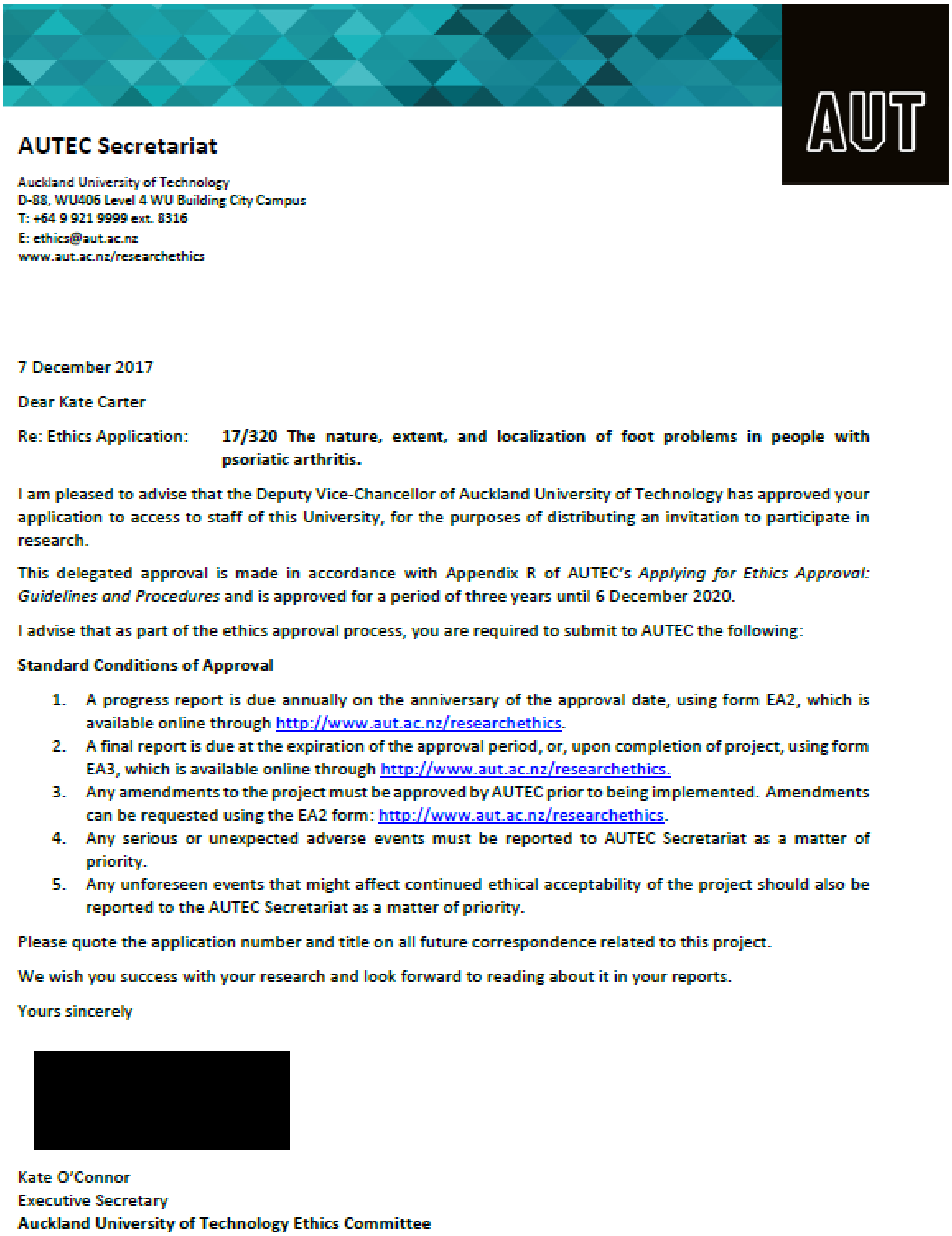
While the study does not initially involve the Waitematā or Auckland District Health Boards, if there are not enough participants attending the AUT clinic some participants might be recruited through Waitemata DHB. During discussion with the Matauranga Maori Committee you informed them that you would meet with me and acting in good faith we have meet and discussed the study.

On behalf of the Waitematā and Auckland District Health Boards Māori Research Committee the study has been approved. We wish you well.

Heoi ano

H.A Wihongi

Dr Helen Wihongi /
Research Advisor – Māori/Senior Research Fellow
He Kamaka Waiora/Waitematā and Auckland DHB
Level 1, Kahui Manaaki – Building 5
North Shore Hosptial/ Auckland 0740, New Zealand
p: +64 9 486 8920 ext. 3204, m: + 64 21 0203 1167
email helen.wihongi@waitematadhb.govt.nz



AUTEC Secretariat

Auckland University of Technology
D-88, WU406 Level 4 WU Building City Campus
T: +64 9 921 9999 ext. 8316
E: ethics@aut.ac.nz
www.aut.ac.nz/researchethics

7 December 2017

Dear Kate Carter

Re: Ethics Application: **17/320 The nature, extent, and localization of foot problems in people with psoriatic arthritis.**

I am pleased to advise that the Deputy Vice-Chancellor of Auckland University of Technology has approved your application to access to staff of this University, for the purposes of distributing an invitation to participate in research.

This delegated approval is made in accordance with Appendix R of AUTEC's *Applying for Ethics Approval: Guidelines and Procedures* and is approved for a period of three years until 6 December 2020.

I advise that as part of the ethics approval process, you are required to submit to AUTEC the following:

Standard Conditions of Approval

1. A progress report is due annually on the anniversary of the approval date, using form EA2, which is available online through http://www.aut.ac.nz/researchethics.
2. A final report is due at the expiration of the approval period, or, upon completion of project, using form EA3, which is available online through http://www.aut.ac.nz/researchethics.
3. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form: http://www.aut.ac.nz/researchethics.
4. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
5. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.

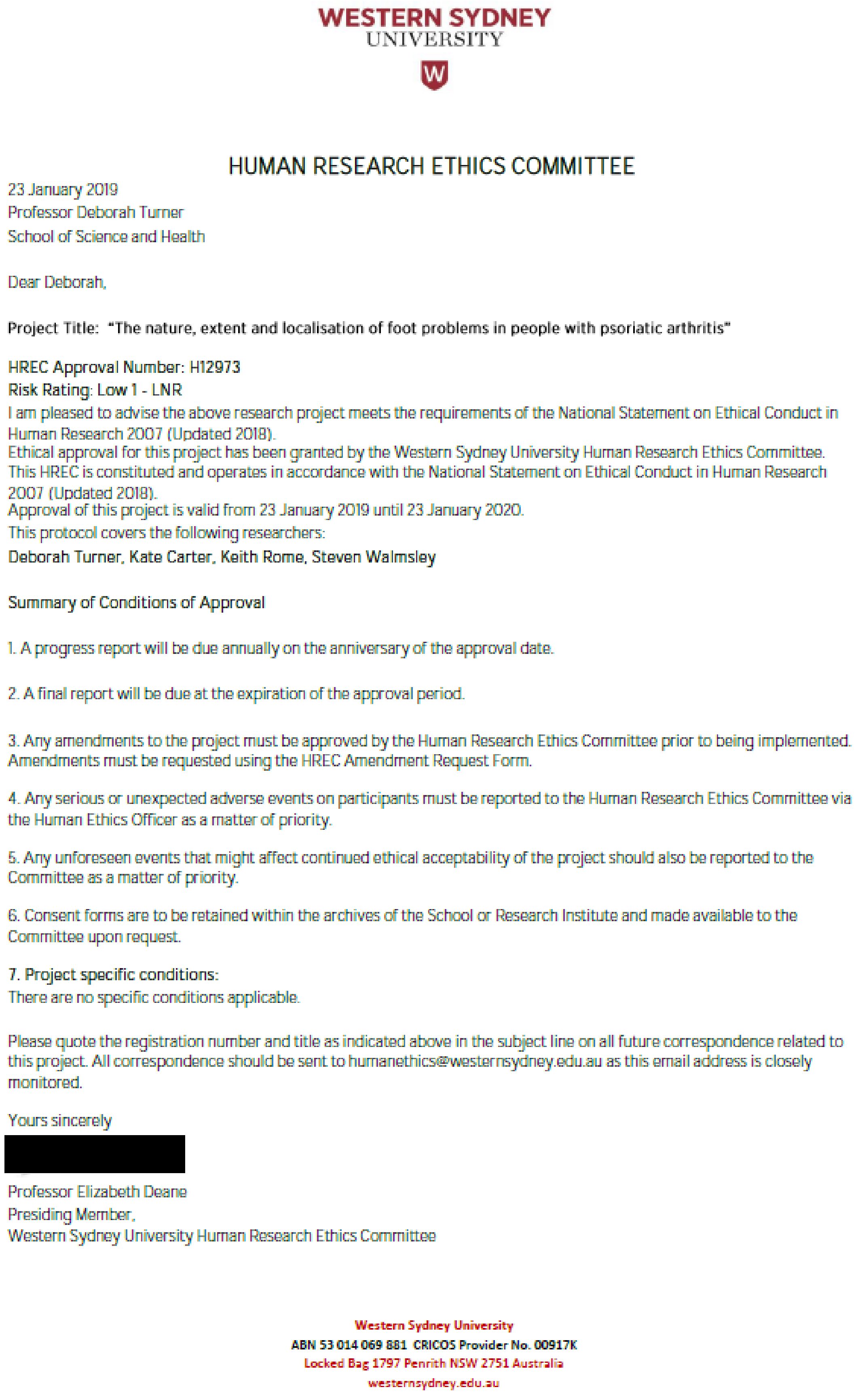
Please quote the application number and title on all future correspondence related to this project.

We wish you success with your research and look forward to reading about it in your reports.

Yours sincerely

[redacted]

Kate O'Connor
Executive Secretary
Auckland University of Technology Ethics Committee



WESTERN SYDNEY
UNIVERSITY

HUMAN RESEARCH ETHICS COMMITTEE

23 January 2019
Professor Deborah Turner
School of Science and Health

Dear Deborah,

Project Title: "The nature, extent and localisation of foot problems in people with psoriatic arthritis"

HREC Approval Number: H12973
Risk Rating: Low 1 - LNR

I am pleased to advise the above research project meets the requirements of the National Statement on Ethical Conduct in Human Research 2007 (Updated 2018).
Ethical approval for this project has been granted by the Western Sydney University Human Research Ethics Committee. This HREC is constituted and operates in accordance with the National Statement on Ethical Conduct in Human Research 2007 (Updated 2018).
Approval of this project is valid from 23 January 2019 until 23 January 2020.
This protocol covers the following researchers:
Deborah Turner, Kate Carter, Keith Rome, Steven Walmsley

Summary of Conditions of Approval

1. A progress report will be due annually on the anniversary of the approval date.

2. A final report will be due at the expiration of the approval period.

3. Any amendments to the project must be approved by the Human Research Ethics Committee prior to being implemented. Amendments must be requested using the HREC Amendment Request Form.

4. Any serious or unexpected adverse events on participants must be reported to the Human Research Ethics Committee via the Human Ethics Officer as a matter of priority.

5. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the Committee as a matter of priority.

6. Consent forms are to be retained within the archives of the School or Research Institute and made available to the Committee upon request.

7. Project specific conditions:
There are no specific conditions applicable.

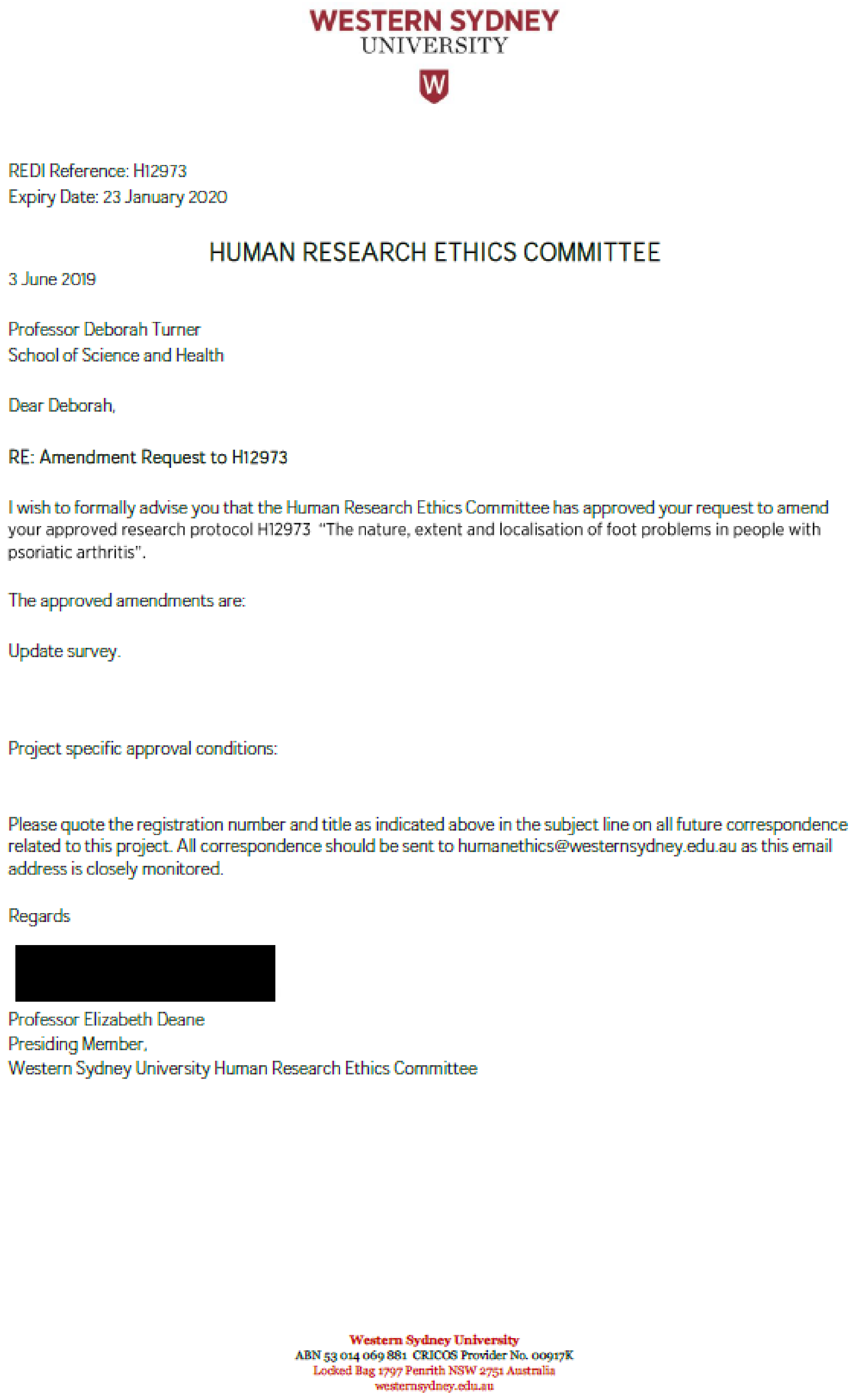
Please quote the registration number and title as indicated above in the subject line on all future correspondence related to this project. All correspondence should be sent to humanethics@westernsydney.edu.au as this email address is closely monitored.

Yours sincerely

[redacted]

Professor Elizabeth Deane
Presiding Member,
Western Sydney University Human Research Ethics Committee

Western Sydney University
ABN 53 014 069 881 CRICOS Provider No. 00917K
Locked Bag 1797 Penrith NSW 2751 Australia
westernsydney.edu.au



WESTERN SYDNEY
UNIVERSITY

REDI Reference: H12973
Expiry Date: 23 January 2020

HUMAN RESEARCH ETHICS COMMITTEE

3 June 2019

Professor Deborah Turner
School of Science and Health

Dear Deborah,

RE: Amendment Request to H12973

I wish to formally advise you that the Human Research Ethics Committee has approved your request to amend your approved research protocol H12973 "The nature, extent and localisation of foot problems in people with psoriatic arthritis".

The approved amendments are:

Update survey.

Project specific approval conditions:

Please quote the registration number and title as indicated above in the subject line on all future correspondence related to this project. All correspondence should be sent to humanethics@westernsydney.edu.au as this email address is closely monitored.

Regards

[redacted]

Professor Elizabeth Deane
Presiding Member,
Western Sydney University Human Research Ethics Committee

Western Sydney University
ABN 53 014 069 881 CRICOS Provider No. 00917K
Locked Bag 1797 Penrith NSW 2751 Australia
westernsydney.edu.au

Appendix 2: Participant consent forms, information sheets and data collection forms

Site names were added as per site specific agreement to each of the following forms:

[Insert Site Name]

CONSENT FORM

Interviews of people with psoriatic arthritis

Study Title: The nature, extent and localization of foot problems in people with psoriatic arthritis.

1. I,..
of...
agree to participate in the study described in the participant information statement attached
this form.

2. I acknowledge that I have read the participant information statement, which explains why I have been selected, the aims of the study and the nature and the possible risks of the investigation, and the statement has been explained to me to my satisfaction.

3. Before signing this consent form, I have been given the opportunity of asking any questions relating to any possible physical and mental harm I might suffer as a result of my participation and I have received satisfactory answers.

4. I understand that I can withdraw from the study at any time without prejudice to my relationship with the [insert site]

5. I acknowledge that the information obtained in this study will be used as part of the development of the self-administered patient survey. I agree that research data gathered from the results of the study may be published, provided that I cannot be identified.

6. I understand that if I have any questions relating to my participation in this research, I may contact Kate Carter on telephone +61 0410 855 915, who will be happy to answer them.

7. I acknowledge receipt of a copy of this Consent Form and the Participant Information Statement.

8. I consent to the collecting of information from my medical records.

9. I agree to the interview being audio recorded. I understand that all personal information will be kept strictly confidential and safeguarded in a password-protected file. I understand that the data will be analysed at Western Sydney University.

10. I wish to receive a copy of the findings from this study (please tick one):
Yes ☐ No ☐ (If yes, please state your email or postal address below)

________________________ ______________________ _______________

Signature of participant Please PRINT name Date

________________________ ______________________ _______________

Signature of witness Please PRINT name Date

________________________ ______________________ _______________

Signature of investigator (if applicable) Please PRINT name Date

[Insert Site Name]

CONSENT FORM

Focus groups with health professionals

Study Title: The nature, extent and localization of foot problems in people with psoriatic arthritis.

1. I,...
of...
agree to participate in the study described in the participant information statement attached this form.

2. I acknowledge that I have read the participant information statement, which explains why I have been selected, the aims of the study and the nature and the possible risks of the investigation, and the statement has been explained to me to my satisfaction.

3. Before signing this consent form, I have been given the opportunity of asking any questions relating to any possible physical and mental harm I might suffer as a result of my participation and I have received satisfactory answers.

4. I understand that I can withdraw from the study at any time without prejudice to my relationship with the [insert site]

5. I acknowledge that the information obtained in this study will be used as part of the development of the self-administered patient survey. I agree that research data gathered from the results of the study may be published, provided that I cannot be identified.

6. I understand that if I have any questions relating to my participation in this research, I may contact Kate Carter on telephone +61 0410 855 915, who will be happy to answer them.

7. I acknowledge receipt of a copy of this Consent Form and the Participant Information Statement.

8. I agree to the focus group being audio recorded. I understand that all personal information will be kept strictly confidential and safeguarded in a password-protected file. I understand that the data will be analysed at Western Sydney University.

9. I wish to receive a copy of the findings from this study (please tick one):
Yes ☐ No ☐ (If yes, please state your email or postal address below)

Signature of participant Please PRINT name Date

Signature of witness Please PRINT name Date

Signature of investigator (if applicable) Please PRINT name Date

Participant Information Sheet

Interviews of people with psoriatic arthritis

Health/Social Science Research

[Insert Site Name]

Title	The nature, extent and localisation of foot problems in people with psoriatic arthritis.
Protocol Number	Protocol Version 1.0
Co-Investigators	[Insert Investigators]
Principal Investigator	[Insert Investigators]
Location	Rheumatology clinic, [Insert Site Name]

1. Introduction

You are invited to take part in this research project, which is called the nature extent and localisation of foot problems in people with psoriatic arthritis. You are invited to participate in this study because you have psoriatic arthritis and foot problems and are attending the Rheumatology Clinic at [Insert Site Name]. We wish to know more about your experiences of foot problems and how they impact on your life.

This Participant Information Sheet and the Consent Form tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local health worker.

Participation in this research is voluntary. If you don't wish to take part, you don't have to. If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to be involved in the research described
- Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information Sheet to keep.

2. What is the purpose of this research?

The objective of this study is to interview people with psoriatic arthritis to gain insight and understanding into their experience of foot problems and the impact of these problems on life and daily activities.

The purpose of this study is to find out about the foot problems experienced by people with psoriatic arthritis. The information from the interview will be used to inform the development of a survey to find out about the foot problems experienced by a much larger group of people with psoriatic arthritis in Australia, New Zealand and Singapore. The results of this research will be used by the researcher Miss Kate Carter to obtain a Doctor of Philosophy [PhD] degree.

Little is known about the prevalence of foot problems in this patient group and most of our knowledge comes from studies done in Europe. We wish to better understand foot problems in this patient group by developing a survey that will be completed by a large group of people with psoriatic arthritis in Australia, New Zealand and Singapore. We hope that this body of work will lead to more effective assessment and treatment of psoriatic arthritis-related foot problems in the future.

The study has been initiated and will be conducted by the researcher, Miss Kate Carter, from the School of Health and Science at Western Sydney University, together with the Division of Rheumatology at [Insert Site Name].

3. What does participation in this research involve?

To take part in this study you should be over 20 years old, have psoriatic arthritis and have experience of past or present foot problems. If you decide to take part in the study, the researcher will confirm your eligibility to take part in the study using the screening information provided. If the screening form shows that you meet the requirements and you agree to participate, then you will be enrolled in the study. If you do not meet the criteria on the screening form, we will regretfully be unable to include you in this study.

Your participation in the study will involve taking part in an interview to talk about your experiences of foot problems related to your psoriatic arthritis and how it impacts on your life. Before you begin the interview you will be asked to complete a questionnaire about your foot health. Additional information will be collected by looking through your medical records, this will include age, gender, ethnicity, body mass index, occupation, duration of psoriatic arthritis, disease activity measures and current medications. In the interview you will be asked questions about your foot health, footwear, how foot problems may affect your daily activities and about previous treatments you may have received for your feet.

The interview will be audio recorded to help with data analysis. The audio recording will be transcribed and during this process participants will be de-identified ensuring anonymity during data analysis. The data will be used to develop a survey to evaluate foot problems and their associated impact in a large group of people with psoriatic arthritis. This research project has been designed to make sure the researchers interpret the results in a fair and appropriate way.

Approximately 18 patients will be taking part in this study. This research project will take place between November 2017 and February 2018. Your participation in the study will take approximately 60 minutes of your time on one occasion. The study will be conducted at [Insert Site Name]. There are no costs associated with participating in this research project, nor will you be paid.

4. Other relevant information about this research project

We will be conducting interviews at [Insert Site Name] and at [Insert Site Name]. This will allow us to collect local data that will be used to inform the content of the survey that will be completed by a large group of people with psoriatic arthritis in Australia, New Zealand and Singapore.

5. Do I have to take part in this research project?

Taking part in this study is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. Your decision on whether to participate or not will not affect your treatment or medical care at [Insert Site Name]. If you decide to take part, you will be given this Participation Information Sheet and Consent Form to sign and you will be given a copy to keep.

6. What are the possible benefits of taking part?

There will be no clear benefit to you from your participation in this research. However, by improving our understanding foot involvement in people with psoriatic arthritis, future patients may be able to receive better assessments and treatments. In addition, by finding out about the epidemiology of foot complaints and the impact they have on patient's lives, rheumatologists and podiatrists will have a better awareness of how people with the disease are affected.

7. What are the possible risks and disadvantages of taking part?

There will be no risks or side effects from the interview carried out in this study. If you experience any distress during the interview, please inform the researcher and the interview will be discontinued.

8. What if I withdraw from this research project?

If you decide to leave the research project, the researchers will not collect additional personal information from you, although personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected up to the time you withdraw will form part of the research project results. If you do not want your data to be included, you must tell the researchers when you withdraw from the research project.

9. What happens when the research project ends?

If you decide to participate, you will be told of any important information that is learnt from the study, which might affect your assessment and management of this patient group. If you wish to receive feedback on the result of this research please indicate yes on the applicable section in the consent form, and then the results will be sent out to you in the form of a written summary. Any published work will be accessible upon request.

10. What will happen to information about me?

By signing the Consent Form, you consent to the research team collecting and using personal information about you for the research project. Any information obtained in connection with this research project that can identify you will remain confidential.

Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law. The personal information that the research team collect and use will be your personal information and information from the interview.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your express permission.

Each participant will be allocated an identifying code under which all data will be recorded. This will ensure that anonymity is achieved during data analysis and any future publications. The data from the study will be stored electronically on a secure server, which can only be accessed by the study investigators.

In accordance with relevant Australian, New Zealand and/or [Insert State/Territory of Site] privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

11. Who is organizing and funding the research?

The research is being conducted by Miss Kate Carter, a PhD student at Western Sydney University. This study has no sponsor and no source of funding. You will not be paid to participate in this research study.

12. Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the HREC of [Insert Site Name]. This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

13. Further Information and who to contact

The person you may need to contact will depend on the nature of your query. For further information about this study you may contact the primary researcher Kate Carter.

Research contact person

Name	Kate Carter
Position	PhD student at Western Sydney University
Telephone	+61 0410 855 915
Email	Kate.carter@westernsydney.edu.au

14. Complaints contact person

The conduct of this study at [Insert Hospital Name] has been authorised by the South Western Sydney Local Health District, any person with concerns or complaints about the conduct of this study may also contact the Research Governance Officer on (02) 8738 8304, email: research.support@sswahs.nsw.gov.au and quote project number [xx/xxx]

Thank you for taking the time to consider this study.
If you wish to take part in it, please sign the attached consent form.
This information sheet is for you to keep.

Participant Information Sheet

Focus groups with health professionals

Health/Social Science Research

[Insert Site Name]

Title	The nature, extent and localisation of foot problems in people with psoriatic arthritis.
Protocol Number	Protocol Version 1.0
Co-Investigators	[Insert Investigators]
Principal Investigator	[Insert Investigators]
Location	Rheumatology clinic, [Insert Site Name]

1. Introduction

You are invited to take part in this research project, which is called the nature extent and localisation of foot problems in people with psoriatic arthritis. Thank you for responding to our email. You have been invited because we are looking for health professionals with past or current experience of managing people with psoriatic arthritis and foot problems. Your contact details were obtained from the consultant rheumatologist [insert name, at insert site name] and co-investigator [insert name, at insert site name].

This Participant Information Sheet and the Consent Form tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local health worker.

Participation in this research is voluntary. If you don't wish to take part, you don't have to. If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:
- Understand what you have read
- Consent to take part in the research project
- Consent to be involved in the research described
- Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information Sheet to keep.

2. What is the purpose of this research?

The objective of this preliminary study is to undertake a focus group with health professionals involved in the management of patients with psoriatic arthritis. Health professionals including rheumatology nurses, podiatrists and consultant rheumatologists will be asked to share their knowledge and understanding of foot problems and the associated impacts experienced by this patient group. The information from the focus group will be used to inform the development of the patient survey to find out about the foot problems experienced by people with psoriatic arthritis in Australia, New Zealand and Singapore. The results of this research will be used by the researcher Kate Carter to obtain a Doctor of Philosophy [PhD] degree.

Little is known about the prevalence of foot problems in this patient group and most of our knowledge comes from studies done in Europe. We wish to better understand foot problems in this patient group by developing a survey that will be completed by a large group of people with psoriatic arthritis in Australia, New Zealand and Singapore. We hope that this body of work will lead to more effective assessment and treatment of psoriatic arthritis-related foot problems in the future.

The study has been initiated and will be conducted by the researcher, Miss Kate Carter, from the School of Health and Science at Western Sydney University, together with the Division of Rheumatology at [Insert Site Name].

3. What does participation in this research involve?

To take part in this study you must be over 20 years old and have experience of or are currently managing patients with psoriatic arthritis. If you decide to take part in the study, the researcher will confirm your eligibility to take part in the study using the screening information provided on your invitation email. If you meet those requirements and you agree to participate, then you will be enrolled in the study. If you do not meet the criteria on the screening form, we will regretfully be unable to include you in this study.

Your participation in the study will involve taking part in a focus group to talk about your knowledge and experience of managing patients with psoriatic arthritis-related foot problems. Before you begin the focus group you will be asked for some personal information including your age, gender, ethnicity, occupation, qualifications and the number of years of experience you have managing people with psoriatic arthritis. In the focus group you will be asked questions about your experience and perspectives on the following items relating to patients with psoriatic arthritis: foot health, footwear, impact of foot problems on daily activities and emotional health, foot assessments and foot care.

The focus group discussion will be audio recorded to facilitate data analysis. The audio recording will be transcribed and during this process participants will be de-identified ensuring anonymity during data analysis. The data will be used to develop a survey to evaluate foot problems and their associated impact in a large group of people with psoriatic arthritis. This research project has been designed to make sure the researchers interpret the results in a fair and appropriate way.

Approximately 6 to 8 health professionals will be taking part in this focus group. You will have until the end of October to decide whether or not you would like to participate in this study. This research project will take place between November 2017 and February 2018. You will be contacted during this period to arrange a suitable date and time for the focus group, which will take approximately 60 minutes of your time on one occasion. The study will be conducted at [Insert Site Name]. There are no costs associated with participating in this research project, nor will you be paid.

4. Other relevant information about this research project

We will be conducting two focus groups, one at [Insert Site Name] and one at [Insert Site Name]. This will allow us to collect local data that will be used to inform the content of the survey that will be completed by a large group of people with psoriatic arthritis in Australia, New Zealand and Singapore.

5. Do I have to take part in this research project?

Taking part in this study is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. Your decision on whether to participate or not will not affect your employment or relationship with your manager. If you decide to take part, you will be given this Participation Information Sheet and Consent Form to sign and you will be given a copy to keep.

6. What are the possible benefits of taking part?

There will be no clear benefit to you from your participation in this research. However, by improving our understanding foot involvement in people with psoriatic arthritis, future patients may be able to receive better assessments and treatments. In addition, by finding out about the epidemiology of foot complaints and the impact they have on patient's lives, rheumatologists and podiatrists will have a better awareness of how people with the disease are affected.

7. What are the possible risks and disadvantages of taking part?

There will be no risks or side effects anticipated from the focus group carried out in this study. Whilst all care will be taken to maintain privacy and confidentiality, you may experience embarrassment if one of the group members were to repeat things said in a confidential group meeting. If you experience any distress during the focus group, please inform the study investigator and the discussion will be discontinued.

8. What if I withdraw from this research project?

If you decide to leave the research project, the researchers will not collect additional personal information from you, although personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected up to the time you withdraw will form part of the research project results. If you do not want your data to be included, you must tell the researchers when you withdraw from the research project.

9. What happens when the research project ends?

If you decide to participate, you will be told of any important information that is learnt from the study, which might affect your assessment and management of this patient group. If you wish to receive feedback on the result of this research please indicate yes on the applicable section in the consent form, and then the results will be sent out to you in the form of a written summary. Any published work will be accessible upon request.

10. What will happen to information about me?

By signing the Consent Form, you consent to the research team collecting and using personal information about you for the research project. Any information obtained in connection with this research project that can identify you will remain confidential.

Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law. The personal information that the research team collect and use will be your demographic personal information and information from the focus group interview.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your express permission.

Each participant will be allocated an identifying code under which all data will be recorded. This will ensure that anonymity is achieved during data analysis and any future publications. The data from the study will be stored electronically on a secure server, which can only be accessed by the study investigators.

In accordance with relevant Australian, New Zealand and/or [Insert State/Territory of Site] privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

11. Who is organizing and funding the research?

The research is being conducted by Miss Kate Carter, a PhD student at Western Sydney University. This study has no sponsor and no source of funding. You will not be paid to participate in this research study.

12. Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the HREC of [Insert Site Name]. This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

13. Further Information and who to contact

The person you may need to contact will depend on the nature of your query. For further information about this study you may contact the primary researcher Kate Carter.

Research contact person

Name	Kate Carter
Position	PhD student at Western Sydney University
Telephone	+61 0410 855 915
Email	Kate.carter@westernsydney.edu.au

14. Complaints contact person

The conduct of this study at [Insert Hospital Name] has been authorised by the South Western Sydney Local Health District, any person with concerns or complaints about the conduct of this study may also contact the Research Governance Officer on (02) 8738 8304, email: research.support@sswahs.nsw.gov.au and quote project number [xx/xxx]

Thank you for taking the time to consider this study.
If you wish to take part in it, please sign the attached consent form.
This information sheet is for you to keep.

Interviews of people with psoriatic arthritis - Data Collection Form
Title: The nature, extent and localisation of foot problems in people with psoriatic arthritis
[Insert Site Name]
Interview time:
Study number:

Demographic data			
Age (years)		Ethnicity	
Gender (M/F)		Body weight (kg)	
Education level (qualifications)		Height (cm)	
Marital status		Employment status	
Postcode		Occupation	

Clinical data		
Disease duration (years)		Medications:
Hospital Anxiety and Depression Scale		
CRP		
ESR		
Global pain (VAS 0-100mm)		
Foot pain (VAS 0-100mm)		
Patient global assessment (joint and skin) VAS (0-100), mm		
Patient global assessment (skin) VAS (0-100), mm		
Patient global assessment (joint) VAS (0-100), mm		
Health Assessment Questionnaire Score		
Co-morbidities: (Diabetes y/n)		

[Insert Site Logo]

Thank you for agreeing to participant in this study.

1. Have you **ever** had aching, stiffness or pain in your feet, which you think might be because of the psoriatic arthritis that lasted one day or longer?

Yes ☐ No ☐

AND IF YES, when was the last time you experienced these foot problems?

☐ In the past month ☐ In the past 3 month ☐ In the past 12 month ☐ Over a year

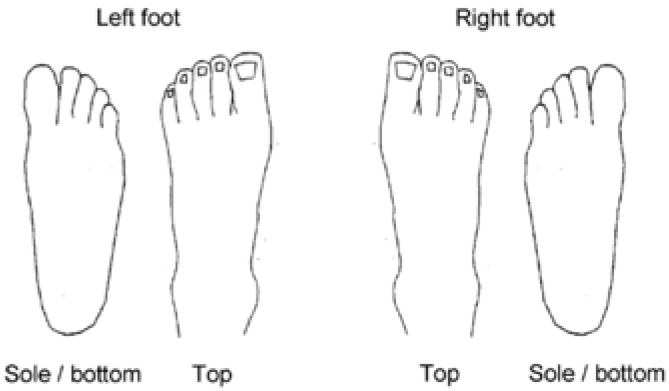
2. Do you have pain in your feet **today** that you think might be because of the psoriatic arthritis?

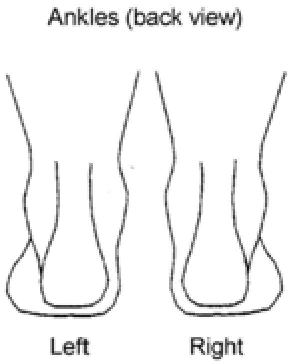
Yes ☐ No ☐

AND IF YES, please mark on the line your level of foot pain **today**

No pain ____ **Worst pain ever**

IF YES, please mark on the picture below ALL the areas of your feet that are affected by pain **today:**





3. What type of footwear are you wearing today?

In all the ways that your PSORIASIS and ARTHRITIS, as a whole, affects you, how would you rate the way you felt over the **past week**?

Please place a vertical mark on the line below to rate the way you have felt.

0 Excellent	100 Poor

In all the ways that your ARTHRITIS affects you, how would you rate the way you have felt over the **past week**?

Please place a vertical mark on the line below to rate the way you have felt.

0 Excellent	100 Poor

In all the ways that your PSORIASIS affects you, how would you rate the way you have felt over the **past week**?

Please place a vertical mark on the line below to rate the way you have felt.

0 Excellent	100 Poor

How much pain have you had because of your psoriatic arthritis over the **past week**?

Please place a vertical mark on the line below to indicate how severe your pain has been.

0 No pain	100 Worst pain ever

Leeds Foot Impact Scale

Please choose the response that applies best to you <u>at the moment</u>.

		TRUE	NOT TRUE
1.	My feet get painful when I'm standing	☐	☐
2.	My feet hurt me	☐	☐
3.	I find the pain in my feet frustrating	☐	☐
4.	The pain is worse when I've been on my feet all day	☐	☐
5.	At the end of the day there is pain and tension in my feet	☐	☐
6.	I never get rid of the stiffness in the background	☐	☐

Please remember to read each statement thinking about your feet.
Please choose the response that applies best to you <u>at the moment</u>.

		TRUE	NOT TRUE
7.	My feet throb at night	☐	☐
8.	My feet wake me up at night	☐	☐
9.	I feel as though I've got pebbles in my shoes	☐	☐
10.	I get pain every time I put my foot down	☐	☐
11.	I get a burning sensation all the time	☐	☐
12.	I cry with pain	☐	☐

Please check you have ticked a box for every statement on this page

Please remember to read each statement thinking about your feet. Please choose the response that applies best to you at the moment.

		TRUE	NOT TRUE
13.	I can only walk in certain shoes............................	☐	☐
14.	I need shoes with plenty of room in them............	☐	☐
15.	I am limited in my choice of shoes.......................	☐	☐
16.	I need a wider fit of shoes....................................	☐	☐
17.	I feel I need a lot of padding under my feet...........	☐	☐
18.	My footwear always feels heavy............................	☐	☐
19.	I have to keep swapping and changing my shoes...	☐	☐
20.	I can't get any shoes on...	☐	☐
21.	I walk bare foot all the time...................................	☐	☐

Please remember to read each statement thinking about your feet. Please choose the response that applies best to you at the moment.

		TRUE	NOT TRUE
22.	I feel unsafe on my feet..	☐	☐
23.	I have to walk for a bit and sit for a bit..................	☐	☐
24.	I can't run...	☐	☐
25.	I find I shuffle around...	☐	☐
26.	I am limping about all the time..............................	☐	☐
27.	I have to use a walking stick or walking frame.......	☐	☐

Please check you have ticked a box for every statement on this page

Please remember to read each statement thinking about your feet.
Please choose the response that applies best to you <u>at the moment</u>.

		TRUE	NOT TRUE
28.	It takes me all my time to climb the stairs…………	☐	☐
29.	I need help to climb stairs………………………………	☐	☐
30.	I can't walk on cobbles…………………………………	☐	☐
31.	I am unsteady on uneven surfaces…………………….	☐	☐
32.	I can't walk as far as I would like to…………………	☐	☐
33.	It takes me longer to do things……………………….	☐	☐
34.	My whole life has been adapted…………………………	☐	☐

Please remember to read each statement thinking about your feet.
Please choose the response that applies best to you <u>at the moment</u>.

		TRUE	NOT TRUE
35.	My feet restrict my movement………………………….	☐	☐
36.	I get annoyed because I'm slower………………………	☐	☐
37.	I get frustrated because I can't do things so quickly….	☐	☐
38.	My whole life has slowed down………………………	☐	☐
39.	It's reduced the range of things I can do…………….	☐	☐
40.	I have to plan everything out……………………………	☐	☐
41.	I can't keep up like I used to…………………………….	☐	☐
42.	Socially its affected me a lot…………………………….	☐	☐
43.	I am ashamed of how I walk…………………………….	☐	☐
44.	I'm nervous of missing a curb edge………………….	☐	☐

Please check you have ticked a box for every statement on this page

Please remember to read each statement thinking about your feet.
Please choose the response that applies best to you at the moment.

		TRUE	NOT TRUE
45.	I feel isolated because I can't go very far..............	☐	☐
46.	I feel I slow other people down.............................	☐	☐
47.	I can't do some of the things I take for granted......	☐	☐
48.	I can't go for walks with the people close to me.....	☐	☐
49.	I'm finding it difficult to be independent..............	☐	☐
50.	I dread finishing up in a wheelchair........................	☐	☐
51.	I get frustrated because I can't do things for myself..	☐	☐

Please check you have ticked a box for every statement on this page

Thank you. Please return this form to the study researcher.

Hospital Anxiety and Depression Scale (HADS)

Instructions: Emotions can affect how we experience pain. Read each item and circle the reply that comes closest to how you have been feeling in the past week. Don’t take too long over your replies: your immediate reaction is best.

I feel tense or ‘wound up’:	**A**
Most of the time	3
A lot of the time	2
Time to time, occasionally	1
Not at all	0

I still enjoy the things I used to enjoy:	**D**
Definitely as much	0
Not quite so much	1
Only a little	2
Not at all	3

I get a sort of frightened feeling like something awful is about to happen:	**A**
Very definitely and quite badly	3
Yes, but not too badly	2
A little, but it doesn’t worry me	1
Not at all	0

I can laugh and see the funny side of things:	**D**
As much as I always could	0
Not quite so much now	1
Definitely not so much now	2
Not at all	3

Worrying thoughts go through my mind:	**A**
A great deal of the time	3
A lot of the time	2
From time to time but not too often	1
Only occasionally	0

I feel cheerful:	**D**
Not at all	3
Not often	2
Sometimes	1
Most of the time	0

I can sit at ease and feel relaxed:	**A**
Definitely	0
Usually	1
Not often	2
Not at all	3

I feel as if I am slowed down:	**D**
Nearly all of the time	3
Very often	2
Sometimes	1
Not at all	0

I get a sort of frightened feeling like ‘butterflies in the stomach’:	**A**
Not at all	0
Occasionally	1
Quite often	2
Very often	3

I have lost interest in my appearance:	**D**
Definitely	3
I don’t take as much care as I should	2
I may not take quite as much care	1
I take just as much care as ever	0

I feel restless as if I have to be on the move:	**A**
Very much indeed	3
Quite a lot	2
Not very much	1
Not at all	0

I look forward with enjoyment to things:	**D**
A much as I ever did	0
Rather less than I used to	1
Definitely less than I used to	3
Hardly at all	2

I get sudden feelings of panic:	**A**
Very often indeed	3
Quite often	2
Not very often	1
Not at all	0

I can enjoy a good book or radio or TV programme:	**D**
Often	0
Sometimes	1
Not often	2
Very seldom	3

HEALTH ASSESSMENT QUESTIONNAIRE (HAQ)

Tick (√) the one response which best describes your usual abilities over the past week.

		Without ANY difficulty (0)	With SOME difficulty (1)	With MUCH difficulty (2)	Unable to do (3)
1.	**DRESSING & GROOMING** **Are you able to:**				
	Dress yourself, including tying shoelaces and doing buttons ?	☐	☐	☐	☐
	Shampoo your hair?	☐	☐	☐	☐
2.	**RISING** **Are you able to:**				
	Stand up from an armless straight chair?	☐	☐	☐	☐
	Get in and out of bed?	☐	☐	☐	☐
3.	**EATING** **Are you able to:**				
	Cut your meat?	☐	☐	☐	☐
	Lift a full cup or glass to your mouth?	☐	☐	☐	☐
	Open a new carton of milk (or soap powder)?	☐	☐	☐	☐
4.	**WALKING** **Are you able to:**				
	Walk outdoors on flat ground?	☐	☐	☐	☐
	Climb up five steps?	☐	☐	☐	☐

PLEASE TICK ANY AIDS OR DEVICES THAT YOU USUALLY USE FOR ANY OF THESE ACTIVITIES.

Walking stick ☐

Walking frame ☐

Crutches ☐

Devices used for dressing (button hook, zipper pull, long-handled shoe horn) ☐

Built up or special utensils ☐

Other (Please specify)

Special or built up chair ☐

Wheelchair ☐

Please tick any categories for which you usually need help from another person.

Dressing and grooming ☐ Rising ☐ Eating ☐ Walking ☐

		Without ANY difficulty (0)	With SOME difficulty (1)	With MUCH difficulty (2)	Unable to do (3)
5.	**HYGIENE** **Are you able to:**				
	Wash and dry your entire body?	☐	☐	☐	☐
	Take a bath?	☐	☐	☐	☐
	Get on and off the toilet?	☐	☐	☐	☐
6.	**REACH** **Are you able to:**				
	Reach and get down a 5lb object (eg bag of potatoes) from just above your head?	☐	☐	☐	☐
	Bend down to pick up clothing from the floor?	☐	☐	☐	☑
7.	**GRIP** **Are you able to:**				
	Open car doors?	☐	☐	☐	☐
	Open jars which have previously been opened?	☐	☐	☐	☐
	Turn taps on and off?	☐	☐	☐	☐
8.	**ACTIVITIES** **Are you able to:**				
	Run errands and shop?	☐	☐	☐	☐
	Get in and out of a car?	☐	☐	☐	☐
	Do chores such as vacuuming, housework or light gardening?	☐	☐	☐	☑

PLEASE TICK ANY AIDS OR DEVICES THAT YOU USUALLY USE FOR ANY OF THESE ACTIVITIES

Raised toilet seat ☐ Bath rail ☐ Bath seat ☐ Long-handled appliances for reach ☐

Jar opener (for jars previously opened) ☐ Other (please specify)

Please tick any categories for which you usually need help from another person.

Hygiene ☐ Reach ☐ Gripping & opening things ☐ Errands & housework ☐

Focus Groups with health professionals - Data Collection Form
Title: The nature, extent and localisation of foot problems in people with psoriatic arthritis
[Insert Site Name]
Focus group time:
Focus group study number:

Demographic data			
Age (years)		Ethnicity	
Gender (M/F)		Experience managing psoriatic arthritis (years)	
Public/private sector practice		Occupation	
Qualifications:			

Example of cognitive interview script

- The purpose of this interview is to find out how easy it is for you to complete the survey and how relevant the questions are to you.
- You will be asked to read and answer the survey questions one by one and then answer questions about what you think of the survey instructions and questions.
- The information you provide in the interview will be used to correct any errors in order to ensure that the survey is clear to understand, straightforward to complete and that it asks questions about what is important and relevant to you.
- There are no right and wrong answers to the question and please do not worry about criticising the survey as it will only improve it.

Survey Introduction

Do you think the introductory statement is easy or hard to follow [**Comprehension**]?

Do you have any particular comments or suggestions about the introduction [**General probe**]? Introduction

Section 1 About who you see

Can you tell me, in your own words, what the instructions are asking you to do [**Interpretation**]? Q1 and 2

Do you have any particular comments or suggestions about this part of the survey [**General probe**]? Section1 About who you see

Section 2 About you

Do you find it easy or hard to answer the general questions about you in this section [**Comprehension**]? Do you think anything is missing? Q3 to 8

Do you think that the answers you can choose from allow you to answer the questions in the way that you want [**Response**]? Do you think anything is missing? Q 9, 10, 11 and 12.

Do you find this question easy or hard to answer [**General probe**]? Q13

What do the words ‘anxiety’ and ‘depression’ mean to you [**Interpretation**]? Q14

How does answering this question make you feel? For example, happy or sad [**Specific probe**]? Q14

Can you tell me, in your own words, what the instructions are asking you to do [**Interpretation**]? Q15

How confident are you that you can remember how many times you fell over the past 12 months? On a scale of one (not at all confident) to seven (extremely confident) [**Judgement**]? Q15

Do you have any particular comments or suggestions about this part of the survey [**General probe**]? Section2 About you

Section 3 About your psoriatic arthritis

Is it easy or hard for you to remember when your symptoms first started [**Recall**]? Q16

Is it easy or hard for you to remember when you received a diagnosis of your condition [**Recall**]? Q17

Do you think that the response options allow you to answer the questions in the way that you want [**Response**]? Would you prefer to put a **date** instead? Q16 and 17

Do you think the order of these two questions should be reversed? Q16 and 17

How confident are you that you can remember your medications? On a scale of one (not at all confident) to seven (extremely confident) [**Recall, confidence**] Q18

Do you feel confident answering this question? [**Confidence**]? Q19

Do you think that the answers you can choose from allow you to answer the question in the way that you want [**Response**]? Q19

Can you tell me, in your own words, what the instructions are asking you to do [**Interpretation**]? Q20

Do you think the instructions are easy or hard to follow [**Comprehension**]? Q20

How confident are you that you could record the correct location of your body pain on the diagram? [**Confidence**] Q20

How else would you like to record your body pain [**Specific probe**]? Can you think of a better way? [**Specific probe**]? Q20

What does the term ‘all the ways that your PSORIASIS and ARTHRITIS affects you’, ‘all the ways that your PSORIASIS affects you’ and ‘all the ways that your ARTHRITIS affects you’ mean to you? [**Interpretation, comprehension**] Q21

How confident are you that you can remember how much pain you have had over the **past week**? On a scale of one (not at all confident) to seven (extremely confident) [**Recall, confidence**] Q21

Is this question relevant to you [**General probe**]? Q22

Do you think you can remember how long the stiffness in your joints last for in the morning over the **past week** [**Recall**]? Q22

Is it easy or hard to follow the skip instruction **[Comprehension]**? Q22

Do you have any particular comments or suggestions about this part of the survey [**General probe**]? Section3 About your psoriatic arthritis

Section 4 About your feet

How confident are you that you can remember if you have **ever** had pain in your feet and ankles which lasted for one day or longer [**Recall**]? Q23

Do you feel that the timescale of this question is appropriate [**Specific probe**]? Q23

Is it easy or hard to follow the skip instruction **[Comprehension]**? Q23

Do you think you can remember if you have had pain over the **past month** your feet and ankles which lasted for one day or longer [**Recall**]? Q24

Do you feel that the timescale for asking about your foot pain is appropriate [**Specific probe**]? Q24

How confident are you that you are able to mark accurately where you have or had experienced pain on the diagram? On a scale of one (not at all confident) to seven (extremely confident) [**Judgement**]? Q24

Can you show me by pointing to your feet where you have previously experienced pain [**Comprehension, judgement**]? Q24 [interviewer records on data sheet]

How else would you like to record your foot pain [**Specific probe**]? Can you think of a better way? [**Specific probe**]? Q24

Is it easy or hard for you to remember the severity of pain you have experienced over the **past month** [**Recall**]? Q24 (VAS)

Can you repeat this question in your own words [**Paraphrase**]? Q25 and 26

Do you think the instructions are easy or hard to follow [**Comprehension**]? Q27

Do you think you can remember how the symptoms in your feet and ankles change during a typical day [**Recall**]? Q27

What do the words ‘my feet are better if I keep my joints moving’ mean to you [**Interpretation**]? Q27

What do the words ‘randomly change’ mean to you [**Interpretation**]? Q27

Do you think that the answers you can choose from allow you to answer the questions in the way that you want [**Response**]? Q27

Do you think that any of the questions are repetitious? Please indicate the questions you think are and why [**Repetition**]. Q27

How comprehensive do you think this section is with asking about pain in the feet and ankles? On a scale of one (not at all comprehensive) to seven (extremely comprehensive) [**Judgement**]? Section4 About your feet

Do you have any particular comments or suggestions about this part of the survey [**General probe**]? Section4 About your feet

Section 5 About other foot and ankle symptoms

Do you think the instructions are easy or hard to follow [**Comprehension**]? Q28

How confident are you that you remember the different types of symptoms you experience in your feet and ankles [**Recall**]? Q28

What do the words 'numbness, tingling or altered sensation' mean to you [**Interpretation**]?

Can you repeat this question in your own words [**Paraphrase**]? Q29

Do you find it easy or hard to decide to what extent the symptoms in your feet and ankle have been troublesome [**Judgement**]? Q29

Do you think that the question 28 and 29 are repetitious? Please suggest any changes [**Repetition**]. Q28 and 29

Do you think that the answers you can choose from allow you to answer the question in the way that you want [**Response**]? Would you prefer to provide more details? Q30

What do the words 'deformity', 'crooked', 'bunions' and 'sausage toe' mean to you [**Interpretation**]? Q30

Can you show me 'the front of your foot (excluding toes)' by pointing to it [**Comprehension, judgement**]? Q30 [interviewer records response on data sheet]

How important do you think this section about other symptoms in the feet and ankles is to people with psoriatic arthritis? On a scale of one (not at all important) to seven (extremely important) [**Judgement**]? Section5 About other foot and ankle symptoms

Do you have any particular comments or suggestions about this part of the survey [**General probe**]? Section5 About other symptoms

Section 6 About your lower legs and feet skin psoriasis

Do you think the instructions are easy or hard to follow [**Comprehension**]? Q31

Can you show me 'your lower legs' by pointing to it [**Comprehension, judgement**]? Q31 [interviewer records response on data sheet]

Do you think the instructions are easy or hard to follow [**Comprehension**]? Q32

What do the words 'skin psoriasis' mean to you [**Interpretation**]? Q31 and Q32

Is it easy or hard to follow the skip instructions **[Comprehension]**? Q32

How confident are you that you can remember if you have had skin psoriasis affecting your feet and ankles over the **past month** [**Recall, confidence**]? Q32

Do you feel that the timescale of this question is appropriate [**Specific probe**]? Q32

How confident are you that you are able to mark accurately where you have or had experienced skin psoriasis on the diagram? On a scale of one (not at all confident) to seven (extremely confident) [**Judgement**]? Q32

How else would you like to record the location of your skin psoriasis on your feet [**Specific probe**]? Can you think of a better way? [**Specific probe**]? Q32

Do you think that the answers you can choose from allow you to answer the question in the way that you want [**Response**]? Would you prefer to provide more details? Q32

What do the words ‘thick hard skin (callus)’ and ‘splitting’ mean to you? [**Interpretation, comprehension**]

Can you tell me, in your own words, what the instructions are asking you to do [**Interpretation**]? Q32

Do you think that the answers you can choose from allow you to answer the question in the way that you want [**Response**]? Q32

How important do you think this section about skin psoriasis affecting the feet is to people with psoriatic arthritis? On a scale of one (not at all important) to seven (extremely important) [**Judgement**]? Section6 About your skin psoriasis

Do you have any particular comments or suggestions about this part of the survey [**General probe**]? Section6 About your skin psoriasis

Section 7 About your toenails

Do you think the instructions are easy or hard to follow [**Comprehension**]? Q33

What do the words ‘toenail psoriasis’ mean to you [**Interpretation**]? Q33

Is it easy or hard to follow the skip instructions **[Comprehension]**? Q33

What does the term ‘toenail psoriasis affecting your life’ mean to you [**Interpretation, comprehension**]? Q33

Do you feel that the timescale of this question is appropriate [**Specific probe**]? Q33

Do you think that the answers you can choose from allow you to answer the question in the way that you want [**Response**]? Would you prefer to provide more details? Q33

How do words like ‘embarrassed’ and ‘self-conscious’ make you feel? [**Specific probe**] Q33

How will you can remember how many toenails have been affected over the **past month** [**Recall**]? Q33

Can you tell me, in your own words, what the instructions are asking you to do [**Interpretation**]? Q33

What do the words ‘pitting’, ‘ridges’, in-grown’ and ‘thick skin under the nail’ mean to you? [**Interpretation, comprehension**] Q33

Do you think that the answers you can choose from allow you to answer the question in the way that you want [**Response**]? Would pictures be helpful? Q33

How important do you think this section about toenail psoriasis is to people with psoriatic arthritis? On a scale of one (not at all important) to seven (extremely important) [**Judgement**]? Section7 About your toenail psoriasis

Do you have any particular comments or suggestions about this part of the survey [**General probe**]? Section7 About your toenail psoriasis

Section 8 About your experiences with footwear

Can you tell me, in your own words, what the instructions are asking you to do [**Interpretation**]? Q34

Do you think that the answers you can choose from allow you to answer the question in the way that you want [**Response**]? Q34

Is this question relevant to you [**General probe**]? Q34

Can you tell me, in your own words, what the instructions are asking you to do [**Interpretation**]? Q35

Do you think that the answers you can choose from allow you to answer the question in the way that you want [**Response**]? Q35

Is this question relevant to you [**General probe**]? Q35

Can you tell me, in your own words, what the instructions are asking you to do [**Interpretation**]? Q36

Do you think that the answers you can choose from allow you to answer the question in the way that you want [**Response**]? Q36

Do you think any of the items in questions 34, 35 and 36 are repetitious? Please suggest any changes [**Repetition**]. Q34, 35 and 36

Can you repeat this question in your own words [**Paraphrase**]? Q37

Do you think that any of the questions are repetitious? Please indicate the questions you think are and why [**Repetition**]. Q37

What do the words ‘prescription extra-deep/wide footwear’ and ‘self-bought extra deep/wide footwear’ mean to you [**Interpretation**]? Would pictures be helpful? Q37

Can you repeat this question in your own words [**Paraphrase**]? Q38

Do you think that the answers you can choose from allow you to answer the question in the way that you want [**Response**]? Q38

Can you repeat this question in your own words [**Paraphrase**]? Q39

How confident are you that you know that cold weather is a reason for making your foot symptoms better or worse [**Judgement, Confidence**]? Q39

Can you repeat this question in your own words [**Paraphrase**]? Q40

How confident are you that you know that hot weather is a reason for making your foot symptoms better or worse [**Judgement, confidence**]? Q40

How important do you think this section about footwear is to people with psoriatic arthritis? On a scale of one (not at all important) to seven (extremely important) [**Judgement**]? Section8 About your experiences with footwear

Do you have any particular comments or suggestions about this part of the survey [**General probe**]? Section8 About your experiences with footwear

Section 9 About your feet and your daily life

Can you tell me, in your own words, what the instructions are asking you to do [**Interpretation**]? Q41

Do you think that the answers you can choose from allow you to answer the question in the way that you want [**Response**]? Q41

Can you repeat this question in your own words [**Paraphrase**]? Q42

Do you think the instructions are easy or hard to follow [**Comprehension**]? Q42

Do you think that the answers you can choose from allow you to answer the question in the way that you want [**Response**]? Q42

Is it easy or hard to follow the skip instruction **[Comprehension]**? Q42

Do you think the instructions are easy or hard to follow [**Comprehension**]? Q43

Do you think you can remember how many times you did these activities in the **past week** [**Recall**]? Q43

Do you think the instructions are easy or hard to follow [**Comprehension**]? Q44

Do you think that the answers you can choose from allow you to answer the question in the way that you want [**Response**]? Q44

How confident are you that you can remember to what extent your feet have interfered with your daily activities [**Judgement**]? Q45

Do you think that the answers you can choose from allow you to answer the question in the way that you want [**Response**]? Q45

What do the words ‘embarrassment’ and ‘self-conscious’ mean to you [**Interpretation**]? Q46

Do you think that the answers you can choose from allow you to answer the question in the way that you want [**Response**]? Would you prefer to provide more details? Q46

How does answering this question make you feel? For example, happy or sad [**Specific probe**]? Q46

What do the words ‘size of my foot’, ‘deformity at my ankle and heel’ and ‘swelling’ mean to you [**Interpretation**]? Q46

Can you repeat this question in your own words [**Paraphrase**]? Q47

How confident are you that you can remember how well you have coped with your foot problems over the **past month** [**Recall, confidence**]? Q47

How important do you think this section about how your feet affect daily activities is to people with psoriatic arthritis? On a scale of one (not at all important) to seven (extremely important) [**Judgement**]? Section9 About your daily activities

Do you have any particular comments or suggestions about this part of the survey [**General probe**]? Section9 About your daily activities

Section 10 About your foot problems and who you see

Can you repeat this question in your own words [**Paraphrase**]? Q48

How confident are you that you can remember how much of a problem your feet have been over the **past month** [**Recall, confidence**]? Q48

Can you repeat this question in your own words [**Paraphrase**]? Q49

Do you think that the answers you can choose from allow you to answer the question in the way that you want [**Response**]? Q49

What does the word ‘dermatologist’ and ‘pedicure’ mean to you [**Interpretation**]? Q49

Can you repeat this question in your own words [**Paraphrase**]? Q49

How confident are you that you can decide how effective the help you received has been [**Judgement**]? Q49

Is it easy or hard to follow the skip instruction **[Comprehension]**? Q49

Can you repeat this question in your own words [**Paraphrase**]? Q50

Do you find it easy or hard to decide how effective your management of your own foot problems has been [**Judgement**]? Q50

Is it easy or hard to follow the skip instruction **[Comprehension]**? Q50

Can you repeat this question in your own words [**Paraphrase**]? Q51

Do you feel that the timescale of this question is appropriate [**Specific probe**]? Q51

What does the word ‘rheumatologist’ mean to you [**Interpretation**]? Q52

Do you find this question easy or hard to answer [**General probe**]? Q52 to Q57

How important do you think this section about who you see and how you manage your foot problems is to people with psoriatic arthritis? On a scale of one (not at all important) to seven (extremely important) [**Judgement**]? Section10 About your foot problems and who you see

Do you have any particular comments or suggestions about this part of the survey [**General probe**]? Section10 About who you see

End of Survey

Would you provide your contact details in order to be invited to participate in future studies related to this research?

Would you like the option to go back and edit or review your responses?

Do you think the option to complete a separate questionnaire is burdensome?

Overall, do you have any particular comments or suggestions about the survey [**General probe**]?

Do you feel, on the face of it, that the draft survey appears to measure the problems you have with your feet and the impact it has on your life [**Face validity**]?

Do you feel that the draft survey consists of a broad range of items that are all relevant, in their coverage, to the problems you have with your feet and the impact it has on your daily life [**Content validity**]?

Example of focus group survey pre-testing script

The purpose of this focus group will be to identify and correct as many issues and potential sources of error as possible with the draft survey, based on your own knowledge and insight. Please read through the draft survey. Below is a list of questions that ask you to appraise the draft survey based on your own knowledge of patients with feet affected by psoriatic arthritis. The questions ask you to consider the acceptability of the survey in different ways; quality of the questions, anticipated respondent burden and clarity of instructions from the patients' perspective. We will discuss as a group the problems identified and your recommendations for addressing the problems in each section of the draft survey.

General questions to consider:

1) Do you think that the **wording and terminology** of the items are clear?
2) Do you feel that the **response options** of the items are acceptable?
3) Can you think of any **problems or issues** that you might encounter as a patient?
4) Do you think that the instructions are clear and that it is simple to **navigate**?
5) Do you think that any of the items are **repetitious**? Please indicate which items and why.
6) Do you think that the respondents will have the **motivation, knowledge and ability** to answer the questions?
7) Do you feel that the items that make up the survey are **meaningful** to patients?
8) Do you think there is sufficient **coverage of items** in each section?

Web-based survey questions:

1) Are you able to use the **navigation features** easily?
2) Do you have **difficulty clicking** the correct radio buttons when filling out the grids?
3) Is it easy or hard to **scroll** to see the questions?
4) What **issues** do you encounter on your electronic device?
5) Do the **interactive pain diagrams** perform in the way that you would like?
6) Do you think the **time and number of steps** to complete the survey is acceptable?

Face Validity

Overall, do you feel, on the face of it, that the survey appears to measure the nature, extent, localisation and impact of psoriatic arthritis-related foot involvement on patients' daily lives?

Content Validity

Overall, do you feel that the survey consists of a broad range of items that are all relevant, in their coverage, to the nature, extent, localisation and impact of psoriatic arthritis-related foot involvement on patients' daily lives?

Google Forms

Google Form1: Link and examples

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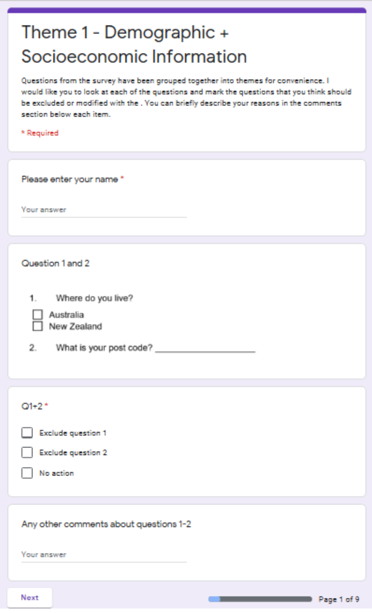


Theme 1 - Demographic + Socioeconomic Information

Questions from the survey have been grouped together into themes for convenience. I would like you to look at each of the questions and mark the questions that you think should be excluded or modified with the . You can briefly describe your reasons in the comments section below each item.

* Required

Please enter your name *

Your answer

Question 1 and 2

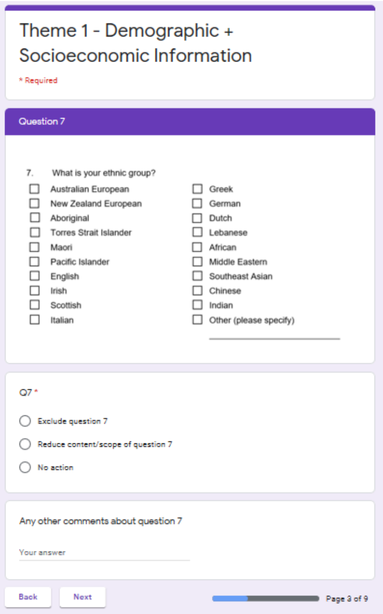
1. Where do you live?
☐ Australia
☐ New Zealand
2. What is your post code? ______________

Q1+2 *

☐ Exclude question 1
☐ Exclude question 2
☐ No action

Any other comments about questions 1-2

Your answer



Theme 1 - Demographic + Socioeconomic Information

* Required

Question 7

7. What is your ethnic group?
☐ Australian European
☐ New Zealand European
☐ Aboriginal
☐ Torres Strait Islander
☐ Maori
☐ Pacific Islander
☐ English
☐ Irish
☐ Scottish
☐ Italian
☐ Greek
☐ German
☐ Dutch
☐ Lebanese
☐ African
☐ Middle Eastern
☐ Southeast Asian
☐ Chinese
☐ Indian
☐ Other (please specify) ______________

Q7 *

○ Exclude question 7
○ Reduce content/scope of question 7
○ No action

Any other comments about question 7

Your answer

Google Form2: Link and examples

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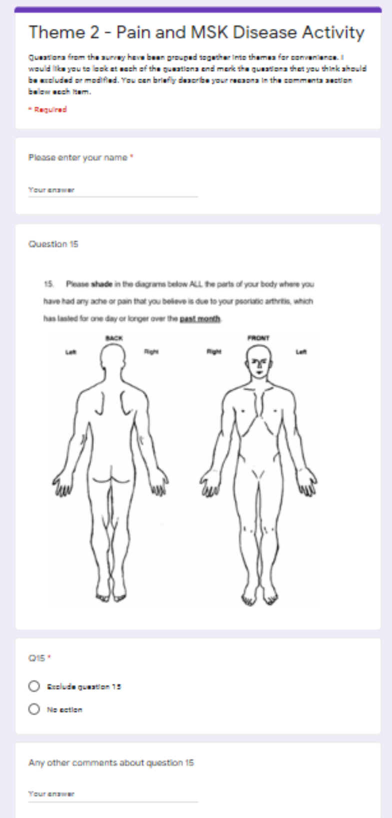


Theme 2 - Pain and MSK Disease Activity

Questions from the survey have been grouped together into themes for convenience. I would like you to look at each of the questions and mark the questions that you think should be excluded or modified. You can briefly describe your reasons in the comments section below each item.

* Required

Please enter your name *

Your answer

Question 15

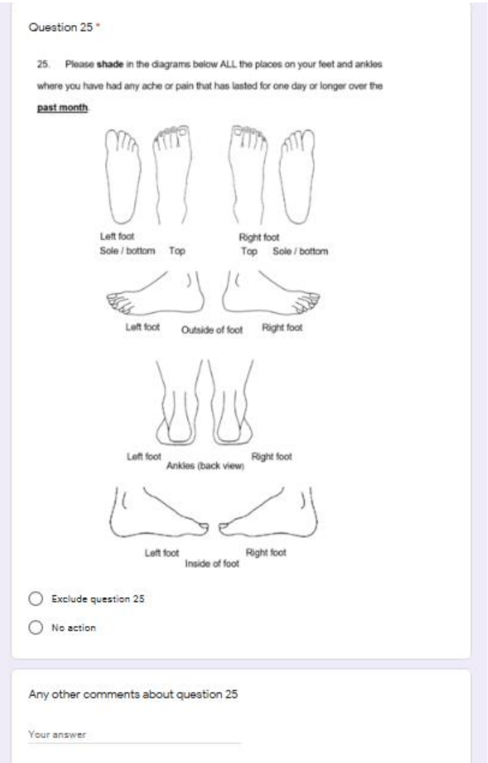
15. Please **shade** in the diagrams below ALL the parts of your body where you have had any ache or pain that you believe is due to your psoriatic arthritis, which has lasted for one day or longer over the **past month**.

Q15 *

○ Exclude question 15
○ No action

Any other comments about question 15

Your answer



Question 25 *

25. Please **shade** in the diagrams below ALL the places on your feet and ankles where you have had any ache or pain that has lasted for one day or longer over the **past month**.

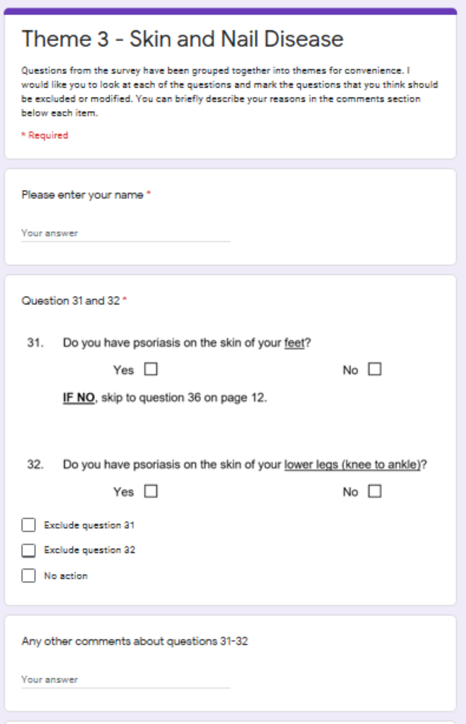
○ Exclude question 25
○ No action

Any other comments about question 25

Your answer

Google Form3: Link and examples

https://docs.google.com/forms/d/1R4vR9eLg96rA71xn1AYCmJqlPC5jCLCZQ6MQQF6Ze4o/viewform?edit_requested=true



Theme 3 - Skin and Nail Disease

Questions from the survey have been grouped together into themes for convenience. I would like you to look at each of the questions and mark the questions that you think should be excluded or modified. You can briefly describe your reasons in the comments section below each item.

* Required

Please enter your name *

Your answer

Question 31 and 32 *

31. Do you have psoriasis on the skin of your feet?

Yes ☐ No ☐

IF NO, skip to question 36 on page 12.

32. Do you have psoriasis on the skin of your lower legs (knee to ankle)?

Yes ☐ No ☐

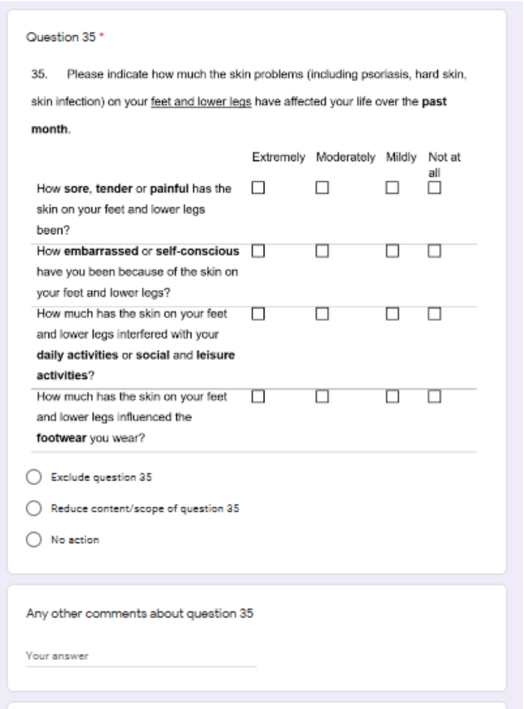
☐ Exclude question 31

☐ Exclude question 32

☐ No action

Any other comments about questions 31-32

Your answer



Question 35 *

35. Please indicate how much the skin problems (including psoriasis, hard skin, skin infection) on your feet and lower legs have affected your life over the **past month**.

	Extremely	Moderately	Mildly	Not at all
How **sore**, **tender** or **painful** has the skin on your feet and lower legs been?	☐	☐	☐	☐
How **embarrassed** or **self-conscious** have you been because of the skin on your feet and lower legs?	☐	☐	☐	☐
How much has the skin on your feet and lower legs interfered with your **daily activities** or **social** and **leisure activities**?	☐	☐	☐	☐
How much has the skin on your feet and lower legs influenced the **footwear** you wear?	☐	☐	☐	☐

○ Exclude question 35

○ Reduce content/scope of question 35

○ No action

Any other comments about question 35

Your answer

Google Form4: Link and examples

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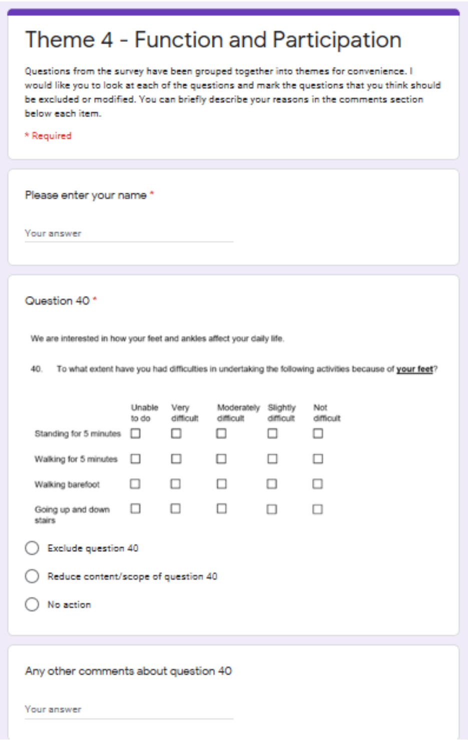


Theme 4 - Function and Participation

Questions from the survey have been grouped together into themes for convenience. I would like you to look at each of the questions and mark the questions that you think should be excluded or modified. You can briefly describe your reasons in the comments section below each item.

* Required

Please enter your name *

Your answer

Question 40 *

We are interested in how your feet and ankles affect your daily life.

40. To what extent have you had difficulties in undertaking the following activities because of **your feet**?

	Unable to do	Very difficult	Moderately difficult	Slightly difficult	Not difficult
Standing for 5 minutes	☐	☐	☐	☐	☐
Walking for 5 minutes	☐	☐	☐	☐	☐
Walking barefoot	☐	☐	☐	☐	☐
Going up and down stairs	☐	☐	☐	☐	☐

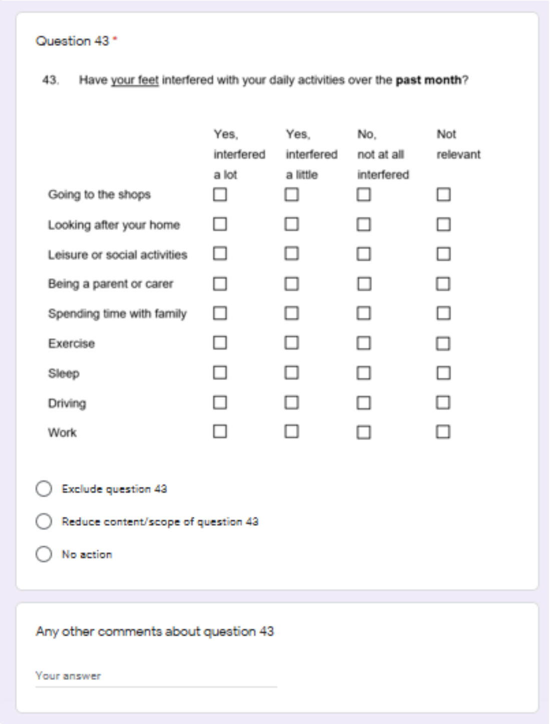
○ Exclude question 40

○ Reduce content/scope of question 40

○ No action

Any other comments about question 40

Your answer



Question 43 *

43. Have your feet interfered with your daily activities over the **past month**?

	Yes, interfered a lot	Yes, interfered a little	No, not at all interfered	Not relevant
Going to the shops	☐	☐	☐	☐
Looking after your home	☐	☐	☐	☐
Leisure or social activities	☐	☐	☐	☐
Being a parent or carer	☐	☐	☐	☐
Spending time with family	☐	☐	☐	☐
Exercise	☐	☐	☐	☐
Sleep	☐	☐	☐	☐
Driving	☐	☐	☐	☐
Work	☐	☐	☐	☐

○ Exclude question 43

○ Reduce content/scope of question 43

○ No action

Any other comments about question 43

Your answer

Google Form5: Link and examples

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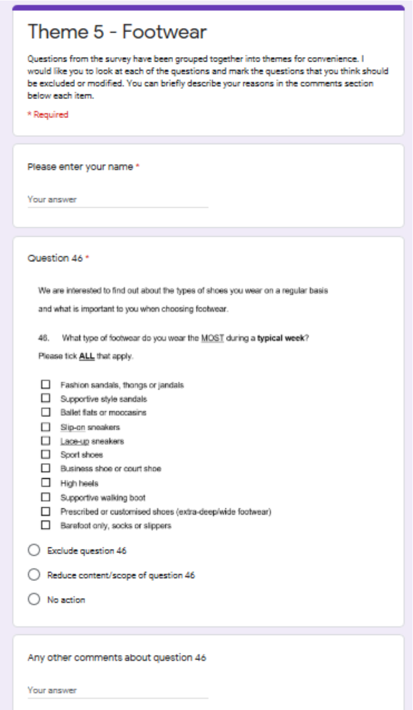


Theme 5 - Footwear

Questions from the survey have been grouped together into themes for convenience. I would like you to look at each of the questions and mark the questions that you think should be excluded or modified. You can briefly describe your reasons in the comments section below each item.

* Required

Please enter your name *

Your answer

Question 46 *

We are interested to find out about the types of shoes you wear on a regular basis and what is important to you when choosing footwear.

46. What type of footwear do you wear the MOST during a **typical week**?
Please tick **ALL** that apply.

- ☐ Fashion sandals, thongs or jandals
- ☐ Supportive style sandals
- ☐ Ballet flats or moccasins
- ☐ Slip-on sneakers
- ☐ Lace-up sneakers
- ☐ Sport shoes
- ☐ Business shoe or court shoe
- ☐ High heels
- ☐ Supportive walking boot
- ☐ Prescribed or customised shoes (extra-deep/wide footwear)
- ☐ Barefoot only, socks or slippers

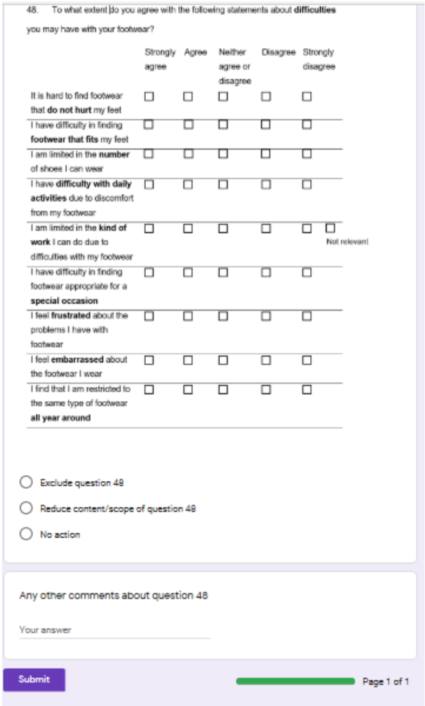
○ Exclude question 46

○ Reduce content/scope of question 46

○ No action

Any other comments about question 46

Your answer



48. To what extent do you agree with the following statements about **difficulties** you may have with your footwear?

	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree	
It is hard to find footwear that **do not hurt** my feet	☐	☐	☐	☐	☐	
I have difficulty in finding **footwear that fits** my feet	☐	☐	☐	☐	☐	
I am limited in the **number** of shoes I can wear	☐	☐	☐	☐	☐	
I have **difficulty with daily activities** due to discomfort from my footwear	☐	☐	☐	☐	☐	
I am limited in the **kind of work** I can do due to difficulties with my footwear	☐	☐	☐	☐	☐	☐ Not relevant
I have difficulty in finding footwear appropriate for a **special occasion**	☐	☐	☐	☐	☐	
I feel **frustrated** about the problems I have with footwear	☐	☐	☐	☐	☐	
I feel **embarrassed** about the footwear I wear	☐	☐	☐	☐	☐	
I find that I am restricted to the same type of footwear **all year around**	☐	☐	☐	☐	☐	

○ Exclude question 48

○ Reduce content/scope of question 48

○ No action

Any other comments about question 48

Your answer

Google Form6: Link and examples

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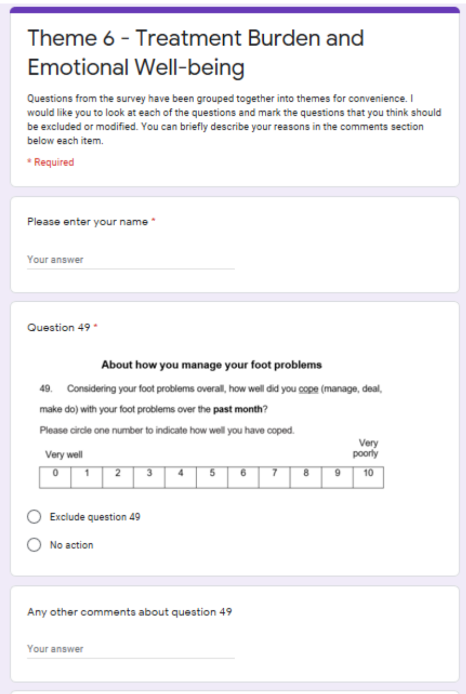


Theme 6 - Treatment Burden and Emotional Well-being

Questions from the survey have been grouped together into themes for convenience. I would like you to look at each of the questions and mark the questions that you think should be excluded or modified. You can briefly describe your reasons in the comments section below each item.

* Required

Please enter your name *

Your answer

Question 49 *

About how you manage your foot problems

49. Considering your foot problems overall, how well did you cope (manage, deal, make do) with your foot problems over the **past month**?

Please circle one number to indicate how well you have coped.

Very well … Very poorly

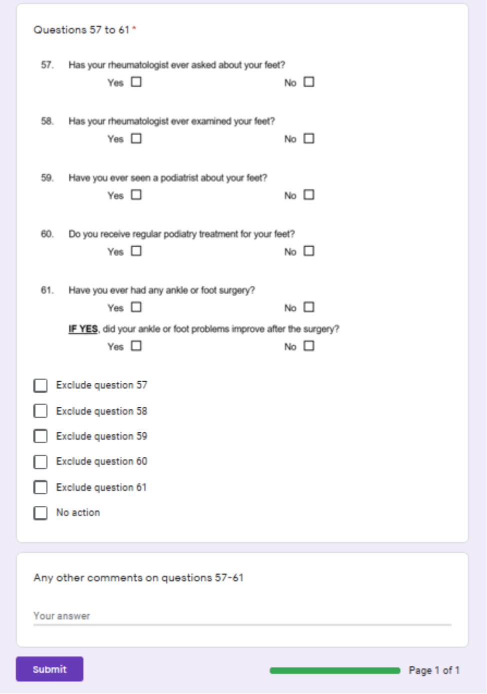
0	1	2	3	4	5	6	7	8	9	10

○ Exclude question 49

○ No action

Any other comments about question 49

Your answer



Questions 57 to 61 *

57. Has your rheumatologist ever asked about your feet?
Yes ☐ No ☐

58. Has your rheumatologist ever examined your feet?
Yes ☐ No ☐

59. Have you ever seen a podiatrist about your feet?
Yes ☐ No ☐

60. Do you receive regular podiatry treatment for your feet?
Yes ☐ No ☐

61. Have you ever had any ankle or foot surgery?
Yes ☐ No ☐

IF YES, did your ankle or foot problems improve after the surgery?
Yes ☐ No ☐

- ☐ Exclude question 57
- ☐ Exclude question 58
- ☐ Exclude question 59
- ☐ Exclude question 60
- ☐ Exclude question 61
- ☐ No action

Any other comments on questions 57-61

Your answer

WESTERN SYDNEY
UNIVERSITY

Participant Information Sheet

Project Title: The nature, extent and localization of foot problems in people with psoriatic arthritis.

Project Summary:
You are invited to participate in a research study being conducted by podiatry PhD student Kate Carter under the supervision of Professor Deborah Turner, from the School of Health and Science at Western Sydney University, Australia, and of Professor Keith Rome, from the Faculty of Health and Environmental Science at Auckland University of Technology, New Zealand.

Foot problems are common in people with inflammatory arthritis. However, little is known about the nature and extent of foot problems related to psoriatic arthritis. Most of our knowledge comes from a few studies conducted in European countries. We wish to better understand the foot problems and the impact they have on daily life, footwear choice and the foot care needs of people with psoriatic arthritis. Findings from this study will help us understand the level of foot involvement in this disease and will direct future work on how to better assess and treat the problems. The study aim is to find out about the foot problems experienced by people with psoriatic arthritis in Australia and New Zealand.

How is the study being paid for?
The research is part of a PhD being undertaken at Western Sydney University. This study has no sponsor and no source of funding. You will not be paid to participate in this research study.

What will I be asked to do?
You will be asked to complete an online or paper-based survey. The survey will ask for some personal information about you such as your age, gender and ethnicity and questions related to your psoriatic arthritis and any foot problems you may have.

To take part in this study you should be aged 18 or over, have psoriatic arthritis and live in Australia or New Zealand. If you agree to participate in this study, you will not need to sign a Participant Consent Form. Consent will be implied by returning or completing the survey.

How much of my time will I need to give?
The survey should take no more than 20 minutes to complete.

What benefits will I, and/or the broader community, receive for participating?
There will be no clear benefit to you from your participation in this research. However, by finding out what is important to people with psoriatic arthritis related foot problems and the impact they have on daily life, health professionals will have a better understanding of how people with the disease are affected and better assessments and treatments can be developed in future studies.

Will the study involve any risk or discomfort for me? If so, what will be done to rectify it?
There are no risks anticipated with the completion of the survey. However, if you do not want to answer a question, then you will have the option to proceed to the next question. If you wish to stop completing the survey, then you have the option to discontinue at any time.

How do you intend to publish or disseminate the results?
It is anticipated that the results of this research project will be published and/or presented in a variety of forums including student theses, peer-reviewed journals and conference

presentations. In any publication and/or presentation, information will be provided in such a way that the participant cannot be identified.

Will the data and information that I have provided be disposed of?

Please be assured that only the researchers will have access to the raw data you provide. However, your data may be used in other related projects for an extended period of time. The related projects include all those about foot problems affecting people with inflammatory arthritis and these projects may be ongoing over the next 5 years.

The survey responses are anonymous and all data from the survey will be stored electronically on a secure server, which can only be accessed by the study investigators. If you wish to participate in future related studies you will have the option to provide your contact details, this information will be securely stored electronically but separately from the main survey data. Each participant will be allocated a unique identifying number under which all data will be recorded ensuring anonymity will be achieved during data analysis and any future publishing of results.

Can I withdraw from the study?

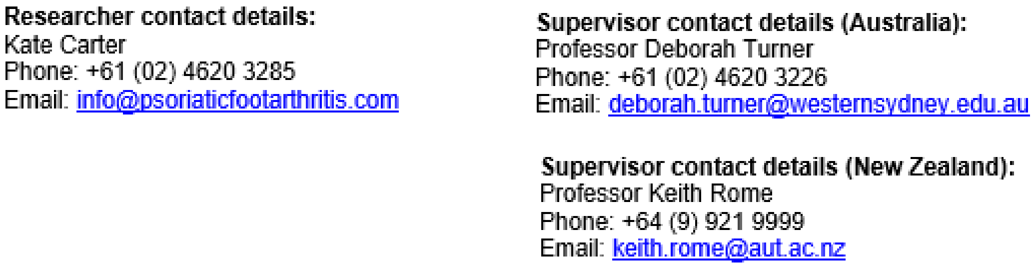
Participation is entirely voluntary and you are not obliged to be involved. If you do participate you can withdraw at any time by discontinuing your completion of the survey. If you do participate you will be unable to withdraw the information you have submitted. This is because the survey responses are anonymous, not including identifiable information, and therefore the research team will be unable to identify what responses were specifically given by you in order to remove them. Whatever your decision related to completion of the survey, it will not affect your medical treatment or your relationship with the medical staff or the organisation.

Can I tell other people about the study?

Yes, you can tell other people about the study by providing them with the researcher's contact details below. They can contact the researcher Kate Carter to discuss their participation in the research project and obtain the web-link for the survey or a paper-based information sheet and survey (with stamped addressed envelope).

What if I require further information?

Please contact Kate Carter should you wish to discuss the research further before deciding whether or not to participate.



Researcher contact details:
Kate Carter
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Email: info@psoriaticfootarthritis.com

Supervisor contact details (Australia):
Professor Deborah Turner
Phone: +61 (02) 4620 3226
Email: deborah.turner@westernsydney.edu.au

Supervisor contact details (New Zealand):
Professor Keith Rome
Phone: +64 (9) 921 9999
Email: keith.rome@aut.ac.nz

What if I have a complaint?

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through Research Engagement, Development and Innovation (REDI) on Tel +61 2 4736 0229 or email humanethics@westernsydney.edu.au.

Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome. The information sheet is for you to keep.This study has been approved by the Western Sydney University Human Research Ethics Committee. The Approval number is H12973.

Appendix 3: Supplementary data for qualitative study

Supplementary Data Tables. Perspectives of patients and health professionals on the experience of living with psoriatic arthritis-related foot problems: A qualitative investigation

Theme 1 – Foot and ankle structural and functional manifestations of psoriatic arthritis. Exemplars from the transcripts were identified to support each of the themes

Foot and ankle manifestations	Descriptions and exemplars
Foot pain	
Quality of pain	Foot pain descriptors included ‘sore’, ‘throbbing’, ‘sharp’, ‘burning’ and ‘aching’.
Severity of pain	Foot pain severity ranged from mild to ‘unbearable’ pain. Severe foot pain was described as ‘excruciating’, ‘phenomenal’, ‘through the roof’, ‘intense’, ‘killing me’, ‘a world of pain’, ‘makes you want to cry’, ‘massive’, ‘crawling on the floor with pain’, ‘extreme’, ‘the worst pain I have ever had’, ‘ridiculous’, ‘hurts like hell’ and ‘absolute agony’. Sites of involvement were at the forefoot, midfoot and rearfoot.
Walking with pain	Foot pain was likened to walking on ‘stones’, ‘pebbles’, ‘lumps’ ‘hot rocks’, ‘the bone’ and ‘it feels like every bone is crushed’.
Unpredictable and persistent nature of pain	“they are totally random” (S16), “there’s no rhyme nor reason” (S13 and S16), “it’s just such an unpredictable illness” (S06), “it never actually goes away, it’s always there” (S21), “it’s there all the time” (S17), “it’s underlying” (S02), “It’s been constant” (S10)
Difficulty with describing and localising foot pain	Difficulty with describing and localising foot pain appeared to be related to 1) participants being unable to distinguish between symptoms related to the joints or the skin, 2) the fluctuating nature of symptoms or 3) the lack of attention given to long-standing manifestations by patients; *“I can’t pin-point identify where the pain is coming from but the pain is there” (S10), “The joints ache but it’s hard to tell when you’ve got the um skin condition as well.” (S14), “It’s hard to say because it varies” (S02), “it’s just a part of me because I’ve had it for so long” (S14)*
Objectification of foot pain	Some participants described their pain as an entity with a separate existence or identity. The objectification of pain appeared to be a coping strategy by gaining control and creating a distinction between their body and the disease; *“it’s like this thing that just doesn’t shut itself off” (S02), “I live in my body but this is something that shouldn’t be there…I do feel like I’m disconnected from it” (S11)*

Other foot symptoms Swelling	Most participants reported swelling in the feet and ankles; “My ankles both of them were double to what they were, really ridiculous.” (S03). Swelling was worst in hot weather; “In summer I find like my foot is quite swollen, I think that is because of the heat.” (S09)
Stiffness	Stiffness was worst in the morning, after rest or in cold weather; “The stiffness is there” (S21), “I have to get up and move around because of the stiffness” (S04), “kind of stiff in the mornings” (S12)
Numbness	Some participants reported a loss of sensation in their feet. Although there were different distributions of numbness, it was mainly reported to affect the toes; *“I do get numbness in my feet…mainly my toes um tingling and numbness.” (S14)*
Cramp	Some participants reported sensations of cramp in the feet or lower legs at night, at rest and when walking; *‘cramping” (S02), “goes into a bit of spasm” (S20), “I get a bit of cramp in my toes” (S19)*
Fatigue	“By a few hours you’re really sort of starting to feel the fatigue in your feet and the pain is coming back” (S02), “My feet get tired very quickly” (S21)
Sensations relating to temperature	“I know cold definitely affects me now” (S16), “I can wake up with it ice cold” (S21), “my feet are quite cold, they feel cold most of the time” (S02), “my toes don’t hurt, like I can feel the heat in them but they’re not painful” (S11)
Deformity Toe deformity	Toe deformities included claw, hammer, bunion, subluxation, splayed toes, joint thickening and acro-osteolysis. Descriptors of toe deformity included ‘angular’, ‘crooked’, ‘curled over’, ‘buckled up’, ‘notches’, ‘the bone is really thick’ ‘disfiguring’, ‘disjointed’, ‘scrunched up’, ‘shrunk’, ‘twisted’, ‘seized up’, ‘can’t grip with my toes’, ‘movement has decreased’ and ‘can’t bend that joint’. Toe deformity was a commonly reported manifestation, the consequences of which were loss of movement and grip, and difficulty with walking and footwear.
Ankle deformity Midfoot deformity	Deformity at the ankle and midfoot was reported by 4 participants and related to tarso-metatarsal bony remodelling to the dorsal midfoot, acquired flat foot deformity, subluxation of the navicular and ankle joint arthritis with malalignment. Descriptors of ankle and midfoot deformity included ‘rolling over’, ‘prolapsed’, ‘curving in’, ‘that bit there sticking out’ and ‘they’re deformed’.
Skin and toenail changes Skin psoriasis	The main features of skin psoriasis on the feet included ‘soreness’, ‘itching’, ‘splitting’, ‘bleeding’, ‘dry’, ‘cracked’, ‘deep cuts’, ‘redness’ and ‘scaly skin’. The pain related to plantar skin psoriasis was described as like ‘walking on broken glass’ or ‘needles’. *“I can’t walk. It really stops me from functioning…at times I’ve been crawling on the ground to get from A to B until I went to the hospital” (S14), “The only thing that does stop me is breaks in the feet…yes it does stop you doing a lot of things” (S03)*
Corns and calluses	

Venous skin changes Ulcers and wounds	Callus and corns were described mainly at the plantar metatarsophalangeal joints and dorsal aspects of the toes and were associated with a lack of fatty-padding, pressure from footwear and alterations to their walking pattern; ‘thick skin’, ‘painful corn’. Venous skin changes such as telangiectasia, haemosiderosis, varicose eczema, varicose veins and venous ulcers were reported to affect the lower legs, ankles and dorsum of the feet; “*that’s the staining from the varicose veins” (S21)*
Toenail psoriasis Foot surgery	A few participants had experienced ulcerations and infections in their feet including cellulitis; “I have had an infection and um it took ages to clear up. I think it was that one [left 2nd proximal interphalangeal joint dorsal aspect] ...Shoes rub on the joint, it does blister and can get infected” (S19) Toenail psoriasis descriptors included ‘thick’, ‘hard’, ‘split’, ‘break off easily’, ‘lifts up’, ‘wave shaped’, ‘painful’, ‘psoriasis under the nail’, ‘thin’, ‘discoloured’ and ‘pitting’. When compared with fingernail psoriasis, equal proportions of participants felt that their fingernails (n=5) or toenails (n=5) were worse affected by psoriasis. Foot surgery had been performed in 3 participants including an ankle triple arthrodesis with surgical revisions, and tendon repairs of a tibialis posterior tendon tear and an Achilles tendon rupture.

Theme 2 – The impact of foot problems on the lives of people with psoriatic arthritis. Exemplars from the transcripts were identified to support each of the themes

Impact areas	Descriptions and exemplars
Body image	Male and female participants commonly felt their feet were ‘not normal’, ‘revolting’, ‘horrible’, ‘ugly’, ‘awful’ and ‘hideous’.
Skin and toenail change Foot shape change Walking change	The manifestations of psoriatic arthritis including skin and toenail psoriasis, swelling and deformity were disliked by participants due to being visibly different to others; “*I hate the way they look” (S11), “tree stumps for legs” (S02), “everybody’s eyes goes there.” (S01), “they look like little claws to me.” (S11), “they’ve actually got fatter or wider” (S03), “aesthetically it’s like always trying to cover what that front of the foot looks like” (S05)*
Footwear and clothes restrictions Body weight	“I feel a bit embarrassed to walk alongside with my family members because I mean, I used to be limping.” (S10); “I’ll be limping around right and people will be asking me ‘what’s wrong with your feet?’…It doesn’t feel good” (S07) “you can’t really dress to look good” (S06), “I can’t wear open shoes” (S18), “I think that’s probably more acute for woman” (F05 –rheumatologist) “wearing trousers…so I cover up the legs” (S19)

Strategies to hide the appearance of foot problems	Increased body weight attributed to foot pain that affected their ability to walk was associated with negative comments about body image; *“Now look at me - big fat heap” (S04), “because of this (plantar skin psoriasis) and the arthritis you put a lot of weight on… Like with my ankle now I can’t exercise” (S14), “the vicious cycle” (F06 - rheumatologist)* “I don't do much for the simple fact I get embarrassed” (S14), “I’m always wearing a closed-in shoe” (S18), “I don’t want to draw attention to the feet” (S19). Participants worried about people’s perceptions that they might have an underlying medical conditions; “I don’t want to be noticeable with these things” (S20), “they don’t want to look outwardly disabled” (F06 – rheumatologist)
Functional limitations	Participants described experiencing foot pain and stiffness in the mornings or after periods of inactivity such as sitting; “when I get out of bed um it’s extremely painful” (S17), “you’ll get up out of a chair and you’ll walk and you get this excruciating pain” (S16)
Difficulty sitting and standing	Standing for longer than 5 to 20 minutes for some participants aggravated their foot symptoms. All participants who reported difficulty standing had rearfoot problems such as ankle arthritis, ankle tendinopathy, plantar fasciitis or plantar skin psoriasis. Participants reported standing and waiting for the pain to ease before initiating gait, weight bearing carefully to start, feet not working properly and taking a while to get going. Other participants reported that foot pain intensified with sitting and after periods of activity; *“if I sit down that’s when my feet start to hurt” (S11).* Participants reported shifting weight from one foot to the other and having to either keep moving or sit down. *“if I stand I sort of lift my foot up” (S09)*
Difficulty walking and running	“Well when its bad you just can’t walk” (S03), “The most troublesome thing at the moment is just not being able to walk at a normal speed” (S12), “the longer I walk the more pain I get” (S04), “I am quite conscious that I can’t help but limp” (S20), “you can’t walk, you can’t run, you can’t do anything you want to do” (S21)
Difficulty with stairs	Participants felt they had to take one step at a time, they had to pace themselves and be careful due to pain and unsteadiness. “*I avoided climbing up and down stairs” (S10), “just hold onto the rails and walk slower” (S14)*
Instability and falls	Foot pain affected foot stability for some participants who felt ‘unsteady (S09, S17)’ or ‘unstable (S16)’ on their feet or that they had a loss of ‘balance (S03, S19, S21)’ in their feet. Plantar skin psoriasis, numbness, a sudden flare of foot psoriatic arthritis and loss of foot strength were also attributed to sensations of foot instability. One participant used a walking stick because of foot problems (S17), but 2 participants refused to use a walking aid not wanting to look older than their years. Five participants reported falling with a subsequent fear of falling that limited walking activity.

Daily activity limitations Daily routine	The majority of participants expressed how functional limitations meant that they could not do what they wanted to do in daily life and how it was ‘debilitating (S17)’, ‘interferes with life (S20)’, ‘makes life difficult (S16)’ and ‘life is ruined (S01)’. *“I have to change my life around…I can’t do a quarter of the stuff I used to do” (S04)*
Driving	Driving was reported to be difficult because of foot pain for some participants, but for others the main problem was the worsening of foot pain and stiffness after driving due to prolonged sitting; *“while driving is fine, it’s just after getting out of the car” (S07)*
Sleep	Sleep functions were affected by foot pain for a few participants relating to sleep interruptions and difficulty falling asleep on some or most nights. For some, the bed sheets caused foot pain by putting pressure on painful toes or catching on split toenails, and for others foot soreness, throbbing, cramp, plantar skin psoriasis caused sleep loss. Participants described positioning feet carefully in bed or taking pain medication to facilitate sleep. Feelings of stress and irritability were a result of sleep loss; *“I’ve learnt how to sleep without too much discomfort. But as I said the feet cannot even touch each other because it hurts” (S13), “I don’t sleep properly and that puts stress on me” (S08)*
Self-care ability	Difficulty with self-care was related to thick psoriatic toenails being difficult to cut and toe deformities that require the ability to reach further; “*I can’t cut my toenails…they’re quite thick now and because the toes are turned over” (S06), “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” (S19)*
Affective and cognitive elements	“it makes me feel that I’m useless” (S10), “that can be embarrassing if you’re shopping…all of sudden you look down and there’s blood and you think no!” (S03), “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.” (S09). For some, there was a strong sense of ‘losing control’ and “a snow-balling kind of effect” (S02)
Social participation restrictions Loss of social activities and leisure time	*“my social life was ruined” (S10)*. Many participants felt unable to engage in social activities that required weight bearing and non-weight bearing for any length of time. For example, participants were unable to walk barefoot on the beach due to foot pain or the surgical boot, they were concerned about walking much slower than other people, taking too long to climb or descend stairs, being unable to dance at a wedding and with having difficulty sitting for too long in the car or at the cinema; *“Oh very painful yep. And I can’t really go out with friends much. I really just stay at home yeah” (S07)* Leisure activities were important in the context of social participation and restrictions included walking for pleasure, hiking, fishing and dance classes. Loss of sports activities included the gym, Pilates, swimming, aqua-aerobics, golf, Tai Chi, a marathon and playing soccer due to weight bearing difficulties and being unable to run; “*But you know like*

	always I used to be (at the) gym, I used to play soccer, a lot of things like, I always used to be fit and active… But now everything is stopping me. Yeah I feel lazy." (S01)
Lack of understanding about the disease	"other people just don't realise they go 'Oh yeah get over it' you know, they don't understand how it does affect your life with getting up, walking, just simple things." (S14)
Footwear restrictions	The social stigma of having skin and toenail psoriasis, toe deformity, walking differently and footwear restrictions were mentioned as reasons for limiting social participation. *"I don't like to go out because I hate wearing, I can't wear some sort of shoes. And so I don't really want to go out.... It's like affected a little bit of my life but like I just have to try and just move on you know." (S09)*
Affective and cognitive elements	Weddings were frequently cited by participants and health professionals as a source of significant distress due to footwear restrictions as well as the expectation of dancing and prolonged standing; *"if I go to a wedding...I can't wear thong…I just go there and sit down there, I don't do much. Don't do dancing" (S01), "it's just a nightmare for them" (F04 – rheumatologist)* "if I was in pain I would still force myself to participate" (S02) Exercise was considered a valued activity by some participants for the benefits of improved health and psychological well-being; *"I want to walk because I want to stay active and fit you know. I don't want to be you know housebound." (S06).* The harbouring of shame and judgement was expressed through their reluctance to attend social occasions.
Fear of foot injury	Fear of foot injury caused by themselves, others or environmental factors; *"I've constantly got a fear of somebody um stepping on my feet." (S05), "I'm absolutely petrified. It drives me nuts." (S13).* All participants who had a fear of foot injury described extreme levels of pain in relation to any type of physical trauma sustained to the foot; 'unbelievably painful' (S11), 'really painful' (S20). Injuries to the feet and hands playing sports in younger life were also described by some participants as a perceived cause of disease onset in later life; "*I put that down to sporting injuries the same as my hands" (S13)*
Family life Loss of family activities	Walking disability interfered with planning and going on holiday with the spouse and family members for 3 participants; "last year we went to India you know, it was a dream trip of a lifetime trip, I could not walk... the pain was very bad" (S10)
Difficulty parenting	For those participants with children, the impact on their ability to be a parent was a key concern. Participants referred to missing out on time with their children, having difficulties playing with and looking after the children and being unable to drive the children to the park. *"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." (S11). The selfless nature of being a parent served as a coping strategy for a few women, who focused their attention on their children and away from their foot pain and disease.
	Fear for the future was also associated with being worried about their children inheriting the disease, which was described by participants and by the health professionals; "*it will limit my mobility, that's more of a concern than the pain really. Or it's more kind of …upsetting or frightening I guess (S12 – having newborn baby)*
	The proactive choice not to engage in an intimate relationship and not to have children (to spare them the possibility of inheriting the disease) was reported by one female participant (S05).
Lack of understanding about the disease	Participants avoided talking about their foot pain and condition because of a perceived lack of understanding about the disease by close family members; "*you get sick and tired of justifying why you're not getting better" (S16)*
Family members with IA	Having family members with IA conditions served as a point of comparison in terms of symptom severity and disease course, which appeared to have a positive influence on coping skills such as stoic attributes, acceptance and motivation; *"my son has got skin psoriasis, he was covered in it and his nails are in a worse state than mine." (S19), "my whole family like my mum, my dad, my brothers and sisters, I am the youngest in the family and they are all nice and healthy, and I am the only one that got sick, and they're all worried why this thing happened." (S01)*
Family support	Family support included assistance with self-care (toenail and skin care, foot massage, taking shoes/socks on and off), allowing the participant time to rest, doing the shopping, and providing financial security. Talking with their spouse and close family members about their psoriatic arthritis-related foot problems and gaining their understanding was important for some participants; *"thankfully my wife and my son they're quite understanding. They understood the problem and they helped me a lot." (S10)*
Affective and cognitive elements	Emotions relating to family activities restrictions included sadness, helplessness, worry, frustration, depression and low self-worth; "*sometimes I feel bad for everything, like I'm a disappointment to my wife." (S01), "It's sad…I was very much depressed" (S10)*
	Some participants described trying to hide their foot pain and emotions from family members to prevent overburdening them; "But I like to hide my pain. I do not like to show my pain to others. I take my pain myself… I do not like to disturb my wife." (S01)
	Participants reported how family gatherings and going out with their spouse to a restaurant or social event had interfered with existing coping strategies such as pacing and planning and pain avoidance behaviour; "*it's ridiculous that you have to plan for your feet and shoes." (S11)*

Work life High levels of unemployment	Thirteen of the twenty-one participants had either retired or ceased working due to PsA. The impact of foot problems on the ability to work were in relation to the nature of the occupation such as having to sit, stand, walk and use stairs or ladders; *“I quit my job...because it’s mostly you have to stand…get on the ladder…physically get down on the floor…It’s very physical.” (S07 – with Achilles tendinopathy and plantar fasciitis).* Some of the health professionals reported that their patients who were manual labourers, drove for a living or worked in the retail industry were affected the most by foot problems at work; *“I was working in a factory…the whole day standing. So that's how it got worse you know.” (S01)*
Difficult to perform work activities	“I have to go between sitting and standing…it impacts the way I facilitate.” (S05), “if you’re sitting at the desk your whole body starts ceasing up…the feet also play up the same as the rest of the body” (S16), “mainly sitting at a desk um there really hasn't been any work impacts” (S12), “it’s racing between the different locations” (S05)
Lack of understanding about the disease	Whilst it was considered that some employers were willing to make workplace adaptations to enable individuals at work, most felt that employers were unsympathetic and lacked understanding about their disease, and thus failed to make work-related changes; *“There’s just no recognition, understanding or acceptance at all of doing even minor things to modify their workplace environment to keep them at work.” (F04 – rheumatologist)* The consequence of that being that 6 participants had to leave the workplace entirely or try to find a less physically demanding job with skills that may not be transferable. Modifications requested but denied included regular breaks, more time in the office and a chair for sitting.
Experiences with work footwear	Of the participants who were unemployed, they talked about a perceived lack of understanding by disability employment services and difficulty finding suitable employment; *“they are pushing me hard to like go and find a job. I like to work. I love to work…they see me like this they think I am healthy, but the pain is there” (S01)* Being unable to wear job-related footwear was also cited as a cause of potential job loss by one of the rheumatologists working in a public hospital in a lower socioeconomic area of Sydney Australia; *“I know one patient…he was going to lose his job if he couldn’t wear the steel capped boots.” (F05 - rheumatologist)* For female participants, they experienced difficulty with or finding suitable footwear for work pertaining to comfort, fit and support; *“I really have to watch what shoes I wear” (S09)* Female participants were also generally dissatisfied with footwear provision services due to limited choice of styles for work; *“they’re not great looking shoes…how many you know suit pants am I going to be able to wear that to work with.” (S11 – female).*

Affective and cognitive elements	Men and women who need to present a business-like, professional or a fashionable look were mentioned by health professionals as having difficulties with work footwear aesthetics; *“supportive footwear may not have the appearance that that individual wants for certain things like their work role” (F02 – rheumatologist)* One participants expressed relief in finding a comfortable shoe provided by an orthopaedic service in Auckland New Zealand, which enabled her to continue working in her retail job; *“...getting shoes that are comfortable…that made a huge difference because I was in a job that was standing all day…” (S19 – therapeutic shoe)* Feelings of stress, helplessness, low self-worth and frustration were also alluded to; *“I don’t know what to do” (S01).* Fear of discrimination and fear of future inability to work were identified. Stress related to inconvenient medical appointments during working hours, taking sick leave, loss of independence and financial insecurity were reported. Coping with work involved strategies such as pushing yourself, pacing and planning and desire to maintain independence; “I don’t try to let it, like I still have to go to work and 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 to go and do it. So yeah that’s a bit hard but I manage” (S09) For 2 participants the non-disclosure of their disease and foot functional limitations to work colleagues and managers was of personal importance; *“you try to keep everything a secret especially people that you worked with. Because you know you don’t want to be discriminated against” (S05), “I don’t tell anyone at work like it’s really sort of gossipy…and I just don’t want to be a part of that” (S11)*

Theme 3 – Mediating factors that influenced the severity of impact from foot problems on the lives of people with psoriatic arthritis. Exemplars from the transcripts were identified to support each of the themes

Mediating factors	Description and exemplars
Demographic characteristics Age	Younger age groups were identified as experiencing a greater severity of impact from foot involvement on altered body image and limitations to daily activities, social and work life. Pre-existing lifestyle changes related to increasing age was considered to reduce disease impact; “*Some of the hardest ones I’ve had to treat are the younger ones.” (F16 – rheumatologist)*
Gender	Females experienced a greater severity of impact from foot problems on their body image and ability to find suitable footwear for work and social occasions compared with men; *“for women it’s important” (F09 – rheumatologist), “especially females who like shoes, it’s a big psychological problem for them.” (F16 – rheumatologist)*
Ethnicity	

Socioeconomic status	Polynesian ethnicities such as Mauri and Pacific Islander people were reported by the health professionals in Auckland New Zealand as tending to have more comorbidities and being more likely to have poor medication compliance and disease activity control. This appeared to reflect the nature of marginalised populations, vulnerable groups and cultural traits; *“the comorbidities particularly diabetes with the Polynesians is quite big” (F12 – rheumatologist)* Bigger sized feet in this ethnic group was also reported to cause a greater impact on footwear restrictions; “Steel capped boots for particularly Pacific Islanders that have big feet to start with…it is very difficult” (F12 – rheumatologist) Having a lower socioeconomic status was associated with delayed access to health care, more comorbidities and fewer resources (for example health insurance, income and available monies), which resulted in a greater difficulty with foot disease management and a greater severity of impact from foot involvement in psoriatic arthritis; *“When I think about the ones that I’ve struggled with…I think they’re probably lower socioeconomic on average” (F16 –rheumatologist).* Diagnostic delay of foot problems was reported by a rheumatologist working in both the public and private sector in Sydney Australia to be a consequence of lower socioeconomic status.
Disease characteristics Disease duration	Disease characteristics such as late diagnosis, longer disease duration, an unpredictable disease course and additional morbidity were reported by health professionals to lead to a greater severity of impact on foot problems related to psoriatic arthritis. An earlier diagnosis was described by health professionals as resulting in positive disease outcomes; *“I think earlier in the disease it’s a little bit clearer the inflammatory aspects” (F06 – rheumatologist), “in general we’re all better at treating and managing these problems if you get the patient early enough hopefully” (F14- rheumatologist)* People with psoriatic arthritis receiving an earlier diagnosis were more likely to be those attending a private rheumatology practice, to have a higher socioeconomic status and acute inflammatory foot involvement. Whilst having a longer disease duration was related to more complex and established foot disease, it was also associated with positive coping strategies reported by participants and health professionals such as a greater degree of acceptance and adaptation; *“I’m at the point now where I wouldn’t mind. In the past I wouldn’t have done it [wear open-shoes with toenail psoriasis].” (S02)*
Disease activity and course	Health professionals reported that disease course variability was a distinct feature of psoriatic arthritis and made it a difficult disease to manage; *“…Whereas if you had rheumatoid arthritis with the equivalent problem you either would be able to play soccer or you wouldn’t be able to play soccer and you would adjust to it.” (F13 – rheumatologist)* Having to contend with the volatility and constancy of foot symptoms as part of an unpredictable disease course was reported by participants to have a detrimental effect on their ability to cope and on their emotional well-being*; “they come and go, that is the annoying part of the whole thing. If it was constant all the time I think it would be more easy to get your head around it” (S13)*

Importance and severity of foot problems	"And I think too I've learnt ways around using the hands um whereas the foot I haven't yet and I'm not sure what to do because you need your feet to get around" (S20), "the Achilles tendons they're tender nearly all the time…that worries the hell out of me" (S13), "It is very important…when the pain is there I am just locked…I can't drive, can't walk, that's the worst thing." (S01), "Everything else I can deal with. But it's the psoriasis, so the psoriasis can be quite debilitating. So I can, if I had to trade one off for the other I'd take the sore feet and let go of the psoriasis" (S05), "it's not something that you look at every day in the sense of – you know I've got my hands right … they're in my face basically, I see them all the time, but my feet are in my shoes and you know they're sort of down there and you know – you don't really look at them so you kind of forget about them" (S02)
Lack of understanding about the disease and foot problems by patients	Some participants revealed a lack of knowledge about their foot problems associated with psoriatic arthritis; "but that [metatarsalgia] of course has got nothing to do with the psoriatic arthritis or I don't know if it does or not. I don't know" (S03), "I didn't realise that this [skin psoriasis] could affect that [Achilles tendon] you know" (S13), "No I mean I'd never heard of psoriatic arthritis…I had no idea that could be where I was going with psoriasis" (S11) A lack of understanding and awareness about the disease led to diagnostic delays for some participants; "I didn't even know I had arthritis in my feet…when I first started having foot problems, which was in my early 20's, it didn't even dawn on me that I should go and see a doctor…the pain was just so ridiculous…I don't even know why I didn't pursue it" (S02) Non-disclosure of foot problems by patients to the rheumatologists due to a lack of understanding about foot involvement led to symptoms being tolerated until they become a lot worse; "*it started happening about half way through last year. Yeah. Well I didn't know, I just thought 'Oh it's the arthritis' and it kept getting worse so I told [my rheumatologist] towards the end of last year and she sent me for a scan" (S014 – torn peroneal tendon)* A few participants felt that education about their foot condition and how to maintain foot health was very important and one participant suggested that too much information could be detrimental; *"I think education is huge, huge really is" (S21), "I try to do as much research as I can and look after myself as much as I can so" (S05), "I don't know whether it's better to read information or better to live in the dark sometimes" (S11), "They feel happier to understand what the problem is a bit better…I think that's very powerful, um just the education about it [foot involvement]" (F14 – rheumatologist)*
Experiences with health care services	Positive experiences with health care services, providers and interventions; "You know it's like I've had the best care, the best doctors, the best nurses looking after me" (S05), "on the Remicade I started to notice a lessening in the pain in the feet, hands, everywhere…the psoriasis basically fell off me within the first 6 weeks it was gone or not gone like…so yes I cannot thank the doctors enough." (S13), "after the new insertion [foot orthotic] it has just sort of improved so much that I

mean I just can't stop talking about it" (S10), "it's been wonderful…I wasn't going to the rheumatologist until…one of the [podiatrists] suggested that I go" (S03)

Negative experiences with health care services and suboptimal foot disease management.

Over one third of participants (n=8) reported a delay to receiving a diagnosis of PsA, of which over half (n=5) presented at onset with foot problems including plantar skin psoriasis (S14), metatarsophalangeal joint synovitis (S19), ankle joint synovitis (S02), tibialis posterior tendinopathy (S12), plantar fasciitis (S07) and Achilles enthesitis (S07, S19). Diagnostic delays in those presenting at onset with foot problems were reportedly due to either 1) participants ignoring foot symptoms due to a lack of awareness about the disease and the connection between skin psoriasis and musculoskeletal symptoms (S02, S14, S19), or 2) health professionals treating it as a non-inflammatory musculoskeletal condition (S07, S12). Overall there was a strong sense of resentment regarding diagnostic delay, with one participant recognising the detrimental consequences to the severity and extent of his joint-related disability (S13).

Diagnostic delay; "It's harder to diagnose psoriatic arthritis… GPs don't think about it…I think the bottleneck is the referring point" (F17 – rheumatologist), "I was treating it as a normal Achilles tendinitis and plantar fasciitis" (S07), "I think one of the difficulties that I've had is just finding specialists who um have seen my particular um problems or something like them." (S12), "people who have psoriasis, nail disease, scalp disease, are not warned that they should be looking out for [psoriatic arthritis] …but the vast majority of people have never been told that." (F14 - rheumatologist)

Non-disclosure of foot problems to rheumatologists by patients; "The other thing about the foot pain is that people often, I think, don't complain of it because we don't specifically ask about it." (F04 – rheumatologist), "not being able to walk on your feet was part of the auto-immune…I thought it was normal" (S18), "it's just something that I tolerate and I just put up with it…like how much help can I truly get? ...can anything be done?" (S02), "it [the foot problem] doesn't seem to be as debilitating as the you know, the pain in the shoulder" (S16)

Lack of foot examination during rheumatology consultations; "I look at what people complain about. If they don't complain about their feet, I don't look at them" (F13 – rheumatologist), "you've got 200 things to cover in the visit" (F04 – rheumatologist).

Nearly all the rheumatologist agreed that they would not routinely ask about or assess the feet unless the patient reported having foot and ankle symptoms. This combined with the non-disclosure of foot problems by patients to the rheumatologists suggests that opportunities for diagnosing foot involvement and referring to podiatry services are being missed.

Lack of understanding about the disease and foot problems by health professionals	Challenges related to foot examination; "…they can be really hard to examine" (F04 - rheumatologist). Challenges related to foot management; "their biologic agent has actually helped all the rest of them, but it's done nothing much for their feet" (F04 – rheumatologist), "My hardest people with foot problems is usually psoriatic not rheumatoid" (F16 – rheumatologist), "what is the standard of care we should provide for people with inflammatory arthritis…what does the literature say?" (F05 – rheumatologist), "I also acknowledge that it's just a um you know it's a difficult condition to treat and assess so um yeah I understand there's just not that many resources available" (S12) Multiple comments from the health professionals suggested that active foot disease persisted in many cases despite achieving tight control of the disease with pharmacological treatment. Minimal improvements from pharmacological management triggered feelings of uncertainty and frustration. Lack of access to podiatry services; "We don't have a podiatry service" (F13 – rheumatologist –New Zealand), "there is a huge need in the public system…you need this interdisciplinary approach" (F08 – podiatrist). The unknown cause of foot pain and lack of access to podiatry services reinforced the reluctance to examine the feet to the extent where a position of non-progression was reached between the rheumatologist and patient due to the persistence of foot symptoms; *"you don't examine them because you and the patient kind of become co-dependent about how bad their feet are! And you don't do anything about it." (F04 - rheumatologist)* Barriers preventing uptake of podiatry services by people with PsA were 1) lack of podiatry service provision in the public health system, 2) lack of referral by their GP or rheumatologist, 3) lack of understanding of the role of podiatry with the perception that no further care options were available, 4) low priority given to foot problems, 5) low expectations of non-pharmacological therapy effectiveness, 6) dissatisfaction with previous podiatry care received and 7) financial constraints; *"my thoughts of podiatry was more um you know err just clipping nails…not thinking about insoles or correcting the posture or anything like that (S02), "I would have thought I'd get more benefit out of having another immunosuppressant" (S02)* A lack of podiatrists with specialist interest, training and knowledge in inflammatory was identified; *"I may as well have gone and paid 20 bucks to get my toes painted" (S11)* The high cost of podiatry care also contributed to unfulfilled expectations from expensive but ineffective treatments; "Private podiatrists can be very expensive, $600 not uncommon (F17 – rheumatologist) …and they're still not better" (F16 - rheumatologist) Lack of understanding about the disease; "when it first started the pain was in the pads of my feet and up the back of my heels...it was quite a severe pain and of course my doctor really didn't seem to know anything much about it" (S19),

	“Unless you see a proper skin doctor, doctors do not understand” (S14), “I’ve asked other podiatrists what that could be and they haven’t been able to give me an answer on it either” (S03), “I think most don’t actually bring up those fears in their routine consultation” (F14 – rheumatologist), “I think as clinicians we just concentrate on trying to get the disease in remission but we sort of don’t realise how much that has an impact on their quality of life” (F09 – rheumatologist) This was reinforced by receiving conflicting information from health professionals about their condition, which led to confusion and a loss of confidence in the quality of their health care; *“Very conflicting! ...What one person says another person will contradict it 10 times over…Does anyone know? …that’s frustrating too” (S03),*
Social support	Whilst lack of social support increased physical and emotional burden, supportive relationships with family, friends, employers and health professionals had a positive impact on functioning, participation, self-care strategies, personal finances and emotional well-being; *“Yeah like I have heaps of support.” (S09)* A few participants found it easier to confide in people with psoriatic arthritis; “it’s just hard to talk to anyone about it, like I said I must say um if they’ve got it themselves they understand” (S14)
Self-management strategies	Coping strategies included stoicism, adaptation, gaining control, endurance, hope, learning, pacing and planning, adjusting expectations, comparison, setting goals, self-tolerance, attuning to the body, acceptance and detachment. Feelings relating to the impact of foot involvement included bad temper, fear, depression, embarrassment, envy, frustration, helplessness, stress, uncertainty and low self-worth. Self-care included massage, pedicure, gel insoles, use of a pumice stone and hot or cold foot baths, with a trial and error approach. Those with plantar skin psoriasis were amongst the most experimental, having reportedly tried a wide range of moisturising ointments, washes, creams and lotions. The most commonly reported self-care activities for foot pain was to take pain medication, to rest or to keep moving. Self-care strategies; *“I’ve got them shoes for wearing around at day time – they are the best thing that happened to me [sketcher slip-on shoes]. They’re great.” (S04), “I lost about 12 kilos and the relief in my feet was great.” (S11).* Although there was some knowledge about the increased risk of infection related to their medication, a small number of participants undertook self-care that could be considered inappropriate; *“I’ve got an oversized pair of wire cutters believe it or not” (S13), “you name it I’ve tried it…I’ve you know, I’ve tried weeing on it because someone said that helps with the urea, that didn’t help that only stung like anything” (S03), “I tried them massage thongs and that but they’re too bad, you know the ones with the long spikes on them, but they go right through me bones and everything” (S08)*
Experiences with footwear	Important footwear features that provided comfort and accommodation for foot and ankle manifestations of psoriatic arthritis included ‘adjustable straps’, ‘wide fitting’, ‘flat heel’, ‘flexible heel’ counter, ‘room for toes’, ‘leather lining’ or

Important features and commonly worn footwear	upper, ‘light weight’, easy to get on/off, ‘soft’ and ‘stretchable’ materials, ‘supportive’, ‘thick cushioning sole’ and with arch support or room for an insole; “*the fact that you can adjust the width to suit.” (S19)* Commonly worn footwear by the participants included Sketchers (slip-on and lace-up), slippers (indoors), thongs, Ugg boots, walking shoes (sneakers and sports shoes), therapeutic sandals, a surgical boot, sandals, contoured thongs and contoured sandals*; “if I go out anywhere, I pretty well wear sketchers” (S15), “I wear sketchers and those sandals…but that’s all I can wear.” (S17)* Whilst all 3 participants in Auckland New Zealand made reference to contoured sandals, one participant of 18 in Sydney Australia used a contoured sandal; “*an orthotic type shoe” (S20), “they’re Ziera… because they do have a slight arch support…they’re wide and they’re comfortable and usually they’re leather and they’ve got more give (S21)”*
Enabling factors and difficulties with footwear	Enabling factors; “I am very happy with the shoes I have with the inserts (sports shoes with insole) …it’s very helpful… I’m quite happy the pain has sort of improved by about 75 to 80%” (S10), “I kind of get paranoid in having an open-toed shoe… there’s more risk of damage to your feet…so I just always go to the sneakers” (S02) Difficulties; “I just find it hard to wear different shoes” (S09), “I’m very limited in the type of shoes, they all have to be soft and it makes it difficult.” (S05), “I’ve tried a lot of shoes…they’re about the only ones I can wear” (S13 – male participant), “I can’t really wear any shoes that I can’t put my orthotic in and that kind of really limits you” (S06), “I can’t wear normal shoes.” (S21), “wherever I go its just sneakers… you’d like to be able to um have something that’s a bit different.” (S02) Sensations of pressure and tightness exacerbated foot symptoms; “tight shoe – no good” (S04), “they [toes] are twisted upward now, the impact that that has rubbing in my shoes makes it very very hard to find shoes” (S05). Difficulties also included not being able to reach to tie laces or to take shoes on and off; “I need help getting them on at the back” (S04) Participants reported needing to wear a shoe one size bigger than their actual foot size to improve comfort; “my foot’s got bigger…it’s really hard to get a shoe on my foot that’s the main, it’s not the length it’s the width” (S14) One participant reported that wearing a thong one size too big caused her to fall outside twice; “taking the next size gave more toe room…it was the shoes both times that caused the fall” (S21)
Female footwear shame	Some participants reported having multiple pairs of the same shoe or prolonged use of a comfortable shoe. A few female participants reported having multiple pairs of shoes at home in their cupboards that remain unworn due to foot pain and altered foot shape; “*I have a whole cupboard full of designer shoes that I can’t touch” (S21), “I have a massive shoe collection…that I can’t wear” (S11), “I’ve got about 8 pairs of Merrells now” (S20)*

Activity limitation Affective and cognitive elements	Female participants reported being unable to wear nice looking shoes, high-heeled shoes or shoes appropriate for the occasion, which also limited clothes choice; *“Women are very vocal about not being about to wear high heeled shoes.” (F06 – rheumatologist), “They still want to conform to those social norms.” (F02 - rheumatologist), “shoes are the biggest problem for me” (S11)* Female participants expressed dissatisfaction with footwear provision services, the high cost of footwear and the design of supportive footwear ranges; *“People don't design shoes properly” (S21), “apart from being expensive to buy footwear…I bought some…can’t fit my foot in it” (S02), “Even some of the sports shops fit you with shoes and you go home and they hurt you even more than ever.” (S21)* “By the end of the night I’m limping around like an old man of a hundred” (S04), “if I have to wear different footwear like then I go ‘oh nah’ I can’t go there coz I haven’t got those shoes” (S09), “you can’t go in sandals in an evening dress…so I just don't go.” (S21) “Like if I go to a wedding, funeral, club or anything I dread it! I’ve got to put socks and shoes on.” (S04), “the sizing is really frustrating” (S02), “not being able to wear my shoes and that sort of stuff really annoys me.” (S11), “it’s embarrassing” (S18)
Climate Foot symptoms Climate influencing footwear choice	More participants reported difficulties with footwear and foot symptoms worsening in warm/summer weather (n=7) due to hot feet, sweating and swelling; fewer reported worsening in cold/winter weather (n=5) due to cold feet, joint pain and enclosed shoes; *“I think sometimes the weather has something to do with it. I wonder sometimes those really humid days” (S17), “in summer I find like my foot is quite swollen, I think that is because of the heat. Um winter is fine” (S09), “it’s worse in summer” (S11), “the arthritis is more active in your feet because of the winter because of the cold” (S14)* Climate was reported by two thirds of participants (n=14) to have a minimal influence on footwear choice with the same style of shoe being worn all year round regardless of the season. Thongs, walking shoes (including sneakers and sports shoes) and sandals (including a therapeutic sandal) were worn in both summer and winter seasons by most participants; *“Jangles all year round!” (F12 – rheumatologist in New Zealand).* Some participants expressed a general preference to wear socks, slippers and closed-in shoes (including Ugg boots) in the winter and to be barefoot or in open shoes (thongs and sandals) during the summer. A few participants experienced difficulty wearing closed-in shoes in the summer from swelling and feet becoming too hot and conversely open shoes in summer hindered the ability to hide visible foot problems; *“I struggle to get my shoes on in summer” (S11 - Australia)*

Appendix 4: Conference abstracts

EULAR 2019 Abstract 1

Category: (b) Health Professional in Rheumatology/Practice and Research.
Sub-category: Clinical topics by disease (21) Psoriatic arthritis.

PATIENT AND CLINICIAN PERSPECTIVES USED FOR SURVEY DEVELOPMENT TO INVESTIGATE THE NATURE, EXTENT AND IMPACT OF FOOT PROBLEMS IN PEOPLE WITH PSORIATIC ARTHRITIS

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Background: Despite recognition that hallmark features of psoriatic arthritis (PsA), such as enthesitis, are predominant and persistent in the foot and ankle [1], limited research has focused on the foot. Few published studies have used RA-specific outcome measures unlikely to capture the dermatological impact in PsA and there has been little incorporation of the patient perspective [1]. The importance of patient and clinician involvement as a central component of research design has been identified in PsA [2, 3], and provides a basis for defining what should be measured to represent comprehensively the experience of people with PsA-related foot problems and important domains of impact.

Objectives: To develop a survey based on the views of people with PsA and clinicians on foot problems, their impact and the foot care needs.

Methods: Interviews of people with PsA-related foot problems and focus groups with clinicians on their understanding of the patient experience were undertaken in Sydney, Australia and Auckland, New Zealand. A representative sample from public and private sector, from lower and higher socioeconomic geographical areas, as well as clinicians with different professional backgrounds was sought. Based on the themes from the qualitative interviews, previous research [1, 3] and clinical experience, survey items were generated by the research team using a consensus based approach. The survey was pre-tested using a 4-stage method that comprised; cognitive de-briefing of people with PsA, expert review panels of subject and survey design experts, cultural sensitivity assessment and pilot testing. All focus groups and interviews were audio-record, transcribed verbatim and survey items were revised based on comments made.

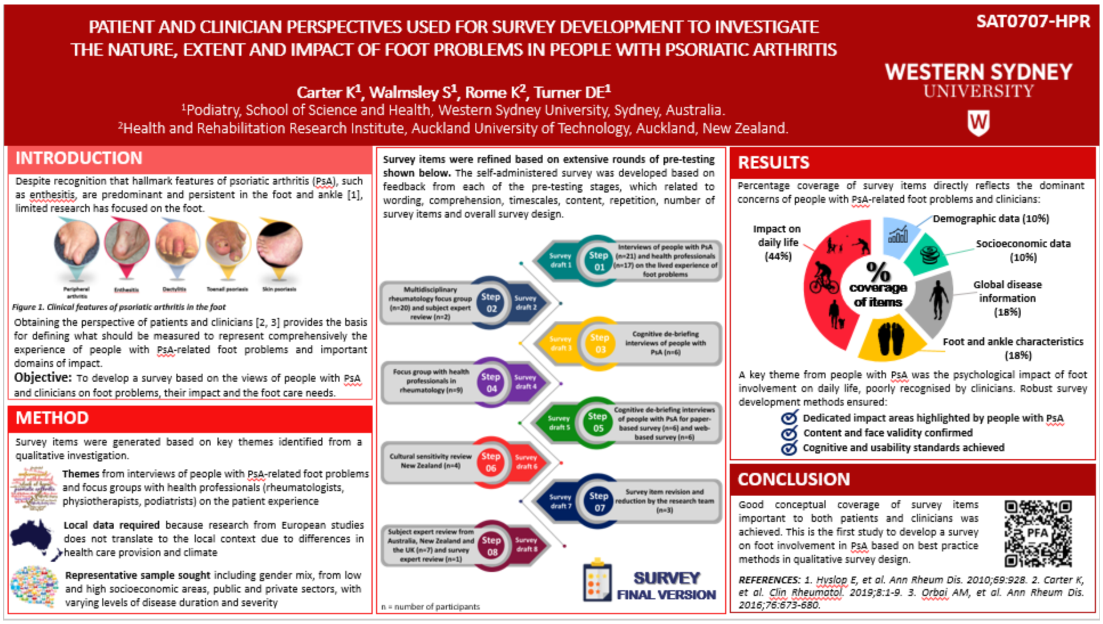
Results: The final 60-item self-administered survey was developed based on feedback from each of the 4-stages, which related to wording, comprehension, timescales, content, repetition, number of survey items and overall survey design. Key survey domains included demographic (10%) and socioeconomic data (10%), global disease information (18%), foot and ankle characteristics (18%), and the impact of foot problems on daily life including daily routine, footwear choice, family life, work and accessing health care (44%). Percentage coverage of items directly reflects the dominant concerns of people with PsA-related foot problems and clinicians. Whilst priorities for clinicians included the diverse expression of disease and determining the nature of foot symptoms as mechanical or inflammatory, a key theme from patients was the psychological impact of foot involvement on daily life coupled with self-management strategies (coping skills, self-care activities and availability of social support), which was poorly recognised by clinicians. Consequently, nearly a quarter of survey content was dedicated to these areas of impact highlight by patients (23%). Engaging patients and clinicians in the survey development methods ensured that face and content validity were confirmed and cognitive and usability standards were achieved.

Conclusions: By incorporating the views of those with the disease and of clinicians into the survey development process, good conceptual coverage of items important to both patients

and clinicians was achieved whilst minimising responder burden. This is the first study to develop a survey on foot involvement in PsA based on best practice methods in qualitative survey design, which may have utility in the future development of assessment or screening tools.

References:

1. Hyslop E, et al. Ann Rheum Dis. 2010;69:928.
2. Carter K, et al. Clin Rheumatol. 2019;8:1-9.
3. Orbai AM, et al. Ann Rheum Dis. 2016;76:673-680.



SAT0707-HPR

PATIENT AND CLINICIAN PERSPECTIVES USED FOR SURVEY DEVELOPMENT TO INVESTIGATE THE NATURE, EXTENT AND IMPACT OF FOOT PROBLEMS IN PEOPLE WITH PSORIATIC ARTHRITIS

Carter K[1], Walmsley S[1], Rome K[2], Turner DE[1]

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INTRODUCTION

Despite recognition that hallmark features of psoriatic arthritis (PsA), such as enthesitis, are predominant and persistent in the foot and ankle [1], limited research has focused on the foot.

Figure 1. Clinical features of psoriatic arthritis in the foot

Obtaining the perspective of patients and clinicians [2, 3] provides the basis for defining what should be measured to represent comprehensively the experience of people with PsA-related foot problems and important domains of impact.

Objective: To develop a survey based on the views of people with PsA and clinicians on foot problems, their impact and the foot care needs.

METHOD

Survey items were generated based on key themes identified from a qualitative investigation.

Themes from interviews of people with PsA-related foot problems and focus groups with health professionals (rheumatologists, physiotherapists, podiatrists) on the patient experience

Local data required because research from European studies does not translate to the local context due to differences in health care provision and climate

Representative sample sought including gender mix, from low and high socioeconomic areas, public and private sectors, with varying levels of disease duration and severity

Survey items were refined based on extensive rounds of pre-testing shown below. The self-administered survey was developed based on feedback from each of the pre-testing stages, which related to wording, comprehension, timescales, content, repetition, number of survey items and overall survey design.

Step 01 – Interviews of people with PsA (n=21) and health professionals (n=17) on the lived experience of foot problems – Survey draft 1
Step 02 – Multidisciplinary rheumatology focus group (n=20) and subject expert review (n=2) – Survey draft 2
Step 03 – Cognitive de-briefing interviews of people with PsA (n=6) – Survey draft 3
Step 04 – Focus group with health professionals in rheumatology (n=9) – Survey draft 4
Step 05 – Cognitive de-briefing interviews of people with PsA for paper-based survey (n=6) and web-based survey (n=6) – Survey draft 5
Step 06 – Cultural sensitivity review New Zealand (n=4) – Survey draft 6
Step 07 – Survey item revision and reduction by the research team (n=3) – Survey draft 7
Step 08 – Subject expert review from Australia, New Zealand and the UK (n=7) and survey expert review (n=1) – Survey draft 8

SURVEY FINAL VERSION

n = number of participants

RESULTS

Percentage coverage of survey items directly reflects the dominant concerns of people with PsA-related foot problems and clinicians:

A key theme from people with PsA was the psychological impact of foot involvement on daily life, poorly recognised by clinicians. Robust survey development methods ensured:

- ✓ Dedicated impact areas highlighted by people with PsA
- ✓ Content and face validity confirmed
- ✓ Cognitive and usability standards achieved

CONCLUSION

Good conceptual coverage of survey items important to both patients and clinicians was achieved. This is the first study to develop a survey on foot involvement in PsA based on best practice methods in qualitative survey design.

PFA

REFERENCES: 1. Hyslop E, et al. Ann Rheum Dis. 2010;69:928. 2. Carter K, et al. Clin Rheumatol. 2019;8:1-9. 3. Orbai AM, et al. Ann Rheum Dis. 2016;76:673-680.

EULAR 2019 Abstract 2
Category: (b) Health Professional in Rheumatology/Practice and Research.
Sub-category: Clinical topics by disease (21) Psoriatic arthritis.

LINKING THE PATIENT EXPERIENCE OF FOOT INVOLVEMENT RELATED TO PSORIATIC ARTHRITIS TO THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH

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Background: Previous research has shown merit in linking domains of impact in psoriatic arthritis (PsA) to the International Classification of Functioning, Disability and Health (ICF) to categorise the effect of global disease [1, 2]. Localised disease predominance and persistence in the foot in PsA is well recognised [3], but limited foot-specific research exists and there are no outcome measures to comprehensively assess foot involvement and its impact in PsA. To date little is known about the patient experience of foot involvement and how this may link to the ICF to capture disease impact.

Objectives: To categorise the patient experience of PsA-related foot problems by linking it to the ICF.

Methods: Participants were recruited from rheumatology outpatient clinics in Sydney, Australia and Auckland, New Zealand. People with PsA were interviewed about their foot problems and the impact they have on daily living until qualitative data saturation. Three multi-disciplinary focus groups were undertaken with clinicians to explore their understanding of the patient experience. All interviews were audio-recorded and transcribed. Codes, representing concepts obtained from the interviews, were linked to the most appropriate ICF category according to established linking rules [4]. All codes were independently linked to the ICF by 2 investigators and a third investigator for adjudication. Investigator professional backgrounds included occupational therapy and podiatry.

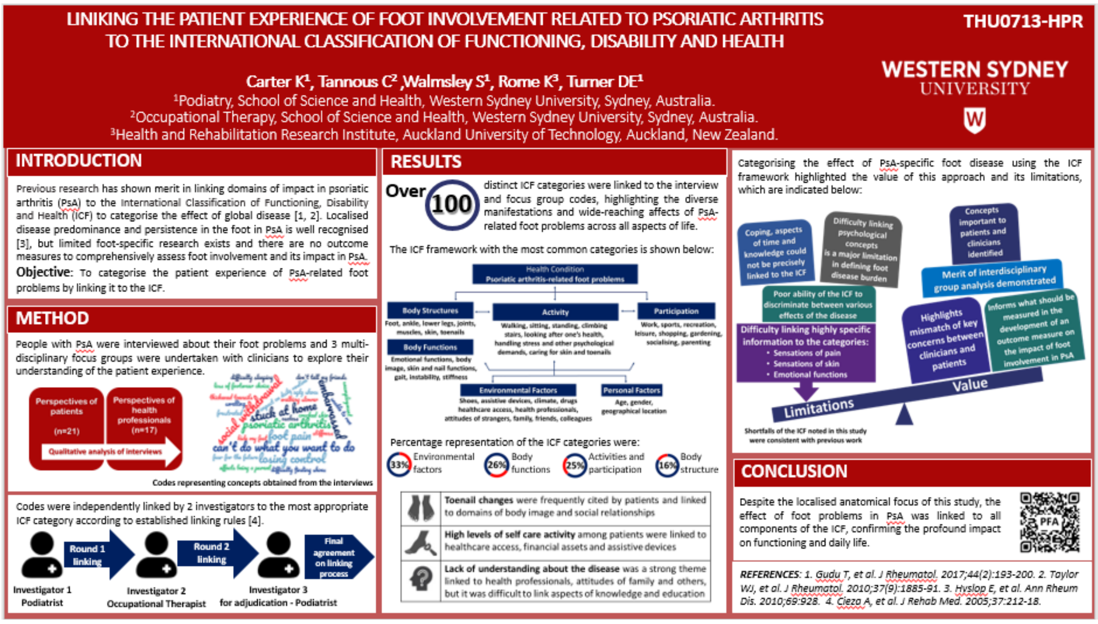
Results: Twenty-one people with PsA-related foot problems and 17 experienced clinicians participated. Over 100 distinct ICF categories were linked to the interview and focus group codes. The most represented ICF category was environmental factors (33%) followed by body functions (26%), activities and participation (25%) and body structure (16%). Environmental factors relevant to patients were shoes and assistive devices, healthcare access and climate. Clinicians identified a greater proportion of body functions and fewer activity and participation categories compared with patients, indicating a possible mismatch of key concerns. Concepts that could not be precisely linked to the ICF were related to coping, aspects of time and knowledge, consistent with previous work. Difficulties in linking highly specific information to categories such as sensations of pain, sensations of skin and emotional functions revealed a limitation in the ICFs ability to discriminate between various effects of the disease, a shortfall previously noted. Toenail changes were frequently cited by patients and linked to domains of body image and social relationships. Interdisciplinary group analysis demonstrated merit as differences between the predominantly medical approach by podiatry and psychosocial approach by occupational therapist in clinical practice led to additional ICF categories being identified between clinicians, which mostly related to cognitive functions.

Conclusions: Despite the localised anatomical focus of this study, the effect of foot problems in PsA was linked to all components of the ICF, confirming the profound impact on functioning and daily life. Difficulties with linking psychological concepts reflect deficiencies

is a major limitation in defining foot disease burden. These findings offer new knowledge using patient and clinician perspectives that could inform the development of an instrument to measure the impact of foot involvement in PsA.

References:

1. Gudu T, et al. J Rheumatol. 2017;44(2):193-200.
2. Taylor WJ, et al. J Rheumatol. 2010;37(9):1885-91.
3. Hyslop E, et al. Ann Rheum Dis. 2010;69:928.
4. Cieza A, et al. J Rehab Med. 2005;37:212-18.



LINIKING THE PATIENT EXPERIENCE OF FOOT INVOLVEMENT RELATED TO PSORIATIC ARTHRITIS TO THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH

THU0713-HPR

Carter K[1], Tannous C[2], Walmsley S[1], Rome K[3], Turner DE[1]

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INTRODUCTION

Previous research has shown merit in linking domains of impact in psoriatic arthritis (PsA) to the International Classification of Functioning, Disability and Health (ICF) to categorise the effect of global disease [1, 2]. Localised disease predominance and persistence in the foot in PsA is well recognised [3], but limited foot-specific research exists and there are no outcome measures to comprehensively assess foot involvement and its impact in PsA.

Objective: To categorise the patient experience of PsA-related foot problems by linking it to the ICF.

METHOD

People with PsA were interviewed about their foot problems and 3 multi-disciplinary focus groups were undertaken with clinicians to explore their understanding of the patient experience.

Perspectives of patients
(n=21)

Perspectives of health professionals
(n=17)

Qualitative analysis of interviews

Codes representing concepts obtained from the interviews

Codes were independently linked by 2 investigators to the most appropriate ICF category according to established linking rules [4].

Investigator 1
Podiatrist

Round 1 linking

Investigator 2
Occupational Therapist

Round 2 linking

Investigator 3
for adjudication - Podiatrist

Final agreement on linking process

RESULTS

Over 100 distinct ICF categories were linked to the interview and focus group codes, highlighting the diverse manifestations and wide-reaching affects of PsA-related foot problems across all aspects of life.

The ICF framework with the most common categories is shown below:

Health Condition
Psoriatic arthritis-related foot problems

Body Structures
Foot, ankle, lower legs, joints, muscles, skin, toenails

Body Functions
Emotional functions, body image, skin and nail functions, gait, instability, stiffness

Activity
Walking, sitting, standing, climbing stairs, looking after one's health, handling stress and other psychological demands, caring for skin and toenails

Participation
Work, sports, recreation, leisure, shopping, gardening, socialising, parenting

Environmental Factors
Shoes, assistive devices, climate, drugs healthcare access, health professionals, attitudes of strangers, family, friends, colleagues

Personal Factors
Age, gender, geographical location

Percentage representation of the ICF categories were:

33% Environmental factors
26% Body functions
25% Activities and participation
16% Body structure

Toenail changes were frequently cited by patients and linked to domains of body image and social relationships

High levels of self care activity among patients were linked to healthcare access, financial assets and assistive devices

Lack of understanding about the disease was a strong theme linked to health professionals, attitudes of family and others, but it was difficult to link aspects of knowledge and education

Categorising the effect of PsA-specific foot disease using the ICF framework highlighted the value of this approach and its limitations, which are indicated below:

Coping, aspects of time and knowledge could not be precisely linked to the ICF

Difficulty linking psychological concepts is a major limitation in defining foot disease burden

Poor ability of the ICF to discriminate between various effects of the disease

Difficulty linking highly specific information to the categories:
- Sensations of pain
- Sensations of skin
- Emotional functions

Concepts important to patients and clinicians identified

Merit of interdisciplinary group analysis demonstrated

Highlights mismatch of key concerns between clinicians and patients

Informs what should be measured in the development of an outcome measure on the impact of foot involvement in PsA

Limitations

Value

Shortfalls of the ICF noted in this study were consistent with previous work

CONCLUSION

Despite the localised anatomical focus of this study, the effect of foot problems in PsA was linked to all components of the ICF, confirming the profound impact on functioning and daily life.

REFERENCES: 1. Gudu T, et al. J Rheumatol. 2017;44(2):193-200. 2. Taylor WJ, et al. J Rheumatol. 2010;37(9):1885-91. 3. Hyslop E, et al. Ann Rheum Dis. 2010;69:928. 4. Cieza A, et al. J Rehab Med. 2005;37:212-18.

2019 Patient Experience Symposium Abstract 1
Oral Presentation

The abstract aligns with the following key words:

- Customer empowerment: The patient voice
- Improving our workforce: Staff and provider engagement
- Customer empowerment: Integrated care

Abstract 1:

Psoriatic arthritis (PsA) can lead to marked functional impairments with involvement in the lower limbs including joints and tendons. Research from the UK shows that foot-related impairment and disability persists in a high proportion of people with PsA despite targeted pharmacological management. The basis for this is poorly understood in the UK, where podiatry services are integrated within multidisciplinary rheumatology teams, and there is a lack of locally representative information on PsA-related foot involvement. The study objective was to explore the nature, burden and management of foot problems in people with PsA by interviewing patients and health professionals in Australia and New Zealand. Findings revealed that foot problems caused functional disability and altered body-image, which impacted on work, social and family life and had psychological consequences. Positive self-management strategies and experiences with health-care was found to help reduce the severity of impact from foot problems. Whilst health professionals recognised the functional and visual impact that foot problems have on daily life, the emotional burden may be under-appreciated. Both patients and health professionals perceived deficiencies in the diagnosis, assessment and treatment of foot problems. This was the first study to explore foot involvement from the perspective of people with PsA and health professionals in Australia and New Zealand. This research approach provided an in-depth insight into the experiences of people with PsA who live with foot problems. Future work involves generating large-scale local data on foot involvement in PsA needed to develop targeted disease-specific interventions.

Summary of abstract 1:

This study explored the nature, burden and management of foot problems in psoriatic arthritis (PsA) from the perspective of patients and health professionals in Australia and New Zealand. Concepts relevant and important to people with PsA-related foot problems were identified and the health professionals understanding of the patient experience was revealed. The impact of foot involvement in PsA is wide-reaching and spread across all aspects of life. Both patients and health professionals perceived suboptimal foot disease management from symptom onset, through to diagnosis and treatment.

2019 Patient Experience Symposium Abstract 2
Oral Presentation

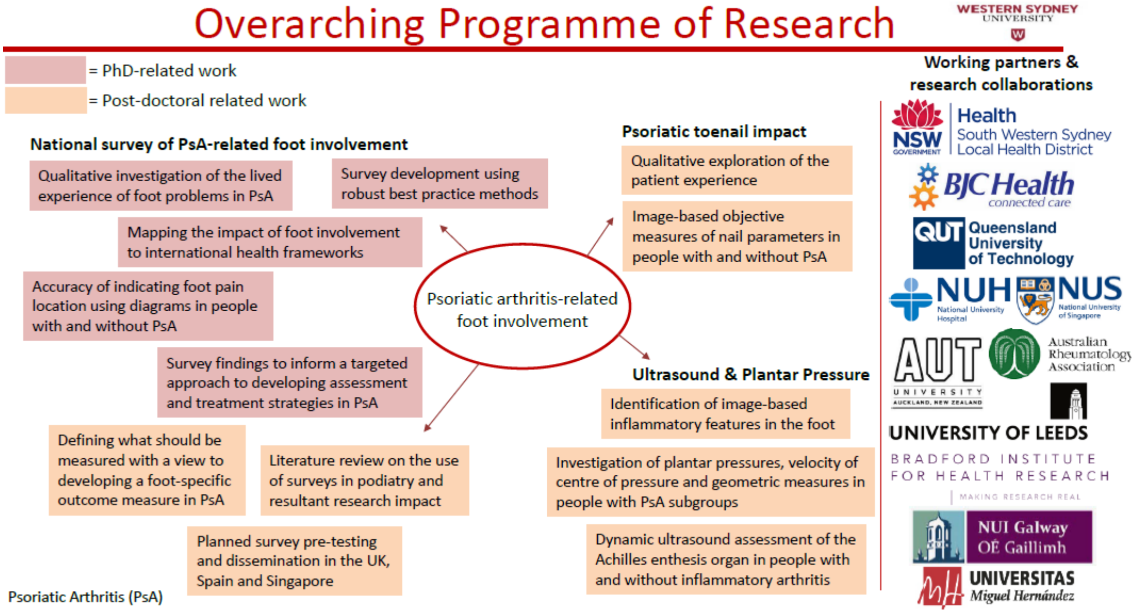
The abstract aligns with the following key words:

- Change for the better: Creative solutions in healthcare
- Change for the better: Education
- Improving our workforce: Clinical excellence
- Customer empowerment: Integrated care

Abstract 2:
As many features of inflammatory arthritis (IA) manifest early in the feet, podiatrists have a prominent role in the screening, diagnosis and management of IA-related foot disease. International recommendations advocate integration of podiatry within rheumatology multidisciplinary teams (MDT) to optimise patient outcomes. Despite widespread recognition of the importance of foot care, podiatry services for people with IA in Australia are not well embedded within the public health system. Currently, two key challenges exist 1) unmet demand for IA-related foot care due to inadequate provision of podiatry services within rheumatology MDTs and 2) lack of specialist training and knowledge across medical and allied health professions for the management of foot problems in IA. To ameliorate these issues, a monthly specialist foot clinic, delivered by a university academic centre within a private rheumatology MDT clinic, was piloted for 2-years. Aims were to provide expert-led podiatry consultations for people with IA, develop rheumatology-podiatry partnerships, rapid referral pathways and undergraduate podiatry training in complex foot care. Main findings were that a relatively high proportion of patients had previously accessed individual foot care services. Consequently, patient's recognised the benefits to a comprehensive, one-stop, coordinated package of care. Patient's reported having better understanding of their foot problems with two key objective measures providing visual representation of inflammatory (ultrasound imaging) and mechanical (plantar pressure) features. Disease activity detected in the foot informed change to pharmacological intervention or targeting of residual inflammation with local intra-articular injection therapy. Personalised non-pharmacological interventions for mechanical impairments delivered a combined therapeutic approach.

Summary of abstract 2:
To better meet the needs of people with inflammatory arthritis (IA)-related foot problems in Australia a specialist foot clinic was established through an academic clinical partnership and was piloted for 2-years. Key priorities were to provide expert-led high quality foot care, to facilitate knowledge transfer between professions, and to build future capacity within the podiatry work force with embedded university undergraduate training. Fully integrated rheumatology-podiatry consultations ensure compliance with international quality standards. Caseload data will be presented and the key take-home findings from provision of targeted foot care for people with IA by specialist podiatrists working in a rheumatology team.

New South Wales Musculoskeletal Network meeting, August 2019.



Overarching Programme of Research

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🟥 = PhD-related work

🟧 = Post-doctoral related work

National survey of PsA-related foot involvement

- Qualitative investigation of the lived experience of foot problems in PsA
- Survey development using robust best practice methods
- Mapping the impact of foot involvement to international health frameworks
- Accuracy of indicating foot pain location using diagrams in people with and without PsA
- Survey findings to inform a targeted approach to developing assessment and treatment strategies in PsA
- Defining what should be measured with a view to developing a foot-specific outcome measure in PsA
- Literature review on the use of surveys in podiatry and resultant research impact
- Planned survey pre-testing and dissemination in the UK, Spain and Singapore

Psoriatic arthritis-related foot involvement

Psoriatic toenail impact

- Qualitative exploration of the patient experience
- Image-based objective measures of nail parameters in people with and without PsA

Ultrasound & Plantar Pressure

- Identification of image-based inflammatory features in the foot
- Investigation of plantar pressures, velocity of centre of pressure and geometric measures in people with PsA subgroups
- Dynamic ultrasound assessment of the Achilles enthesis organ in people with and without inflammatory arthritis

Psoriatic Arthritis (PsA)

Working partners & research collaborations

NSW GOVERNMENT | Health South Western Sydney Local Health District
BJC Health connected care
QUT Queensland University of Technology
NUH National University Hospital
NUS National University of Singapore
AUT UNIVERSITY AUCKLAND, NEW ZEALAND
Australian Rheumatology Association
UNIVERSITY OF LEEDS
BRADFORD INSTITUTE FOR HEALTH RESEARCH | MAKING RESEARCH REAL
NUI Galway OÉ Gaillimh
UNIVERSITAS Miguel Hernández

Appendix 5: Linking to the International Classification of Functioning, Disability and Health

Supplementary Table 1. Examples of linking qualitative concepts to ICF categories.

Examples of linking concepts to ICF categories:
“Toe deformity” – s75021: Ankle joint and joints foot and toes.
“Tendon problems - Achilles tendon” - s7502: Structure of ankle and foot.
“Walking change – Slower” – b770: Gait pattern functions.
“Daily life impact - Difficulty standing” - d4154: Maintaining a standing position.
“Footwear choice – Difficulty finding shoes” – e1150: General products and technology for personal use in daily living.
Examples of more than one concept being linked to an ICF category:
Body function ICF category b28015: Pain in lower limb was linked to concepts such as “aching”, “burning”, “deep pain”, “dull”, “generalised pain”, “heavy pain”, “niggling pain”, “nagging pain”, “sharp”, “stabbing”, “stinging”, “sore”, “tender”, “severe”, “shooting” and “throbbing”.
Body function ICF category b152: Emotional functions was linked to concepts such as “fear”, “embarrassment”, “envy”, “frustration”, “upset”, “distressed”, “worried”, “bad tempered”, “dread” and “depressed”.
Environmental factor ICF category e1150: General products and technology for personal use in daily living was linked to concepts relating to difficulties with footwear characteristics such as “fit”, “heel-height”, “width”, “closed-in”, “open-toed”, “heel counter” and “fastening”.
Examples of more than one ICF category being linked to a concept that contains sub-concepts:
“Family support with toenail cutting” - e310: Immediate family, and d5204: Caring for toenails.
“Foot pain trigger – Walking” - b28015: Pain in lower limb, and d450: Walking.
“High cost of footwear” – e1150: General products and technology for personal use in daily living, and e1650: Financial assets.
“Toenail change – Splits” - s8301: Toenails, and b860: Functions of nails.

"Work impact - Difficulty sitting for long periods" - d4153: Maintaining a sitting position, and d850: Remunerative employment.
"Climate/Summer - Difficult wearing closed-in shoes to hide toenails" - s8301: Toenails, b1801: Body image, e225: Climate, and e1150: General products and technology for personal use in daily living.

ICF International Classification of Functioning, Disability and Health.

Accuracy of Analysis

In total, 66 additional ICF categories were identified by the 2nd rater during the independent linking process. Nearly half of the additional ICF categories identified were from the component Body Functions (n=31, 47%), with chapter b1: mental function being the most represented including higher-level cognitive functions, temperament and personality, experience of self and time, energy and drive, and orientation functions. Disagreements between the raters occurred most frequently with the 3rd level ICF categories.

The percentage total agreement (PTA) for health professional concepts and the ICF components ranged from a minimum of 63.8% for Activities and Participation to a maximum of 85.5% for Body Functions. Similarly, with the patient concepts the PTA was lowest for Activities and Participation (74.9%), but highest for Body Structures (87.5%). Overall, for patient and health professional concepts combined, the PTA ranged from a maximum of 86.3% for Body Functions to a minimum of 72% for Activities and Participation (Supplementary Table 2).

Good levels of interrater agreement were identified for the majority of ICF categories in relation to the linking of patient and health professional concepts, ranging from 0.62 (95% confidence interval (CI) 0.55, 0.69) for patient concepts and the Activities and Participation Component to 0.79 (CI 0.72, 0.86) for patient concepts and the Body Structures component. However, very good interrater reliability was identified for Body Functions and the patient concepts at 0.81 (CI 0.78, 0.86), while moderate interrater reliability was established for health professional concepts and Activities and Participation at 0.48 (CI 0.38, 0.58). When patient and health professional concepts were combined, interrater reliability ranged from moderate to very good levels across the ICF components, ranging from moderate interrater reliability for Activities and

Participation at 0.59 (CI 0.53, 0.64) to very good for Body Functions at 0.81 (CI 0.78, 0.85) (Supplementary Table 3).

Supplementary Table 2. Percentage total agreement between two raters for concepts linked from health professionals, patients and overall for each of the ICF components.

ICF component	Concepts linked from health professionals (%)	Concepts linked from patients (%)	Concepts linked from health professionals and patients combined (%)
Body Structures	80.8	87.4	85.6
Body Functions	85.5	86.5	86.3
Activities and Participation	63.8	74.9	72.0
Environmental Factors	82.4	85.0	84.1

ICF International Classification of Functioning, Disability and Health.

Supplementary Table 3. Kappa values and 95% confidence intervals for interrater agreement between two raters for concepts linked from health professionals, patients and overall for each of the ICF components.

ICF component	Concepts linked from health professionals (CI)	Concepts linked from patients (CI)	Concepts linked from health professionals and patients combined (CI)
Body Structures	0.71 (0.61, 0.81)	0.79 (0.72, 0.86)	0.76 (0.71, 0.82)
Body Functions	0.70 (0.63, 0.79)	0.81 (0.78, 0.86)	0.81 (0.78, 0.85)
Activities and Participation	0.48 (0.38, 0.58)	0.62 (0.55, 0.69)	0.59 (0.53, 0.64)
Environmental Factors	0.70 (0.60, 0.80)	0.72 (0.65, 0.79)	0.71 (0.65, 0.77)

ICF International Classification of Functioning, Disability and Health, *CI* Confidence intervals.

Appendix 6: Target sample calculation

The estimated worldwide prevalence of PsA is 0.16% to 0.35% in the general population. In a total Australian population of 24.77 million, 0.16% and 0.35% of the general Australian population is approximately 40,000 to 80,000 people. In a total New Zealand population of 4.78 million, approximately 7600 and 16,700 people in the general population in New Zealand could have PsA.

Appendix 7: Summary of survey item revisions

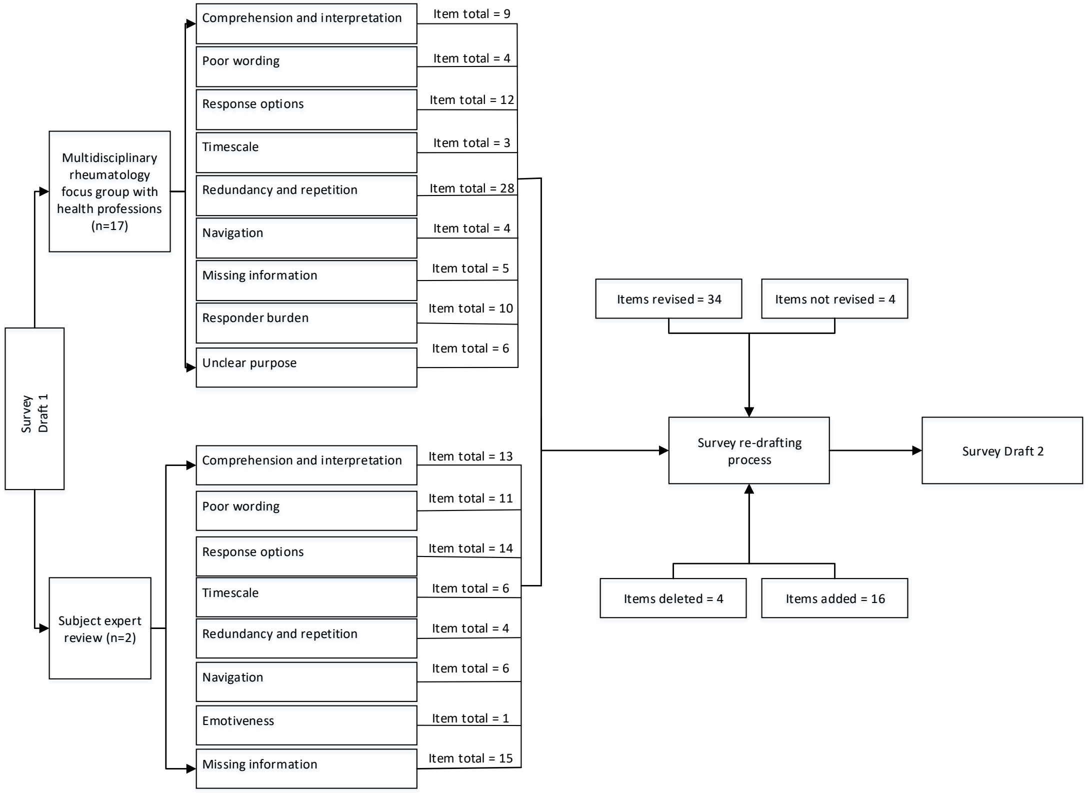

Figure 1 of 7. Process and outcome of the revision and refinement of the paper-based survey draft 1 based on the multidisciplinary rheumatology focus group and subject expert review.

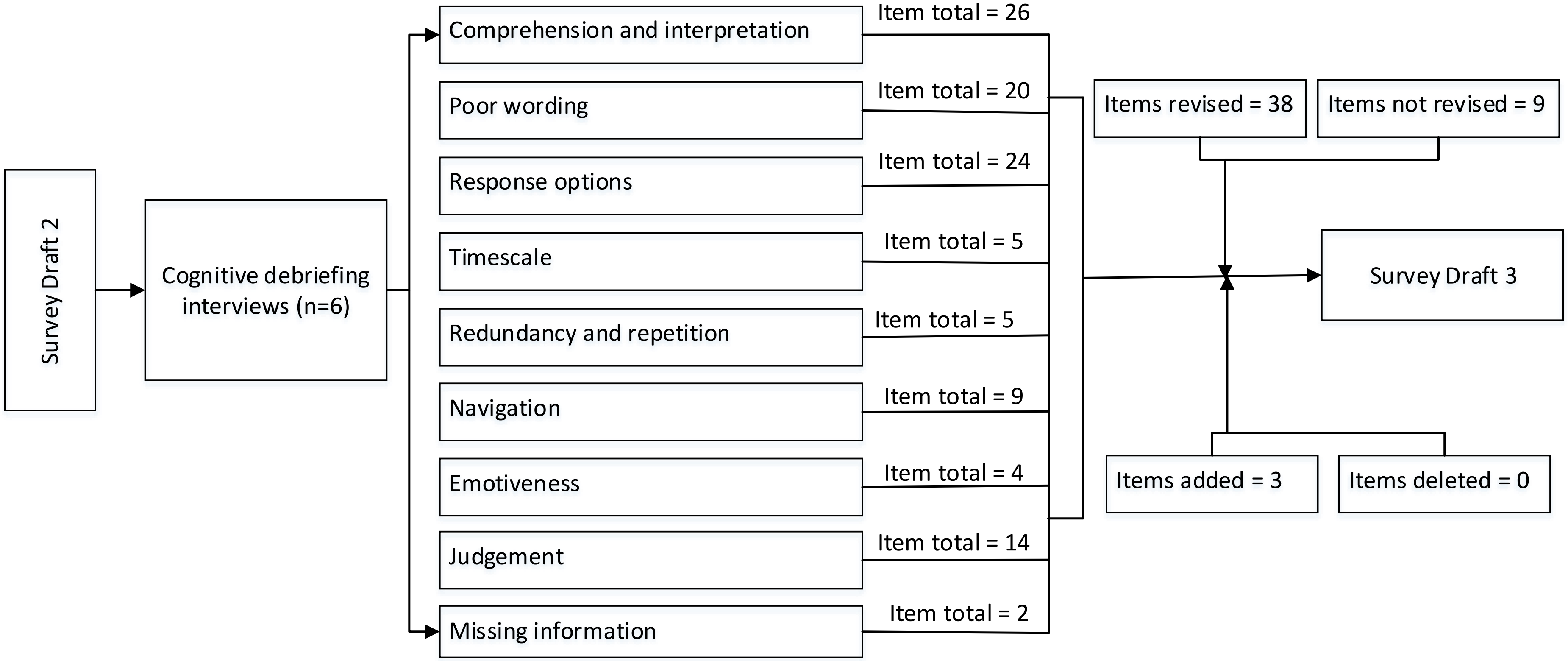

Figure 2 of 7. Process and outcome of the revision and refinement of the paper-based survey draft 2 based on cognitive interviews of people with psoriatic arthritis-related foot involvement.

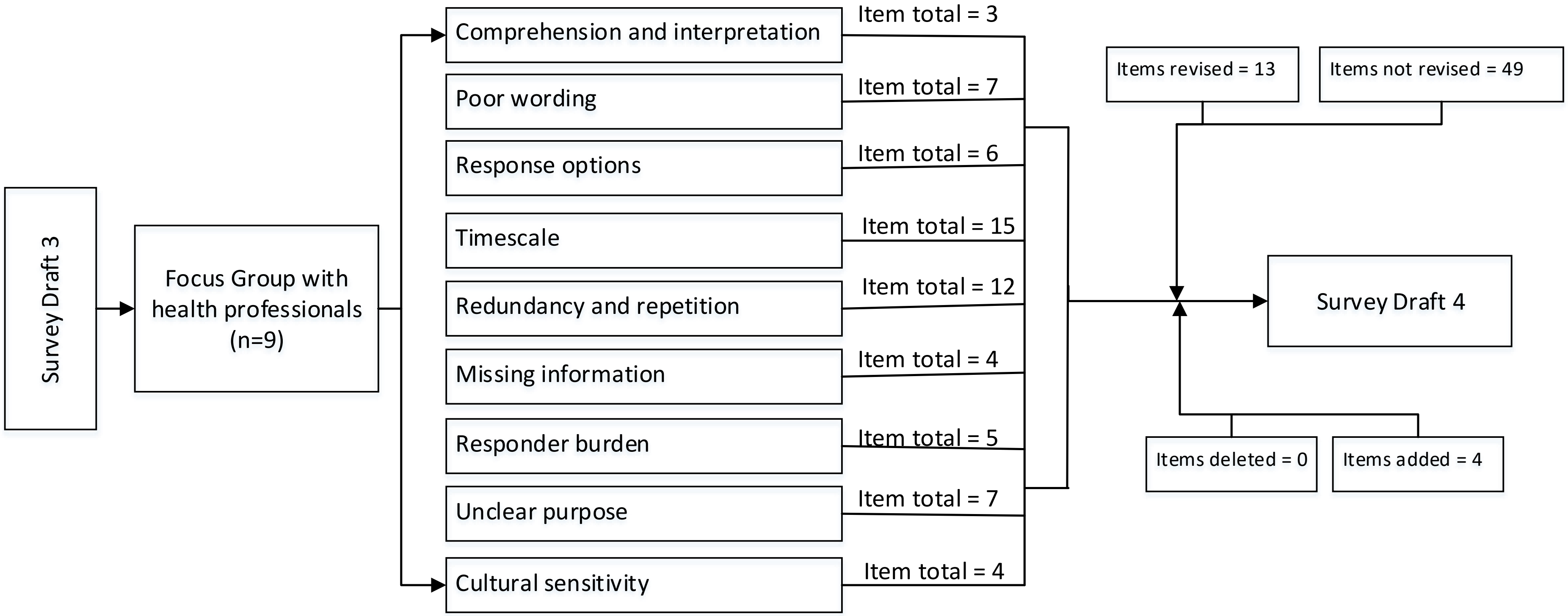

Figure 3 of 7. Process and outcome of the revision and refinement of the paper-based survey draft 3 based on the focus group with health professionals.

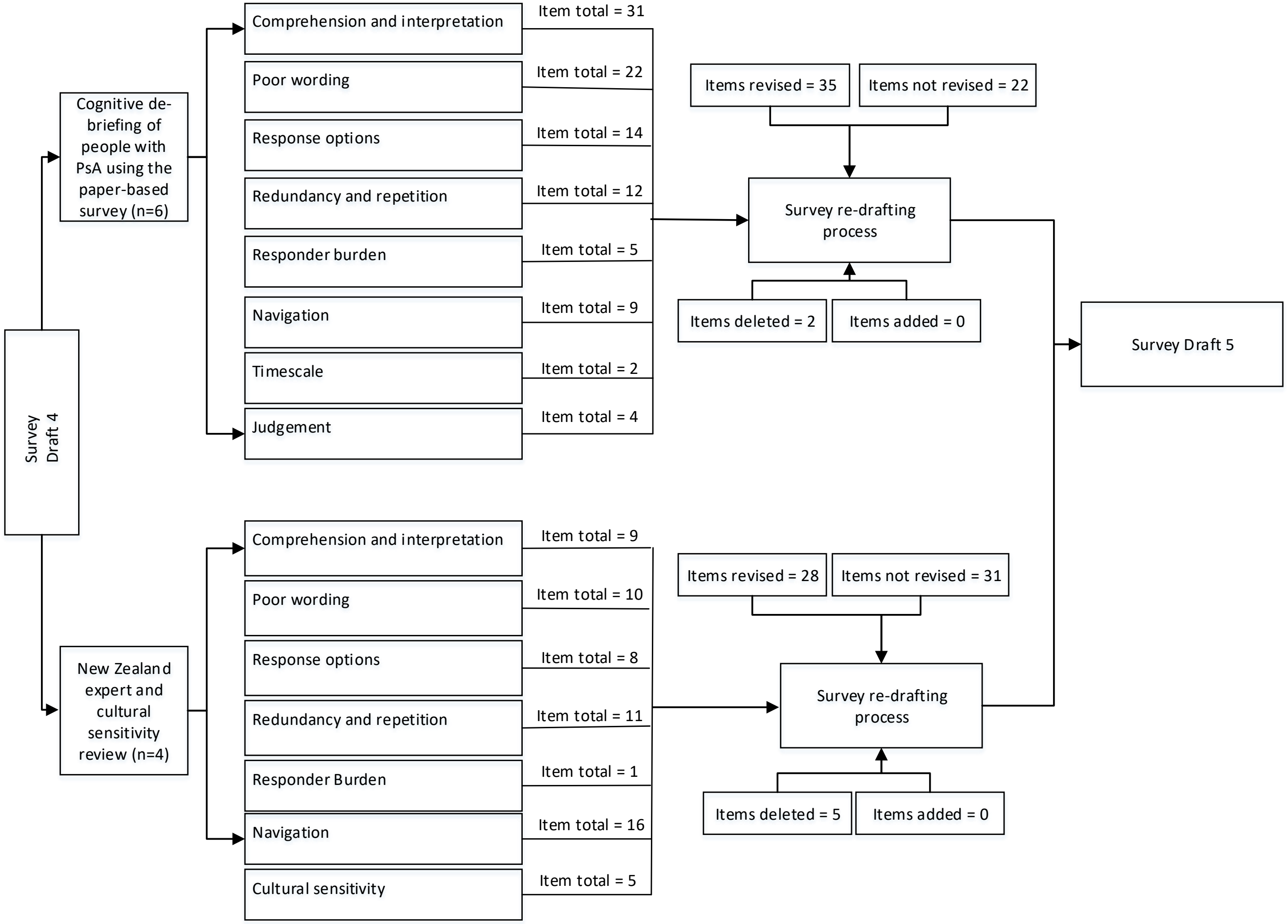

Figure 4 of 7. Process and outcome of the revision and refinement of the paper-based survey draft 4 based on cognitive interviews of people with psoriatic arthritis-related foot involvement and the New Zealand cultural sensitivity review.

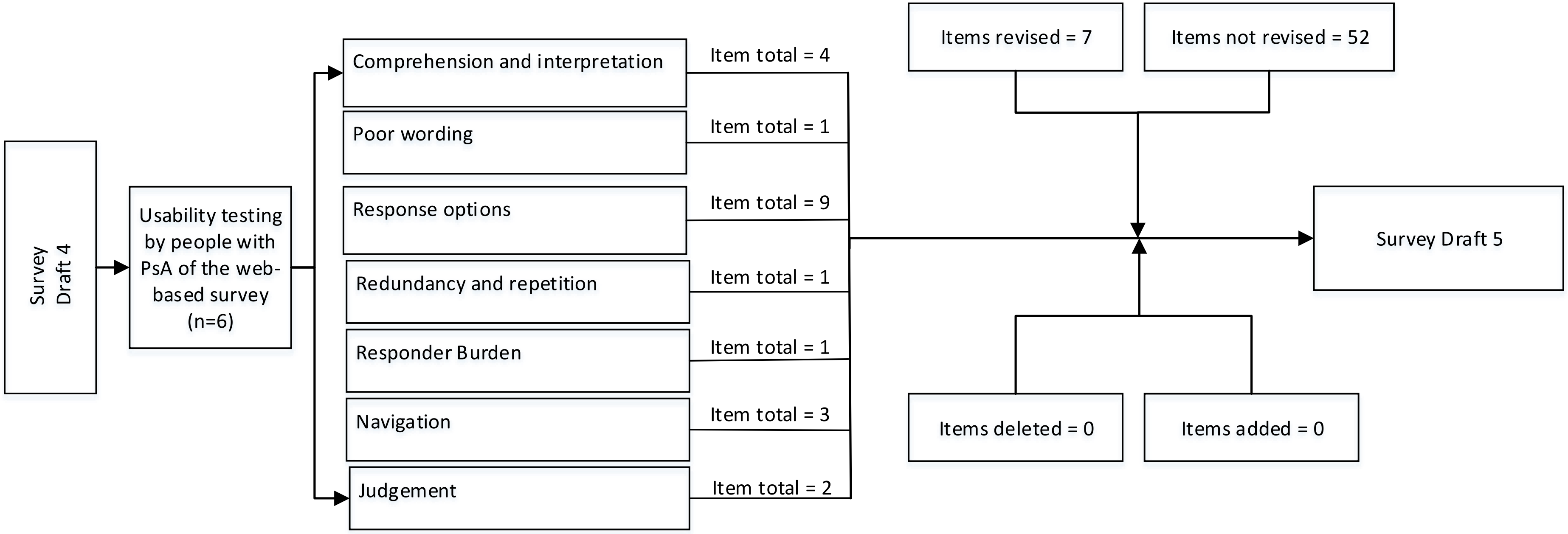

Figure 5 of 7. Process and outcome of the revision and refinement of the web-based survey draft 4 based on the cognitive interviews of people with psoriatic arthritis-related foot involvement.

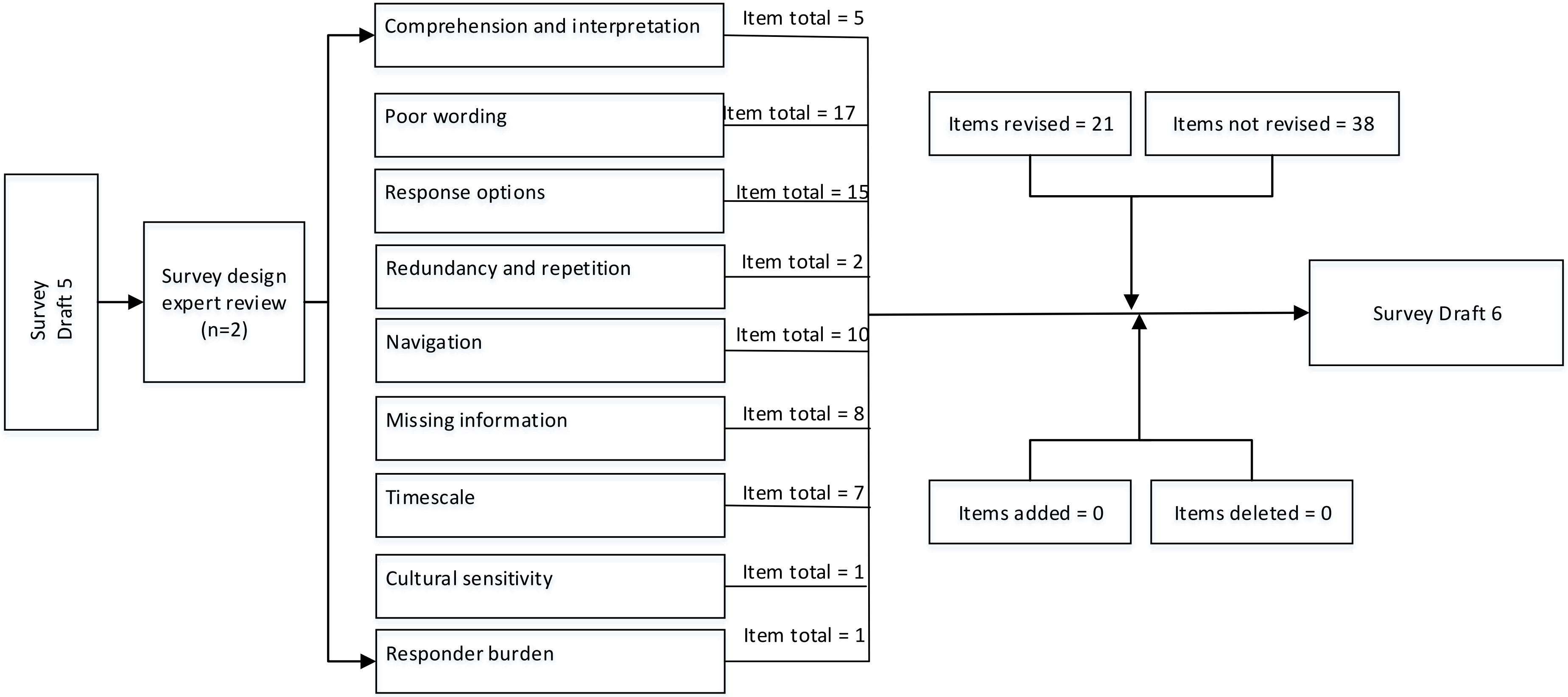

Figure 6 of 7. Process and outcome of the revision and refinement of the survey draft 5 based on the survey design expert review.

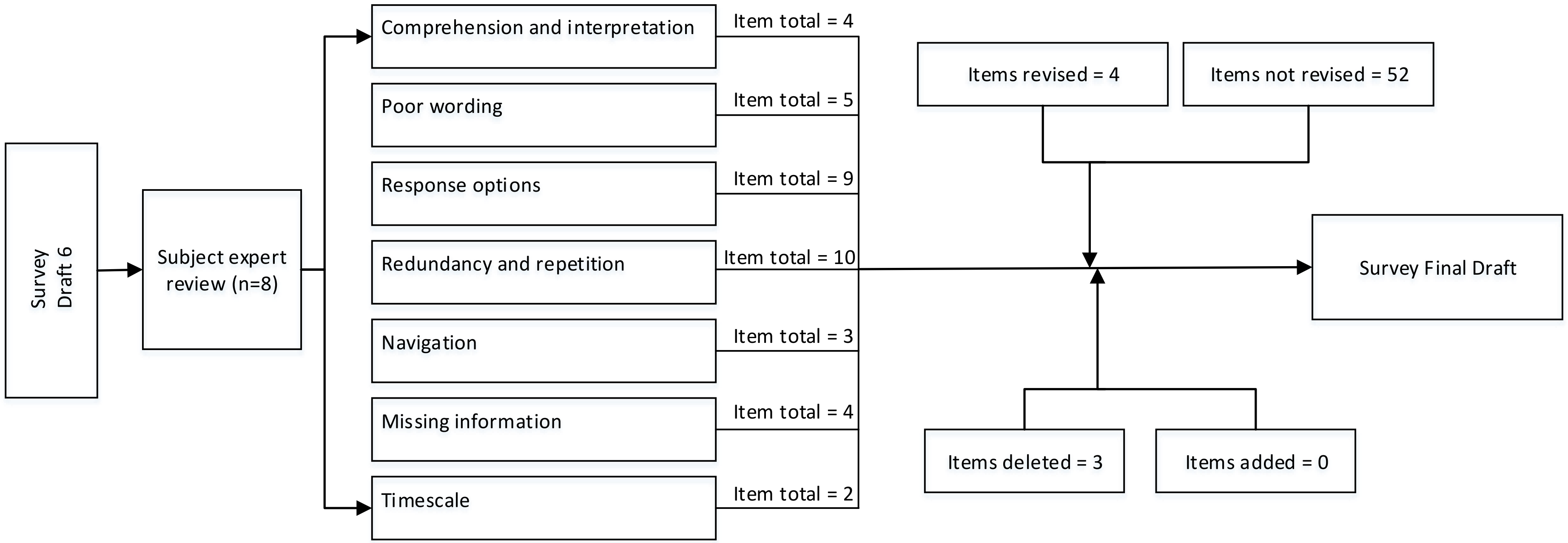

Figure 7 of 7. Process and outcome of the revision and refinement of survey draft 6 based on the subject expert review resulting in the final survey instrument (draft 7). Pilot testing of the paper-based survey (n=3) and the web-based survey (n=3) among people with psoriatic arthritis followed the process outlined above, and no further changes were made to the survey thus resulting in the final survey draft.

Appendix 8: Survey code book

Question Number	Question	Response Codes
1	Where do you live?	Australia = 1 New Zealand = 2
2	What is your post code?	Post code
3	How old are you?	Years
4	Are you male or female?	0 = male, 1 = female, 2 = Prefer not to state
5	Approximately how tall are you?	Feet and Inches OR cm
6	Approximately how much do you weight	Stone/lbs OR kg
7	What is your ethnic group	1 = Australian European 2 = English 3 = Irish 4 = Scottish 5 = Italian 6 = Lebanese 7 = Greek 8 = New Zealand European 9 = German 10 = Dutch 11 = African 12 = Middle Eastern 13 = Southeast Asian 14 = Chinese 15 = Indian 16 = Aboriginal 17 = Torres Strait Islander 18 = Maori 19 = Pacific Islander 20 = Other
8	What is your current work status? Please tick all that apply?	1 = In full time paid work 2 = In part time paid work 3 = In casual or contracted paid work 4 = Completely retired/pensioner 5 = Partially retired 6 = Disabled or too sick to work 7 = Self-employed 8 = Doing unpaid work 9 = Studying 10 = Looking after home/family 11 = Unemployed 12 = Other (please specify in the box below)

Question Number	Question	Response Codes
9	Has your work status changed due to your psoriatic arthritis?	Yes = 1 No = 0 Not originally coded
10	What is your highest qualification? Please tick the appropriate box.	1 = No school certificate or other qualifications 2 = School or intermediate certificate (or equivalent) 3 = Higher school or leaving certificate (or equivalent) 4 = Trade/apprenticeship 5 = Certificate/diploma 6 = University degree or higher
11	Do you currently see a rheumatology for your psoriatic arthritis?	Yes = 1 No = 0
12	Approximately how long ago did your symptoms of PsA start?	Years and months
13	Approximately how long ago where you diagnosed with psoriatic arthritis?	Years and months
14	Please tick any medications that you are currently taking for your psoriatic arthritis or psoriasis	1 = Methotrexate 2 = Arava (Leflunomide) 3 = Salazopyrin (Sulphasalazine) 4 = Plaquenil (Hydroxychloroquine) 5 = Enbrel (Etanercept) 6 = Otezla (Apremilast) 7 = Orencia (Abatacept) 8 = Cyclosporin 9 = Anti-inflammatories (Nurofen, Voltaren, Mobic, Celebrex) 10 = Humira (Adalimumab) 11 = Cosentyx (Secukinumab) 12 = Stelara (Ustekinumab) 13 = Remicade (Infliximab) 14 = Simponi (Golimumab) 15 = Cimzia (Certolizumab) 16 = Xeljanz (Tofacitinib) 17 = Prednisolone (Steroids) 18 = Not currently taking any medication for my psoriatic arthritis or skin 19 = Other medications for psoriatic arthritis or psoriasis not on the list 20 = Alternative or complementary medicines
15	Please mark on the diagrams below ALL the parts of your body where you	Hot spots – 10 clicks per diagram

Question Number	Question	Response Codes
	have had any ache or pain that you believe is due to your psoriatic arthritis, which has lasted for one day or longer over the past month:	BACK And FRONT 1 = pain 2 = no pain
16	Which part of your body has been the MOST painful or sore over the **past month**? Please tick **ONE** box only.	1 = Head and neck 2 = Shoulders 3 = Elbows 4 = Wrists 5 = Hands and Fingers 6 = Back 7= Hips 8 = Knees 9 = Ankles 10 = Feet and toes 11 = Or Not sure 12 = Unable to select only one 0 = No pain
17	In all the ways that your ARTHRITIS affects you, how would you rate the way you have felt over the past week? Please pick one number to rate the way you have felt.	0 = Excellent to 10 = Poor 11 point NRS
18	In all the ways that your **PSORIASIS** affects you, how would you rate the way you have felt over the **past week**?	0 = Excellent to 10 = Poor 11 point NRS
19	In all the ways that your ARTHRITIS and PSORIASIS, as a whole, affects you, how would you rate the way you felt over the past week? Please pick one number to rate the way you have felt.	0 = Excellent to 10 = Poor 11 point NRS
20	How much PAIN have you had because of your psoriatic arthritis over the past week? Please pick one number to indicate how severe your pain has been.	0 = Excellent to 10 = Poor 11 point NRS
21	Have you been diagnosed with any of these conditions? Please tick **ALL** that apply.	1 = Diabetes 2 = OA 3 = Fibromyalgia 4 = Anxiety 5 = Depression
22	In the **past month**, have you had pain	1 = Yes

Question Number	Question	Response Codes
	in your feet and ankles that has lasted for one day or longer?	0 = No
23	**IF YES**, please pick one number to indicate how severe your foot and ankle pain has been over the **past month**.	0 = No Pain to 10 = worst pain ever 11 point NRS IF NO, skip to question 26. -998 = Skipped question
24	Please mark on the diagrams below **ALL** the places on your feet and ankles where you have had any ache or pain that has lasted for one day or longer over the **past month**.	Hot Spot Maximum 10 clicks per diagram Left and right foot - top and bottom Left and right foot – medial and lateral views Left and right foot – posterior view 1 = pain 2 = no pain -998 = Skipped question
25	How do the symptoms (such as pain, ache, discomfort) in your feet and ankles change during a **typical day**? To what extent you agree with the following statements? The symptoms in my feet are worse in the morning The symptoms in my feet are worse at the end of the day The symptoms in my feet are worse after rest or inactivity The symptoms in my feet are better with activity such as walking The symptoms in my feet are there all day The symptoms in my feet can seem to randomly change from day to day	1 = Strongly Agree 2 = Agree 3 = Neither agree or disagree 4 = Disagree 5 = Strongly disagree -998 = Skipped question
26	Apart from pain, how often do you have any of the other following symptoms in your feet and ankles? Swelling Stiffness Cramp at the back of the leg or foot Numbness, burning or tingling Hot feet Cold feet	4 = All the time 3 = Very often 2 = Often 1 = Not very often 0 = Never

Question Number	Question	Response Codes
	Tired feet – aching feeling	
27	Overall, to what extent do you find the symptoms listed above in your feet and ankles troublesome (cause trouble, annoyance or difficulty)? Please pick one number to indicate how troublesome your symptoms have been.	0 = Not troublesome at all to 10 = Extremely troublesome 11 point NRS
28	What problems have you had or currently have with your feet? Please tick **ALL** that apply.	1 = Crooked or bent toes 2 = Bony bump at the side of the big toe (Bunions) 3 = Swelling of the entire toe (Sausage toe) 4 = Hard skin or corn 5 = Deformity at the front of the foot (excluding toes) 6 = Open wound / sore that has taken over a week to heal 7 = Achilles tendon (**back of the heel**) 8 = Plantar fascia (**under the heel or arch**) 9 = Flat feet 10 = Dry cracked heels 11 = Deformity at the ankle and heel 12 = Size of my feet (changes in length and width)
29	Have you ever felt **embarrassed** or **self-conscious** about any of the foot problems listed above?	Yes = 1 No = 0
30	Do you have psoriasis on the skin of your feet?	Yes = 1 No = 0
31	Do you have psoriasis on the skin of your lower legs (knee to ankle)?	Yes = 1 No = 0 IF NO, skip to question 35. -998 = Skipped question
32	Do you currently see a **dermatologist** for your psoriasis?	Yes = 1 No = 0 -998 = Skipped question
33	Please indicate how psoriasis has affected the skin on your feet and ankles over the **past month**. Please tick **ALL** that apply.	1 = Splitting of the skin 2 = Itching of the skin 3 = Bleeding of the skin 4 = Redness of the skin 5 = Pain and discomfort of the skin 6 = Thick hard skin (callus) 7 = Scaling or flaking of the

Question Number	Question	Response Codes
		skin -998 = Skipped question
34	Please indicate how much the skin problems (including psoriasis, hard skin, skin infection) on your feet and lower legs have affected your life over the **past month.** How **sore**, **tender** or **painful** has the skin on your feet and lower legs been? How **embarrassed** or **self-conscious** have you felt because of the skin on your feet and lower legs? How much has the skin on your feet and lower legs interfered with your daily activities or social and leisure activities? How much has the skin on your feet and lower legs influenced the **footwear** you wear?	0 = Not at all 1 = Mildly 2 = Moderately 3 = Extremely -998 = Skipped question
35	Do you think that you currently have toenail psoriasis?	1 = Yes 0 = No
36	Please indicate any problems you have had with your toenail psoriasis over the **past month**. Please tick **ALL** that apply.	1 = Thickened nail 2 = Splits in the nail 3 = Nail lifts up (nail separates from the skin underneath) 4 = Pitting in the nail (small pits in the nail) 5 = Nail peels or breaks off 6 = Ridges in the nail (lines across the nail) 7 = Discoloured nail (white, yellow, brown) 8 = Build up under the nail 9 = Wave shaped nail 10 = In-grown toenail IF NO, skip to question 38. -998 = Skipped question
37	Please indicate how much your toenail psoriasis has affected your life over the **past month**. How **tender** or **painful** have your toenails been? How **embarrassed** or **self-conscious** have you felt because of your toenails?	0 = Not at all 1 = Mildly 2 = Moderately 3 = Extremely -998 = Skipped question

Question Number	Question	Response Codes
	How much have your toenails interfered with your **daily activities** or **social** and **leisure activities**? How much have your toenails influenced the **footwear** you wear?	
38	To what extent have you had difficulties in undertaking the following activities because of **your feet**? Standing for 5 minutes Walking for 5 minutes Walking barefoot Going up and downstairs	5 = Unable to do 4 = Very difficult 3 = Moderately difficult 2 = Slightly difficult 1 = Not difficult
39	Have you had difficulties with any of the activities listed above because of problems **in other parts of your body**?	Yes = 1 No = 0
40	How many times did you do each of these activities in the **past week**? Walking continuously for at least 10 minutes (for recreation or exercise or to get to or from places) Moderate physical activity (like gentle swimming, social tennis, gardening or work around the house) Vigorous physical activity (that made you breathe harder or puff and pant, like jogging, cycling, aerobics, competitive tennis, but not household chores or gardening)	1 = Every day of the week 2 = 4 – 6 times in a week 3 = 2 – 3 times in a week 4 = Once a week or less 5 = Never
41	Have your feet interfered with your daily activities over the **past month**? Going to the shops Looking after your home Leisure or social activities Being a parent or carer Spending time with family Exercise Sleep Driving Work	5 = Yes, interfered a lot 4 = Yes, interfered a little 3 = No, not at all interfered 0 = Not relevant
42	To what extent do you agree with the following statements?	1 = Strongly agree 2 = Agree 3 = Neither agree nor

Question Number	Question	Response Codes
	I walk slower than others I limp or shuffle or feel unstable when I walk I feel embarrassed or self-conscious about the way that I walk I feel frustrated by the problems with my feet I stay indoors most of the day because of my foot problems	disagree 4 = Disagree 5 = Strongly disagree
43	How many times have you fallen to the floor or ground over the **past 12 months**?	0 = 0 falls 1 = 1 fall 2 = 2 falls 3 = 3 falls 4 = 4 or more falls
44	What type of footwear do you wear the MOST during a **typical week**? Please tick **ALL** that apply.	1 = Fashion sandals, thongs or jandals 2 = Supportive style sandals 3 = Ballet flats or moccasins 4 = slip on sneakers 5 – lace-up sneakers 6 = sports shoes 7 = Business or court shoe 8 = High heels 9 = Work boot such as steel toe-capped 10 = Supportive walking boot 11 = General boot (heeled or flat) 12 = Prescribed or customised shoes (extra deep/wide footwear) 13 = Barefoot only, socks or slippers
45	What are the top 5 most important factors to you when choosing footwear? Please tick FIVE boxes only.	1 = Plenty of room around my toes 2 = Style 3 = Wider fit 4 = Support 5 = Closed-in 6 = Arch support or fits insole 7 = Cushioning shoe 8 = Adjustable straps 9 = Light weight 10 = Cost 11 = Soft around the back of my heel 12 = Breathability 13 = Easy to get on/off 14 = Other (please specify

Question Number	Question	Response Codes
		in box below) 15 = Heel height 16 = Open-toed
46	To what extent do you agree with the following statements about **difficulties** you may have with your footwear? It is hard to find footwear that do not hurt my feet I have difficulty in finding footwear that fits my feet I am limited in the number of shoes I can wear I have difficulty with daily activities due to discomfort from my footwear I am limited in the kind of work I can do due to difficulties with my footwear I have difficulty in finding footwear appropriate for a special occasion I feel frustrated about the problems I have with footwear I feel embarrassed about the footwear I wear I find that I am restricted to the same type of footwear all year around	1 = Strongly agree 2 = Agree 3 = Neither agree or disagree 4 = Disagree 5 = Strongly disagree
47	Considering your foot problems overall, how well did you cope (manage, deal, make do) with your foot problems over the past month? Please pick one number to indicate how well you have coped.	0 = Coped very well to 10 coped very poorly 11 point NRS
48	Please indicate the typical ways in which you cope with your foot problems. Please tick **ALL** that apply.	1 = Accept limitations 2 = Pace and plan 3 = Get on with it, despite the problem 4 = Hide the problem from others 5 = Do not think about the problem 6 = Try to keep in control of the problem 7 = Get support from family, friends and/or health professionals 8 = None, I do not use coping strategies
49	Considering all the people around you (family, partner, friends and others), do you believe that there is a:	1 = Lack of understanding about the disease 2 = Lack of support for

Question Number	Question	Response Codes
	Please tick **ALL** that apply.	people with the disease 3 = Neither of these
50	Do you belong to a patient support group (such as Arthritis Australia or Arthritis New Zealand) for your psoriatic arthritis or psoriasis?	Yes = 1 No = 0
51	Do you need assistance to help take care of your feet properly?	Yes = 1 No = 0
52	Have you tried to manage your own foot problems (such as applying products, using devices or purchasing particular footwear)?	Yes = 1 No = 0
52	**IF YES**, how effective do you feel you have been at managing your foot problems?	4 = Extremely effective 3 = Very effective 2 = Moderately effective 1 = Mildly effective 0 = Not at all effective IF NO, skip to question 54. -998 = Skipped question
53	Considering all the ways you may have tried to care for your feet (for example, paying for nail care, footwear, padding, creams, insoles, massage etc.) in the **past 12 months**, approximately how much have you spent of your own money?	$ Value -998 = Skipped question
54	Who have you seen about your foot problems? Please tick ALL that apply.	0 = Occupational therapist 1 = GP/Doctor 2 = Other (please specify in the box below) 3 = Rheumatologist 4 = Dermatologist 5 = Podiatrist 6 = Foot massage/reflexologist 7 = Physiotherapist 8 = Surgeon 9 = TCM 10 = Nurse 11 = Pedicure 12 = I have not seen anyone
54	**IF YES**, how effective was the help you received overall?	4 = Extremely effective 3 = very effective 2 = moderately effective 1 = Mildly effective 0 = Not effective at all IF NO, skip to question 55. -998 = Skipped question
54	**IF YES**, overall how confident were you	1 = Extremely confident

Question Number	Question	Response Codes
	that the health professionals you have seen had a good understanding of how psoriatic arthritis affects your feet?	2 = Very confident 3 = Moderately confident 4 = Mildly confident 5 = Not at all confident -998 = Skipped question
55	Has your rheumatologist ever asked about your feet?	1 = Yes 0 = No
56	Has your rheumatologist ever examined your feet?	1 = Yes 0 = No
57	Have you ever seen a podiatrist about your feet?	1 = Yes 0 = No
58	Do you receive regular podiatry treatment for your feet?	1 = Yes 0 = No
59	Have you ever had any ankle or foot surgery?	1 = Yes 0 = No
59	**IF YES**, did your ankle or foot problems improve after the surgery?	1 = Yes 0 = No IF NO, skip to end. -998 = Skipped question

Missing data = -999

Appendix 9: Study promotion materials

Study poster

IMPROVING FOOT HEALTH

PSORIATIC ARTHRITIS FOOT STUDY

INVITATION TO TAKE PART IN A NATIONAL SURVEY

TO FIND OUT ABOUT FOOT PROBLEMS IN PEOPLE WITH PSORIATIC ARTHRITIS

This research project is led by Kate Carter at Western Sydney University and is part of her PhD in podiatry.

Our research has shown that foot problems are common in people with psoriatic arthritis. Pain and swelling in the feet and ankles can make walking difficult and can greatly limit daily activities.

Little is known about the impact of foot problems from the perspective of people with psoriatic arthritis.

We need a better understanding of foot problems related to psoriatic arthritis so that we can help to treat it better in the future.

It is essential that we seek information from people with psoriatic arthritis to identify the most important and relevant concerns.

The survey asks how foot problems impact on daily life, footwear choice and the foot care needs of people living with psoriatic arthritis.

TO TAKE PART, YOU SHOULD:
Be aged 18 or over
Have psoriatic arthritis
Have past or present foot problems
Live in Australia or New Zealand

Complete the survey online on www.psoriaticfootarthritis.com

or

Complete the paper survey, please contact Kate Carter at info@psoriaticfootarthritis.com to be sent a paper copy

WESTERN SYDNEY UNIVERSITY

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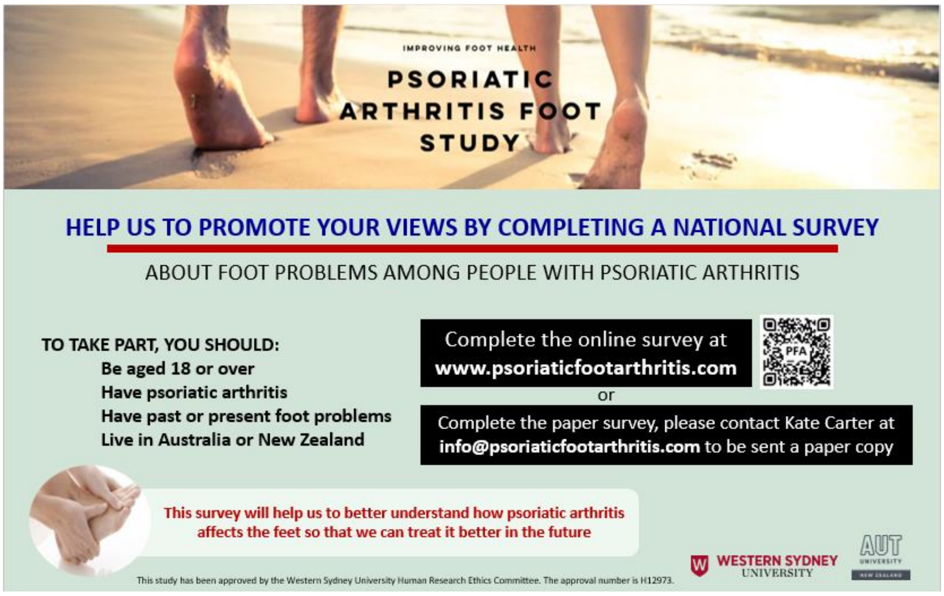
This study has been approved by the Western Sydney University Human Research Ethics Committee. The approval number is H12973.

Study flyer



IMPROVING FOOT HEALTH

PSORIATIC ARTHRITIS FOOT STUDY

HELP US TO PROMOTE YOUR VIEWS BY COMPLETING A NATIONAL SURVEY

ABOUT FOOT PROBLEMS AMONG PEOPLE WITH PSORIATIC ARTHRITIS

TO TAKE PART, YOU SHOULD:
Be aged 18 or over
Have psoriatic arthritis
Have past or present foot problems
Live in Australia or New Zealand

Complete the online survey at www.psoriaticfootarthritis.com

or

Complete the paper survey, please contact Kate Carter at info@psoriaticfootarthritis.com to be sent a paper copy

This survey will help us to better understand how psoriatic arthritis affects the feet so that we can treat it better in the future

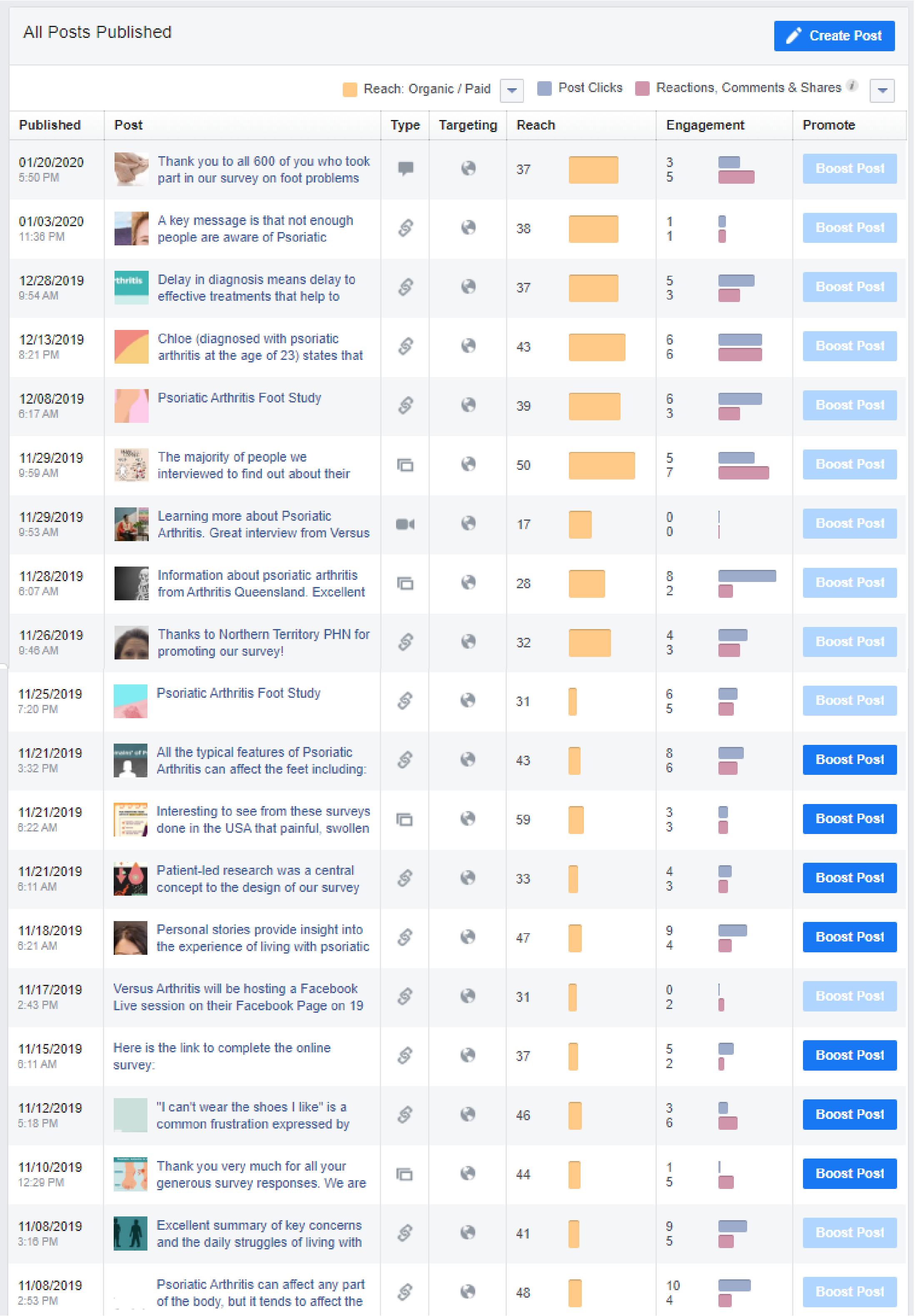
WESTERN SYDNEY UNIVERSITY

AUT

This study has been approved by the Western Sydney University Human Research Ethics Committee. The approval number is H12973.

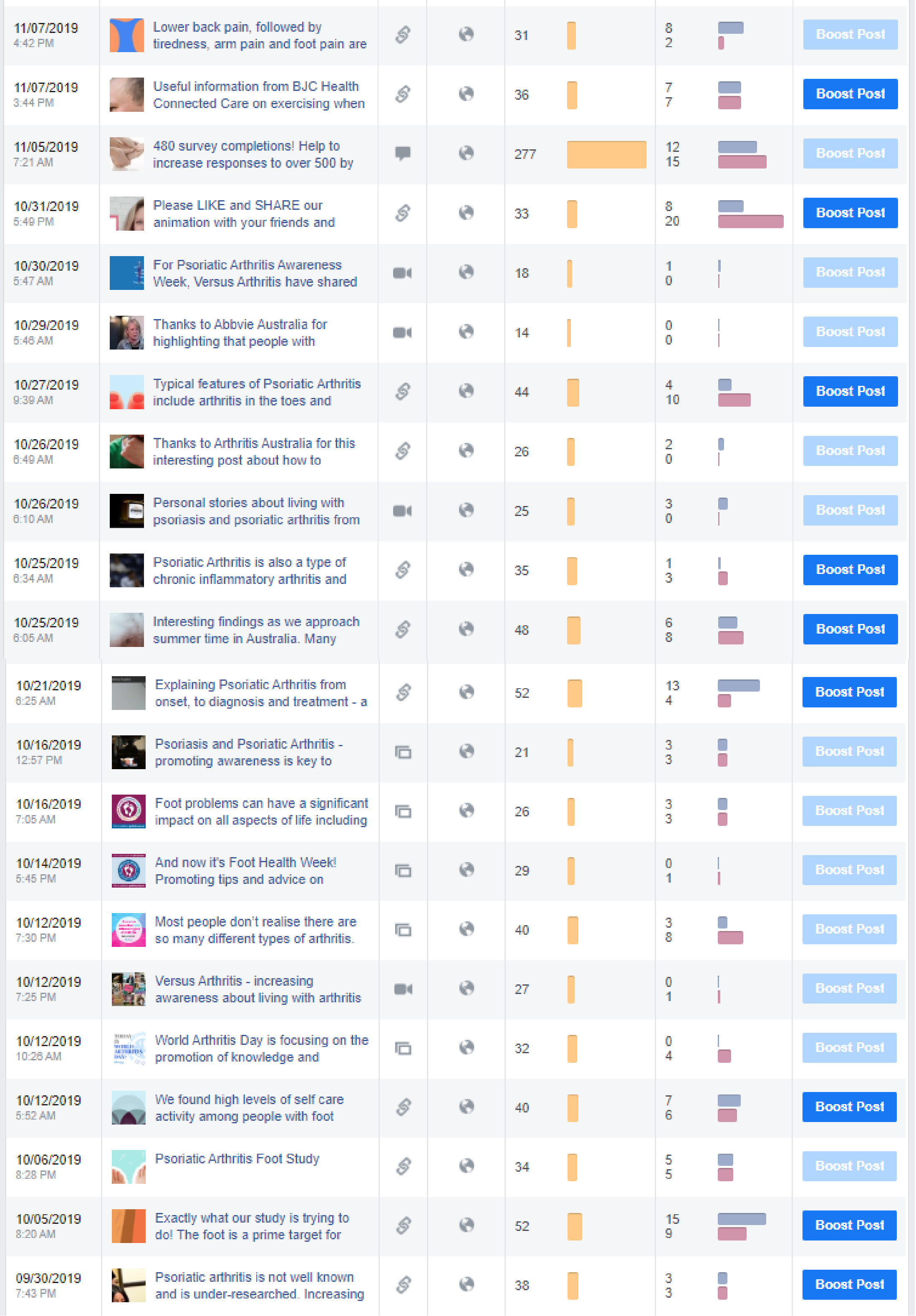
Organisations that helped to promote the survey.

Facebook page posts and shares

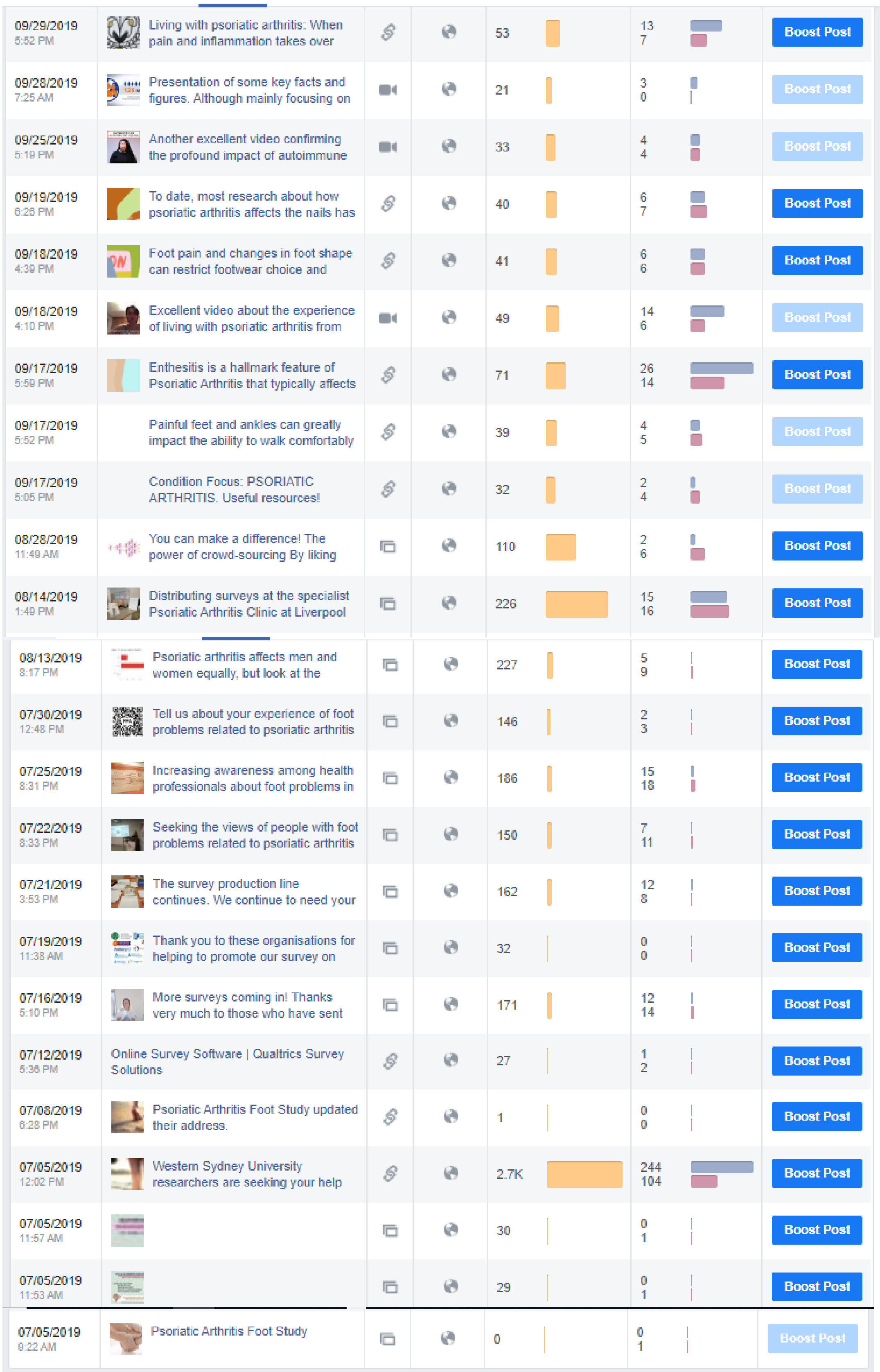


All Posts Published

Published	Post	Type	Targeting	Reach	Engagement	Promote
01/20/2020 5:50 PM	Thank you to all 600 of you who took part in our survey on foot problems	💬	🌐	37	3 5	Boost Post
01/03/2020 11:36 PM	A key message is that not enough people are aware of Psoriatic	🔗	🌐	38	1 1	Boost Post
12/28/2019 9:54 AM	Delay in diagnosis means delay to effective treatments that help to	🔗	🌐	37	5 3	Boost Post
12/13/2019 8:21 PM	Chloe (diagnosed with psoriatic arthritis at the age of 23) states that	🔗	🌐	43	6 6	Boost Post
12/08/2019 6:17 AM	Psoriatic Arthritis Foot Study	🔗	🌐	39	6 3	Boost Post
11/29/2019 9:59 AM	The majority of people we interviewed to find out about their	▭	🌐	50	5 7	Boost Post
11/29/2019 9:53 AM	Learning more about Psoriatic Arthritis. Great interview from Versus	📹	🌐	17	0 0	Boost Post
11/28/2019 6:07 AM	Information about psoriatic arthritis from Arthritis Queensland. Excellent	▭	🌐	28	8 2	Boost Post
11/26/2019 9:46 AM	Thanks to Northern Territory PHN for promoting our survey!	🔗	🌐	32	4 3	Boost Post
11/25/2019 7:20 PM	Psoriatic Arthritis Foot Study	🔗	🌐	31	6 5	Boost Post
11/21/2019 3:32 PM	All the typical features of Psoriatic Arthritis can affect the feet including:	🔗	🌐	43	8 6	Boost Post
11/21/2019 6:22 AM	Interesting to see from these surveys done in the USA that painful, swollen	▭	🌐	59	3 3	Boost Post
11/21/2019 6:11 AM	Patient-led research was a central concept to the design of our survey	🔗	🌐	33	4 3	Boost Post
11/18/2019 6:21 AM	Personal stories provide insight into the experience of living with psoriatic	🔗	🌐	47	9 4	Boost Post
11/17/2019 2:43 PM	Versus Arthritis will be hosting a Facebook Live session on their Facebook Page on 19	🔗	🌐	31	0 2	Boost Post
11/15/2019 6:11 AM	Here is the link to complete the online survey:	🔗	🌐	37	5 2	Boost Post
11/12/2019 5:18 PM	"I can't wear the shoes I like" is a common frustration expressed by	🔗	🌐	46	3 6	Boost Post
11/10/2019 12:29 PM	Thank you very much for all your generous survey responses. We are	▭	🌐	44	1 5	Boost Post
11/08/2019 3:16 PM	Excellent summary of key concerns and the daily struggles of living with	🔗	🌐	41	9 5	Boost Post
11/08/2019 2:53 PM	Psoriatic Arthritis can affect any part of the body, but it tends to affect the	🔗	🌐	48	10 4	Boost Post

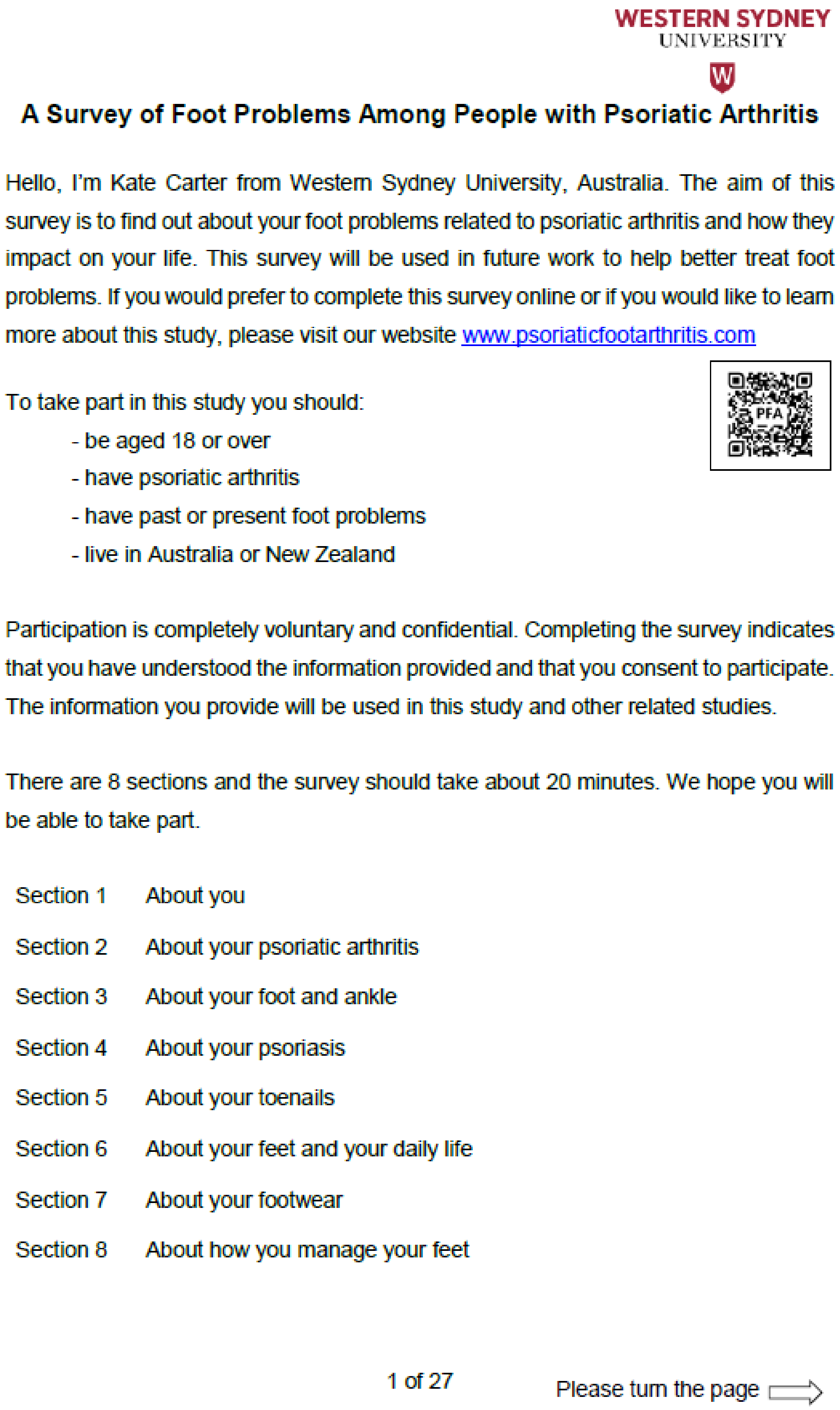


11/07/2019 4:42 PM	Lower back pain, followed by tiredness, arm pain and foot pain are	🔗	🌐	31	8 2	Boost Post
11/07/2019 3:44 PM	Useful information from BJC Health Connected Care on exercising when	🔗	🌐	36	7 7	Boost Post
11/05/2019 7:21 AM	480 survey completions! Help to increase responses to over 500 by	💬	🌐	277	12 15	Boost Post
10/31/2019 5:49 PM	Please LIKE and SHARE our animation with your friends and	🔗	🌐	33	8 20	Boost Post
10/30/2019 5:47 AM	For Psoriatic Arthritis Awareness Week, Versus Arthritis have shared	🎥	🌐	18	1 0	Boost Post
10/29/2019 5:46 AM	Thanks to Abbvie Australia for highlighting that people with	🎥	🌐	14	0 0	Boost Post
10/27/2019 9:39 AM	Typical features of Psoriatic Arthritis include arthritis in the toes and	🔗	🌐	44	4 10	Boost Post
10/26/2019 6:49 AM	Thanks to Arthritis Australia for this interesting post about how to	🔗	🌐	26	2 0	Boost Post
10/26/2019 6:10 AM	Personal stories about living with psoriasis and psoriatic arthritis from	🎥	🌐	25	3 0	Boost Post
10/25/2019 6:34 AM	Psoriatic Arthritis is also a type of chronic inflammatory arthritis and	🔗	🌐	35	1 3	Boost Post
10/25/2019 6:05 AM	Interesting findings as we approach summer time in Australia. Many	🔗	🌐	48	6 8	Boost Post
10/21/2019 6:25 AM	Explaining Psoriatic Arthritis from onset, to diagnosis and treatment - a	🔗	🌐	52	13 4	Boost Post
10/16/2019 12:57 PM	Psoriasis and Psoriatic Arthritis - promoting awareness is key to	▭	🌐	21	3 3	Boost Post
10/16/2019 7:05 AM	Foot problems can have a significant impact on all aspects of life including	▭	🌐	26	3 3	Boost Post
10/14/2019 5:45 PM	And now it's Foot Health Week! Promoting tips and advice on	▭	🌐	29	0 1	Boost Post
10/12/2019 7:30 PM	Most people don't realise there are so many different types of arthritis.	▭	🌐	40	3 8	Boost Post
10/12/2019 7:25 PM	Versus Arthritis - increasing awareness about living with arthritis	🎥	🌐	27	0 1	Boost Post
10/12/2019 10:26 AM	World Arthritis Day is focusing on the promotion of knowledge and	▭	🌐	32	0 4	Boost Post
10/12/2019 5:52 AM	We found high levels of self care activity among people with foot	🔗	🌐	40	7 6	Boost Post
10/06/2019 8:28 PM	Psoriatic Arthritis Foot Study	🔗	🌐	34	5 5	Boost Post
10/05/2019 8:20 AM	Exactly what our study is trying to do! The foot is a prime target for	🔗	🌐	52	15 9	Boost Post
09/30/2019 7:43 PM	Psoriatic arthritis is not well known and is under-researched. Increasing	🔗	🌐	38	3 3	Boost Post



09/29/2019 5:52 PM	Living with psoriatic arthritis: When pain and inflammation takes over	🔗	🌐	53		13 7	Boost Post
09/28/2019 7:25 AM	Presentation of some key facts and figures. Although mainly focusing on	📹	🌐	21		3 0	Boost Post
09/25/2019 5:19 PM	Another excellent video confirming the profound impact of autoimmune	📹	🌐	33		4 4	Boost Post
09/19/2019 6:26 PM	To date, most research about how psoriatic arthritis affects the nails has	🔗	🌐	40		6 7	Boost Post
09/18/2019 4:39 PM	Foot pain and changes in foot shape can restrict footwear choice and	🔗	🌐	41		6 6	Boost Post
09/18/2019 4:10 PM	Excellent video about the experience of living with psoriatic arthritis from	📹	🌐	49		14 6	Boost Post
09/17/2019 5:59 PM	Enthesitis is a hallmark feature of Psoriatic Arthritis that typically affects	🔗	🌐	71		26 14	Boost Post
09/17/2019 5:52 PM	Painful feet and ankles can greatly impact the ability to walk comfortably	🔗	🌐	39		4 5	Boost Post
09/17/2019 5:05 PM	Condition Focus: PSORIATIC ARTHRITIS. Useful resources!	🔗	🌐	32		2 4	Boost Post
08/28/2019 11:49 AM	You can make a difference! The power of crowd-sourcing By liking	▭	🌐	110		2 6	Boost Post
08/14/2019 1:49 PM	Distributing surveys at the specialist Psoriatic Arthritis Clinic at Liverpool	▭	🌐	226		15 16	Boost Post
08/13/2019 8:17 PM	Psoriatic arthritis affects men and women equally, but look at the	▭	🌐	227		5 9	Boost Post
07/30/2019 12:48 PM	Tell us about your experience of foot problems related to psoriatic arthritis	▭	🌐	146		2 3	Boost Post
07/25/2019 8:31 PM	Increasing awareness among health professionals about foot problems in	▭	🌐	186		15 18	Boost Post
07/22/2019 8:33 PM	Seeking the views of people with foot problems related to psoriatic arthritis	▭	🌐	150		7 11	Boost Post
07/21/2019 3:53 PM	The survey production line continues. We continue to need your	▭	🌐	162		12 8	Boost Post
07/19/2019 11:38 AM	Thank you to these organisations for helping to promote our survey on	▭	🌐	32		0 0	Boost Post
07/16/2019 5:10 PM	More surveys coming in! Thanks very much to those who have sent	▭	🌐	171		12 14	Boost Post
07/12/2019 5:36 PM	Online Survey Software | Qualtrics Survey Solutions	🔗	🌐	27		1 2	Boost Post
07/08/2019 6:28 PM	Psoriatic Arthritis Foot Study updated their address.	🔗	🌐	1		0 0	Boost Post
07/05/2019 12:02 PM	Western Sydney University researchers are seeking your help	🔗	🌐	2.7K		244 104	Boost Post
07/05/2019 11:57 AM		▭	🌐	30		0 1	Boost Post
07/05/2019 11:53 AM		▭	🌐	29		0 1	Boost Post
07/05/2019 9:22 AM	Psoriatic Arthritis Foot Study	▭	🌐	0		0 1	Boost Post

Appendix 10: Survey



WESTERN SYDNEY
UNIVERSITY

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 or if you would like to learn more about this study, please visit our website 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.

There are 8 sections and the survey should take about 20 minutes. We hope you will be able to take part.

Section 1	About you
Section 2	About your psoriatic arthritis
Section 3	About your foot and ankle
Section 4	About your psoriasis
Section 5	About your toenails
Section 6	About your feet and your daily life
Section 7	About your footwear
Section 8	About how you manage your feet

Please turn the page ⇨

Section 1 of 8. About you

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

1. Where do you live?

☐ Australia
☐ New Zealand (Aotearoa)

2. What is your post code? ____________________

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

7. What is your ethnic group?

☐ Australian European
☐ New Zealand European
☐ Aboriginal
☐ Torres Strait Islander
☐ Maori
☐ Pacific Islander
☐ English
☐ Irish
☐ Scottish
☐ Italian
☐ Greek
☐ German
☐ Dutch
☐ Lebanese
☐ African
☐ Middle Eastern
☐ Southeast Asian
☐ Chinese
☐ Indian
☐ Other (please specify)

____

Please turn the page ⇨

8. What is your **current** work status? Please tick **ALL** that apply.

☐ In full time paid work
☐ In part time paid work
☐ In casual or contracted paid work
☐ Completely retired/pensioner
☐ Partially retired
☐ Disabled or too sick to work
☐ Self-employed
☐ Doing unpaid work
☐ Studying
☐ Looking after home/family
☐ Unemployed
☐ Other (please specify) ____________________

9. Has your work status changed due to your psoriatic arthritis?

Yes ☐ No ☐

10. What is your highest qualification? Please tick the most appropriate box.

☐ No school certificate or other qualifications
☐ School or intermediate certificate (or equivalent)
☐ Higher school or leaving certificate (or equivalent)
☐ Trade/apprenticeship
☐ Certificate/diploma
☐ University degree or higher

Please turn the page ⇨

Section 2 of 8. About your psoriatic arthritis

In this section we are asking some general questions about your psoriatic arthritis so that we can find out how it affects you overall.

11. Do you currently see a **rheumatologist** for your psoriatic arthritis?

Yes ☐ No ☐

12. Approximately how long ago did your **symptoms** of psoriatic arthritis start?

______Years ______Months

13. Approximately how long ago were you **diagnosed** with psoriatic arthritis?

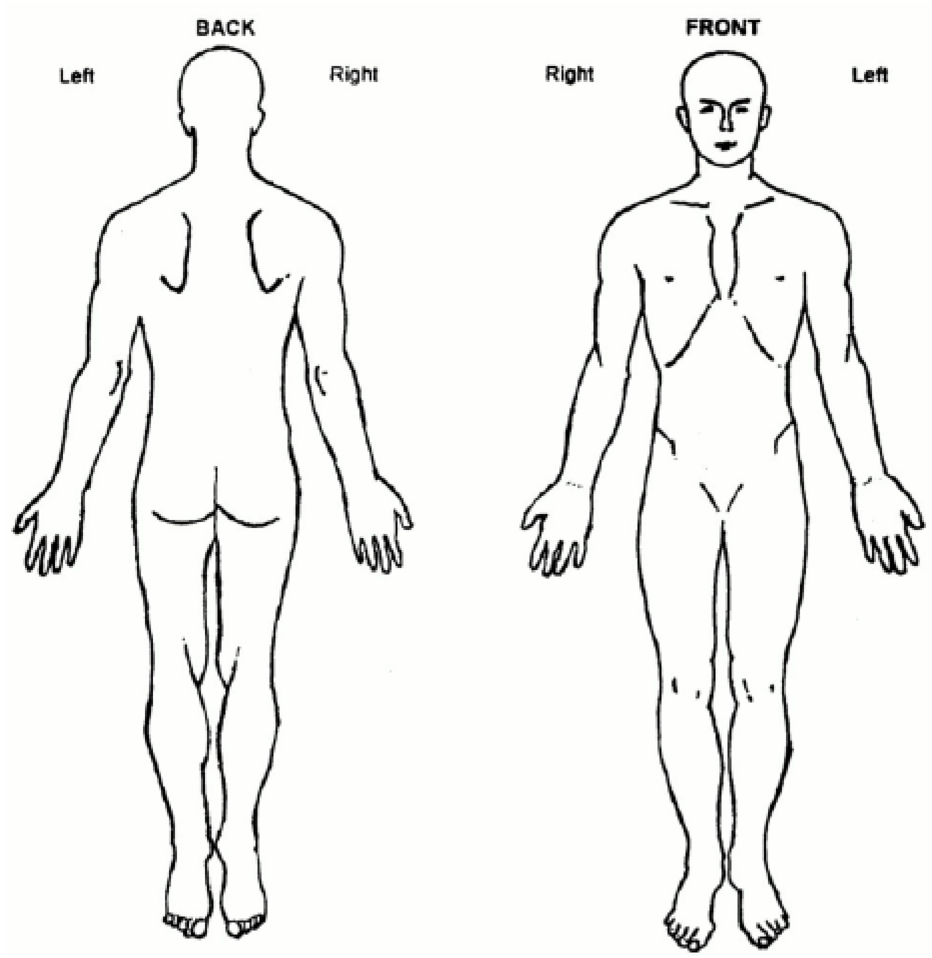
______Years _______Months

14. Please tick any medications that you are **CURRENTLY** taking for your psoriatic arthritis or psoriasis:

Methotrexate	☐	Humira (Adalimumab)	☐
Arava (Leflunomide)	☐	Cosentyx (Secukinumab)	☐
Salazopyrin (Sulphasalazine)	☐	Stelara (Ustekinumab)	☐
Plaquenil (Hydroxychloroquine)	☐	Remicade (Infliximab)	☐
Enbrel (Etanercept)	☐	Simponi (Golimumab)	☐
Otezla (Apremilast)	☐	Cimzia (Certolizumab)	☐
Orencia (Abatacept)	☐	Xeljanz (Tofacitinib)	☐
Cyclosporin	☐	Prednisolone (Steroids)	☐
Tremfya (Guselkumab)	☐	Anti-inflammatories (Nurofen, Voltaren, Mobic, Celebrex)	☐
Alternative or complementary medicines	☐	Not currently taking any medication for my psoriatic arthritis or psoriasis	☐
Other medications for psoriatic arthritis or psoriasis not on the list	☐		

Please turn the page ⇨

15. Please **shade** in the diagrams below **ALL** the parts of your body where you have had any ache or pain that you believe is due to your psoriatic arthritis, which has lasted for one day or longer over the **past month**.



16. Which part of your body has been the MOST painful or sore over the **past month**? Please tick **ONE** box only.

☐ Head and neck
☐ Shoulders
☐ Elbows
☐ Wrists
☐ Hands and fingers

☐ Back
☐ Hips
☐ Knees
☐ Ankles
☐ Feet and toes

OR Not sure ☐

Please turn the page ⇨

17. In all the ways that your **ARTHRITIS** affects you, how would you rate the way you have felt over the **past week**?

Please circle one number to rate the way you have felt.

Excellent Poor

0	1	2	3	4	5	6	7	8	9	10

18. In all the ways that your **PSORIASIS** affects you, how would you rate the way you have felt over the **past week**?

Please circle one number to rate the way you have felt.

Excellent Poor

0	1	2	3	4	5	6	7	8	9	10

19. In all the ways that your **ARTHRITIS and PSORIASIS**, as a whole, affects you, how would you rate the way you felt over the **past week**?

Please circle one number to rate the way you have felt.

Excellent Poor

0	1	2	3	4	5	6	7	8	9	10

20. How much **PAIN** have you had because of your psoriatic arthritis over the **past week**?

Please circle one number to indicate how severe your pain has been.

No pain Worst pain ever

0	1	2	3	4	5	6	7	8	9	10

Please turn the page ⇨

21. Have you been diagnosed with any of these conditions?

Please tick **ALL** that apply.

☐ Diabetes

☐ Osteoarthritis

☐ Fibromyalgia

☐ Anxiety – feeling nervous

☐ Depression – feeling blue

Please turn the page ⇨

Section 3 of 8. About your foot and ankle

In this section we are particularly interested in how your psoriatic arthritis affects your feet.

22. In the **past month**, have you had pain in your feet and ankles that has lasted for one day or longer?

Yes ☐ No ☐

IF NO, skip to question 26 on page 11.

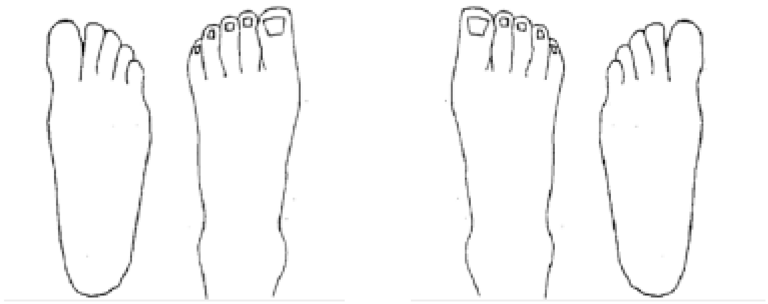
23. **IF YES**, please circle one number to indicate how severe your foot and ankle pain has been over the **past month**.

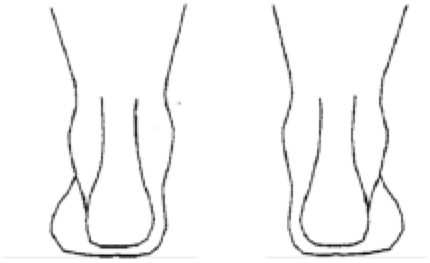
No pain — Worst pain ever

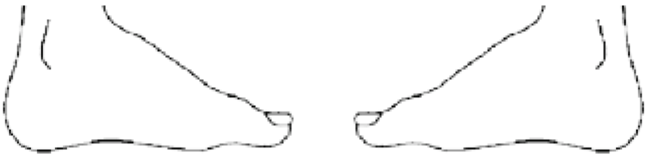
0	1	2	3	4	5	6	7	8	9	10

Please turn the page ⇨

24. Please **shade** in the diagrams below **ALL** the places on your feet and ankles where you have had any ache or pain that has lasted for one day or longer over the **past month**.







Please turn the page ⇨

25. How do the symptoms (such as pain, ache, discomfort) in your feet and ankles change during a **typical day**? To what extent do you agree with the following statements?

	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree
The symptoms in my feet are worse in the morning	☐	☐	☐	☐	☐
The symptoms in my feet are worse at the end of the day	☐	☐	☐	☐	☐
The symptoms in my feet are worse after rest or inactivity	☐	☐	☐	☐	☐
The symptoms in my feet are better with activity such as walking	☐	☐	☐	☐	☐
The symptoms in my feet are there all day	☐	☐	☐	☐	☐
The symptoms in my feet can seem to randomly change from day to day	☐	☐	☐	☐	☐

Please turn the page ⇨

26. Apart from pain, how often do you have any of the other following symptoms in your feet and ankles?

	All the time	Very often	Often	Not very often	Never
Swelling	☐	☐	☐	☐	☐
Stiffness	☐	☐	☐	☐	☐
Cramp at the back of the leg or foot	☐	☐	☐	☐	☐
Numbness, burning or tingling	☐	☐	☐	☐	☐
Hot feet	☐	☐	☐	☐	☐
Cold feet	☐	☐	☐	☐	☐
Tired feet - aching feeling	☐	☐	☐	☐	☐

27. Overall, to what extent do you find the symptoms listed above in your feet and ankles troublesome (cause trouble, annoyance or difficulty)?

Please circle one number to indicate how troublesome your symptoms have been.

Not troublesome at all

Extremely troublesome

0	1	2	3	4	5	6	7	8	9	10

Please turn the page ⇨

28. What problems have you had or currently have with your feet?

Please tick **ALL** that apply.

☐ Crooked or bent toes

☐ Bony bump at the side of the big toe (Bunions)

☐ Swelling of the entire toe (Sausage toe)

☐ Hard skin or corn

☐ Deformity at the front of the foot (excluding toes)

☐ Open wound / sore that has taken over a week to heal

☐ Achilles tendon (**back of the heel**)

☐ Plantar fascia (**under the heel or arch**)

☐ Flat feet

☐ Dry cracked heels

☐ Deformity at the ankle and heel

☐ Size of my feet (changes in length and width)

29. Have you ever felt **embarrassed** or **self-conscious** about any of the foot problems listed above?

Yes ☐ No ☐

Please turn the page ⇨

Section 4 of 8. **About your psoriasis**

Psoriasis is a skin rash that forms red scaly or silvery white patches. In this section we are interested in how psoriasis affects your feet and lower legs.

30. Do you have psoriasis on the skin of your feet?

Yes ☐ No ☐

IF NO, skip to question 35 on page 15.

31. Do you have psoriasis on the skin of your lower legs (knee to ankle)?

Yes ☐ No ☐

32. Do you currently see a **dermatologist** for your psoriasis?

Yes ☐ No ☐

33. Please indicate how psoriasis has affected the skin on your feet and ankles over the **past month**. Please tick **ALL** that apply.

☐ Splitting of the skin
☐ Bleeding of the skin
☐ Redness of the skin
☐ Thick hard skin (callus)
☐ Itching of the skin
☐ Scaling or flaking of the skin
☐ Pain and discomfort of the skin

Please turn the page ⇨

34. Please indicate how much the skin problems (including psoriasis, hard skin, skin infection) on your feet and lower legs have affected your life over the **past month**.

	Extremely	Moderately	Mildly	Not at all
How **sore**, **tender** or **painful** has the skin on your feet and lower legs been?	☐	☐	☐	☐
How **embarrassed** or **self-conscious** have you felt because of the skin on your feet and lower legs?	☐	☐	☐	☐
How much has the skin on your feet and lower legs interfered with your **daily activities** or **social** and **leisure activities**?	☐	☐	☐	☐
How much has the skin on your feet and lower legs influenced the **footwear** you wear?	☐	☐	☐	☐

Please turn the page ⇨

Section 5 of 8. About your toenails

In this section we are interested in how psoriasis affects your toenails. If your toenails are thick, discoloured or separating from the skin underneath you may have toenail psoriasis.

35. Do you think that you currently have toenail psoriasis?

Yes ☐ No ☐

IF NO, skip to question 38 on page 17.

36. Please indicate any problems you have had with your toenail psoriasis over the **past month**. Please tick **ALL** that apply.

☐ Thickened nail
☐ Splits in the nail
☐ Nail lifts up (nail separates from the skin underneath)
☐ Pitting in the nail (small pits in the nail)
☐ Nail peels or breaks off
☐ Ridges in the nail (lines across the nail)
☐ Discoloured nail (white, yellow, brown)
☐ Build up under the nail
☐ Wave shaped nail
☐ In-grown toenail

Please turn the page ⇨

37. Please indicate how much your toenail psoriasis has affected your life over the **past month**.

	Extremely	Moderately	Mildly	Not at all
How **tender** or **painful** have your toenails been?	☐	☐	☐	☐
How **embarrassed** or **self-conscious** have you felt because of your toenails?	☐	☐	☐	☐
How much have your toenails interfered with your **daily activities** or **social** and **leisure activities**?	☐	☐	☐	☐
How much have your toenails influenced the **footwear** you wear?	☐	☐	☐	☐

Please turn the page ⇨

Section 6 of 8. About your feet and your daily life

In this section we are interested in how your feet and ankles affect your daily life.

38. To what extent have you had difficulties in undertaking the following activities because of **your feet**?

	Unable to do	Very difficult	Moderately difficult	Slightly difficult	Not difficult
Standing for 5 minutes	☐	☐	☐	☐	☐
Walking for 5 minutes	☐	☐	☐	☐	☐
Walking barefoot	☐	☐	☐	☐	☐
Going up and down stairs	☐	☐	☐	☐	☐

39. Have you had difficulties with any of the activities listed above because of problems **in other parts of your body**?

Yes ☐ No ☐

Please turn the page ⇨

40. How many times did you do each of these activities in the **past week**?

	Every day of the week	4 – 6 times in a week	2 – 3 times in a week	Once a week or less	Never
Walking continuously for at least 10 minutes (for recreation or exercise or to get to or from places)	☐	☐	☐	☐	☐
Moderate physical activity (like gentle swimming, social tennis, gardening or work around the house)	☐	☐	☐	☐	☐
Vigorous physical activity (that made you breathe harder or puff and pant, like jogging, cycling, aerobics, competitive tennis, but not household chores or gardening)	☐	☐	☐	☐	☐

Please turn the page ⇨

41. Have <u>your feet</u> interfered with your daily activities over the **past month**?

	Yes, interfered a lot	Yes, interfered a little	No, not at all interfered	Not relevant
Going to the shops	☐	☐	☐	☐
Looking after your home	☐	☐	☐	☐
Leisure or social activities	☐	☐	☐	☐
Being a parent or carer	☐	☐	☐	☐
Spending time with family	☐	☐	☐	☐
Exercise	☐	☐	☐	☐
Sleep	☐	☐	☐	☐
Driving	☐	☐	☐	☐
Work	☐	☐	☐	☐

Please turn the page ⇨

42. To what extent do you agree with the following statements?

	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree
I walk **slower** than others	☐	☐	☐	☐	☐
I **limp** or **shuffle** or feel **unstable** when I walk	☐	☐	☐	☐	☐
I feel **embarrassed** or **self-conscious** about the way that I walk	☐	☐	☐	☐	☐
I feel **frustrated** by the problems with my feet	☐	☐	☐	☐	☐
I stay **indoors most of the day** because of my foot problems	☐	☐	☐	☐	☐

43. How many times have you fallen to the floor or ground over the **past 12 months**?

0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 or more ☐

Please turn the page ⇨

Section 7 of 8. About your footwear

In this section we are interested to find out about the types of shoes you wear on a regular basis and what is important to you when choosing footwear.

44. What type of footwear do you wear the MOST during a **typical week**?

Please tick **ALL** that apply.

☐ Fashion sandals, thongs or jandals
☐ Supportive style sandals
☐ Ballet flats or moccasins
☐ Slip-on sneakers
☐ Lace-up sneakers
☐ Sport shoes
☐ Business shoe or court shoe
☐ High heels
☐ Work boot such as steel toe-capped
☐ Supportive walking boot
☐ General boot (heeled or flat)
☐ Prescribed or customised shoes (extra-deep/wide footwear)
☐ Barefoot only, socks or slippers

45. What are the top 5 most important factors to you when choosing footwear?

Please tick **FIVE** boxes only.

☐ Wider fit
☐ Cushioning sole
☐ Plenty of room around my toes
☐ Breathability
☐ Open-toed
☐ Closed-in
☐ Cost
☐ Style
☐ Adjustable straps
☐ Support
☐ Soft around the back of my heel
☐ Arch support or fits an insole
☐ Light-weight
☐ Heel height
☐ Easy to get on/off
☐ Other (please specify)

____

Please turn the page ⇨

46. To what extent do you agree with the following statements about **difficulties** you may have with your footwear?

	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree	
It is hard to find footwear that **do not hurt** my feet	☐	☐	☐	☐	☐	
I have difficulty in finding **footwear that fits** my feet	☐	☐	☐	☐	☐	
I am limited in the **number** of shoes I can wear	☐	☐	☐	☐	☐	
I have **difficulty with daily activities** due to discomfort from my footwear	☐	☐	☐	☐	☐	
I am limited in the **kind of work** I can do due to difficulties with my footwear	☐	☐	☐	☐	☐	☐ I do not work
I have difficulty in finding footwear appropriate for a **special occasion**	☐	☐	☐	☐	☐	
I feel **frustrated** about the problems I have with footwear	☐	☐	☐	☐	☐	
I feel **embarrassed** about the footwear I wear	☐	☐	☐	☐	☐	
I find that I am restricted to the same type of footwear **all year around**	☐	☐	☐	☐	☐	

Please turn the page ⇨

Section 8 of 8. About how you manage your feet

In this section we are interested to find out how you take care of your feet and how you cope with any foot problems.

47. Considering your foot problems overall, how well did you <u>cope</u> (manage, deal, make do) with your foot problems over the **past month**?

Please circle one number to indicate how well you have coped.

Coped very well

Coped very poorly

0	1	2	3	4	5	6	7	8	9	10

48. Please indicate the typical ways in which you <u>cope</u> with your foot problems. Please tick **<u>ALL</u>** that apply.

☐ Accept limitations

☐ Pace and plan

☐ Get on with it, despite the problem

☐ Hide the problem from others

☐ Do not think about the problem

☐ Try to keep in control of the problem

☐ Get support from family, friends and/or health professionals

☐ None, I do not use coping strategies

49. Considering all the people around you (family, partner, friends and others), do you believe that there is a:

Please tick **<u>ALL</u>** that apply.

☐ Lack of understanding about the disease

☐ Lack of support for people with the disease

<u>OR</u> ☐ Neither of these

Please turn the page ⇨

50. Do you belong to a patient support group (such as Arthritis Australia or Arthritis New Zealand) for your psoriatic arthritis or psoriasis?

Yes ☐ No ☐

51. Do you need assistance to help take care of your feet properly?

Yes ☐ No ☐

52. Have you tried to manage your own foot problems (such as applying products, using devices or purchasing particular footwear)?

Yes ☐ No ☐

<u>**IF NO**</u>, skip to question 54 on page 25.

<u>**IF YES**</u>, how effective do you feel you have been at managing your foot problems?

Extremely effective ☐ Very effective ☐ Moderately effective ☐ Mildly effective ☐ Not at all effective ☐

53. Considering all the ways you may have tried to care for your feet (for example, paying for nail care, footwear, padding, creams, insoles, massage etc.) in the **past 12 months**, approximately how much have you spent of your own money?

$_______________

Please turn the page ⇨

54. Who have you seen about your foot problems? Please tick **ALL** that apply.

☐ GP/Doctor
☐ Rheumatologist
☐ Occupational therapist
☐ Dermatologist
☐ Podiatrist
☐ Foot massage or reflexologist
☐ Physiotherapist
☐ Surgeon
☐ Traditional Chinese medicine
☐ Nurse
☐ Pedicure
☐ I have not seen anyone
☐ Other (please specify) ______________________________

IF NO you have not seen anyone, skip to question 55.

IF YES, how effective was the help you received overall?

Extremely effective ☐ Very effective ☐ Moderately effective ☐ Mildly effective ☐ Not at all effective ☐

IF YES, overall how confident were you that the health professionals you have seen had a good understanding of how psoriatic arthritis affects your feet?

Extremely confident ☐ Very confident ☐ Moderately confident ☐ Mildly confident ☐ Not at all confident ☐

55. Has your rheumatologist ever asked about your feet?

Yes ☐ No ☐

56. Has your rheumatologist ever examined your feet?

Yes ☐ No ☐

57. Have you ever seen a podiatrist about your feet?

Yes ☐ No ☐

58. Do you receive regular podiatry treatment for your feet?

Yes ☐ No ☐

Please turn the page ⇨

59. Have you ever had any ankle or foot surgery?

Yes ☐ No ☐

<u>IF YES</u>, did your ankle or foot problems improve after the surgery?

Yes ☐ No ☐

END

Please turn the page ⇨

Would you be willing to be contacted in the future about studies related to this research?

Providing your contact details indicates that you consent to be contacted by our research team about future studies related to foot problems affecting people with psoriatic arthritis. Your contact details will be kept strictly confidential, stored securely, will only be used by the research team and your identity will not be revealed in any future publications. Your contact details will be kept for the next 5 years; after which time they will be destroyed. Participation in future projects is completely voluntary and you are free to withdraw at any time if you later change your mind.

Yes ☐ No ☐

IF YES, please put your name and telephone number or email address below:

____

____

If you would you like to find out the results from this study, please go to our website www.psoriaticfootarthritis.com. The study results will be available from January 2020.

If you have any queries please contact Kate Carter on +61 (02) 4620 3285 or email info@psoriaticfootarthritis.com. For Maori participants please contact the Maori Advisor; Associate Professor Nichola Kayes from the Mātauranga Māori Consultation Committee, AUT University on +64 (09) 921-9999 ex 7309.

Thank you for taking the time to complete this survey

Please return the completed survey in the stamped addressed envelope to:

Miss Kate Carter
Podiatric Medicine, Room 24.2.59, Building 24, Western Sydney University, School of Science and Health, Campbelltown Campus, Sydney NSW, 2214, Australia.

Appendix 11: Discussion comparison table

Table to compare the results of the previous clinic-based foot-specific study in psoriatic arthritis with the current survey results.

	Current study	Hyslop, et al., (2010a)
Number of people with PsA	606	104
Male/Female	68/532	44/60
Age, years	51 (12)	51 (12)
Body mass index, kgm^2	31 (7)	NR
Disease duration, years	8.5 (10)	10 (9)
Foot pain, n (%)	519 (92%)	64 (62%)
Foot pain (NRS 0-10, VAS 0-100mm)	6 (2)	NR
Global pain (NRS 0-10, VAS 0-100mm)	6 (2)	36 (29)
Plantar fasciitis, n (%)	321 (57%)	27 (26%)
Achilles enthesitis, n (%)	213 (38%)	19 (18%)
Joint deformity, n (%)	530 (94%)	8 (4)
Dactylitis, n (%)	223 (40%)	25 (24%)
Skin psoriasis, n (%)	161 (29%)	8 (8%)
Toenail psoriasis, n (%)	321 (57%)	13 (13%)
DMARD therapy, n (%)	340 (59%)	73 (70%)
Biologic therapy, n (%)	249 (43%)	12 (12%)

Data presented as mean (SD) unless specified. *DMARD* Disease modifying anti-rheumatic drug, *NR* Not reported, *NRS* Numerical rating scale, *PsA* Psoriatic arthritis, *VAS* Visual analogue scale.