Foot Health Education
For People with Rheumatoid Arthritis

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This one’s for you, Mum and Dad.

Declaration of Originality: Statements of candidates' independent work and contributory authors by publication number.

As a PhD by published works, this thesis comprises seven papers which have previously been accepted in, or submitted to, peer-reviewed journals and have been, or are to be, published in the public domain. The papers have been written in collaboration with co-authors and the extent to which the author contributed to each paper is defined in the table below and verified by collaborating authors in Appendix A.

Number of paper	Authors	Detail of Independent contribution	Detail of joint contribution
1	Andrea Graham, Professor Alison Hammond, Dr Anita Williams	Undertook the literature search, completed the data extraction and narrative review of the literature	Principal author of the paper
2	Andrea Graham, Professor Alison Hammond, Steven Walmsley, Dr Anita Williams	Conceived and created the study design.	Principal author of the paper, conducted primary thematic analyses
3	Andrea Graham, Professor Alison Hammond, Dr Anita Williams	Conceived and created the study design.	Principal author of the paper, conducted primary thematic analyses
4	Dr Anita Williams, Andrea Graham	Fieldwork observer for focus groups	Co-author of the paper, conducted thematic analyses
5	Andrea Graham, Dr Anita Williams	Conceived and created the study design, developed, tested and modified the online survey.	Principal author of the paper, conducted thematic analysis
6	Andrea Graham, Dr Anita Williams	Conceived and created the study design, developed, tested and modified the online survey, conducted statistical analyses.	Principal author of the paper, conducted thematic analyses
7	Andrea Graham, Dr John Stephenson, Dr Anita Williams	Conceived and created the study design, developed, tested and modified the online survey.	Principal author of the paper, co-conducted descriptive and inferential data analyses.

Table (i) – Author and Co-author contribution by publication

Abstract

Foot problems for people with rheumatoid arthritis (RA) are common resulting in significant pain, activity restriction and reduced quality of life. Provision of information and health education in respect of foot health would therefore seem to be an essential aspect of foot health management for people with RA, in order to maintain their foot health and overall well being. Although educational resources exist for this group of people, their exact needs and preferred methods of receiving education about foot health have not been formally sought.

The aim of this body of work was to investigate patients' and podiatrists' perspectives of current foot health education provision for people with RA in the UK; firstly aiming to identify any evidence to support the use of foot health education, then exploring patient and podiatry practitioner experiences of foot health education provision. This thesis therefore presents seven works published between 2011 and 2017 that explore the perceptions of people with RA and podiatrists about foot health education provision in the UK.

This body of work has been critically reviewed through; personal reflection of the author's perceptions of patient education and in the context of the work within the public domain. The methodological approaches used, the wider impact of the work and its' translation into practice have been critically evaluated through analysis of citation/download and Altmetric data and review of the current literature, demonstrating the works' broad utilisation and impact.

This work demonstrates an original and distinctive contribution to research design within the podiatry profession, the understanding of foot health education needs of people with RA and the continuing significant burden that diminished foot health has on this population of people.

Overall, the publications within this thesis have culminated in the identification of the need for future research to develop a foot-health related educational needs analysis tool that will facilitate a more timely and tailored approach to FHE provision.

Chapter 1

1.1 Introduction: the research in context

The purpose of this section is to provide a contextual background to the overarching development of the research focus of this thesis and the portfolio of publications contained within it. I will also reflect upon my journey both as a clinician and evolving researcher. It will provide the reader with insight into the process by which the research problem was identified and how the aims and objectives of the research evolved. Further within this thesis I will reveal how undertaking the research has challenged my personal perceptions of what ‘patient education’ is. Hence, I will share how my personal understanding can be used to develop the provision of foot health education (FHE) by clinicians. Specifically, through the publications and also conference presentations I have aimed to facilitate clinicians’ understanding of what ‘patient education’ is and how we can identify the foot health educational needs of the patients we manage with RA- related foot pathology.

Patient education can be viewed as a spectrum of interventions, from basic information giving to programmes that enable behavioural change. Through enhancing the clinician’s understanding of this spectrum of educational provision and how *health education* and *health information* can be defined, we may be able to more effectively enable people with RA to understand what is meant by a ‘tailored approach’ to FHE. In doing this both the person with RA and the clinician can arrive at a mutual consensus of what the person requires and acknowledge the context within which it is required. Approaching the provision of FHE in this way can be considered not just for people with rheumatoid arthritis (RA), but across a range of people presenting with various foot pathologies.

1.1.1: Patient education and the Podiatry profession

Patient education for effective foot health management is a core component of podiatric clinical practice. Foot health promotion and health education are key elements of the 2001 Podiatry Quality Assurance Agency (QAA) Benchmark statement (QAA, 2001) and the 2013 Health and Care Professions Council (HCPC) Standards of Proficiency for Chiropodists/Podiatrists (HCPC, 2013) wherein they reinforce the requirement for practitioners to:

> “Understand the need to empower patients to manage their foot health and related issues and recognise the need to provide advice to the patient on self-management where appropriate.” (HCPC, 2013 pp 9)

Research in relation to patient education (PE) and foot care appears within the published literature as early as 1975 with Hymes and Hymes’ paper in the Journal of the American Podiatry Association; “How long shall I keep these pads on?” (Hymes and Hymes, 1975) thus the concept of patient education within the profession is far from new. A search of the literature using the key words “podiatry” AND “patient education”/ “chiropody” AND “patient education” reveals 94 publications up to the current date (87 excluding those included in this thesis). The first decade of publications have no available abstracts, although the titles reveal that much of the literature was concerned with diabetes and foot health, with (Scarlett et al, 1976) publishing a pilot study of the use of diabetic foot care education. Research into foot health education in relation to diabetes has remained the dominant focus for patient education from the 1970’s up to the present day. However, a number of studies have been published within the last 10 years that focus upon foot health care advice in relation to; readability of online education resources (Sheppard et al, 2014; Rosenbaum and Ellis, 2016), plantar fasciitis (Beischer et al, 2008), falls (Cockayne et al, 2014), footwear advice (van der Zwaard et al, 2014; Farndon et al, 2016) and self-management strategies for foot care in the elderly (Waxman et al, 2003; Cockayne et al, 2014). More specifically, with the exclusion of those publications that form the basis of this thesis, research has been undertaken to establish the ability of people with RA to participate in a foot care self-management programme (Semple et al, 2009). The next section identifies the current context of FHE for people with RA.

1.1.2: The current context of foot health education for people with rheumatoid arthritis

Therapeutic patient education is recognized and recommended as an integral component in the management of people with inflammatory arthropathy, including RA (Zangi et al, 2015). The last decade alone, during which this research and its’ associated publications were completed, has seen the development and publication of a number of international and national guidelines and recommendations that support the use of PE for people with RA, (Zangi et al, 2015; NICE, 2009; PRCA, 2008), demonstrates recognition of the significant impact that PE can have upon the ability of people to manage their illness, adjust to their condition and maintain their quality of life (Newman et al, 2004; deRidder et al, 2008). Research in relation to PE interventions has shown that it can result in significant outcomes, although short term, such as improvements in the knowledge, pain levels, functional ability, positive coping behaviours and levels of depression (Riemsma et al, 2003) of people with RA. Therefore, it could be reasonable to assume that a FHE intervention could be expected to have similar outcomes in relation to RA and foot-related pathology.

As there has been no research to date (2017) that demonstrates these outcomes directly, studies that have evaluated the impact of FHE as an intervention in people with diabetes-related foot pathology such as diabetic foot ulceration (DFU) may parallel the potential impact of FHE upon clinical outcomes for people with RA foot pathology. Such research has demonstrated conflicting results with regards the occurrence and reoccurrence of DFU (Calle-Pascual et al, 2002; Lincoln et al, 2008). However, a systematic review (Dorresteijn et al, 2010) indicated some short-term positive effects on patients' knowledge and positive health behaviour changes. It may be possible to draw parallel conclusions in people with RA who are at risk of developing similar significant foot pathology such as the development of deformity, ulceration, vascular and neurological deficit as people with foot pathology arising from the complications of diabetes. It may be pragmatic, therefore, to assume that the effect of FHE upon the RA population would yield similarly conflicting results. The danger with such assumptions may lie in the physiological differences in etiological development and different symptoms between RA and diabetes related-foot pathology, in addition it should be recognised that people with RA may lack the physical ability to engage in foot health self-management programmes (Semple et al, 2009). It is justifiable, therefore, to investigate FHE for people with RA in its' own right. The following section reflects upon the motivating factors and drivers that influenced my developing interest in FHE provision and how my understanding of 'patient education' as a concept, evolved over time.

1.1.3: The personal context – reflections on the personal drivers behind the research

In 2002 I was a Senior Podiatrist about to embark upon a newly created specialist role within Rheumatology, with only my undergraduate academic training and nine years of clinical experience of general podiatry practice to refer to in relation to the management of Rheumatic Diseases. In order to equip myself with the depth of knowledge I would need to apply in practice, I completed a Master's degree focussing on Rheumatic disease assessment and management, with the dissertation being a critical review of foot health interventions for people with RA (Graham A, MSc dissertation, 2006) The subject of the dissertation was driven by my need to understand how I could best manage the patients in my care, the majority of whom had profoundly painful feet and foot related pathology due to RA. At this time I was also a member of the North West Clinical Effectiveness Group for the Management of Foot Health in People with Rheumatic Diseases and was involved in the creation of clinical guidelines with the focus of my contribution also being FHE.

As I became more familiar with the clinical needs of my patients, and the literature (in support of my MSc dissertation), I found that there was no published research to support the provision of foot health education for people with RA and hence no recognition of it as an intervention in the guidelines that supported clinical practice. Specifically, there was no published research that identified the kind of information that this patient group might require, should have access to or the methods by which it would most effectively be delivered. As part of my role I routinely provided verbal and written information in the form of leaflet 'packs' that I created from patient leaflets developed by Arthritis Research UK. The packs contained patient information leaflets on Rheumatoid Arthritis and on Foot Health in relation to arthritis and I felt that I had 'ticked the box' for patient education in providing that. However, through the process of writing my dissertation I realised that there was no parity between the standard and depth of foot health education provision for my patients with RA and, for example, patients with diabetes. Further, there was a body of evidence that supported foot health education for patients with diabetes. There was a clear gap in the evidence to support foot health education for people with RA.

Reflecting on my clinical experiences within podiatry services in the NHS I had evolved from a novice practitioner in podiatry to becoming an ‘expert’ within a specialised field of practice. However, in relation to patient education provision I still practised as I had upon graduating twelve years earlier. I relied upon the tacit knowledge I had built over the years, of how to assess a patient’s physical requirements very quickly within the time constraints of an NHS appointment and according to published guidance, but realised that I hadn’t really ever sought out what the individual might have wanted to know and understand about their own foot health. In the early 1990’s, as a trainee and newly qualified novice podiatrist, patient education for all patients with foot health problems was very much an ‘add-on’ component of podiatric management; there were no ‘expert patient’ or management programmes available for patients to be referred into. Thus the ‘traditional’ provision of patient education was very much an adjunct to routine, hands-on practice. We had begun to move away from the ‘medical model of care’ (Beck 2004) and were utilising a more ‘patient-centred’ approach. However, during the time that I was an undergraduate, a consultation that embraced the identification of a patient’s health beliefs i.e. the ‘person-in context’ approach (Allen, 1996) was not a concept that was overtly taught within the podiatry curriculum. I carried this very ‘traditional’ approach to patient education provision with me, even as I became an ‘expert’ practitioner, an approach that allowed my patients no real acknowledgement of their educational needs and was reinforced by the time and financial limitations of NHS podiatry services.

The people with RA that I had treated within the NHS had varied reactions to RA affecting the feet. This ranged from being surprised and distressed by the level of foot pain they had to endure, the significance with which it impacted upon their ability to function on a day-to-day basis and by the potential impact of the pharmacological management, to having no real awareness of how RA might affect their future foot health. The level of knowledge of how RA and its general management could impact upon foot health needed to be raised amongst those who were diagnosed with the disease. In order to begin to address this lack of awareness and with the aim of reaching those patients who were not referred to me, I invited the multi-disciplinary team (MDT) members with whom I collaborated to a short presentation session aimed at raising awareness of my role and how podiatrists could play a key role in managing people with rheumatic diseases affecting the feet. I was fortunate enough to work within a specialist hospital, with a consultant rheumatologist who was a strong advocate for the inclusion of podiatrists within their MDT. However, I was surprised at the number of times that patients who had been referred to me couldn't understand why a podiatrist would have a role to play in the management of their RA. Further to this, the more junior medical practitioners and some other members of the MDT seemed to lack awareness of the role of the podiatrist and thus would rarely refer patients into the podiatry service. This lack of understanding about the professional role of a podiatrist, seemed to me to be a fundamental barrier to people with RA being able to access timely foot care and information so they could raise their understanding of the potential impact of RA on their foot health and how they might maximise their own foot health.

Through my own increasing experience of treating people with RA and related foot problems, shared anecdotal experiences with peers within the North West Clinical Effectiveness group for Rheumatology and from reading the literature, I recognised that locally and nationally, there were gaps. These were in clinical practice, patient awareness and generally in the evidence base around the provision of foot health education for people with RA. At this point in my career I moved from working within the NHS to being a full time lecturer in podiatry and was able to use the opportunities, resources and facilities I now had available to me, to explore this apparent gap in the provision of foot health interventions for people with RA. I initially wanted to carry out research that would ultimately enable the development of a 'package' of foot health education that could be provided to this patient group. However, through the process of considering my own personal journey I recognised my own philosophical beliefs that had been with me throughout my clinical and academic career; I wanted to provide an opportunity for people with RA to have a 'voice' on this, and ultimately to empower them to initiate a dialogue about their foot health needs with the members of the multi-disciplinary team responsible for their holistic management. Hence, a number of fundamental questions evolved; what was it that people with RA wanted and needed to know about their foot health? When was the best time to provide foot health education? What was the most effective way of providing it? And, what prevented their access to foot health education resources? However, before I could answer these questions I needed to understand what the current status of foot health education provision was for this group of people, from both a practitioner (podiatrist) and patient perspective. In this way I could ascertain more clearly what was already being utilised in clinical practice and develop insight as to any differences in what practitioners thought was being provided and what patients felt was being offered.

The need to understand what patient education ‘is’ and the aims of its application in practice became a driving influence in my own development as a novice researcher within this subject area. As there was no specific published literature in relation to foot health education and RA, I searched the literature to help me understand the nature and role of patient education as an intervention for the management of RA and its’ impact on the individual from a more global perspective, additionally drawing on the literature as it related to foot health education for people with diabetes because of the similar nature with which some of the lower limb complications can manifest themselves. The literature (WHO, 1998; Jones, 2002; Makelainen et al, 2006; Albano et al, 2010; Jotterand et al, 2016) revealed a broad range of definitions relating to ‘patient education’ that encompassed a spectrum of educational methodology from simple informal information giving to systematic, patient-centred strategies that had at the heart of their creation the recognition of key pedagogical principles such as the acknowledgement of an individuals’ learning style and the use of appropriate learning resources. This dichotomy that exists between the two ends of the ‘patient education spectrum’, challenged my own perceptions of what I had considered patient education to be and the process of completing this portfolio of research redefined my personal philosophical approach to the provision of FHE.

1.2: Aims and Objectives:

Having explored the literature and conducted focus groups in respect of FHE for people with RA the aims and objectives of the research evolved to become those outlined below:

Research question: What is the current status of foot health education provision for people with rheumatoid arthritis in the UK?

Aim: to investigate patients' and podiatrists' perspectives of current foot health education provision for people with RA in the UK.

Objectives:

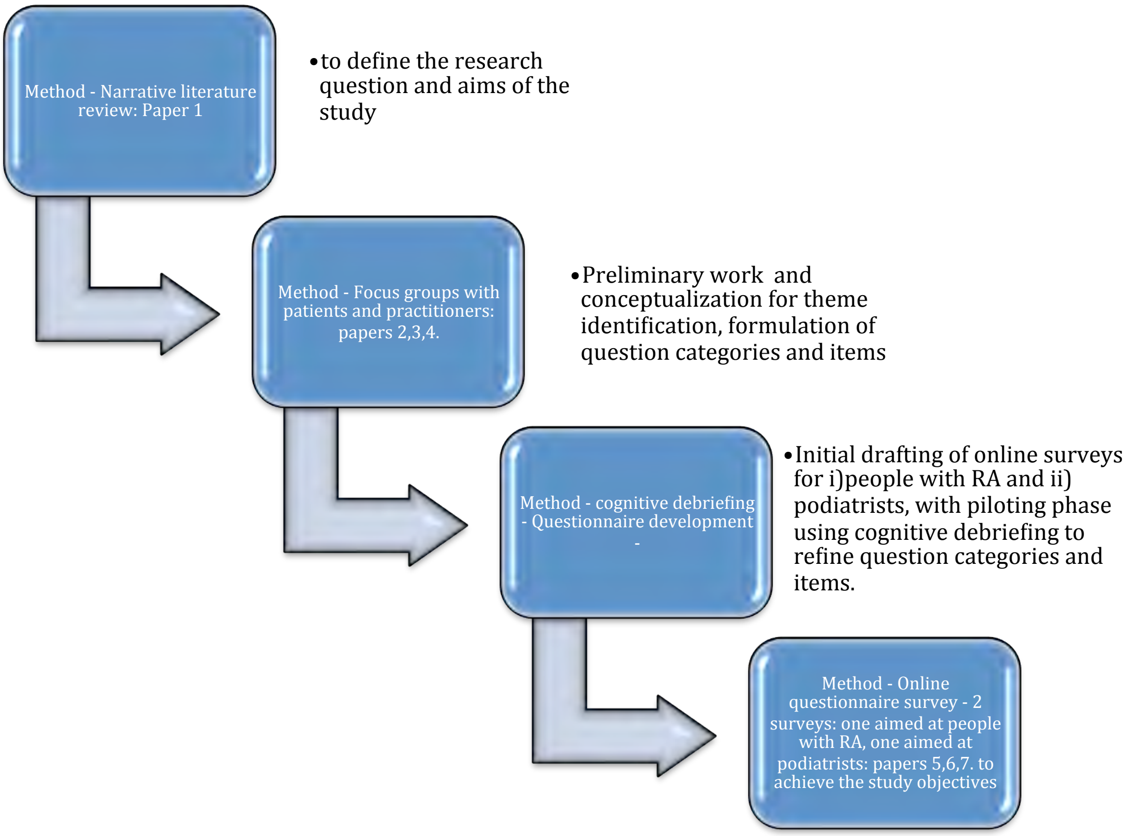
From the practitioners' perspective:

To identify the nature of the current provision of FHE to people with RA.
To explore the content of the current provision of FHE to people with RA.
To gain insight into the current barriers to the provision of FHE to people with RA.

From the perspective of the person with RA:
To gain insight into patient experiences of FHE in respect of its' nature.
To explore patient experiences' of FHE in respect of its' content.
To gain insight into patient experiences' of FHE in respect of its' accessibility.

Figure 1 illustrates the methods used in each paper and how they have informed the objectives of the research according to each publication

Figure 1 illustrates the methods used within each paper and the stage of each publication.



The following section presents the published works that constitute the output of this PhD in relation to papers published within peer-reviewed journals, with the aim of achieving the objectives of the research.

Chapter 2 – The published works and linking commentaries

This section sequentially presents each of the published works, which constitute the body of research for this PhD. Each paper will be introduced via short commentary to show how the findings of each publication; i) illustrate the intellectual journey and ii) led into the subsequent paper. It will conclude with the key findings of the overall project. The papers demonstrate the range of methodologies that have been used to systematically acquire new knowledge in respect of the research aims and objectives; a literature review, focus groups and surveys. Where the commentaries refer to '*the study',* it refers to the individual piece of research undertaken in relation to that particular publication. Where additional material was published with each paper, it will appear separately at the end of each relevant paper.

2.1 Commentary – Paper 1

Title: Therapeutic foot health education for people with rheumatoid arthritis: a narrative review.

Authors: Andrea S Graham, Professor Alison Hammond and Doctor Anita E Williams.

The aim of the narrative review was to identify any evidence to support the use of FHE for people with RA and related foot pathology with a focus upon the content, use and delivery methods employed in its' dissemination. The narrative review refined the initial research question and the aims of the overall study as themes emerged through the literature review process. These themes illustrated the most common aspects of patient education that appeared to be significant in the development, provision and evaluation of educational interventions.

The initial search strategy was narrowed to a ten-year time frame and used three main key search terms of 'patient education', 'rheumatoid arthritis', 'foot-health and/or podiatry'. However, this only resulted in a return of two publications with a focus upon feet and so the key search terms were expanded to include 'diabetic foot' and 'diabetic foot ulcer', justified because of the similarities in foot problems between RA and diabetes. Additionally, papers that presented results in relation to the use of generic patient education in people with RA were included, as they might also inform the development of FHE as an intervention. The paper selection process followed the standard suggested by the Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) (Liberati et al, 2009). The result of the selection process yielded 32 papers that met the inclusion criteria and were summarized according to study design, population characteristics, key findings and the theoretical approach of the educational intervention. The findings were presented thematically; content of the educational intervention, mode of delivery, timing of delivery, the effect of the therapeutic relationship between patient and practitioner on the effectiveness of the intervention and the effect of the intervention on clinical outcomes.

The narrative review found no publications that directly related to the use of FHE as an intervention for people with RA, highlighting the lack of research and justifying the need for further inquiry. However, the review did reveal broadly similar topic areas of; disease causation and effects, medical management and self-care, when comparing educational interventions for people with diabetic foot pathology and general RA related PE interventions. Further to this the review highlighted the need for educational interventions to be used in a staged-approach over the life-time of the individual and driven by their stated individual educational needs, at any given time in the disease process. The review supported the positive influence that PE for people with RA and people with foot problems (in patients with diabetes) could have on key clinical outcomes of; patients levels of knowledge, pain, functional ability and self-efficacy and highlighted the potential barriers to the effectiveness of PE as an intervention.

The findings of the narrative review provided the foundations for the schedule of the focus group interviews conducted within papers 2,3, and 4 through the identification of the key themes; content, modes and effectiveness of delivery, the timing of and barriers to foot health education provision.

INNOVATIONS:

This paper is the key underpinning publication in support of improving the development of foot health educational interventions. The findings of this unique narrative review identify for the first time that FHE for people with RA should be targeted to the individual and should be used to inform future clinical protocols for the management of people with RA and foot-related pathology.

Paper 1:

Title: Therapeutic Foot Health Education for patients with Rheumatoid Arthritis – a Narrative Review.

Authors: Graham AS[1], Hammond A[2], and Williams AE[1,2]

RESEARCH ARTICLE

Therapeutic Foot Health Education for Patients with Rheumatoid Arthritis: A Narrative Review

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Abstract

Purpose. Foot health interventions such as foot orthoses for people with rheumatoid arthritis (RA) reduce pain, improve function and improve overall quality of life. Additionally, patient education (PE) is considered essential in achieving good outcomes with interventions such as foot orthoses, footwear and self-care. The aim of this literature review was to identify evidence in relation to the content, use and delivery of PE in the management of RA foot problems.

Methods. An electronic search of the following databases was performed: PubMed, CINAHL, AMED, Medline and the Cochrane Library, between March 2000 and March 2010. In order to be included, studies had to be published in English, involve adults (>18 years) with RA, and assist in answering the research question. No publications regarding PE for the management of foot health-related problems in RA were found. However, other key terms emerged that embraced PE for people with RA and informed a further search. Thirty-two papers met the inclusion criteria and were reviewed with regard to the subject area, content of the paper, methodological issues and their key findings.

Results. The present review provides evidence for the effectiveness of PE for people with RA delivered via a staged approach, with the content and timing of education provision being driven by the needs of the patient.

Conclusions. The effect of PE delivered from a podiatric context needs to be explored, and the nature and requirements of PE for individuals with RA-related foot problems from a patient and practitioner perspective requires investigation. Alternative and innovative ways of providing PE and, potentially, self-management need to be investigated and defined. Copyright © 2011 John Wiley & Sons, Ltd.

Keywords

Patient education; rheumatoid arthritis; podiatry; foot health

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Introduction

Up to 80% of people with rheumatoid arthritis (RA) report foot pain (Grondal et al., 2008; Otter et al., 2010). Foot deformity is common (Grondal et al., 2008) and some people develop serious complications, such as foot ulceration (Firth et al., 2008). These foot problems can affect the person physically, psychologically and emotionally, leading to a reduced quality of life (Wickman et al., 2004). National Guidelines (Arthritis and Musculoskeletal Alliance, 2004; National Institute for Clinical Excellence, 2009; Podiatric Rheumatic Care Association (PRCA), 2008) support the use of interventions such as foot orthoses and therapeutic footwear in reducing the impact of these foot problems. However, to achieve the maximum potential health benefits from these interventions, patients need to use them. A lack of understanding of both the purpose of foot interventions and how they should be used influences their use (Williams et al., 2007a). Incorporating information during the consultation can improve patients' understanding and subsequent engagement in foot health interventions and health behaviour (Williams et al., 2007a). A holistic approach, focusing on patients' physical, psychological and emotional needs, improves receptiveness to explanations, advice and education, resulting in improved health outcome (Lorig et al., 2005; PRCA, 2008).

The World Health Organization (WHO, 1998) differentiates between 'informal' patient education that occurs naturally within the consultation and therapeutic patient education (TPE) conducted by pedagogical criteria and methods (Hammond, 2003). WHO (1998) defines TPE as: 'education managed by healthcare providers trained in the education of patients and designed to enable a patient to manage the treatment of their condition and prevent avoidable complications, while maintaining or improving quality of life'. While it is recognized that many patients will develop their own coping strategies as part of chronic disease self-management, TPE seeks to make the efforts of patients more productive using a systemic and patient-centred learning process based on key pedagogical principles, such as the recognition of different learning styles, appropriate learning resources, methods of evaluation and accreditation, embedded within the TPE programme design (WHO, 1998).

'Informal' and TPE approaches could both be considered essential to the effective management of people with RA-related foot problems and in supporting appropriate foot health-related behaviour (Hammond, 2003). Therefore, the aims of the present review were to evaluate the evidence for the effectiveness of TPE and 'information giving' for people with RA-related foot problems and to identify the most effective methods of delivering this.

Methods

The present review focuses on literature over a ten-year period from March 2000 to March 2010. The rationale for this was that recent studies are likely to apply more robustly developed interventions as a result of developments in TPE research. PubMed, CINAHL, AMED, Medline and the Cochrane Library were searched. Additionally, reference lists from the papers retrieved from these databases were searched for additional papers.

The key search terms used were 'rheumatoid arthritis, 'patient education', 'foot health' and/or 'podiatry'. Two papers were identified. One investigated the feasibility of a foot self-management programme (FOOTSTEP) specifically in RA (Semple et al., 2009), while the second evaluated its effectiveness in the elderly (Waxman et al., 2003). Consequently, papers that evaluated the effectiveness of TPE in information-giving, drug management and self-management were identified and included in the review, as they might also inform foot health education development. Additionally, the search was expanded to include foot health education for people with diabetes because of the potential similarities in foot health problems to people with RA, using additional key terms of 'diabetic foot' and 'diabetic foot ulcer'.

Eligibility criteria for studies were: publication in English; inclusion of adults (>18 years); systematic reviews, randomized or non–randomized controlled trials, cohort studies or questionnaire-based studies; and investigations of the use of patient education (TPE or informal) from either a patient or health practitioner perspective. These criteria were applied by a single reviewer (A.G.) to titles, abstracts and full-text articles.

Appendix 1 illustrates the article selection process in accordance with the Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) statement for reporting systematic reviews (Liberati et al., 2009).

Results

From 472 abstracts, 32 met the inclusion criteria and are summarized according to study design, population characteristics, the key findings and the theoretical approach of the educational intervention. Tables detailing the included studies can be accessed via the online version of this paper.

Study designs ranged from reviews ($n = 4$), randomized controlled trials ($n = 15$), non-randomized controlled trials/cohort studies ($n = 6$) and questionnaire studies ($n = 7$). It was not possible to conduct a meta-analysis of the findings within randomized controlled trials because of the varied nature of the client groups, interventions and outcome measures used, as some related to people with diabetes (Lincoln et al., 2008; Sun et al., 2009).

In the 32 studies selected, sample sizes varied from 23 participants (Gray et al., 2007) to 308 (Calle-Pascual et al., 2002), with study duration ranging from six months (Freeman et al., 2002; Hill et al., 2001; Waxman et al., 2003) to six years (Calle-Pascual et al., 2002).

The present review found no studies evaluating the effectiveness of foot-related TPE in RA, either embedded in the foot healthcare consultation or as a stand-alone intervention. Two studies (Giraudet-Le Quintrec et al., 2007; Hammond et al., 2008) had elements of foot care within the intervention but there were no specific outcomes relating to the use of foot health behaviour. Thus, it is not possible to evaluate the contribution that the foot health education component had on overall benefits. Only one non-randomized trial (Semple et al., 2009) assessed the potential ability of patients with RA to participate in the FOOTSTEP programme (Waxman et al., 2003). Foot health education for people with RA has clearly not been a focus of attention compared with other conditions, such as diabetes (Valk et al., 2001).

Studies were considered in terms of how their content, mode of delivery, timing and the effect of the therapeutic relationship may have influenced TPE effectiveness, in addition to the effect of TPE on clinical outcomes.

Content of TPE

Seven studies (Abourazzak et al., 2009; Calle-Pascual et al., 2002; Giraudet-Le Quintrec et al., 2007; Hammond et al., 2008; Lincoln et al., 2008; Sun et al., 2009; Waxman et al., 2003) provided information relating to foot health and/or footwear, of which three were in people with RA (Abourazzak et al., 2009; Giraudet-Le Quintrec et al., 2007; Hammond et al., 2008), three in people with diabetes (Calle-Pascual et al., 2002; Lincoln et al., 2008; Sun et al., 2009) and one in an elderly population (Waxman et al., 2003). Those relating to RA did not specify the content provided in detail.

Foot health education provision covered broadly similar topics: footwear/hosiery advice, safe and unsafe self-management practices, foot hygiene, warning signs of foot health deterioration and what to do when they occur (Calle-Pascual et al., 2002; Lincoln et al., 2008; Sun et al., 2009; Waxman et al., 2003). One study (Lincoln et al., 2008) provided information relating to the causes of foot ulceration and one (Waxman et al., 2003) to a workshop in which patients practised safe foot self-management skills under the supervision of a podiatrist.

Most studies included information relating to the disease, medical management (RA or diabetes, depending on the programme) and self-care, with the exception of Meesters et al. (2009), Newman et al. (2009) and Waxman et al. (2003). Eight studies (Ellard et al., 2009; Freeman et al., 2002; Hammond and Freeman, 2001; Hammond et al., 2008; Lincoln et al., 2008; Mäkeläinen et al., 2007; Masiero et al., 2007; Riemsma et al., 2003a; Waxman et al., 2003) stated that they had provided additional supportive material in the form of information leaflets, handbooks, workbooks/diaries or audiovisual aids to reinforce the material delivered within the sessions.

Mode of delivery of TPE

The mode of delivery ranged from simple information giving (Gray et al., 2007; Hill and Bird, 2003; Lincoln et al., 2008; Mäkeläinen et al., 2007, 2009; Newman et al., 2009) to educational–behavioural training (Abourazzak et al., 2009; Freeman et al., 2002; Giraudet-Le Quintrec et al., 2007; Hammond and Freeman, 2001, 2004; Hammond et al., 2008; Hill et al., 2001; Lovisi Neto et al., 2009; Masiero et al., 2007; Mayoux-Benhamou et al., 2008; Riemsma et al., 2003a, 2003b; Semple et al., 2009; Sun et al., 2009; Waxman et al., 2003) or a combination (Calle-Pascual et al., 2002; Ellard et al., 2009; Kirwan et al., 2005).

Simple ‘information-giving’, using leaflets, had short-term effects of only up to six months on patient knowledge in those with RA (Hill and Bird, 2003). The majority of information given was focused on symptoms, the nature of the disease, management of joint pain and stiffness (Mäkeläinen et al., 2007), although patients expressed dissatisfaction with the information provided because of a lack of tailoring to their individual needs, especially in those with shorter disease duration (less than five years) (Mäkeläinen et al., 2009). One-to-one information-giving also had no impact on clinical outcomes with regard to the incidence of foot ulcers (Lincoln et al., 2008).

Studies employing a group educational–behavioural approach proved more successful in the longer term (at least 12 months) in RA in relation to outcomes such as pain (Hammond and Freeman, 2001; Hammond et al., 2008), disease activity (Abourazzak et al., 2009; Hammond and Freeman, 2001, 2004), functional ability (Hammond and Freeman, 2001, 2004; Masiero et al., 2007), physical and mental health status (Hammond et al., 2008), patient adherence to interventions (Calle-Pascual et al., 2002; Hammond et al., 2008; Masiero et al., 2007) patient knowledge (Abourazzak et al., 2009; Giraudet-Le Quintrec et al., 2007; Masiero et al., 2007), self efficacy (Giraudet-Le Quintrec et al., 2007; Hammond et al., 2008; Masiero et al., 2007; Riemsma et al., 2003a, 2003b) and fatigue (Hammond et al., 2008; Riemsma et al., 2003a, 2003b). One-to-one educational–behavioural education has been little studied; it has been shown to improve drug adherence but was found to be relatively expensive (Hill et al., 2001).

Timing of TPE delivery

In patients recently diagnosed with RA, with an average disease duration of less than six months, no benefit seemed to be gained from an educational–behavioural intervention (Freeman et al., 2002). While those who attended a pilot study day (Ellard et al., 2009) had improved self-efficacy scores at follow-up, qualitative feedback reflected that a number of the participants found the visual content 'frightening' with regard to the images used to illustrate disease progression.

In patients who had been diagnosed for up to five years, the results seem more promising, with improvements seen in joint protection behaviour and functional ability (Hammond and Freeman, 2001, 2004). At the three-year follow-up, arthritis and self-management knowledge was significantly improved in an educational–behavioural programme group (mean disease duration 5.4 years) (Abourazzak et al., 2009).

In those with longer mean disease duration (more than seven years), the results were mixed. Three studies (Giraudet-Le Quintrec et al., 2007; Kirwan et al., 2005; Lovisi Neto et al., 2009) found no significant changes at final follow-up in favour of the intervention, while two (Hammond et al., 2008; Masiero et al., 2007) found improvement in health behaviour, pain and self-efficacy.

Effect of the 'therapeutic relationship' on TPE

No studies directly measured the influence of educational interventions on the development of an effective therapeutic relationship, or vice versa; however, it was a theme that developed within four studies (Gray et al., 2007; Mäkeläinen et al., 2007, 2009; Rajan et al., 2007) and was found to have a positive effect on the educational process and the enablement of patients to self-care.

Clinical outcomes

The clinical outcomes most commonly measured were pain; fatigue; disability/functional ability; disease status; patient knowledge; patient adherence; quality of life; self-efficacy; health behaviour change and coping (Abourazzak et al., 2009; Barlow et al., 2002; Calle-Pascual et al., 2002; Ellard et al., 2009; Freeman et al., 2002; Giraudet-Le Quintrec et al., 2007; Hammond and Freeman, 2001, 2004; Hammond et al., 2008; Hill and Bird, 2003; Hill et al., 2001; Kirwan et al., 2005; Lincoln et al., 2008; Lovisi Neto et al., 2009; Masiero et al., 2007; Mayoux-Benhamou et al., 2008; Neil et al., 2003; Ooi et al., 2007; Rajan et al., 2007; Riemsma et al., 2003a, 2003b; Semple et al., 2009; Sun et al., 2009; Waxman et al., 2003).

Overall, there is as yet limited evidence that TPE can have a longer-term (e.g. more than one year) impact on pain; only three studies reported a significant improvement in pain scores (Hammond and Freeman, 2001; Hammond et al., 2008; Masiero et al., 2007). Two studies (Freeman et al., 2002; Kirwan et al., 2005) were underpowered to detect significant changes in pain scores at final follow–up, as patients declined the intervention following randomization or dropped out. Initial 'over-recruitment' may serve to avoid this situation for future research.

The effects of TPE on functional ability are more robust. Significant improvements were found by four studies (Hammond and Freeman 2001, 2004; Hammond et al., 2008; Masiero et al., 2007), with a further four (Abourazzak et al., 2009; Giraudet-Le Quintrec et al., 2007; Kirwan et al., 2005; Waxman et al., 2003) reporting no deterioration in functional ability over the study duration. In studies with follow-up periods of up to four years (Abourazzak et al., 2009; Hammond and Freeman, 2004), the functional ability of the intervention participants was maintained over the duration of the study.

Levels of pain and function have been shown to be associated with health status; therefore, those studies which found improvements in pain (Hammond and Freeman, 2001; Hammond et al., 2008; Masiero et al.,

2007) and function (Hammond and Freeman, 2001, 2004; Hammond et al., 2008; Masiero et al., 2007) would be expected to have a positive impact on outcomes for health status. This was reflected in the findings of two studies (Masiero et al., 2007; Hammond et al., 2008), where improvements in health status were maintained at eight and 12 months, respectively. Short study duration (less than six months) may not have been long enough to detect any changes in health status scores in two studies (Kirwan et al., 2005; Lovisi Neto et al., 2009).

Three studies found improvements in RA disease activity (Abourazzak et al., 2009; Hammond and Freeman 2001, 2004). Improvements in Disease Activity Score for 28 Joints (DAS 28) scores in one study (Abourazzak et al., 2009) were not directly attributed to the intervention. These were most likely due to a combination of factors, such as increased levels of adherence to treatment regimes, a larger number of follow-up appointments and, thus, tighter disease management, as an indirect result of the intervention (Abourazzak et al., 2009). In diabetes studies, results are less clear; Calle-Pascual et al. (2002) report a reduction in foot ulcer incidence, whereas in a later study, no impact on diabetic foot ulcer recurrence (as a marker of disease activity) was found (Lincoln et al., 2008).

All studies using an educational–behavioural programme and simple information-giving methods, using patient adherence as an outcome measure, showed significantly improved adherence to the interventions compared with control at final follow-up. One exception was the study by Mayoux-Benhamou et al. (2008), where initial adherence at six months was lost at 12 months. With regard to the impact on foot health, Calle-Pascual et al. (2002) found that adherence to TPE reduced the incidence of diabetic foot ulceration in patients with neuropathy, although this was not supported by the findings of Lincoln et al. (2008). ‘Booster’ sessions to ensure that optimal results are maintained following initial delivery have been suggested as beneficial (Koehn and Esdaile, 2008) and this approach was successfully used in one study (Hammond et al., 2008). However, at the 12-month follow-up, two studies (Mayoux-Benhamou et al., 2008; Riemsma et al., 2003a) that evaluated the use of ‘booster’ sessions found no significant effect on patient adherence.

Overall, TPE resulted in improvements in patient knowledge at final follow-up in five studies (Abourazzak et al., 2009; Giraudet-Le Quintrec et al., 2007; Hill and Bird, 2003; Lovisi Neto et al., 2009; Ooi et al., 2007). One study (Ellard et al., 2009) found that knowledge remained stable over the study duration of six to seven weeks and three (Neil et al., 2003; Sun et al., 2009; Waxman et al., 2003) that patient knowledge levels did not improve at all. One study (Kirwan et al., 2005) evaluated patient knowledge at four weeks and found that it had improved significantly, by 21%, in the intervention group. No further knowledge follow-up was included, so it is unclear whether this outcome would have been sustained over time. One study (Masiero et al., 2007) measured patients’ knowledge at baseline only and found disease knowledge to be poor. Again, lack of follow-up meant that change in knowledge during the study was not ascertained.

Only one study (Lovisi Neto et al., 2009) found any positive effect on Health-Related Quality of Life (HRQoL) scores and this was limited to the domain of general health in the intervention group.

Self-efficacy significantly improved in five studies (Ellard et al., 2009; Hammond and Freeman, 2001, 2004; Hammond et al., 2008; Kirwan et al., 2005). Factors such as short study duration of six weeks (Ellard et al., 2009) and short disease duration of 4.5 months (Freeman et al., 2002) may have influenced the results of these studies.

Only two studies (Hammond and Freeman, 2004; Hammond et al., 2008) found improvements in psychological status. In others, psychological status remained stable during the studies.

Discussion

Although the present review found no studies evaluating the effectiveness of RA foot-related TPE, the findings suggest that foot TPE addresses broadly similar topic areas, such as disease causation and effects, medical management and self-care. One study (Waxman et al., 2003) used a patient-centred approach to reflect the educational needs of its target population, ensuring that the content was tailored to their requirements. This should be considered to be the foundation of foot health-related TPE delivery for people with RA; indeed, the timing of educational delivery is extremely influential in determining its success.

There is a lack of consensus as to the optimal time for presenting patients with information. Patients can be overwhelmed with too much information, especially upon their initial diagnosis, when support of a more emotional nature may be required (Mäkeläinen et al., 2009), although it has been suggested that the point of diagnosis of RA may be the optimal time for patients to self-manage from an early stage (Hennell et al., 2004). However, TPE or the provision of self-management programmes at pre-set points within the patient's 'management journey', such as at the point of diagnosis, could be considered to be too prescriptive. Patients move through periods of adjustment to their disease as a transitional process, such as described by Shaul (1995). They may move back and forth through these stages, depending on the fluctuating nature of the disease, and therefore their educational needs will differ over time (Hammond, 2003). In addition, the time that each individual spends within any one stage will vary from person to person, reinforcing the need for the timing of educational interventions to be based on patients' individual requirements and an assessment of their readiness to change (Hammond and Freeman, 2004).

'Information-giving' does not necessarily result in changes to health behaviour (Barlow et al., 2002). However, leaflets, as well as audiotapes, DVDs or computer multimedia presentations (Newman et al., 2009) could be used as part of a patient-driven, staged approach to general information-giving (Barlow and Wright, 1998; Barlow et al., 2002; Newman et al., 2009) throughout the disease course, at timely intervals, to increase or maintain patients' understanding of the disease and its management. Information provision in combination with an educational–behavioural approach would seem to produce the best outcomes for the patients, in terms of improved foot health in the elderly and in diabetes (Calle-Pascual et al., 2002; Waxman et al., 2003), suggesting that this approach would also be more effective in RA-related foot health education.

Disease duration is a factor that appears to influence the clinical outcomes of TPE. Those with longer disease duration and of a more advanced age were found to be less able to participate in self-management of foot health (Semple et al., 2009) but were more likely to have a greater level of foot care and medical knowledge (Giraudet-Le Quintrec et al., 2007; Rajan et al., 2007; Sun et al., 2009). It is important that patients are assessed not only in their willingness to make changes, but also in their physical ability to carry out self-care tasks safely. Those unable to self-manage foot care may benefit from additional interventions, such as hand rehabilitation, prior to commencement on this type of self-management programme. People diagnosed close to the starting point of a research study will potentially have more recent information about the disease process/drug management (Ellard et al., 2009), which should be taken into consideration when interpreting results relating to patient knowledge. Additional factors that impact on knowledge levels include the method of delivery and education duration. Again, a mixed methods approach, including provision of written material, is most likely required for a more effective result (Abourazzak et al., 2009; Giraudet-Le Quintrec et al., 2007; Fautrel et al., 2005). Fewer hours (four) of educational provision resulted in poorer results in one study (Sun et al., 2009), in contrast to more hours (between seven and 12.5 hours) provided in others (Abourazzak et al., 2009; Kirwan et al., 2005; Lovisi Neto et al., 2009). A greater amount of time spent on educational delivery could facilitate improved patient knowledge outcomes.

Participants with a shorter mean disease duration (less than seven years) appeared to be more likely to adhere to educational–behavioural programmes (Hammond and Freeman, 2001, 2004; Hammond et al., 2008) than those who have had the disease for longer than 10 years (Mayoux-Benhamou et al., 2008; Riemsma et al., 2003a). Adherence to both educational and treatment interventions is influenced by a number of factors. Research has shown that drug adherence levels in patients with RA, for example, are sub-optimal (Hill et al., 2001). One study showed how the use of TPE can help to increase drug adherence (Hill et al., 2001). Factors such as timing (Calle-Pascual et al., 2002), willingness to participate (Hammond and Freeman 2001, 2004), disease activity/severity (Calle-Pascual et al., 2002), the maintenance of motivation (Hammond et al., 2008; Mayoux-Benhamou et al., 2008), self-efficacy (Hammond et al., 2008; Masiero et al., 2007) and the perceived benefits on the individual will all impact on the success of the intervention.

Foot health TPE should focus on supporting the interventions that are known to reduce pain and improve function (Magalhaes et al., 2006; Williams et al., 2007b; Woodburn et al., 2002). However, in evaluating the impact of TPE on these, it needs to be considered that the experience of pain varies between individuals. The highly subjective nature of the pain experience and variable coping ability may have had an impact on the poor results seen for the effect of TPE on pain in people with RA. Additionally, patients with higher levels of perceived self-efficacy or coping are more likely to adhere to interventions than those with low perceived self-efficacy (Niedermann et al., 2004). In support of this notion, recent research by Somers et al. (2010) has shown that lower levels of self-efficacy are associated with higher pain scores and poorer physical function in people with RA. Hammond et al. (2008) showed that group TPE maintained improvements in pain and self-efficacy scores over 12 months, although this was the only study to demonstrate prolonged improvements in both pain and self-efficacy. One study by Kirwan et al. (2005) found results related to self-efficacy for pain were only maintained in the short term. It could be concluded that the less favourable results in this study were due to other confounding variables, such as coping mechanisms, functional ability, disease duration and psychological status. These factors can influence perceived self-efficacy and must be considered in the development of educational–behavioural programmes.

The results of the studies investigating TPE for those with diabetes-related foot problems are conflicting (Calle-Pascual et al., 2002; Lincoln et al., 2008). Lincoln et al. (2008) found that engagement with positive health behaviour as a result of an education programme had no impact on the primary outcome measure of ulcer recurrence, whereas Calle-Pascual et al. (2002) found that ulcer incidence was reduced. These conflicting results concur with the findings of Valk et al. (2001) and the subsequent update of this paper by Dorresteijn et al. (2010), which found that foot health education aiming to reduce ulcer incidence in patients with diabetes had only a short-term positive effect on patient knowledge and self-reported behaviour. In individuals who are classified as 'high risk' with regard to foot health, other physiological factors may outweigh the impact of educational interventions. People with RA foot health problems are also at risk of developing complications similar to those with diabetes, such as ulceration (Firth et al., 2008). This should be considered in the development of foot health-related TPE for people with RA, as physiological factors in the causation of ulceration may outweigh any potential impact of behaviour change achieved with educational interventions.

It is not clear if TPE, embracing an educational–behavioural approach, has any impact on quality of life. The relatively short study duration (less than a year) of all studies, with the exception of two (Hammond et al. 2008; Abourazzak et al., 2009), may mean that the potential longer-term improvements in quality of life were unable to be detected. The use of qualitative methods to assess HRQoL in addition to traditional outcome measures, such as the Short Form 36 (SF-36) (Ware and Sherbourne, 1992) and Arthritis Impact Measurement Scales version 2 (AIMS 2), could allow for more meaningful data collection (Abourazzak et al., 2009; Lillegraven and Kvien, 2007) in relation to patients' perception of physical health, quality of life and psychological status.

Poor psychological status has been cited as a barrier to successful outcomes in patient education (Albano et al., 2010). In addition, patients with chronic diseases such as RA are more likely to suffer from psychological distress (Gettings, 2010). This may adversely influence patients' cognitive ability to engage in the behavioural changes recommended in educational programmes. Many educational–behavioural programmes provide information relating to the nature of RA and the fact that there is no cure. Such information could potentially cause psychological distress to individuals with RA (Lovisi Neto et al., 2009). However, as there was no deterioration in psychological status in these studies, TPE effectively mitigates the impact of such information.

In order to assess potential barriers to TPE success, patients' feelings and worries, information needs and learning capabilities should be discussed on an individual basis. Such an approach aims to enhance the educational process for that individual, especially in the newly diagnosed (Mäkeläinen et al., 2007, 2009). The development of a 'concordant' therapeutic relationship enhances self-esteem, positive coping strategies, maintenance of self-efficacy and adherence to medication (Hill et al., 2001) and is beneficial in enabling patients to self-care (Hammond, 2003; Luqmani et al., 2006; Rajan et al., 2007). Issues relating to feelings of hostility and judgement of negative health behaviour, such as smoking, can become a barrier to the development of a therapeutic relationship and erode any potential progress toward health behaviour change (Gray et al., 2007).

Conclusion

There is no specific research relating to the development and effect of TPE on the management of foot health-related problems in RA. However, the present review provides evidence for the effectiveness of TPE for people with RA that is delivered via a staged approach, using mixed methods over the lifetime of the patient, with the content and timing of education provision being driven by patients' educational needs. These factors are currently being applied by the authors to the development of a foot TPE programme for people with RA. This will then be evaluated in relation to foot health.

REFERENCES

Abourazzak F, El Mansouri L, Huchet D, Lozac'hmeur R, Hajjaj-Hassouni N, Ingels A, Chales G, Perdriger A (2009). Long-term effects of therapeutic education for patients with rheumatoid arthritis. Joint, Bone, Spine 76: 648–53.

Albano MG, Giraudet-Le Quintrec JS, Crozet C, d'Ivernois JF (2010). Characteristics and development of therapeutic patient education in rheumatoid arthritis: Analysis if the 2003–2008 literature. Joint Bone Spine 77: 405–10.

Arthritis and Musculoskeletal Alliance (ARMA) (2004). Standards of care for people with inflammatory arthritis. Available at http://www.arma.uk.net/care.html [Accessed 8 September 2009].

Barlow J, Wright C (1998). Knowledge in patients with rheumatoid arthritis: A longer term follow-up of a randomized controlled study of patient education leaflets. British Journal of Rheumatology 3: 373–6.

Barlow JH, Cullen LA, Rowe IF (2002). Educational preferences, psychological well-being and self-efficacy among people with rheumatoid arthritis. Patient Education and Counselling 46: 11–9.

Calle-Pascual A, Durán A, Benedí A, Calvo M, Charro A, Diaz J, Calle JR, Gil E, Maranes JP, Cabezas-Ceratto J (2002). A preventative foot care programme for people with diabetes with different stages of neuropathy. Diabetes Research in Clinical Practice 57: 111–7.

Dorresteijn JAN, Kriegsman DMW, Assendelft WJJ, Valk GD (2010). Patient education for preventing diabetic foot ulceration. Cochrane Database of Systematic Reviews, Issue 5. Art. No. CD001488. Available at http://www.thecochranelibrary.com/details/browseReviews/577059/Diabetic-foot-ulcer-prevention.html [Accessed 22 November 2010].

Ellard D, Barlow J, Paskins Z, Stapley J, Wild A, Rowe I (2009). Piloting education days for patients with early rheumatoid arthritis and their partners: a multidisciplinary approach. Musculoskeletal Care 7: 17–30.

Fautrel B, Pham T, Gossec L, Combe B, Flipo R, Goupille P, Le Loet X, Puechal X, Wendling D, Schaeverbeke T, Sibilia J, Sany J, Dougados M (2005). Role and modalities of information and education in the management of patients with rheumatoid arthritis: Development of recommendations for clinical practice based on published evidence and expert opinion. Joint, Bone, Spine 72: 163–70.

Firth J, Helliwell P, Hale C, Hill J, Nelson E (2008). The predictors of foot ulceration in patients with rheumatoid arthritis: A preliminary investigation. Clinical Rheumatology 27: 1423–8.

Freeman K, Hammond A, Lincoln N (2002). Use of cognitive-behavioural arthritis education programmes in newly diagnosed rheumatoid arthritis. Clinical Rehabilitation 16: 828–36.

Gettings L (2010). Psychological well being in rheumatoid arthritis: A review of the literature. Musculoskeletal Care 8: 99–106.

Giraudet-Le Quintrec J, Mayoux-Benhamou A, Ravaud P, Champion K, Dernis E, Zerkak D, Ouslimani A, Courpied JP, Revel M, Kahan A, Dougados M (2007). Effect of a collective educational program for patients with rheumatoid arthritis: A prospective 12-month randomized controlled trial. Journal of Rheumatology 34: 1684–91.

Gray J, Eden G, Williams M (2007). Developing the public health role of a front line clinical service: Integrating stop smoking advice into routine podiatry services. Journal of Public Health (Oxford) 29: 118–22.

Grondal L, Tengstrand B, Nordmark B, Wretenberg P, Stark A (2008). The foot: Still the most important reason for walking incapacity in rheumatoid arthritis: Distribution of symptomatic joints in 1,000 RA patients. Acta Orthopaedica 79: 257–61.

Hammond A (2003). Patient education in arthritis: Helping people change. Musculoskeletal Care 1: 84–97.

Hammond A, Freeman K (2001). One-year outcomes of a randomized controlled trial of an educational-behavioural joint protection programme for people with rheumatoid arthritis. Rheumatology (Oxford) 40: 1044–51.

Hammond A, Freeman K (2004). The long-term outcomes from a randomized controlled trial of an educational-behavioural joint protection programme for people with rheumatoid arthritis. Clinical Rehabilitation 18: 520–8.

Hammond A, Bryan J, Hardy A (2008). Effects of a modular behavioural arthritis education programme: A pragmatic parallel-group randomized controlled trial. Rheumatology (Oxford) 47: 1712–8.

Hennell SL, Brownsell C, Dawson JK (2004). Development, validation and use of a patient knowledge questionnaire (PKQ) for patients with early rheumatoid arthritis. Rheumatology (Oxford) 43: 467–71.

Hill J, Bird H (2003). The development and evaluation of a drug information leaflet for patients with rheumatoid arthritis. Rheumatology (Oxford) 42: 66–70.

Hill J, Bird H, Johnson S (2001). Effect of patient education on adherence to drug treatment for rheumatoid arthritis: A randomised controlled trial. Annals of the Rheumatic Diseases 60: 869–75.

Kirwan J, Hewlett S, Cockshott Z, Barrett J (2005). Clinical and psychological outcomes of patient education in rheumatoid arthritis. Musculoskeletal Care.3: 1–16.

Koehn CL, Esdaile JM (2008). Patient education and self-management of musculoskeletal disease. Best Practice and Research Clinical Rheumatology 22: 395–405.

Liberati A, Altman D, Tetzlaff J, Mulrow C, Gøtzsche P, Ioannidis J, Clarke M, Devereaux PJ, Kleijnen J, Moher D (2009). The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: Explanation and elaboration. Journal of Clinical Epidemiology 62: e1–34.

Lillegraven S, Kvien TK (2007). Measuring disability and quality of life in established rheumatoid arthritis. Best Practice and Research Clinical Rheumatology 21: 827–40.

Lincoln N, Radford K, Game F, Jeffcoate W (2008). Education for secondary prevention of foot ulcers in people with diabetes: A randomised controlled trial. Diabetologia 51: 1954–61.

Lorig K, Ritter P, Plant K (2005). A disease-specific self-help program compared with a generalized chronic disease self-help program for arthritis patients. Arthritis and Rheumatism 53: 950–7.

Lovisi Neto B, Jennings F, Barros Ohashi C, Silva P, Natour J (2009). Evaluation of the efficacy of an educational program for rheumatoid arthritis patients. Clinical and Experimental Rheumatology 27: 28–34.

Luqmani R, Hennell S, Estrach C, Birrell F, Bosworth A, Davenport G, Fokke C, Goodson N, Jefferson P, Lamb E, Mohammed R, Oliver S, Stableford Z, Walsh D, Washbrook C, Webb F (2006). The British Society of Rheumatology (BSR) and British Health Professions in Rheumatology (BHPR): Guidelines for the management of rheumatoid arthritis (the first 2 years). Rheumatology 45: 1167–9.

de P Magalhaes E, Davitt M, Filho DJ, Battistella LR, Bertolo MB (2006). The effect of foot orthoses in rheumatoid arthritis. Rheumatology 45: 449–53.

Mäkeläinen P, Vehviläinen-Julkunen K, Pietilä A (2007). Rheumatoid arthritis patients' education – Contents and methods. Journal of Clinical Nursing 16: 258–67.

Mäkeläinen P, Vehviläinen-Julkunen K, Pietilä A (2009). Rheumatoid arthritis patient education: RA patients' experience. Journal of Clinical Nursing 18: 2058–65.

Masiero S, Boniolo A, Wassermann L, Machiedo H, Volante D, Punzi L (2007). Effects of an educational-behavioral joint protection program on people with moderate to severe rheumatoid arthritis: A randomized controlled trial. Clinical Rheumatology 26: 2043–50.

Mayoux-Benhamou A, Giraudet-Le Quintrec J, Ravaud P, Champion K, Dernis E, Zerkak D, Roy C, Kahan A, Revel M, Dougados M (2008). Influence of patient education on exercise compliance in rheumatoid arthritis: A prospective 12-month randomized controlled trial. Journal of Rheumatology 35: 216–23.

Meesters JJL, Vliet TPM, Hill J, Ndosi ME (2009). Measuring educational needs among patients with rheumatoid arthritis using the Dutch version of the Educational Needs Assessment Tool (DENAT). Clinical Rheumatology 28: 1073–7.

National Institute for Clinical Excellence (2009). Rheumatoid arthritis: The management of rheumatoid arthritis in adults. Available at http://guidance.nice.org.uk/CG79 [Accessed 5 May 2009].

Neil JA, Knuckey CJ, Tanenberg RJ (2003). Prevention of foot ulcers in patients with end stage renal disease. Nephrology Nursing Journal 30: 39–43.

Newman M, Ziebland S, Barker K (2009). Patients' views of a multimedia resource featuring experiences of rheumatoid arthritis: Pilot evaluation of www.healthtalkonline.org. Health Informatics Journal 15: 147–59.

Niedermann K, Fransen J, Knols R, Uebelhart D (2004). Gap between short- and long-term effects of patient education in rheumatoid arthritis patients: A systematic review. Arthritis and Rheumatism 51: 388–98.

Ooi GS, Rodrigo C, Cheong WK, Mehta RL, Bowen G, Shearman CP (2007). An evaluation of the value of group education in recently diagnosed diabetes mellitus. International Journal of Lower Extremity Wounds 6: 28–33.

Otter S, Lucas K, Springett K, Moore A, Davies K, Cheek L, Young A, Walker-Bone K (2010). Foot pain in rheumatoid arthritis prevalence, risk factors and management: An epidemiological study. Clinical Rheumatology 29: 255–71.

Podiatric Rheumatic Care Association (2008). Standards of care for people with musculoskeletal foot health problems. Available at http://www.prcassoc.org.uk [8 September 2009].

Rajan M, Pogach L, Tseng CL, Reiber G, Johnston M (2007). Facility-level variations in patient-reported foot-care knowledge sufficiency: Implications for diabetes performance measurement. Primary Care Diabetes 1: 147–53.

Riemsma R, Taal E, Rasker J (2003a). Group education for patients with rheumatoid arthritis and their partners. Arthritis and Rheumatism 49: 556–66.

Riemsma RP, Kirwan JR, Taal E, Rasker HJJ (2003b). Patient education for adults with rheumatoid arthritis.

Cochrane Database of Systematic Reviews, Issue 2. Art. No.: CD003688. Available at: http://onlinelibrary.wiley.com/o/cochrane/clsysrev/articles/CD003688/frame.html [Accessed 15 November 2009].

Semple R, Newcombe L, Finlayson G, Hutchison C, Forlow J, Woodburn J (2009). The FOOTSTEP self-management foot care programme: Are rheumatoid arthritis patients physically able to participate? Musculoskeletal Care 7: 57–65.

Shaul MP (1995). From early twinges to mastery: The process of adjustment in living with rheumatoid arthritis. Arthritis Care and Research 4: 290–7.

Somers TJ, Shelby RA, Keefe FJ, Godiwala N, Lumley MA, Mosley-Williams A, Rice JR, Caldwell D (2010). Disease severity and domain-specific arthritis self-efficacy: Relationships to pain and functioning in patients with rheumatoid arthritis. Arthritis Care and Research 62: 848–856.

Sun P, Jao S, Lin H, Chan R, Chou C, Wei S (2009). Improving preventive foot care for diabetic patients participating in group education. Journal of American Podiatric Medicine Association 99: 295–300.

Valk GD, Kriegsman DMW, Assendelft WJJ (2001). Patient education for preventing diabetic foot ulceration. Cochrane Database of Systematic Reviews, Issue 4. Art. No. CD001488. Available at: http://onlinelibrary.wiley.com/o/cochrane/clsysrev/articles/rel0002/CD001488/frame.html [Accessed 15 November 2009].

Ware JE, Sherbourne CD (1992). The MOS 36-Item Short-Form Health Survey (SF-36®): I. Conceptual framework and item selection. Medical Care 30: 473–83.

Waxman R, Woodburn H, Powell M, Woodburn J, Blackburn S, Helliwell P (2003). FOOTSTEP: A randomized controlled trial investigating the clinical and cost effectiveness of a patient self-management program for basic foot care in the elderly. Journal of Clinical Epidemiology 56: 1092–9.

Wickman A, Pinzur M, Kadanoff R, Juknelis D (2004). Health-related quality of life for patients with rheumatoid arthritis foot involvement. Foot Ankle International 25: 19–26.

Williams AE, Nester CJ, Ravey MMI (2007a). Rheumatoid arthritis patients' experiences of wearing therapeutic footwear – A qualitative investigation. BMC Musculoskeletal Disorders 8: 104.

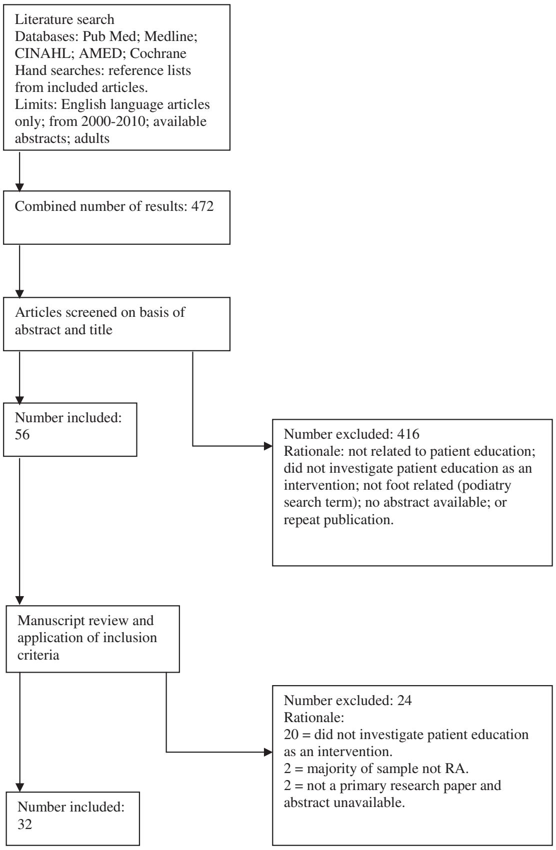
Williams AE, Rome K, Nester CJ (2007b). A clinical trial of specialist footwear for patients with rheumatoid arthritis. Rheumatology 46: 302–7.

Woodburn J, Barker S, Helliwell P (2002). A randomized controlled trial of foot orthoses in rheumatoid arthritis. Journal of Rheumatology 29: 1377–83.

World Health Organization (1998). Therapeutic patient education. Continuing educational programmes for health care providers in the field of prevention of chronic disease: A report of a WHO working group. WHO Regional Office for Europe.

Appendix 1

Article selection process applying the Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) statement for reporting systematic reviews (Liberati et al., 2009).



Paper 1 - Additional File 1 – Tables of Included Studies appended to the publication.

Additional file 1: Narrative Review paper: Tables of included studies.

Abbreviation Key:

AIMS: Arthritis Impact Measurement Scale
CRP: C-Reactive Protein
DAS: Disease Activity Score
HAQ: Health Assessment Questionnaire
MFDQ: Manchester Foot Disability Questionnaire
NAFF: Nottingham Assessment of Functional Footcare
PV: Plasma Viscosity
QoL: Quality of Life
RA: Rheumatoid Arthritis
SMP: Self-Management Programme
TPE: therapeutic patient education
VAS: Visual Analogue Scale

Table 1 – Systematic Review papers

Author/Date	Study Design	Population Characteristics	Key Findings
Riemsma et al, 2003	Systematic Review	People with R.A.	T.P.E. has small beneficial effects in the short term on disability, joint counts, physical status, depression and global assessment. There is no evidence of long term (>9m) effects
Niedermann et al, 2004	Systematic Review	People with R.A.	There is limited evidence for long-term changes in health status. There is no consistent confirmation that changes in health behaviour lead to changes in health status. The greater the degree of behavioral change required, the less adherence is seen and thus less effectiveness of the intervention.
Schrieber&Colley, 2004	Review	People with Rheumatic Disease	T.P.E programmes are an accepted part of management. Good scientific evidence to suggest it modestly improves patient knowledge of the disease. Smaller effects on behaviour change & symptoms
Valk et al, 2001 (2nd version – updated 2004)	Systematic Review	People with Diabetes	There is a need to find better strategies to enhance patient's adherence over the long term. Weak evidence to suggest.T.P.E. may reduce incidence of diabetic foot ulceration/amputation in high - risk patients.

Table 2 – Randomised control trials

Author/Year	Study Design; Duration	Population Characteristics & Sample size	Delivery method; theoretical approach	Key Findings
Hammond & Freeman, 2001	RCT; 12 months	N =127 people with R.A. Control :62 m= 18, f= 44. Mean age: 51 =56 yr. RA duration: 21.34 mths. Intervention: N = 65: m=12, f=53. Mean age: 49.49 yr. RA duration: 17.52 mths	Group educational -behavioural - 4x wkly 2hr sessions with supportive information pack/workbook	Significant improvement in: adherence to positive health behaviours; pain; disease status and functional ability compared with the control group at 12 month follow up.
Hill et al, 2001	RCT; 6 months	100 people with R.A. Control = 49. Median disease duration: Control =13 yr, Intervention group = 12 yr Median age: Control = 62 yr, Intervention group = 63 yr.	1 -to-1, monthly 30 min sessions	P.E. improved drug adherence. 1-to-1 method relatively expensive. No other beneficial clinical outcomes shown.
Freeman et al, 2002	RCT 6 month duration	64 Newly diagnosed people with R.A. Control = 30.. Mean disease duration = 4-5 months	Group educational-behavioural: 4x wkly 2hr sessions	No significant benefits to the health or functional status of newly diagnosed patients with R.A. were found. No evidence that education programmes early in disease onset is effective
Hill & Bird, 2003	RCT 24 weeks duration Single blind.	100 people with R.A. Control= 49: m= 10, f= 39 Intervention=51; m= 17, f= 34. Mean age: control = 62 intervention = 63. Mean disease duration: control = 12 intervention = 13.	Drug information leaflet for d-penicillamine (DPA) and verbal information – intervention group. Leaflet alone for the control group.	Week 24: no differences between groups in knowledge about DPA. Both groups improved. Providing verbal explanations increases RA drug-related knowledge compared to a leaflet alone.
Riemsma et al, 2003	RCT 12 month duration. Single blind.	218 people with R.A. randomized to 3 groups: 71 - group education with a partner (a) mean age: 57.2, disease: 12.1 71 – group education, no partner (b) Mean age:55.1disease duration:11.7 76 – control group (c) mean age: 57, disease duration: 11.4	Group behavioural educational programme (a+b): 5x2 hour sessions 1xweekly plus 2hr booster sessions at 3,6,9 mths	Long-term effects at 12mths for fatigue and self-efficacy. Participation of a significant other reduced self-efficacy at 12 mths. Those without a significant other present showed increased self-efficacy. Booster sessions had no significant effect on any outcome measures.
Waxman et al	RCT 6 month duration	153 individuals >60 yrs. Control = 75. Mean age: Control= 72yr Intervention = 73yr.	Small group workshops, demos and supportive video/written info:1 hr.	Self-management reduced foot disability scores (MFDQ).

2003				Self-management is potentially more cost-effective in the longer term.
Hammond & Freeman, 2004	RCT – 4 years duration – follow up study to Hammond & Freeman, (2001)	107 people with R.A.followed up at 4 years: control,= 49 intervention = 58	Group behavioural educational programme: 4x wkly 2hr sessions with supportive information and workbook	Long-term benefits in maintenance of function and reduced levels of morning stiffness. Educational Behavioural training is more effective in the long term than standard educational programme.
Kirwan et al 2005	RCT 36 weeks duration Single blind	58 people with RA. Control= 28 75% female. Intervention = 30 63% female. Mean age: control= 57.1yr Intervention = 56.4yr Mean disease duration: control = 16.7 yr Intervention = 13.2 yr	Group educational behavioural programme – 5x 2.5hr, 1x week sessions for 4 weeks plus 1 session at 8weeks. Plus supportive written information booklet.	No significant change in primary outcomes of pain and self-efficacy for pain at 36 weeks No significant change in secondary outcome measures of HAQ, morning stiffness, PV, CRP, depression, stress, control, coping, satisfaction. At 4 weeks statistically significant improvement in knowledge of RA scores
Giraudet-le Quintrec et al, 2007	RCT 12 month duration Single blind.	208 people with R.A. Control = 104: 89% female. Intervention – 89% female. Mean age: control- 54.3 yr intervention – 55.3 yr, Mean disease duration: control- 14.25yr, intervention – 11.85 yr	Group educational behavioural programme – 8x5hour, 1x wk sessions 'v' info booklet.	No statistically significant changes seen in HAQ or disability scores, behavior (diet/physical exercise), physical activity compliance or on disease activity (DAS 28). Significant improvement in: coping, knowledge and satisfaction.
Masiero et al 2007	RCT 8 month duration. Single blind.	70 people with R.A. Control = 34: m=6, f=28 Intervention = 36: m=7, f=29. Mean age: control – 52.2yr intervention – 54.2yr Mean disease duration: control – 16.1yr intervention – 14.8yr.	Group educational behavioral programme – 4x3hr meetings every 3 wks, plus monthly telephone follow-up. .	Improved HAQ, AIMS2 (symptoms, physical functioning & social interaction domains) scores, but no change in the work and psychological domain scores. Significantly lower pain scores (VAS). Improvements in knowledge translated into improved health behaviors and perceived self-efficacy. Motivation sustained due to telephone support & patient diary keeping.

Mayoux-Benhamou et al 2007	RCT 12 month duration Single blind.	208 people with R.A. Control = 104: 89% female. Intervention – 89% female. Mean age: control- 54.3 yr intervention – 55.3 yr, Mean disease duration: control- 14.25yr, intervention – 11.85 yr	Group educational behavioural programme – 8x5hour, 1x wk sessions 'v' info booklet.	At 6mth compliance with home-based exercise and leisure activity was higher but not continued at 12mth follow-up. Motivational strategies needed to facilitate long term adherence to physical training, plus raising patient awareness of exercise benefits and provision of tailored advice. Identification of patient psychological profile may help identify those most likely to comply.
Hammond et al 2008	RCT 12 month duration	167 people with R.A., I.A or PsA Modular prog (mp)- 86. M= 29 f= 57. Standard prog (sp) – 81. M=30 f=51. Mean age: mp- 55.29yr sp- 55.56yr Mean disease duration: mp- 7.56yr sp- 7.20yr RA majority within each group.	Group educational behavioural programme: Modular (MP): 2 modules of 4 x 2.5 hr plus review meeting of 2hr attended over 3-9mth and participant workbooks. Standard (SP): 5x2hr meeting – 1 meeting per week. Each programme supplied educational leaflets.	At 6mth follow up: MP had significantly improved pain scores, fatigue, functional ability, perceived health, self-efficacy, helplessness, use of exercise and joint protection & disease control. At 12mth follow up: the improvements remained for; pain, self-efficacy, perceived control, helplessness, action stage of change, use of joint protection & fatigue management.
Lincoln et al 2008	RCT 12 month duration Single blind.	172 people with diabetes and ulcer free for 28 days prior to start of study. Usual care group – 85; m=71% f=28%. Intervention – 87; m= 62% f= 38%.	1 to 1 education; 1 hour in patients' home within 4wk of randomization. Telephone follow-up 4 wk later.	No impact on prevention of ulcer incidence found, despite improved scores relating to foot care behaviour (NAFF scores) at 12 mth follow up. Patients who are 'high risk' may have other psychological factors, which outweigh the impact of educational interventions.
Lovisi Neto et al 2009	RCT 180 days duration. Single blind.	64 people with R.A. control= 30; m= 17% f= 83%. Intervention = 28; m=7% f= 93%. Mean age: control= 46.2yr intervention= 45.7yr. Mean disease duration: control= 9.41yr intervention = 9.43yr Matched for medication.	Group education sessions- 6x1hour sessions 1xwk.	Patient knowledge scores were significantly higher at final follow up No significant changes seen for pain, disability, depression, anxiety and QoL. Behavioral changes require strategies that increase self-

				efficacy and social support. The inclusion of patient prioritized outcomes will impact on compliance.
Sun et al 2009	RCT 2 years duration Single blind. Single centre.	302 people with diabetes. Control – 147. Intervention – 155. Mean age: control= 66yr Intervention = 63yr. Mean disease duration: control= 11.9yr Intervention= 13.3yr HbA1c: control= 7.8% Intervention= 7.1%	Group education – 8 x 3-4 hours over 2 years.	No significant impact upon patient foot care knowledge or the rate of reported foot care examinations at follow up. No changes in 'poor' foot health behaviors – despite self-identification of high-risk status. Patients require tailored educational interventions based upon their needs at initial assessment.

Table 3 – Non – randomised controlled Trials and Cohort Studies

Author/Year	Study Design & duration	Population Characteristics & Sample size	Delivery method; theoretical approach	Key Findings
Calle-Pascual et al 2002	Prospective clinical trial Mean follow up time; 4-6 yr	308 people with diabetes and a Neuropathy Disability Score of >6. Low risk group = 124 (VPT <25V) High risk group = 184 (VPT >25V)	Group education programme & one to one: Group ed = 4x 2hr over 1 week One to one = 30-60min session 1xmth over 6mths, plus reviews up to 12mths	Compliance with P.E. programme reduces incidence of diabetic foot ulceration in patients with neuropathy. Most effective in early diagnosis/less severe neuropathy.
Neil et al 2003	Pilot study	Convenience sample of 21 people with type 1 or 2 diabetes and End Stage Renal Disease (ESRD). Male = 6 Female = 15 Mean age: 60yr. Mean disease duration: 15yr Intervention= 11 Control = 13 (at start of study)	Intervention = group and individual foot care education plus information 'handouts'.	No significant difference in Patient knowledge of foot health scores (using Siriraj footcare scale) between the control and intervention groups.
Ooi et al 2007	Cohort study Recruitment duration: 5 months	59 people with newly diagnosed Type 2 diabetes (<1 yr). Male = 31 Female = 28 Mean age: 60 yr	Group education programme – 1x 2 hr session in groups ranging from <10 participants to >10 participants.	Patient knowledge of foot care scores significantly improved post intervention with smaller groups showing significantly higher scores than bigger groups (>10 participants).
Abourazzak et al 2009	Controlled clinical trial: Duration: 3 yr	77 people with R.A. Control= 38. Mean age: Control = 55yr Intervention = 52yr Mean disease duration: Control= 10.39yr Intervention = 5.45yr Male: control = 9 Intervention = 1 Female: control= 29 Intervention = 32	Group educational-behavioural- 3x 6 hour sessions, split into 3x3 hour information giving & 3x3hour workshops.	Knowledge of RA was significantly better at follow up. DAS28 score was significantly lower at follow up. HAQ and AIMS2 scores remained stable. Patient satisfaction rated as good overall (from 5.02- 8.94 out of 10)
Ellard et al 2009	Pilot study – 2 educational days. Duration: 6-7wk	Day 1 :12 people with R.A.median age = 46yr Day 2: 19 people with R.A.median age = 57.5yr Disease duration: < 6 mths	Group education – presentations, workshops and written information packs, plus 'conference' stands on 2nd day.	High global rating day 1 & 2: patients' median score was 10 (out of 10) and partners 9 (out of 10). Effectiveness rated high for both days. Information pack 'usefulness' score: 9/10 at follow-up. Knowledge scores remained stable. Patient RA self-efficacy significantly improved at follow up,
Semple et al 2009	Cohort study Recruitment duration = 12wks	30 R.A. patients undergoing podiatry care. Median age: 61 yr. Median disease duration: 10 yr	Ability to participate in self-management foot care programme (SMP).	17 patients passed all tests and would be considered able to participate in SMP. Functional challenges to foot care programme for patients with R.A. provision identified.

		Male = 10 Female = 20		

Table 4 – Questionnaire- based studies

Author/Date	Study Design	Population Characteristics & Sample size	Key Findings
Barlow et al 2002	Longitudinal (12 mths) Patient – administered questionnaire and follow-up via telephone interview	60 people with R.A. Mean disease duration = 17 years. Mean age = 59.2 years	Leaflets good for general information/as memory aid. Group education preferred for information sharing, exercise adherence and skills based activities 1-to-1 education for emotive, QoL and disease specific information. Video demonstration is good for practical demonstration. T.P.E. should be encouraged throughout patients care.
Gray et al 2007	Questionnaire to assess Podiatrists' perceptions re: introduction of providing advice on smoking cessation.	23 Community based Podiatrists	Increase in number of consultations to address issue of smoking seen. Cost effective way to introduce health improvement advice. Patient 'resistance' can lead to conflict and deterioration of relationship. Research required into effect of patient/clinician attitudes on health improvement activity
Makelainen et al 2007	Questionnaire to assess content and methods of TPE use by rheumatology nurses for people with RA. 1 year duration.	80 Rheumatology nurses	Content: information regarding symptoms, nature of R.A, pain, joint stiffness and treatment variety. Majority provide 1-to-1 delivery, 71% gave written info, 38% used demonstration/visual aids, 4% used group education. More self-management education, new methods to support oral/written info, investigation of the content of Rheumatology Nurse Education required. P.E. should be encouraged throughout patients care
Rajan et al, 2007	Questionnaire to investigate patient knowledge of foot care education. Multi-centre, 1yr duration	72 people with diabetes. Cross-sectional 'risk' sample. Male majority, mean age: 62 yrs, Mean disease duration: 16 yrs.	Majority had an unmet educational need. Wide cross-site variety of standard of foot health education. Foot health education should be developed in partnership with the patient to meet their individual needs/goals and incorporate a behavioural component.
Makelainen et al 2009	Questionnaire survey of patient's experience of patient education provided by Rheumatology Nurses. Over 8 months. Multi-centre.	173 people with R.A. Mean age: 57 yr. 88% - Female. Median disease duration: 11 yr – split into: 1/3 of the cohort 1-5yr, 1/3 6-15yr and 1/3 over 15yr since diagnosis.	Content: information relating to: RA- 8%, medication -26%, motivation to 'self-care' – 17%', joint protection – 9%, blood tests – 10%, access to rehab facilities -3% Half were satisfied, expressed dissatisfaction due to; lack of tailoring to individual needs, poor continuity once diagnosed & lack of consideration of emotional wellbeing. Those with shorter disease duration tended to be more dissatisfied. Patients emotional and information needs should be supported especially for newly diagnosed patients.

Meesters et al 2009	Questionnaire survey of educational needs of people with R.A. in Holland Single centre.	165/319 questionnaires returned: 146 female, 19 males. Median age – 68yrs median disease duration – 13yr.	Arthritis process, treatments and self-help measure rated highest followed by movement and managing pain/support systems.'feelings' rated the lowest. Younger patients reflected a higher need re: pain, feelings and support systems. Patients with longer disease duration reflected a higher need re: support systems Assessment of patient's individual educational needs is required.
Newman et al 2009	Questionnaire survey regarding an online resource	34 people with R.A and 8 people with PsA Mean age: 53 yr. Mean disease duration: 14yr.	85% said they would revisit the site, 84% stated the site was easy to navigate, 62% chose specific topics summaries to visit.22% felt the topic summaries were negative.Video interviews of people with RA –highly valued. Site content could be depressing for those newly diagnosed.

2.2 Commentary – Paper 2

Title: “My feet visible but ignored…” A qualitative study of foot care for people with rheumatoid arthritis.

Authors: Dr A E Williams and A. S. Graham

Based on the findings of the narrative review (Paper 1) it was clear that there was no evidence to show how people with RA perceive foot health management or foot health education provision and its’ effectiveness. It is important to have insight as to how people with RA perceive their foot health and the provision of foot health services before narrowing the focus to that of foot health education provision, in order to ascertain what aspects of general foot health management are considered to be of significance. Therefore, the aim of this study was to explore patient experiences of foot problems related to RA, from the onset of problems to the point of provision of foot health interventions.

Using patient focus groups as a method and thematic analysis to interpret the data, this paper identified that for these participants, health professionals generally ignore foot health. There was poor access to foot health services, indicating a potential lack of knowledge about foot health service provision between both health care practitioners and people with RA. The participants appeared to have poor knowledge about foot symptoms in relation to RA and its’ potential impact upon foot health, despite the fact that this group of people clearly articulated that they had significant foot health issues. This apparent lack of knowledge about foot health services and symptoms in relation to RA can be considered to be a barrier to accessing timely and effective management of foot pathology. The participants within this study wanted a ‘voice’ with which to express the nature of their foot problems and the care they required to help manage those problems. The findings of this study reflected a lack of knowledge of the foot health interventions available to the participants and indicated the need for timely management of foot health in this group. The benefits of foot health interventions need to be clearly articulated to people with RA in order for them to have the potential to maximise positive foot health.

The results of this study illustrated the participants’ need for an increased awareness of foot health problems in relation to RA, by both practitioners and people with RA.

Further, it highlighted the need for increased awareness about the availability/ accessibility of foot health services. The contribution of this paper to my subsequent research was that there was a need to understand what people with RA and podiatrists, (as the health professionals most likely to be providers of foot health information and education), perceive the *current status* of foot health education to be. The aims and objectives of this body of works evolved to reflect the need to explore both the practitioner perspective and that of the person with RA and retained the general themes that had emerged from the narrative review of: content, mode of delivery, timing, influence of the therapeutic relationship and perceived effectiveness of education.

INNOVATIONS:

This publication provided a profound insight into the patients' perspective of their whole experience of foot problems. It showed that foot problems are ignored at multiple levels, from initial diagnosis of RA and beyond. The findings of this study demonstrated the clear and strong desire that this group of people have for a voice about their foot problems and the care they wish to receive.

Paper 2:

Title: ‘My Feet- visible but ignored…’ A qualitative study of foot care for people with rheumatoid arthritis.

Authors: Anita E Williams and Andrea S Graham.

Clinical Rehabilitation
http://cre.sagepub.com/

'My feet – visible, but ignored . . . ' A qualitative study of foot care for people with rheumatoid arthritis

Anita E Williams and Andrea S Graham

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'My feet – visible, but ignored . . .' A qualitative study of foot care for people with rheumatoid arthritis

Anita E Williams[1,2] and Andrea S Graham[1]

Abstract

Objective: To explore patients' experiences of foot problems associated with rheumatoid arthritis, from onset of symptoms to being provided with foot health interventions.

Design: A qualitative design was used with an interpretive phenomenological approach to the data collection and analysis.

Setting: University of Salford, School of Health Science.

Subjects: Sixteen female and six male adults with rheumatoid arthritis-related foot problems and experience of receiving foot health interventions.

Method: Data were collected through digital recordings of three focus groups which were conducted by an experienced researcher. An observer made field notes. Transcribed data were analysed using a thematic framework. Data were verified with randomly selected participants and agreement achieved with the participants, researcher and observer.

Results: The results were organized into five themes: the significance of foot symptoms in relation to diagnosis of rheumatoid arthritis; knowledge of and explanation about foot symptoms; accessing foot health interventions; the effectiveness of foot health interventions; and improvements to foot health interventions. Despite foot problems being of concern to the participants, they were often ignored by practitioners from before diagnosis through to foot management.

Conclusions: This study has highlighted a polarity between what these participants need in relation to their foot symptoms and the management of them. That foot problems are often ignored is of concern at multiple levels. These range from the implications of ignoring foot symptoms that may aid diagnosis of rheumatoid arthritis, to ignoring the need for effective foot health interventions.

Keywords

Foot and ankle, healthcare, qualitative study, rheumatoid arthritis

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Introduction

A number of studies have described the common structural and functional changes in the foot affected by rheumatoid arthritis,[1–6] with up to 89% of people with rheumatoid arthritis having some form of foot pathology.[7] These foot problems have the potential to impact negatively on physical function, social participation and quality of life,[8–10] with pain affecting the majority on a daily basis even when the disease is in remission.[11] Further, the multidimensional implications of living with feet affected by rheumatoid arthritis include restrictions in the choice of footwear and clothing.[12–14]

The aims of managing feet affected by rheumatoid arthritis are to relieve pain and preserve foot function, thereby improving the individual's mobility and activity. The therapeutic components that are central to achieving these aims are foot health management,[15] foot orthoses and specialist therapeutic footwear.[16,17] Foot health management includes the appropriate care of skin callosities, which contribute to foot symptoms and foot ulceration.[18]

In support of the need for foot health management, it is recommended[19–21] that people with rheumatoid arthritis have access to foot health services and a specialist podiatrist. Despite this, there is evidence of patchy service provision[22,23] with some indication of the impact of this on individuals. However, what is not known is the patient's perspective of their whole experience of foot problems. Therefore, the aim of this study was to explore patients' personal experiences of rheumatoid arthritis-related foot problems from the initial onset of foot symptoms through to their management.

Method

Study design

A qualitative methodology was used with an interpretive phenomenological approach[24] being adopted for both the data collection and analysis. This approach considers the experiences of the participants and acknowledges the researcher's previous experiences of the subject.[25] This results in a 'fusion of horizons'[26] and an agreed level of understanding. Focus groups were chosen as the method of data collection. The group dynamics, social interaction and group synergy are distinct features of this method, creating a richness of data.[27] It is suggested that three or four groups of six to eight participants will achieve sufficient data for the aim of the study to be achieved.[28]

Participants

Following ethical approval from the University of Salford Ethics Committee, participants were purposively recruited. The inclusion criteria were adults (>18 years) who could read speak and understand the English language, a positive diagnosis of rheumatoid arthritis[29] and experience of foot problems, foot orthoses, foot surgery and/or specialist therapeutic footwear. The exclusion criteria were those with an unconfirmed diagnosis of rheumatoid arthritis, no experience of foot problems or foot health interventions, those who could not speak and understand the English language and those who declined to be involved. The participants were recruited from the National Rheumatoid Arthritis Society branches in the north west of England. Twenty-five people who met the inclusion criteria were provided with written information about the study. Three people declined due to reasons of hospital appointments or holidays.

Data collection

Twenty-two participants agreed to proceed to one of three focus groups which were carried out at the University of Salford. The focus groups comprised one with eight participants and two with seven in each and were a mix of males and females. Formal informed consent was obtained and the participants were assured that they could withdraw from the study at any time.

All the focus groups were conducted by an experienced researcher with an independent observer taking field notes. Both had 10 years of clinical experience of working as podiatrists within a rheumatology service. The dialogue was recorded on a digital voice recorder. The researcher (AW) asked an initial question: 'Tell me about your experiences of foot problems and how they have been managed.' Further ad hoc prompts were used if the participants wandered off the subject of feet for too long. All were encouraged to contribute when a specific issue was raised to ensure that the experiences revealed were not just those of one or two participants.

Data analysis

The dialogue was transcribed verbatim immediately after the focus groups by the researcher (AW) and confidentiality achieved by replacing participants' names with pseudonyms. Analysis was carried out using a thematic approach[30] with the framework agreed by the researcher and the observer. To enhance credibility of the analysis, we reviewed and coded the data, discussed the themes, further coded the data and then the agreed codes were then organized into themes. Exemplars from the transcripts were identified in order to illuminate the true 'authentic' nature of the participants' experiences and to support the trustworthiness of the findings. Four of the participants from each group were randomly selected to read and verify that the transcripts and results reflected the experiences of the groups.

Results

Sixteen females – mean (SD) age was 58 (11.9) years and mean (SD) disease duration was 15 (5.2) years. Six males – mean (SD) age was 59 (6.0) years and mean (SD) disease duration was 13 (5.0) years.

All participants reported experience of foot pain. One participant had been recently diagnosed with diabetes but had no known complications associated with it. None of the participants were house bound and only one female used a walking aid.

All participants had accessed some form of professional foot care for their nails and skin with all but two participants having experience of foot orthoses. Four females and one male had experience of being provided with specialist therapeutic footwear but only one female wore the footwear on a regular basis. Three had experience of foot surgery.

The results indicate that despite foot problems being of concern to them, their foot problems and their needs are often ignored by practitioners from before the diagnosis of rheumatoid arthritis through to the management of their foot problems. This global theme is supported by the following five themes. These five themes were evident in all three focus groups.

Theme 1 – The significance of foot symptoms in relation to the diagnosis of rheumatoid arthritis

Many of the participants reported that they had experienced problems with their feet before a diagnosis of rheumatoid arthritis was made. Most reported that their feet were ignored by their general practitioners (GPs) even if they mentioned foot symptoms during a consultation. Foot symptoms were of great concern to the participants and one of the most worrying aspects of their disease. They also perceived that their GPs did not understand the significance of foot symptoms in relation to the possibility of rheumatoid arthritis:

> 'It wasn't picked up even though I kept saying that it was rheumatoid . . . felt I wasn't listened to by my doctor . . . even when I complained about my feet I was told that it was my shoes.' [F 54]

Some of the participants reported a delay in being referred to a rheumatologist and had to be proactive in achieving this:

> 'It took months to get a diagnosis . . . mine was four years and I had joint pain and particularly foot pain . . . all that time . . . I had to change to another practice and then I was listened to.' [M 60]

They felt anxious and this was compounded by the thought that they might be perceived as being a nuisance. Some recognized that delays in referral for diagnosis and then delayed intervention had a detrimental effect on their feet:

> 'No one asked about it until it seemed too late and my feet had deformed. . . . I am so angry about that . . . something might have been done if . . . well its no use now is it?' [F 59]

The fact that their feet were ignored by their GPs resulted in an overall lack of confidence in them and anger that their foot symptoms had been ignored.

Theme 2 – Knowledge of and explanation about foot symptoms

The participants reported that they had patchy knowledge of what causes the foot problems associated with rheumatoid arthritis. Some had been referred to podiatry services where they had received the information that they needed:

> ‘Didn’t associate pain in foot with rheumatoid arthritis . . . stupid really . . . and then they started changing shape . . . I was referred to the podiatrist and was so relieved when I was told what was going on.’ [F 55]

However, a small number suggested that too much information could be detrimental. All agreed that it would be more appropriate for the patient to take the lead as to when information should be given;

> ‘I don’t think I would have liked too much info in the beginning as you don’t take it in but it would have been good to have the opportunity to be able to ask when needs arise.’ [F 57]

Further, some thought that written information can be frightening if it is not supported with verbal explanation:

> ‘The information leaflet on feet left me quite traumatized. . . . There was no reassurance (in leaflet) that things could be done to prevent it – he (the podiatrist) didn’t discuss it.’ [F 52]

The majority expressed relief once they had acquired knowledge about their foot symptoms. However, the lack of timely ‘information giving’ by many practitioners resulted in them being left to work out what their foot problems were. Many were never asked what they needed to know or when they needed it.

Theme 3 – Accessing foot health interventions

When they had been diagnosed with rheumatoid arthritis by a rheumatologist, some reported that they had difficulty getting foot care, with delays in both being referred and then getting an appointment with a podiatrist:

> ‘When I eventually got referred to the consultant he asked all about my feet . . . but it then took ages to get to see a podiatrist.’ [M 68]

For some, the lack of attention given to feet during their consultation with a rheumatologist resulted in delayed referral for podiatry. Some reported that their feet were ignored until, almost by accident, they were seen in a context other than the usual or expected referral route:

> ‘I was visiting my mother in hospital and she had a lady to look after her feet . . . I asked her how I could get it . . . now I go . . . and feel good when I have been.’ [F 59]

Having their feet ignored invoked feelings of anger and desperation:

> ‘They don’t ask about the feet . . . . Heather Mills can walk and she has a false leg. I wondered if it would be better to have a below-knee amputation and get on with it . . . it took me to get angry and say to my consultant “you have to do something!”.’ [F 64]

These same feelings were expressed in relation to accessing foot surgery:

> ‘I had to bang doors down to get it and get very angry with my consultant . . . they are my feet and I know what will help . . . it should be my choice . . . now I have less pain . . . I knew it would get rid of it.’ [F 59]

There appeared to be a reluctance to refer people for foot surgery:

> ‘I didn’t get referred for a surgical opinion until my podiatrist discussed it with me as an option . . . I could

> have cried . . . just to think that I could have all these toes straight sooner so I could have worn more decent shoes for my son's wedding.' [F 62]

The overall impression was that their rheumatologists had to be more focused on the medical management and other areas of the body but it was identified that: 'if they did take the shoe off then perhaps they wouldn't ignore them' [M 62].

Theme 4 – The effectiveness of foot health interventions

Frequently, it was reported that the potential effectiveness of foot orthoses was limited by the footwear styles that the participants liked to wear. They thought that this problem is often ignored:

> 'I got insoles but they were not comfortable at all, particularly in certain shoes. . . . She said keep trying but I could only wear them in my boots . . . you will get used to them she said.' [F 61]

Abnormal wear of their footwear caused by the orthoses stopped some participants using them or they had to purchase new footwear:

> 'You get a line in the shoes where the end of the insole finishes and that means the shoes wear out quicker . . . and then they crack and break. . . . Need more shoes . . . so that's another problem.' [M 48]

However, when foot orthoses fitted into a variety of footwear styles, engagement was much better and hence foot symptoms improved:

> 'I had these supplied by the specialist podiatrist . . . she really listened to me and then made suggestions for shoes . . . I got them and then she checked them over . . . then made the insoles to fit in with my feet . . . they are really comfy and I can't walk without them.' [F 58]

Some had experience of wearing specialist therapeutic footwear but all reported a loss in choice of clothes and associated loss of femininity. They thought that the practitioners providing this footwear did not understand this:

> 'I hate these shoes but they are the only things I can wear . . . the man at the hospital was really nice but 'erm . . . I don't think he understands what it is like to be a woman wearing men's shoes.' [F 65]

However, despite these feelings most acknowledged some benefits:

> 'I look and feel like an old lady with these on but they are comfy . . . at least.' [F 60]

Most had accessed general foot care for nails, corns and callus. They valued this in respect of improvements in comfort:

> 'Having feet looked after is one of the things I don't have to worry about.' [F 63]

They understood the difference between generalist and specialist podiatrists and valued the links that the specialists had with the wider multidisciplinary team:

> 'I have a good podiatrist . . . she is very clever and understands my problems . . . she specializes in this . . . I only have to ask her and she sees me . . . my feet are so much better with the insoles and treatment . . . she knows all about the drugs too unlike the one I went to before.' [M 55]

> 'This one can get me into the consultant and the nurse when I need it . . . and that's really good it's like being in a big family.' [F 59]

It was also acknowledged that the option for open access to podiatry was reassuring in that they could get immediate help when new problems arose.

Theme 5 – Improvements to foot health interventions

The majority expressed the opinion that GPs should have knowledge about rheumatoid arthritis and the significance of foot problems in its diagnosis. Once a diagnosis has been made then referral to podiatry services was considered to be essential for those with foot pain.

There was overarching agreement that podiatry services should be valued more with a perception that lack of finances and managerial support being an obstacle:

> 'I would like more importance to be given to foot care and orthotics so it's not bottom of the pile . . . perhaps it needs more investment so there are no waiting lists for foot care . . . do you think the managers know how important it is to us?' [F 64]

In relation to finding footwear in which to accommodate both their feet and their foot orthoses was an issue for the majority. It was suggested that in an age of technological advances therapeutic footwear should be designed and manufactured in contemporary styles with improvements in fit:

> 'I know a lady who went to France and they put her feet in a scanner . . . her shoes fitted perfectly . . . it is so hit and miss with the dressmaker's tape measure . . . no wonder it goes wrong.' [F 55]

The need for a variety of therapeutic shoes for different functions was expressed:

> 'Someone should invent a sandal that will take the insole and support your foot. . . . You put up with your feet being roasted in the summer.' [F 56]

Informed decision-making was considered to be vital to regaining control over their foot problems:

> 'Just because you have arthritis it doesn't mean that you have to live with feet like this . . . if surgery will help then it should be available.' [F 54]

Discussion

This qualitative study has revealed much about the participants' experiences of their foot problems from the point of disease onset, through to diagnosis and management. Foot problems continue to be common and disabling[7,11] despite the progress in new treatments[11] and therefore should not be ignored. The potential for the effective management of feet[15–17] has been clearly evidenced. However, this study has highlighted a polarity between what people with rheumatoid arthritis perceive their needs to be and what is provided. The result of this is that for the participants of this study there is a gap between what the outcomes of foot health interventions could be and what they actually are. This study is not without its limitations. This was a relatively small number of participants and they were all from the north west of England and therefore the study is not a fully representative cross-section of the wider population of people with rheumatoid arthritis-related foot problems. The results may also have cultural specificity and generalizability may be limited to healthcare systems such as those in the north west of England. Bias could also have occurred in that the people volunteering to take part in the study may have done so because they have had negative experiences. In that respect we cannot claim that the results of this study reflect the experiences of the wider population of people with rheumatoid arthritis-related foot problems.

Although there are these limitations, it is clear that the participants of this study have revealed much about their experiences from which we can learn. That foot problems are ignored is of concern at multiple levels, ranging from the implications of ignoring foot symptoms that may aid diagnosis, to ignoring the need for foot health interventions. As rheumatoid arthritis often presents in the early stages in the small joints of the feet,[2,6] ignoring this at initial presentation may delay diagnosis and the commencement of appropriate medical management. Most of the participants in this study thought that feet were ignored even when a diagnosis was made when compared with the attention given to hands. The focus on hands places feet in a relegated position and therefore it is of no surprise to find that the participants consider that their feet are ignored. Also, ignoring feet at the point of diagnosis means that the 'window of opportunity' is being missed for the provision of foot orthoses which have the potential to contribute to the maintenance of good foot structure.[31]

Given the evidence for the clinical benefits of foot health management[15–17] it is of concern that for these participants, referral is patchy and often delayed. However, even when they were referred, some participants reported negative experiences, particularly in relation to therapeutic footwear and foot orthoses. This may reflect the difficulty in achieving marriage between the function of these interventions and their aesthetic acceptability. However, there was little evidence of empathy being demonstrated by practitioners as highlighted in previous studies.[12,13]

Timely management of their foot health by empathic and knowledgeable practitioners with attention to the patient's needs were considered to be pivotal in ensuring that the known benefits of these interventions are realized.

Further work will be to survey a wider population of people with rheumatoid arthritis to ascertain a more comprehensive picture.

Despite being ignored in the clinical context, it is clear that people with rheumatoid arthritis wish to have a voice about their foot problems and the care that they need. Meeting their needs is important in relation to the potential for good foot health and as such, it is our duty to listen.

Clinical messages

- Patients consider that foot symptoms are important in relation to the potential for a diagnosis of rheumatoid arthritis.
- Foot symptoms should instigate referral for foot health interventions, including surgery.
- Foot health interventions and patient education need to be provided with consideration for the patients needs.

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Conflict of interest

The authors declare that there are no conflicts of interest in relation to this study.

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References

1. Sharma M, Dhanendran M, Hutton WC and Corbett M. Changes in load bearing in the rheumatoid foot. *Ann Rheum Dis* 1979; 38: 549–552.
2. Vidigal E, Jacoby RK, Dixon AS, Ratliff AH and Kirkup J. The foot in chronic rheumatoid arthritis. *Ann Rheum Dis* 1997; 34: 292–297.
3. Minns RJ and Craxford AD. Pressure under the forefoot in rheumatoid arthritis. *Clin Orthop Relat Res* 1984; 187: 235–242.
4. Laroche D, Pozzo T, Ornetti P, Tavernier C and Maillefert JF. Effects of loss of metatarso-phalangeal joint mobility on gait in rheumatoid arthritis patients. *Rheumatology* 2006; 45: 435–440.
5. Woodburn J, Helliwell PS and Barker S. Three-dimensional kinematics at the ankle joint complex in rheumatoid arthritis patients with painful valgus deformity of the rearfoot. *Rheumatology* 2002; 41: 1406–1412.
6. Turner DE, Helliwell PS, Emery P and Woodburn J. The impact of rheumatoid arthritis on foot function in the early stages of disease: a clinical case series. *BMC Musculoskel Dis* 2006; 7: 102.
7. Grondal L, Tengstrand B, Nordmark B, Wretenberg, P and Stark, A. The foot: still the most important reason for walking incapacity in rheumatoid arthritis: Distribution of symptomatic joints in 1,000 rheumatoid arthritis patients. *Acta Orthop* 2008; 79: 257–261.
8. Wickman AM, Pinzur, MS. Kadanoff R and Juknelis D. Health-related quality of life for patients with rheumatoid arthritis foot involvement. *Foot Ankle Int* 2004; 25: 19–26.
9. O'Connell PG. Forefoot deformity, pain and mobility in rheumatoid and non-arthritic subjects. *J Rheumatol* 1988; 25: 278–304.
10. Michelson J, Easley M, Wigley FM and Hellmann D. Foot and ankle problems in rheumatoid arthritis. *Foot Ankle Int* 1994; 15: 608–613.
11. Otter SJ, Lucas K, Springett K, et al. Foot pain in rheumatoid arthritis prevalence, risk factors and management: an epidemiological study. *Clin Rheumatol* 2010; 29: 255–271.
12. Williams AE, Nester CJ and Ravey MI. A qualitative investigation of rheumatoid arthritis patients' experiences of therapeutic footwear – a qualitative investigation. *BMC Musculoskel Dis* 2007; 8: 104.
13. Williams AE, Nester CJ, Ravey MI, Kottink A and Morey-Klapsing G. Women's experiences of wearing therapeutic footwear in three European countries. *J Foot Ankle Res* 2010; 3: 23.
14. Goodacre LJ and Candy FJ. 'If I didn't have RA I wouldn't give them house room': the relationship between RA, footwear and clothing choices. *Rheumatology* 2011; 50: 513–517.

15. Williams AE, Davies S, Graham A, et al. Guidelines for the management of the foot health problems associated with rheumatoid arthritis. *Musculoskeletal Care* 2011; 9: 86–92.
16. Farrow SJ, Kingsley GH and Scott DL. Interventions for foot disease in rheumatoid arthritis: a systematic review. *Arthritis Rheum* 2005; 53: 593–602.
17. Williams AE, Rome K and Nester CJ. A Clinical trial of specialist footwear for patients with rheumatoid arthritis. *Rheumatology* 2007; 46: 302–307.
18. Firth J, Helliwell P, Hale C, Hill J and Nelson EA. The predictors of foot ulceration in patients with rheumatoid arthritis: a preliminary investigation. *Clin Rheumatol* 2008; 27: 1423–1428.
19. Arthritis and Musculoskeletal Alliance. *Standards of care for inflammatory arthritis*, 2004. www.arma.uk.net (accessed May 2011).
20. National Institute for Clinical Excellence. *Guidelines for the management for the adult with rheumatoid arthritis*, 2009. http://guidance.nice.org.uk/CG79/Guidance/pdf/English (accessed May 2011).
21. Podiatry Rheumatic Care Association. *Standards of care for people with musculoskeletal foot health problems*. www.prcassoc.org.uk/standards-project (accessed May 2011).
22. Steward K and Land M. *Perceptions of patients and professionals on rheumatoid arthritis care. A Consultancy Report by The King's Fund for the Rheumatology Futures Group*. London: The Kings Fund, 2009.
23. National Audit Office. *Services for people with rheumatoid arthritis*. London: The Stationery Office, 2009.
24. Mulhall S. *Heidegger and being and time*. London: Routledge, 1996.
25. Silverman D. *Doing qualitative research: a practical handbook*. London: Sage, 2000.
26. Gadamer HG. *Truth and method*, second edition. London: Continuum Publishing, 2004.
27. Thomas L, MacMillan J, McColl E, Hale C and Bond S. Comparison of focus group and individual interview methodology in examining patient satisfaction with nursing care. *Social Sci Health* 1995; 1: 206–219.
28. Krueger RA and Casey MA. *Focus groups: a practical guide for applied research*, third edition. Thousand Oaks, CA: Sage, 2000.
29. Arnett FC, Edworthy SM, Bloch DA, et al. The American Rheumatism Association 1987 revised criteria for the classification of rheumatoid arthritis. *Arthritis Rheum* 1988; 31: 315–324.
30. Attride-Stirling J. Thematic Networks: an analytic tool for qualitative research. *Qual Res* 2001; 3: 385–405.
31. Woodburn J, Barker S and Helliwell PS. A randomized controlled trial of foot orthoses in rheumatoid arthritis. *J Rheumatol* 2002; 29: 1377–1383.

2.3 Commentary – Paper 3

The results of the study published in paper 2, indicated that people with RA lacked knowledge of foot health services, the foot-related symptoms they could potentially experience due to RA and how foot health interventions could potentially manage their foot health problems. It was clear that people with RA view foot health problems as having a significant impact on their day-to-day lives. Patient education is recognised as important for people with RA and providing education about the purpose/use of foot health interventions for people with RA can potentially improve patients' use of them. To understand how foot health education (FHE) can best meet the needs of people with RA and support self-management, we need to identify their perception of what FHE is, what they want to know about foot health and RA, how it is currently delivered and what the perceived barriers are to accessing FHE. The aim of the study within paper 3 was to explore the experiences of FHE in people with RA, using a patient focus group and to use the findings to inform the development of a survey to be distributed to a larger population of people with RA.

This study uniquely identified that participants lacked clarity as to the role of the podiatrist in the management of their RA- related foot health problems because of the retention of the dual titles: 'chiropodist' and 'podiatrist'. It also meant that participants lacked clarity as to the scope of podiatric practice. Participants perceived that there was a lack of high-quality, patient-centred information in relation to foot health and RA. Participants viewed written educational resources as important to help support verbal information provided during medical consultations. Group education sessions were not viewed as particularly useful. A flexible approach to delivery and the timing of delivery, to meet the needs of the individual, was seen as a valuable consideration in the provision of FHE. Ensuring their educational requirements were 'current' and reflected their needs at a given point in time was a significant theme. Time constraints within the medical consultation and the often negative nature of the patient/ practitioner relationship, were expressed as barriers to obtaining foot-health related information during medical appointments. This study identified for the first time, that the gender of the podiatrist and their ability to empathise with the individual was particularly influential in the development of the therapeutic relationship.

This study added to and consolidated the individual items and sub-topics to be considered within the survey for people with RA originally considered for further exploration by the narrative review and the focus groups conducted within paper 2. Identifying which health professionals and which web resources were commonly used to provide foot health information became additional items for consideration within the development of a wider survey. This was in order to provide clarity about the sources of foot health information available to people with RA. Further to this, the results from the study published in paper 3 indicated the potential factors that could be considered to influence the provision of FHE for people with RA such as gender, role of the professional and podiatry practitioner experience.

INNOVATIONS:

The findings within this publication show that much more work is required in educating patients and the general public about the role of the podiatrist and their scope of practice, especially their role in the management of complex diseases such as RA. This should be a key component of FHE provision. This study identified the high value that people with RA place upon written information resources provided by health professionals and such resources should be made available for people to take away and refer to, following the medical consultation. The importance of tailored and patient-centred FHE, provided within the context of a strong and trusting therapeutic relationship that will foster positive health behaviour, emerged as a key theme within this study.

Paper 3:

Title: Foot health education for people with rheumatoid arthritis – some patient perspectives.

Authors: Andrea S Graham, Alison Hammond, Steven Walmsley, Anita E Williams.

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Foot health education for people with rheumatoid arthritis ¿ some patient perspectives

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Foot health education for people with rheumatoid arthritis – some patient perspectives

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Abstract

Background

Patient education is an important component of foot health management for people with rheumatoid arthritis (RA). The content and strategies for delivery require investigation in relation to the patients‟ needs. This study explores patients‟ experiences of foot health education, to inform how the patients‟ needs could be identified in clinical practice and inform effective education delivery.

Method

A focus group was used to collect data. The dialogue was recorded digitally, transcribed verbatim and analysed using a structured thematic approach. Member checking and peer review added to credibility of the data.

Six themes emerged; (i) content and purpose of patient education – what it should be, (ii) content of patient education – what it should not be, (iii) timing of information on foot health, (iv) method of delivery, (v) ability to engage with foot health education and (vi) the patient/practitioner relationship.

Conclusions

This study identified aspects of patient education considered important by this group of patients in relation to content, timing and delivery, forming the basis for further research on clinical and patient focussed outcomes of patient education.

Identifying health education needs and provision of supportive verbal and written information can foster an effective therapeutic relationship, supporting effective foot health education for people with RA.

Keywords

Podiatry, Patient, Foot health education, Rheumatoid arthritis

Background

National Health Service reviews and reports focus on the need for increased self-management in the overall management of patients with long-term conditions, such as Rheumatoid Arthritis (RA) [1,2]. In support of this the Department of Health „information revolution‟ [1] provides resources that aim to improve health related behaviour, support aspects of self-management and thereby maximise the potential for health benefits [1]. For people with RA, it is known that patient education, including verbal and written information, self-study, websites and psycho-educational programmes, have a positive effect in relation to disease management and general health [3].

Patient education is recognised as important for people with RA in relation to foot health [4-6]. Up to 80% of people with RA report foot pain on a regular basis [7,8]. Providing education during podiatry consultations, in the form of information on the purpose and use of clinical interventions, such as foot orthoses and specialist footwear [9], could potentially improve patients‟ use of them [10].

The skills required to deliver patient education, are now embedded in the undergraduate curriculum and are considered a core component of podiatry care. Podiatrists perceive it as a valued and beneficial activity supporting aspects of foot management that patients can perform themselves [11]. Despite recommendations for an increased role of the patient in foot health [4-6], little is known from the patient perspective.

It is important to consider that practitioners and patients may have diverging opinions about what is important [12]. Despite benchmark standards [13] that state that patient education should be patient centred, based around patient need, there is some evidence that this is not being fully met [14,15].

For foot health education to meet the needs of the patient and support self-management we need to understand their perceptions of what and how it is currently delivered. Therefore, the aim of this study was to explore patients‟ experiences of foot health education, in order to inform how the patients‟ needs could be identified in clinical practice. In achieving this, effective education as an intervention could be delivered.

Methods

Design

A qualitative approach using focus groups was selected because: focus groups are an effective method of exploring people"s experiences of their health condition and its management; they produce a richness of data from a small group of people simultaneously [16]; and can generate data where there is little existing knowledge [17]. Four to nine participants were required for the focus group. This is considered to be the optimum size for such interviews [16,18,19] and appropriate for the generation of data for analysis using a thematic framework [20].

Participants

Using a purposive sample framework, six people aged over 18 years, with a diagnosis of RA [21] and foot problems; able to read and speak English; and able to provide written consent were recruited from a North West England rheumatoid arthritis support group. People with severe mental illness were excluded due to their inability to fully consent.

Procedures

Following ethical approval from the University of Salford, the Chair of the RA support group distributed an invitation letter, participant information leaflet and response form to all members with RA. The information leaflet provided contact details of the first author (AG) to allow members interested in participating the opportunity to ask questions about the study. Immediately prior to the focus group a presentation about the study was given to the RA support group. Members then had the additional opportunity to ask questions and written consent was obtained from those members who wished to participate.

Trigger questions with additional prompts were created by the first author (AG) and agreed by the co-authors. The questions were based on the first author"s previous knowledge of foot health education provision to people with RA and focus group work with practitioners. Potential participants were invited to view the trigger questions before consenting to take part in the focus group. This ensured that the questions could be clearly understood and took into account the views of the participants as collaborators in the research process [22]. No amendments were required. The focus group took place where the participants met as a support group, providing a familiar and private environment [23]. The members were advised that the focus group would last approximately one hour, using the interview questions to generate discussion. Breaks could be taken at any time, if required. The focus group was facilitated by AG and an independent observer, (SW) made additional observations and took field notes. The first author transcribed the dialogue verbatim.

Focus group questions: details of the questions used to generate participant discussion during the course of the patients" focus group

In your opinion, what is Patient Education? (in relation to foot health)

- What do you think the purpose of it is?
- What is the usefulness of it?

What kind of information is given?

Prompts:

- What kind of things are you told about Rheumatoid Arthritis?
- About Podiatry?
- About what can be done for your feet?

When is patient education given?

Prompts:

- Think about when you were first diagnosed/first saw a podiatrist – were you given any foot health related information or advice then?
- Have you been given any information/education about your feet since then, if so when?
- Is this something you discuss regularly or was it a „one-off"?

How is the information/education provided for you?

Prompts:

- For example were you simply given verbal advice?
- Did you receive any written information such as leaflets provided by the Trust, AR UK, NRAS, from the podiatrist or any other Healthcare professional relating to your feet?
- Were you prompted to use any websites?
- What did you think about the resources that you were provided with?

In your opinion, what prevents you from obtaining the foot health information/education that you want?

Prompts:

- Is there anything that stops you from getting the information or advice that you need at the time that you need it?
- How easy is it for you to access your podiatrist for example?
- Do you know where to go for the right kind of information?
- Do you have easy access to the internet for example?

Data Analysis

The participants verified the transcription, which was sent electronically to the chair of the group for dissemination, to support the trustworthiness of the data [24,25]. Paper copies of the transcription were available on request. The verified dialogue transcription was subject to thematic analysis [20]. A thematic framework was used, allowing the researcher to illustrate the main themes within the text and make transparent the methodical systematisation of textual data. To achieve this, a six-stage process was used involving: coding the text; theme identification; thematic network construction; description and exploration of networks; summarisation of networks; and pattern interpretation [26]. The data was categorised into „Basic" and „Organising" themes (Table 1). This approach acknowledges the researchers" experience and knowledge of the subject being researched and the influence of this throughout the data collection and interpretation. The thematic analysis framework was agreed by one of the co-authors (AW) to evaluate validity of the data and exemplars were extracted to demonstrate truthfulness of the data within each theme [24,25].

Table 1 Outline of the basic and organising themes developed from the thematic analysis

Basic Themes	Organising Themes
• Information Provision • Signposting • Preparedness • Explanation of service and interventions • Self-management • The podiatrists role and scope of practice • The role of other Allied Health Professionals	The Content and purpose of Patient Education – what it should be.
• Information from internet sources • Fear of the future – prognosis for foot health • Comparison of foot health in RA to that in other diseases • Fear of interventions	The Content of Patient Education – what it shouldn"t be.
• Timing of referral to podiatry • Timing of delivery of educational material • Time available within a consultation • Time to reflect	Timing of Information on Foot Health
• Internet resources • Group Education • One-to-one • Written • Verbal	Method of delivery
• Finance • Time • Access • Information Retention	Ability to engage with Patient Education
• Helpfulness • Being listened to • Influence of gender	The Patient - Practitioner Relationship

Results

Out of twenty members of the support group approached, six participants who met the inclusion criteria initially consented. One was unable to attend the focus group due to ill health. All five participants were women, with a mean age of 62 years (SD 5.3) and mean disease duration 5.9 years (SD 2.7). All participants had experienced foot problems and had received National Health Service (NHS) podiatry services. Two participants had attended group Patient Education sessions, relating to RA but not foot health, subsequent to their diagnosis. The remaining participants had not received any formalised patient education. Participants‟ names have been replaced with a pseudonym for confidentiality.

Global theme: Barriers to engagement with foot health education

The unifying global theme was that there are barriers to receiving foot health education from podiatrists, leading to information being sought from sources that resulted in confusion and fear. In support of this six organising themes emerged:

The content and purpose of patient education – what it should be

Participants considered that patient education (PE) was primarily an information resource that could guide them to other sources of information, such as the Internet. As Mary highlighted:

> “*(patient education is) what you are told by your Specialist, what you can find out on the web and other sources.”*

Identifying how to access foot health information resources and what they should know about foot health were issues for all the group:

> “*A lot of it is that you don‟t know what you don‟t know*!” (Kitty).

All participants considered they had received little or no information regarding their foot health. However, they wanted to be prepared for what might lie ahead: potential foot-related morbidity; prevention of foot health deterioration; and the side effects of medication on foot health. They also wanted information on the availability of foot health services and foot health interventions:

> “*You need details of specific foot problems… the sort of thing we all experience really, like fallen arches or pains in your toes, what this is caused by or how you can help it (and) what treatment is available for each problem*” (Mary).

Participants wanted information to facilitate safe and effective self-management. Some had received general footwear advice. However, they expressed disillusionment with it, as their individual needs had not been considered, such as their ability to find accommodating footwear:

> *“She said wear trainers, I can‟t even wear trainers…my instep is so high”* (Joan).

None of the participants had been informed about the scope of practice of podiatry but did perceive that „chiropodists‟ and „podiatrists‟ were different in relation to the level of expertise. This indicates confusion, as in reality they are the same:

> *“You would expect them [podiatrist‟s] to know more in depth about your foot problems really, a chiropodist I would look on as more for cosmetic things really like hard skin, toenails”* (Mary).

Participants emphasised the need for clarification on the podiatrists‟ scope of practice, as well as that of other health professionals involved in foot health.

The content of patient education – what it should not be

Most participants had accessed foot health information through the Internet and found it frightening and overwhelming, reinforcing their fear of developing foot problems:

> “*Sometimes they cannot be very helpful, or they can tell you too much, they‟ll blind you with science which you don‟t understand or they‟ll tell you something and you think „oh my feet are going to drop off!‟”*(Lynne).

This negative view of their future foot health was further reinforced by comparing their foot pathology with those of others they knew (friends/family) with chronic diseases, such as diabetes:

> *“…they get told that when they‟ve got diabetes, that different things can happen to them [their feet]”* (Bernice).

Lack of appropriate education and information about interventions often invoked fear, anxiety and concern, particularly in relation to footwear styles required to accommodate both changing foot shape and orthoses:

> *“It‟s not possible to get something that works and is fashionable as well is it?”* (Mary).

Mary‟s question highlights the participant‟s concerns relating to the image that therapeutic footwear represents and the function that it provides and this is further reinforced by Lynne who stated that:

> *“Well none of us [indicates to the group] has special shoes and if we did, I think we'd all throw them to the back of the wardrobe as soon as we got them home. Because I've seen them… and I‟d have to be dead to wear them.”* (Lynne).

Timing of information on foot health

Early referral to a podiatrist was considered crucial for timely access to appropriate foot health information. Participants stated that such information should be presented in a way that was not overwhelming. It should allow them to first absorb the meaning of being diagnosed with RA:

> *“You need to have a bit [of information] to tell you what can happen to your feet when you‟ve got RA, but more when you go to see the podiatrist because by then you‟ll have soaked in a bit, you can take a bit more.”* (Lynne).

Limited time during consultations was perceived as preventing foot health questions being raised:

> *“...and then there‟s the time factor as well, if I go into this podiatrist and say „what are you going to do for me?‟ there‟s only so much time.”* (Joan).

Time for reflecting on information provided was deemed essential to enable asking further questions at subsequent appointments.

Method of delivery

The Internet was the most accessed resource. Frustration with limited information about RA and feet was expressed. Certain websites were considered too difficult to navigate to find the right information:

> *“I had a terrible time with the NHS website, never found what I want.”* (Lynne).

Group education, provided by a range of health professionals, was considered best for arthritis-related information and self-management strategies within a supportive environment. Participants also considered that group education could provide information relating to topics they had not thought about. However, two participants who had attended education groups found them of little benefit. They were frustrated that group leaders allowed more vociferous individuals to dominate:

> *”I can remember going to a group and getting so exasperated with a guy that I ended up telling him I‟d come to listen to the tutor, not him.”* (Kitty).

The majority of participants had experienced one-to-one „verbal‟ foot health education about general foot health issues together with an explanation of interventions, such as foot orthoses. The effectiveness of the patient /practitioner relationship influenced both the information provided and whether the patient‟s agenda was identified:

> *“...I thought he‟s not really picking up on the main reason why I'd actually gone to see him.”* (Mary).

None had received written foot health information from any health professional, including podiatrists. Leaflets were viewed as an extremely useful „aide memoir‟ as they considered that RA affects retention of information. Leaflets were considered useful to impart general information, such as frequently asked questions and were a reference source about who to contact for attention to foot problems.

Ability to engage with foot health education

The financial cost of improving foot health behaviours, such as buying appropriate footwear and aids to facilitate self-management, were seen as barriers to engaging with advice:

> *“They (long-handled files) are expensive if you go to a mobility shop, which is the only place you‟ll get them.“* (Lynne).

Other education resources, such as local support groups, can incur costs, which could be a barrier to people joining. Further, they perceived that practitioners experienced many time pressures and subsequently felt unable to approach Podiatry services to receive education.

The participants unanimously voiced that there was a distinct lack of information, which provided explanation without inciting fear and anxiety:

> *We didn"thave the insight to ask for the information before because we didn"t know there was any available… it"s not there, podiatry wise it"s just not there."* (Lynne).

The patient/practitioner relationship

Generally, when advice or foot-health education was provided, they considered podiatrists to be helpful. Despite this, they considered that their point of view was often not heard, being dismissed without their key concerns being addressed:

> *"…I went back again and said I can"twear these [insoles] except for in my boots and they said „ohwell you"llget used to them"and sent me home. And that were it, that"s theamount of information I got."* (Lynne).

Participants considered female practitioners had a greater understanding of their needs:

> *"I got on better with a female one (podiatrist)…she was absolutely brilliant, I felt I got a lot out of the appointment, the orthotics seemed to work better and she did give me a lot of information."* (Mary).

Discussion

Using focus group methodology and a thematic approach to data analysis has revealed a richness of data about the participants‟ experiences and opinions about the purpose, content, methods of delivery and barriers to foot health education provision.

The small sample size and restricted geographical area means that caution must be taken in generalising the results to the wider population. The homogenous nature of the focus group participants could have led to sample bias and may have influenced the results due to the gender of the group and group facilitator. As the participants were members of a patient support group, it could be argued that this was a group of highly motivated individuals who were well informed with regards their condition and the health system, influencing the results further. The influence of the „groupthink‟ phenomena could be considered a limitation in the use of focus groups, especially where the group has a high degree of cohesiveness and homogeneity [27]. However, the aim of the focus group was to gain insight into patients‟ views on foot health education and to this end the methodology was appropriate. The limitations and criticism of using established groups can be countered by the benefits that using participants from an already established support group can add richness to the data as the group are more aligned to the research topic [19].

The strengths of this study lie with congruency of the overall themes that emerged from this and a previous study that revealed the practitioners‟ perceptions with regards to the purpose, timing, content, best methods of delivery and barriers to the provision of foot health education [28], allowing triangulation of the data sources to better understand the area. This agreement reinforces the need for the development of a foot health education strategy that embraces both perspectives [29]. Identifying service users‟ views as part of the development of foot health education has already been shown to be successful in an elderly population [30].

The role of health professionals in foot health management, accessing foot health services, general foot health information in the context of RA and good foot care self-management practices were considered to be essential components of foot health education provision. These areas have also been identified as key topics within foot health guidelines [5].

These participants were confused about the role of „podiatrists‟ and „chiropodists.‟ This resulted in a lack of clarity about the services they could access and what to expect from them. Discarding the title „chiropodist‟ may help to improve understanding of the podiatry profession from the public perspective, an issue that has been identified by members of the podiatry profession [28,31-33]. Where „specialist‟ roles were discussed during the focus group, there was the perception that the term „specialist podiatrist‟ generated more confidence in the practitioner. Information about the podiatrist‟s role and scope of practice is required to ensure that patients are aware of the level of expertise they can expect from the individual practitioner.

When foot health information was sourced it was reported as “frightening” or written in language that was difficult to interpret. All participants had used the Internet to seek foot health information, suggesting it is a well utilized resource. There is no lack of web based foot health information. Arthritis Research UK and the National Rheumatoid Arthritis Society (NRAS) provide resources that address foot health from both a general and RA specific perspective [34,35]. However, the participants were unaware of these resources, although all were members of NRAS. Patients concerns about locating high quality, patient-centred information relating to RA have been identified [36]. The findings of this study support this. Furthermore, a study of podiatrists found they directed patients to these web sites infrequently [28] potentially reinforcing patients‟ perception that there is a lack of such information.

Participants wanted patient education leaflets to support verbal information given during consultations. Written information was considered an aide memoir, prompting questions at future appointments, especially as there is a risk of being „overwhelmed‟ with information at the point of diagnosis. Written information for people with RA is considered the most effective way for people to refer to information once they have left the hospital setting [37]. The participants in this study viewed that RA had a negative impact on memory retention with pain and depression leading to poor cognitive function [38-40]. Written information was thus seen as highly valuable. Despite evidence for the effectiveness of patient information leaflets being weak [41], they are beneficial in increasing patient knowledge in the short term [42] but this must be individualised and supported by the practitioner for it to be effective [43], although this evidence relates to people with diabetes, the same may be true in RA.

Generally, group education was not viewed as beneficial by those members who had attended these sessions, as neither foot health education nor self-management was addressed. The potential value of group education was thought to be in providing a supportive environment for general foot health information and self-management education, if planned and facilitated appropriately. The implementation of group foot health self-management programmes for people with RA may be an effective method of delivery, providing members can perform self care tasks, such as basic nail cutting [44].

During their consultations with health professionals, participants found that individual information and education was often not provided as limited consultation time restricted them from asking questions. Individuals without foot pathology or few symptoms may not request foot health information, as they perceive their needs to be minimal [45]. However, within the context of a patient-centred consultation it is still important to identify their educational needs early in the disease [5]. This view was strongly articulated by the participants, as they felt let down and un-prepared for the way in which RA affected their feet and thus their daily activities. The feet are often the first part of the body to be affected in RA [7] with most experiencing foot pain early in the disease [8]. It is therefore essential to provide foot health education in a timely and targeted way.

In this study, the development of a strong and trusting therapeutic relationship was viewed as a critically influential factor for appropriate education. McInnes et al. [46] advocate a timely and individualized approach to diabetes foot health education provision. This requires investment of the practitioner‟s time and identifying the patient‟s agenda through using motivational interviewing techniques [47]. Identifying a person‟s „readiness‟ to change and motivation to engage in positive health behaviours is a key component of a patient-centred approach and should be undertaken during the course of any consultation [48].

Participants described the experience of being „listened to‟ more by female practitioners as resulting in positive outcomes. This perceived higher level of empathy was also identified in a study with practitioners, who found it easier to advise female patients on „difficult‟ foot health issues such as foot wear styles [28]. „Gender related communication skills‟, most notably „patient-centeredness‟, as opposed to gender alone, are thought to influence the development of a positive therapeutic relationship [49]. Although female practitioners are more likely to exhibit such skills [50], this does not preclude male practitioners from developing and demonstrating them. Thorough assessment and developmental feedback in relation to communication skills at undergraduate level may ensure similarities in development by male and female practitioners. It should be taken into consideration that the participants and facilitators of this study and the study with practitioners [28] were all female. The fact that the group participants and facilitators were of the same gender could have influenced the results. The development of a dynamic discussion is more likely where there is group homogeneity from both a gender and shared experience perspective [51]. Further research, exploring the perspectives of men, could provide a more comprehensive picture of the foot health education needs of people with RA.

Patients in this study wanted access to information from a variety of sources, together with a tailored approach and verbal explanation, to meet their needs. Group education was considered beneficial if structured, with ground rules applied so that individual needs were respected. However, patients strongly considered information should be staged according to their needs and preferences as their disease progressed. To achieve this, the patients‟ needs must be identified to guide them to the most appropriate foot health information. An Education Needs Assessment Tool, focusing on RA and its management has been developed and evaluated [52]. A similar approach to identifying foot health educational needs would enable practitioners to tailor their education provision to patients‟ needs.

Conclusions

This study provides insight into the patient perspective on foot health education provision for people with RA. There were clear similarities to practitioner perspectives [27]. The data will inform a survey to ascertain the views of a wider population of people with RA and Podiatrists.

Time is needed during consultations to ascertain patients‟ needs and readiness to engage in positive foot health behaviour. Written information, supported with a practitioner‟s explanation and tailoring to the patients‟ needs, will reduce anxiety and facilitate better patient education and patient uptake of positive foot health behaviours. Further, this will encourage a therapeutic relationship enabling positive health behaviour and self-management, as recommended in the Darzi report [2]. Teaching and assessment of undergraduate communication skills to ensure patient-centred consultation skills may result in an improved patient experience of the consultation and reduce gender bias overall.

Abbreviations

NHS, National Health Service; NRAS, National Rheumatoid Arthritis Society; RA, Rheumatoid Arthritis

Competing interests

The authors declare they have no competing interests.

Authors' contributions

AG conceived and executed the study design (with contributions from AW and AH), interpreted the findings with assistance from SW and drafted the manuscript with assistance from AW and AH. All authors read and approved the final manuscript.

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References

1. Department of Health (DoH): *Equity and Excellence-Liberating the NHS.*; 2010. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353.

2. Professor the Lord Darzi of Denham KBE - Department of Health (DoH): *High Quality Care for all. NHS Next Stage Review: Final Report.*; 2008. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825.

3. Albano MG, Giraudet-Le Quintrec JS, Crozet C, D'Ivernois JF: **Characteristics and development of therapeutic patient education in rheumatoid arthritis: analysis of the 2003–2008 literature.** *Joint Bone Spine* 2010, **77**:405–410.

4. Arthritis and Musculoskeletal Alliance (ARMA): *Standards of Care for People with Inflammatory Arthritis*.; 2004. http://www.arma.uk.net/care.html.

5. Podiatric Rheumatic Care Association (PRCA): *Standards of care for people with musculoskeletal foot health problems*.; 2008. http://www.prcassoc.org.uk Sept, 2009.

6. Williams AE, Davies S, Graham A, Dagg A, Longrigg K, Lyons C, Bowen C: **Guidelines for the management of the foot health problems associated with rheumatoid arthritis.** *Musculoskeletal Care* 2011, **9**:86–91.

7. Grondal L, Tengstrand B, Nordmark B, Wretenberg P, Stark A: **The foot: still the most important reason for walking incapacity in rheumatoid arthritis: distribution of symptomatic joints in 1,000 RA patients.** *Acta Orthop* 2008, **79**:257–261.

8. Otter S, Lucas K, Springett K, Moore A, Davies K, Cheek L, Young A, Walker K: **Foot pain in rheumatoid arthritis prevalence, risk factors and management: an epidemiological study.** *Clin Rheumatol* 2010, **29**:255–271.

9. National Collaborating Centre for Chronic Conditions: *Rheumatoid arthritis: national clinical guideline for management and treatment in adults*. http://guidance.nice.org.uk/CG79/guidance.

10. Williams AE, Nester CJ, Ravey MI: **Rheumatoid arthritis patients' experiences of wearing therapeutic footwear - a qualitative investigation.** *BMC Musculoskelet Disord* 2007, **8**:104.

11. Graham A, Hammond A, Williams AE: **Therapeutic Foot Health Education for patients with Rheumatoid Arthritis:A Narrative Review.** *Musculoskeletal Care* 2011, **9**:141–151.

12. Kirwan JR: **Patient education in rheumatoid arthritis.** *Curr Opin Rheumatol* 1990, **2**:336–339.

13. Burckhardt CS: **Arthritis and musculoskeletal patient education standards.** *Arthritis Care Res* 1994, **7**:1–4.

14. Neame R, Hammond A, Deighton C: **Need for information and involvement in decision making among patients with rheumatoid arthritis: a questionnaire survey.** *Arthritis Rheum* 2005, **53**:249–255.

15. Mäkeläinen P, Vehviläinen-Julkunen K, Pietilä A: **Rheumatoid arthritis patient education: RA patients' experience.** *J Clin Nurs* 2009, **18**:2058–2065.

16. Kitzinger J: **Education and Debate: Qualitative Research – Introducing Focus Groups.** *BMJ* 1995, **311**:299–302.

17. Powell RA, Single HM: **Methodology Matters V – Focus Groups.** *Int J Qual Health Care* 1996, **8**:499–504.

18. Krueger RA, Casey MA: *Focus Groups: A practical guide for applied research*. 3rd edition. Sage Publications: Thousand Oaks CA; 2000.

19. Denscombe M: *The Good Research Guide: for small-scale social research*. 3rd edition. McGraw Hill: Open University Press; 2007.

20. Braun V, Clarke V: **Using Thematic Analysis in Psychology.** *Qual Res Psychol* 2006, **3**:77–101.

21. Arnett FC, Edworthy SM, Bloch DA, McShane DJ, Fries JF, Cooper NS, Healey LA, Kaplan SR, Liang MH, Luthra HS, Medsger TA, Mitchell DM, Neustadt DH, Pinals RS, Schaller JG, Sharp JT, Wilder RL, Hunder GG: **The American Rheumatism Association 1987 Revised Criteria for the Classification of Rheumatoid Arthritis.** *Arthritis Rheum* 1987, **31**:315–324.

22. Redmond R, Curtis E: **Issues in Research: Focus Groups: principles and process.** *Nurse Res* 2009, **16**:57–69.

23. Halcomb E, Gholizadeh L, DiGiacomo M, Phillips J, Davidson PM: **Literature review: considerations in undertaking focus group research with culturally and linguistically diverse groups.** *J Clin Nurs* 2007, **16**:1000–1011.

24. Barbour R: **Education and Debate; Checklist for improving rigour in qualitative research: a case of the tail wagging the dog?** *BMJ* 2001, **322**:1115–1117.

25. Mays M, Pope C: **Rigour and qualitative research.** *BMJ* 1995, **311**:109–112.

26. Attride-Stirling J: **Thematic Networks and analytical tool for qualitative research.** *Qual Res* 2001, **1**:385–405.

27. Turner ME, Pratkanis AR: **Twenty-five years of group think theory and research: lessons from the evaluation of a theory.** *Organ Behav Hum Decis Proces* 1998, **73**:105–115.

28. Graham AS, Hammond A, Williams AE: **Foot health education for people with rheumatoid arthritis – the practitioner's perspective.** *J Foot Ankle Res* 2012, **5**:2. http://www.jfootankleres.com/content/5/1/2.

29. Li LC: **If knowledge is power, why don't rheumatoid arthritis education programmes show better outcomes?** *J Rheumatol* 2007, **34**:1645–1646.

30. Waxman R, Woodburn H, Powell M, Woodburn J, Balckburn S, Helliwell P: **FOOTSTEP: A randomized controlled trial investigating the clinical and cost-effectiveness of a patient self-management programme for basic foot care in the elderly.** *J Clin Epidemiol* 2003, **56**:1092–1099.

31. Manley A, Tinley P: **Burnout and Occupational Stress: Comparison between United Kingdom and Australian podiatrists.** *J Am Podiatr Med Assoc* 2004, **94**:282–291.

32. Vernon W, Borthwick A, Farndon L, Nancarrow S, Walker J: **Issues of Podiatry status in the UK.** *British Journal of Podiatry* 2005, **8**:6–10.

33. Farndon L, Vernon W, Parry A: **What is the evidence for the continuation of core podiatry services in the NHS? A review of foot surveys.** *British Journal of Podiatry* 2006, **9**:89–94.

34. Arthritis Research UK. http://www.arthritisresearchuk.org.

35. National Rheumatoid Arthritis Society. http://www.nras.org.uk.

36. Newman MA, Ziebland S, Barker L: **Patient views of a multimedia resource featuring experiences of rheumatoid arthritis: pilot evaluation of www.healthtalk online.org.** *Health Informatics J* 2009, **15**:147–159.

37. Kyngas H, Kukkurainen ML, Makelainen P: **Patient education from the perspective of patients with arthritis (in Finnish).** *Journal of Nursing Science* 2004, **16**:225–234. cited in Kaariainen M, Kukkurainen ML, Kyngas H, Karppinen L: **Improving the quality of rheumatoid arthritis patients' education using written information**. *Musculoskeletal Care* 2011, **9:**19–24.

38. Brown SC, Glass JM, Park DC: **The relationship of pain and depression to cognitive function in rheumatoid arthritis patients.** *Pain* 2002, **6**:279–284.

39. Dick B, Eccleston C, Crombez G: **Attentional functioning in fibromyalgia, rheumatoid arthritis and musculoskeletal pain patients.** *Arthritis Rheum* 2002, **47**:639–644.

40. Appenzeller S, Bertolo MB, Costallat LT: **Cognitive impairment in rheumatoid arthritis.** *Methods Find Exp Clin Pharmacol* 2004, **26**:339–343.

41. Riemsma RP, Kirwan JR, Taal E, Rasker HJJ: **Patient education for adults with rheumatoid arthritis.** *Cochrane Database Syst Rev*, **Art. No.: CD003688**:Issue 2. doi:10.1002/14651858.CD003688.

42. Hill J, Bird H: **The development and evaluation of a drug information leaflet for patients with rheumatoid arthritis.** *Rheumatology* 2003, **42**:66–70.

43. Ronnemaa T, Hamalainen H, Toikka T, Liukkonen I: **Evaluation of the impact of podiatrist care in the primary prevention of foot problems in diabetic subjects.** *Diabetes Care* 1997, **20**:1833–1837.

44. Semple R, Newcombe L, Finlayson G, Hutchison C, Forlow J, Woodburn J: **The FOOTSTEP self-management foot care programme: are rheumatoid arthritis patients physically able to participate?** *Musculoskeletal Care* 2009, **7**:57–65.

45. Prochaska JO, DiClemente CC: **Transtheoretical therapy: toward a more integrative model of change.** *Psychotherapy: Theory, Research and Practice* 1982, **19**:276–288.

46. McInnes A, Jeffcoate W, Vileikytet L, Game F, Lucas K, Higson N, Stuart L, Church A, Scanlan J, Anders J: **Footcare education in patients with diabetes at low risk of complications: a consensus statement.** *Diabet Med* 2011, **28**:162–167.

47. Miller WR, Rollnick S: *Facilitating Change. Motivational Interviewing: Preparing people for change*. 2nd edition. New York: Guilford Press; 2002.

48. Hammond A: **Patient education in arthritis: helping people change.** *Musculoskeletal Care* 2003, **1**:84–97.

49. Christen RG, Alder J, Bitzer J: **Gender differences in physicians' communication skills and their influence on patient satisfaction in gynaecological outpatient consultations.** *Soc Sci Med* 2008, **7**:1474–1483.

50. Law SAT, Britten N: **Factors that influence the patient centredness of a consultation.** *Brit J Gen Pract* 1995, **45**:520–524.

51. Hennick MM: *International Focus Group Research; A Handbook for the Health and Social Sciences*. Cambridge UK: Cambridge University Press; 2007.

52. Hill J, Tennant A, Adebajo A: **Further development of an educational needs assessment tool (ENAT) for patients with rheumatoid arthritis.** *Arthritis Rheum* 2004, **50**:S274–S275.

In your opinion, what is Patient Education? (in relation to foot health)
- What do you think the purpose of it is?
- What is the usefulness of it?

What kind of information is given?

Prompts:
- What kind of things are you told about Rheumatoid Arthritis?
- About Podiatry?
- About what can be done for your feet?

When is patient education given?

Prompts:
- Think about when you were first diagnosed/first saw a podiatrist – were you given any foot health related information or advice then?
- Have you been given any information/education about your feet since then, if so when?
- Is this something you discuss regularly or was it a 'one-off'?

How is the information/education provided for you?

Prompts:
- For example were you simply given verbal advice?
- Did you receive any written information such as leaflets provided by the Trust, AR UK, NRAS, from the podiatrist or any other Healthcare professional relating to your feet?
- Were you prompted to use any websites?
- What did you think about the resources that you were provided with?

In your opinion, what prevents you from obtaining the foot health information/education that you want?

Prompts:
- Is there anything that stops you from getting the information or advice that you need at the time that you need it?
- How easy is it for you to access your podiatrist for example?
- Do you know where to go for the right kind of information?
- Do you have easy access to the internet for example?

Figure 1

2.4 Commentary – Paper 4

Patient education is a key role for podiatrists as part of the management of people with RA (Podiatric Rheumatic Care Association, 2008). Providing information about the purpose and use of foot interventions, together with a patient-centred approach to the design and delivery of foot health self-management interventions has been shown to be effective in people with RA, but the most appropriate content and delivery strategies for RA-related FHE was not known. Additionally, the methods by which FHE is currently delivered by podiatrists involved in the management of people with RA was not known and the potential barriers to its' delivery needed to be identified before effective strategies could be developed in the future. There was a need to understand how patient 'v' practitioner perceptions compare in order to identify if any disparities and areas of commonality exist. Further, there remained the 'unknowns' in relation to what podiatry practitioners think they provide in relation to FHE, compared to what the patients think they need, as identified within papers 2 and 3.

This exploratory study, using a focus group method, aimed to identify the nature, content, the methods, timing and the potential barriers to the provision of FHE by podiatrists. The results were used to inform the development of a survey to be distributed to a larger sample population of podiatrists across the UK and provide a practitioners' perspective to the future development of FHE strategies for people with RA.

The participants viewed patient education as a mechanism for facilitating foot health self-management and enabling informed consent. The paper identified for the first time, the content of FHE that the participants perceived that people with RA need to know about; the disease in general, the cause of foot related pathology and its' impact on future foot health, symptoms that should prompt urgent attention and aspects of safe self-management of foot care. Further to this the participants articulated the need to stress lifestyle modification to people with RA, especially in respect to cardiovascular risk modification. A combination of verbal and written modes of delivery were felt to be the most appropriate methods of delivery, in conjunction with sign-posting people with RA to patient information / support group web-sites. The participants felt that FHE provision should be flexible in relation to the timing with which it was delivered and provided within the context of a patient-centred approach to the medical consultation. However, this study also identified, for the first time, the tension that was thought to exist within the use of techniques such as motivational interviewing; it was felt that more novice podiatrists may lack the experience of managing patients with more complex needs and the negotiating skills required to manage those patients who ‘resist’ making positive changes to health-behaviour. Further barriers that were perceived by the participants in the provision of FHE were; the poor recognition by both patients and the wider MDT of the scope of podiatric practice. The retention of the dual titles of ‘chiropodist’ and ‘podiatrist’ were again identified as being a factor that led to confusion within patient perceptions of the profession. Participants were also of the view that the additional factor of time constraints within the consultation and financial constraints within the NHS trusts to provide educational resources. Finance was also considered a limitation in relation to patients being able to engage with foot health advice, such as the purchase of new, more appropriate footwear.

Uniquely, the results of this study revealed that thematic congruency existed between the perceptions of this group of practitioners and the perceptions of people with RA that had participated in the patient focus groups in relation to; the purpose, timing, content and perceived barriers to FHE provision. These results facilitated the identification of the key sub-topics and items that a broader, UK-wide survey should use to seek a wider geographical perspective. The results supported the need to obtain the views of both the patient and practitioner through the development of two surveys that reflected my own experience, knowledge from the narrative review and the emergent themes from the focus groups that would allow for general comparison of results across the surveys.

INNOVATIONS:

The results from this paper have contributed new knowledge to what we needed to know about how podiatry practitioners viewed FHE provision in order to begin to develop effective FHE strategies in the future. The need to stress lifestyle modification in relation to risk factor identification and management, within the content of FHE delivery for people with RA was strongly articulated and should be a key component.

The strong thematic congruency that exists between the findings of the studies of ‘patient’ and ‘practitioner’, especially in relation to the development of effective therapeutic relationships, indicates that this is an area of clinical practice that should be nurtured and developed to facilitate the educational and clinical needs of the patient and to ensure the podiatry practitioners fulfil their clinical responsibilities.

Paper 4:

Title: Foot health education for people with rheumatoid arthritis: the practitioner's perspective.

Authors: Andrea S Graham, Alison Hammond, Anita E Williams.

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Foot health education for people with rheumatoid arthritis: the practitioner's perspective

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Abstract

Background

Patient education is considered to be a key role for podiatrists in the management of patients with rheumatoid arthritis (RA). Patient education has undoubtedly led to improved clinical outcomes, however no attempts have been made to optimise its content or delivery to maximise benefits within the context of the foot affected by rheumatoid arthritis. The aim of this study was to identify the nature and content of podiatrists' foot health education for people with RA. Any potential barriers to its provision were also explored.

Methods

A focus group was conducted. The audio dialogue was recorded digitally, transcribed verbatim and analysed using a structured, thematic approach. The full transcription was verified by the focus group as an accurate account of what was said. The thematic analysis framework was verified by members of the research team to ensure validity of the data.

Results

Twelve members (all female) of the north west Podiatry Clinical Effectiveness Group for Rheumatology participated. Six overarching themes emerged: (i) the essence of patient education; (ii) the content; (iii) patient-centred approach to content and timing; (iv) barriers to provision; (v) the therapeutic relationship; and (vi) tools of the trade.

Conclusion

The study identified aspects of patient education that this group of podiatrists consider most important in relation to its: content, timing, delivery and barriers to its provision. General disease and foot health information in relation to RA together with a potential prognosis for foot health, the role of the podiatrist in management of foot health, and appropriate self-management strategies were considered to be key aspects of content, delivered according to the needs of the individual. Barriers to foot health education provision, including financial constraints and difficulties in establishing effective therapeutic relationships, were viewed as factors that strongly influenced foot health education provision. These data will contribute to the development of a patient-centred, negotiated approach to the provision of foot health education for people with RA.

Background

Foot deformity and the associated symptoms of pain and stiffness are common in people with rheumatoid arthritis (RA), with up to 80% reporting pain at some point during the disease course [1, 2]. Patient education is recommended as an integral part of the treatment regimen in RA [3]. Increased self-management through patient education is associated with improved clinical outcomes [4]. Patient education can range from simple information given as part of care, to more complex cognitive-behavioural education programmes that aim to support patient adherence to treatment [4].

Patient education is considered to be a key role for podiatrists in the management of people with RA [5, 6]. Providing information relating to the purpose and use of clinical interventions, such as foot orthoses and specialist footwear, has the potential to improve patient adherence [7]. Using a patient-centred approach in the design and delivery of self-management programmes for foot health has been proven to be effective [8]. However, the most appropriate content of and delivery strategies for foot health patient education have not been investigated [9]. Refining these could improve foot health outcomes. How this education is delivered by podiatrists working with people with RA is also unknown.

Therefore, the aim of this study was to identify the nature and content of podiatrists' foot health education for people with RA. Any potential barriers to its provision were also explored.

Methods

Design

A focus group was conducted, as this is the most pragmatic approach for exploring attitudes, perceptions and ideas in this new area of research [10]. Individual interviews, whilst equally appropriate for ideas generation, do not have interaction between focus group participants, which promotes both consensus and clarifying diverse views between individuals [11]. The audio dialogue was digitally recorded and transcribed verbatim. A thematic framework was used to analyse the data, allowing the researcher to illustrate the main themes within a piece of text and enabling the transparent, methodical systematisation of textual data. To achieve this, a six stage process was used involving: coding the text; theme identification; thematic network construction; description and exploration of networks; summarisation of networks; and pattern interpretation [12].

Participants

Participants were purposively recruited from Rheumatology Podiatry Clinical Effectiveness Group members working in National Health Service (NHS) Trusts across the north west region of England. The participants had to be qualified podiatrists, experienced in managing patients with RA, able to speak and read English and provide written consent. The proposed sample size was

7 to 12 participants, which is considered the optimum size for focus group interviews [10, 13]

Procedures

Ethical approval for the study was obtained by the University of Salford Research Ethics Committee and written informed consent was obtained from all participants prior to recruitment. The focus group questions were devised by the first author (AG), based on a review of the literature and contributions from the other two authors, one with patient education expertise (AH) and one with qualitative research expertise (AW). The questions were open-ended and designed to instigate in-depth discussion between the group participants across five sub-topics relating to the provision of foot-health education [Figure 1].

The focus group took place at the University of Salford as part of a regular scheduled meeting of the Rheumatology Podiatry Clinical Effectiveness Group. It was facilitated by the first author (AG) and field-notes taken by one of the other authors (AW). Any unanticipated topic areas were followed up with more questions by the first author. The dialogue was recorded digitally, transcribed verbatim by the first author and returned to the participants for verification and to support the trustworthiness of the data [14, 15].

Data analysis

The verified transcription of the dialogue was subject to thematic analysis [13] and categorised into ‘Basic’ and ’Organising’ themes [Table 1]. Agreement for this categorisation was achieved between the first author (AG) and one of the other authors (AW) for both the thematic analysis and the data extracted [14, 15]. Exemplars from the dialogue were extracted to demonstrate truthfulness of the data within each theme.

Results

Twelve participants consented to participate. All had experience in managing people with RA and ranged from newly qualified podiatrists with an interest in working with patients with RA to those with experience within a Rheumatology multidisciplinary team. The average number of years since qualification within the group was 17.8 (SD = 9.8). Newly qualified podiatrists would have experience of working with people with RA across all undergraduate levels of clinical study and to a lesser extent, after qualification as an autonomous practitioner. Those working within the multidisciplinary team (n=5) in acute services were more likely to work with consultant rheumatologists and specialist nurses. Those working in Primary Care Trust services (n=7) had limited contact with a rheumatology multidisciplinary team.

Six organising themes emerged from the data analysis. Participants’ names have been replaced with a pseudonym to ensure anonymity and confidentiality.

Theme 1: The essence of patient education:

This theme describes the participants’ perception of patient education as a mechanism for patient empowerment. They considered that the process of information giving can impart the ‘power’ to patients to make appropriate decisions about consent and self-management. When asked what patient education *is,* the responses were short and to the point such as:

(Patient education allows) "…Informed consent so that they can participate in the management regime" [Maria].

Patient education was considered useful for guiding patients according to their individual needs, and as Lisa stated, some of the content may not even be related to their feet:

"... *if they've got a question, you can say "well here's where you need to go and find out," you can put them in the right direction with the right agency. It's not even necessarily all about podiatry. Sometimes it's just helping them to find a way."*

The podiatrist's role as a point of access to other services that patients may not know about in relation to their specific health care needs was clearly thought of as a component of patient education.

Theme 2: Content – what and why?

The participants considered that patients wanted general information. This included: how the disease and the drugs used to manage it, would impact upon their foot health; signs and symptoms relating to foot health that should prompt them to seek immediate advice from a healthcare professional; and the potential changes to their foot health as the disease progresses. Jane articulated that patients need:

"…*general information if they haven't got a specific problem, about foot health, about the impact of the drugs on their foot health and what sort of things (stops and thinks)...preventative advice…" [Jane].*

There was a strong view that patients needed an explanation about foot health interventions and how they can help foot symptoms. As 'Ann' highlighted:

"*If they need orthotics then you've gotta do all kinds of explanations as to why they need them and how it's gonna help them, and then of course it's gonna be footwear to accommodate the orthotics. So I may have to explain y'know why you're doing...and find out y'know what they're willing to go along with..."*

The participants were often asked to provide information and advice that did not directly relate to foot health. This included the need for support for intimate personal issues, how to access welfare and support services and health promotion, such as smoking and alcohol consumption. The participants viewed this as a holistic approach to patient education:

"I asked a patient about alcohol consumption… and was told like, seven pints, but he said it was every night… all sort of things came out of that. It was just a

question I was asking, he was talking about methotrexate, medication …” [Sara].

Informing patients about the role of the podiatrist was viewed with equal importance as providing foot health advice, in order to support patients in foot health self-management and in some cases, to ensure patient attendance at appointments with a podiatrist:

“Patients turned up and they didn't know what they had been referred for. Or they weren't turning up and it was because they didn't know what they'd been referred for” [Ann].

The content of patient education was primarily not only to ensure that patients are aware of the disease, it’s impact on lower limb health and the podiatrists’ role, but also the medical management of RA, and the physical, social and personal issues associated with it.

Theme 3: Patient-centred approach to content and timing of patient education

The content of patient education was influenced by: the patients’ individual needs; disease status; age; and expectations of what podiatry can offer. The information provided was either general, such as basic foot health advice, or more specific, as identified by Jane:

“I suspect at new diagnosis you’re talking about the basics, how to manage general foot care (pauses)….general information if they haven’t got specific foot problems… (pauses) I think early and late disease does have a slightly different slant on what you pick out as possibly more relevant at that point in time” [Jane].

The need for a patient–centred approach to foot-health education, that identifies the expectations of the patient, was articulated by Louise:

“I think part of it [patient education] as well is patient expectations of what they’re going to end up like...” [Louise].

This theme strongly illustrates the participants’ view that foot health education cannot be overly prescriptive in its content and that timing needs to take into account the patient’s defined needs.

Theme 4: Barriers to provision of education

Other health practitioners’ knowledge about the role of the podiatrist was thought to impact on the timely referral for foot care. As Jane highlighted:

“*Even if patients complain, the likelihood of actually getting looked at, y’know at new diagnosis...People just don’t understand what it is we can do.” [Jane].*

The group thought that there should be a team approach to the provision of foot health education when patients are being managed within a multidisciplinary team, with a consensus as to what basic information all team members should be providing to avoid provision of detrimental and conflicting advice. However, foot health education provided by health practitioners, other than podiatrists, was viewed with scepticism by one participant:

"*That's a bit dodgy 'cos it's not always good." [Lisa].*

Lack of time, due to overbooked clinics and a lack of finances with which to develop educational resources, were identified as further barriers to foot health education:

".. and the numbers, the numbers of patients. It's very numbers-orientated in the acute [trust] (pauses)…..there's no money for leaflets [development]!' [Louise].

Patients' lack of understanding or acknowledgement that they need to change health behaviour was seen as an essential barrier to overcome in order to improve foot health. The 'domestic burden' of the patients' home circumstances, with other family members' needs being prioritised, or a poor financial status, were also viewed as barriers to patients following foot health advice:

"You're giving them good shoe advice but they can't follow through 'cos they can't afford it." [Ann].

The ability of the podiatrist to empathise with the patients' experiences and employ appropriate consultation skills was seen as another barrier, notably amongst new graduates:

"*When I was newly qualified I couldn't understand why they didn't want to help themselves to get the best outcome" [Julie].*

The challenges encountered when patients 'play off' one professional against another led to the labelling of such patients as 'non-compliant', resulting in patient education that was ineffectual, with reduced motivation for its provision. Participants described the refinement of consultation skills as a process requiring practice in negotiating with patients considered ambivalent:

"When you've got patients in that are just like "oh yeah, yeah…" like that when you are talking to them, I think that you've got to keep practising it, to be encouraged, otherwise you do get a little bit demoralised." [Gill].

This theme clearly highlighted barriers to foot health education provision as: poor timing of referral by other members of the multidisciplinary team, lack of resources, such as time and money; perceived low patient compliance; and inexperience of novice podiatrists.

Theme 5: The therapeutic relationship

The development of the therapeutic relationship describes the dynamic that exists between patient and practitioner and, in this context, focuses on how it influences patient education. The participants considered that the 'educational' role of the podiatrist was subtly altered when they are no longer the primary resource for information but act as a filter for what is 'good' and 'bad' information gained from elsewhere:

"*It is hard, you do have to sometimes say to them that… anybody can put anything they like on the internet… they seem to believe that if it's there in print it's go to be right" [Gill].*

The patients' attitudes to their disease, was an influential factor in the development of the therapeutic relationship. Participants felt that patients who were in 'denial' about their diagnosis, or did not have foot health issues on their 'agenda', should not have foot health education "thrust upon them". The participants thought that, for some patients, engaging in foot health related 'activity', such as attending group educational sessions, would reinforce the perception that they were 'sick'. This may negatively influence the relationship with the practitioner and the potential to change their health behaviour:

"They don't want to become part of the 'rheumatology world' because 'I'm not one of the sick people' y'know? Which you can understand." [Lisa].

Practitioner attitudes appeared to impact on the provision of education during the consultation. The need to be 'firm' or 'compromising' with patients was described:

"I try to make everything sound like a compromise now. Especially for women it has to be a compromise" [Julie].

Empathy between these female practitioners and their female patients appeared to influence the patient – practitioner relationship and thus the effectiveness of foot health education. It was considered that those of the same gender would be able to relate to each other more effectively. Discussion of 'difficult' subject areas (such as footwear style with female patients) influenced the participants' ability to relate to their patients:

"*We all like to wear high heels and nice shoes when we go out….you have that empathy with them" [Nancy].*

The public's perception of the podiatrist was viewed by the participants as an influencing factor on the patient – practitioner relationship. It was thought by the group that 'podiatrists' are typically viewed by patients as having a more specialised role, with 'chiropodists' having more basic expertise. This confusion over professional title, and hence expertise, can influence patients' expectations about the information they expect.

"*They [patients] have some concept that there is some difference between a podiatrist and a chiropodist, they say "you're not quite the same as that, what is it that you do?"' [Lisa].*

A number of factors influence the therapeutic relationship including: the patients' level of foot health and disease knowledge prior to the initial consultation; the subtle change in the subsequent role of the podiatrist as an educator to re-educator; the patients' attitude to the disease; the age and gender of both the patient and the podiatrist; and the patients' confusion over the professional title.

Theme 6: 'Tools of the trade'

This theme describes the methods most commonly used and the issues most relevant to the participants in the delivery of foot health education. Information provided in a one-to-one context, using written advice and visual aids (such as examples of moisturising products) to reinforce verbal advice, was most commonly used. Some used locally produced leaflets and some used other sources, such as footwear company catalogues and literature from charities (for example Arthritis Research UK). It was considered that care was needed when providing such written information, as the language used might be difficult for some patients to understand and could become a barrier to effective patient education. Directing patients in using the Internet appropriately was seen as additional supportive information, although this method was not used by all participants.

The combination of verbal and written information was viewed as important to enable the patient to reflect upon what had been said during the consultation and to act as a 'aide memoire':

“*You could provide verbal education on top of having a minimum to hand out and then they’ve had something to reflect on after their consultation. [Patients] tend to forget half of what you tell them anyway’ [Meg].*

Group education was considered useful in providing peer support for patients, reducing the feeling of isolation and as a conduit for the provision of general information. However, it was not widely used, due to a lack of: evidence for its’ effectiveness; feasibility; patient motivation; and finance. One-to-one patient education was considered more useful as it provided more tailored, individualised information in an environment that might be more comfortable for patients to discuss personal issues:

“*‘I think some people are just more comfortable on a one to one basis… it’s quite a personal thing isn’t it?” [Maria].*

This theme illustrates the most widely used format for patient education is one-to-one verbal delivery, supported with written material.

Discussion

The participants’ views on patient education for people with RA are that it is a mechanism for facilitating foot health self-management and enabling informed consent for foot health interventions. The literature relating to foot health education in patients with diabetic foot problems [16] supports structured education and information giving to enhance self-efficacy and improve health behaviour.

The participants perceived that patients needed to know about RA, its cause and its impact on future foot health. Patients also want to know about symptoms requiring urgent attention and good self-care to prevent deterioration. These are the key topics any podiatrist should address, together with modifying lifestyle factors such as smoking and excessive alcohol consumption. These topics are recommended in the Podiatric Rheumatic Care Association Musculoskeletal Foot Health Standards [5]. Educating patients about such risk factors for cardiovascular disease is vital, given the association between RA and cardiovascular disease [17]. Podiatrists have the skills and knowledge to assess and monitor patients' lower limb vascular status and are well placed to discuss the effect of smoking on lower limb health, such as the development of peripheral arterial disease, which is accelerated in people with RA [18, 19]. Patient education for people with RA about cardiovascular disease has been recognised as being poorly promoted by health care professionals [20].

It was strongly considered that the scope of practice of podiatrists in relation to managing people with RA is not widely recognised within the medical community or by patients. If patients and other members of the multidisciplinary team are unaware of what can be provided about foot health management, then timely and appropriate referral cannot be achieved. Members of the rheumatology multidisciplinary team need to be agreed as to the foot health education provided to patients in their service [5] to avoid conflicting information being given to patients. This issue reflects the need for podiatrists to educate other members of the multidisciplinary team about foot health. Ensuring that team members are fully conversant with each others' role within the wider management of people with RA may help to resolve this. Care pathways which detail traditional foot health interventions and educational needs of people with RA [6] can provide evidence-based guidance that supports all multidisciplinary team members in foot health management.

A perceived lack of awareness of the podiatrist's role by the members of the multidisciplinary team creates confusion. This was thought to be due to 'dual professional identity' resulting from the continued use of 'podiatrist' and 'chiropodist' as professional titles. The retention of the title 'chiropodist' reflects the original role of social foot-care [21] compared with the current role including lower limb assessment, independent diagnosis and extended skills such as steroid injection therapy and non-medical prescribing.

Health education provision for people with RA should be flexible, timely and patient-centred [22,23]. The participants expressed that foot health education content should be tailored according to individual need, disease stage, age, gender and recognition of ability to engage in positive health behaviour. The trans-theoretical model of behavioural change [24] is acknowledged as being a useful tool for identifying a persons' readiness to make changes in health behaviour [25]. The participants identified the need to '…move patients from the stage of pre-contemplation to contemplation' in order to effect positive behaviour change.

Motivational interviewing techniques [26] can be highly effective in engaging patients in change talk, though the use of these techniques is a skill in itself. The lack of such skills was identified as a potential barrier to the provision of foot health education, particularly in those who were more recently qualified and who had less clinical experience. Participants felt well prepared by their undergraduate training in terms of understanding the underlying theory of motivational interviewing techniques, but in the 'real world' their expectations had been lowered through experience of patients who 'did not want to help themselves by complying with foot health advice'. Perhaps the challenge here lies in equipping podiatrists with strategies to cope with patient resistance to changing health behaviour, alongside skills in effective patient-centred consultation. This should be provided within the undergraduate curriculum and as part of continuous professional development.

There is no consensus as to the most appropriate time to provide foot health education. Patients should have timely access to relevant foot health specific advice and information that enables them to recognise variations in disease activity, focussing on issues of particular relevance at any given time [5]. The use of one-to-one consultations that can be responsive to the patient's individual needs and provide a less intimidating environment is more appropriate in these circumstances. Further, practitioners should be mindful of the fact that not all patients desire or see the benefits of changes in health behaviour in the short term, but their perceptions may alter with time [25].

This study found that one-to-one delivery of foot health education during the consultation, combining verbal and written material was the most common method of delivery, with minimal use of group education and charity websites such as Arthritis Research UK and the National Rheumatoid Arthritis Society. There has been no direct comparison of one-to-one versus group education for people with RA. The use of group education can provide a supportive environment in which patients can discuss common issues together with the use of individualised verbal information supported by printed documents and reputable patient support group websites [22]. Further to this the implementation of educational behavioural programmes has been found to maintain benefits, such as improved pain scores and self-efficacy, for up to 12 months [27] and may prove cost-effective to the NHS in the long term [8]. However, this should be balanced with the potential additional ‘cost-to-self’ for patients, as this study highlighted that socioeconomic factors are thought to influence patients’ ability to comply with certain aspects of foot health education such as the purchasing of appropriate footwear that may cost more than they would normally spend. There are currently no foot health education programmes that cater for people with RA, though the feasibility of patients with RA participating in a foot health self-management programme has been investigated [28]. At initial diagnosis patients may not be ready to participate in a comprehensive programme of foot health education, though this is yet to be ascertained.

This is the first study to explore podiatrists’ perceptions of foot health education for people with RA. The views expressed within this study are restricted to podiatrists working within rheumatology who attend a Clinical Effectiveness Group (CEG) and were thus purposively selected. It could be argued that focus groups should consist of participants that do not know each other to avoid the influence of pre-existing relationships upon the outcomes of the discussion and promote a more honest response [29]. Further to this the presence of more experienced, senior practitioners within the group may have resulted in the modification of the responses from their junior or less experienced colleagues. However, the trust that can be found within members of groups who already know each other can be a positive and encouraging influence upon the discussion; participants may feel more able to challenge each other's views if they feel comfortable with each other [10, 30]. A constant positive group dynamic was observed throughout this focus group, facilitating involvement of all participants in the discussion, without stifling the richness of data generated.

It is acknowledged that the use of other qualitative methods such as Interpretative Phenomenological Analysis [31] could reveal more complex interpretative aspects within this data. However, the use of thematic framework analysis in this study allows for a thematic description of the entire data set, which is appropriate for the investigation of this under-researched area and the identification of the most predominant themes [32].

The number of participants in this focus group could be viewed as relatively high, the ideal number being suggested as between 6 and 10 [10, 29, 30]. However, larger numbers can be used where it aligns with the research aims and the generation of concepts is required [33]. A similar argument may be applied to the number of focus groups conducted. Only one focus group was conducted and additional focus groups may have added to the data. However, there is no consensus as to the ideal number of focus groups that should be conducted, with the literature suggesting a single group [34] to over 50 groups [30]. Therefore, a pragmatic approach was adopted that considered the purpose of the study, the financial cost, time available and perceived attainment of data saturation.

The participants were from the northwest region of England, which may mean that the results are not generalisable. However, they were from a range of services and duration of clinical experience and so are likely to be representative of UK podiatrists. Future research into podiatrists' opinions of foot health education should involve both male and female practitioners, those from a wider geographical area and those in private practice. Additionally, a wider perspective that investigates the perceptions of other allied health practitioners and consultant rheumatologists in relation to the provision of foot health education may be of potential importance. The patients' perspective on their experiences and educational needs requires investigation from a wide geographical perspective.

The ultimate aim of future research should be the development of a patient-centred and negotiated approach to foot health education, through which the individuals' needs and preferences are identified.

Conclusion

This study has identified aspects of patient education that this group of podiatrists found most influential in its delivery including; what they perceive the role of foot health education to be, the main content including general disease and foot health related information, appropriate strategies for self-management and the role of the podiatrist in managing the foot health of people with RA. The need for a tailored approach to delivery, according to the needs of the individual over the life span of the patient through identification of the patient's agenda, was highlighted as being influential in the development of an effective therapeutic relationship. Potential barriers to its delivery included a lack of patient-centred consultation skills, the financial status of the patient and the NHS trust and time constraints. From the podiatrists' perspective this identifies a need to develop foot health education that encompasses both the patients' needs and podiatrists' responsibilities. The ultimate aim of this would be to support self-efficacy and appropriate foot health behaviour, thereby improving the foot health for people with RA.

Competing interests

The authors declare they have no competing interests.

Authors' contributions

AG conceived and executed the study design (with contributions from AW and AH), interpreted the findings with assistance from AW and drafted the manuscript with assistance from AW and AH. All authors read and approved the final manuscript.

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References

1. Grondal L, Tengstrand B, Nordmark B, Wretenberg P, Stark A: **The foot: still the most important reason for walking incapacity in rheumatoid arthritis: distribution of symptomatic joints in 1,000 RA patients**. *Acta Orthop* 2008,**79**:257-61

2. Otter S, Lucas K, Springett K, Moore A, Davies K, Cheek L,Young A, Walker-Bone K: **Foot pain in rheumatoid arthritis prevalence, risk factors and management: an epidemiological study**. *Clin Rheumatol* 2010,**29**:255-71.

3. National Institute for Clinical Excellence (NICE): **Rheumatoid arthritis: National clinical guideline for management and treatment in adults**. [http://www.nice .org.uk/nicemedia/pdf/CG79FullGuideline.pdf]

4. Albano MG, Giraudet-Le Quintrec JS, Crozet C, d'Ivernois JF : **Characteristics and development of therapeutic patient education in rheumatoid arthritis: Analysis of the 2003-2008 literature.** *Joint Bone Spine* 2010,**77**:405-10.

5. Podiatric Rheumatic Care Association (PRCA): **Standards of care for people with musculoskeletal foot health problems** 2008. [http://www.prcassoc.org.uk. Sept, 2009]

6. Williams, A. E., Davies, S., Graham, A., Dagg, A., Longrigg, K., Lyons, C. and Bowen, C: **Guidelines for the Management of the Foot Health Problems Associated with Rheumatoid Arthritis**. *Musculoskeletal Care* 2011,**9:**86-92.

7. Williams AE, Nester CJ, Ravey MI: **Rheumatoid arthritis patients' experiences of wearing therapeutic footwear - A qualitative investigation.** *BMC Musculoskelet Disord* 2007,**8:**104.

8. Waxman R, Woodburn H, Powell M, Woodburn J, Balckburn S, Helliwell P: **FOOTSTEP: A Randomized controlled trial investigating the clinical and cost-effectiveness of a patient self-management programme for basic foot care in the elderly**. *J Clin Epidemiol* 2003,**56:**1092-9.

9. Graham A, Hammond A, Williams AE: **Therapeutic Foot Health Education for patients with Rheumatoid Arthritis – a Narrative Review**. *Musculoskeletal Care* 2011,**9:**141-151.

10. Denscombe M: *The Good Research Guide: for small-scale social research projects.* Third Edition. McGraw Hill: Open University Press; 2007.

11. Morgan DL: **Focus Groups**. *Annu Rev Sociol*. 1996,**22**:129-52

12. Attride – Stirling J: **Thematic Networks: an analytical tool for qualitative research**. *Qual Res* 2001,**1**:385-405.

13. McLafferty I: **Methodological Issues in Nursing Research: Focus Group Interviews as a data collecting strategy.** *J Adv Nurs* 2004,**48**:187-194

14. Barbour R: **Education and Debate; Checklist for improving rigour in qualitative research: a case of the tail wagging the dog?** *BMJ* 2001,**322:**1115-7.

15. Mays M, Pope C: **Rigour and qualitative research** *BMJ* 1995,**311**:109-112.

16. Stuart L, Wiles P: **The role of patient education in preventing foot ulcers: the elusive pimpernel**. *Evidenced-Based Healthcare and Public Health* 2005,**9**:359-360.

17. Maradit-Kremers H, Nicola PJ, Crowson CS, Ballman KV, Gabriel SE: **Cardiovascular Death in Rheumatoid Arthritis – A Population Based Study.** *Arthritis Rheum* 2005,**52:**722-732.

18. Alkaabi JK, Ho M, Levison R, Pullar T, Belch JJF: **Rheumatoid Arthritis and Macrovascular Disease**. *Rheumatol* 2003,**42**:292-297.

19. Stamatelopoulos KS, Kitas GD, Christos M Papamichael CM, Kyrkou K, Zampeli E, Fragiadaki K, Panoulas VF, Mavrikakis M, Sfikakis PP: **Subclinical Peripheral Arterial disease in rheumatoid arthritis**. *Atherosclerosis* 2010,**212**:305-9.

20. John H, Hale ED, Treharne GJ, Carroll D, Kitas GD: **'All singing from the same hymn sheet': Healthcare professionals' perceptions of developing patient education material about the cardiovascular aspects of rheumatoid arthritis**. *Musculoskeletal Care* 2009,**7:**256-271.

21. Vernon W, Borthwick A, Farndon L, Nancarrow S, Walker J: **Issues of Podiatry status in the UK**. *Br J Podiatry* 2005,**8:**6–10.

22. Fautrel B, Pham T, Gossec L, Combe B, Flipo R, Goupille P, Le Loet X, Puechal X, Wendling D, Schaeverbeke T, Sibilia J, Sany J, Dougados M: **Role and modalities of information and education in the management of patients with rheumatoid arthritis: development of recommendations for clinical practice based on published evidence and expert opinion.** *Joint Bone Spine* 2005,**72**:163-70.

23. Koehn CL, Esdaile JM: **Patient education and self-management of musculoskeletal disease**. *Best Prac Res Clin Rheumatol* 2008,**22**:395-405.

24. Prochaska JO, DiClemente CC: **Transtheoretical therapy: Toward a more integrative model of change**. *Psychotherapy: Theory, Research and Practice* 1982,**19**:276-288.

25. Hammond A: **Patient education in arthritis: helping people change.** *Musculoskeletal Care* 2003,**1**:84-97.

26. Miller WR, Rollnick S. *Facilitating Change: Motivational Interviewing: Preparing people for change*. 2nd Edition. New York: Guilford Press;2002.

27. Hammond A, Bryan J, Hardy A: **Effects of a modular behavioural arthritis education programme: a pragmatic parallel-group randomized controlled trial.** *Rheumatol* 2008,**47**:1712-8.

28. Semple R, Newcombe L, Finlayson G, Hutchison C, Forlow J, Woodburn J: **The FOOTSTEP self-management foot care programme: are rheumatoid arthritis patients physically able to participate?** *Musculoskeletal Care* 2009**,7**:57-65.

29. Powell RA, Single HM: **Methodology Matters V – Focus Groups.** *Int J Qual Health Care* 1996,**8:**499-504.

30. Kitzinger J: **Education and Debate: Qualitative Research – Introducing Focus Groups**. *BMJ* 1995,**311:**299-302.

31. Smith JA: **Beyond the divide between cognition and discourse: using Interpretative Phenomenological Analysis in health psychology.** *Psychol Health* 1996,**11:**261-71.

32. Braun V and Clarke V: **Using Thematic Analysis in Psychology.** *Qualitative Research in Psychology* 2006,**3:**77-101.

33. Fern E.F: **The use of focus groups for idea generation: the effects of group size, acquaintanceship, and moderator on response quantity and quality**. *J Mark* Res 1982 **19**:1-13 cited in McLafferty I: **Methodological Issues in Nursing Research: Focus Group Interviews as a data collecting strategy.** *J Adv Nurs* 2004,**48**:187-194.

34. Stewart D, Shamdasani P: *Focus Groups Theory and Practice.* Sage Publications, Beverly Hills, CA 1990.

Figure legend

Figure 1: Focus group questions: figure 1 gives details of the questions used to generate participant discussion during the course of the podiatrists' focus group.

Table 1 - Outline of the basic and organising themes developed from the thematic analysis.

Basic Themes	Organising Themes
• Information Provision • Empowerment	The Essence of Patient Education
• Disease Diagnosis, Process & Prognosis • Interventions • Role of the Podiatrist • Assessments • Non-podiatry related topic	Content – the what and why
• General 'vs' specific education • Timing	A patient centred approach to content and timing
• External barriers to provision – organisational • Psychosocial barriers • Education with regards professional roles • Professional experience • Impact of patient concordance	Barriers to provision of Patient education
• The impact of patient knowledge • The impact of patient attitudes • The impact of practitioner attitudes • The influence of age & gender • Role/title confusion • 'Taboo' subject areas	The Therapeutic Relationship
• Group 'vs' individual provision • Verbal & written material • Audio-visual material • Web-based resources	'Tools of the Trade'

Focus group questions:

In your opinion, what is Patient Education?

What type of education/information do you give?

Prompts

- with regards content
- with regards topics
- general ‘vs’ foot specific
-

When would you typically provide this education/information?

Prompts

- Timing: at diagnosis? Every consultation? Established disease?
- Appropriate timing of delivery?

How is patient education/information provided? (mode of delivery)

Prompts

- Verbal ‘vs’ written

- Patient support groups and the use of websites
- Group ‘vs’ individual
- Visual aids

What are your perceived barriers to the provision of patient education/information?

Prompts

- Patients’ health behaviours and concordance
- Practitioner roles and education
- Finances

Figure 1

2.5 Commentary – Paper 5

Despite the acknowledgement that podiatrists should be delivering FHE (PRCA, 2008; NWCEG, 2012) to date there are no specific FHE interventions for people with RA and foot-related pathology. Therefore, in order to develop and evaluate the potential effectiveness of FHE in the future we need to ascertain what the key components of such an intervention should be and how it might work in practice, in line with the modelling phase of the MRC Complex Intervention Framework (Craig et al, 2013). Exploratory work, published within papers 1,2,3 and 4, has indicated what is required for the potential development of FHE in relation to; methods of delivery, timing, content, barriers to FHE and potential influences on FHE delivery. In addition, this exploratory work (papers 2,3,4) has indicated that people with RA and podiatrists perceive that an individuals' gender, age and time since qualifying (podiatrists) may also be influential factors upon FHE provision. This exploratory work was limited geographically to participants within the North West of England. As this area of England has been shown to have higher levels of access to foot health services for people with rheumatic disease, compared with other areas of the UK (Redmond et al, 2006), a broader geographical perspective was needed to reflect the actual UK-wide picture of FHE provision.

The primary aim of this study was to understand the practitioner opinions and perceptions about FHE for people with RA from the viewpoint of podiatrists. A secondary aim was to identify the influence of gender, age and time since qualifying as a podiatrist on FHE provision.

A UK-wide, podiatrists' perspective of FHE provision for people with RA had not been previously identified and therefore the results from this online survey of UK podiatrists have the potential to influence future FHE strategy development. The sample of 47 participants was recruited via the podiatry and Rheuma-foot JISC mail databases and local clinical effectiveness group links, which have a total UK-HCPC registered population size of 88 producing a 50% response rate. This could be viewed as a small sample size when compared with that of the response rate of people with RA (n=543), however access to the UK population of registered podiatrists (n=approx 13,000 at time of the survey) via the Society of Chiropodists and Podiatrists database was not permissible and so an alternative database that would include podiatry specialist practitioners was utilised.

The results from this study identified that the participants felt that they had enough professional knowledge to allow for effective FHE provision to people with RA and that female participants were most likely to access information resources to support that provision. The time since the podiatry practitioners had qualified did influence FHE provision; those with a greater duration of years qualified were more likely to agree with the overall aims of FHE, more likely to disagree with providing FHE only when asked for it and perceived that verbal FHE was less likely to be effective than other methods of delivery. The view that more novice podiatrists had less insight into identifying a persons' readiness to make a behaviour change remained a potential barrier to FHE provision, as did time constraints within the consultation and lack of educational resources. All aspects of FHE content were valued highly by the participants, with the requirement that content be tailored to the needs of the individual patient at the time of the consultation. The most commonly used methods of delivery were information leaflets (written) combined with provision of verbal information and supported by sign-posting patients to patient support group web-sites.

This study identified the components of FHE that podiatrists and also other AHP's should aim to provide during a consultation, contextualized by the individual educational needs of the patient at that given point in time. Further, it identified the need for a simple foot health educational needs analysis tool, such as that used for general disease education (Ndosi et al 2009), that can enable people with RA to easily identify what they want to know in relation to foot health and RA, but can be undertaken in such a way that minimizes the time burden upon the practitioner.

INNOVATIONS:

This publication was the first to identify the current UK-wide status of FHE for people with RA from the perspective of the podiatry practitioner. The results from this study identified the key components of FHE that should be provided, as a minimum, in an individualized way to people with RA. This study illustrated how highly podiatry practitioners value the provision of FHE to this group of patients, in spite of the identified barriers; ensuring that they are enabled to do so is essential to patient-centred, comprehensive and effective foot health management.

Paper 5:

Title: Foot health education for people with rheumatoid arthritis – an online survey of UK podiatrists' perceptions.

Authors: Andrea S Graham and Anita E Williams

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RESEARCH **Open Access**

Foot health education provision for people with rheumatoid arthritis–an online survey of UK podiatrists' perceptions

Andrea S Graham[1,2*] and Anita E Williams[1,2]

Abstract

Background: Patient education supports general disease self-management and in relation to foot problems, it is recommended as a key intervention for people with rheumatoid arthritis (RA). Further, it is known what the foot health educational (FHE) needs are in relation to their experiences of foot problems. Podiatrists are the key health professionals who provide the management of RA-related foot pathology and this includes the delivery of FHE. However, we do not know what is currently provided and what podiatrists' perceptions are of this intervention. It is possible that there is a difference between what is provided and what patients need in order to maximise their foot health benefits and hence this may contribute to the persistence of foot problems and symptoms. This study primarily aims to define what UK podiatrists' perceptions of FHE are in relation to; what is delivered, how it is delivered, and the timing of its delivery, in the context of its' accessibility. The secondary aim is to identify any influence of the participants' gender, age and duration of professional qualification on their responses.

Method: An online survey of UK HCPC registered podiatrists was used to capture quantitative data in relation to the perceived; aims, content, methods and effectiveness, timing and barriers to FHE provision to people with RA. Data was analysed to assess significant associations between the participant responses and their gender, age and duration of professional qualification. Free text comments were analysed using thematic analysis.

Results: 43 podiatrists across the UK completed the survey. The majority of participants stated that, they provided FHE and agreed with its overall aims. The most common methods of delivery that were perceived to be most effective were: verbal, written and website based information. The best times at which to deliver FHE were thought to be at the point of diagnosis of RA and at any available opportunity of health care delivery. The majority of participants thought they had enough knowledge and access to information resources to effectively deliver FHE, but half of the participants felt that consultation duration limited their ability to do so. Gender and duration of professional qualification influenced participants' perceptions of FHE.

Conclusion: The importance and content of FHE for people with RA has been defined, but time limitations are seen to restrict its delivery. The development of an education needs analysis tool to facilitate efficient identification of patients FHE needs could enable timely and tailored delivery of FHE to people with RA.

Keywords: Patient education, Rheumatoid arthritis, Foot health, Podiatrist

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Background

Foot health education is recommended as a key intervention for people with rheumatoid arthritis (RA) related foot problems [1, 2] in order to support self-management. Podiatrists are ideally placed to provide foot health education (FHE) as an intervention [1]. As up to 80 % of people with RA will develop foot-related pathology throughout the duration of their disease [3, 4], even when the disease is in remission, there is clearly a need for foot health interventions [1] and the inclusion of FHE as in intervention in its own right.

We know that patient education that supports disease self-management is effective in improving patient knowledge [5, 6], self-efficacy [7], disease activity scores [5], functional ability [6], mental health status [7] and in reducing pain [7]. Hence it could be considered essential for podiatrists to provide specific patient education that could improve self-management of foot problems, which are a significant burden to those with RA.

There are no specific FHE interventions for people with RA [8] therefore in order to develop and evaluate the potential effectiveness of FHE as a definable intervention for people with RA, there is a need to understand what its possible key components are and how it works. In gaining an understanding of this, the development of FHE as an intervention will align with the modelling phase of the MRC Complex Intervention Framework [9].

We know from previous work what people with RA have experienced and what they need in relation to foot health education (FHE) [10]. However, given that podiatrists are the main providers of FHE, we need to know the methods, timing, content and effectiveness of its provision, together with the potential influences on the delivery of FHE. This knowledge is key in defining the information 'needs' of both the patient and practitioner. Foot health information that is tailored for the individual can potentially improve patient adherence to foot health interventions and therefore positive foot health outcomes in this patient group [11]. Further, exploratory work has indicated that people with RA [10] and podiatrists [12] perceive that factors such as gender, age and time since qualification (podiatrists) may also influence the provision of FHE in relation to the therapeutic relationship.

Therefore the primary aim of this study was to understand podiatrists' opinions and perceptions about FHE for people with RA. The secondary aim was to identify the current status of RA-related FHE provision in the UK and what may influence this, for example; gender, age and duration of time since qualification. Podiatrists' opinions on what should be delivered, how it should be delivered and at what point in the persons' experience of foot problems it would be most effective, are not known. To date, this has not been explored and has the potential to contribute significantly in relation to the provision of foot health education, not just by podiatrists but by any professional involved in managing people with RA who have foot problems.

Methods

The study was granted ethical approval from the University of Salford, Research Innovation and Academic Engagement Ethical Approval Panel (HSCR12/35).

Survey questionnaire design

The survey questionnaire was designed to capture quantitative data from podiatrists. Questions were developed from a literature search and the results of previous focus group work with UK National Health Service (NHS) podiatrists, which informed the content of the questionnaire [10, 12]. To ensure face and content validity the questionnaire was piloted with four UK NHS podiatrists that work within rheumatology. 'Think aloud' cognitive debriefing [13, 14] was used in order to reduce sources of response error, ensure clarity of questions and refine the overall structure of the questions. The results of the pilot led to a small number of changes to improve the clarity of the question completion instructions.

The final survey consisted of five sections, plus demographics (Additional file 1) with 17 questions in total.

1. Aims of Foot health education
2. The best ways of providing foot health education
3. What should be included in foot health education provision
4. When is the best time to provide foot health education
5. Accessing foot health education/information

A free text comment section was included for additional comment.

The questionnaires were anonymous, self-administered and of a cross-sectional observational design using a web based survey through the Bristol Online Survey website (https://www.onlinesurveys.ac.uk/). A mixture of open-ended, closed-ended dichotomous, contingency, nominal and ordinal polytomous questions were used to reduce the risk of missing data [15, 16].

Participants

Inclusion criteria were: podiatrists with current Health and Care Professions Council (HCPC) registration, working within the UK National Health Service and with access to the Internet. The participants were recruited between September and November 2013, through the Podiatry JISC-Mail service, via e-mail invitation with a web-link to the survey. A second 'reminder' e-mail was sent after 2 weeks. Consent was implicit by the completion of the survey and participants were informed of this at the start of the survey.

Data analysis

Data was analysed using SPSS v 20.0 (SPSS, Chicago, IL, USA). The primary analysis was descriptive statistics. Secondary analyses were cross-tabulation; Fishers Exact test was performed to determine the strength of any associations between the participants' demographic variables of Gender, Age Range, Years Qualified and the responses to the items in section 2–6. Fishers Exact test was applied where cell frequencies in 2x2 cross-tabulated contingency tables was less than 5. A $p < 0.05$ was considered to indicate statistical significance (Additional file 2).

Free text comments (Additional file 3) were subject to thematic analysis by the primary author (AG) to develop a thematic framework using the six-step approach outlined by Braun and Clarke [17] and to illustrate the main themes within the comments provided. The thematic framework was agreed by the co-author (AW) to evaluate validity of the data [18].

Results

Demographics

42 podiatrists (f = 31, m = 11) completed the survey (Table 1), all were Health and Care Professions Council registered.

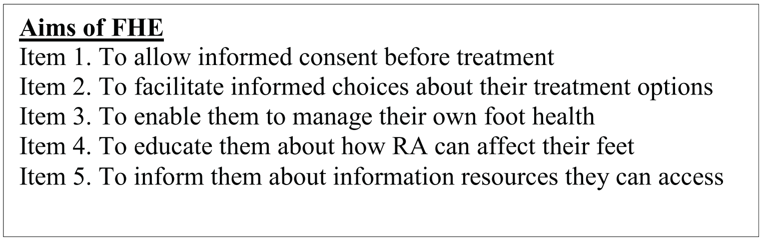
Results from the survey

Aims of foot health education

The majority of podiatrists (88 %, $n = 37$) agreed with the aims of foot health education (Fig. 1). Two podiatrists disagreed with item 1.

Table 1 Participant Demographics

Gender		Female (n)	Male (n)	Total
(S.D = 0.45)		31	11	42
Age Range (S.D = 0.89)	21-30 years	2	0	2
	31-40 years	10	4	14
	41-50 years	12	5	17
	51-60 years	7	1	8
	More than 60 years	0	1	1
Duration of time qualified	up to 1 year	1	0	1
	2-5 years	1	1	2
	5-10 years	4	2	6
	10-20 years	14	2	16
	20-30 years	9	4	13
	30-40 years	2	2	4
HCPC registered		31	11	42
Service type	Primary Care	15	8	23
	Secondary Care	13	2	15
	Equal Split	3	1	4
Geographic location	SE England	3	0	3
	NW England	17	3	20
	SW England	2	2	4
	Greater London	0	0	0
	West Midlands	1	0	1
	East Anglia	0	0	0
	Yorkshire/N Humberside	2	0	2
	East Midlands	3	0	3
	S Central England	2	0	2
	NE England	0	2	2
	Wales	0	0	0
	Scotland	1	3	4
	N. Ireland	1	0	1



Aims of FHE

Item 1. To allow informed consent before treatment
Item 2. To facilitate informed choices about their treatment options
Item 3. To enable them to manage their own foot health
Item 4. To educate them about how RA can affect their feet
Item 5. To inform them about information resources they can access

Fig. 1 Section 2 survey items: the aims of foot health education. Legend: Fig. 1 shows the items that constitute section 2 of the FHE survey in relation to the AIMS of FHE

All items, were statistically significant ($p = <0.05$) in relation to duration of years qualified and the gender of the participants. Participants who had been qualified for over 10 years and female tended to agree more strongly with the aims of FHE. Only one item, 'To inform patients about information resources they can access' did not reach statistical significance.

The best ways of providing/receiving foot health education

97.6 % ($n = 40$) stated that they provided FHE. The methods of delivery were, verbal information (97.5 %, $n = 39$), written information (69 %, $n = 29$) and signposting patient to websites (57.5 %), $n = 24$). The relationship between the provision of verbal foot health information and the gender of the participants approached statistical significance ($p = 0.064$), with 100 % ($n = 31$) female participants stating that they provided verbal foot health information in comparison to 82 % ($n = 9$) of males. There were no other statistically significant results in relation to methods of FHE delivery.

Other methods of delivery such as group education sessions and the use of audio-visual aids such as DVDs, self-care demonstrations or the specific uses of images to aid delivery of education are infrequently used.

In relation to the effectiveness of the methods of delivery, written (76 %, $n = 32$) and verbal (100 %, $n = 42$) provision were ranked the highest, followed by website based information (62.8 %) [Arthritis Research UK (ARUK), $n = 22$; Arthritis Care $n = 16$; National Rheumatoid Arthritis Society (NRAS) $n = 15$].

There was no statistically significant relationship between the age, gender or years qualified and perceived effectiveness of any method of FHE with the exception of verbal information which approached statistical significance for gender ($p = 0.069$), with females tending to rate verbal information as more effective than men and years since qualification ($p = 0.081$), with participants who have been qualified longer (>20 years) finding verbal information to be less effective than those with fewer years since qualifying.

The content of foot health education

All of the participants considered all the items to be important or very important with gender being the only independent variable to have a statistically significant relationship ($p = <0.05$) in relation to the following items: signs and symptoms of foot problems related to RA, management options relating to foot health and how patients should manage their own foot health. Female participants attributed a higher level of importance to these items of FHE content, than male participants.

The timing of foot health education

78.6 % ($n = 33$) of participants agree that patients should be provided with FHE at the point of diagnosis and 90.5 % ($n = 38$) think it should be provided at every available opportunity but disagree that FHE should only be provided when asked for it by the patient. However, the participant's opinion was split equally when asked about providing FHE when the patient develops foot related symptoms; 47.6 % ($n = 20$) disagreed whilst 52.4 % ($n = 22$) agreed (Fig. 2).

There was a statistically significant relationship between the years since qualification and the items: 'FHE should be provided only when asked for it' ($p = 0.034$), participants who had been qualified more than 30 years were more likely to disagree with this statement and 'FHE should be provided when or if the person develops foot-related symptoms' ($p = 0.022$). Participants that had been qualified for duration of time of more than 5 years were more likely to agree with this statement.

Accessing and barriers to the provision of foot health education/information

54.8 % ($n = 23$) participants thought there was enough time during consultations to provide FHE. The majority (78 %, $n = 33$) of participants stated that they had access to RA-specific foot health information such as leaflets and that the patients they treated used it. The majority of participants (92.9 %, $n = 39$) stated that they had enough knowledge about how RA affected the feet in order to provide effective FHE. However, approximately 30 % ($n = 13$)

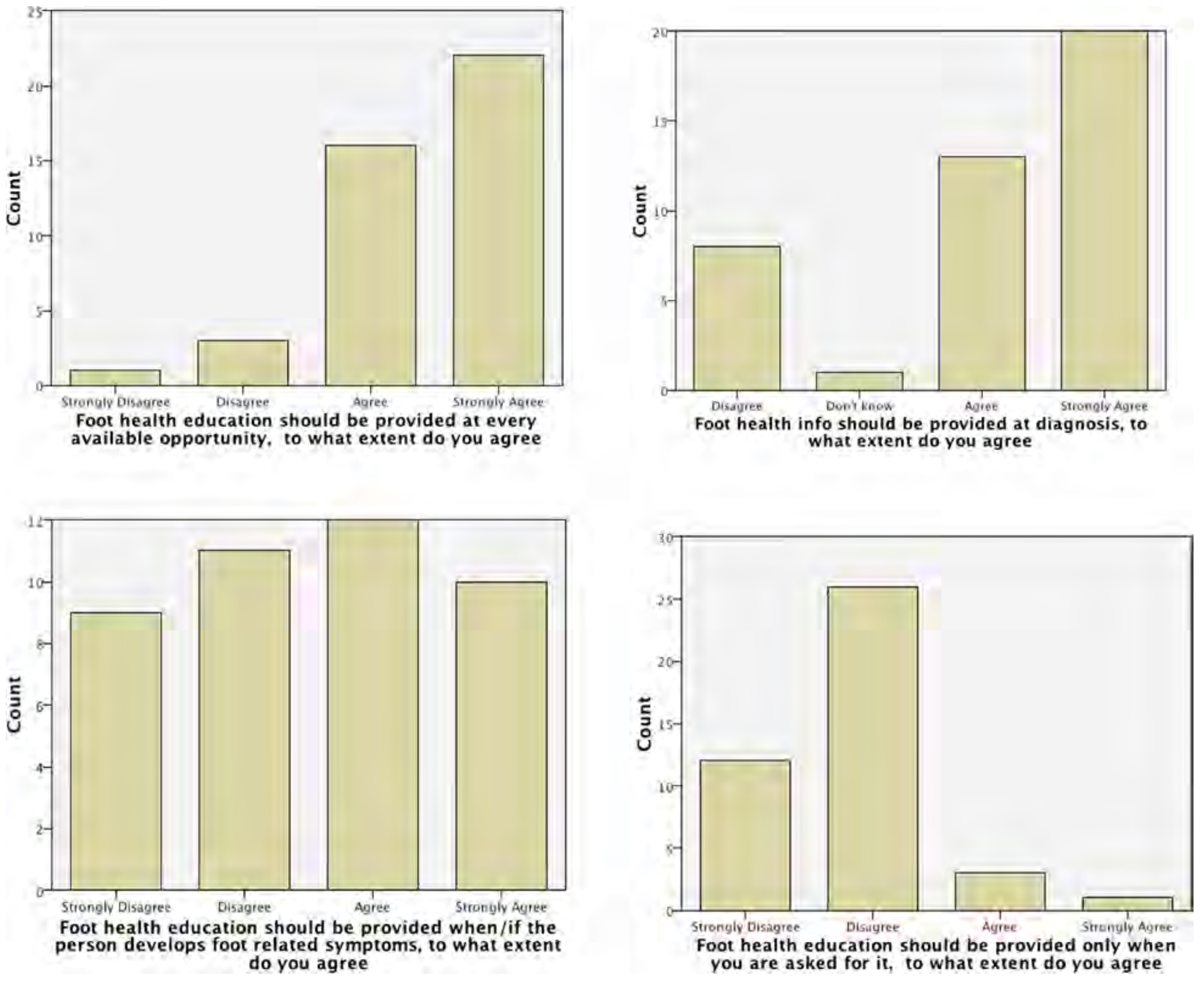


Fig. 2 Agreement with the timing of FHE. Legend: Bar charts show the level to which podiatrists' agree with items for the timing of FHE provision

stated that patients did not use the FHE provided due to financial constraints or that it lacked personal relevance.

The only item to reach statistical significance was 'You have access to foot health information' in relation to the gender of participants ($p = 0.031$), with more female participants strongly agreeing with the statement compared with males who either agreed or strongly disagreed. There was no statistically significant relationship between the genders, the age or the duration of years qualified and perceived barriers to FHE provision.

Thematic analysis of free text comments

There were seven questions that allowed free text comments within the survey. 14 free text comments were provided in total for sub-questions 15 and 11 for sub-questions 16. Eleven participants provided additional free text comments within question 17, the 'Any other comments' section (Table 2).

Discussion

This study has been the first to describe the opinions and perceptions of NHS podiatrists about RA related FHE in relation to its' aims, method and timing of delivery, its' content and potential barriers to its provision. Given the re-profiling of many NHS specialist podiatry services, resulting in reduced access to podiatrists, it is crucial that FHE is provided in a way that supports self-efficacy and self-management by all healthcare practitioners that are involved in the management of people with RA. This work will inform practitioners from a specialist and professional context, what patients need in relation to self-care, so that those people who do develop serious foot problems can be seen by the few specialists that remain and also prevent problems from having a more significant impact upon the individual.

The response rate for this study represents 50 % of the sample population invited to participate, which is

Table 2 Outline of the basic and organising themes developed from the thematic analysis

Basic Themes	Organising Themes
Time restriction in consultations	Influence of time
Timing of delivery–	
Limited financial resources	Limited Resources
Limited knowledge of impact of RA on feet	
Limited access to group education sessions or patient support group sessions	
Gender influence on engagement with footwear advice	Footwear and behaviour change
Influence of Age/occupation of patient on engagement with footwear advice	
Influence of patients negative perceptions of podiatrist-advised footwear styles	
Too soon–overwhelming/lacks relevance	Negative impact of information provision
Too late–damage already done	
Can be perceived as 'threatening' if provided 'incorrectly'	

deemed an acceptable rate for a survey method of data collection. Responses came from participants working in both UK Primary Care (health care services directly accessed by patients) and UK Secondary Care (health care services that generally require General Practitioner referral), although a question about their experience within the specialist area of Rheumatology was not included and may have provided insight about how their experience influenced their responses. Responder bias should remain a consideration in the interpretation of the results as it is possible that the respondents were those that had an interest in the subject area and we cannot know if the responses of those who did not complete the survey would have been different [19]. In addition, although there was a geographical spread of participants across the UK, the majority were based in the North West of England and therefore the secondary aim of the study was not fully achieved. The primary aim of the study was achieved by providing insight about how FHE for people with RA is perceived by podiatrists, the barriers and influences upon its provision.

The majority of participants agreed with the aims of FHE and stated that they provided some FHE to people with RA as part of their overall foot care. However, many people with RA are unable or unaware that they can access NHS podiatry services and thus are denied access to podiatrists who are considered a key information resource [20]. Further to this, for some people who do receive podiatry care, they perceive that podiatrists and other health care practitioners lack knowledge of how RA can impact on both the foot and the individual [21]. Hence if health care practitioners are perceived to lack insight into the bio-psychosocial impact of RA on foot health, then they may not be able to provide the FHE that patients need. This may be reflective of a training need across the health care professions that are involved in the management of people with RA, not just podiatrists.

In this study the majority of the participants felt that they had enough knowledge to allow them to provide effective FHE to people with RA. Indeed, females were more likely to access information resources to support FHE, aligning with the work of Roter et al.,[22] who found that female health care providers were more patient-centred and spent more time on psychosocial/socio-emotional exchange than males during the consultation. This poses a challenge in relation to recommendations. However, it may be that female gender traits lend more to this supportive action and this approach could be part of under and post-graduate training. In this study, thematic analyses of the free text data identified podiatrists' perceptions that; the patients' gender, age and historical perceptions of footwear for example, potentially influenced their engagement with positive foot health behaviours. This is echoed in the findings of research undertaken with people with RA, where the impact of having limited footwear as a female with RA has been poignantly expressed [21, 23]. Understanding the reasons why a person with RA may be 'resistant' to change in relation to foot health behaviour may assist practitioners in developing a more patient-centred approach to the provision of FHE.

Further, the years of post-qualification practice also appeared to influence the participant's opinions and perceptions of FHE. The more novice podiatrists may not have the experience for managing the more complex patient needs in a time limited consultation [12] or have developed the insight to identify when patients are more likely to be receptive to the provision of FHE [24]. Identification of a persons readiness to engage in positive health behaviour change is a key component of a patient-centred approach to the consultation [24]. Firmly embedding the use of motivational interviewing techniques in the undergraduate curriculum, together with rigorous assessment and developmental feedback with respect to communication skills may help to equip undergraduate healthcare practitioners with the skills to manage complex patient needs and ensure similarities in communication skills development between male and female undergraduates.

Many identified the lack of time within the consultation and lack of resources as a barrier to being able to focus on anything other than the physical needs of the patient and this is consistent with the findings of previous work with both people with RA and podiatrists [10, 12, 21]. This lack of time reduces or removes the opportunity for a podiatrist to provide patient focussed FHE based on their physical, but also their psychological and social needs.

Despite the barriers of lack of time and inexperience, the participants did value FHE and identified what should be provided and tailored to their patients' individual needs and priorities. In order to achieve this in a time limited consultation, podiatrists need to identify what the patients' needs and priorities are. An Educational Needs Analysis Tools (ENAT) has been developed and validated for use in people with RA to facilitate timely and relevant patient education [25]. A specific foot health educational needs assessment tool may efficiently identify what the patient's requirements are. However, until this tool is developed, we recommend that as a minimum, podiatrists should ask about what their patients would like to know and signpost them to the appropriate resources such as web sites or leaflets. Indeed, leaflets and other locally produced written information were reported to be the main vehicle for FHE. The use of combined methods of FHE delivery, such as verbal information being reinforced with written information, aligns with research findings that demonstrated that such an approach is the most effective in the provision of general RA information [26].

Over half of the participants stated that they do direct patients to RA or arthritis specific web sites such as Arthritis Research UK (www.arthritisresearchuk.org), Arthritis Care (www.arthritiscare.org.uk) and the National Rheumatoid Arthritis Society (www.nras.org.uk). These provide flexible, on-demand access to information and peer support [27]. In addition, patients can choose to access information that is the most pertinent to them at that point in time, thereby tailoring it to their own needs. Therefore, people with RA should be directed to the web-based resources if they are able to access the Internet and/or provided with foot health specific leaflets.

The participants viewed all content items for FHE as being either important or very important in agreement with the results from work with people with RA [10]. The fact that the participants place such high value upon all items in relation to the educational content, suggests that FHE needs to be considered as an intervention in itself. Further, considering 'education provision' as a treatment modality aligns with the need for healthcare practitioners being ethically obliged to provide patients with enough information about their disease and its management options in order to facilitate informed consent [28]. Therefore, it could be argued that 'education provision' should be viewed as a distinct entity from the provision of information which is an ethical 'must'.

The timing of FHE was considered important and the participants considered that FHE should be provided at the point of diagnosis and at every available opportunity. Equally they agreed that they shouldn't wait to provide information until patients asked for it. Despite the knowledge that many people can feel overwhelmed with too much information upon their initial diagnosis [29], there is a need to ensure that people have information at a point in time that allows them to self-manage from as early as possible [30]. It is recognised that foot and general health educational needs are temporal, in relation to the fluctuating nature of the disease and in relation to the individual's ability to adjust to their diagnosis [12, 24]. Hence, providing people with RA an opportunity at each consultation to identify their educational needs, will allow them to ask questions that are pertinent to the current state of their feet and general health. Further to this it will enable the practitioner to contextualize their educational needs by attempting to understand the motivation that underlies the persons health behaviour goals. This '*person-in-context*' approach [31] enables the practitioner to identify the influence of the psychological, cognitive, self-efficacy beliefs, demographic, environmental and situational factors upon their information needs, as outlined by the Wilson Model [25]. Understanding such an approach should enable practitioners to fully consider; why, what and how to meet the FHE needs of

- FHE should be encouraged at each consultation and be an individualized intervention according to the educational needs of the person at the time of the contact.
- FHE should include foot health self-management advice and if necessary demonstration.
- FHE should include explanation of foot problems, their impact on the individual, changes in foot health that should prompt immediate health care practitioner attention.
- FHE should include information on general disease management and sign posting for future foot health needs to NHS Podiatry service providers
- FHE should include information about patient support groups/websites.
- If the consultation is short or time-limited simply ask '*how are your feet at the moment?*' can give the patient an opportunity to provide some indication of foot health status

Fig. 3 Components of FHE for people with RA. Legend: Fig. 3 highlights the key minimum FHE components that should be provided to people with RA patients in practice [32]. This study has identified what the components of FHE should be (Fig. 3) in relation to what people with RA need in order to reduce foot symptoms and maximise their foot health. Figure 3 outlines the general components of foot health education that podiatrists and other health professionals should aim to provide dependant upon the needs of the person with RA.

Conclusion

In order to reduce the impact and burden of foot problems on people with RA, there needs to be a tailored and timely approach to FHE provision that both supports self-management and that takes into account the patients' needs over the course of their disease journey. The podiatrists have defined the importance and content of FHE from a specialist professional perspective, but as a primary intervention delivered by them in a time limited consultation; it is relegated to an adjunct to treatment rather than an intervention in its own right.

Future research will be focussed on the development and validation of a simple foot health needs analysis tool so that patients can easily and accurately identify both their needs for foot health interventions (including specific FHE) and signposting for FHE that supports self-management.

Additional files

Additional file 1: Practitioner Survey of FHE for people with RA. The file includes the survey questions and all raw data of the responses. (PDF 113 kb)

Additional file 2: Table of results from statistical analyses. The table illustrates the influence of the years qualified, age range and gender of the podiatrists on their survey responses. (DOCX 187 kb)

Additional file 3: Free text comments from RA FHE survey of podiatrists. This file shows the free text comments taken from Rheumatoid Arthritis foot health education survey for practitioners. (DOCX 24 kb)

Abbreviations

ARUK: arthritis research UK; ENAT: educational needs analysis tool; FHE: foot health education; HCPC: health and care professions council; NHS: national health service; NRAS: national rheumatoid arthritis society; RA: rheumatoid arthritis.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

AG conceived and participated in the study design, drafted the manuscript and carried out the statistical analysis. AW participated in the study design and assisted in the drafting of the manuscript. Both authors approved the final manuscript.

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References

1. Podiatric Rheumatic Care Association (PRCA). Standards of care for people with musculoskeletal foot health problems. Podiatric Rheumatic Care Association. 2008.
2. Williams AE, Davies S, Graham A, Dagg A, Longrigg K, Lyons C, et al. Guidelines for the management of the foot health problems associated with rheumatoid arthritis. Musculoskeletal Care. 2011;9:86–92.
3. Grondal L, Tengstrand B, Nordmark B, Wretenberg P, Stark A. The foot: still the most important reason for walking incapacity in rheumatoid arthritis: distribution of symptomatic joints in 1,000 RA patients. Acta Orthop. 2008;79:257–61.
4. Otter SJ, Lucas K, Springett K, Moore A, Davies K, Cheek L, et al. Foot pain in rheumatoid arthritis prevalence, risk factors and management: an epidemiological study. Clin Rheumatol. 2010;29:255–71.
5. Abourazzak F, El Mansouri L, Huchet D, Lozac'hmeur R, Hajjaj-Hassouni N, Ingels A, et al. Long-term effects of therapeutic education for patients with rheumatoid arthritis. Joint Bone Spine. 2009;76:648–53.
6. Masiero S, Boniolo A, Wassermann L, Machiedo H, Volante D, Punzi L. Effects of an educational-behavioral joint protection program on people with moderate to severe rheumatoid arthritis: a randomized controlled trial. Clin Rheumatol. 2007;26:2043–50.
7. Hammond A, Bryan J, Hardy A. Effects of a modular behavioural arthritis education programme: a pragmatic parallel-group randomized controlled trial. Rheumatology (Oxford). 2008;47:1712–8.
8. Graham A, Hammond A, Williams A. Therapeutic foot health education for patients with rheumatoid arthritis: a narrative review. Musculoskeletal Care. 2011;9:141–51.
9. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: the new Medical Research Council guidance. Int J Nurs Stud. 2013;50:587–92.
10. Graham AS, Hammond A, Walmsley S, Williams AE. Foot health education for people with rheumatoid arthritis-some patient perspectives. J Foot Ankle Res. 2012;5:23.
11. Williams AE, Nester CJ, Ravey MI. Rheumatoid arthritis patients' experiences of wearing therapeutic footwear-a qualitative investigation. BMC Musculoskelet Disord. 2007;8:104.
12. Graham AS, Hammond A, Williams AE. Foot health education for people with rheumatoid arthritis: the practitioner's perspective. J Foot Ankle Res. 2012;5:2.
13. Willis G. Cognitive Interviewing: A Tool for Improving Questionnaire Design. Thousand Oaks, CA: Sage Publishing Inc; 2005.
14. Beatty P. The dynamics of cognitive interviewing. In: Presser S, Rothgeb J, Couper M, Lessler J, Martin M, Martin J, Singer E, editors. Methods for testing and evaluating questionnaires. Hoboken, New Jersey: John Wiley and Sons Inc; 2004.
15. Reja U, Manfreda K, Hlebec V, Vehovar V. Open-ended versus closed-ended questions in web questionnaires: Advances in methodology and statistics. Metodoloski zvezki. 2003;19:159–77.
16. Sue V, Ritter L. Conducting Online Surveys. 2nd ed. Thousand Oaks, CA: Sage Publications, Inc; 2012.
17. Braun V, Clarke V. Using Thematic Analysis in Pscyhology. Qual Res Psychol. 2006;3:77–101.
18. Barbour RS. Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? BMJ. 2001;322:1115–7.
19. Denscombe M. The Good Research Guide: for small scale social research projects. 3rd ed. Open University Press: McGraw Hill; 2007.
20. Blake A, Mandy PJ, Stew G. Factors influencing the patient with rheumatoid arthritis in their decision to seek podiatry. Musculoskeletal Care. 2013;11:218–28.
21. Graham AS, Williams AE. Foot Health Education for People with Rheumatoid Arthritis: '… A Game of Chance…'-A Survey of Patients' Experiences. Musculoskeletal Care. 2015.
22. Roter DL, Hall JA, Aoki Y. Physician gender effects in medical communication: a meta-analytic review. JAMA. 2002;288:756–64.
23. Williams AE, Nester CJ, Ravey MI, Kottink A, Klapsing MG. Women's experiences of wearing therapeutic footwear in three European countries. J Foot Ankle Res. 2010;3:23.
24. Hammond A. Patient education in arthritis: helping people change. Musculoskeletal Care. 2003;1:84–97.
25. Hardware B, Lacey E, Shewan J. Towards the development of a tool to assess educational needs in patients with arthritis. Clin Eff Nurs. 2004;8:111–7.
26. Kääriäinen M, Kukkurainen ML, Kyngäs H, Karppinen L. Improving the quality of rheumatoid arthritis patients' education using written information. Musculoskeletal Care. 2011;9:19–24.
27. Newman MA, Ziebland S, Barker KL. Patients' views of a multimedia resource featuring experiences of rheumatoid arthritis: pilot evaluation of http://www.healthtalkonline.org. Health Informatics J. 2009;15:147–59.
28. Jones JJ. Patient education is not a treatment modality. BMJ. 2002;325:971.

29. Mäkeläinen P, Vehviläinen-Julkunen K, Pietilä AM. Rheumatoid arthritis patient education: RA patients' experience. J Clin Nurs. 2009;18:2058–65.
30. Hennell S, Brownsell C, Dawson J. Development, validation and use of a patient knowledge questionnaire (PKQ) for patients with early rheumatoid arthritis. Rheumatology (Oxford). 2004;43:467–71.
31. Allen BL. Information Tasks: Towards a User-Centred Approach to Information Systems. San Diego CA: Academic; 1996.
32. Ormandy P. Defining information need in health-assimilating complex theories derived from information science. Health Expect. 2011;14:92–104.

Paper 5 – Additional File 2 – Rheumatoid arthritis foot health education survey for practitioner – results raw data.

Rheumatoid Arthritis foot health education survey for practitioners

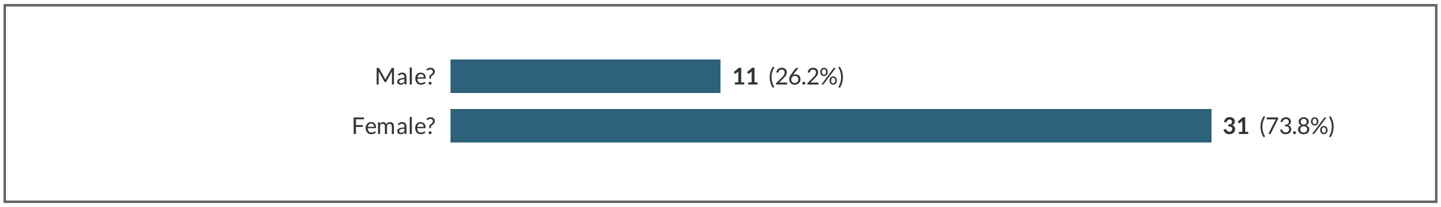
Showing 42 of 42 responses

Showing **all** responses

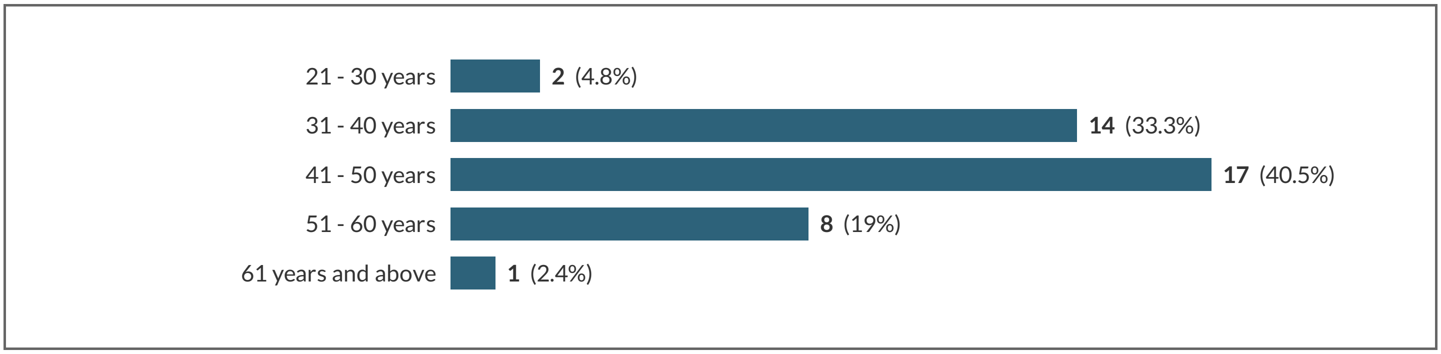
Showing **all** questions

Section 1

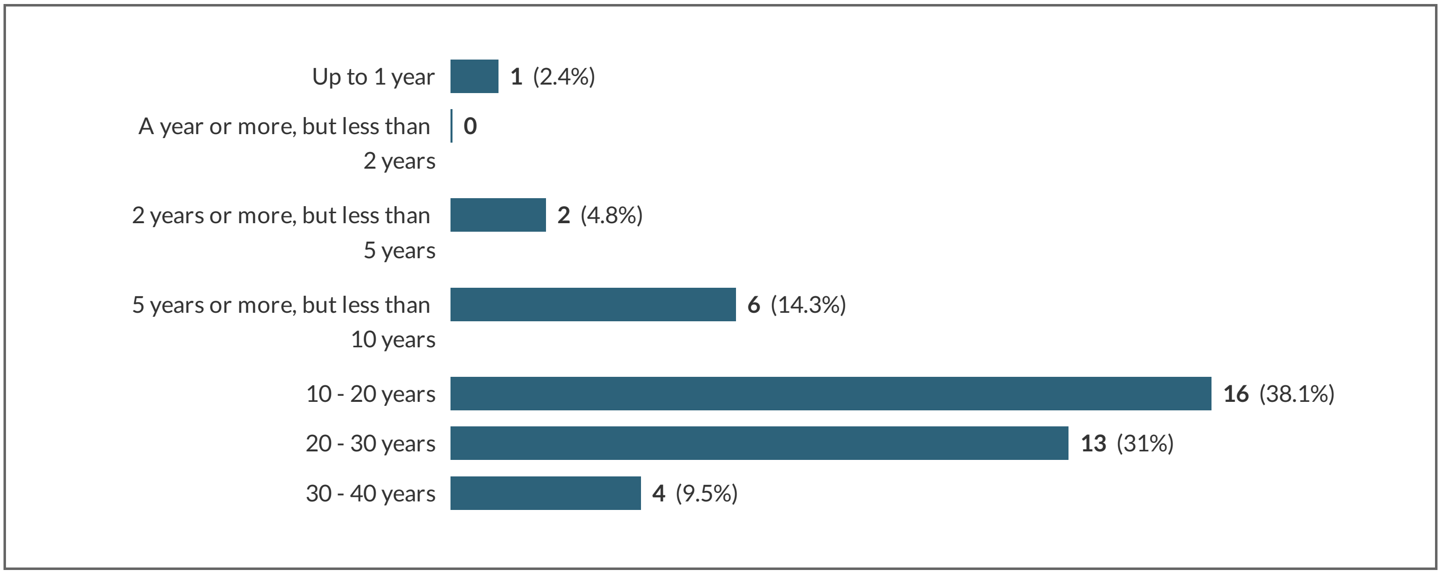
1 Are you



2 What age range are you? please select one option from the list.

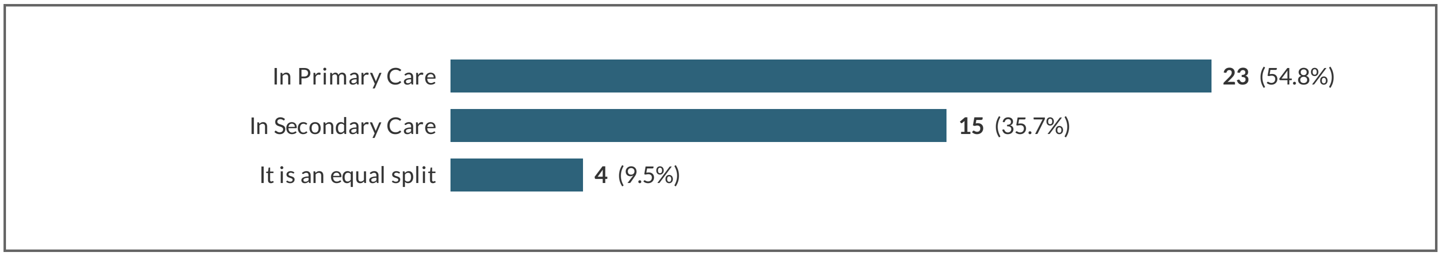


3 Please select the length of time since you qualified as a podiatrist.

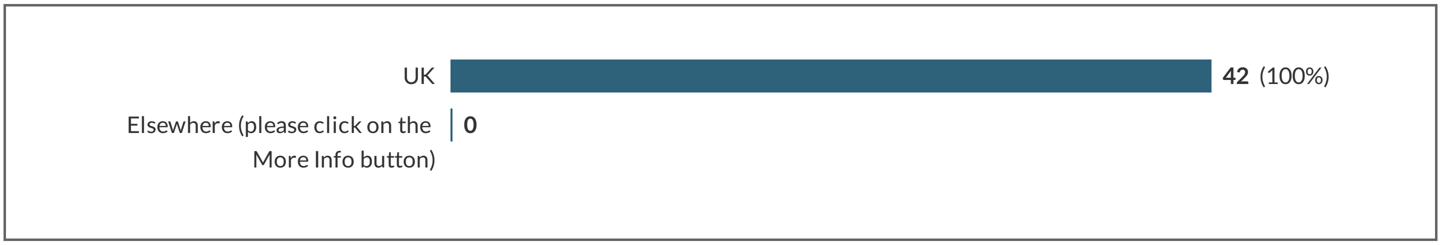


4 Are you registered with the Health & Care Professions Council?

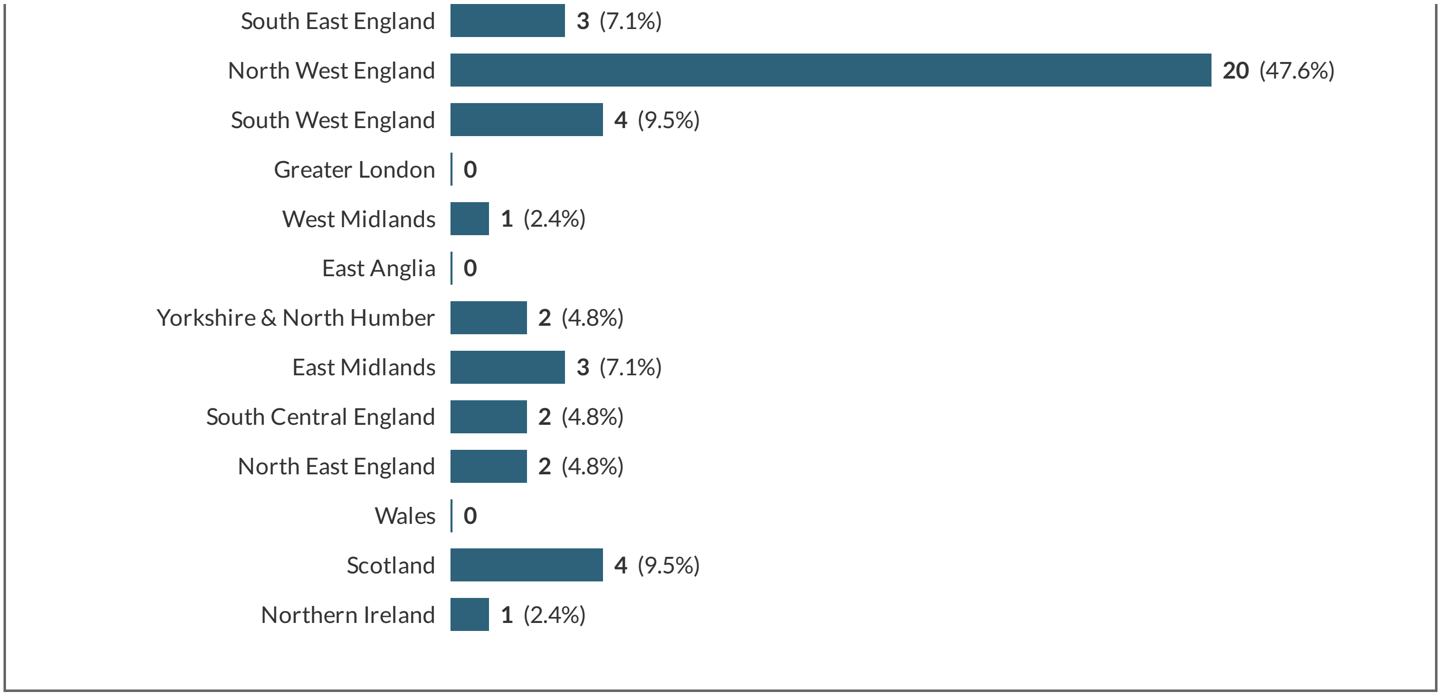
5 Please select where you practice for the MAJORITY of the time.



6 Do you work in the UK or elsewhere?



7 Which UK geographic location do you work within? (select ONE area only)

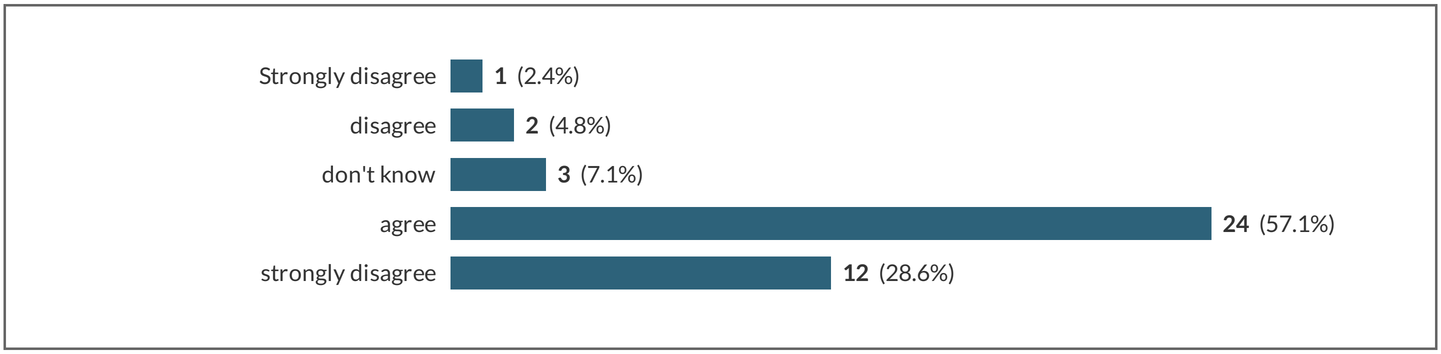


Section 2: The aims of foot health education.

8 To what extent do you agree with the following statements in relation to the AIMS of foot health education.

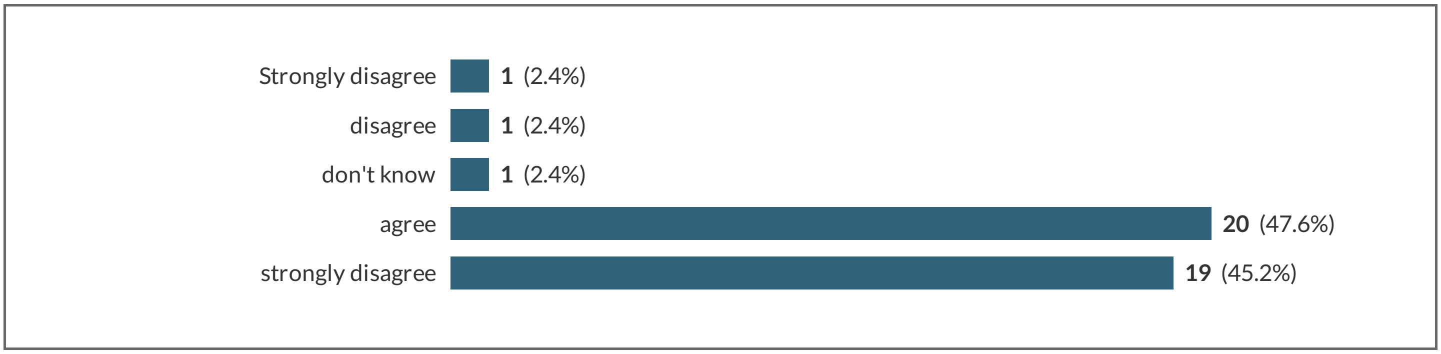
8.1 To allow informed consent before treatment

8.1.a To allow informed consent before treatment - Select the level to which you agree for each statement



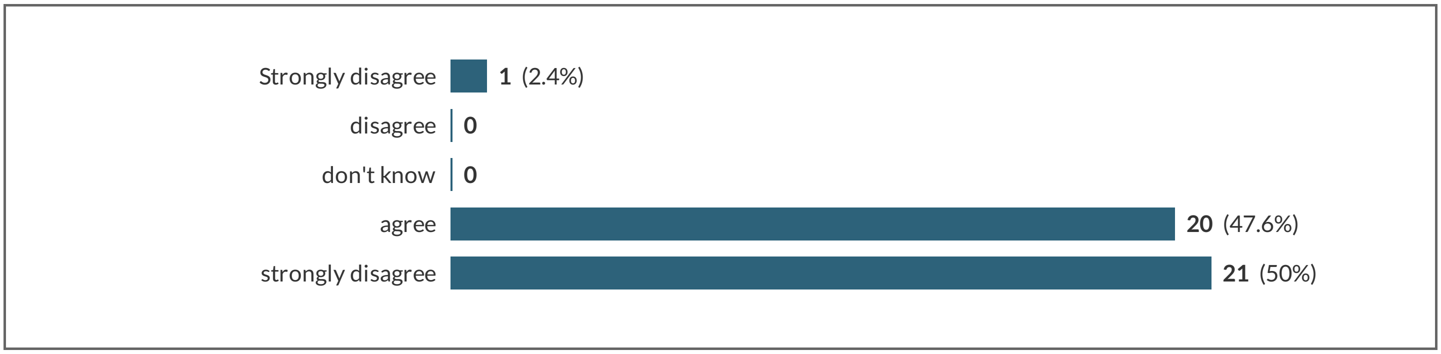
8.2 To facilitate informed choices about their treatment options

8.2.a To facilitate informed choices about their treatment options - Select the level to which you agree for each statement



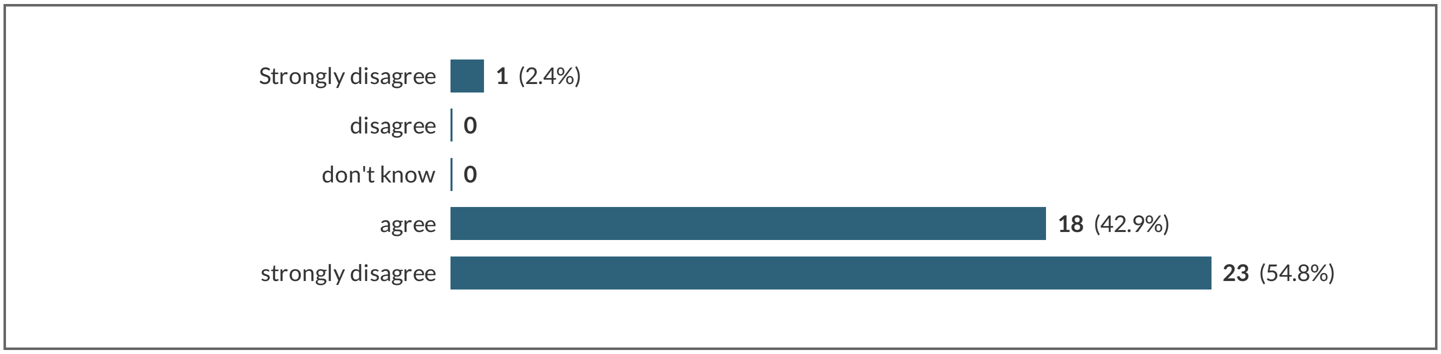
8.3 To enable them to manage their own foot health

8.3.a To enable them to manage their own foot health - Select the level to which you agree for each statement



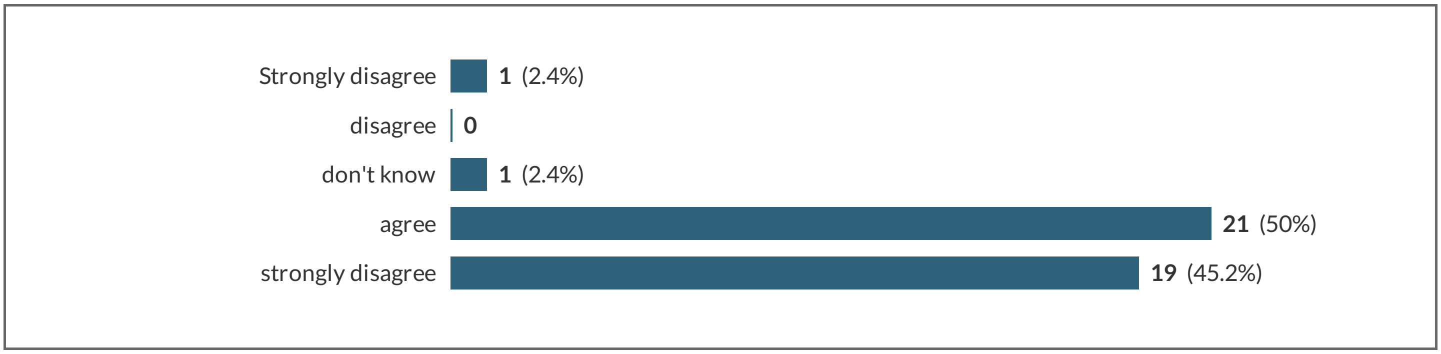
8.4 To educate them about how RA can affect their feet

8.4.a To educate them about how RA can affect their feet - Select the level to which you agree for each statement



8.5 To inform them about information resources they can access

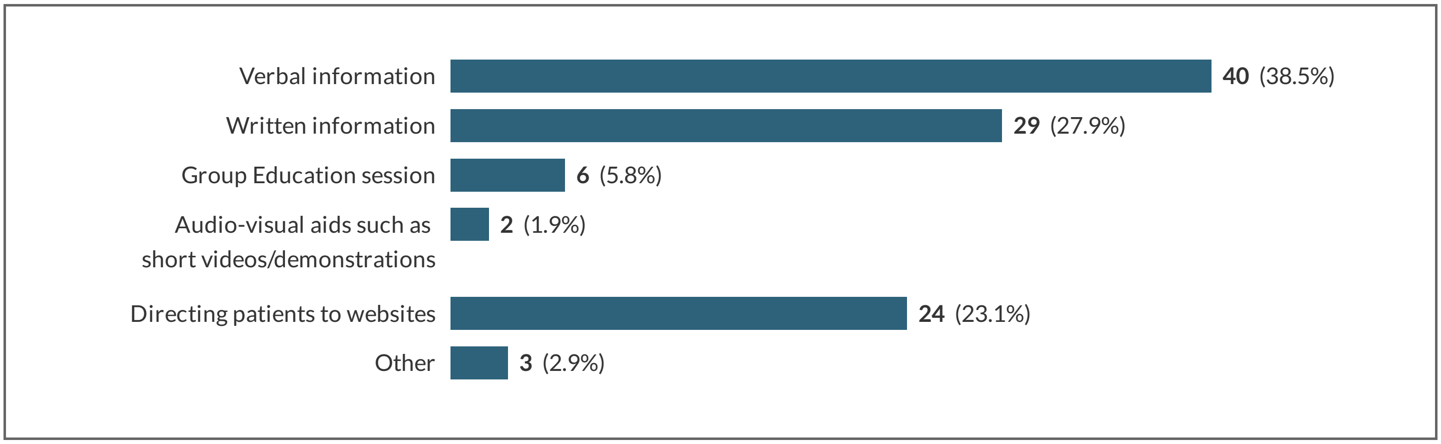
8.5.a To inform them about information resources they can access - Select the level to which you agree for each statement



Section 3: Methods of providing foot health education

9 Do you provide people with RA, foot health information/ education?

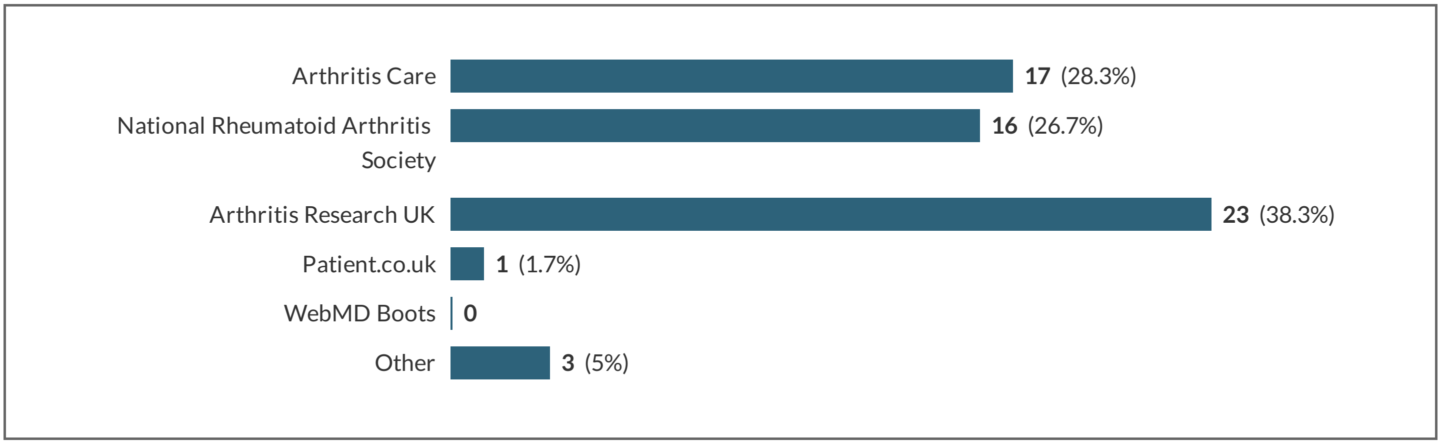
10 If you answered YES please indicate which types of information you have provided from the list below. Select all that apply.If NO, please move onto the next question.



10.a If you selected Other, please specify:

Showing all 3 responses	
Weekly MDT clinic for newly diagnosed infl.arthritis shared with rheum. physio and rheum O.T. Used to hold group session but feedback better for this format	120812-120806-6760694
leaflets are available if needed	120812-120806-6760696
Examples of footwear in the clinic	120812-120806-6760704

11 If you direct your patients to a foot health or disease-related website can you please select from the list below the ALL ones that you use. If there are websites we have not included, please list them in the txet box available.



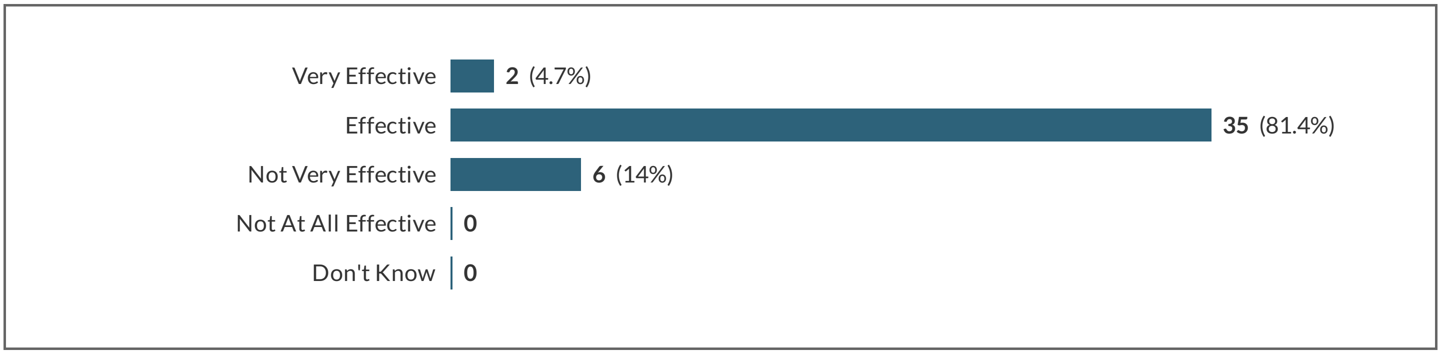
11.a If you selected Other, please specify:

Showing all 3 responses	
Shoemed in Stratford.	120812-120806-6760693
Footwear related websites	120812-120806-6760700
make sure www sites use are pref "UK" and are 'mainstream'.	120812-120806-6760710

12 From the options given,to what extent do you think they are effective.

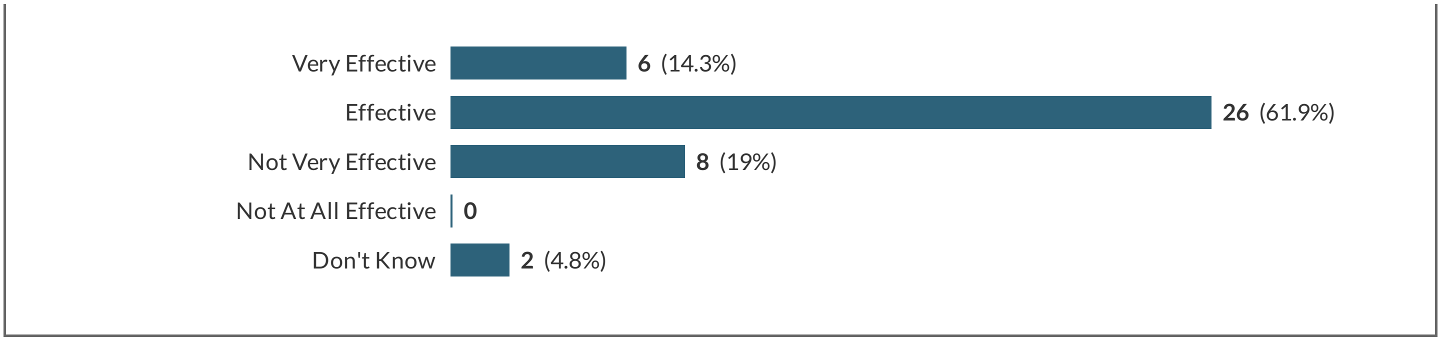
12.1 Verbal Information

12.1.a Verbal Information - Please select from Very Effective to Don't KNow



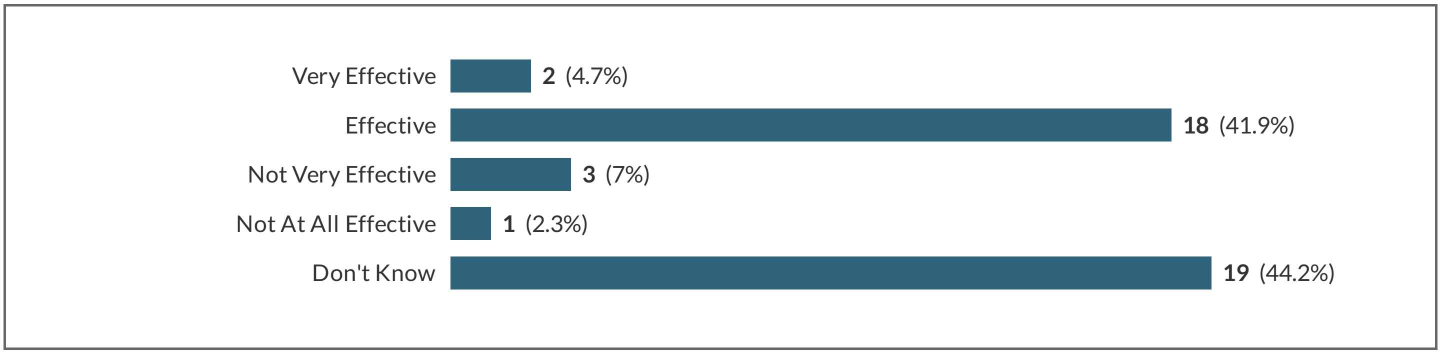
12.2 Written Information

12.2.a Written Information - Please select from Very Effective to Don't KNow



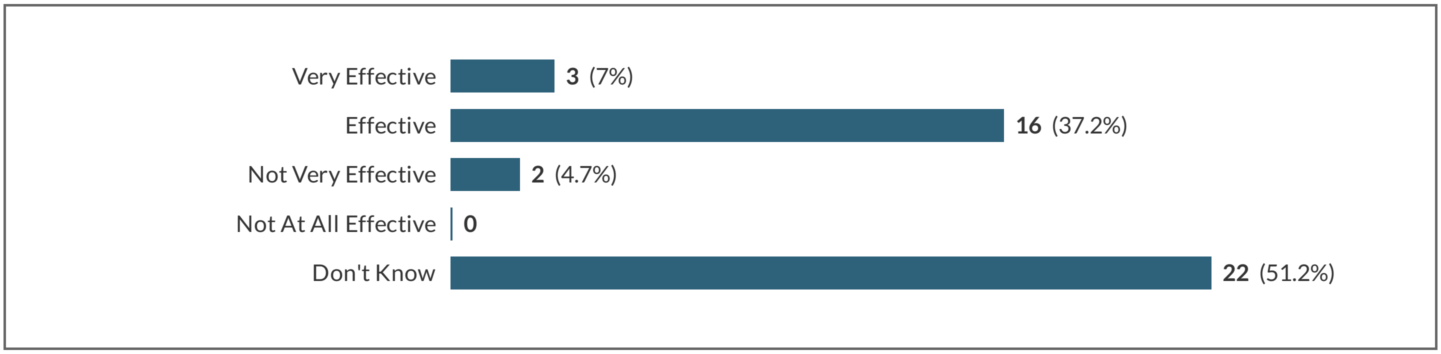
12.3 Group Education sessions

12.3.a Group Education sessions - Please select from Very Effective to Don't KNow



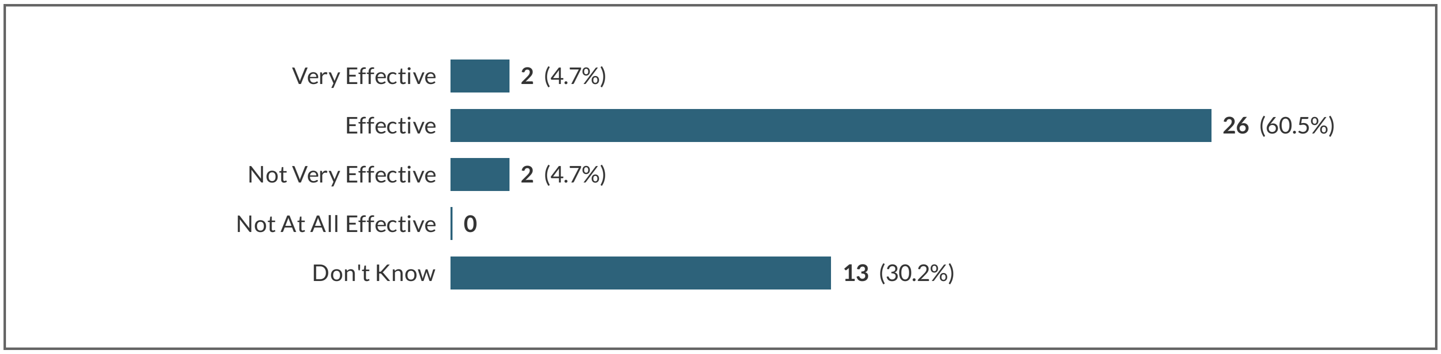
12.4 Audio-visual aids such as videos/demonstrations

12.4.a Audio-visual aids such as videos/demonstrations - Please select from Very Effective to Don't KNow



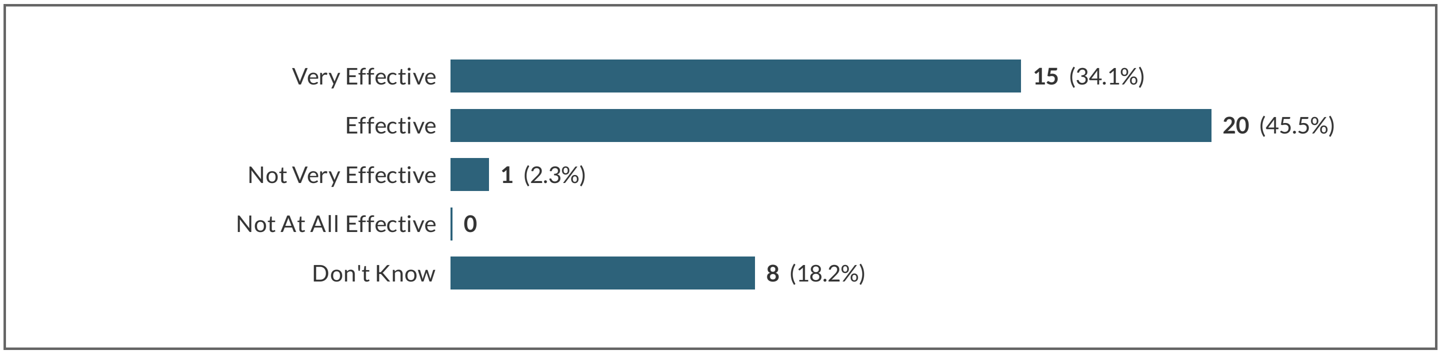
12.5 Web sites

12.5.a Web sites - Please select from Very Effective to Don't KNow



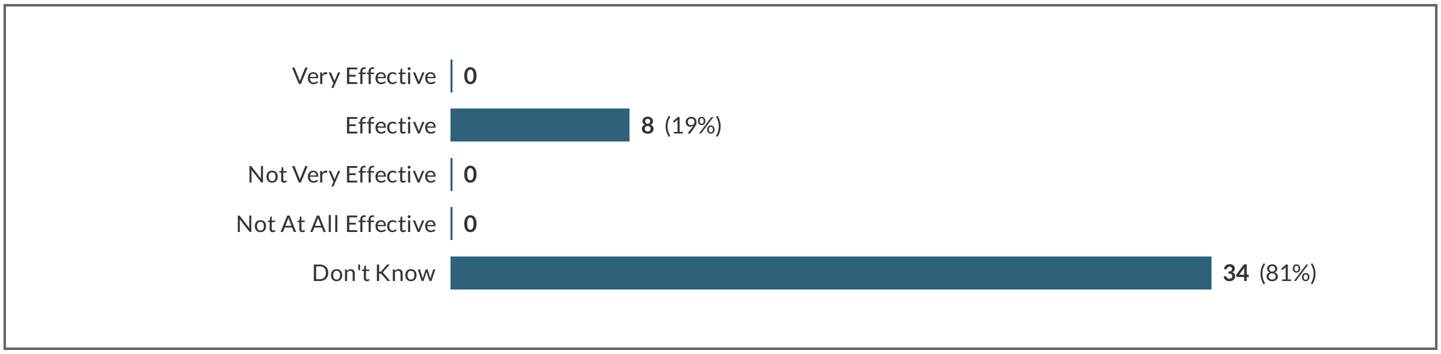
12.6 Combination of resources

12.6.a Combination of resources - Please select from Very Effective to Don't KNow



12.7 Other (in relation to additional methods you gave)

12.7.a Other (in relation to additional methods you gave) - Please select from Very Effective to Don't KNow

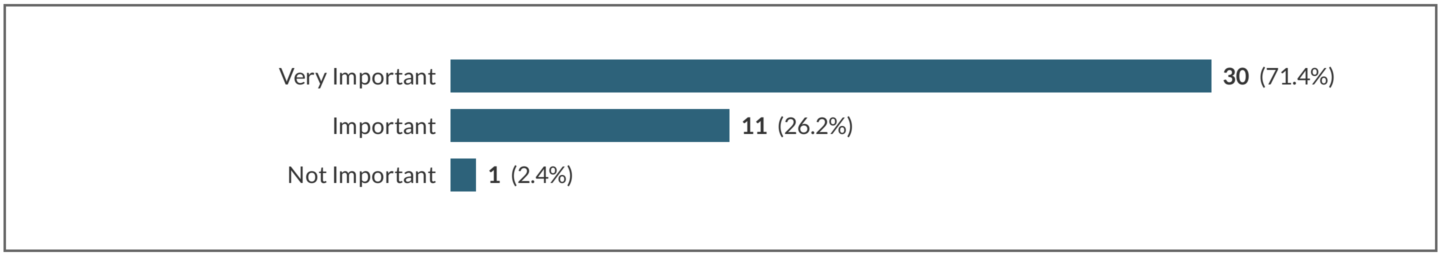


Section 4: The content of foot health education

13 To what extent do you think it is important for people with RA to know about the following areas of foot health education? Select from Very Important to Not Important for each item. They are in no particular order.

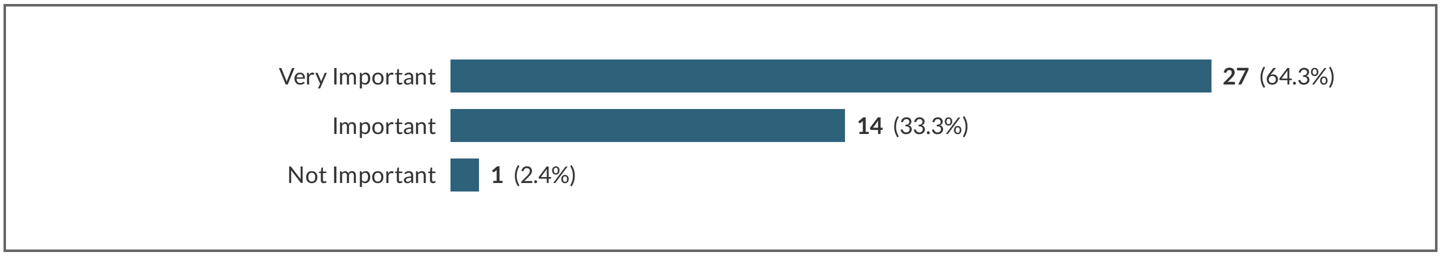
13.1 The role of the podiatrist in managing foot health

13.1.a The role of the podiatrist in managing foot health - Please select from Very Important to Not Important



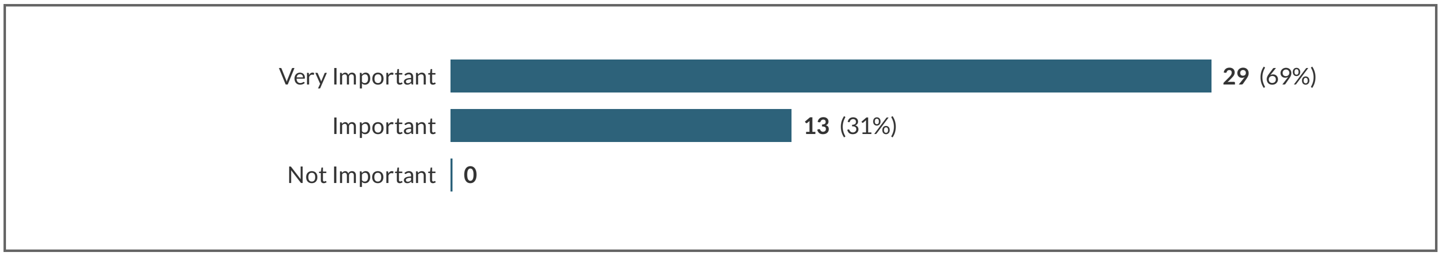
13.2 General disease related information (e.g what is RA? Causes etc..)

13.2.a General disease related information (e.g what is RA? Causes etc..) - Please select from Very Important to Not Important



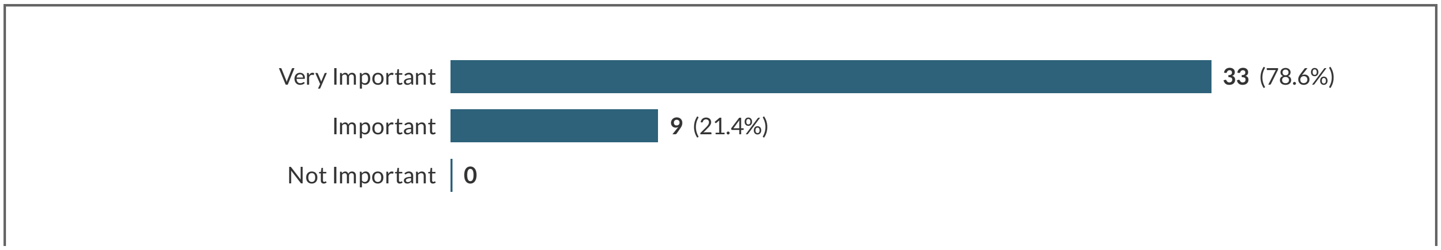
13.3 Information relating to the medication taken for RA and how it can affect the feet

13.3.a Information relating to the medication taken for RA and how it can affect the feet - Please select from Very Important to Not Important



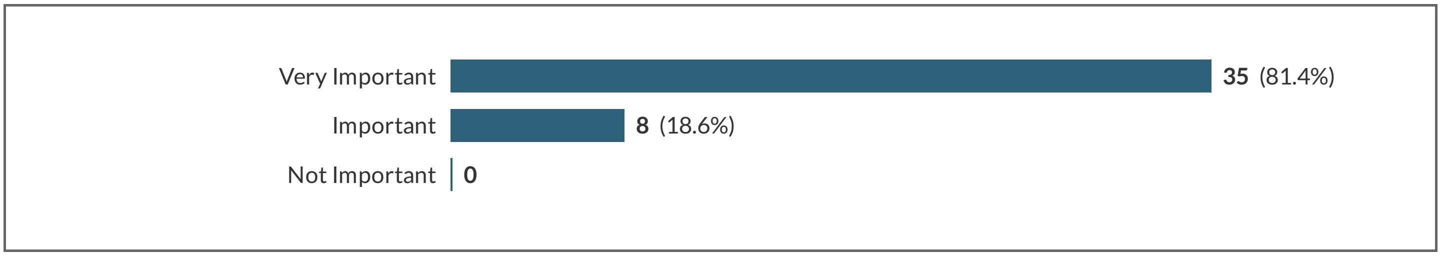
13.4 Signs and symptoms of foot problems related to RA

13.4.a Signs and symptoms of foot problems related to RA - Please select from Very Important to Not Important



13.5 Contact details for podiatry services (when its an emergency, how and who to contact)

13.5.a Contact details for podiatry services (when its an emergency, how and who to contact) - Please select from Very Important to Not Important



13.6 Management options relating to foot health

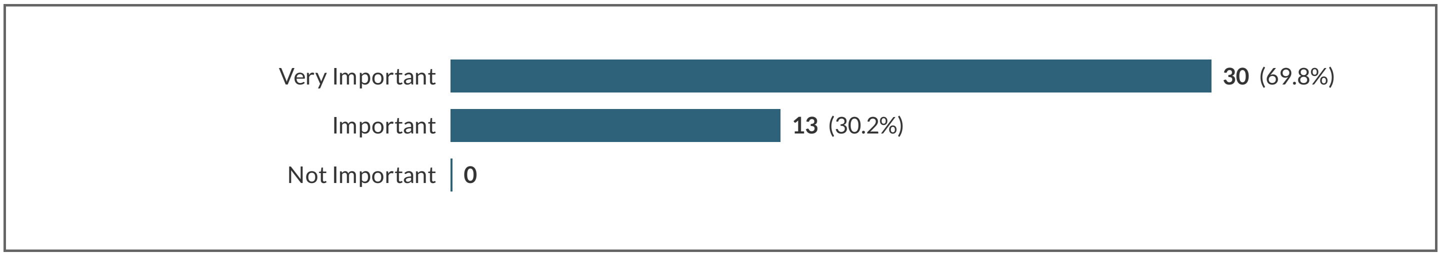
13.6.a Management options relating to foot health - Please select from Very Important to Not Important

13.7 How to manage their own foot health (footwear advice, safe nail cutting practice, use of moisturiser..)

13.7.a How to manage their own foot health (footwear advice, safe nail cutting practice, use of moisturiser..) - Please select from Very Important to Not Important

13.8 The consequences of not looking after their feet

13.8.a The consequences of not looking after their feet - Please select from Very Important to Not Important



13.9 The role of other professions in managing foot health

13.9.a The role of other professions in managing foot health - Please select from Very Important to Not Important

13.10 Information relating to Patient support groups/resources such as websites (e.g NRAS, Arthritis Care)

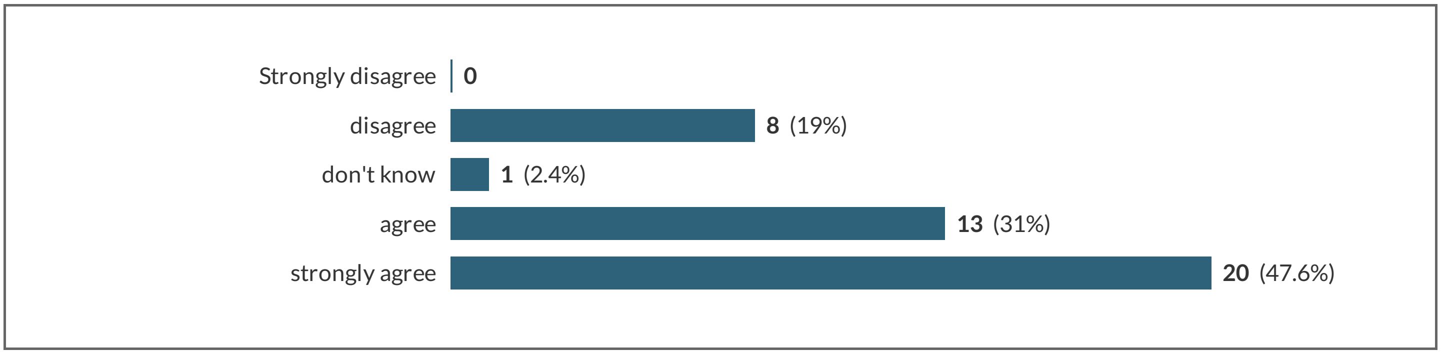
13.10.a Information relating to Patient support groups/resources such as websites (e.g NRAS, Arthritis Care) - Please select from Very Important to Not Important

Section 5: The timing of foot health education

14 To what extent do you agree with the following statements in relation to the timing of foot health education provision.

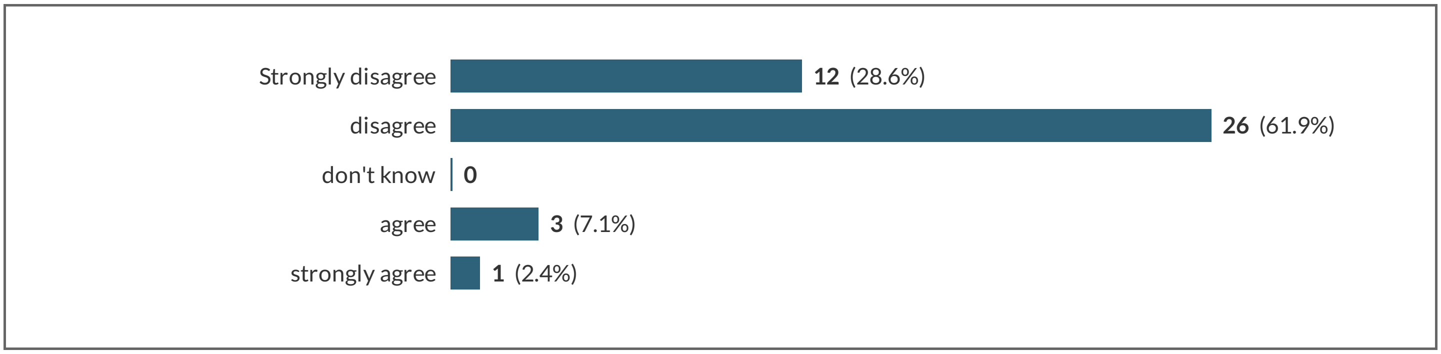
14.1 Foot health education should be provided at the point of diagnosis of RA

14.1.a Foot health education should be provided at the point of diagnosis of RA - To what extent do you agree with the following statements



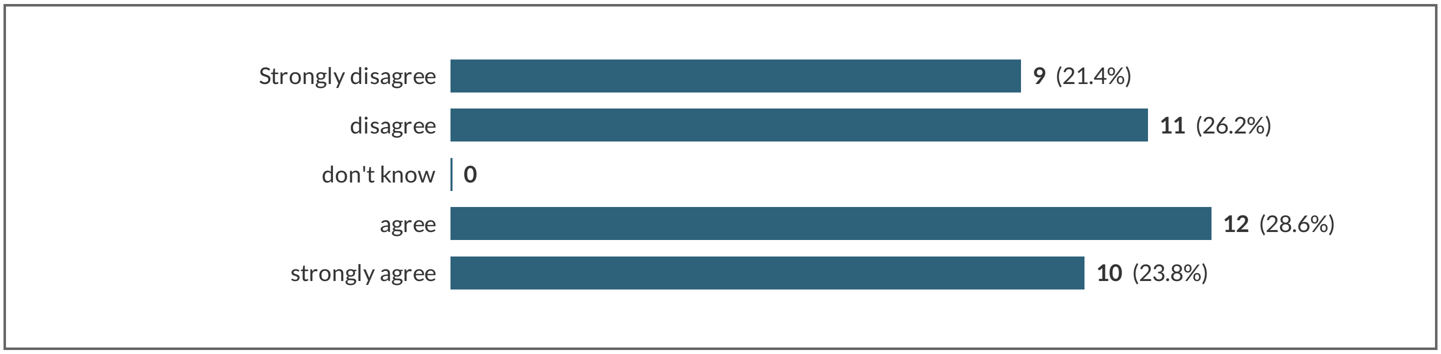
14.2 Foot health education should be provided only when you are asked for it

14.2.a Foot health education should be provided only when you are asked for it - To what extent do you agree with the following statements



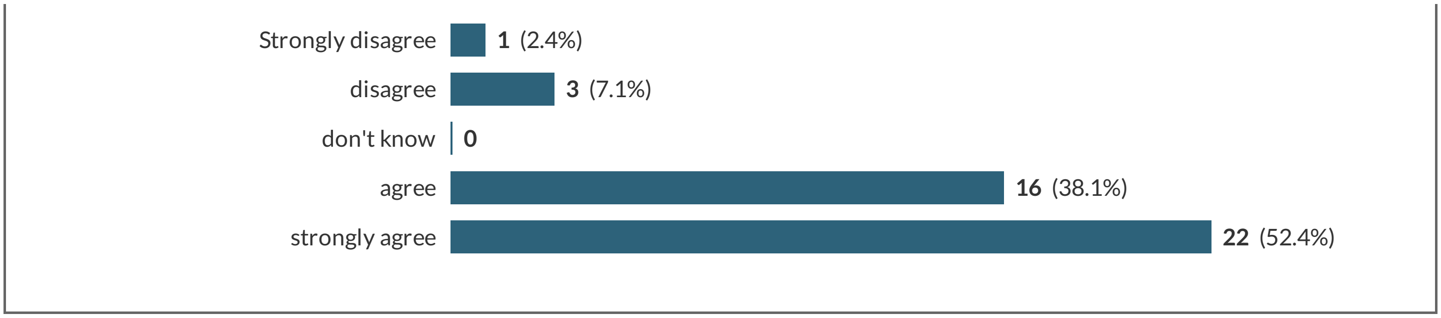
14.3 Foot health education should be provided when/if the person develops foot related symptoms

14.3.a Foot health education should be provided when/if the person develops foot related symptoms - To what extent do you agree with the following statements



14.4 Foot health education should be provided at every available opportunity

14.4.a Foot health education should be provided at every available opportunity - To what extent do you agree with the following statements

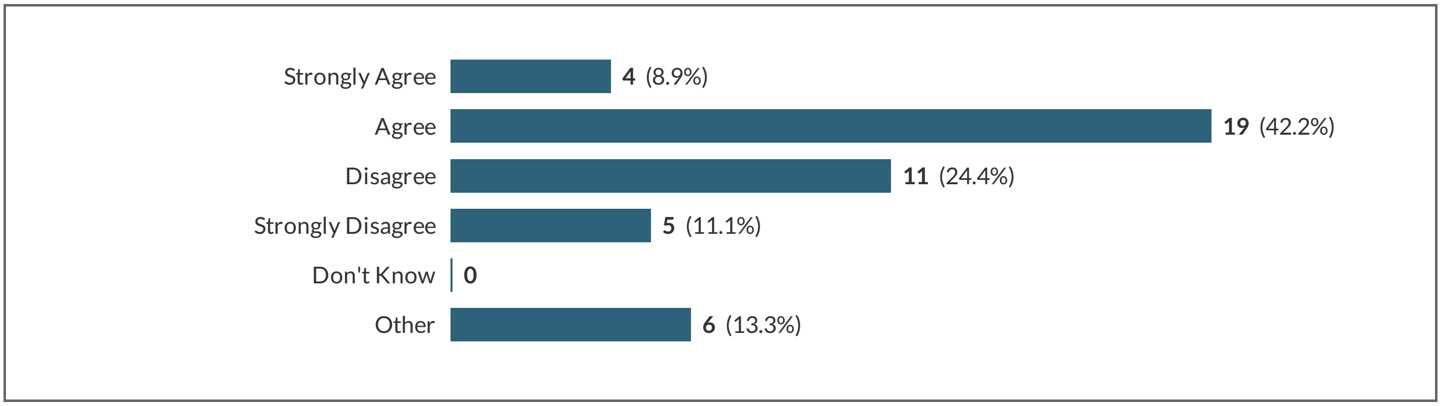


Section 6: Barriers to providing foot health education

15 To what extent do you agree with the following statements? Select one response for each item.

15.1 There is enough time during consultations to provide foot health education

15.1.a There is enough time during consultations to provide foot health education - Please select from Strongly Agree to Strongly Disagree for each item. If you are unsure please select 'Don't Know'. There is space in the final column for each item if you wish to add any other comment.

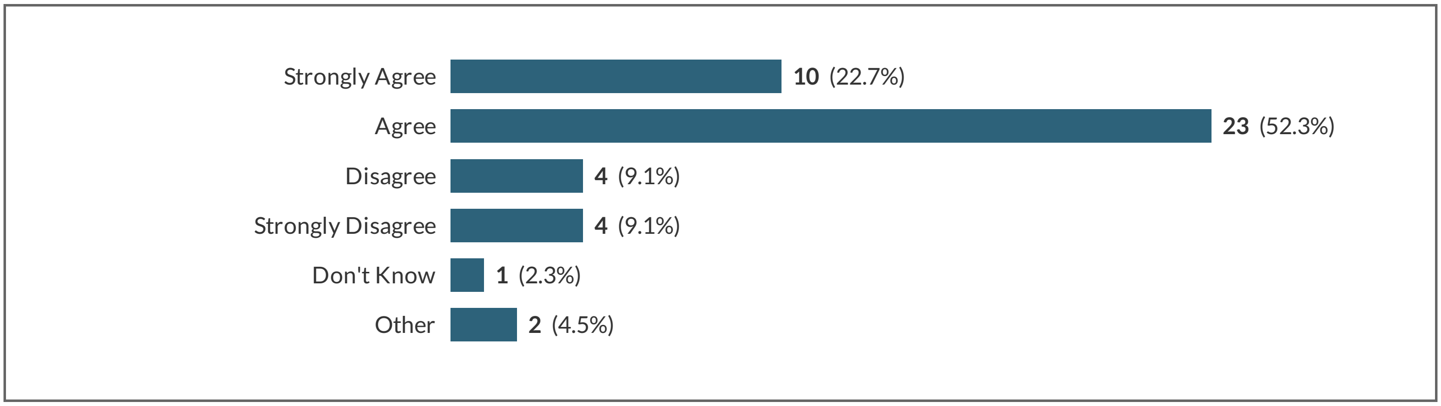


15.1.b There is enough time during consultations to provide foot health education - If you selected Other, please specify:

Showing 5 of 6 responses	
there can be enough time for small, focused, discussions on a particular area of health edcaution. there is not enough time to engage with the patient and determine THEIR individual fears,especations	120812-120806-6760689
talk while your working	120812-120806-6760696
This depends on how services have been set up. I am lucky enough to have a set up that allows time to explain, educate and negotiate. I would say however that podiatry services have very little time and resource for foot health education	120812-120806-6760697
We are always under pressure for time but foot health education should be made a priority.	120812-120806-6760707
caseloads, overbooking lateness, extras put enormous pressure on clinical appointments	120812-120806-6760711

15.2 You have access to RA-specific foot health information such as leaflets, provided either by your Trust or from Patient support organisations such as NRAS or Arthritis Research UK

15.2.a You have access to RA-specific foot health information such as leaflets, provided either by your Trust or from Patient support organisations such as NRAS or Arthritis Research UK - Please select from Strongly Agree to Strongly Disagree for each item. If you are unsure please select 'Don't Know'. There is space in the final column for each item if you wish to add any other comment.

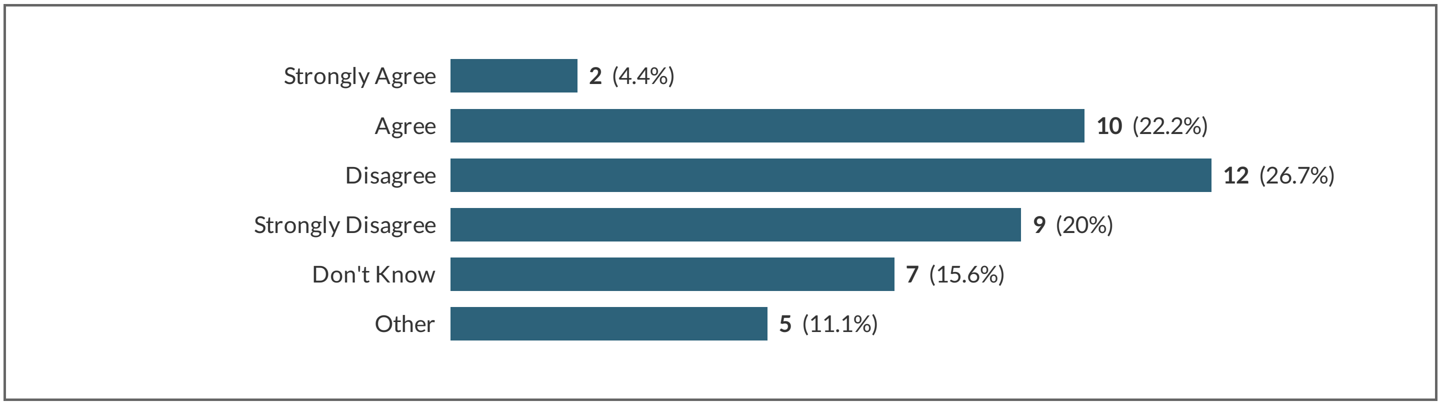


15.2.b You have access to RA-specific foot health information such as leaflets, provided either by your Trust or from Patient support organisations such as NRAS or Arthritis Research UK - If you selected Other, please specify:

Showing all 2 responses	
I have a limited supply from NRAS and the trust does not provide health leaflets.	120812-120806-6760707
Trust ones currently being developed. just provide ARC leaflets at moment	120812-120806-6760716

15.3 You are aware of any Group Education programmes that you could refer your patients into

15.3.a You are aware of any Group Education programmes that you could refer your patients into - Please select from Strongly Agree to Strongly Disagree for each item. If you are unsure please select 'Don't Know'. There is space in the final column for each item if you wish to add any other comment.

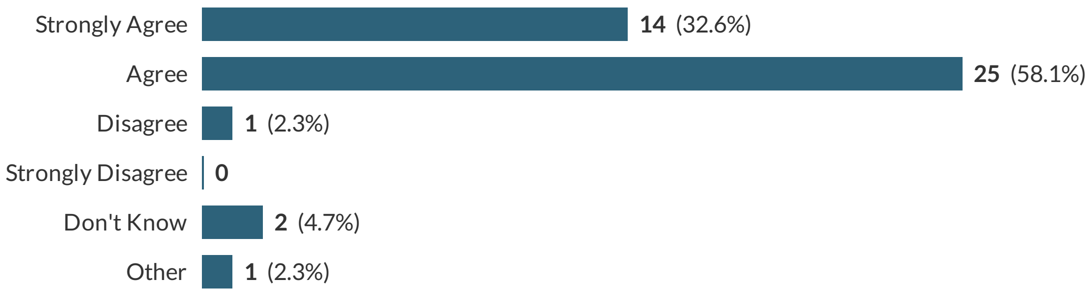


15.3.b You are aware of any Group Education programmes that you could refer your patients into - If you selected Other, please specify:

Showing all 5 responses	
not for RA in particula- we have 'pain managment, long term conditions' sessions	120812-120806-6760689
Decision was made to discontinue group sessions although do use fibromyalgia group sessions for those RA who have a fibromyalgic component in their disease	120812-120806-6760694
Arthritis care Groups - some don't do groups but they work if they do them.	120812-120806-6760696
Although not specific to Rheumatoid Arthritis	120812-120806-6760707
only for those with consultant in area not for those will cross boundary care	120812-120806-6760716

15.4 You have enough knowledge about how RA effects the feet in order to provide effective foot health education

15.4.a You have enough knowledge about how RA effects the feet in order to provide effective foot health education - Please select from Strongly Agree to Strongly Disagree for each item. If you are unsure please select 'Don't Know'. There is space in the final column for each item if you wish to add any other comment.

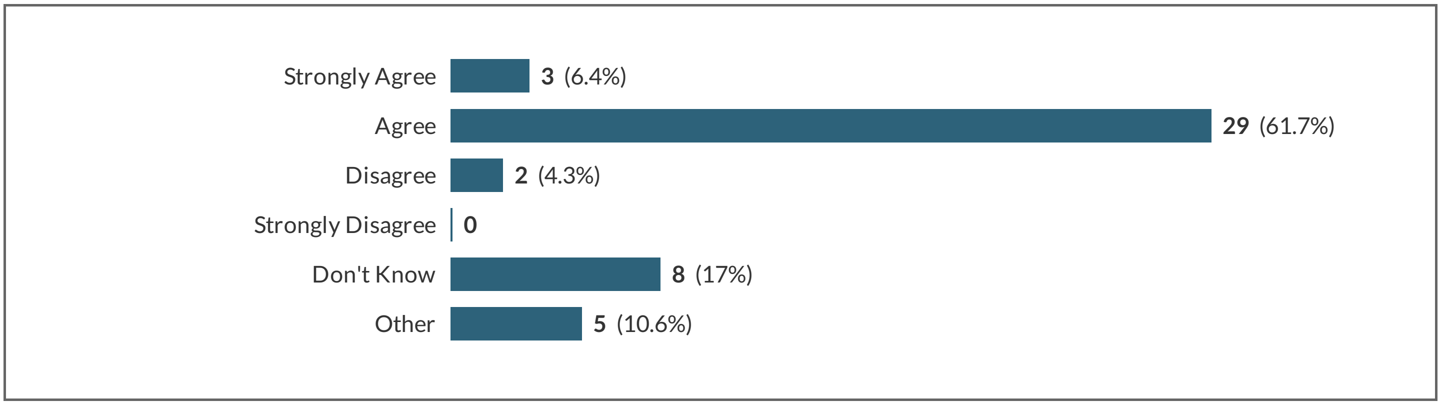


15.4.b You have enough knowledge about how RA effects the feet in order to provide effective foot health education - If you selected Other, please specify:

Showing 1 response	
RA can be very distruptive to the foot joints and I am unsure as to which extend suitable footwear can prevent problems. When problems do occur, RA patients in particular, are very good at finding ways to relief their symproms. They are more receptive at that stage, I think.	120812-120806-6760698

15.5 The people that you manage with RA use the foot health education that you provide

15.5.a The people that you manage with RA use the foot health education that you provide - Please select from Strongly Agree to Strongly Disagree for each item. If you are unsure please select 'Don't Know'. There is space in the final column for each item if you wish to add any other comment.



15.5.b The people that you manage with RA use the foot health education that you provide - If you selected Other, please specify:

Showing all 5 responses	
other than some female patients and footwear advice	120812-120806-6760694
Over time, not straight away.	120812-120806-6760698
Some do, some don't	120812-120806-6760700
Sometimes.	120812-120806-6760707
in the main yes but they have gross foot deformity due to RA for many years and sometimes object to styles of shoes available	120812-120806-6760716

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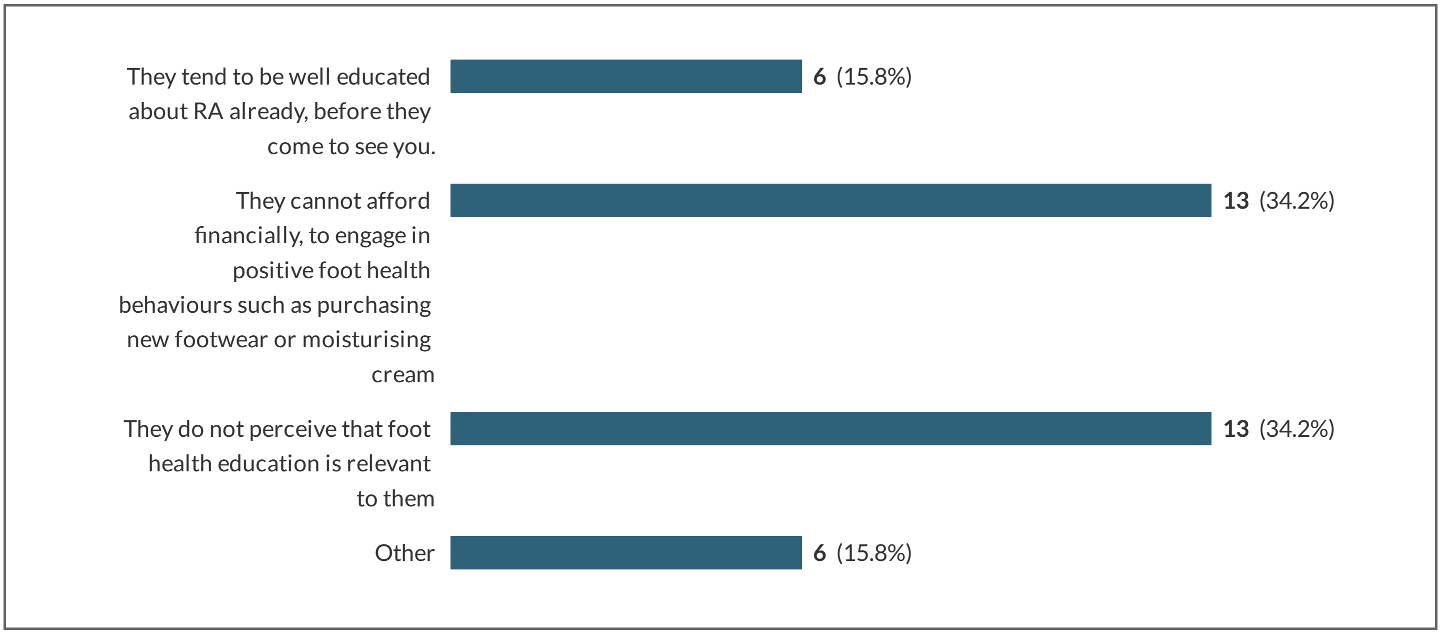
16 If people with RA DO NOT use the foot health education that you provide, is this because (please select all that apply)...



16.a If you selected Other, please specify:

Showing 5 of 6 responses	
they are unable to due to physical constraints and lack of help by others	120812-120806-6760695
some do some don't - barriers are cost, motivation - it won't happen to me or I know that but it's too late or just too much bother. Until it happens.	120812-120806-6760696
People find it generally difficult to alter behaviours and this includes changing footwear type. This is more of a proble with women rather than with men. Additionally, elderly people can find that social barriers hinders them from wearing trainer-type shoes but don't want to wear 'shoes for old people'either.	120812-120806-6760698
Often receptiveness to HE relates to symptom only. People experiencing foot pain can appreciate the relevance and use of FHE. Often the newly diagnosed without foot pain can't see the relevance to them and disregard it. FHE is best given at all opportunities but I think best received when the person given FHE has a personal interest	120812-120806-6760705
Excuses I hear most often: They are young and do not want to wear certain shoe types. Their occupation dictates a shoe type. Only flip flops are comfortable. 'They might not be good for me but they're comfortable!'	120812-120806-6760707

17 This free text box is for you to add any additional comments or information that you feel is relevant and has not been addressed by this survey. Thank you.

Showing 5 of 13 responses	
Section 2 Q8 titles appear to have a typo as both ends of the scale are strongly disagree. I meant strongly AGREE for my response. Good luck,	120812-120806-6760685
Re timing, foot health education is important in early diagnosis but patients are often overwhelmed with new information at this time and therefore foot health education is perhaps best delivered as part of a staggered education approach by the team.	120812-120806-6760686
Section number 2 has choices wrong both strongly disagree	120812-120806-6760687
A barrier to the importence of foot health education is the foot involvement in RA is not given the same priority (by the MDT) as other aspects of care.	120812-120806-6760691
Working in the private sector I have to refer them into the NHS anyway, it would be immoral not to.	120812-120806-6760696

Paper 5 – Additional File 3 – Statistical analysis data.

Appendix 2: Statistical analyses: influence of Podiatrists' Years Qualified, Age Range and Gender on survey responses.

(* denotes statistical significance of *p*=<0.05)

Section 1: the aim of foot health education is to:	Years qualified	**Fishers Exact Test Value**	**Exact Sig. (2-sided)**	Age Range	**Fishers Exact Test Value**	**Exact Sig. (2-sided)**	Gender	**Fishers Exact Test Value**	**Exact Sig. (2-sided)**
Allow informed consent	Years Qualified range	15.943	0.472	Age Range	11.873	0.59	Gender	7.138	**0.047***
Facilitate informed choices about treatment options		23.856	0.062		14.822	0.536		11.463	**0.005***
Enable them to manage their own foot health		6.001	0.339		3.363	0.579			**0.013***
Educate them about how RA can affect their feet		9.329	**0.051***		2.69	0.714			**0.033***
Inform about information resources they can access		13.551	0.24		8.218	0.742		4.258	0.097
Section 2: Methods of FHE provision									
Do you provide FHE to people with RA		6.079	1		5.386	0.595			0.262
Do you provide verbal information		3.647	1		3.086	1			0.064
Do you provide Written information		2.79	0.81		3.435	0.507			0.713
Do you provide Group Education		4.512	0.472		2.916	0.615			0.644
Do you use Audio-visual aids such as demonstrations/videos		5.194	0.619		3.086	1			0.46
Do you direct patients to Arthritis related websites		6.33	0.229		2.114	0.878			0.483
If you use websites do you use: Arthritis care		5.709	0.305		6.221	0.131			1
If you use websites do you use: NRAS		8.648	0.073		2.238	0.79			0.485
If you use websites do you use: Arthritis Research UK		7.315	0.15		2.535	0.771			0.504
If you use websites do you use: Patient.co.uk		6.079	1		4.997	1			1
If you use websites do you use: WebMD Boots		no responses	no responses		no Reponses	no responses		no responses	no responses
If you use websites do you use: other		6.116	0.31		6.746	0.12			**0.014***
How effective do you think verbal information is		14.668	0.081		11.781	0.131		5.28	0.069
How effective do you think written information is		14.662	0.513		11.898	0.532		2.912	0.413
How effective do you think group education is		26.807	0.114		17.337	0.629		2.176	0.826
How effective do you think audio-visual aids are		12.094	0.88		9.572	0.881		1.349	0.929
How effective do you think websites are		13.302	0.825		10.863	0.784		4.355	0.228
How effective do you think a combination of resources are		16.295	0.5		11.729	0.699		3.041	0.414
Section 3: How important is it for people with RA to know about:									
The role of the podiatrist in managing their foot health		13.379	0.25		7.943	0.74		3.045	0.203
General disease related information		8.026	0.99		7.756	0.804		0.588	1
How RA-related medication can affect the feet		4.269	0.552		2.624	0.737			0.713
The signs and symptoms of foot problems related to RA		1.922	0.972		3.596	0.496			**0.038***
Contact details for podiatry services		1.88	0.961		1.528	0.927			**0.063**
Management options relating to foot health		8.138	0.984		9.677	0.435		11.379	**0.003***
How to manage their own foot health		5.238	0.387		3.803	0.45			**0.07***
The consequences of not looking after their feet		2.909	0.797		3.333	0.558			0.243
The role of other health professions in managing foot health		9.436	0.874		11.148	0.228		0.506	1
Information relating to patient support groups/websites		6.321	0.235		3.594	0.481			0.299
Section 4: Timing - FHE should be provided:									
At the point of diagnosis		14.723	0.707		11.496	0.738		1.975	0.618
Only when you are asked for it		23.408	**0.034***		14.954	0.317		1.357	0.899
When or if the person develops foot-related symptoms		21.809	**0.022***		13.141	0.257		0.385	1
At every available opportunity		16.438	0.54		15.541	0.248		2.979	0.476
Section 5: Barriers to FHE provision									
There is enough time during consultations to provide FHE		20.078	0.408		14.364	0.687		1.833	0.842
You have access to RA specific foot health information such as leaflets, provided by your Trust or patient support organisations		18.916	0.78		18.871	0.332		8.74	**0.031***
You are aware of any Group Education programmes that you could refer your patients into		23.621	0.598		25.045	0.094		4.885	0.409
You have enough knowledge about how RA affects the feet to provide effective FHE		19.134	0.275		13.518	0.556		3.993	0.259
The people that you manage with RA use the FHE that you provide		12.947	0.785		12.358	0.52		3.434	0.278
People don't use your FHE because they are already well educated		2.818	0.801		5.273	0.237			1
People don't use your FHE because they cannot afford to for financial reasons		6.304	0.228		1.947	0.875			0.464
People don't use your FHE because they do not perceive that it is relevant to them		5.687	0.302		1.524	1			0.713
People don't use your FHE because of other reasons		7.523	0.128		2.849	0.659			0.303

Paper 5 – Additional File 4 – Free text comments from Foot Health Education Survey for practitioners.

Free text comments taken from Rheumatoid Arthritis foot health education survey for practitioners.

15.1.b –There is enough time during consultations to provide foot health education – If you selected Other, please specify:

Showing all 6 responses

1. there can be enough time for small, focused, discussions on a particular area of health edcaution. there is not enough time to engage with the patient and determine THEIR individual fears,especations
2. talk while your working
3. This depends on how services have been set up. I am lucky enough to have a set up that allows time to explain, educate and negotiate. I would say however that podiatry services have very little time and resource for foot health education
4. We are always under pressure for time but foot health education should be made a priority.
5. caseloads, overbooking lateness, extras put enormous pressure on clinical appointments
6. pertinent to the presenting problem or request from the patient in reality is what health ed is given during a consultation

15.2.b -You have access to RA-specific foot health information such as leaflets, provided either by your Trust or from Patient support organisations such as NRAS or Arthritis Research UK - If you selected Other, please specify:

Showing all 2 responses

1. I have a limited supply from NRAS and the trust does not provide health leaflets.
2. Trust ones currently being developed. just provide ARC leaflets at moment

15.3.b -You are aware of any Group Education programmes that you could refer your patients into - If you selected Other, please specify:

Showing all 5 responses

1. not for RA in particula- we have 'pain managment, long term conditions' sessions
2. Decision was made to discontinue group sessions although do use fibromyalgia group sessions for those RA who have a fibromyalgic component in their disease
3. Arthritis care Groups - some don't do groups but they work if they do them.
4. Although not specific to Rheumatoid Arthritis
5. only for those with consultant in area not for those will cross boundary care

15.4.b - You have enough knowledge about how RA effects the feet in order to provide effective foot health education - If you selected Other, please specify:

Showing 1 response

1. RA can be very distruptive to the foot joints and I am unsure as to which extend

Showing 1 response

suitable footwear can prevent problems. When problems do occur, RA patients in particular, are very good at finding ways to relief their symproms. They are more receptive at that stage, I think.

16. The people that you manage with RA use the foot health education that you provide - If you selected Other, please specify:

Showing all 5 responses

1. other than some female patients and footwear advice
2. Over time, not straight away.
3. Some do, some don't
4. Sometimes.
5. in the main yes but they have gross foot deformity due to RA for many years and sometimes object to styles of shoes available

Question 16: If people with RA DO NOT use the foot health education that you provide, is this because (please select all that apply)...

Question 16.a: If you selected Other, please specify:

Showing all 6 responses

1. they are unable to due to physical constraints and lack of help by others
2. some do some don't - barriers are cost, motivation - it won't happen to me or I know that but it's too late or just too much bother. Until it happens.
3. People find it generally difficult to alter behaviours and this includes changing footwear type. This is more of a proble with women rather than with men. Additionally, elderly people can find that social barriers hinders them from wearing trainer-type shoes but don't want to wear 'shoes for old people'either.
4. Often receptiveness to HE relates to symptom only. People experiencing foot pain can appreciate the relevance and use of FHE. Often the newly diagnosed without foot pain can't see the relevance to them and disregard it. FHE is best given at all opportunities but I think best received when the person given FHE has a personal interest
5. Excuses I hear most often:
   They are young and do not want to wear certain shoe types.
   Their occupation dictates a shoe type.
   Only flip flops are comfortable.

Showing all 6 responses

'They might not be good for me but they're comfortable!'

6. usually footwear related problems and would rather wear their own instead of hospital footwear

Question 17: This free text box is for you to add any additional comments or information that you feel is relevant and has not been addressed by this survey. Thank you.

1. Re timing, foot health education is important in early diagnosis but patients are often overwhelmed with new information at this time and therefore foot health education is perhaps best delivered as part of a staggered education approach by the team.
2. A barrier to the importence of foot health education is the foot involvement in RA is not given the same priority (by the MDT) as other aspects of care.
3. Working in the private sector I have to refer them into the NHS anyway, it would be immoral not to.
4. FHE in RA is a long-term investment. Podiatry and NHS Trust managers only see the end of the current financial year. Perhaps a survey to pod managers to ask how much resource they allocate to the above might be an area to look at, as 50% of the positive responses in this survey have been achieved by my own dedication, commitment and unpaid work!!!
5. I don't think that enough effort has been made to offer people with altered foot shape desirable custome-made footwear; neither is the current fashion accommodating the -so called- 'deformed feet'.
6. I work in private practice. RA patients I see are already managed within the NHS. My role as I see it is to reiterate health care advice and refer to medical/nursing practitioners as required
7. Patient education can be a challenge depending on age, duration of disease, previous foot surgery and level of pain etc. In my experience, Pain can be generally a good motivating factor for patients to listen to advice and education.
8. foot heath foot ed can give "worse case" scenario, can sound like "threat". To give info to eg. JIA like that is very negative. Little bytes are better that big chunks!!
9. Too foot focussed? No mention of the systemic impact of RA and for example cardiovascular and peripheral vascular risks.
10. as podiatrists we perceive foot health education as a need at first diagnosis. If there are no evident visual or symptomatic foot problems at this stage it is difficult to

convince patients/other professionals that podiatry intervention is important at this stage. in my experience patients often attend podiatry 'once the damage is done'

11. Types of education and those who respond to it caries from person to person on the whole I find this group more receptive re thier disease than for examples patients with diabetes.

2.6 Commentary – Paper 6

Exploratory work (papers 2,3 and 4) has indicated that people with RA lack awareness and understanding of their FHE needs, that they perceive that there is very little high quality/easily accessible foot health information available and access to foot health services is limited to them. This work has also indicated that this group of people would value the provision of FHE to facilitate timely management / self-management of their foot problems. This exploratory work indicated the items and sub-topics that could be used in the development of an online survey for people with RA and identified the need to seek a wider UK perspective as focus group work was limited to participants from the North West of England.

The aim of this study therefore was to build on the findings from exploratory work and identify the FHE needs of people with RA in relation to content, timing, most common and effective modes of delivery and perceived barriers to accessing FHE, using an online survey method.

This paper presents the results of the qualitative analysis of the free-text comments provided by participants in respect of additional information they felt had not been addressed by the survey or that they wished to use to add in support of their responses to the items within each sub-section. The qualitative data that was generated from this component of the survey was of a substantial volume and therefore it was justifiable to present these findings in their own right.

This particular study has been presented at this point in the order of the publications in part due to the chronological order of publication, but also because it presents the reader with a profoundly emotional participant perspective that was felt to fundamentally represent the ‘voice’ of the person with RA and foot related pathology, in the context of this study. I wanted this ‘voice’ to be heard prior to the presentation of the quantitative data results, which whilst providing a clear illustration of the current status of FHE for people with RA, do not reflect the true depth of the participants’ experience. Having an understanding of this experience when reading the seventh and final publication, I believe allows the reader to truly understand the participant perspective.

The results of the thematic analysis of the qualitative data revealed much about the participants' experiences in relation to FHE provision, in complement to the quantitative results. It is the first time that this approach to obtaining qualitative data has been used within podiatric research and was an unpredicted aspect of data collection and analysis when the survey was first developed. The significant number of respondents and additional free-text comments illustrated the profound impact that foot health has on people with RA and provided an insight into the 'hidden' backstory underlying the participants' survey responses.

This distinctive approach to qualitative data collection and its thematic analysis identified and supported the need for FHE strategies to be employed from the point of diagnosis of RA and throughout the whole experience of the condition. It strongly supported the fact that feet remain marginalized and ignored with the medical consultation as identified in paper 2 and 3, leading to frustration within the participant population and denying them the opportunity to raise concerns about their foot health. Further to this, the time constrained nature of the medical consultation as identified in paper 5, limitations in patient assessment (use of the DAS 28 excludes the joints of the feet) and the poor timing of FHE provision (when it was provided), meant that the window of opportunity to manage foot health problems in a timely way was missed. A lack of awareness of foot health problems amongst people with RA and health care practitioners meant that participants had not been referred to foot health services in a timely manner, if at all. Most significantly, the participants expressed a profoundly emotional response to the physical impact of living with RA-related foot problems and having to fight to receive foot health care.

The findings of this study powerfully triangulate with those of the quantitative component of the survey and the results of the podiatry practitioner-based survey, strongly reinforcing the need for people with RA to be provided with the opportunity to raise their foot health concerns during the medical and podiatric consultation; to be given a voice.

INNOVATIONS:

This study uniquely, gives voice to the person with RA on their perspective of FHE provision. It revealed a profound depth of emotion related to living with the physical impact of RA-related foot pain and pathology and about how this appears to be continually marginalised by health care practitioners. This, in essence denies them a voice on their foot health in the one place where they should be able to express it. People with RA should be enabled to articulate their foot health concerns during their medical consultations with ANY health care practitioner to ensure the timely access to appropriate foot health management strategies and tailored FHE.

Paper 6:

Title: Foot Health Education for People with Rheumatoid Arthritis: '…A Game of Chance…' – A Survey of Patients' Experiences.

Authors: Andrea S Graham and Anita E Williams.

RESEARCH ARTICLE

Foot Health Education for People with Rheumatoid Arthritis: '.... A Game of Chance...' – A Survey of Patients' Experiences

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Abstract

Objective: Up to 90% of people with rheumatoid arthritis (RA) experience foot problems leading to reduced function, mobility, quality of life and social participation, and impacts on body image, but these can be improved with general foot care, orthoses, footwear and patient education. Foot health patient education is lacking, so the aim of the present study was to identify the foot health educational needs of people with RA in relation to its content, timing, mode of delivery and the perceived barriers to its provision.

Methods: People with RA completed an online survey and provided free-text comments for thematic analysis.

Results: A total of 249 people completed the free-text section of the survey. Five main themes emerged: 'Forgotten feet'; 'Too little, too late'; 'Lacks and gaps'; 'I am my feet' and 'Game of chance'.

Conclusion: Foot pathology in people with RA has a bio-psychosocial impact on their lives. Foot health and related information appears to be considered rarely within the medical consultation. Access to foot health information and services is limited owing to a lack of patient and/or health professional awareness, with a detrimental impact on the prognosis of their foot health. The importance of foot health in people with RA should be reinforced for patients and health professionals alike. Opportunities to discuss foot health within the medical consultation should be provided regularly. Copyright © 2015 John Wiley & Sons, Ltd.

Keywords

Patient Education; foot health; rheumatoid arthritis; podiatry.

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Introduction

Foot pathology is seen in up to 50% of people with rheumatoid arthritis (RA) at diagnosis, progressing to 80–90% of those with established disease (Borman et al., 2012; Grondal et al., 2008) and is manifested in a wide variety of ways, ranging from the structural and functional (Barn et al., 2013; Hooper et al., 2012; Woodburn et al., 2002a), to pressure-related problems such as callus and ulceration (Firth et al., 2008; Siddle et al., 2012), with peripheral arterial disease (PAD) (Alkaabi et al., 2003; Stamatelopoulos et al., 2010) and peripheral neuropathy (Lanzillo et al., 1998; Sim et al., 2014) adding to the symptom burden. The pharma \cological management of RA – significantly, the use of biological therapies, such as infliximab, etanercept and anakinra, and corticosteroids – increases the risks associated with infection (Otter et al., 2004). Foot pathology can lead to loss of function, reduced mobility, impact on body image, reduced social participation and a poorer quality of life (Wickman et al., 2004).

Timely foot care intervention for these pathologies can relieve pain, maintain function and hence improve a person's quality of life (Woodburn and Helliwell, 1997). These can be achieved with early access to foot health assessment, and management which includes foot orthoses, therapeutic footwear (Arthritis and Rheumatism Musculoskeletal Alliance, 2004; National Institute for Clinical Excellence, 2009), and the care of nail and skin problems, together with patient education on how to contribute to this management (Williams et al., 2011). As patient education for people with RA has a positive effect in relation to their general disease management and overall health (Albano et al., 2010; Fautrel et al., 2005), foot health education (FHE) is also recognized as being essential (Graham et al., 2012a,b, Podiatric Rheumatic Care Association, 2008; Williams et al., 2011). Figure 1 outlines the general aspects of foot health that healthcare professionals should aim to provide, depending on the needs of the person with RA and based on current guidelines (North West Podiatry Clinical Effectiveness Group, 2014).

Despite recommendations for the management of foot pathology, there is evidence that people with RA do not know why they develop these problems, or understand the implications of having these problems (Graham et al., 2012a). Further, they do not understand the role of the podiatrist, the interventions themselves (Blake et al., 2013) or self-management(Blake et al., 2013; Graham et al., 2012a). This results in sub-optimal foot health, which may be damaging to overall health (Steward and Land, 2009); therefore, improving knowledge is critical. Before developing strategies to achieve this, it is necessary to identify what patients need, when and in what form they want it delivered.

The aim of the present study was to identify the FHE needs of people with RA in relation to its content, timing, mode of delivery and the perceived barriers to its provision. Building on previous exploratory work by the authors (Graham et al., 2012a,b), an online survey was considered to be the most effective method of collecting the data.

Methods

Ethical approval

The study was granted ethical approval by the University of Salford, Research Innovation and Academic Engagement Ethical Approval Panel (HSCR12/35).

Survey development

The online survey was developed from the results of a patient focus group, which informed both the content and the structure of the survey (Graham et al., 2012a). Four participants (people with RA and experience of receiving podiatry foot care) piloted the survey, with 'think aloud' cognitive debriefing (Willis, 2005). This reduces sources of response error and ensures clarity of questions and their overall structure, and led to a small number of changes relating to the clarity of three questions and the consolidation of items within two sections.

The final survey consisted of six sections:

1. Participant demographics;
2. The aims of FHE;
3. The best ways of providing FHE;
4. What should be included in FHE provision;
5. When is the best time to receive FHE;
6. Accessing FHE/information.

- FHE should be encouraged at each consultation and be individualized according to the educational needs of the person at the time of the contact.
- FHE should include foot health self-management advice and if necessary demonstration.
- FHE should include explanation of foot problems, their impact on the individual and changes in foot health that should prompt immediate health-care practitioner attention.
- FHE should include information on general disease management and sign-posting for future foot health needs to National Health Service podiatry service providers
- FHE should include information about patient support groups/websites.

Figure 1 Foot health education (FHE) for health practitioner provision (North West Podiatry Clinical Effectiveness Group, 2014)

A free-text comment section for participants, to include further details or information they felt had not been addressed by the survey, was included at the end.

Participants

Participants were recruited through the National Rheumatoid Arthritis Society (NRAS) membership via email invitation, with a web link to the survey. Recruitment ran from September to November 2013, with potential participants receiving an initial email invite, followed by a second 'reminder' email two weeks later. People with a diagnosis of RA, patient membership of the NRAS, living in the UK, and with the ability to read and write in English and to complete an online survey were eligible. The survey was designed to be completed anonymously so that no participants could be identified. Consent was implicit by the completion of the survey and participants were informed of this at the start of the online survey.

Results

The qualitative data generated within the free-text section of the survey was substantial and so these results are presented in this paper, as they are illuminating in their own right.

Demographics

A total of 543 people responded to the survey – 10.3% ($n = 56$) male and 89.7% ($n = 487$) female. Participants were given the opportunity to provide additional comments and details at the end of the survey. A total of 249 individual responses were given, and analysed thematically. Demographic data are shown in Table 1 and geographic data are shown in Table 2.

Data analysis

An inductive, qualitative approach of thematic analysis was used to create a framework in order to illustrate the main themes in the text and the transparent, methodical systematization of textual data. This approach to thematic analysis can be said to be rooted within a phenomenological approach to research methodology because it focuses on the individual's subjective experiences, expressed as perceptions, thoughts and feelings in the individual's own words. However, thematic analysis does not have to be associated with any pre-existing theoretical framework as it can be used within a number of research methodologies, including realist/essentialist paradigms (Braun and Clarke, 2006).

Table 1. Participant demographics

		Female [*n* (%)]	Male [*n* (%)]	Totals (%)
Gender		487 (89.7%)	56 (10.3%)	543 (100%)
Age range (SD = 1.1)	18–29 years	5 (0.9%)	0 (0.0%)	5 (0.9%)
	30–39 years	18 (3.3%)	3 (0.6%)	21 (3.9%)
	40–49 years	86 (15.8%)	4 (0.7%)	90 (16.6%)
	50–59 years	168 (30.9%)	10 (1.9%)	178 (32.8%)
	60–69 years	169 (31.1%)	27 (5.0%)	196 (36.1%)
	70–79 years	40 (7.3%)	8 (1.5%)	48 (8.8%)
	80–89 years	1 (0.2%)	3 (0.55%)	4 (0.7%)
	>90 years	0 (0.0%)	1 (0.2%)	1 (0.2%)
Disease duration (SD = 1.4)	0–12 months	15(2.8%)	2 (0.4%)	17 (3.2%)
	1–2 years	37 (0.5%)	5 (0.9%)	42 (7.7%)
	2–5 years	105 (19.3%)	14 (2.6%)	119 (21.9%)
	5–10 years	118 (21.7%)	23 (4.2%)	141 (25.9%)
	10–15 years	84(15.5%)	4 (0.8%)	88 (16.3%)
	>15 years	128 (23.6%)	8 (1.5%)	136 (25.1%)
Lives with	Alone	84 (15.5%)	9 (1.6%)	93 (17.1%)
	Spouse	372 (68.5%)	47 (8.6%)	419 (77.1%)
	Other family member or carer	31(5.7%)	0 (0.0%)	31 (5.7%)

SD, standard deviation

A six-stage process was used: coding the text; theme identification; thematic network construction; description and exploration of networks; summarization of networks; and pattern interpretation (Attride-Stirling, 2001). This approach allows acknowledgement of the researcher's experience and knowledge of the subject at hand and the influence of this on data collection and analysis. The results were agreed by one of the authors (AEW), to enhance the validity of the data, with exemplars extracted to demonstrate truthfulness within each theme. As the survey was designed to be anonymous, it was not possible to seek external review of the data from the participants. Five organizing themes were identified from the data and were further split into basic themes:

1. 'Forgotten feet';
2. 'Too little, too late';
3. 'Lacks and gaps';
4. 'I am my feet';
5. 'Game of chance'.

Table 2. Podiatry provision and geographic location of participants

		Female [*n* (%)]	Male [*n* (%)]	Totals (%)
Currently receives podiatry	Yes	199 (36.6%)	18 (3.3%)	217 (39.9%)
	No	288 (53.1%)	38 (7.0%)	326 (60.1%)
Where is treatment provided?	NHS	127 (23.4%)	13(2.4%)	140 (25.8%)
	Independent practice	60 (11%)	4 (0.8%)	64 (11.8%)
	Both	22(4.0%)	0 (0.0%)	22 (4.0%)
Geographical location	Southeast England	110 (20.3%)	9 (1.6%)	119 (21.9%)
	Northwest England	51(9.4%)	9 (1.6%)	60 (11.0%)
	Southwest England	67 (12.3%)	8 (1.5%)	75 (13.8%)
	Central London	37 (6.8%)	3 (0.6%)	40 (7.4%)
	West Midlands	36 (6.6%)	3 (0.6%)	30 (7.2%)
	East Anglia	36 (6.6%)	2 (0.4%)	38 (7.0%)
	Yorkshire/North Humberside	31 (5.7%)	3 (0.6%)	34 (6.3%)
	East Midlands	28 (5.1%)	4 (0.8%)	32 (5.9%)
	South Central England	15 (2.7%)	4 (0.8%)	19 (3.5%)
	Northeast England	28 (5.1%)	3 (0.6%)	31 (5.7%)
	Wales	14 (2.5%)	2 (0.4%)	16 (2.9%)
	Scotland	29 (5.4%)	5 (0.9%)	34 (6.3%)
	Northern Ireland	5 (0.9%)	1 (0.2%)	6 (1.1%)

Themes

'Forgotten feet'

For many of the participants, feet and their significantly painful symptoms were not given any priority by the healthcare professionals during the consultation. Participants felt as if their foot problems were not important enough for the consultant or health professional to acknowledge or to provide any education about. Even when their primary concern was their feet, the focus of the healthcare professional during the examination was elsewhere in the body:

> *'My hands were always examined and my feet ignored, even though my biggest concern was my feet'*. (P242)

For some participants, healthcare professionals systematically ignored RA-related foot symptoms because they had no apparent awareness of how the feet can be affected by RA or because they saw discussion of foot problems as low priority:

> *'Feet aren't assessed in rheumatology appointments and the health professionals seem … disinterested in feet'*. (P38)

An overwhelming number of participants cited the lack of foot joint examination within the Disease Activity Score (DAS) as having a profound influence on the topic of 'feet' being raised during consultation with healthcare professionals. Participants felt that this directly influenced the attitude of healthcare professionals to the assessment of feet during the consultation process:

> *'The absence of foot assessment from the DAS scoring system has been a serious flaw and has led to foot problems being marginalized in my case…'* (P226)

This perceived absence of acknowledgement of foot-related pain and disability by healthcare professionals left participants feeling that their feet lacked relevance in the overall symptoms of the disease or in the global management of their RA. They felt that their feet were neglected.

'Too little, too late'

The majority of participants, from those recently diagnosed to those with established disease, had no information from healthcare professionals in relation to their foot health and RA, despite reporting symptoms of pain and disability:

> *'I have had RA for the past 23 years and have not really received any advice from a podiatrist, apart from 15 years later, when I began to suffer … my feet now give me the most pain…'*. (P98)

Participants were frequently told that they should only seek help or advice when a problem with their feet arose, which for many was perceived as being far too late and detrimental to their foot health. They felt that information should be provided early on in the disease, as a preventative measure, based around written information or more formal educational sessions:

> '…*more written information and education sessions on foot health would be a good idea when RA is first diagnosed, to hopefully prevent/reduce foot problems*'. (P133)

However, the prevailing theme was that information should not be presented on diagnosis but a short time later, to avoid overwhelming individuals when they might not be able to process it. Information provided at this early point should be focused on foot health prognosis, clinical contact details, potential foot-related complications and sources of well-fitting footwear. Further to this, some participants also felt that information should be sought on a more regular basis to reflect their changing needs, or that information provision should be organized more formally:

> '…*I need the information to be reinforced regularly as I forget and the importance of different information to me changes as my needs change*'. (P211)

In this way, it might offer healthcare professionals greater scope for providing foot health information, rather than patients feeling as if the consultation is time restricted.

Additionally, participants commonly felt that their treatment was delayed and thus not provided in a timely manner. For many, this time delay to treatment or being informed about their treatment options came at a price to their foot health; they felt that being informed of their treatment options could have resulted in an earlier resolution to a serious recurrent problem; for others, delayed treatment led to prolonged suffering due to their painful foot symptoms:

> '*Not one health professional took any interest in my deformed feet. I could have cut them off at the ankle… I needed major surgery to have my feet reconstructed… this major surgery could have been avoided*'. (P203)

Delays in information provision about foot health and treatment options, and a perceived lack of time during consultations meant that, for many participants, their foot health was compromised. The perception was that their current poor foot health could have been avoided if they had known what they could do to prevent or manage it themselves at an earlier stage in their disease.

'Lacks and gaps'

Sixty per cent of the participants had not received any podiatry care. For some participants, this was simply because it had never been offered to them or suggested as an option in the management of their RA; others had been denied National Health Service (NHS) podiatry treatment, even when they had sought it from the medical team during the process of their consultation. Access to foot health services was deemed to be a rare occurrence within the NHS for people with RA, despite demand for it to be made available to them:

> '*Chiropody on the NHS is like 'gold dust" and it should be made much more widely available…*'. (P70)

As a consequence of being unable to access NHS foot health services, participants found it difficult to access foot health-related information, even when they specifically requested it from their consultant:

> '*I have never been informed by my rheumatologist about the effect RA has on my feet and I have asked for this before*'. (P106)

It was not only access to a podiatrist that was difficult for a number of participants; obtaining the foot health information they sought from the podiatrist, a perceived expert in foot health matters, proved to be frustrating too, as podiatrists also seem to lack this awareness. Furthermore, the podiatrists' awareness of how to manage patients' foot health during a critical point in their disease was also perceived to be lacking:

> '*The podiatrist I asked to see only gave general advice… She seemed bewildered that I had asked to see her, as though RA was not a cause of foot pain*'. (P38)

Poor access to foot health services and information, and awareness by other healthcare professionals in relation to the role of a podiatrist and their scope of practice, means that people with RA are not referred because it is not seen as necessary or appropriate:

> *'I don't see a podiatrist, despite having problems with my feet. My GP said they weren't bad enough for any operation so there wasn't any point seeing a podiatrist*'. (P68)

Many participants were unaware of the potential for foot-related pathology to develop owing to their RA, or what could be done to help them manage their symptoms. For some, not having received any information from healthcare professionals in relation to their feet meant that they felt unable to ask questions and thus begin the process of learning about foot health and RA.

This lack of access to foot health services and information, and a poor awareness of RA-related foot health issues and their management by patients and healthcare professionals alike meant that participants faced many barriers to receiving foot health information or education.

'I am my feet'

Foot problems caused by RA evoked a strong response in the participants, in terms of the physical and emotional impact that the disease had on their ability to function in their day-to-day lives. Many expressed difficulty in being able to mobilize on feet affected by RA and the profound emotional response they had to that experience:

> '*…upsetting when it's your feet that have been ravaged the most, and without them it's difficult to walk*'. (P22)

For some, the symptoms within their feet prevented them from having the independence of being able to drive, or being able to participate in positive health behaviours in the management of RA:

> '*Exercise is so important for physical and mental health, and sore, painful feet make this so much more hard work*'. (P26)

Not only did participants express the difficulties they experienced with functionally limiting symptoms such as pain, but many also reported that the effects of RA on their feet meant that they were unable to wear shoes that would allow them to continue with their usual 'lifestyle', and that this forced alteration to their day-to-day wardrobe resulted in significant emotional distress:

> '*…a high percentage of my pain and distress is caused by my feet .It is very depressing having such limited footwear*'. (P2)

Others felt that they should be forewarned of the potential psychological impact that alterations in self-image can have on an individuals' psychological well-being, as a result of having to change their footwear habits because of RA:

> '*There are also psychological aspects to foot health… having to stop wearing heels that I've found have had such a huge impact on my self-image, which I also think should be addressed*'. (P233)

Many participants expressed disappointment that their foot-related symptoms are not addressed during medical consultations and were clearly distressed by the lack of readily available information that might help them to manage their significant foot pathology. They expressed this as feelings of desperation about their foot health. Their desire for information was tangible. From a physical and emotional perspective, participants appeared to feel strongly that their foot health was significant enough to have a long-term impact on their overall well-being.

'Game of chance'

Many participants proactively sourced foot health information and services in the absence of its provision by the medical team. For some, taking the initiative to source information about foot health had led to independent management of it themselves:

> '*As an RA sufferer, I have found I have had to be very proactive in my care and seek knowledge for myself*'. (P158)

They expressed a strong sense of having to fight for access to foot health services, having to undertake a prolonged campaign for podiatry treatment or having to convince other healthcare professionals of their need for foot-related treatment:

> '*I got diagnosed in 1985 and only this year got NHS podiatry, after years of fighting*'. (P48)

Contrary to this strong element of proactive health information-seeking behaviour was the feeling that access to 'good' foot health information was more related to chance:

> *'It was only by chance that I was referred to a podiatrist'*. (P173)

Some felt that the fact that a podiatrist was treating them was more by chance than design, or that the fact that the healthcare professional who was treating them was 'good' meant that they were one of the 'lucky' ones:

> *'I was so lucky to get a good podiatrist early in the disease'*. (P190)

Even in the absence of being managed within the NHS, participants felt that there was an element of luck in receiving independent sector foot health services:

> *'I am lucky to be able to afford it'*. (P228)

Discussion

Study limitations and strengths

The qualitative component of the survey revealed a rich depth of data about participants' experiences in relation to RA-related FHE provision and foot health services. The survey employed free-text comment, as used in other studies, in order to achieve this (Corner et al., 2013; Richards et al., 2009), but in this subject area it was the first time such an approach has been used.

The participants were recruited from a patient support organization (NRAS), and this was a pragmatic approach. It could be argued that this population may not have represented the whole population of people with RA. However, the study population is defined in the results section and represented a wide geographical area of the UK (Table 2).

The themes that were identified from the data illuminate previous studies that have focused on other aspects of foot care, such as the foot interventions (Williams et al., 2007; Williams and Graham, 2012) and access to services (Blake et al., 2013; Redmond et al., 2006) and the impact of living with feet affected by RA (Graham et al., 2012a; Walmsley et al., 2012; Williams and Graham, 2012). The present study revealed the need for FHE strategies to be employed at an early stage of disease diagnosis through their whole experience of the condition and living with foot problems.

There is evidence for foot health interventions for people with RA (National Institute for Clinical Excellence, 2009; Williams et al., 2011), and for patient education in supporting self-management and improving clinical outcomes (Albano et al., 2010). However, the present study revealed that, for many individuals, their foot health and related information is rarely considered within the medical consultation, with the 28-joint DAS (van der Heijde et al., 1993) being the focus of the consultation and hence driving the patient education 'agenda'. The participants found this frustrating as it focused on everywhere except their feet, despite the fact that they had foot symptoms. For participants who did not have access to a podiatrist, this meant that the opportunity to raise concerns about their feet was extremely limited. Even on those occasions when foot-related symptoms were highlighted by the participant, they were treated as a low priority or disregarded by medical staff. This perception of 'feet being ignored or marginalized' has been expressed in previous work (Williams and Graham, 2012).

Early intervention with foot orthoses has been shown to maintain good foot structure in people with RA (Woodburn et al., 2002) and their use in early RA is supported by current national guidelines (National Institute for Clinical Excellence, 2009). Many participants felt that their foot health had been compromised because of absent foot health information and timely referral for interventions, with some being declined intervention as their feet 'weren't bad enough'. The time-constrained nature of consultations made them feel that these had been 'rushed', leaving little opportunity to raise concerns about their foot health. If people with RA are not signposted to foot health services during medical consultations, then the chance to intervene early and potentially prevent more serious foot morbidity will have been missed.

Participants felt that the ideal time to receive FHE would be dependent upon the stage of the disease, and being provided with information at the point of diagnosis was viewed as being potentially overwhelming. By contrast, receiving FHE early in the disease was seen as essential in enabling people to be proactive about their foot health and to help prevent early deterioration. Early FHE provision, together with regular opportunities to 'boost' their knowledge as the disease and their education needs changed, was considered to be a beneficial strategy.

Not being able to access foot health services remains a widespread issue for many people with RA owing to a lack of patient knowledge about services or because the health professionals fail to refer them because they too have no knowledge of such services. Problems with access to NHS podiatry or foot health-related services are longstanding (Redmond et al., 2006), despite the introduction of national and local guidelines (National Institute for Clinical Excellence, 2009; Podiatric Rheumatic Care Association, 2008; Williams et al., 2011), and means that many people find it difficult to access appropriate foot health-related information. Participants found that when they had raised concerns about their foot health with other members of the medical team, they found that their knowledge was lacking, highlighting the need for a specialist podiatry service. Additionally, poor awareness of how RA can have an impact on the foot was also perceived to be evident in podiatrists who were not specialists; indeed, this problem has already been identified (Williams et al., 2013).

Participants expressed profound emotion relating to the physical impact of living with RA-related foot problems. The negative emotions, desperation and distress are further compounded if the information to help them understand their foot problems is denied and foot health services are inaccessible. They spoke about having to seek this out for themselves or fight for it without support from other health professionals. When they did get access to ‘good’ foot health information and services, they viewed this to be by chance rather than design. These concepts of people with RA having to fight for access to services and information and the patchy service delivery that they experience are not new. Marked regional variations in rheumatology foot health service provision were identified and published in 2006 (Redmond et al., 2006). More recently, the Rheumatology Futures Group report on patients’ and professionals’ perceptions of RA care highlighted the ‘lack of access [to podiatry] and lost opportunities’ to help people with RA and foot problems (Steward and Land, 2009).

Conclusion

It is essential that people with RA are allowed to raise their foot health concerns during their medical consultations on a regular basis, ideally during their review appointments. This will enable the timely signposting of individuals with foot-related pathology to appropriate foot health resources such as specialist podiatrists or patient support group websites providing foot health-related material that has been developed for and with people that have RA foot-related problems such as the National Rheumatoid Arthritis Society website (www.nras.org.uk).

Further research is required to determine the effectiveness and accessibility of current FHE resources for people with RA, to ensure that they can easily access information that does not create fear for the future of their foot health.

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REFERENCES

Albano MG, Giraudet-Le Quintrec JS, Crozet C, d’Ivernois JF (2010). Characteristics and development of therapeutic patient education in rheumatoid arthritis: Analysis of the 2003–2008 literature. Joint Bone Spine 77: 405–10.

Alkaabi JK, Ho M, Levison R, Pullar T, Belch JJ (2003). Rheumatoid arthritis and macrovascular disease. Rheumatology (Oxford) 42: 292–7.

Arthritis and Rheumatism Musculoskeletal Alliance (ARMA) (2004). Standards of care for people with inflammatory arthritis: Arthritis and Musculoskeletal Alliance. http://arma.uk.net/resources/standards-of-care/#inflammatory-arthritis [17 April 2015].

Attride-Stirling J (2001). Thematic networks: An analytic tool for qualitative research. Qualitative Research 1: 385–405.

Barn R, Turner DE, Rafferty D, Sturrock RD, Woodburn J (2013). Tibialis posterior tenosynovitis and associated pes plano valgus in rheumatoid arthritis: Electromyography, multisegment foot kinematics, and ultrasound features. Arthritis Care and Research (Hoboken) 65: 495–502.

Blake A, Mandy PJ, Stew G (2013). Factors influencing the patient with rheumatoid arthritis in their decision to seek podiatry. Musculoskeletal Care 11: 218–228. DOI: 10.1002/msc.1044

Borman P, Ayhan F, Tuncay F, Sahin M (2012). Foot problems in a group of patients with rheumatoid arthritis: An unmet need for foot care. Open Rheumatology Journal 6: 290–5.

Braun V, Clarke V (2006). Using thematic analysis in psychology. Qualitative Research in Psychology 3: 77–101.

Corner J, Wagland R, Glaser A, Richards SM (2013). Qualitative analysis of patients’ feedback from a PROMs survey of cancer patients in England. BMJ Open 3:4 e002316 DOI: 10.1136/bmjopen-2012-002316.

Fautrel B, Pham T, Gossec L, Combe B, Flipo R, Goupille P, Le Loet X, Puechal X, Wendling D, Schaeverbeke T, Sibilia J, Sany J, Dougados M (2005). Role and modalities of information and education in the management of patients with rheumatoid arthritis: Development of recommendations for clinical practice based on published evidence and expert opinion. Joint Bone Spine 72: 163–70.

Firth J, Helliwell P, Hale C, Hill J, Nelson E (2008). The predictors of foot ulceration in patients with rheumatoid arthritis: A preliminary investigation. Clinical Rheumatology 27: 1423–8.

Graham AS, Hammond A, Walmsley S, Williams AE (2012a). Foot health education for people with rheumatoid arthritis – Some patient perspectives. Journal of Foot and Ankle Research 5: 23.

Graham AS, Hammond A, Williams AE (2012b). Foot health education for people with rheumatoid arthritis: The practitioner's perspective. Journal of Foot and Ankle Research 5: 2.

Grondal L, Tengstrand B, Nordmark B, Wretenberg P, Stark A (2008). The foot: still the most important reason for walking incapacity in rheumatoid arthritis: distribution of symptomatic joints in 1,000 RA patients. Acta Orthopaedica 79: 257–261. DOI: 10.1080/17453670710015067

Hooper L, Bowen CJ, Gates L, Culliford DJ, Ball C, Edwards CJ, Arden NK (2012). Prognostic indicators of foot-related disability in patients with rheumatoid arthritis: Results of a prospective three-year study. Arthritis Care and Research (Hoboken) 64: 1116–24.

Lanzillo B, Paponne N, Crisci C, di Girolamo C, Massini R, Caruso G (1998). Subclinical peripheral nerve involvement in patients with rheumatoid arthritis. Arthritis and Rheumatism 41: 1196–202.

National Institute for Clinical Excellence (NICE, 2009). Rheumatoid arthritis: The management of rheumatoid arthritis in adults. http://guidance.nice.org.uk/CG79 [April 2015].

National Rheumatoid Arthritis Society. http//:www.nras.org.uk [May 2015].

North West Podiatry Clinical Effectiveness Group (2014). Guidelines for the management of foothealth for people with rheumatoid arthritis. http://www.prcassoc.org.uk/guidelines [April 2015].

Otter SJ, Young A, Cryer JR (2004). Biologic agents used to treat rheumatoid arthritis and their relevance to podiatrists: A practice update. Musculoskeletal Care 2: 51–9.

Podiatric Rheumatic Care Association (PRCA, 2008). Standards of care for people with musculoskeletal foot health problems. Podiatric Rheumatic Care Association. http://www.prcassoc.org.uk/standards-project [17 April 2015].

Redmond AC, Waxman R, Helliwell PS (2006). Provision of foot health services in rheumatology in the UK. Rheumatology (Oxford) 45: 571–6.

Richards SH, Campbell JL, Walshaw E, Dickens A, Greco M (2009). A multi-method analysis of free-text comments from the UK General Medical Council colleague questionnaires. Medical Education 43: 757–66.

Siddle HJ, Redmond AC, Waxman R, Dagg AR, Alcacer-Pitarch B, Wilkins RA, Helliwell PS (2012). A case series to describe the clinical characteristics of foot ulceration in patients with rheumatoid arthritis. Clinical Rheumatology 31: 541–5.

Sim MK, Kim DY, Yoon J, Park DH, Kim YG (2014). Assessment of peripheral neuropathy in patients with rheumatoid arthritis who complain of neurologic symptoms. Annals of Rehabilitation Medicine 38: 249–55.

Stamatelopoulos KS, Kitas GD, Papamichael CM, Krykou K, Zampeli E, Fragiadaki K, Panoulos VF, Mavrikakis M, Sfikakis PP (2010). Subclinical peripheral arterial disease in rheumatoid arthritis. Atherosclerosis 212: 305–9.

Steward K, Land M (2009). Perceptions of patients and professionals on rheumatoid arthritis care. A consultancy report by the Kings Fund for the Rheumatology Futures Group. London: The Kings Fund.

van der Heijde DM, van't Hof M, van Riel PL, van der Putte LB (1993). Development of a disease activity score based on judgement of clinical practice by rheumatologists. Journal of Rheumatology 20: 579–81.

Walmsley S, Ravey M, Graham A, Teh LS, Williams AE (2012). Development of a patient-reported outcome measure for the foot affected by rheumatoid arthritis. Journal of Clinical Epidemiology 65: 413–22.

Wickman AM, Pinzur MS, Kadanoff R, Juknelis D (2004). Health-related quality of life for patients with rheumatoid arthritis foot involvement. Foot and Ankle International 25: 19–26.

Williams AE, Davies S, Graham A, Dagg A, Longrigg K, Lyons C, Bowen C, and the Northwest Clinical Effectiveness Group for the Foot in Rheumatic Disease (2011). Guidelines for the management of the foot health problems associated with rheumatoid arthritis. Musculoskeletal Care 9: 86–92.

Williams AE, Graham AS (2012). 'My feet: Visible, but ignored…' A qualitative study of foot care for people with rheumatoid arthritis. Clinical Rehabilitation 26: 952–9.

Williams AE, Graham AS, Davies S, Bowen CJ (2013). Guidelines for the management of people with foot health problems related to rheumatoid arthritis: A survey of their use in podiatry practice. Journal of Foot and Ankle Research 6: 23.

Williams AE, Nester CJ, Ravey MI (2007). Rheumatoid arthritis patients' experiences of wearing therapeutic footwear – A qualitative investigation. BMC Musculoskeletal Disorders 8: 104.

Willis G (2005). Cognitive Interviewing – A Tool for Improving Questionnaire Design. Thousand Oaks, California: Sage Publications.

Woodburn J, Barker S, Helliwell PS (2002). A randomized controlled trial of foot orthoses in rheumatoid arthritis. Journal of Rheumatology 29: 1377–83.

Woodburn J, Helliwell P (1997). Foot problems in rheumatology. British Journal of Rheumatology 36: 932–4.

Woodburn J, Helliwell PS, Barker S (2002a). Three-dimensional kinematics at the ankle joint complex in rheumatoid arthritis patients with painful valgus deformity of the rearfoot. Rheumatology (Oxford) 41: 1406–12.

2.7 Commentary – Paper 7

It is well recognised that foot health education is an essential component of foot health management for people with RA (PRCA, 2008; NICE, 2009; NWCEG, 2014) Despite this, there is evidence of both sub-optimal FHE *and* foot health management for this group of people (paper 2,3,4,5,6). It is now known that the people with RA in these studies lack awareness and understanding of FHE, the foot health interventions that are available to them, the role and scope of practice of the podiatrist and of appropriate self-management strategies. Given the emphasis on patient-centred care and the provision of information to facilitate shared decision making (Neame, Hammond and Deighton, 2005; Kjeken et al, 2006) having a comprehensive understanding of the FHE needs of people with RA could be considered crucial to the promotion and achievement of good foot health. This paper presents the quantitative findings of an online survey developed from a fusion of my own experience, the narrative review (paper1) exploratory work (papers 2 and 3) and identifies for the first time, what people with RA need in relation to FHE and the potential and actual barriers to its' current provision. Further to this, this paper presents the influence of participant gender, age, disease duration and living situation (alone or with a significant other) on their responses, as these factors have been shown to influence educational need in people with rheumatic disease (Hjelm et al, 2002; Dragoi et al, 2013). Insight in relation to these factors is required in order to approach the provision of future foot health educational interventions.

The results presented in this paper identified continued patchy access to foot health services across the UK for people with RA and that the highest levels of access remain within those areas of higher population density (SW, SE and NW England). Further to this the results of this paper showed, for the first time, that poor access and low awareness of FHE for people with RA was experienced across the UK and not limited to one or two geographical areas.

Distinctively, this paper confirms that the age and gender of people with RA has some influence on their perceptions of certain aspects of FHE provision, including the aims of FHE, how likely they are to receive FHE, clarity about what they should be asking Health Professionals in relation to their foot health and RA, the aspects of FHE content they most value and the mode of FHE they are more likely to engage with. This has potential implications for the way in which Health Professionals tailor their approach to the design and delivery of FHE for people with RA.

The results of this paper showed that the participants placed a high value on the importance of all aspects of the content of FHE, indicating the significance with which they regard potential FHE provision. In support of the qualitative results (paper 6) and in concurrence with the findings from the survey of podiatrists (paper 5), people with RA require FHE provision early in their diagnosis. However, although this was indicated as preference many barriers appear to remain that prevent this from happening; apart from poor access to foot health services, the majority of participants are not asked about foot health during the medical consultation which may be attributed to time constraints and a lack of practitioner awareness of foot health issues related to RA. The most common method of FHE provision was perceived to be verbal or via sign-posting to patient support group web-sites. Of significant interest, was the finding that many participants did not receive written foot health information from any health professional. This is in direct contrast to the findings of the podiatry practitioner survey (paper 5) where the most commonly stated method for the delivery of FHE was said to be written information The use of written resources is highly valued by people with RA especially in support of verbal information provision. The fact that there is a range of resources freely available to health professionals (such as those provided by Arthritis Research UK), may suggest low awareness amongst podiatrists and other health professionals about the existence of such resources, given that they do not incur a cost to the individual practitioner or the health service.

The recommendations from this paper strongly align with and support the findings of the qualitative analysis (paper 6) and those of the survey conducted with podiatrists (paper 5); people with RA should, as a minimum, be asked about their current foot health at their medical appointments starting at the point of diagnosis and their subsequent foot health education needs should be tailored to their individual requirements at that time.

The findings in this paper support the need to develop strategies that can facilitate personalized, timely and time efficient mechanisms for identification of FHE needs in people with RA.

INNOVATIONS:

This study has identified for the first time, that poor access to AND low awareness of, FHE resources, is experienced by people with RA across the UK and that this is not limited to one or two geographical areas. This highlights a continuing unmet need in the context of access to foot health services for this population of people, resulting in the continued distress of patients and potentially ineffective foot health management. This has clear ramifications for patient quality of life, ability to participate socially and can impact on ability to function within the work environment.

The results of this study also identify that the age and gender of the participants has some influence on their perception of FHE, which could impact on how we should approach the design and delivery of FHE in the future. Further, this paper identified a divergence of opinion between people with RA and podiatry practitioners about the provision of written information, which the participants indicated that they were not receiving. As a minimum to providing the patient with an opportunity to talk about their foot health, this should also be supported by the provision of written FHE.

Paper 7:

Title: A survey of people with foot problems related to arthritis and their educational needs

Authors: Andrea S Graham, John Stephenson and Anita E Williams.

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RESEARCH

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A survey of people with foot problems related to rheumatoid arthritis and their educational needs

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Abstract

Background: Up to 50% of people with rheumatoid arthritis (RA) have foot symptoms at diagnosis, hence early foot health intervention is recommended and this should include patient education. This study identifies, for the first time, the foot health education (FHE) needs of people with RA.

Methods: An online survey of people with RA ($n = 543$) captured quantitative data in relation to the aims, methods of delivery, content, timing and accessibility of FHE.

Results: The majority concurred about the aims of FHE. Verbal delivery and websites were the most common methods. Written and verbal FHE were perceived to be the most effective methods. The point of diagnosis was the preferred time to receive it. Lack of access to FHE included minimal focus on foot health during consultations by both health practitioners and patients with RA. Participant gender, age, disease duration and living situation had a statistically significant influence on the results.

Conclusion: Foot health education is rarely considered within the medical consultation. There is a lack of patient and/or health professional awareness of this need with a detrimental impact on foot health. Patients require health professionals to identify their foot education health needs. Tailored foot health education should begin at initial diagnosis.

Background

Rheumatoid arthritis (RA) has a significant impact on foot-related morbidity [1, 2], with associated physical pathology manifesting in the feet as deformity [3–5], callus and ulceration [6, 7], and both vascular [8] and neurological deficit [9]. Pharmacological management of RA has additional consequences for foot health, with medications being associated with increased risk of infection [10, 11]. The sequelae of this spectrum of foot pathology are loss of function, reductions in mobility, quality of life and social participation [12] and a potential negative impact on self- image [13].

There is a growing body of evidence to support effective management of foot pathology in RA, [14–16], with foot health education (FHE) being recognised as being an essential component, or as an intervention in its own right. However, some people with RA experience sub-optimal foot health with a lack of understanding of the relationship between the disease and foot health or lack of knowledge about the NHS services available to them [17, 18]. Importantly, there is evidence that people with RA do not understand the role of the podiatrist or self-management strategies they might use, in the improvement or maintenance of their own foot health [17–19]. The positive effect of patient education in relation to general disease management and overall health is well recognized in RA [20, 21]. The persistence of sub-optimal foot health in RA can be potentially damaging to overall health [22]. Therefore, improving patient's knowledge of foot health and management (either self or professional) is considered essential to their overall well being, functional ability and quality of life.

Having an understanding of the FHE needs of people with RA in respect of the content, timing, mode of delivery and potential barriers to its provision, is a crucial step to achieving good foot health in this patient group.

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Therefore, this study aims to identify, for the first time, what people with RA need in relation to FHE and the barriers to its' provision.

Methods

Ethical approval was received from the University of Salford, Research Innovation and Academic Engagement Ethical Approval Panel (HSCR12/35).

Questionnaire design

The survey questionnaire was designed to capture quantitative and qualitative data from people with RA from across the UK. Questions were developed from a literature search and the results of previous exploratory work that informed the content of the questionnaire [19, 23]. To ensure face and content validity the survey was piloted with four people with RA, recruited from the University of Salford, Podiatry Clinic. 'Think aloud' cognitive debriefing [24, 25] was used in order to reduce sources of response error, ensure clarity of questions and the overall structure of the questions. The results of the pilot led to a small number of changes relating to the question clarity and the consolidation of items within two sections (section 3 and 4) relating to verbal and 'one-to-one' methods of delivery.

The main components of the final survey consisted of six sections, with 16 questions in total, including demographic questions (section 1, questions 1–7), including an option for participants to add in additional free-text responses (questions 10, 13–15) if they had responses that were not included within the survey response set and a free-text comment question (question16) for the whole survey (Additional file 1). The results from the qualitative analysis of the free text comments have been published [19].

The score obtained by each participant in each section was obtained by a summation of the individual item scores within each section. Table 1 outlines the score system for each section/question.

The questionnaire was anonymous, self-administered and of a cross-sectional observational design using a web based survey the Bristol Online Survey website (https://www.onlinesurveys.ac.uk/). A mixture of open-ended, closed-ended dichotomous, contingency, nominal and ordinal polytomous questions were used to reduce the risk of missing data [26, 27].

Participants

Inclusion criteria were: a diagnosis of RA, patient membership of the National Rheumatoid Arthritis Society (NRAS), ability to understand written English and an ability to access the internet. Participants were recruited through NRAS membership via e-mail invitation with a web-link to the survey. At the time of survey development NRAS membership numbers were 3351, of which approximately 630 were healthcare professionals, giving a potential sample population of 2731. The recruitment period ran from September to November 2013, with potential participants receiving an initial e-mail invite and requesting any members that were health care professionals, spouses or carers not to complete the survey. A 'reminder' e-mail was sent after 2 weeks. Consent was implicit by the completion of the survey and participants were informed of this at the start of the online survey.

Table 1 Survey score system by section and question type

Section & Question type/ number	Section title	Section Score system
Section 2; question 8 – Likert 5-point agree/disagree scale.	What the aims of foot health education are	A summed total of item scores relating to: understanding about treatments consented for; informed choices about treatment options; enablers for foot safety; education about the effects of RA; information about available resources.
Section 3, questions 9–11- Q9- Q10- Q11-Likert 3-point importance scale for perceived effectiveness of method	The best ways of receiving foot health education and effectiveness of method	A summed total of item scores relating to various components of methods of delivery: written, verbal and group information; use of audio-visual demonstrations, images and videos; and websites.
Section 4, question 12 – Likert 5-point agree/disagree scale	What should be included in foot health education	A summed total of item scores relating to the participants' opinions of how important it was to know about each component of FHE content related to RA.
Section 5, question 13: Multiple choice question	When is the best time to receive foot health education	A summed total of item scores relating to participants' opinions of the best time to receive foot health education/information.
Section 6, questions 14–15 Q14– Likert 5-point agree/disagree scale Q 15 -Multiple choice question	Access to foot health education/information and website use.	A summed total of item scores relating to various components of access: positive statements relating to barriers to access negative statements relating to barriers to access, and commonly accessed websites.

Data analysis

Data was analysed using SPSS v 20.0 (SPSS, Chicago, IL, USA). The sample was summarised descriptively. Inferential analyses were conducted. Independent samples *t*-tests were conducted to assess the effect of factors including gender, age (dichotomised into age 59 or younger, age 60 or above) and living situation (dichotomised into living with partner/carer or not living with partner) as appropriate on the component scores which formed the outcome measures of the study.

A *p* value of < 0.05 was considered to indicate statistical significance (Additional file 2).

Results

Five hundred forty-three people with RA completed the survey. The majority of respondents in this study were female (89.7%, *n* = 487), aged between 40 and 69 years of age (85.5%, *n* = 464) and had disease duration of more than 5 years (67.3%, *n* = 365), with younger participants tending to have shorter disease duration (22.5%, *n* = 122 of participants aged under 59 years had a disease duration of less than 5 years, compared with 10.3%, *n* = 56 participants aged over 60 years), though this result could be said to be implicit.

There was a wide geographical spread of participant representation across the UK. Access to foot health services is patchy across England and the non-English regions, with the South East, North West and South West of England showing the largest percentage of respondents to access podiatry (Table 2).

Table 2 Results from survey question 5: the number of participants receiving podiatry, cross-referenced with participants region of residence

Main UK region of residence	Frequency (%) of respondents in each region receiving podiatric treatment
South East England	46 (38.7%)
North West England	27 (45.0%)
South West England	30 (40.0%)
Greater London	10 (25.0%)
West Midlands	10 (25.6%)
East Anglia	7 (18.4%)
Yorkshire and North Humber	15 (44.1%)
East Midlands	16 (50.0%)
South Central England	10 (52.6%)
North East England	16 (51.6%)
Wales	6 (37.5%)
Scotland	20 (58.8%)
Northern Ireland	4 (67.3%)

These results remain similar when both NHS and Private Practice podiatry provision are identified (Table 3). Lack of access to podiatry services could be a potential barrier to people with RA receiving FHE, with only 33.7% (*n* = 183) of the participants stating that they had received FHE.

Aims of Foot health Education

Over 80% of the participants agreed with all the aims of foot health education (Table 4), with between 4 and 10% disagreeing and 10% 'didn't know'.

The age of the participants (dichotomised into under-60 versus 60 or over) was substantively related to the FHE-Aims score; with mean scores of 9.04 in the under 60s group and 8.42 in the 60-and over group. The difference of 0.62 units approached statistical significance (*p* = 0.073) using an independent samples *t*-test. The effect was small in magnitude as measured by Cohen's *d* statistic (*d* = 0.154).

The best ways of receiving foot health education

66.3% of participants had never received information or education about their feet or how to care for them because of RA. For the remaining 33.7%, the most common methods of delivery were; verbal information provided by the Podiatrist (26.3% of the total sample) and other Allied Health Professionals (AHPs) (31.5% of the total sample) and via signposting to websites (23% of

Table 3 Results from survey question 6: number of participants receiving either private or NHS podiatry, cross-referenced with participants region of residence

Main UK region of residence	Frequency (%) of respondents in each region who receive podiatric treatment receiving podiatric treatment from:		
	NHS ONLY	Private practice ONLY	Both NHS and private practice
South East England	30 (61.2%)	14 (28.6%)	5 (10.2%)
North West England	18 (69.2%)	4 (15.4%)	4 (15.4%)
South West England	22 (71.0%)	8 (25.8%)	1 (3.2%)
Greater London	6 (50.0%)	5 (41.7%)	1 (8.3%)
West Midlands	5 (50.0%)	3 (30.0%)	2 (20.0%)
East Anglia	2 (25.0%)	6 (75.0%)	0 (0.0%)
Yorkshire and North Humber	8 (53.3%)	4 (26.7%)	3 (20.0%)
East Midlands	10 (55.6%)	8 (44.4%)	0 (0.0%)
South Central England	7 (70.0%)	3 (30.0%)	0 (0.0%)
North East England	11 (68.8%)	3 (18.8%)	2 (12.5%)
Wales	5 (71.4%)	2 (28.6%)	0 (0.0%)
Scotland	14 (70.0%)	2 (10.0%)	4 (20.0%)
Northern Ireland	2 (50.0%)	2 (50.0%)	0 (0.0%)

Table 4 Survey Items in relation to the aims of Foot Health Education

Survey items in relation to the Aims of FHE:

- So I understand about the treatments I give consent for
- To allow me to make informed choices about my treatment options
- To enable me to look after my own foot health safely
- To educate me about how RA can affect my feet
- To inform me about information resources I can access such as; websites or support groups.

the total sample), a method mostly used by Specialist Nurses and other AHP's (3.3% by podiatrists). Only 81 participants (15%) stated that they had received written information from any profession. Other methods of delivery such as Group Education sessions and the use of audio-visual aids such as DVD's, self-care demonstrations or the specific use of images to aid educational delivery were infrequently accessed.

The living situation of participants (whether they live alone or with a significant other) had a statistically significant effect on the methods of FHE provision experienced by the participants. Specifically, an independent samples *t*-test revealed that there was a statistically significant relationship between the provision of written information ($p = 0.008$) and the living situation of the participants with those that lived with a significant other being more likely to receive written information than those who lived alone.

When asked how effective the methods of delivery were perceived to be, written and verbal provision were ranked the highest by over 75% of participants. Website-based information was 3rd highest, with 70% of participants perceiving this to be an effective mode of delivery.

What should be included in foot health education?

80–93% of the participants considered that information on how RA can affect the feet, how RA-related medication can affect the feet, and what might happen if they didn't look after their own feet as 'very important'. Information about the role of the podiatrist, foot health interventions and how to look after their own feet were also considered very important by 73–79% of participants. Over half (51–68%), considered that general disease related information, contact details for AHPs, how other AHPs are involved with foot health and information relating to patients support groups/website resources, as being very important.

An independent samples *t*-test revealed that there was a statistically significant relationship between the genders of the participants for main effects size in relation to FHE content ($p = 0.022$). The effect was medium in magnitude as measured by Cohen's *d* statistic ($d = 0.326$). Female participants were more likely to consider the inclusion of information on the role of the podiatrist, information about RA medication and its' effect on the feet, contact details and information about treatment options, as very important.

When is the best time to receive foot health education?

Participants were asked when they thought would be the best time to receive foot health education relating to RA. The most popular time for receiving foot health education was considered to be at the point of diagnosis, by 78% of the respondents, with only 36% agreeing that foot health education should only be provided when they asked for it. The association between gender and the timing of FHE achieved statistical significance at the 5% significance level using an independent samples *t*-test ($p = 0.019$) with female participants, who agreed to 2.22 statements on average (SD 1.06) about when FHE should be provided, being more likely to agree with the statements than male participants (who agreed with 1.88 statements on average (SD 0.98). The effect was medium in magnitude as measured by Cohen's *d* statistic ($d = 0.332$). In particular, female participants appeared more likely to agree that it should be provided on demand.

Access to foot health education/information

When asked about factors relating to their ability to access and opportunities for accessing foot health information or education, 46% were not clear about what they should ask AHPs in relation to their foot health and RA. 62% of participants had not been asked about their foot health during their appointments with other AHPs, although 53 people provided additional comments to say that they had initiated a dialogue about their feet with the AHP.

71.5% had not received written foot health information from either their podiatrist or other AHP. However, 64% knew where they could access written information in relation to foot health, either as a leaflet format or through the internet. The majority of participants (92.5%) were able to easily access the internet. Over a third had been able to find information but they had found some difficulty in understanding the information. Time and finances were not a barrier to attending meetings where education could be provided (60 and 71% respectively).

The age of the participants had a statistically significant relationship in relation to their perception of barriers to FHE provision (positive items) ($p = 0.004$) where participants who were less than 59 years of age were more likely to disagree or strongly disagree with the item 'I am clear about what questions to ask my podiatrists or other Health Professional about my feet' and to enter a 'don't know' response to the items. The effect was small in magnitude as measured by the ϕ statistic (ϕ = 0.179).

The most commonly accessed website for foot health information was NRAS at 76.4%, Arthritis Research UK (32.2%) and Arthritis Care (27.6%) with 11–12.7% using WebMD and patient.co.uk. The gender of the participants would achieve statistical significance at the 5% significance level in relation to the website of choice (p = 0.004) with a greater ratio of female participants more likely to use the NRAS website. The effect was small in magnitude as measured by the ϕ statistic (ϕ = 0.122).

Discussion

The aim of this study was to identify what people with RA need in relation to FHE and the potential barriers to its' provision. This is the first study to describe the current provision of foot health education (FHE) to people with RA across the UK. It has identified the lack of access that many people with RA experience in relation to foot health services and this being a significant factor in accessing RA-related information and resources. The participants were very clear in what they required and desired in relation to FHE.

Forty percent (n = 217) of respondents stated that they received podiatry treatment, of which only 162 people receive NHS podiatry. This could reflect a lack of participant awareness of foot health service provision [18] and the geographical skew of a higher proportion of podiatry service provision for people with rheumatic diseases within certain areas of the United Kingdom, such as South Central England, North East England, Scotland and Northern Ireland with over 50% of sample participants from each of these regions were receiving podiatric treatment [28]. However, the largest numbers of participants receiving podiatric treatment were found as expected in the regions of higher population, particularly higher populations of elderly people, including the South West, South East and North West regions of England. This apparent 'post-code' lottery of foot health service provision across the UK means that many people with RA are denied access to those health professionals who are best placed to provide effective and timely FHE. However, poor access to rheumatology-related foot health services is by no means limited to the UK with similar issues relating to timely access to podiatric care identified in Australia [29, 30]. A lack of specialist podiatry services means that it is essential that FHE is provided in a way that is high profile, easily accessible and supports self-management for people with RA-related foot health problems.

The majority of the participants stated that they agreed with the aims of FHE, despite only one third of participants reporting that they had received FHE. Participants who gave a 'don't know' response to the items in this part of the survey were more likely to be under the age of 59 years. This may be because younger participants tended to have shorter disease duration (<5 years) and therefore their educational needs were possibly not as defined. Alternatively, younger participants may have fewer foot symptoms, and hence less physical awareness of the impact that RA can potentially have on their foot health [18]. Further to this, the number of participants in the <59 years age group who had not received FHE (n = 198) was greater than those in the >60 years age group (n = 161) which could also have reduced their awareness of RA foot-related problems. Additionally, when asked if they; 'were clear about what to ask my podiatrist or other AHP regarding my foot health', participants in the younger age group were significantly (p = 0.004) more likely to either 'not know' or 'disagree' with the statement. The effect was small in magnitude as measured by the ϕ statistic (ϕ = 0.179).

The influence of age and disease duration on educational needs in patients with rheumatic disease has been identified by Dragoi et al., [31] who found that older patients with a longer disease duration expressed higher educational needs in relation to pain and movement. Some of the comparisons shown to be significant at the 5% level may not be considered significant in the context of a single finding from multiple testing with a Bonferroni correction applied to correct for multiple comparisons.

Participants rated the importance of the content of FHE as high overall, which supports the value that people with RA place on managing their foot health [18, 19]. Items about the impact that RA and its related medications have on the feet, the role of podiatrist, and the interventions that are used in foot health management and self-management rated particularly highly, showing synergy with the findings of a survey of practitioners' perceptions of FHE [18]. Female participants rated certain items higher than males: the role of the podiatrist, information about RA medication and its effect on the feet, contact details and information about treatment options were more likely to be rated as very important by female participants. The phenomena of gender influence on educational need or engagement with information-seeking behaviour has been previously identified, with women expressing a higher educational need [31]. Further, they are engaged more in information seeking, positive health behaviours and demonstrating self-efficacy than males [32].

People with RA may benefit from self-managed foot care, providing that it is personalized and the individuals' physical capability to undertake self-care is assessed [33]. This can help tailor the educational needs of the person in relation to 'hands-on' skill. However, their 'information-needs' also require recognition and personalization.

This 'needs analysis' should take into account the potentially differing information needs and skills of those with early or established disease, and the age and gender of the individual concerned. This approach to the identification of educational needs has been shown to be successful in people with RA from a general context, both in the UK and other countries in Europe [22, 34, 35]. The development of a specific foot health educational needs tool could enable people with RA to identify and prioritise their educational needs in a way that is timely and prescriptive to their individual requirements.

The participants reported that they should receive FHE at the time of their diagnosis. The participants' requirement for early provision of foot health information is supported by that of practitioners [36] and by findings from the qualitative analysis of the participants' responses [18]. Caution should be exercised so that individuals are not overwhelmed with too much information at the point of diagnosis, although people view access to FHE earlier in the disease with RA as an enabler of self-management and as a way to potentially limit deterioration of foot health [18].

Despite the fact that people with RA *and* practitioners recognize the need for FHE at diagnosis, for many participants there were significant barriers in accessing it. A lack of access to foot health services and poor awareness of how RA can impact on foot health potentially inhibits individuals' ability to understand what questions they should be asking health professionals about their feet. Being invited to articulate their foot health needs during the consultation is very important for people with RA to allow them to open a dialogue about their feet. However, this opportunity appears to be limited by time, the needs and assessment practices of the consulting practitioner in fulfilling their own clinical 'agenda' and the practitioners' awareness of foot health problems related to RA [18]. Many participants in this study reported that they were not asked about their foot health either during the consultation with their podiatrist ($n = 113$) or with another AHP ($n = 337$), so this opportunity was lost.

Not only did participants lose the chance to engage in verbal FHE, a large number of participants did not receive written information either. Participants reported the provision of written information by any AHP or Rheumatologist to be low (13.6%, $n = 74$); this figure may be compared to a concurrent study of podiatrists, of which 69% ($n = 29$) stated they did provide written information [36]. Written material is a method of delivering information to people that is considered useful once they have left the clinical setting [37] and in increasing knowledge in the short term [38]. People with RA and related foot problems require written information in order to support verbal information provided during the consultation [19].

The most common methods of delivery for FHE were verbal information and sign posting to RA or arthritis-related websites. Although access to FHE can be seen to have been limited at the point of consultation, almost all the participants were able to access the Internet and use it for seeking foot health information from patient support group websites, such as NRAS. The NRAS website was the most likely to be used by participants in this study, although as participants were recruited via NRAS membership, this result is not surprising. Female participants were more likely to use web-based information than men, although the reasons for this are not clear. It may be that females are more motivated to self-care and seek information [32] and the impact of foot-related pathology has more of an impact on their self-image [39].

This study may be perceived to have limitations. Whilst this research reports the perspectives of people with RA in relation to FHE provision, it is limited to the views of people who were recruited through a UK patient support group (NRAS) who also had access to the internet. However, there is no evidence for any systematic differences between such patients and the wider RA population; hence no impact on the generalizability of results is expected. Further, the nature of the sample population and a number of questions within the online survey may mean that the data is subject to response and recall bias [40].

Conclusion

This study has provided the first insight into the current status of FHE for people with RA in the UK. It has shown that the 'patchy' geographical provision of foot health services to this group of people remains similar to that of 10 years ago. Of concern is that people with RA lack awareness of the implications of foot health problems, lack knowledge of where to access information on safe self-management and where and when to access professional foot health services. Patients should be asked about foot health and FHE needs at their medical consultation and signposted to the appropriate service and educational resources if we are to improve foot health and subsequently overall health and quality of life.

The most appropriate time to provide FHE is at initial diagnosis of the disease. FHE needs should be identified and tailored to the individual requirements of the person with RA. Assessment of FHE needs should be undertaken regularly during review appointments. This can be carried out by any health professional that has contact with the patient, not just the podiatrist. In this way foot health information can be provided, or the individual can be signposted to it, in a timely and efficient manner that aligns with the ethos of 'Making Every Contact Count' [41].

Verbal information should be offered and supported with written resources, either through the use of leaflets or via appropriate internet-based resources, such as NRAS or Arthritis Research UK.

An information-needs analysis tool should be developed in order to provide an individual with RA the opportunity to articulate their foot health education needs in a way that is personalized, timely and time efficient for their health practitioner. Once this is achieved, an evaluation of FHE will determine how it influences both clinical management and patient outcomes.

Patient education should not be viewed as an adjunct to treatment. Patient education should be at the start and the end of every episode of care and become the mesh through which 'hands-on interventions' are connected.

Additional files

Additional file 1: Rheumatoid Arthritis foot health education survey for patients (PDF 148 kb)

Additional file 2: *P*-values arising from statistical analyses of participants' survey responses by section, in relation to gender, age, disease duration and living situation. * - Denotes significance at the 5% level. (DOCX 80 kb)

Abbreviations

AHP: Allied Health Professional; FHE: Foot Health Education; NHS: National Health Service; NRAS: National Rheumatoid Arthritis Society; RA: Rheumatoid Arthritis

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Availability of data and materials

All data generated or analysed during this study are included in this published article (and its Additional files 1 and 2).

Authors' contributions

AG conceived and participated in the study design, principal author of the manuscript and co-conducted descriptive and inferential data analyses. JS co-conducted descriptive and inferential data analyses and assisted in the drafting of the manuscript where it applied to statistical analyses. AW participated in the study design and assisted in the drafting of the manuscript. All authors approved the final manuscript.

Competing interests

Dr Anita Williams is a Deputy Editor of the Journal of Foot and Ankle Research. It is journal policy that editors are removed from the peer review and editorial decision-making processes for papers they have co-authored. The remaining authors declare no conflicts of interest in relation to this work.

Consent for publication

I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the study. Thus consent for publication is not required.

Ethics approval and consent to participate

Ethical approval was received from the University of Salford, Research Innovation and Academic Engagement Ethical Approval Panel (HSCR12/35). Consent was implicit by the completion of the survey and participants were informed of this at the start of the online survey.

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References

1. Grondal L, Tengstrand B, Nordmark B, Wretenberg P, Stark A. The foot: still the most important reason for walking incapacity in rheumatoid arthritis: distribution of symptomatic joints in 1,000 RA patients. Acta Orthop. 2008;79:257–61. doi:10.1080/17453670710015067.
2. Otter SJ, Lucas K, Springett K, Moore A, Davies K, Cheek L, et al. Foot pain in rheumatoid arthritis prevalence, risk factors and management: an epidemiological study. Clin Rheumatol. 2010;29:255–71. doi:10.1007/s10067-009-1312-y.
3. Barn R, Turner DE, Rafferty D, Sturrock RD, Woodburn J. Tibialis posterior tenosynovitis and associated pes plano valgus in rheumatoid arthritis: electromyography, multisegment foot kinematics, and ultrasound features. Arthritis Care Res (Hoboken). 2013;65:495–502. doi:10.1002/acr.21859.
4. Hooper L, Bowen CJ, Gates L, Culliford DJ, Ball C, Edwards CJ, et al. Prognostic indicators of foot-related disability in patients with rheumatoid arthritis: results of a prospective three-year study. Arthritis Care Res (Hoboken). 2012;64:1116–24. doi:10.1002/acr.21672.
5. Woodburn J, Helliwell PS, Barker S. Three-dimensional kinematics at the ankle joint complex in rheumatoid arthritis patients with painful valgus deformity of the rearfoot. Rheumatology (Oxford). 2002;41:1406–12.
6. Firth J. Lower limb ulceration in rheumatoid arthritis. Nurs Times. 2008;104:38–40.
7. Siddle HJ, Redmond AC, Waxman R, Dagg AR, Alcacer-Pitarch B, Wilkins RA, et al. Debridement of painful forefoot plantar callosities in rheumatoid arthritis: the CARROT randomised controlled trial. Clin Rheumatol. 2013;32:567–74. doi:10.1007/s10067-012-2134-x.
8. Stamatelopoulos KS, Kitas GD, Papamichael CM, Kyrkou K, Zampeli E, Fragiadaki K, et al. Subclinical peripheral arterial disease in rheumatoid arthritis. Atherosclerosis. 2010;212:305–9. doi:10.1016/j.atherosclerosis.2010.05.007.
9. Sim MK, Kim DY, Yoon J, Park DH, Kim YG. Assessment of peripheral neuropathy in patients with rheumatoid arthritis who complain of neurologic symptoms. Ann Rehabil Med. 2014;38:249–55. doi:10.5535/arm.2014.38.2.249.
10. Otter SJ, Young A, Cryer JR. Biologic agents used to treat rheumatoid arthritis and their relevance to podiatrists: a practice update. Musculoskeletal Care. 2004;2:51–9.
11. Wilske KR. Inverting the therapeutic pyramid: observations and recommendations on new directions in rheumatoid arthritis therapy based on the author's experience. Semin Arthritis Rheum. 1993;23(2 Suppl 1):11–8.
12. Wickman AM, Pinzur MS, Kadanoff R, Juknelis D. Health-related quality of life for patients with rheumatoid arthritis foot involvement. Foot Ankle Int. 2004;25:19–26.
13. Williams A, Nester C, Ravey M. Rheumatoid arthritis patients' experiences of wearing therapeutic footwear - a qualitative investigation. BMC Musculoskelet Disord. 2007;8:104.
14. National Institute of Clinical Excellence (NICE). Rheumatoid arthritis: the management of rheumatoid arthritis in adults. London 2009. (https://www.nice.org.uk/guidance/cg79) accessed 30 Jun 2016.
15. Podiatric Rheumatic Care Association (PRCA). Standards of care for people with musculoskeletal foot health problems. PRCA 2008. (http://www.prcassoc.org.uk/standards-project) accessed 30 Jun 2016.
16. Williams AE, Davies S, Graham A, Dagg A, Longrigg K, Lyons C, Bowen C. Guidelines for the management of the foot health problems associated with rheumatoid arthritis. Musculoskeletal Care. 2011;9:86–92. doi:10.1002/msc.200.

17. Blake A, Mandy PJ, Stew G. Factors influencing the patient with rheumatoid arthritis in their decision to seek podiatry. Musculoskeletal Care. 2013;11:218–28. doi:10.1002/msc.1044.
18. Graham AS, Williams AE. Foot health education for people with rheumatoid arthritis: '… a game of chance…' - a survey of patients' experiences. Musculoskeletal Care. 2016;14:37–46. doi:10.1002/msc.1111.
19. Graham AS, Hammond A, Walmsley S, Williams AE. Foot health education for people with rheumatoid arthritis - some patient perspectives. J Foot Ankle Res. 2012;5:23. doi:10.1186/1757-1146-5-23.
20. Fautrel B, Pham T, Gossec L, Combe B, Flipo R, Goupille P, et al. Role and modalities of information and education in the management of patients with rheumatoid arthritis: development of recommendations for clinical practice based on published evidence and expert opinion. Joint Bone Spine. 2005;72:163–70.
21. Albano MG, Giraudet-Le Quintrec JS, Crozet C, d'Ivernois JF. Characteristics and development of therapeutic patient education in rheumatoid arthritis: analysis of the 2003–2008 literature. Joint Bone Spine. 2010;77:405–10. doi:10.1016/j.jbspin.2010.01.010.
22. Steward K, Land M. Perceptions of patients and professionals on rheumatoid arthritis care. A consultancy report by the Kings Fund for the Rheumatology Futures Group. London: The Kings Fund; 2009.
23. Graham AS, Hammond A, Williams AE. Foot health education for people with rheumatoid arthritis: the practitioner's perspective. J Foot Ankle Res. 2012;5:2. doi:10.1186/1757-1146-5-2.
24. Beatty P. The dynamics of cognitive interviewing. In: Presser S, Rothgeb J, Couper M, Lessler J, Martin M, Martin J, et al., eds. Methods for testing and evaluating questionnaires. New York: John Wiley and Sons Inc; 2004.
25. Willis G. Cognitive Interviewing. A Tool for Improving Questionnaire Design. Thousand Oaks: Sage Publishing Inc; 2005.
26. Reja U, Manfreda K, Hlebec V, Vehovar V. Open-ended versus closed-ended questions in web questionnaires: advances in methodology and statistics. Metodoloski zvezki. 2003;19:159–77.
27. Sue V, Ritter L. Conducting Online Surveys. 2nd ed. Thousand Oaks: Sage Publications, Inc; 2012.
28. Redmond AC, Waxman R, Helliwell PS. Provision of foot health services in rheumatology in the UK. Rheumatology (Oxford). 2006;45:571–6.
29. Hendry GJ, Gibson KA, Pile K, Taylor L, du Toit V, Burns J, et al. Provision of foot health services for people with rheumatoid arthritis in New South Wales: a web-based survey of local podiatrists. J Foot Ankle Res. 2013;6:35. doi:10.1186/1757-1146-6-35.
30. Lansdowne N, Brenton-Rule A, Carroll M, Rome K. Perceived barriers to the management of foot health in patients with rheumatic conditions. J Foot Ankle Res. 2015;8:14. doi:10.1186/s13047-015-0071-z.
31. Drăgoi RG, Ndosi M, Sadlonova M, Hill J, Duer M, Graninger W, et al. Patient education, disease activity and physical function: can we be more targeted? A cross sectional study among people with rheumatoid arthritis, psoriatic arthritis and hand osteoarthritis. Arthritis Res Ther. 2013;15:R156. doi:10.1186/ar4339.
32. Hjelm K, Nyberg P, Apelqvist J. Gender influences beliefs about health and illness in diabetic subjects with severe foot lesions. J Adv Nurs. 2002;40:673–84.
33. Semple R, Newcombe L, Finlayson G, Hutchison C, Forlow J, Woodburn J. The FOOTSTEP self-management foot care programme: are rheumatoid arthritis patients physically able to participate? Musculoskeletal Care. 2009;7:57–65. doi:10.1002/msc.142.
34. Hill J, Tennant A, Adebajo A. Further development of an educational needs assessment tool (ENAT) for patients with rheumatoid arthritis. Arthritis Rheum. 2004;50:S274–5.
35. Meesters J, Vliet Vlieland T, Hill J, Ndosi M. Measuring educational needs among patients with rheumatoid arthritis using the Dutch version of the Educational Needs Assessment Tool (DENAT). Clin Rheumatol. 2009;28:1073–7. doi:10.1007/s10067-009-1190-3.
36. Graham AS, Williams AE. Foot health education provision for people with rheumatoid arthritis-an online survey of UK podiatrists' perceptions. J Foot Ankle Res. 2016;9:13. doi:10.1186/s13047-016-0145-6.
37. Kääriäinen M, Kukkurainen ML, Kyngäs H, Karppinen L. Improving the quality of rheumatoid arthritis patients' education using written information. Musculoskeletal Care. 2011;9:19–24. doi:10.1002/msc.192.
38. Hill J, Bird H. The development and evaluation of a drug information leaflet for patients with rheumatoid arthritis. Rheumatology (Oxford). 2003;42:66–70.
39. Williams AE, Nester CJ, Ravey MI, Kottink A, Klapsing MG. Women's experiences of wearing therapeutic footwear in three European countries. J Foot Ankle Res. 2010;3:23. doi:10.1186/1757-1146-3-23.
40. Oppenheimer AJ, Pannucci CJ, Kasten SJ, Haase SC. Survey says? A primer on web-based survey design and distribution. Plast Reconstr Surg. 2011;128:299–304. doi:10.1097/PRS.0b013e3182174413.
41. Local Government Association. Making every contact count: taking every opportunity to improve health and well-being. London: Local Government Association; 2014. http://www.local.gov.uk/documents/10180/5854661/Making+every+contact+count+–+taking+every+opportunity+to+improve+health+and+wellbeing/c23149f0-e2d9-4967-b45c-fc69c86b5424. Accessed 01 Aug 2016.

Paper 7 – Additional File 5 – Rheumatoid arthritis foot health education survey for people with rheumatoid arthritis – results raw data.

Rheumatoid Arthritis foot health education survey for patients

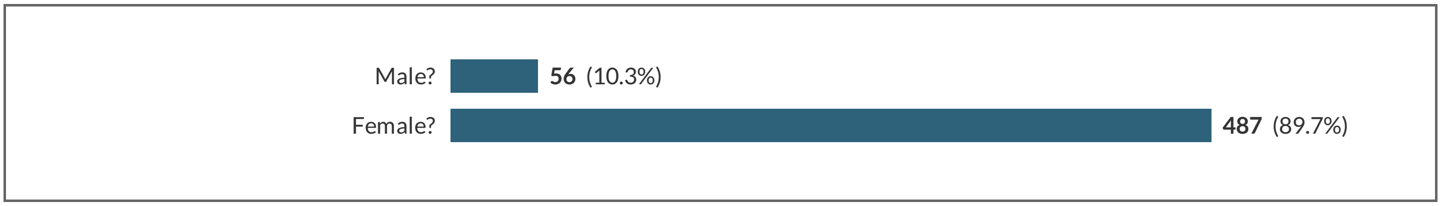
Showing 543 of 543 responses

Showing **all** responses

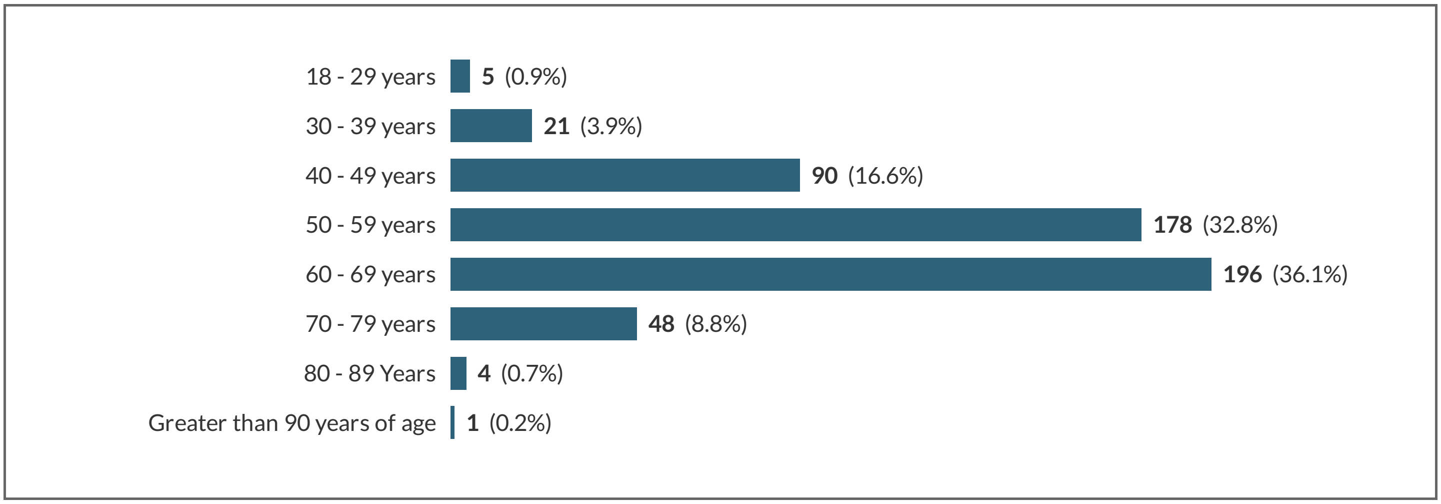
Showing **all** questions

Section 1

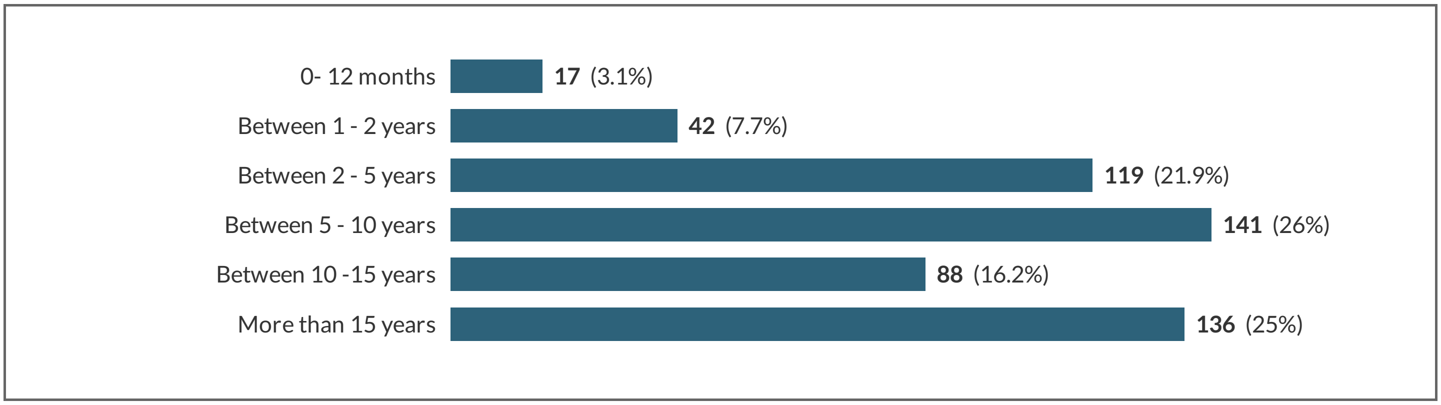
1 Are you



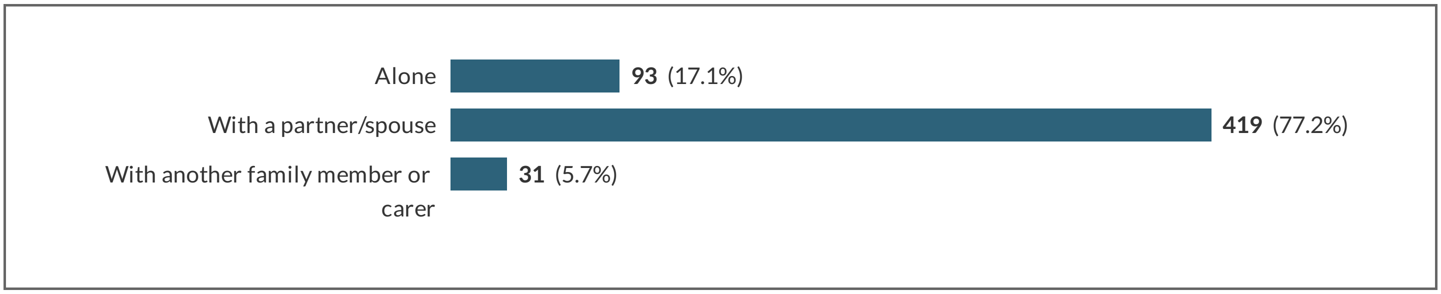
2 What is your current age?From the options below please select the age range that your birth date falls within.



3 Disease duration. Please tell us how long you have been diagnosed with RA by selecting from the options below.

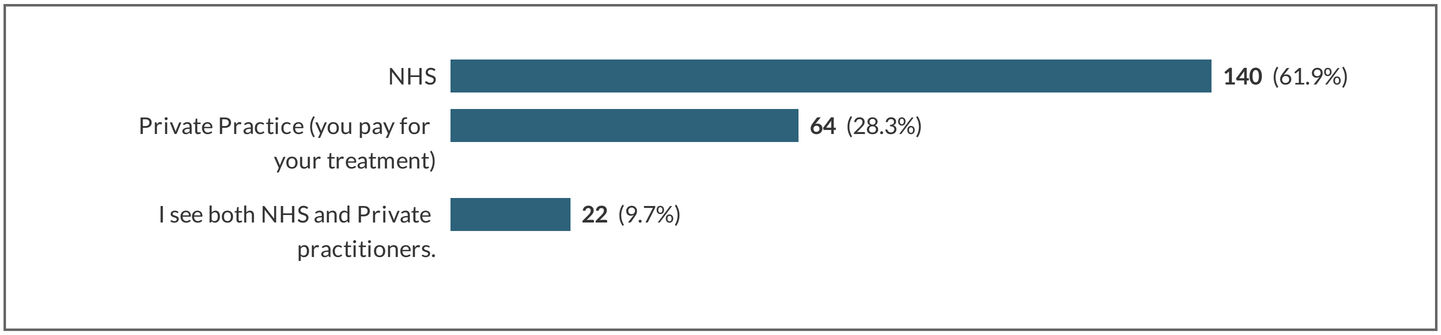


4 Do you live?

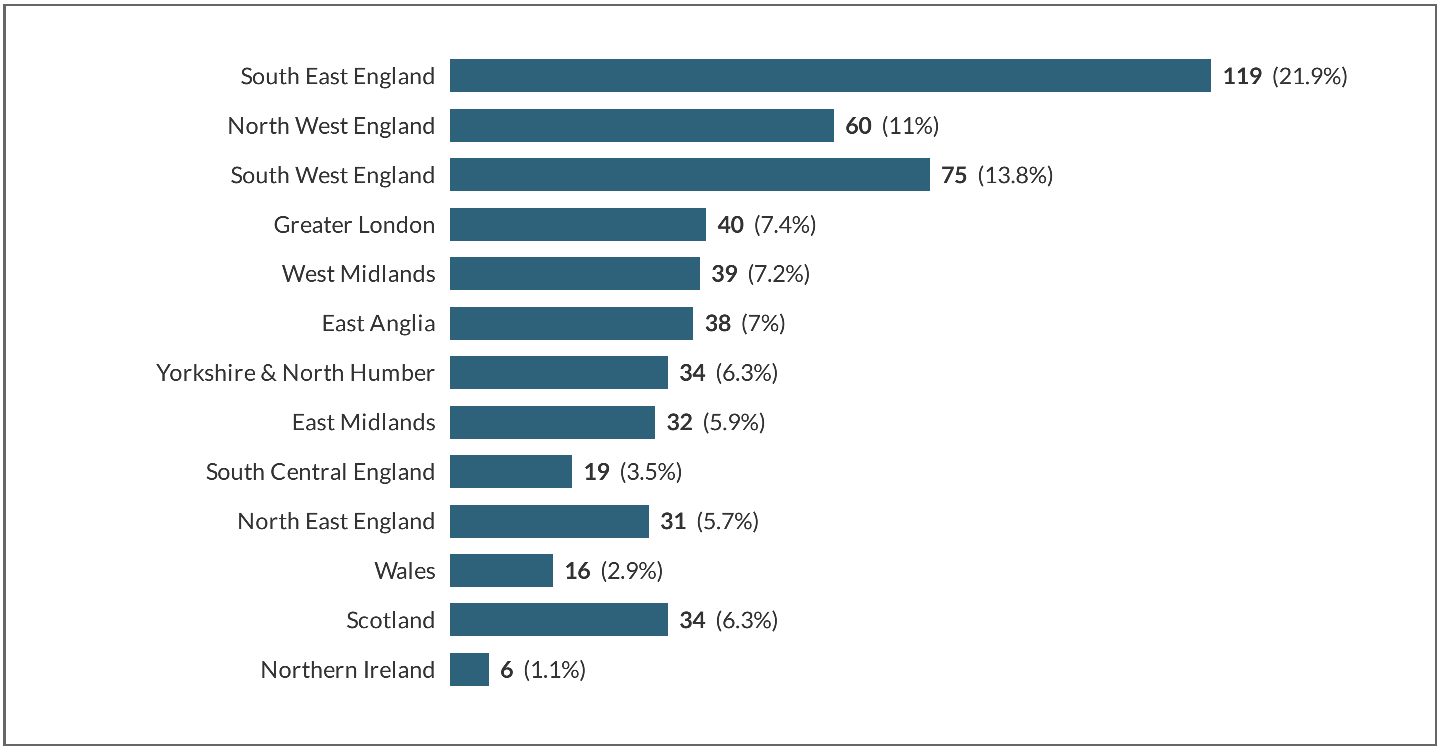


5 Do you currently receive podiatry/chiropody treatment?

6 If you answered YES to question 5, does your podiatrist/chiropodist work in the?



7 Which part of the UK do you mainly live in? (select ONE area only)

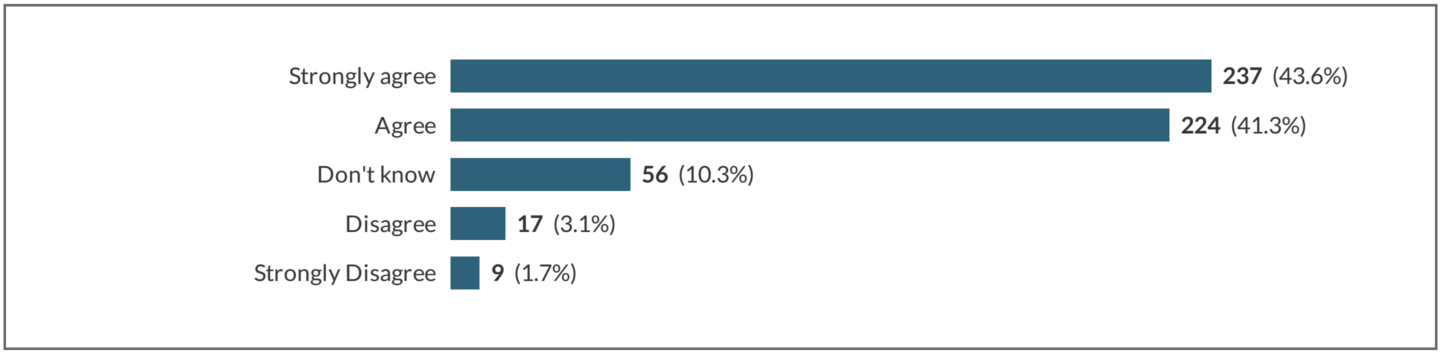


Section 2: The aims of foot health education.

8 To what extent do you agree with the following statements about the AIMS of foot health education.Please select your responses below

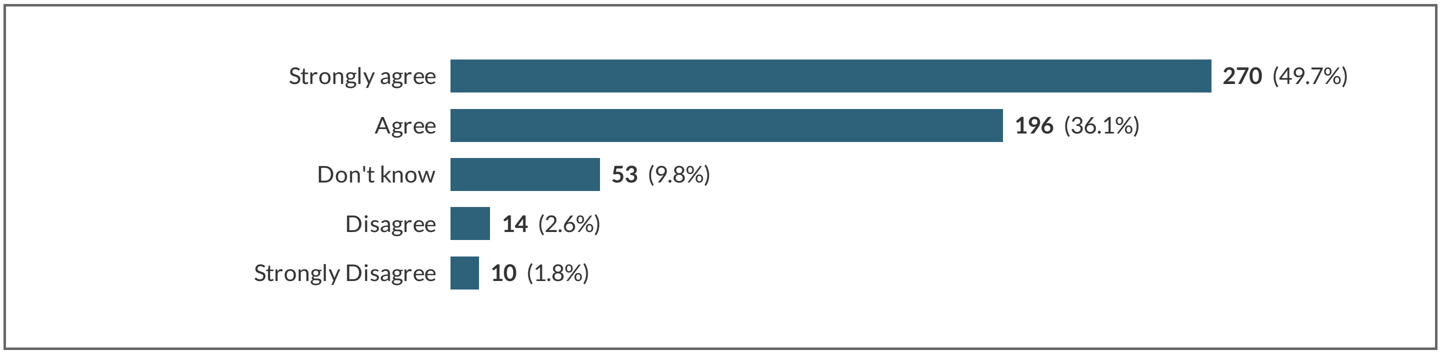
8.1 So I understand about the treatments I give consent for

8.1.a So I understand about the treatments I give consent for - Select the extent to which you agree



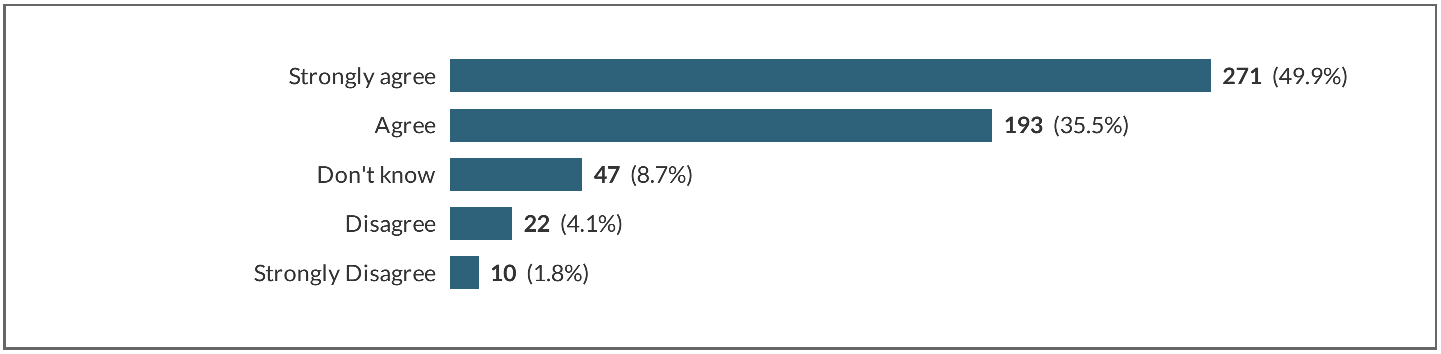
8.2 To allow me to make informed choices about my treatment options

8.2.a To allow me to make informed choices about my treatment options - Select the extent to which you agree



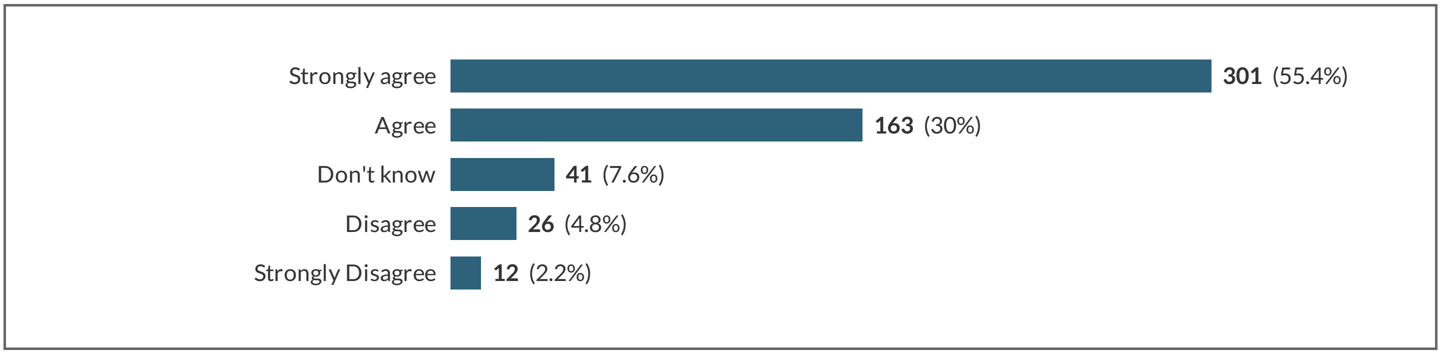
8.3 To enable me to look after my own foot health safely

8.3.a To enable me to look after my own foot health safely - Select the extent to which you agree



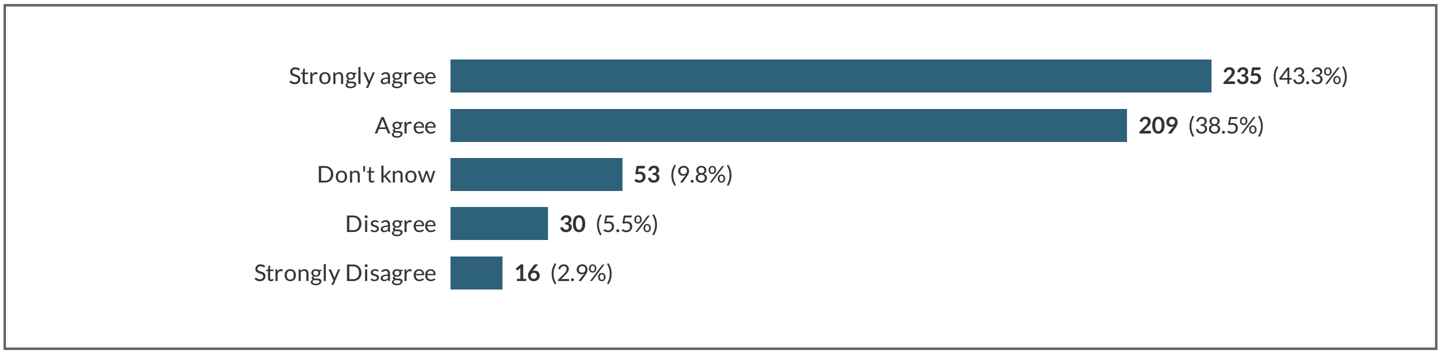
8.4 To educate me about how RA can affect my feet

8.4.a To educate me about how RA can affect my feet - Select the extent to which you agree



8.5 To inform me about information resources I can access such as websites or support groups (e.g. NRAS, Arthritis Care, Arthritis Research UK)

8.5.a To inform me about information resources I can access such as websites or support groups (e.g. NRAS, Arthritis Care, Arthritis Research UK) - Select the extent to which you agree



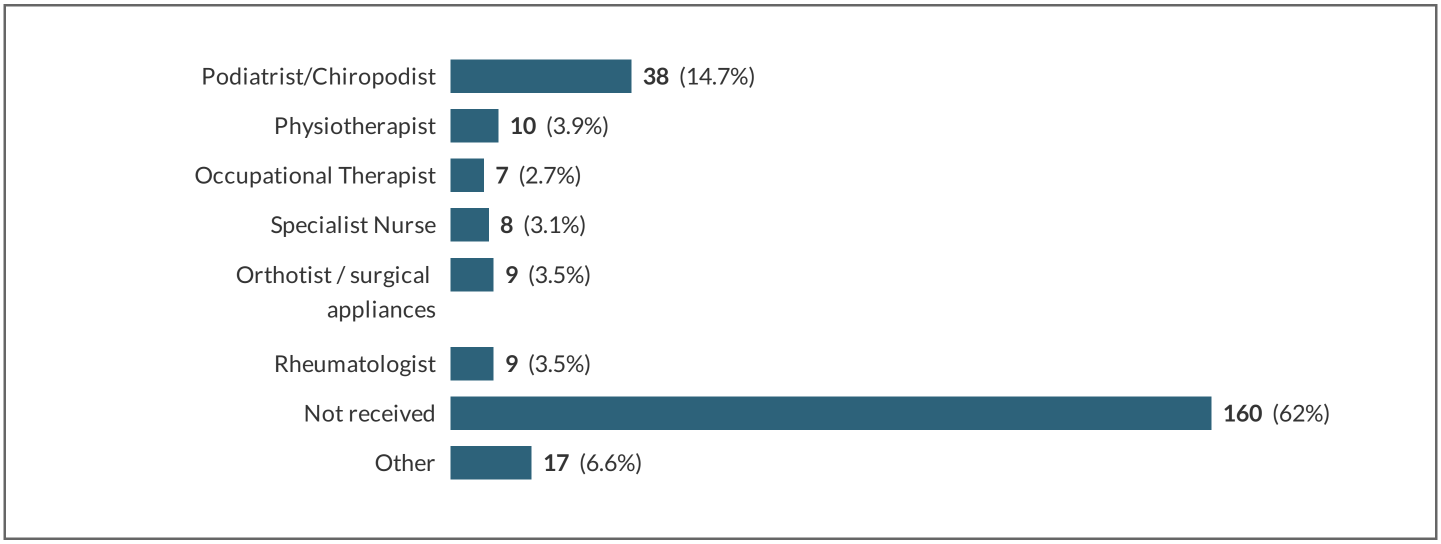
Section 3: The best ways of providing foot health education

9 Have you ever received education or information about how to care for your feet because of your RA?

10 If you answered YES' to question 9 and have received any form of foot health information/education, please indicate which types and from whom via the tick box below. Tick all that apply.

10.1 Written Information

10.1.a Written Information - Tick the boxes for each type of education you have received and indicate who you received it from according to the options in the right hand columns.

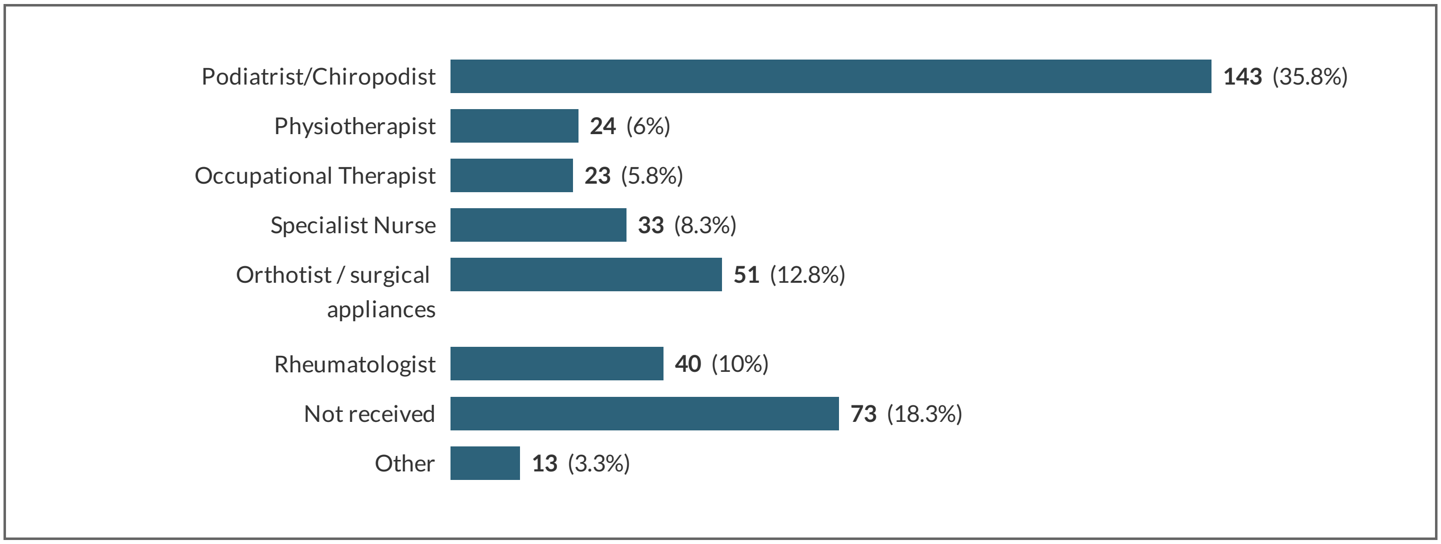


10.1.b Written Information - If you selected Other, please specify:

Showing 5 of 17 responses	
picked the leaflet up myself from hospital	120841-120835-6761313
Arthritis charity website	120841-120835-6761354
Internet	120841-120835-6761450
leaflet	120841-120835-6761655
I downloaded from NRAS site	120841-120835-6761668

10.2 Verbal Information

10.2.a Verbal Information - Tick the boxes for each type of education you have received and indicate who you received it from according to the options in the right hand columns.

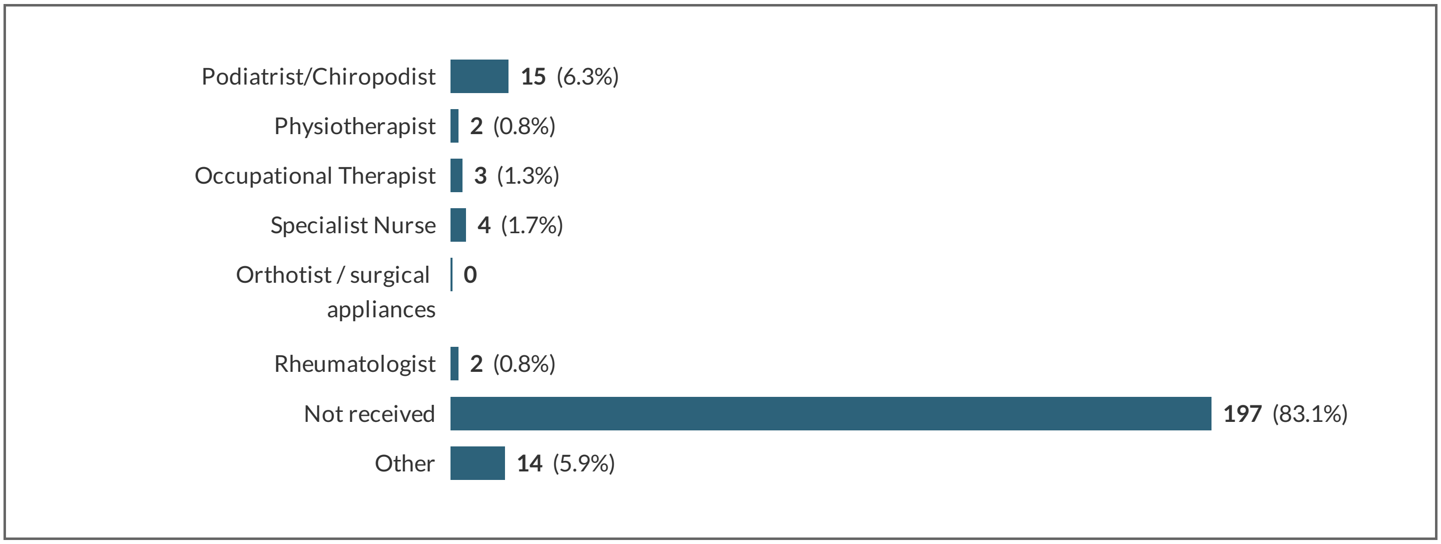


10.2.b Verbal Information - If you selected Other, please specify:

Showing 5 of 13 responses	
foot and ankle orthopaedic surgeon	120841-120835-6761305
podiatrist	120841-120835-6761370
NRAS group	120841-120835-6761425
East Dorset NRAS group	120841-120835-6761488
PRIVATE	120841-120835-6761579

10.3 Group Education sessions

10.3.a Group Education sessions - Tick the boxes for each type of education you have received and indicate who you received it from according to the options in the right hand columns.

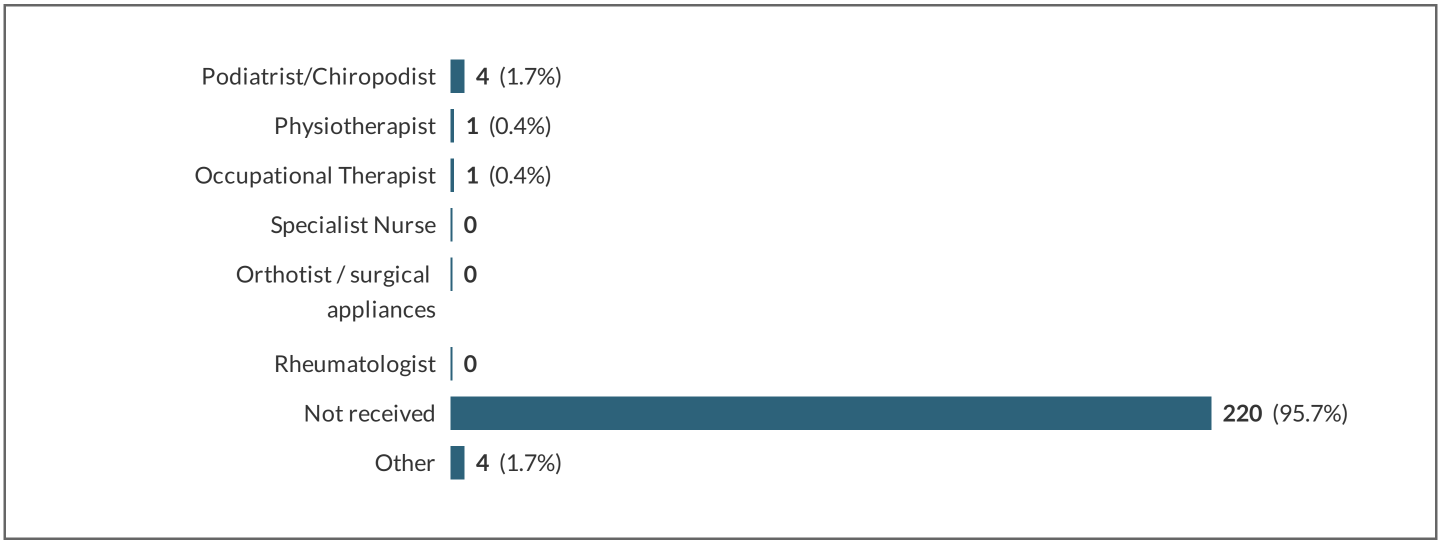


10.3.b Group Education sessions - If you selected Other, please specify:

Showing 5 of 14 responses	
trained reflexologist	120841-120835-6761318
NRAS meeting	120841-120835-6761434
NRAS group	120841-120835-6761425
NRAS info day about footcare	120841-120835-6761454
East Dorset NRAS group	120841-120835-6761488

10.4 Audiovisual aids such as short videos or DVD's

10.4.a Audiovisual aids such as short videos or DVD's - Tick the boxes for each type of education you have received and indicate who you received it from according to the options in the right hand columns.



10.4.b Audiovisual aids such as short videos or DVD's - If you selected Other, please specify:

Showing all 4 responses	
Yes from American arthritis website	120841-120835-6761354
Internet	120841-120835-6761450
Web site on own PC	120841-120835-6761738
can't find/remember	120841-120835-6761764

10.5 Audiovisual aids such as demonstrations of how to care for your feet

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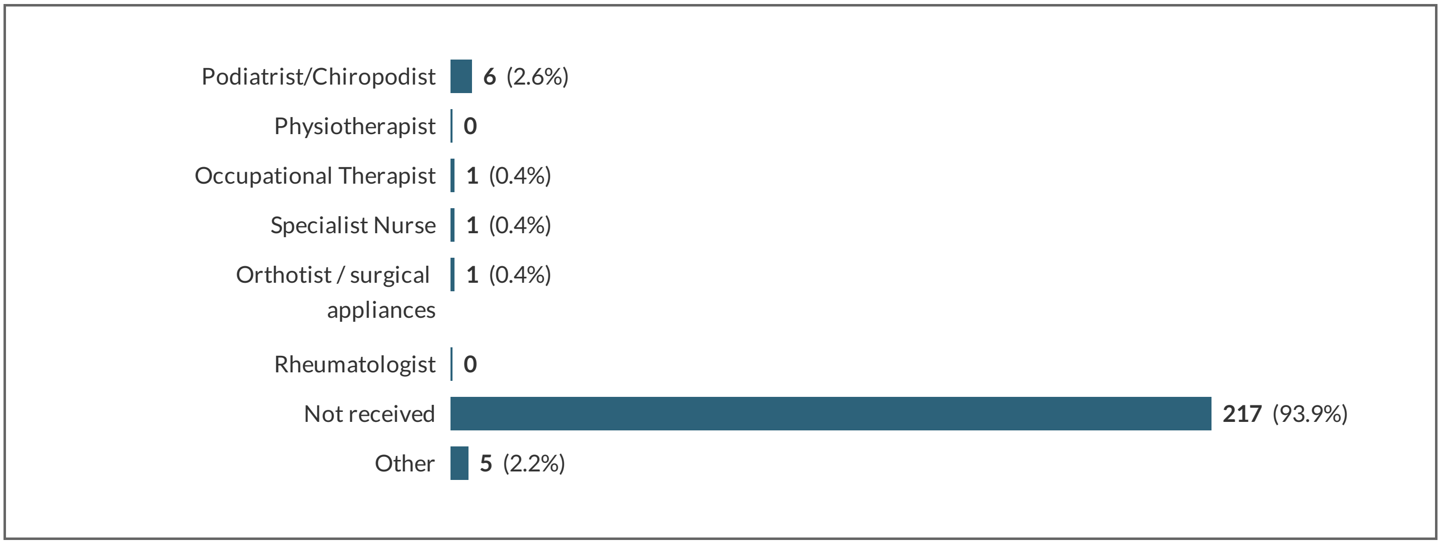
10.5.a Audiovisual aids such as demonstrations of how to care for your feet - Tick the boxes for each type of education you have received and indicate who you received it from according to the options in the right hand columns.

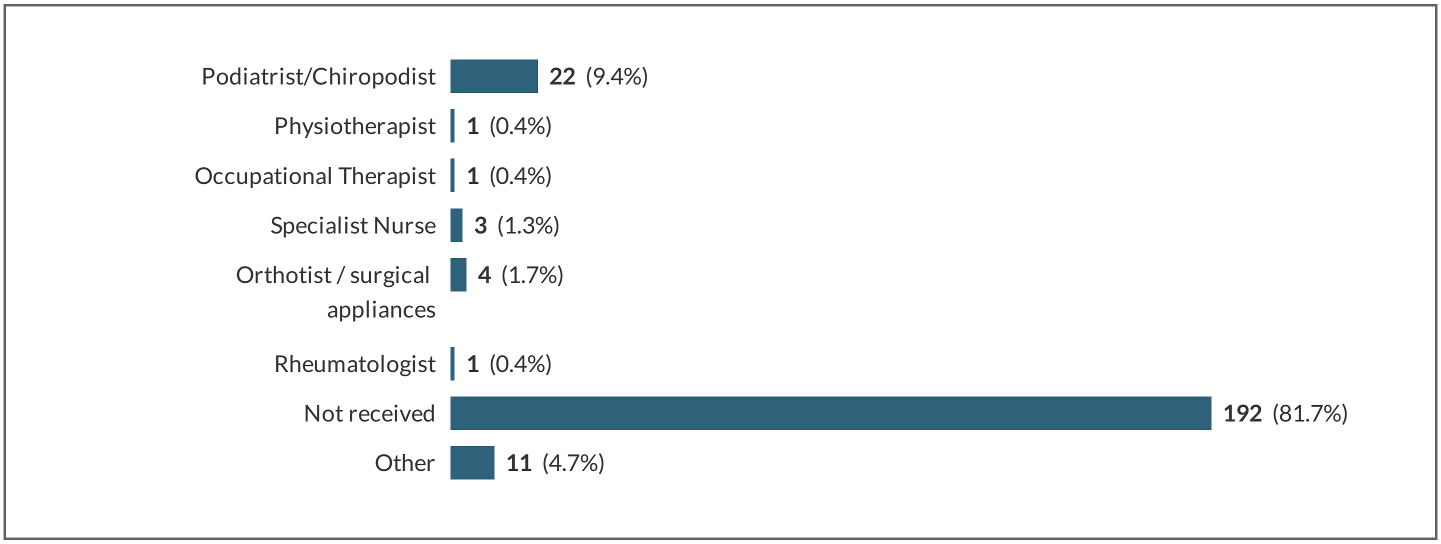


10.5.b Audiovisual aids such as demonstrations of how to care for your feet - If you selected Other, please specify:

Showing all 5 responses	
NRAS meetings	120841-120835-6761434
Internet	120841-120835-6761450
NRAS info day about footcare	120841-120835-6761454
as above	120841-120835-6761738
as above	120841-120835-6761764

10.6 Audiovisual aids such as pictures of footwear/insoles or images of feet

10.6.a Audiovisual aids such as pictures of footwear/insoles or images of feet - Tick the boxes for each type of education you have received and indicate who you received it from according to the options in the right hand columns.

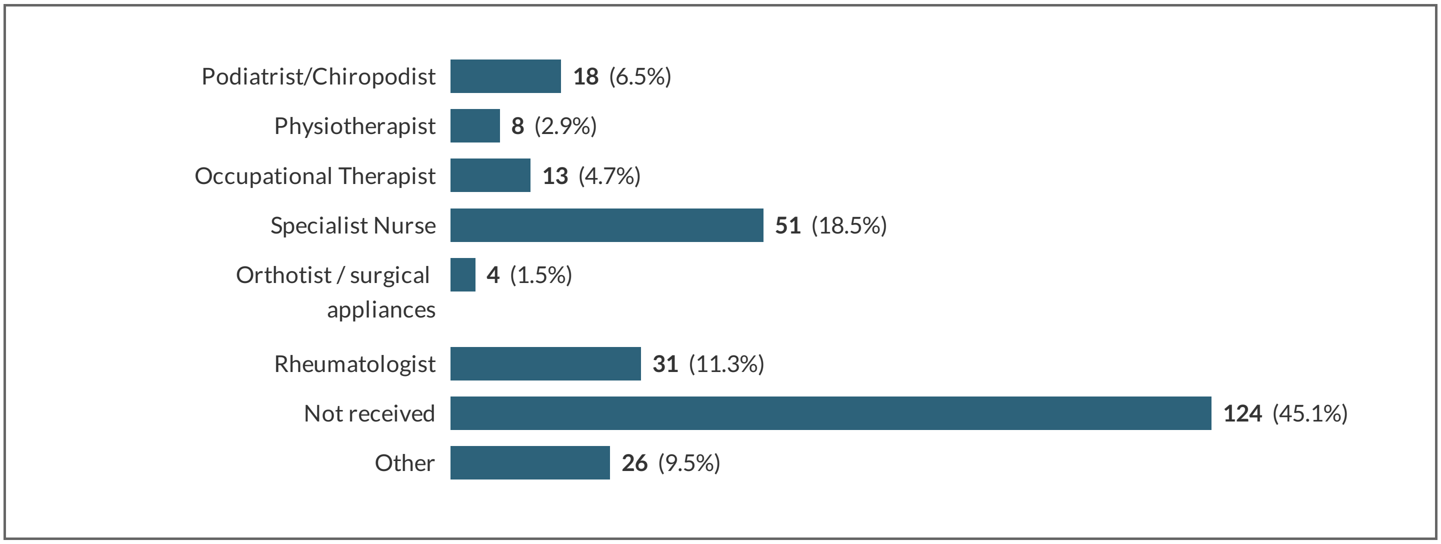


10.6.b Audiovisual aids such as pictures of footwear/insoles or images of feet - If you selected Other, please specify:

Showing 5 of 11 responses	
Arthritis charity website	120841-120835-6761354
NRAS meetings	120841-120835-6761434
Internet	120841-120835-6761450
NRAS info day about footcare	120841-120835-6761454
York rheumatoid arthritis support group	120841-120835-6761605

10.7 Been given information about websites such as NRAS, Arthritis Care, Arthritis Research UK

10.7.a Been given information about websites such as NRAS, Arthritis Care, Arthritis Research UK - Tick the boxes for each type of education you have received and indicate who you received it from according to the options in the right hand columns.



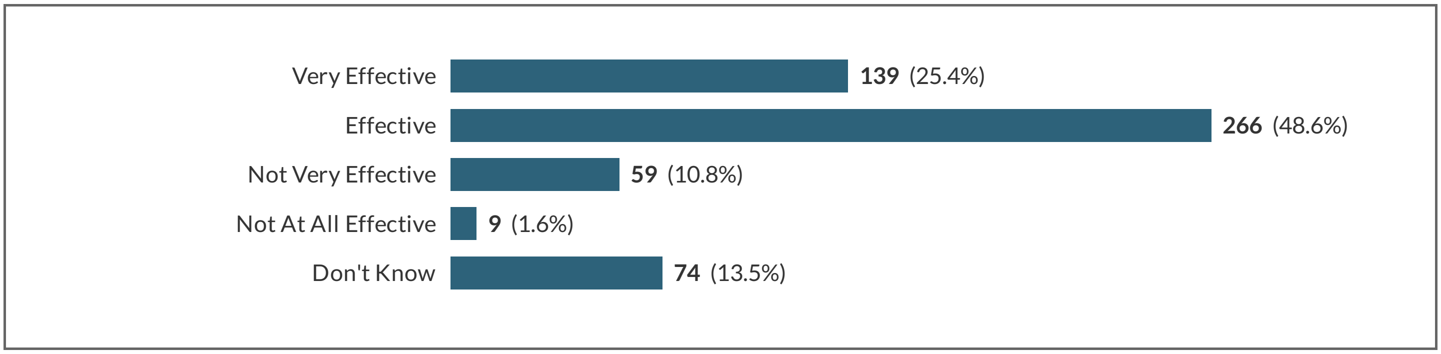
10.7.b Been given information about websites such as NRAS, Arthritis Care, Arthritis Research UK - If you selected Other, please specify:

Showing 5 of 26 responses	
Healthcare @ Home nurses who delivers my anti-TNFs	120841-120835-6761305
Internet search	120841-120835-6761314
self help	120841-120835-6761318
found it myself	120841-120835-6761346
From a friend	120841-120835-6761396

11 To what extent do you think these methods of education are effective, in relation to your foot health?

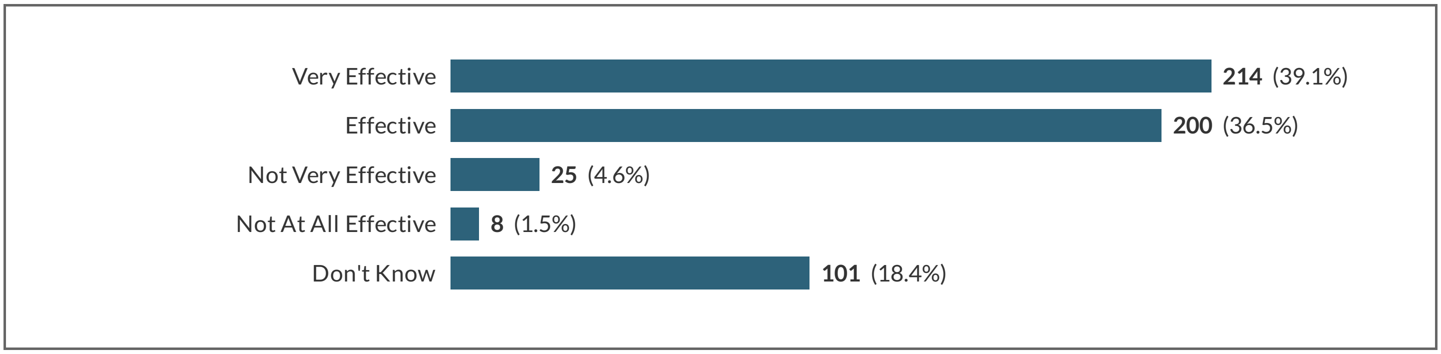
11.1 Verbal Information

11.1.a Verbal Information - Please select from Very Effective to Don't KNow



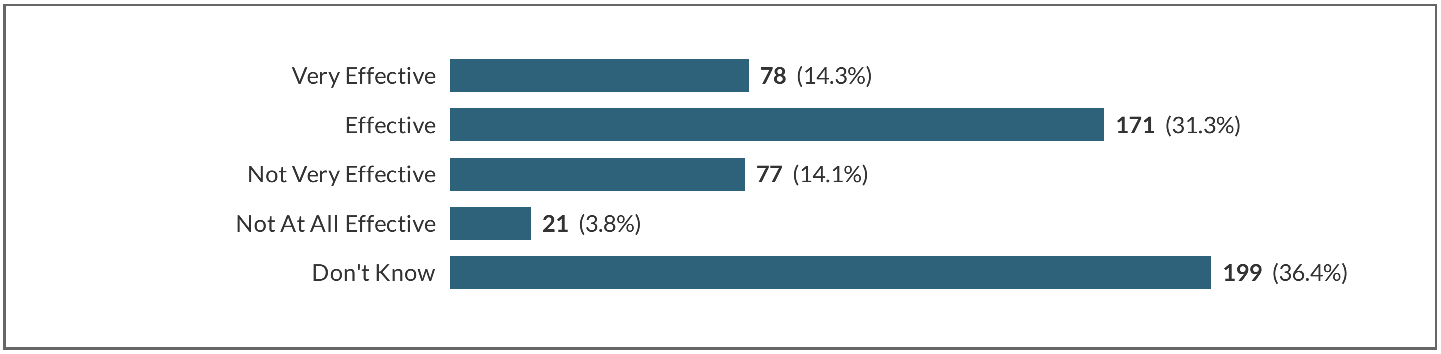
11.2 Written Information

11.2.a Written Information - Please select from Very Effective to Don't KNow



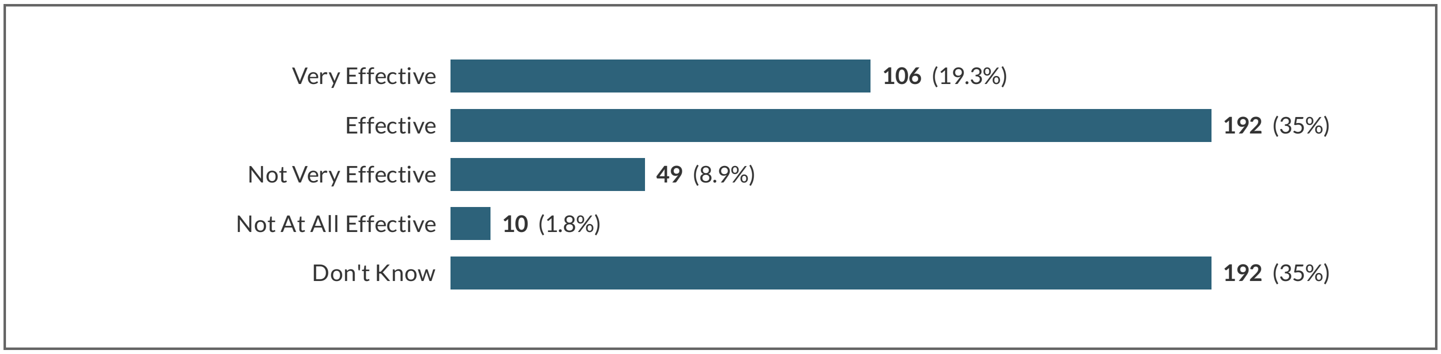
11.3 Group Education sessions

11.3.a Group Education sessions - Please select from Very Effective to Don't KNow



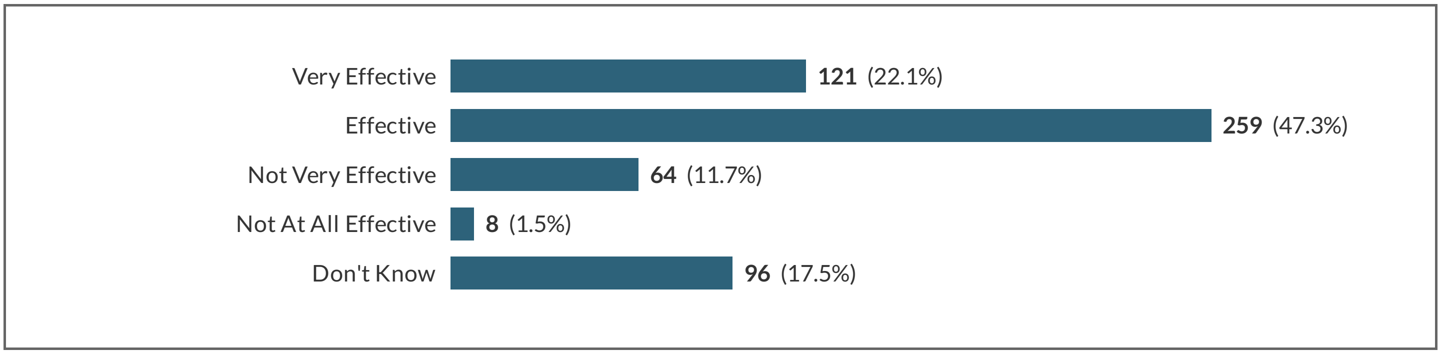
11.4 Audio-visual aids such as videos/demonstrations

11.4.a Audio-visual aids such as videos/demonstrations - Please select from Very Effective to Don't KNow



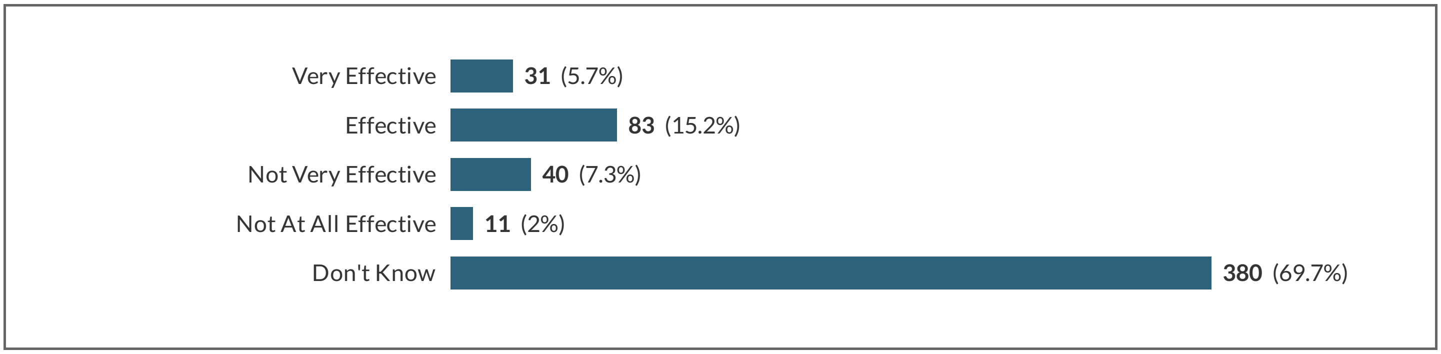
11.5 Web sites

11.5.a Web sites - Please select from Very Effective to Don't KNow



11.6 Other (in relation to additional methods you gave)

11.6.a Other (in relation to additional methods you gave) - Please select from Very Effective to Don't KNow

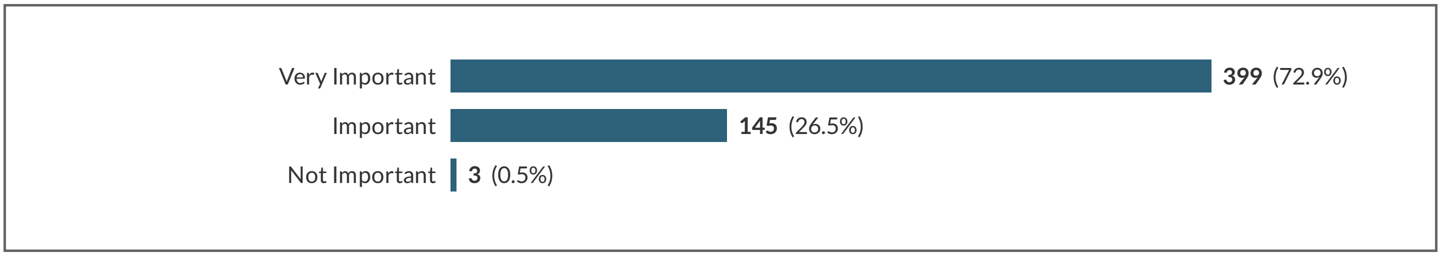


Section 4: What should be included in foot health education provision?

12 To what extent do you think it is important for people with RA to know about the following areas of foot health education? Select from Very Important to Not Important for each item. They are in no particular order.

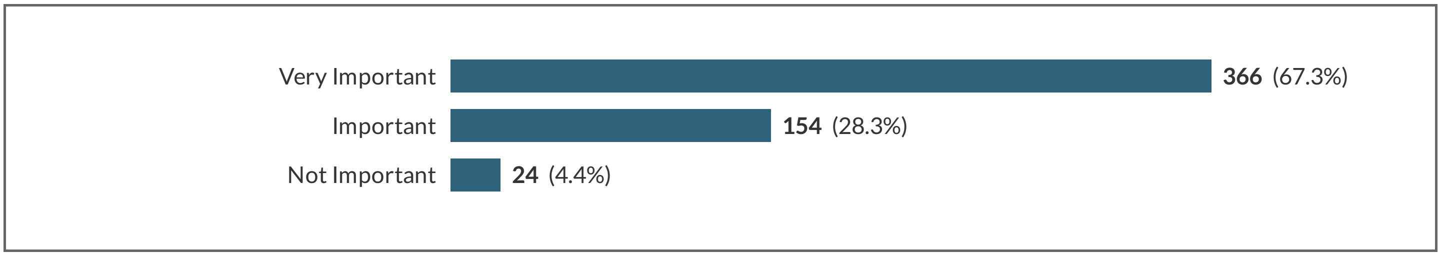
12.1 The role of the podiatrist/chiropodist in looking after my foot health

12.1.a The role of the podiatrist/chiropodist in looking after my foot health - Please select from Very Important to Not Important



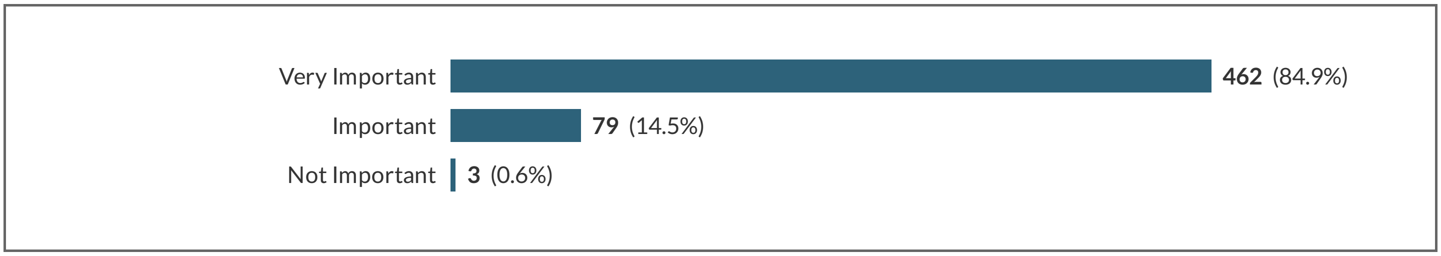
12.2 General disease related information (e.g what is RA? Causes etc..)

12.2.a General disease related information (e.g what is RA? Causes etc..) - Please select from Very Important to Not Important



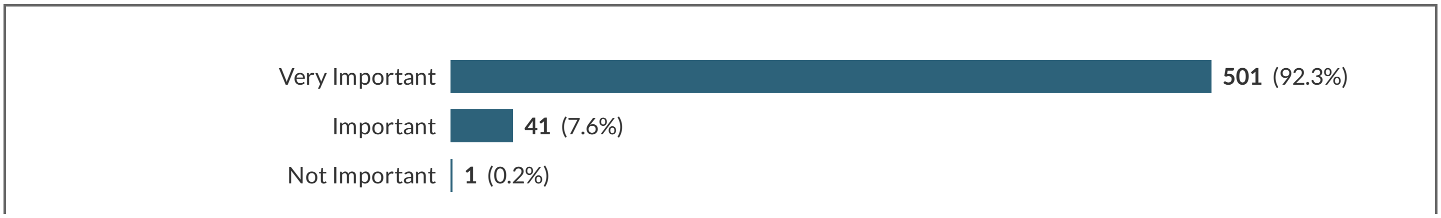
12.3 Information about how the medication I take for RA can affect my feet

12.3.a Information about how the medication I take for RA can affect my feet - Please select from Very Important to Not Important



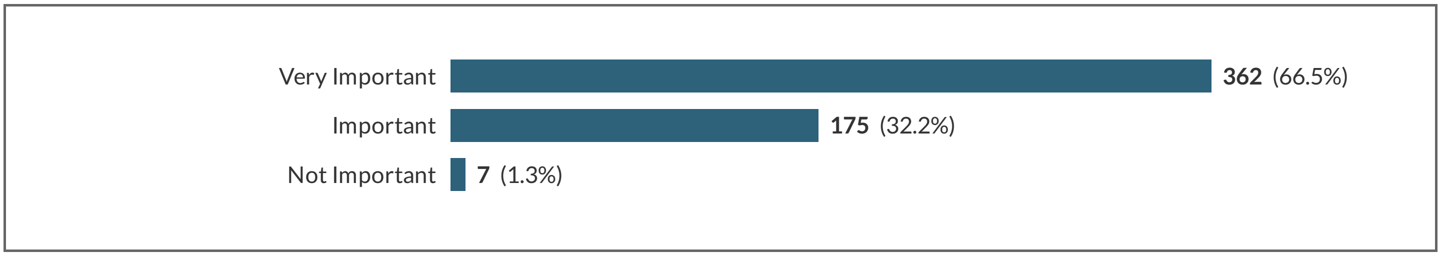
12.4 How RA affects the feet

12.4.a How RA affects the feet - Please select from Very Important to Not Important



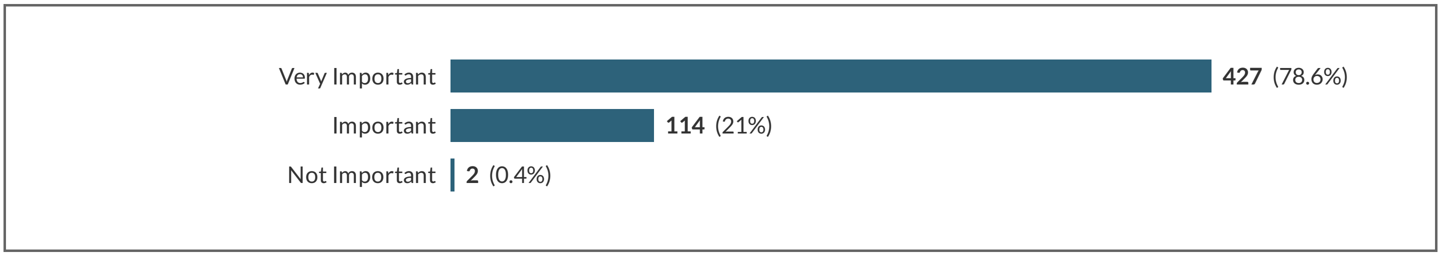
12.5 Contact details for podiatry/chiropody services (what is an emergency, how and who to contact)

12.5.a Contact details for podiatry/chiropody services (what is an emergency, how and who to contact) - Please select from Very Important to Not Important



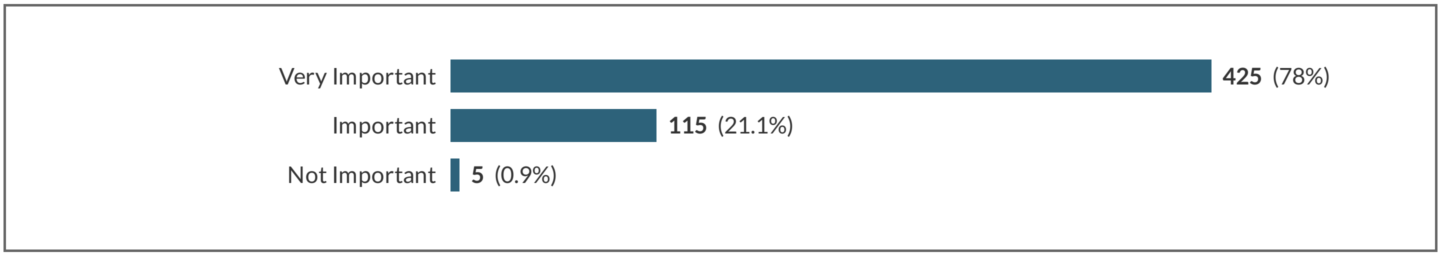
12.6 The different kinds of treatment I can have to help me with my foot problems

12.6.a The different kinds of treatment I can have to help me with my foot problems - Please select from Very Important to Not Important



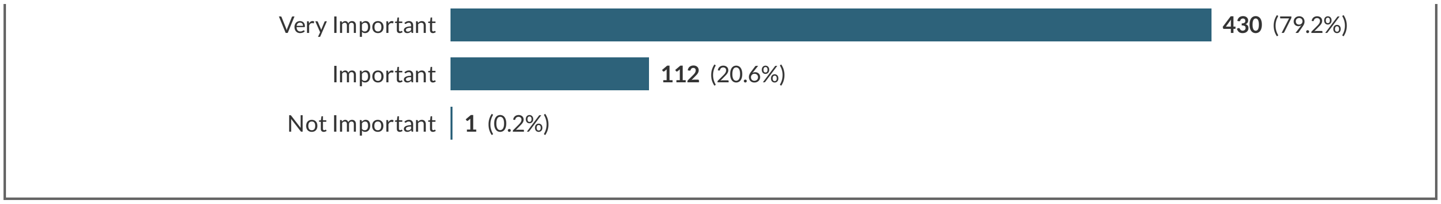
12.7 How to look after my own foot health (footwear advice, how to cut nails safely, use of moisturiser..)

12.7.a How to look after my own foot health (footwear advice, how to cut nails safely, use of moisturiser..) - Please select from Very Important to Not Important



12.8 What might happen if I don't look after my feet

12.8.a What might happen if I don't look after my feet - Please select from Very Important to Not Important

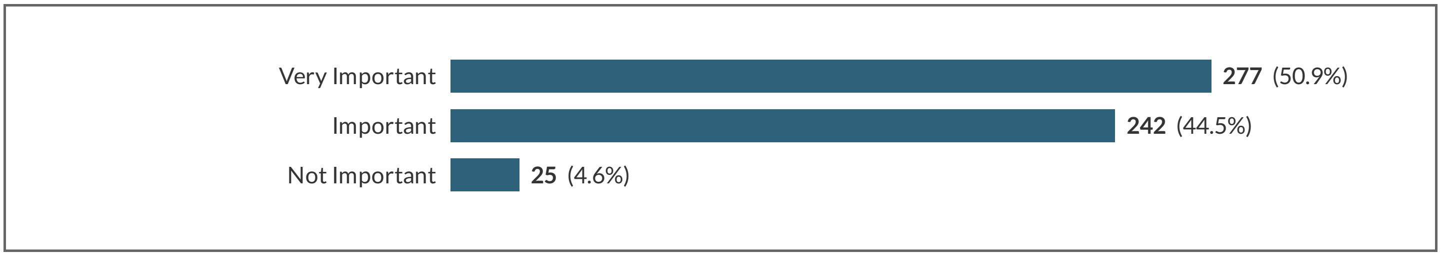


12.9 How other health professionals might be involved in looking after my feet.

12.9.a How other health professionals might be involved in looking after my feet. - Please select from Very Important to Not Important

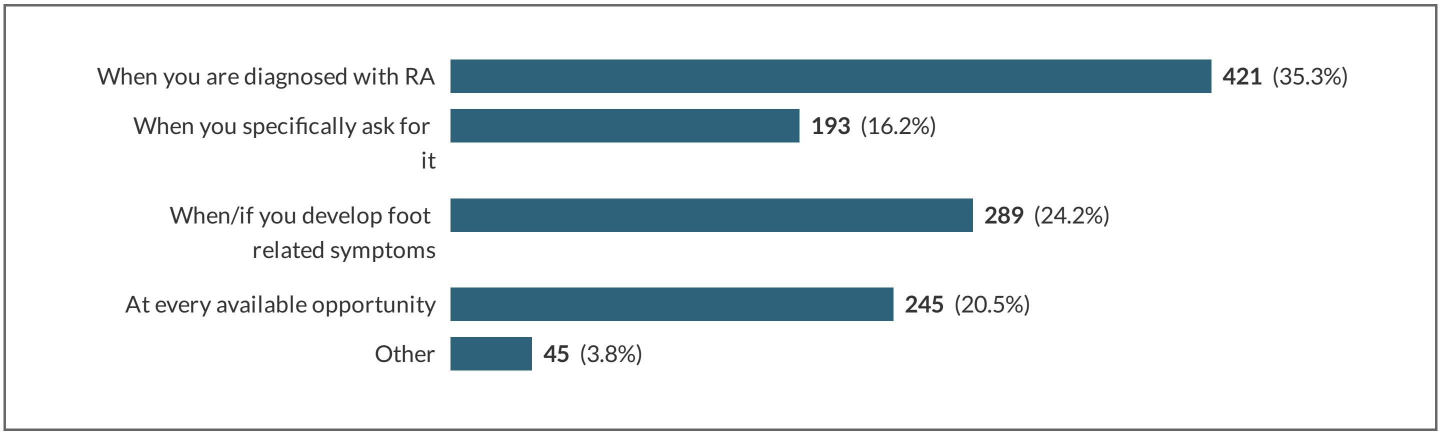
12.10 Information relating to Patient support groups/resources such as websites (e.g NRAS, Arthritis Care)

12.10.a Information relating to Patient support groups/resources such as websites (e.g NRAS, Arthritis Care) - Please select from Very Important to Not Important



Section 5: When is the best time to receive foot health education?

13 When do you think is the best time for you to be given foot health education relating to RA? Select all that you think apply.



13.a If you selected Other, please specify:

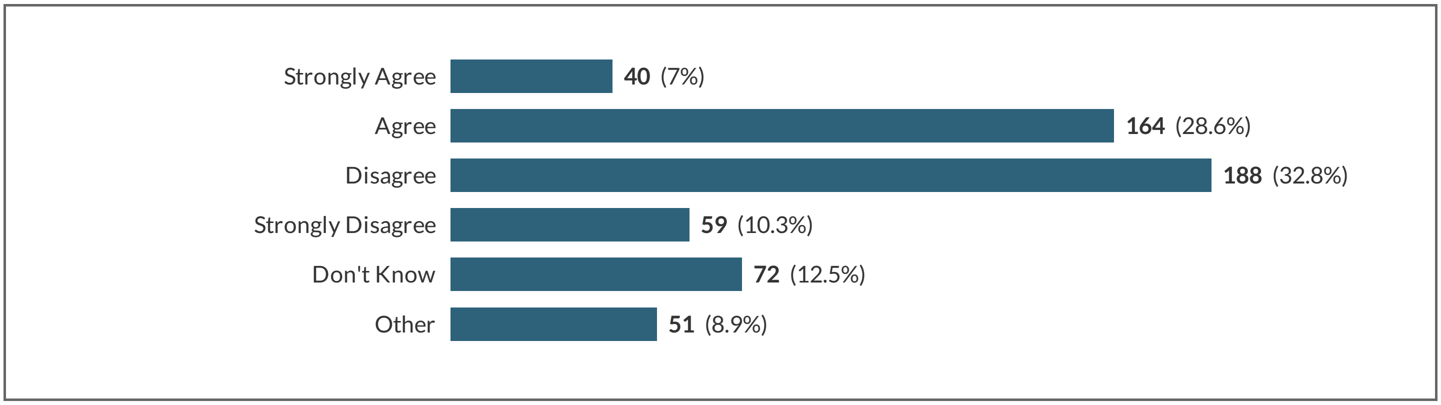
Showing 5 of 45 responses	
I think the specialist nurses and consultants should take my foot pain much more seriously. I told them I had very painful lumps under my feet, they shrug and say nodules. But what are nodules, what can they do for me? No idea.	120841-120835-6761308
I now suffer from a limp from a badly managed Achilles tendon rupture. Never offered any supports which may have protected my ankle from the forementioned damage.	120841-120835-6761318
Perhaps automatically at annual review appointments. There is a lot to take in at point of diagnosis, so perhaps again after 3 & 6 months initially.	120841-120835-6761321
it seems not taken into account	120841-120835-6761341
When the diagnosis has had time to sink in - there is so much to take in at the beginning, I think foot health education would not be appropriate then.	120841-120835-6761346

Section 6: Accessing foot health education

14 To what extent do you agree with the following statements? Select one response for each item.

14.1 I am clear about what questions to ask my podiatrist or other health professional regarding my foot health

14.1.a I am clear about what questions to ask my podiatrist or other health professional regarding my foot health - Please select from Strongly Agree to Strongly Disagree for each item. If you are unsure please select 'Don't Know'. There is space in the final column for each item if you wish to add any other comment.



14.1.b I am clear about what questions to ask my podiatrist or other health professional regarding my foot health - If you selected Other, please specify:

Showing 5 of 51 responses	
Don't really know what the podiatrist does	120841-120835-6761308
Never offered services	120841-120835-6761318
Have never had an appointment	120841-120835-6761353
No offer of referral to podiatry. Never referred to at Rhumatology appointments. All they are interested in is x-raying my feet!	120841-120835-6761354
Not applicable at this time	120841-120835-6761363

14.2 There is enough time during my appointment with the chiropodist/podiatrist to ask questions about foot health education

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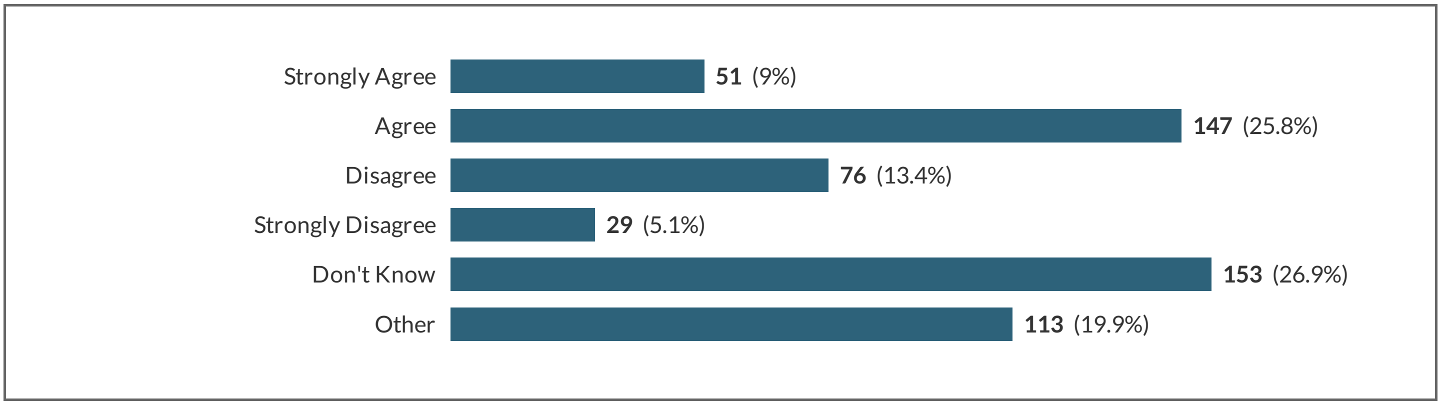
14.2.a There is enough time during my appointment with the chiropodist/podiatrist to ask questions about foot health education - Please select from Strongly Agree to Strongly Disagree for each item. If you are unsure please select 'Don't Know'. There is space in the final column for each item if you wish to add any other comment.

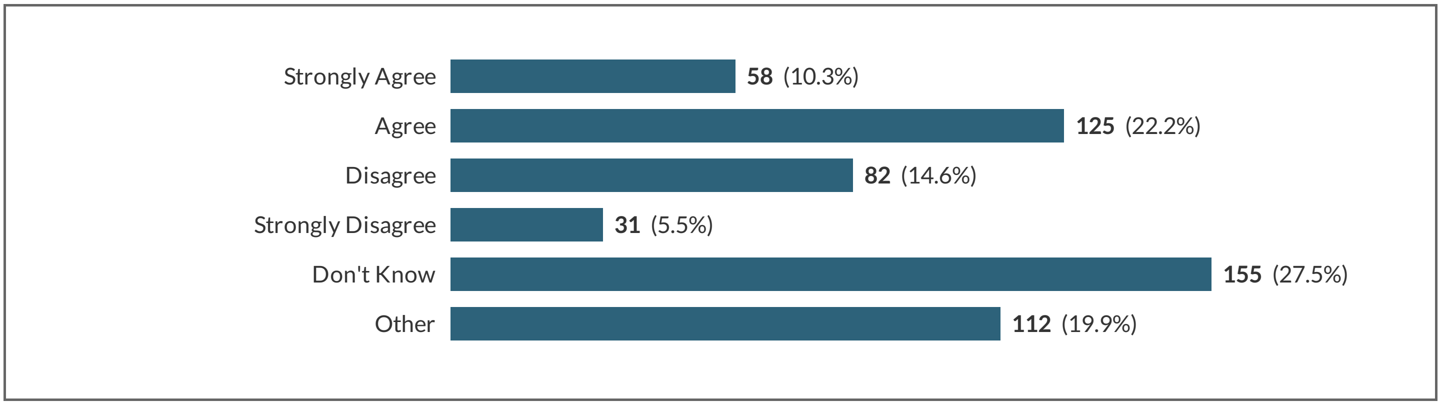


14.2.b There is enough time during my appointment with the chiropodist/podiatrist to ask questions about foot health education - If you selected Other, please specify:

Showing 5 of 113 responses	
I have no foot care offered	120841-120835-6761307
N/A have not been offered podiatry/chiropody support	120841-120835-6761309
I've never been offered an appointment	120841-120835-6761316
Not been	120841-120835-6761327
have not been offered podiatry care	120841-120835-6761331

14.3 My podiatrist/chiropodist asks about my foot health concerns during my appointment

14.3.a My podiatrist/chiropodist asks about my foot health concerns during my appointment - Please select from Strongly Agree to Strongly Disagree for each item. If you are unsure please select 'Don't Know'. There is space in the final column for each item if you wish to add any other comment.

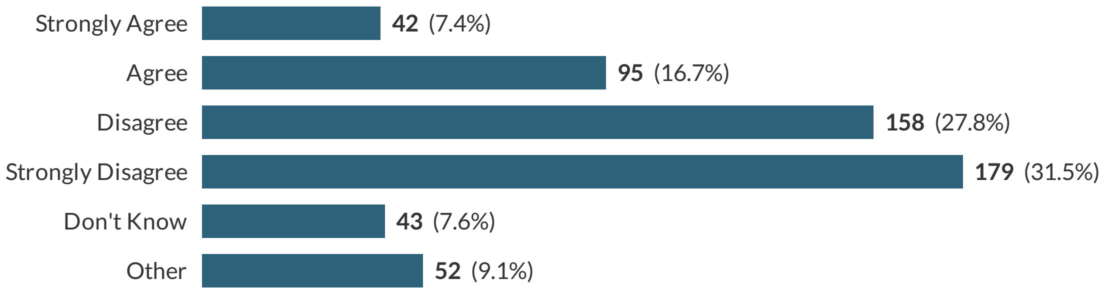


14.3.b My podiatrist/chiropodist asks about my foot health concerns during my appointment - If you selected Other, please specify:

Showing 5 of 112 responses	
I have no foot care offered	120841-120835-6761307
He won't do anything though as I am " in a flare" but I think that's exactly when I need help with my feet.	120841-120835-6761308
N/A have not been offered podiatry/chiropody support	120841-120835-6761309
I don't have one	120841-120835-6761316
Never offered services.	120841-120835-6761318

14.4 Other Health Professionals (such as the Specialist Nurse, Physio, Occupational Therapist or Consultant)ask about my feet during my appointment

14.4.a Other Health Professionals (such as the Specialist Nurse, Physio, Occupational Therapist or Consultant)ask about my feet during my appointment - Please select from Strongly Agree to Strongly Disagree for each item. If you are unsure please select 'Don't Know'. There is space in the final column for each item if you wish to add any other comment.

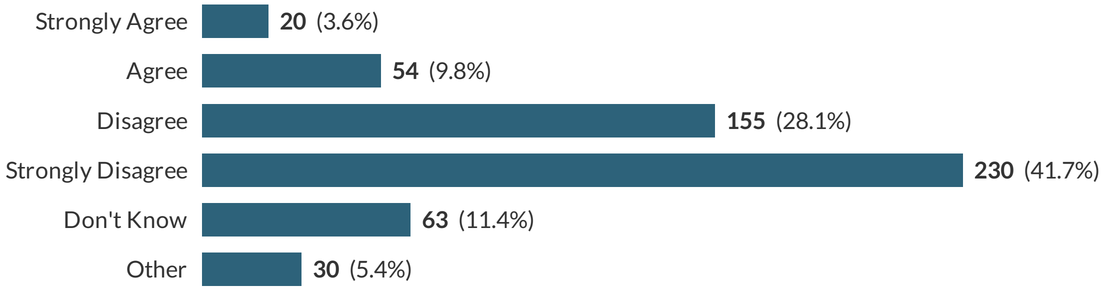


14.4.b Other Health Professionals (such as the Specialist Nurse, Physio, Occupational Therapist or Consultant)ask about my feet during my appointment - If you selected Other, please specify:

Showing 5 of 52 responses	
Only if I bring up my concerns re: foot health.	120841-120835-6761305
Really feel they aren't bothered as its not in the DAS score, therefore not a high priority	120841-120835-6761308
Recently spoke to a physio who advised on foot wear.	120841-120835-6761318
Occupational therapist sometimes asks but I was referred to her about my hands	120841-120835-6761336
wife askes nurse about my feet	120841-120835-6761360

14.5 I have received written foot health information from my Podiatrist or other Health Professional

14.5.a I have received written foot health information from my Podiatrist or other Health Professional - Please select from Strongly Agree to Strongly Disagree for each item. If you are unsure please select 'Don't Know'. There is space in the final column for each item if you wish to add any other comment.



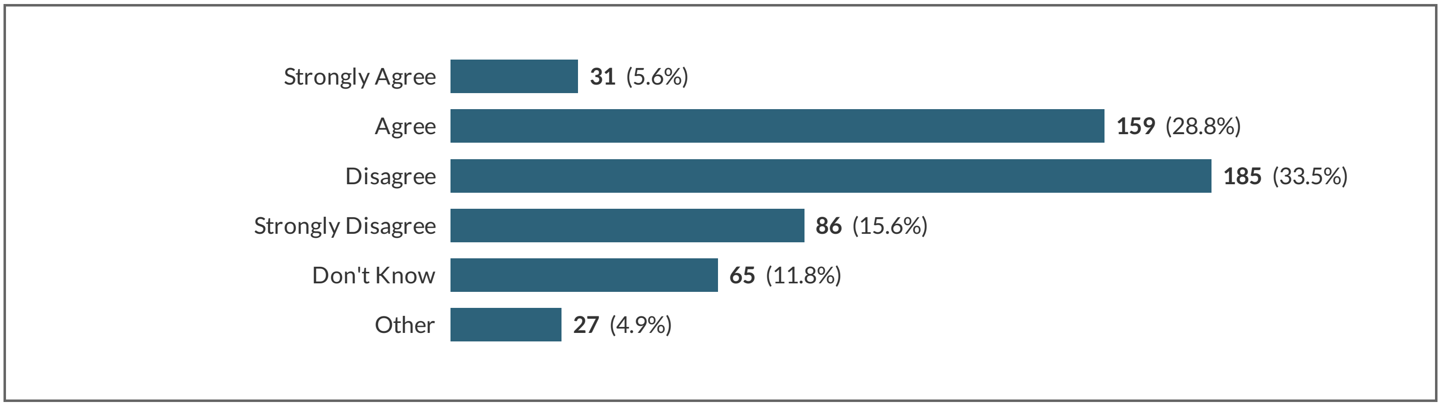
14.5.b I have received written foot health information from my Podiatrist or other Health Professional - If you selected

Other, please specify:

Showing 5 of 30 responses	
Not been	120841-120835-6761327
I never knew it exixted will start looking as my feet are very bad	120841-120835-6761353
only on inserts for my shoes	120841-120835-6761360
Not applicable at this time	120841-120835-6761363
no information received	120841-120835-6761435

14.6 I have received or found information myself relating to RA and foot health, but found it difficult to understand

14.6.a I have received or found information myself relating to RA and foot health, but found it difficult to understand - Please select from Strongly Agree to Strongly Disagree for each item. If you are unsure please select 'Don't Know'. There is space in the final column for each item if you wish to add any other comment.

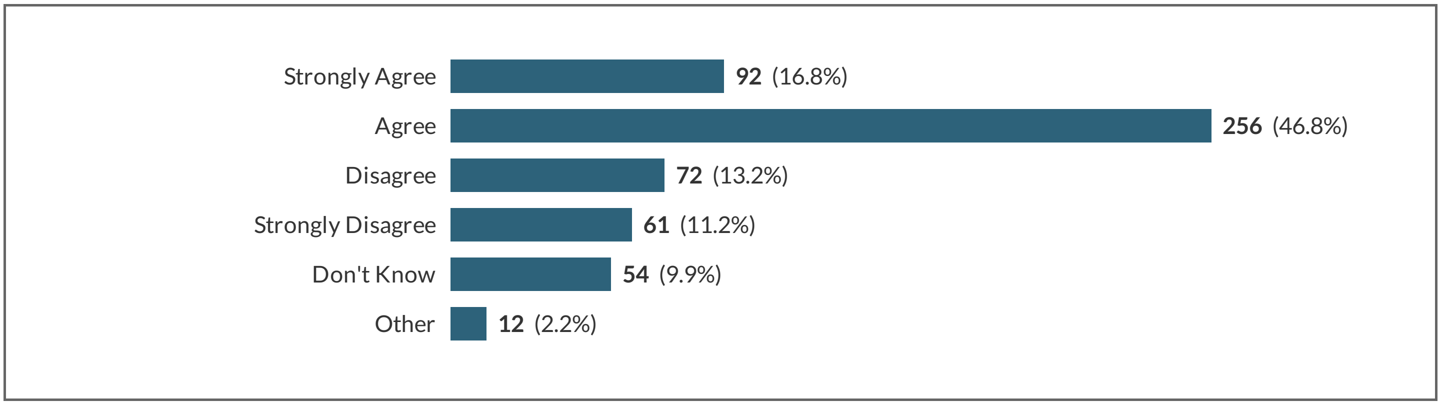


14.6.b I have received or found information myself relating to RA and foot health, but found it difficult to understand - If you selected Other, please specify:

Showing 5 of 27 responses	
This is the first I've heard of it	120841-120835-6761316
NRAS information	120841-120835-6761321
I found the info myself & Lund it easy to understand, but I am a Nurse Educator with RA.	120841-120835-6761354
Didn't know there was any. Didn't know I should be concerned about my feet.	120841-120835-6761378
I sent for info about foot surgery from bras, which was interesting and not particularly hard to understand it was however, rather out if date	120841-120835-6761396

14.7 I know where I can access written foot health information (such as a leaflet or from websites such as NRAS)

14.7.a I know where I can access written foot health information (such as a leaflet or from websites such as NRAS) - Please select from Strongly Agree to Strongly Disagree for each item. If you are unsure please select 'Don't Know'. There is space in the final column for each item if you wish to add any other comment.

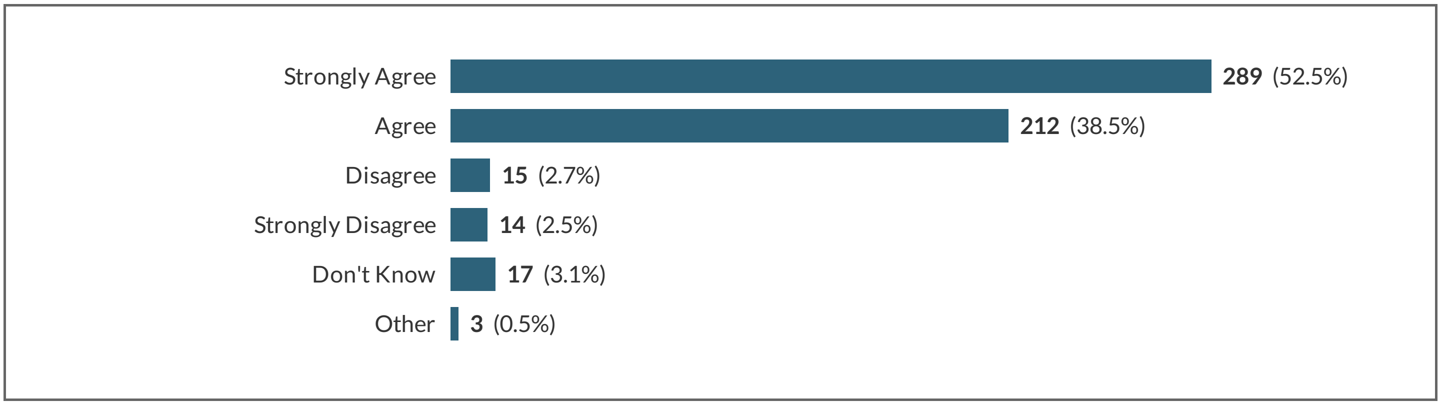


14.7.b I know where I can access written foot health information (such as a leaflet or from websites such as NRAS) - If you selected Other, please specify:

Showing 5 of 12 responses	
one would only think about foot health information and how to go about it once there was a problem, first stop would probably be GP	120841-120835-6761419
Need to get someone to access information for me.	120841-120835-6761458
I know where the local Poidiatrist clinics are held.	120841-120835-6761476
As above.	120841-120835-6761379
As above	120841-120835-6761549

14.8 I am able to access the Internet or someone does it for me

14.8.a I am able to access the Internet or someone does it for me - Please select from Strongly Agree to Strongly Disagree for each item. If you are unsure please select 'Don't Know'. There is space in the final column for each item if you wish to add any other comment.

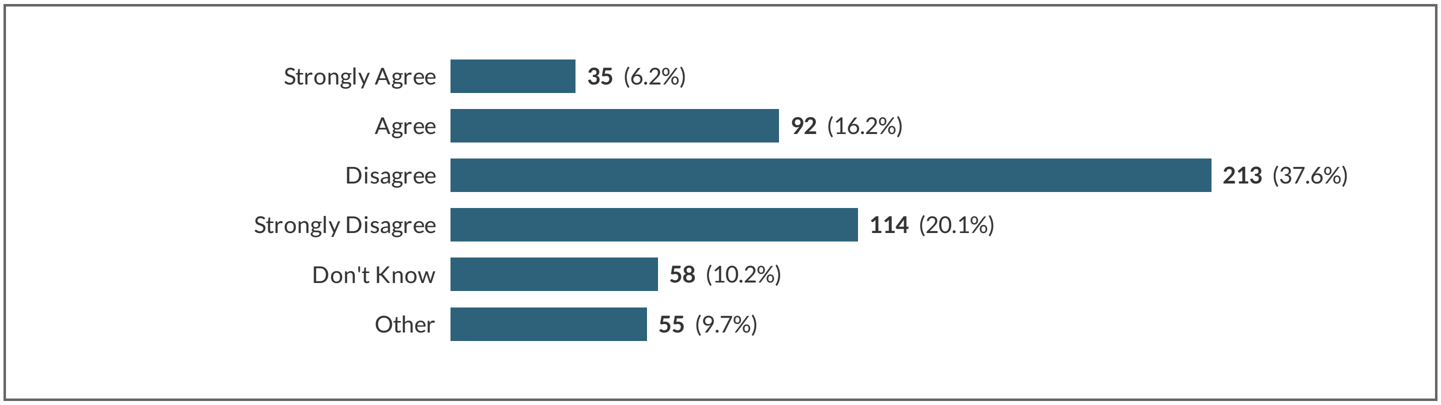


14.8.b I am able to access the Internet or someone does it for me - If you selected Other, please specify:

Showing all 3 responses	
Yes have access to Internet.	120841-120835-6761379
As above	120841-120835-6761549
Myself.	120841-120835-6761764

14.9 I cannot afford the time to attend patient support group meetings

14.9.a I cannot afford the time to attend patient support group meetings - Please select from Strongly Agree to Strongly Disagree for each item. If you are unsure please select 'Don't Know'. There is space in the final column for each item if you wish to add any other comment.

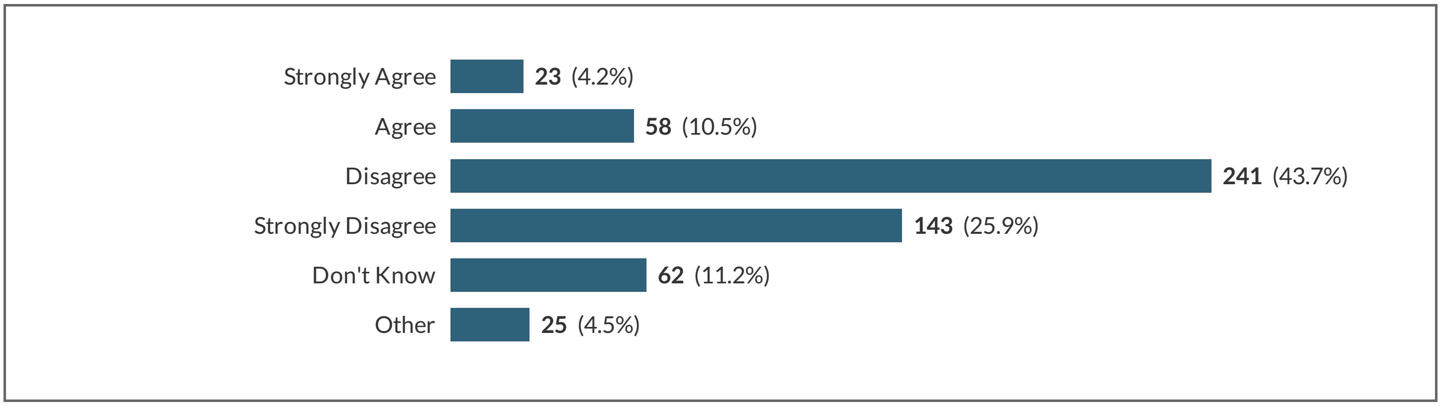


14.9.b I cannot afford the time to attend patient support group meetings - If you selected Other, please specify:

Showing 5 of 55 responses	
Also it's very painful to get to meetings due to sore joints and painful feet. The rheumatology department is at the back of the hospital too.	120841-120835-6761308
The times are what prevent me from attending	120841-120835-6761310
I can now since taking voluntary retirement.	120841-120835-6761318
I cannot attend on my own, so it would involve another person's time.	120841-120835-6761321
not been offered these	120841-120835-6761341

14.10 I cannot afford the money to attend patient support group meetings

14.10.a I cannot afford the money to attend patient support group meetings - Please select from Strongly Agree to Strongly Disagree for each item. If you are unsure please select 'Don't Know'. There is space in the final column for each item if you wish to add any other comment.



14.10.b I cannot afford the money to attend patient support group meetings - If you selected Other, please specify:

Showing 5 of 25 responses	
There are no patient support groups here that I can access - all require a car and I don't have one!	120841-120835-6761326
as above	120841-120835-6761341
see above	120841-120835-6761346
I don't know if there are any?	120841-120835-6761377
doesn't cost money	120841-120835-6761404

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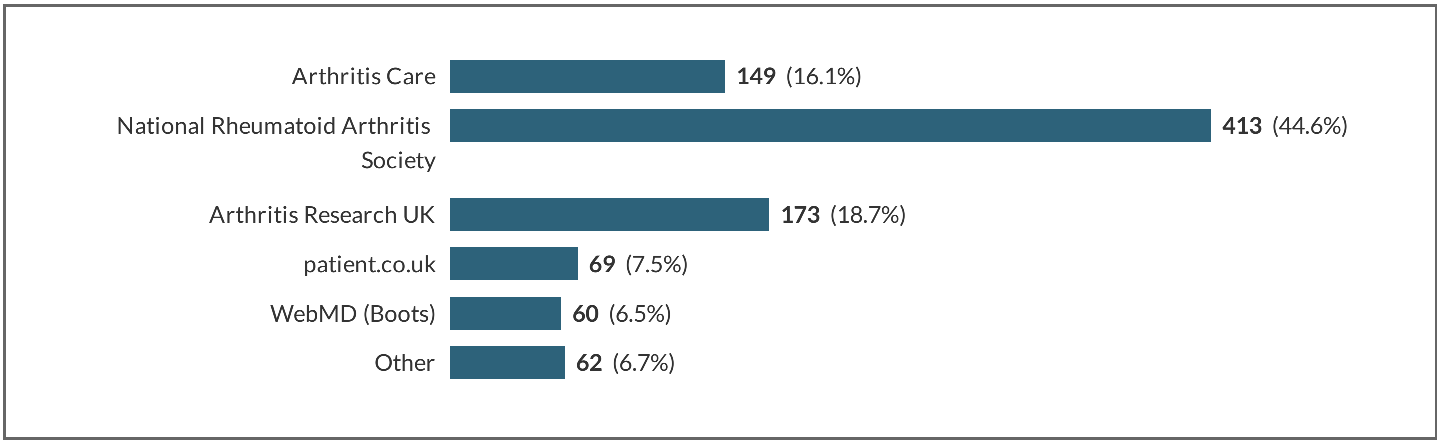
15 If you use the internet to get foothealth information, which websites do you most frequently use? please select all that apply and add any other website that we may not have included in the 'other' box.



15.a If you selected Other, please specify:

Showing 5 of 62 responses	
I Google my problem and see what comes up.	120841-120835-6761312
I didn't know that you had to take care of your feet. With my feet changing shape it would of been good to have known	120841-120835-6761316
Amazon for specialist products.	120841-120835-6761318
Health Unlocked	120841-120835-6761326
I try any and all websites although I find the US ones a bit sensational.	120841-120835-6761335

16 This free text box is for you to add any additional comments or information that you feel is relevant and has not been addressed by this survey. Thank you.

Showing 5 of 249 responses	
I have had a letter today from my GP offering this servce	120841-120835-6761307
I have extremely painful feet and no one takes any notice of my feet pain as it isn't included in my DAS score, so they are not bothered. But for my pain and quality of life it is the biggest thing! Also I was give a pair of thin insoles by a friend hitch are pretty useless.	120841-120835-6761308
Question 11 is ambiguous (as far as I understand) if Question 10 doesn't apply. Particularly Question 11f but the survey says these questions are mandatory. This seems to be a confusing and poorly designed survey for the user.	120841-120835-6761309
Feet are of little interest to the RA professionals. My feet seem to cause me a lot of trouble, but there is no obvious person to ask.	120841-120835-6761312
I don't think enough information/ advice is given during appointments (my experience only) and I have always had to raise the subject myself.	120841-120835-6761314

Paper 7 – Additional File 6 – Statistical analysis data.

Additional file 2: P-values arising from statistical analyses of participants' survey responses by section, in relation to gender, age, disease duration and living situation. * - Denotes significance at the 5% level.

	Independent Variables			
Dependent Variables: by FHE survey section	Gender	Age	Disease duration	Living situation
Aims	0.504	0.073	0.279	0.187
Methods: written	0.877	0.132	0.409	0.008*
Methods: Verbal	0.329	0.225	0.140	0.228
Methods: Group	0.284	0.467	0.878	0.519
Methods: A-V videos	0.350	0.521	0.462	0.805
Methods: A-V demos	0.589	0.929	0.398	0.277
Methods: Images	0.464	0.254	0.354	0.354
Methods: websites	0.245	0.204	0.090	0.737
Effectiveness of methods	0.150	0.720	0.842	0.899
Content	0.022*	0.886	0.956	0.144
Timing	0.019*	0.106	0.163	0.894
Barriers (+ve statements)	0.527	0.004*	0.241	0.985
Barriers (-ve statements)	0.547	0.535	0.147	0.876
Web sites used	0.034*	0.146	0.342	0.498

2.8 – Summary for the PhD by Published Works included papers:

In summary the key findings of the overall body of works can be outlined thus:

- The narrative review identified the need to investigate the nature and requirements of FHE for people with RA from both a patient and podiatry practitioner perspective.
- Identification of FHE needs and the provision of specific, supportive verbal and written information can foster an effective therapeutic relationship, supporting the provision of tailored FHE for people with RA.
- People with RA and podiatry practitioners alike attribute FHE provision during the medical consultation, with high value, but barriers remain to its' provision.
- Awareness of the potential impact of foot pathology and its' management is low amongst both people with RA and podiatry practitioners, leading to a detrimental impact on the prognosis of foot health.
- Foot problems are perceived as 'being ignored' from the point of diagnosis of RA through to established disease, by people with RA. This significantly limits access to FHE/information, which could facilitate effective self-management and/or timely referral to foot health services.
- Foot pathology in people with RA has a profound and strong psychosocial impact upon their day-to-day lives. Having knowledge about potential foot health prognoses and information about how to self-manage could reduce this impact.
- The point of diagnosis of RA (early disease) and as part of subsequent medical consultations (into established disease) were deemed to be the best times for the provision of FHE, by both podiatry practitioners and people with RA.
- Podiatry practitioners are limited in their ability to deliver effective FHE due to time and systematic constraints, particular to foot health service provision.
- People with RA require early (in the disease process) and then on-going identification of their FHE needs to enable timely and tailored FHE provision. The development of a foot-health related educational needs analysis tool would facilitate this in a patient-centred, yet time efficient way.

Part 3 – Critical Review

3.0 - Critical Review

The aim of the critical review is to appraise the body of work from a micro and macro perspective; critically analysing the philosophical approach to the research and the methods employed for data collection and analysis, acknowledging limitations and what has been learned, evaluating the work within the context of others, evaluating the wider impact of the portfolio of publications in respect of clinical practice and implications for future research.

To achieve this aim the review will be presented in five sections:

- A critical reflection of the authors' perception of patient education as a concept and the influence of the authors' personal philosophical stance.
- A critical review of the methodological approaches used throughout the portfolio of published work.
- A critical analysis of the wider impact on the portfolio of work in the context of: citation analysis, download and Altmetric data and journal impact factors.
- A critical review of the portfolio of work in relation to knowledge translation – translating the research into practice and the potential barriers to this process.
- A consideration of the implications for future research as a result of the findings within this portfolio of work.

3.1 Critical Reflection upon the authors' perceptions of patient education.

This section will critically reflect upon my altered perception of patient education and philosophical stand-point as a result of undertaking this research. Providing an accepted working definition of the concepts of *patient education* and *patient information* is worthwhile at this point in order to provide some context as to the evolution of my perception of patient education. Jotterand et al, (2016) put forward the following working definitions for Health Information:

> *"Health information or providing health information to a patient is the act by which a provider communicates all relevant clinical facts to a patient about his or her health condition. This information includes data about the nature of the condition, symptoms, diagnosis, treatments options, etc."*

And Health Education:

> *"...health education is a more complex process since it requires the provider to create a learning environment that promotes learning, communication*

> *with learners (patients), establishing the right context for learning, and addressing potential challenges to the learning process… health education demands knowledge in how to treat a medical condition but also a robust understanding of the principles of teaching and learning geared toward the specific needs of patients and their decisional needs."*

Whilst the overall goals of both health information and health education remain similar in that they assist patients to make informed health choices, health education aims to foster empowerment, promote positive health behaviour and increase patient participation in their individual health care decisions. The achievement of these aims is through educational strategies to enhance patient autonomy and improve quality of life (WHO, 1998; Jotterand et al, 2016).

As a novice lecturer and researcher my initial understanding of what patient education *was*, was a very naïve, simplified view. My view was that people received a diagnosis of a disease or foot health problem and health practitioners provided information (verbal or written leaflets or both) as to how the disease could impact upon them and how it would be managed. According to Jotterand et al (2016) my approach to patient education provision lay very firmly within the defined scope of *health information.* Even though, as a lecturer, I had an understanding of educational theory and pedagogy as it related to people within a higher education context, I had not considered that there would be any parallel with how this theory should or could be transferred into the health care setting. Structured approaches to so-called Therapeutic Patient Education (TPE) have been defined by the World Health Organisation (WHO, 1998) using a stepwise approach, an example of which is illustrated in Table 5.

Table 5: Therapeutic patient education: an example of a systematic approach (Rizzo et al, 2006).

• Identification of the patients educational needs ('educational diagnosis')
• Exchanging education concepts and objectives with the patient ('educational-therapeutic contract')
• Suggesting alternative and interactive teaching approaches ('active teaching/learning')
• Checking educational activity quality and results by qualified methods ('evaluation')

Approaches such as this which seek to understand educational need and base curriculum design, delivery and evaluation upon those requirements are the mainstay of the majority of educational institutions across all sectors of society such as demonstrated within school-based curriculum design (www.gov.scot, 2011) and within resources developed by the Higher Education Academy (HEA) to facilitate flexible approaches to teaching and learning for students based in Higher Education (HEA, 2015).

Further to this recognition of the similarities of pedagogical design, I found that tension existed as to how patient education and its format of provision, was perceived by the medical community. Jones (2002) believes that the provision of patient education should not be viewed as a treatment modality considering rather that it is an ethical obligation that all individuals receive the breadth and depth of information required to enable them to give fully informed consent to their management. In contrast to this, much of the published literature that investigates the impact of patient education on clinical outcomes refers to it as an ‘intervention’; whether the ‘intervention’ is simple information provision or more complex group based counselling or behavioural education programmes based on the pedagogical framework outlined earlier. For those who do not routinely employ such complex interventional strategies, provide or recognise the significance of patient education from both a general and foot health perspective, it could be assumed that it may not be consciously viewed as an overt treatment modality.

Through my research journey, I came to understand the significant influence that providing opportunities for a person with RA to articulate their foot health concerns and fears, had upon how they viewed the management of their foot health. This strengthened my view that regular FHE provision, whether it consists of simple information giving or a more complex educational strategy, should be an essential component in the day-to-day management of people with RA. Even more significantly, I found that in developing the research study and data collection tool with the participants, the study itself and I became a vehicle for foot health education provision and a voice for the patient perspective. I realised that my perception of foot health education and what people with RA needed had been altered by my personal research journey, creating a new personal understanding of the concept of patient (health) education.

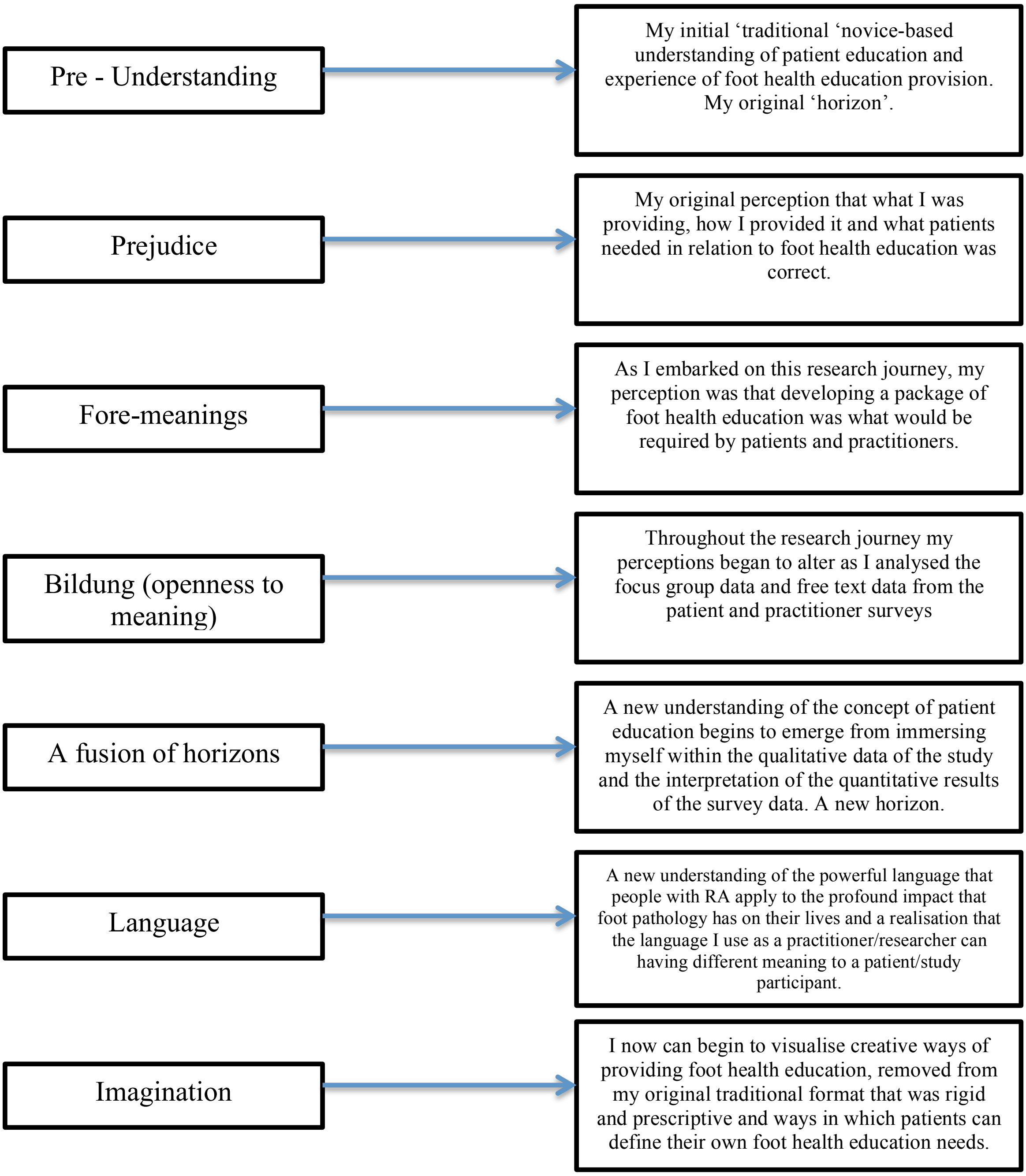
To understand the philosophy underpinning this process of altered perception, the work of German philosopher Hans-Georg Gadamer (Gadamer, 2004) explains the concept philosophical hermeneutics. Hermeneutics promotes human potential for understanding the meaning of language to '*expand the infinite possibilities of human thought'* (Palmer, 1969) to help interpret and understand another's perspective other than one's own. In order to illustrate this concept of understanding, Gadamer (2004) describes the individual as each having their own 'horizon'; which is as far as each individual can see or understand. He describes a horizon as:

> *"The totality of all that can be realised or thought about by a person at a given time in history and in a particular culture."*

Each person's 'horizon' is individual to them and their 'horizons' are changed or modified by encounters with other people and situations, their 'new' understanding moves their 'horizon' and the process of understanding can be said to be a 'fusion of horizons'. Several processes will be running in tandem with each other during the development of the 'new horizon' which Gadamer describes thus: pre-understanding, prejudice, fore-conceptions, 'Bildung' (translated as openness to meaning), language and imagination. These processes can be viewed in the context of my research journey (Figure 2).

This process of horizon-modification can also be applied to the consultation process that occurs between the patient and practitioner, with the patient and the practitioner having their own 'consultation styles'. Patients can be said to have a 'narrative' consultation style, the need to tell their 'story', whilst practitioners can be said to have a 'normative' style, the seeking of pattern recognition within the presented signs and symptoms of the patient (Clark, 2008). Launer (2003) reinforces the need to recognise both the patients' legitimate need for self-expression and the practitioners own need to achieve pattern recognition (a diagnosis), action and closure. Each has their own circle of understanding, their own horizon and this concept resonated with me and the way that I would conduct my own patient consultations in the past and what I had perceived patient's foot health education needs to be. Perhaps what we should be seeking to achieve within our 'encounters' with patients as health care practitioners, is a mutual acknowledgement of each other's circle of understanding and the creation of a new horizon, within which a patient is able to articulate their foot health education needs and then have them met.

Figure 2: Processes of horizon development as described by Gadamer (2004).



Pre - Understanding

My initial ‘traditional ‘novice-based understanding of patient education and experience of foot health education provision. My original ‘horizon’.

Prejudice

My original perception that what I was providing, how I provided it and what patients needed in relation to foot health education was correct.

Fore-meanings

As I embarked on this research journey, my perception was that developing a package of foot health education was what would be required by patients and practitioners.

Bildung (openness to meaning)

Throughout the research journey my perceptions began to alter as I analysed the focus group data and free text data from the patient and practitioner surveys

A fusion of horizons

A new understanding of the concept of patient education begins to emerge from immersing myself within the qualitative data of the study and the interpretation of the quantitative results of the survey data. A new horizon.

Language

A new understanding of the powerful language that people with RA apply to the profound impact that foot pathology has on their lives and a realisation that the language I use as a practitioner/researcher can having different meaning to a patient/study participant.

Imagination

I now can begin to visualise creative ways of providing foot health education, removed from my original traditional format that was rigid and prescriptive and ways in which patients can define their own foot health education needs.

3.2: My research in the public domain – the body of work in context. A critical review of the methodological approaches used.

This section will critically review the published works within this thesis in the context of the philosophical stance of the author and different methodologies used throughout each phase of the research journey and other works published within the podiatric literature. Throughout the published works a range of methods have been used including:

- Narrative Literature review (paper 1)
- Focus Groups/ thematic analysis (papers 2,3,4)
- Cognitive Debriefing (papers 5,7)
- Online Survey methodology/ quantitative and qualitative analysis (papers 5,6,7)

The published works themselves provide in-depth detail as to the methods used and their justification. The two main phases of the research; the initial exploratory, qualitative phase and the subsequent survey, quantitative phase, can be visualised in the context of Crotty's four basic elements of the research process (Figures 3 and 4); epistemology, theoretical perspective, methodology and methods (Crotty, 1998). The natural evolution from one method to the next can be seen as a logical journey within the commentaries provided before each individual paper in section 2.

Figure 3: Phase 1- illustrates how the qualitative components of the research align with Crotty's four basic elements of the research process

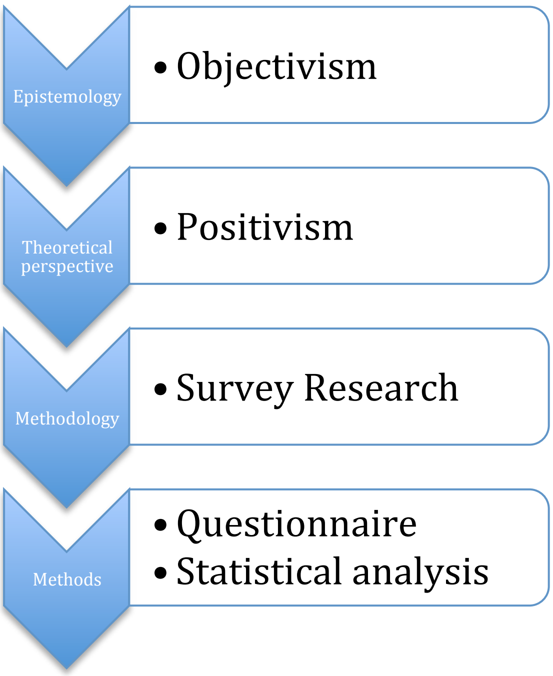


Figure 4: Phase 2- illustrates how the quantitative components of the research align with Crotty's four basic elements of the research process

The nature of the research question that underpins this work demanded a pragmatic approach to enquiry and data collection. The mixed methods approach undertaken here can be said to achieve the multiple goals of explanation, confirmation and triangulation. The narrative review and the qualitative methods (focus groups/cognitive debriefing and thematic analysis) provide an explanatory analysis of what patient education works for whom, in what circumstances, in what respects and how (Pawson, 2005). Then, by adopting a sequential design, the themes that emerged from the first phase were reflected in the questionnaire design (second phase) and thereby in the confirmation and triangulation of the results (Haq, 2014).

The use of narrative as opposed to systematic review as the primary piece of work can be defended in the context of this research because it was used to examine the impact of a complex intervention (patient education), examining themes within the developing narrative that emerged from the synthesis of the data. This 'realist' approach to reviewing the literature rejects the hierarchical approach inherent within systematic reviews, because multiple methods not just randomised controlled trials

(RCTs) are needed to illuminate the picture and provide enlightenment (Gough, Thomas and Oliver, 2012). Thus, the narrative review included the use of systematic reviews, RCTs, non-randomised studies, cohort studies and surveys. Narrative reviews can summarize and make comment on a broad selection of studies, although a weakness of the method can be viewed as their inability to include the calculation of effect sizes, though this was not a stated aim of the review within this portfolio. In order to maintain a rigorous and systematic approach to reporting the results of the narrative review, clear inclusion and exclusion criteria were transparently applied, a process for which is outlined by the Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) statement (Liberati et al, 2009).

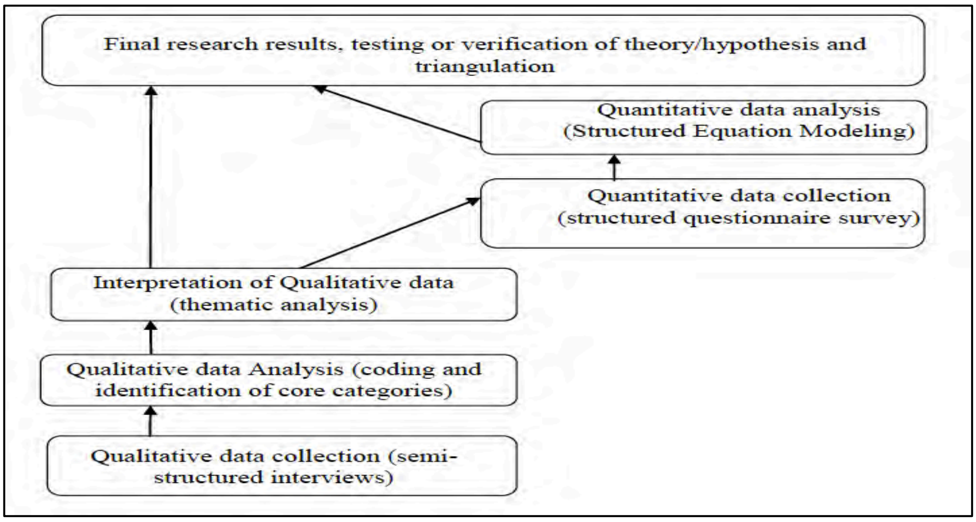
The overall methodological approach to research design across this portfolio of publications therefore, has its‘ roots in mixed methods research; within the relatively recent research paradigm of pragmatism, combining the use of positivistic methods common to quantitative research and the constructivist methods that are aligned with qualitative research (Tariq and Woodman, 2010). In this context, mixed methods research aligns to a more pragmatic approach to research design; there is no subscription to the view that quantitative and qualitative research should remain separate and within ‘incompatible’ paradigms. In this case pragmatism is accepted as a paradigm in and of itself in concordance with the view of Morgan (2014). The ‘traditional’ view of research paradigms; quantitative ‘v’ qualitative, as a philosophical system can be described as post-positivists claiming that the world exists apart from our understanding of it, whilst constructivists believe that the world exists and is created by our conceptions of it (Guba and Lincoln, 2005). From the divide between these two seemingly opposing paradigms has emerged this third paradigm of pragmatism, with the use of Mixed Methods Research being advocated as the most appropriate approach with which to understand social realities; combining the use of qualitative and quantitative methods of data collection and analysis (Creswell, 2002; Caruth, 2013).

The use of mixed methods research is justified where applied to developmental research in readiness for the use of another sequential method such as here with the use of focus groups to inform the development of a wider survey (papers 2,3,4).
Similarly, both qualitative and quantitative approaches to data collection can be used to compliment and/or triangulate results. Again this can be seen with the use of the

results of thematic analysis that were produced from both the patient and practitioner surveys (papers 5,6,7) being triangulated with the descriptive and inferential statistical data from the surveys' quantitative results. The use of mixed methods research within podiatric research is becoming more widespread with a number of studies using a similar sequential approach to research design and incorporating the use of systematic review, semi-structured interviews, focus groups and survey methods (Walmsley et al, 2012; Hendry et al, 2013; Barton et al 2016; de Souza et al, 2016).

Using Tariq and Woodmans' (2010) description of the range of approaches that can be considered within mixed methods research, the work published within this portfolio is of an Exploratory Sequential design; qualitative analysis of focus group data followed by quantitative analysis of survey data. Alongside the quantitative data analysis ran a parallel thematic analysis of free text data generated by each survey. The qualitative phase (focus groups and cognitive debriefing as part of the pilot survey test) allowed identification of new factors, not identified from the thematic analysis undertaken within the narrative review that could be tested on a larger population using a quantitative survey. Figure (5) illustrates a typical example of a sequential mixed methods research design to which the research design of this portfolio of publications can be closely mapped.

Figure (5) Flow chart to illustrate Sequential mixed methods design taken from Haq (2014).



The data that was collected throughout each phase was kept analytically distinct to ensure the preservation of its' integrity, this additionally capitalizes on the possibility for a more advanced understanding of the phenomena in question, through the combining of the two (qualitative and quantitative) data sets (Tariq and Woodman, 2010). An alternate approach could have been to use an integrative strategy to data analyses; the transformation of one type of data into another known as ‘quantitizing’ or ‘qualitizing’, an example of which would be the numerical coding of qualitative data that would enable numerical statement counting or by the use of analytical software such as NVivo to matrix code the transcribed narratives. This approach to data analyses was outwith the scope of the authors experience at the time and thus was not undertaken. A search of the literature using the PubMed data-base, related search terms employing Boolean logic (e.g: “podiatry” AND..””) and no date range restrictions was undertaken to compare the use of the various data collection methods in the published podiatric research with those of the work within this thesis (Table 6).

Table (6) to show the results of the literature search in PubMed for comparison of data collection methods in podiatric related published research.

Key words	Results
“podiatry” AND “mixed methods research”	17 abstracts of which 4 were directly related to mixed methods research. The remainder were either not related to podiatry or did not have a direct focus on Mixed Methods Research.
“podiatry” AND “focus groups”	17 abstracts of which 9 were directly related to the use of focus groups. The remainder were excluded, as they were either part of the body of this thesis, not podiatry related or not directly focus group related.
“podiatry” AND “rheumatoid arthritis”	115 abstracts, on exclusion of those that form part of this thesis and Mixed Methods Research-related studies already included above, those that had a qualitative method used semi-structured interviews.
“podiatry” AND “surveys”	332 abstracts retrieved; 148 of which relate to the use of survey/questionnaires in podiatric research of which only 1, (excluding those which form part of this thesis) used thematic analysis of free text comments. The remainder were not podiatry related, did not use survey or questionnaire methodology, or for which there was no abstract or were not available in English.
“podiatry” AND “cognitive interviews”	3 abstracts retrieved.

The qualitative methods for data collection in this body of work were the use of focus groups (papers 2,3 and 4), cognitive debriefing interviews (papers 5 and 7) and the use of open questions/ additional free-text comments within the construction of the practitioner and patient surveys (papers 5 and 6). The use of focus groups as a qualitative method for data collection within podiatry research has become more established over the last 10-15 years. A search of the literature found nine recent publications (excluding the publications within this thesis) covering a broad range of podiatry-related topics, that used focus groups as a research method (Barnett, Campbell and Harvey, 2005; Drahota et al, 2008; Borthwick et al, 2009; Moran et al, 2012; Burford et al, 2014; Harrison-Blount et al, 2014;Stressing and Borthwick, 2014; de Souza et al, 2016 and Williams et al, 2016). However, as a method within podiatry focussed research, it remains relatively low profile, with semi-structured interviews being the primary method of choice for qualitative data collection.

Although the justification for the use of focus groups has been detailed within each related publication within the body of this thesis it is perhaps prudent at this point, to compare and contrast its use with that of the more popular alternative of semi-structured interviews. The use of qualitative methods for data collection such as in-depth interviews, focus groups and observations, within health care research has grown significantly in popularity over the last 20 years; allowing for the comprehension of social phenomena within a ‘naturalistic’ as opposed to ‘experimental’ setting (Powell and Single, 1996). Focus groups have long been used with the market research setting and share many of the advantages of one-to-one in depth interviews in health care research as a means of data collection, being particularly suited to identification of how individuals define problems, opinions and feelings associated with a particular phenomena (Darlington and Scott, 2002). A number of the positive and negative issues related to the use of focus groups lie within the influential nature of the group dynamic that evolves during the group ‘interview’. Group interaction may spark ideas that would not necessarily be raised during a ‘one to one’ interview, it may feel like a less ‘pressurized’ environment within which individuals can answer questions without feeling that the sole focus is upon them and facilitate the sharing of common experiences among the group. However, group dynamics may mean that less dominant individuals feel supressed and unable to fully participate or pressured to agree with more dominant views and it may reduce the likelihood of individuals discussing subjects that they feel to be of a more personal nature, whereas this is less likely to occur when there is simply a single interviewer/interviewee (Darlington and Scott, 2002).

Using semi-structured interviews with one person can also provide a very rich depth of data within the response, although in the case of the research conducted within this portfolio of work, pragmatically, a range of responses across a number of participants was required in order to generate a large amount of data in a relatively short time frame. Further to this, as there was very little data available of the topic of foot health education for people with RA, the exploratory data produced by the focus groups was ideal for the formulation and design of the larger scale survey study because of the wider range of responses that could potentially be generated (Rabiee, 2004). When comparing the use of focus groups from those studies identified within the podiatric literature this method has been used to inform the development of subsequent larger scale studies (Barnett et al, 2005;de Souza et al, 2016; Williams et al 2016) whilst other studies (Moran et al, 2012;Stressing and Borthwick, 2014) combined the use of focus group data with that derived from semi-structured interviews with selected participants to obtain greater depth of information. Such an approach to the creation of qualitative data using both focus groups and one-to-one semi structured interviews, could have been considered within the research design of the qualitative studies within this portfolio of work and may have mitigated any 'negative' influential group dynamic that were not recognised by the focus group facilitators or fieldworkers.

The use of cognitive debriefing interviews as a method was employed within three other podiatry related studies only (Walmsley et al, 2012; Navarro-Flores et al, 2015 and Williams et al, 2016). Cognitive interviewing is a qualitative method for pre-testing questionnaire survey design in order to identify problems within initial survey design prior to or alongside pilot testing of survey items. Such techniques have been developed to explore the four-stage question response process as suggested by Tourangeau (1984) (see Table 7: Cognitive Model of Question Response)

Table 7: Cognitive Model of Question Response (Torangeau, 1984)

Cognitive stage	Definition	Response errors/Question problems
Comprehension	Understanding and interpretation of questions	Unknown terms/ ambiguous concepts/ long and overly complex questions
Retrieval/Recall	Respondent searches memory for relevant information to answer questions	Recall difficulty/no prior knowledge or experience/ perceived irrelevance of topic
Judgement	Respondent evaluates question and/or estimates response in deciding on an answer	Question biased or sensitive / estimation difficult/ impact of social desirability on judgement
Response	Respondent provides information in response to the question	Incomplete response options/ response options don't fit with understanding or judgement of question/ response influenced by social desirability/ unwilling to answer.

The use of concurrent 'Think Aloud' cognitive testing (using the question: "tell me what you are thinking" as the participant progresses through each item of the survey) was employed for the testing of the surveys within the published works. The participants completed the test online surveys putting their thought processes into words as they progressed through each item and section of the survey. The use of a 'think-aloud' strategy is thought to reduce the risk of bias from the researcher as the participant is not influenced by what they think is important to the researcher conducting the interview. However it can be burdensome for people who find it difficult to articulate their cognitions (Willis, 2005). This method is particularly useful in reducing the need for participants to recall information at a later date and a similar method was used within both Navarro-Flores et al, (2015) and Williams et al, (2016), survey design. In contrast, Walmsley et al (2012) used a retrospective verbal probing approach to cognitive testing during the development of a PROM. Retrospective questioning could be said to be more appropriate where questionnaire surveys are self-administered, as it will replicate the anticipated survey completion conditions (Willis, 2005). This could have been considered as an alternative approach to pre-testing the surveys within the published works for this thesis.

The use of the open-ended question; "Any other comments?" is a relatively traditional closing question at the end of most structured health-research surveys. However, there is a belief that the data generated from the responses to this type of question is rarely analysed or presented within results (O'Cathain and Thomas, 2004). The reasons behind this may be due to a lack of understanding of what to do with the data generated by such open-ended questions or how to analyse and report it (O’Cathain and Thomas, 2004; Riiskjaer et al 2012). Further to this, it has been suggested that ethically, researchers should avoid the use of open-ended questions unless they are prepared to analyse and present the results (Boynton and Greenhalgh, 2004). The use of this kind of question enables respondents to redress the balance of power between researchers and the participants. The closed-ended questions that constitute the mainstay of the survey, even if they have been developed through listening to the views of participants via focus groups and semi-structured interviews, often reflect the agenda of the researcher and therefore the use of open-ended questions allows participants an opportunity to voice their opinion or give more details than the structured questions allow (O’Cathain and Thomas, 2004). Indeed, the number of individual comments, the emotional content and the depth of data generated from the free-text response at the end of the patient survey alone, was such that it justifiably led to the development of a separate publication within this body of work and presented the data analyses and results in their own right (paper 6). Where such responses are limited in number and do not add anything to the quantitative results, formal analyses may not be required, but it is considered good practice to report this within any subsequent publication (Thomas, McColl and Priest,1996).The literature search revealed only one other podiatry-related study to have used thematic analysis of free text comments within a survey (Williams et al, 2017). Therefore, this particular approach to data collection and analyses (used within paper 5 and 6) was unique to the work within this thesis at the time of its’ publication and remains novel and innovative within published podiatric research.

By comparison, the use of survey methodology within podiatric research as a quantitative approach to data collection is extremely commonplace with a search of the literature revealing 148 results overall that relate directly to the use of questionnaires/surveys in podiatric research between 2017 - 1950. Although the abstracts for studies from 1950-1981 (n=51) were not available and thus not easily verifiable as using a survey or questionnaire method, it does demonstrate that this is a firmly established method of data collection within the realms of research led by podiatrists/chiropodists that has been in use for potentially almost 70 years.

However, the research process of podiatry-related survey design has become increasingly more sophisticated over time and this is reflected in the methods by which the surveys within this body of work were developed, constructed and delivered (using an online platform for delivery, collation of results and basic statistical data analysis). From the literature search, 30 of the 148 studies used an online platform (web-based) for survey delivery and dissemination with the earliest online survey being published in 2008, a single survey was disseminated by email as early as 2003, although it was not developed within an online platform.

It should be acknowledged that there are positives and negatives to the use of web-based surveys as outlined by Denscombe (2007). The web-based survey is relatively easy to build and cheap to administer as it requires no postal costs and the results from the survey can be fed straight into a data file which reduces the risk of human error in data transference that can be found with paper questionnaires. However, in the case of the surveys within this body of published works a certain amount of item re-coding was required before the data could be transferred for use in the statistical software of SPSS. This type of re-coding can take time, but takes no more time than that required for paper based questionnaires. The raw data created within the web-based survey is fed straight into a data-base that can produce descriptive and comparative statistical analyses and tabulate data according to the researchers' requirements. However, this requires that the researcher has some technical skill or training in their development and it relies on respondents having both access to a computer and a certain level of computer-literacy skills. The sampling framework is more difficult to apply with the use of web-based questionnaires because of the nature of email and web-addresses. This can be mitigated by the use of ready made email lists such as those used within the body of works published as part of this thesis and by ensuring there are clear, explicit completion instructions within both the initial email invite and first page of the questionnaire. The response rate can be influenced by the visual appeal and the ease with which the questionnaire can be completed and can be boosted by contacting the potential respondents in advance and planning for follow-up reminder e-mails within the study design.

3.2.1: Summary

In summary, a range of methodological approaches can be seen within the body of published works that form the basis of this thesis, these include; narrative review, focus groups, cognitive interviewing, survey methodology and thematic analysis of free-text. The use of some methods are novel (mixed methods research) or the first to be published with the field of podiatry (thematic analysis of free-text comments). The use of this range of techniques shows increasing sophistication and development of research skills over time.

3.3. A critical analysis of the wider impact of the portfolio of work: citation analysis, download and Altmetric data and journal impact factor.

This section explores the impact of the individual published works; presenting an analysis of citation, download, article access and Altmetric data. This review of citation data can allow for judgement of the quality and the utilisation of the authors' work. Although the use of citation analysis as a way of demonstrating impact can be considered controversial because of drawbacks relating to citation behaviour, accessibility of journal articles, the length of the article and the language in which it is written, its use has real world implications for researchers, given its consideration within grant applications for example (West and Stenius, 2008). Viewed within the context of the 'snap-shot' of time within which the citation analysis is conducted the data can reveal to a certain extent, a measure of the influence of the researchers' work.

Three electronic journal tracking databases; Scopus (Elsevier), Google Scholar and Web of Science (Thomson Scientific) have been used to identify author citations. These three databases were chosen due to the differing nature of their scholarly publication coverage (Bakkalbasi et al, 2006) and to provide therefore a more comprehensive approach to the presented citation data. Table (8) illustrates the differences in citation data across the three databases, with the final column showing how often each article has been accessed or downloaded and the Altmetric score for each paper. As Google Scholar has a broader inclusion of unique material than the other two data-bases, includes citations within 'grey literature' sources and is a freely available resource to anyone with an internet connection, for more recent searches of the literature (going back as far as 2006) it does seem to yield a higher citation rate compared with Web of Science and Scopus, as can be seen from the citation data in Table (8). This may suggest that Google Scholar would be the database of choice, purely for ease of access and its' digital reach. However, none of the databases provide a comprehensive set of data alone because of the differing nature inherent within their search algorithms and the variance between the resources indexed within them, as such, for completeness in a literature search, at least two of the three ought to be consulted (Bakkalbasi et al, 2006).

Table (8): Article citations identified by Scopus, Google Scholar and Web of Science (data sourced on 25-04-2017).

Published Works							
Article	**Year**	**Brief title, journal of publication & Impact Factor**	**Scopus (excl self-citations)**	**Google Scholar**	**Web of Science**	**Total Self citation**	**No. of downloads /article accesses/ Altmetric score**
Paper 1	2011	Narrative Review in Musculoskeletal Care *	2	7	not listed	3	Altmetric = 1
Paper 2	2012	Qualitative study of foot care for people with RA in Clinical Rehabilitation**	11	26	12	1	52 – downloads Altmetric = 1
Paper 3	2012	Patient focus group in Journal of Foot and Ankle Research***	0	12	7	3	6068 accesses Altmetric = 5
Paper 4	2012	Practitioner focus group in Journal of Foot and Ankle Research***	7	11	6	4	6811 accesses Altmetric = 4
Paper 5	2016	Practitioner survey results- qualitative & quantitative data in Journal of Foot and Ankle Research***	1	2	2	1	845 accesses Altmetric = 3
Paper 6	2015 (online) 2016 (hard copy)	Patient survey results-qualitative data in Musculoskeletal Care*	1	5	3	2	Altmetric = 11
Paper 7	2017	Patient survey results – quantitative data in Journal of Foot and Ankle Research.***	0	0	0	0	498 accesses Altmetric = 7

* denotes Impact Factor of 0.0, ** denotes Impact Factor of 2.24, ***denotes Impact Factor of 1.481

Altmetrics (alternative-metrics) are a relatively new tool by which to understand the wider impact of research and should be used to compliment other methods, such as citation data and peer-review, but are becoming more widely used in academia. They are not a measure of the quality of the research or the researcher. The Altmetric Attention Score is an automatically calculated, weighted count of all the online attention a research output has received. As Altmetrics monitor all online attention, the data is accumulated much more quickly than citation-based metrics and captures a more diverse illustration of engagement. The Attention Score is based on 3 main factors: volume, sources and authors. The combined attention score represents a weighted approximation of all the attention that is tracked for a particular research output. The score should be viewed in the context within which it was derived; because they are a measure of more diverse engagement with the research including book-marks on reference managers such as Mendeley, news mentions and social media coverage (https://www.altmetric.com). Each of these sources of engagement are weighted according to the amount of attention they are likely to receive thus a newspaper-related source bears more weight than a Tweet or mention via Facebook. For this reason the Altmetric score for each paper will be reviewed according to the profile of engagement, see Table (9).

Taking each paper in turn, removing the self-citation values, replicated citation sources and using the citation data from Google Scholar because of its' broad inclusion criteria, it can be seen from Table (8) that there is a peak in citations during 2012 with a downward trend thereafter; which can be expected given the relative recentness of the publication date for the final three papers.

Paper one was cited four times within four different journals other than that of the original publication; twice in 2012; in a German language rheumatological journal ("Zeitschrift fur Rheumatologie" published by SpringerLink; impact factor 0.569) and in Russian-based language online abstracts of conference proceedings. Following this it was cited once in 2014 within BMC Musculoskeletal Disorders (impact factor 1.684) and once in 2017 within Rheumatology International (impact factor 1.70). The publishing journal; Musculoskeletal Care, requires either Institutional or membership access and is not an open access publication. This may serve to limit the audience numbers that are able to access the article and thus may serve to be a limiting factor in respect of the number of citations over the timeframe of the PhD (2011-2017). However, it is encouraging to note that the citations have a 5-year span and are within international publications in both English and other languages.

Paper two was cited 25 times within 15 separate sources that varied from international peer-reviewed journals (impact factors range from 0.0 in Musculoskeletal Care - 3.299 in Arthritis Care and Research), published research proposals within Higher Education repositories, Masters and Doctoral theses in Norway, the UK and Finland. The paper has been consistently cited since 2012 to 2017 and has been downloaded from its' original journal of publication (Clinical Rehabilitation) on 52 occasions. Direct access to this paper is limited as the journal, Clinical Rehabilitation, requires institutional access or via subscription. Despite this, this particular paper has the highest citation rate of the publication portfolio which may be explained by the higher public and academic profile of the first author; Dr Anita Williams who is internationally renowned for her research with people who have RA- related foot problems.

The Altmetric scores for papers one and two are the lowest (both have a current score of 1) compared to the subsequent publications, this will be driven by the low level of online interest generated as can be seen by the low Tweet count. In addition the level of online interest in both these papers has tapered off over the years since initial publication with the last online interest being generated in 2015 for paper one and 2012 for paper two. However, the geographical reach of interest extended to both the USA and Singapore showing that an international level of interest had been generated.

Paper three was cited consistently six times between 2013 and 2016, within four separate sources, one of which was the original journal of publication; the Journal of Foot and Ankle Research. The remaining sources were diverse in that they ranged from the Cochrane Library of Systematic Reviews (impact factor 6.103) to a Canadian online health profession magazine; the Canadian Association of Foot Care Nurses. Again this range of citations, although limited in number, spans a range of years, types of publication and nationality, demonstrating relative longevity and geographical reach. This paper has reached a current online access rate of 6068, with an average access rate of 106.77 per month since its publication in January, 2012.

Paper four has a citation profile similar to that of Paper three with six consistent citations between 2012 and 2016 within four separate sources, one of which was the Journal of Foot and Ankle Research. The remaining sources show similar diversity in both impact factor (3.045) for the Archives of Physical Medicine and Rehabilitation to (0.574) for the Journal of the American Podiatric Medicine Association (JAPMA) and their international profile; JAPMA and the Journal of New Zealand Medical Association. This paper has a current online access rate of 6811, with an average access rate of 113.52 per month since its publication at the end of Aug, 2012. The high access rate of both papers three and four can be attributed to the open access status of the Journal of Foot and Ankle Research and to the time since the original publication in 2012.

Papers three and four achieved a similar Altmetric score (five and four respectively) and profile of online engagement. Both papers were placed in the top 25% of all research outputs tracked via Altmetrics and generated geographical interest through Twitter and Mendeley in the USA, Canada, Australia, Singapore and Portugal. The outputs were measured consistently from 2012 to Oct, 2016 when the last Tweet was tracked. Both Paper three and four were ranked as having a 'Good' attention score compared with outputs of the same age and from the same source.

Paper five has only a single citation in the Journal of Foot and Ankle research in 2017, with an access rate of 845 since its' publication in 2016 (average of 70.42 accesses per month). It has an above average Altmetric attention score of three compared with outputs of the same age and from the same source with current Tweets (n= 4) last recorded in 2016, the same year as publication. There is no geographical information in relation to the origin of the three Mendeley readers so it is not possible to discern the geographical engagement of the paper through this media. The origin of the Tweets are UK- based health care professions and the journal publisher.

Paper six was published in 2015 within Musculoskeletal Care (online access), 2016 as hard copy, and has a citation rate of three. These citations were within international publications; the Journal of Foot and Ankle Research in 2016, 2017 and Lupus in 2017, which has an impact factor of 2.188. The limited access to and the lack of impact factor of this journal may be contributory negative factors when comparing the citation data of this paper to those with higher access rates published within open access journals or with higher impact factors, however it has not yet been published for a year and so this status may change. In contrast to this comparatively lower citation rate, Paper 6 has the highest Altmetric attention score (11) of all the publications. It has a ranked 'High' attention score when compared with outputs of the same age and is seventh out of 118 outputs tracked by Altmetric from this source. Typically the outputs from Musculoskeletal Care that are tracked by Altmetric, receive a mean attention score of 3.1; which means that this paper is ranked higher than 94% of its peers. The high score is created by the inclusion of two tracked news stories from a single USA based online health news outlet (http://www.everydayhealth.com) in July 2016, two Tweets from within USA and Venezuela and five Mendeley readers of unknown origin. The inclusion of a news-related source of engagement will have elevated the attention score, as it is weighted more highly in the attention score calculation.

The most recent and final publication, paper seven, has yet to receive a citation although since its publication in March, 2017 it has generated a comparatively high access rate of 498 which is an average of 249 per month between March and May 2017. In addition, this paper has generated one of the highest Altmetric scores (7) across the portfolio, placing it in the top 25% of all research outputs tracked via the Altmetric algorthim to date and is ranked as ‘Above Average’ compared with outputs of the same age and from the same source. This attention score of 7 is underpinned by the highest number of Tweets (n=10) between all the publications, across the UK (n=7) and the USA (n=1) and tracked references to the paper within Facebook (n=1) and Mendeley (n=1). The latest recorded Tweet was April, 2017.

Table (9) to show Altmetric score per publication and sources of data from which it is derived (data sourced 05-05-2017).

Article No.	**Year of publication**	**Brief title**	**Altmetric (attention) score**	**Contributory data**
Paper 1	2011	Narrative Review	1 = 1st percentile of all research outputs tracked.	**1 x Tweet** – country of origin unknown **6 x Mendeley readers** – 1= UK, 5 unknown country of origin – all academic by profession
Paper 2	2012	Qualitative study of foot care for people with RA	1 = in the 16th percentile of all research outputs tracked.	**1 x Tweet** – within the USA (Mayo Clinic – Health practitioner) **28 x Mendeley readers** – 2=UK, 1= Singapore, 25 unknown country of origin – all student or academic researchers by profession.
Paper 3	2012	Patient focus group	5 = in the 80th percentile, the top 25% of all research outputs tracked.	**7 x Tweets** – 3= USA, 2= Canada, 1= UK, 1= unknown: 5= general public tweets, 2= science bloggers. **19 x Mendeley readers-** 1= Portugal, 1= Australia, 1=UK, 16 = unknown - all student or academic researchers by profession.
Paper 4	2012	Practitioner focus group	4= in the 78th percentile, the top 25% of all research outputs tracked	**5 x Tweets** – 2= UK, 1= USA, 2= unknown – 4 = general public tweets, 1= science blogger. **6 x Mendeley readers-** 1= Australia, 1= Singapore, 4= unknown - all academic by profession
Paper 5	2016	Practitioner survey results- qualitative & quantitative data	3 = in the 59th percentile	**4 x Tweets -** 2= UK, 2= unknown country of origin – 3 = general public tweets, = science blogger **3 x Mendeley readers –** unknown country of origin – all students by profession.
Paper 6	2015 (online) 2016 (hard copy)	Patient survey results- qualitative data	11 = in the 90th percentile, in the top 10% of all research outputs tracked.	**1 x News outlet** - 2 stories in Every Day Health (online US newsletter). **2 x Tweets –** 1 = USA (health blogger), 1= Venezuela (Consultant Physician). **10 x Mendeley readers –** 1= Singapore, 9= unknown country of origin – all academic by profession.

Paper 7	2017	Patient survey results – quantitative data	7 = in the 84th percentile, in the top 25% of all research outputs tracked.	**10 x Tweets -** 7= UK, 1= USA, 2 = unknown country of origin – 5 = scientists, 4 = general public tweets, 1= health blogger. **1 x Facebook post** **1 x Mendeley reader –** country of origin unknown- Associate Professor by profession.

3.3.1 Summary

This analysis of citation, download, article access and Altmetric data has illustrated the quality, breadth and depth of engagement with this body of works. The analysis of citation and Altmetric data demonstrates that these publications have received world-wide access; from the UK and Europe, North and South America to Singapore, Australia and New Zealand. In terms of the quality of onward citations, this analysis has established that this body of work has demonstrated impact across a broad spectrum of publications from; the 'grey literature' of Masters dissertations and PhD theses (Paper 2) to the Cochrane Library of Systematic Reviews with an Impact Factor of 6.103 (Paper 3). Further to this, because of the scope of the publishing journals within which this body of work is situated, the citing literature sources reflect that the readership and utilisation of the published work extends beyond the scope of the podiatry profession to Medicine and the health profession specialisms of rheumatology and musculoskeletal health practice.

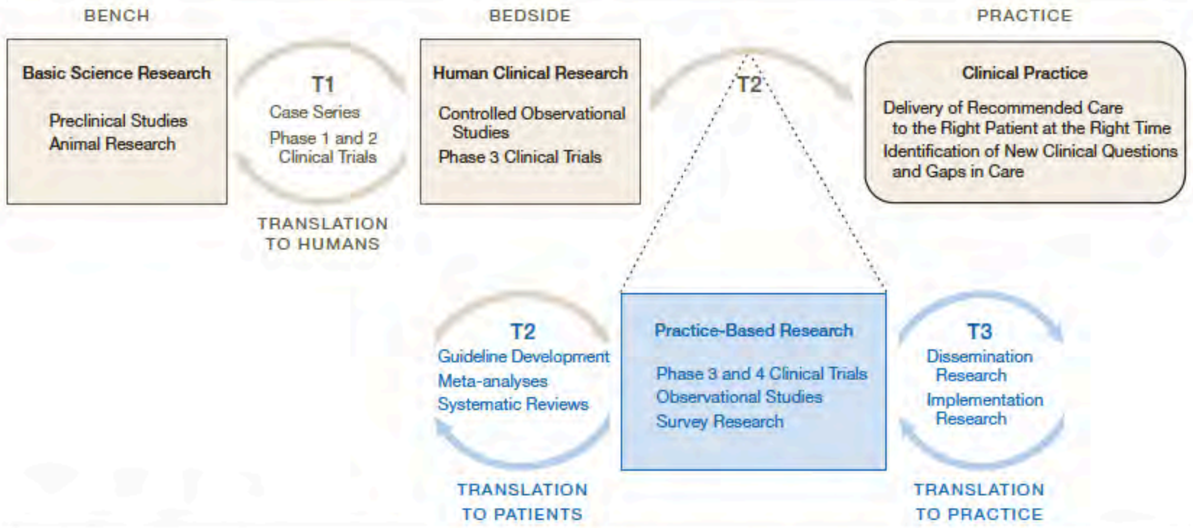
Whilst Altmetrics should not be used as a measure of impact or quality in isolation, they can provide a more comprehensive and immediate picture of engagement with the published body of work. Further, it also demonstrates the level of social media based engagement that is generated by an individual publication. This is significant, given the ever-changing landscape of media outputs and the ways in which we now, as a society of health professionals, choose to disseminate and 'consume' our research.

3.4 Knowledge Translation: Translating the research into practice – moving from the ‘bench-side to the bedside to the curb-side’.

The aim of this section is to illustrate how this body of published works is aligned with the conceptual framework of translational research and the translation of this research output as ‘knowledge’ into practice. This section acknowledges the inherent difficulties that constitute barriers along the pathway of knowledge translation such as professional change management, the influence of the therapeutic relationship and highlights those components of this particular research journey, which could be considered to demonstrate informal strategies that bypass such barriers.

Translational research is widely defined as the ‘bench to bedside’ concept, with the original ‘translational blocks’ (T1 and T2) being described as the transfer of scientific advances to the development of relevant and applicable clinical research (T1) and the translation of trial results into practical clinical application (T2) (Mata and Davies, 2012). A third ‘translational block’ has recently been acknowledged and become part of the translational research narrative (T3) which involves the translation of clinical research into; dissemination, implementation and policy. These ‘blocks’ of translational research; T1, T2, T3 are widely accepted within much of the emerging literature (McGartland et al, 2010; Estape et al, 2014). Estape et al (2014) suggests a slightly modified version of McGartland’s working definition with a fourth phase, (T4) of transition from clinical practice to community and population based application (the ‘curbside’). This is based on Westfall et al’s (2007) interpretation of the NIH Roadmap, which suggested that practice-based research maybe the link between basic and clinical research (Fig 6). The body of work within this thesis, if aligned to Westfalls’ interpretation, would therefore span the translational blocks of T2/T3 through the use of narrative literature review (T2) and survey research (T2) and the dissemination directly to the *health care consumer* (T3) through patient-mediated strategies (Fig 7).

Figure (6) Westfall et al, 2007 “Blue Highways on the NIH Roadmap. Pp 405.



The current National Institutes of Health (NIH) Roadmap for Medical Research includes 2 major research laboratories (bench and bedside) and 2 translational steps (T1 and T2). Historically, moving new medical discoveries into clinical practice (T2) has been haphazard, occurring largely through continuing medical education programs, pharmaceutical detailing, and guideline development. Proposed expansion of the NIH Roadmap (blue) includes an additional research laboratory (Practice-based Research) and translational step (T3) to improve incorporation of research discoveries into day-to-day clinical care. The research roadmap is a continuum, with overlap between sites of research and translational steps. The figure includes examples of the types of research common in each research laboratory and translational step. This map is not exhaustive; other important types of research that might be included are community-based participatory research, public health research, and health policy analysis.

Knowledge translation has been defined by the World Health Organisation (2005) as *“the synthesis, exchange and application of knowledge by relevant stakeholders to accelerate the benefits of global and local innovation in strengthening health systems and in improving people’s health.”*

The aim of knowledge translation is to close the gap between evidence generation and clinical decision-making and has evolved from a number of disciplines of which evidenced based practice and quality improvements are two common concepts within health care. The implementation of research findings into clinical practice has been acknowledged as notoriously difficult, with the recognition that traditional approaches for knowledge translation such as Continuing Professional Development (CPD), do not lead to optimal patient care (Grimshaw et al, 2012). Time and the sheer volume of research available to health care practitioners are additional barriers to knowledge translation and for this reason the use of systematic reviews in relation to a particular intervention and clinical guidelines for evidenced based management of specific patient groups or pathology, are seen as more efficient ways of transferring a relatively large body of knowledge (Grimshaw et al, 2012). As such, the citation of publications that form part of this PhD by Published works within systematic review (Lefevre-Colau et al, 2014) and local evidence- based guidelines

(North West Clinical Effectiveness Group for Rheumatology (NWCEG, 2014) is a positive outcome. However, even when such resources as systematic reviews and guidelines are available, ensuring that their use and implementation in clinical practice is applied consistently between geographical areas, health care teams and by individual practitioners is acknowledged to be equally difficult (NICE, 2007). An example of this type of barrier to knowledge translation, in the context of RA patient management and foot care, has been shown to exist in respect of the use of published guidelines for the management of the foot in people with RA (Williams et al, 2013). Table (10) below illustrates the extent to which UK podiatrists were aware of clinical guidelines in 2013 and identifies the sub-groups of podiatrists most likely to engage with them.

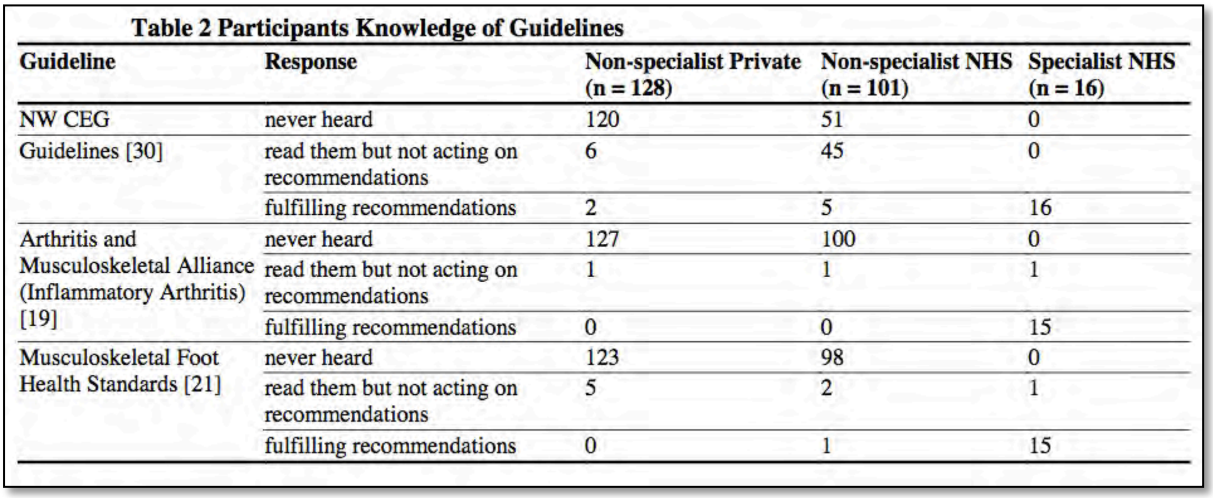


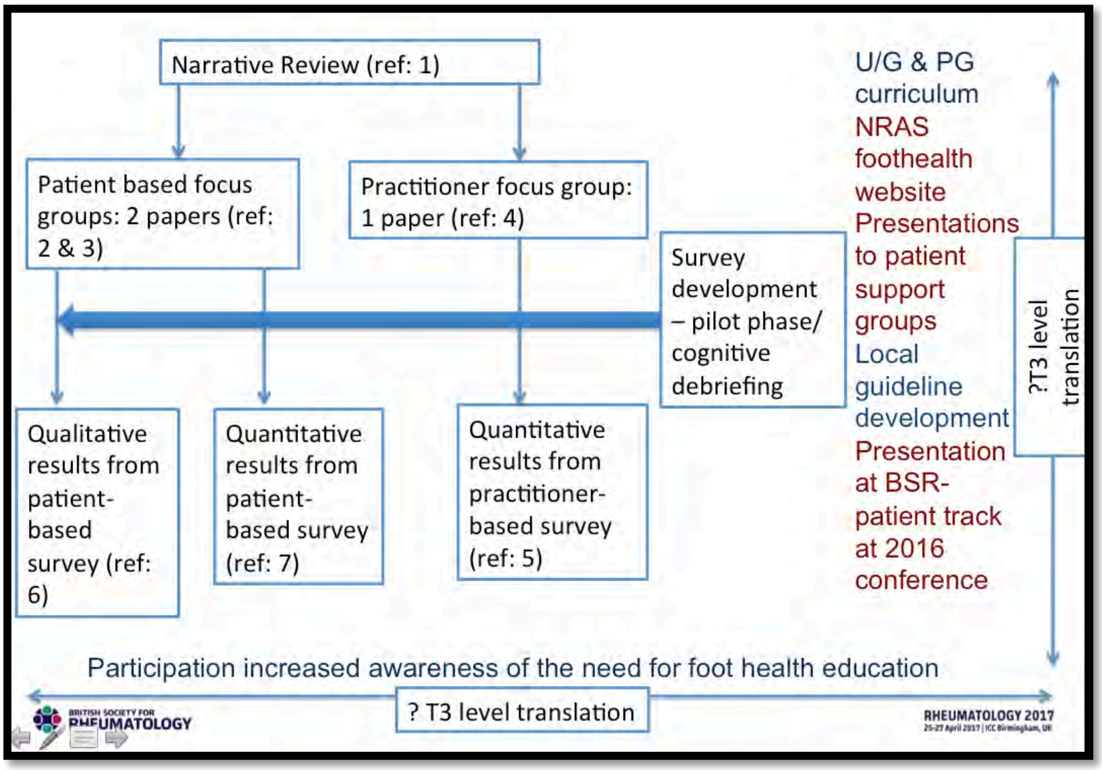
Table 2 Participants Knowledge of Guidelines

Guideline	Response	Non-specialist Private (n = 128)	Non-specialist NHS (n = 101)	Specialist NHS (n = 16)
NW CEG	never heard	120	51	0
Guidelines [30]	read them but not acting on recommendations	6	45	0
	fulfilling recommendations	2	5	16
Arthritis and Musculoskeletal Alliance (Inflammatory Arthritis) [19]	never heard	127	100	0
	read them but not acting on recommendations	1	1	1
	fulfilling recommendations	0	0	15
Musculoskeletal Foot Health Standards [21]	never heard	123	98	0
	read them but not acting on recommendations	5	2	1
	fulfilling recommendations	0	1	15

Table (10) to illustrate participant knowledge of guidelines amongst a sample of UK Podiatrists (Williams et al, 2013)

As a contributor and co-author, with a research focus on patient education for people with RA, to the North West Clinical Effectiveness Group (NW CEG) guidelines used within this particular survey (Williams et al, 2011), the limited extent to which research findings are translated appears conflicting; the evidence base of published research or expert opinion is used to develop the guidelines and the ability of the guidelines to influence clinical practice appears to be limited to those in expert roles. It is difficult to discern from the findings of the survey whether there is partial uptake of the recommendations i.e the individual practitioners who have read the guidelines apply them in practice but only minimally (which may mean that they provide some level of FHE), or not at all. Further, it cannot be assumed that a high article access rate, citation rate or Altmetric score for any publication is an indicator of the degree to which individuals apply the new or additional knowledge they have gained in order to change their clinical behaviour or the working practices of the institution within which they work. NICE (2007) additionally acknowledges that it can take up to three years for guidelines to be fully implemented into clinical practice; this can be due to the realistic scale of the change and the fact that many changes involve the implementation of complex interventions within complex organisational environments (Johnson and May, 2015).

A more direct approach to translating research findings into practice than via publication and guidelines could be in the targeting of the health care *consumer*; the person with RA or their carer. Indeed, NICE (2007) advocates the use of patient mediated strategies such as providing information and educational material directly to patients, in relation to new guidelines for example, so that patients are able to influence decisions made during the consultation. Such strategies have been shown to be effective in changing the behaviour of health care professionals. Figure (6) illustrates how this portfolio of research aligns with the practice-based dissemination phases of translational research (T3) (Westfall et al, 2007) and those components that were targeted directly at patient ‘consumers’ (patient mediated strategies) are on the right hand side.



Narrative Review (ref: 1)

Patient based focus groups: 2 papers (ref: 2 & 3)

Practitioner focus group: 1 paper (ref: 4)

Survey development – pilot phase/ cognitive debriefing

Qualitative results from patient-based survey (ref: 6)

Quantitative results from patient-based survey (ref: 7)

Quantitative results from practitioner-based survey (ref: 5)

U/G & PG curriculum
NRAS foothealth website
Presentations to patient support groups
Local guideline development
Presentation at BSR-patient track at 2016 conference

?T3 level translation

Participation increased awareness of the need for foot health education

? T3 level translation

Figure (7): How the portfolio of research aligns with the phases of translational research

As part of the process of this research journey in 2011, I was invited to lead the redevelopment of the NRAS website section on foot health information (www.nras.org.uk), which was launched at the British Society of Rheumatology conference in May 2012 to raise awareness amongst rheumatology consultants and rheumatology specialist practitioners. In August 2012 I presented, my then current, research findings to a RA patient support group in the NW of England that also aimed to raise awareness of this new information resource. For the first 9 months of 2013 (Google analytics would not go back to the previous year to allow comparison) the NRAS foot health webpage had 18,273 visits, information I had requested from NRAS in preparation for a conference presentation in November, 2013. Although there are no historical figures to compare this statistic to, given that there were approximately 2, 721 non-health profession members of NRAS at the time of the website launch this would suggest a significant volume of ‘traffic’ visiting the foot health section of the NRAS website in the year following its’ launch and some level of engagement with the foot health information available.

Finally, in 2016 I was an invited speaker at the British Society of Rheumatology conference, streamed throughout which were sessions with a purely patient based audience (n= 70). I presented the same final results of the patient survey, both qualitative and quantitative data, as had been presented to the AHP audience with some illustrative and language modification to make it more acceptable to a 'lay' audience. Patient delegates were also provided with a printed hand-out as an overview of the presentation (Appendix F), to enable them to prepare any questions they may have had prior to the start of the presentation itself. This presentation created the opportunity for the delegates to ask questions of me directly, both as a researcher and as a practising clinician and initiated a lively debate about how to get health professionals to recognise foot heath as an issue for people with rheumatic disease. Whilst no firm solutions were concluded on that day, it was a mechanism by which that particular group of people with rheumatic diseases had 'spoken' and been 'heard'. The patients had chosen the programme of presentations that they wished to hear that day and selected my work as a subject on which they wished to receive more information. Further to this, I felt that the results of the research were being fed back directly to at least a small component of its target audience. Although the outcomes from this type of research dissemination are hard to measure, the results of this body of work assert the need for attributing foot health education with the significance it deserves and is echoed here, by the desire of the conference delegates to understand more about foot health and the provision of foot health services. The questions they asked at the conclusion of the presentation reflected a continued low level of awareness of what services they were entitled to access and why they may need to access them in the first place.

Patient education for people with RA and foot problems would benefit from a patient-centred approach to its design and communication before, during and following the medical consultation. However, if people with RA cannot access foot health services or are not even aware that they should, then there is not even a starting point for dialogue between the patient and practitioner. A number of studies have shown that people with RA feel either disempowered or disenfranchised from the process of accessing foot health services (Williams and Graham, 2012; Blake et al, 2013; Hendry et al, 2013; Graham and Williams, 2015) and further to this, that they won't necessarily self-report foot problems unless prompted to do so during the consultation with any medical or health practitioner (Blake et al, 2013; Graham and Williams, 2015).

The solution to this requires a multi-faceted approach. Firstly, the balance of power during the consultation requires attention. This doesn't mean that all the 'power' is placed in the hands of the person with RA but it does mean aiming for the equilibrium between what the practitioner needs to achieve within the medical consultation and what the person with RA wants to achieve in relation to learning about their foot health. People with RA must be given the opportunity to address foot health issues on a regular basis and the provision of information/education should not be restricted to the podiatry profession, given that a significant number of people with RA do not routinely access foot health services, if at all. An inclusion within current national and local guidelines; that health care practitioners should specifically prompt people with RA about any questions they may have with regards their foot health needs, including the access of foot health information, would help to highlight that as a minimum, people with RA should be asked about their foot health. This approach is supported by Blake et al (2013), has been published within the updated NWCEG in 2014 and as a part of a set of minimum standards for FHE for people with RA (Graham and Williams, 2015).

There has been a perceived lack of opportunity for people with RA to discuss their foot health and information needs (Williams and Graham 2012; Graham et al, 2012; Graham and Williams, 2016; Wilson et al, 2017) and this is, in part, due to the influential nature of the therapeutic relationship between the patient and the practitioner. Research shows that, for some people with RA, access to foot health services a potential source of foot health education, is determined by other health care practitioners or the Consultant Physician. Patients rely therefore on the perceived 'expert' knowledge of the practitioner, as a determiner of referral (Blake et al, 2013; Graham and Williams, 2016; Wilson et al, 2017). Thus if members of the MDT do not refer the patient, the patient does not feel it to be necessary either. Providing people with RA with the opportunity to voice their foot health concerns, would at the very least create the potential for timely onward referral and offer an opportunity for information giving.

Secondly, the role of podiatrist in the management of foot health for people with RA appears to have a relatively low profile amongst both patients, General Practitioners, Specialist Nurses, other AHP's and podiatrists themselves. The specialist role of the rheumatology-based podiatrist suffers from a lack of recognition, which is reflected nationally by the comparatively low number of specialist posts in this area when compared with those employed as specialist practitioners for people with diabetes (Redmond et al, 2006; National Audit Office, 2009). This may be due to the fact that the development of the podiatric specialist role within rheumatology has lacked specific detail in health policy and guidelines (NICE, 2009; PRCA, 2008; ARMA, 2004). Further to this, there are no formal educational or experiential prerequisites to achieving specialist role status, in contrast to the requirements for such 'specialist' roles amongst our medical and nursing counterparts (Bacon and Borthwick, 2013). In the 1990's the specialism of rheumatology practice amongst the podiatry profession was pioneered by a small number of highly experienced and specialist podiatrists including; Professor Jim Woodburn, Professor Keith Rome, Dr Anita Williams Professor Cathy Bowen, Professor Antony Redmond, and Robert Field. The profile of this group of practitioners aligns with Bacon and Borthwicks' concept of the utilisation of 'charismatic authority' in the way in which the clinical specialist role of the podiatrist within rheumatology became established. Examples of good clinical practice, the creation and development of local clinical guidelines could be found wherever these particular practitioners were active either in clinical practice, clinical research or within Higher Education Institutions, across the UK. As these individuals had such 'charismatic authority' within the profession, the development of the specialist role grew and gained some recognition and acceptance amongst their medical peers. Furthermore, the transformation of charismatic authority created by this group of practitioners, into routine or more traditional authority and is now becoming linked to a process of education (Giddens, 1971 cited in Bacon and Borthwick, 2013) through the recent development of career and competency frameworks (NW CEG, 2017). However, with changes in political leadership and ever increasing NHS budgetary restrictions, opportunities for the continued growth of this specialist role have been significantly limited. The specialist role of the podiatry practitioner within rheumatology and thus the management of people with RA, remains essential. Education, not only of patients as to the role of the podiatrist, but also our medical and AHP peers appears to be equally essential, if timely access to foot health services and education is to be achieved. In addition, raising the awareness of podiatrists as to the existence of current clinical guidelines in the management of people with RA and foot problems may influence clinical outcomes for this group of patients.

In order to address the poor awareness about current guidelines for the management of foot health in people with RA, the implementation of which would be a driver for the provision of FHE, NICE (2007) advocates the use of 'Opinion Leaders', which could be viewed as an alternative title to the 'charismatic practitioner'. Once identified, Opinion Leaders can be used to influence, motivate and inspire change within a service. Further to this Johnson and May (2015) state that the most effective methods for instigating behaviour change involving complex interventions such as patient education strategies, are most likely to require intervention types that lead to normative and relational restructuring; a focus on collective rather than individual action. The use of audit and feedback is one such mechanism identified as an intervention likely to achieve this change, in combination with the use of local Opinion Leaders to facilitate the audit and feedback. The NWCEG guidelines group (2014) developed an audit tool that can be used to audit current rheumatology service provision in relation to the foot health management of people with Rheumatoid Arthritis against available guidance and evidence standards at the time, which covers four areas; Service Provision, Assessment, Management and Professional Development. The aim of audit is to ensure that service users receive the right treatment, by the right people at the right time. However, clinical audit alone is not a strong enough driver for change, when there is a lack of staff resources, awareness and training.

The acknowledged lack of specialist podiatry practitioners (Redmond et al, 2006; NAO, 2009) means that there are insufficient numbers to meet the needs of the RA population, resulting in increasing numbers of non-specialist practitioners managing the foot health needs of people with rheumatic diseases. The NWCEG guidelines were developed in many ways to address the need to support such practitioners, but did not address the knowledge and skills competencies that should be desirable for health professionals who manage rheumatology-related foot problems. As such the 'Podiatry Career and Competency Framework for Integrated Foot Care for the Foot in Inflammatory Joint Disease and Connective Tissue Disorders' (Pilot version April, 2017) has recently been developed through collaboration between the NW CEG, professional bodies and organisations, such as academic representatives from the Directorate of Prosthetics, Orthotics and Podiatry at the University of Salford. The framework was modelled on that for Diabetes Foot care, the first of its kind in podiatric practice and will benefit a number of stakeholders; clinicians, patients and carers, managers and commissioners and training/educational institutions. Figure (8) illustrates the benefits for stakeholders.

Figure (8) taken from ‘Podiatry Career and Competency Framework for Integrated Foot Care for the Foot in Inflammatory Joint Disease and Connective Tissue Disorders’ (Pilot version April, 2017) pp 6-7.

Who is the framework for?

1. Clinicians can use the framework to:

Benchmark their existing competencies.

Identify areas in which to increase their competency.

Aid them in writing performance reviews.

Identify a career pathway.

2. Patients will benefit from:

The adoption of the framework by clinicians and services

The assurance that they will be treated by a clinician with competencies specific to the management of their foot health needs.

The emphasis the document places on patient empowerment, education and, wherever possible, self-management.

The improvements in patient outcomes that should flow from receiving care from a workforce that is demonstrably competent in the care of the “rheumatoid” foot.

3. Managers and commissioners can use the framework to:

Streamline services (in line with NHS Modernisation Agency guidance) by ensuring the right mix of staff competencies to meet the various levels of foot care needs

Plan appropriate professional development activities, leading to improvements in staff satisfaction, retention, and succession planning.

Achieve Workforce planning based on patient needs

4. Educational and training institutions can use the framework to:

Ensure their curriculums include training in appropriate competencies; specifically, Level C competencies are appropriate for new podiatry graduates and they should be included in undergraduate podiatry syllabi.

Identify where gaps exist in the provision of continued professional development courses.

The framework has been developed with the podiatric practitioner at the heart of its delivery but is relevant to and can be adapted for any health professional involved in the delivery of foot care. The significance of this framework for FHE, lies within the development of a specific competency focused upon Heath Improvement (Competency number 8) which outlines the skills and knowledge that health care assistants and health professionals should be able to demonstrate in order to provide effective health improvement and self-management strategies. This competency requires staff not only to demonstrate knowledge of the disease and psychological impact on the patient, it also requires staff to understand and demonstrate the importance of the subsequent effect of patient education and self-management in a context individualized to that of the patient. At higher staff grade levels of C and above, it requires the staff member to demonstrate an awareness of counseling and motivational interviewing techniques in order to communicate clearly with the patient and/or carer about foot health. This may go some way to alleviating the sometimes, dysfunctional patient 'v' practitioner relationship that has been identified as a key barrier in the provision of FHE for people with RA (Graham et al 2012; Williams and Graham, 2012; Blake et al, 2013; Graham and Williams, 2016; Wilson et al, 2017).

Despite the acknowledgement of the skills that are required to achieve an effective 'therapeutic' relationship, barriers to its development remain. Practitioners are often time and resource constrained and admit as such, with patients submitting to this fact by not wishing to burden the practitioner any further by taking up their time asking questions (Graham and Williams, 2015; Graham and Williams, 2016). This can lead to the fostering of a lack of communicative interaction, a more hegemonic relationship and the involuntary giving of trust, because factors such as adequate time to build continuity of care, friendship and facilitate a near-equal power balance between the two parties, are not able to be met (Habermas, 1987). In their 2010 King's Fund report: "Measuring the Quality in the Therapeutic Relationship", Greenhalgh and Heath put forward the question: *"What is the underpinning logic of the therapeutic relationship?"* Using the view of the Philosopher and ethnographer, Annemarie Mol from her book "The Logic of Care" (Mol, 2008) as a comparator, they state that much of modern health care is driven by an underlying 'Logic of Choice'; medicine is fundamentally about making choices, supporting and informing the decisions of an empowered patient in a linear manner. The 'Logic of Choice' is episodic in nature and has an inherent 'patient-centred' 'v' 'clinician-centred' approach at its heart. One is pitted against the other. The ‘Logic of Choice’ assumes that the patient is an informed, consistently rational decision-maker. The ‘Logic of Care’ concept put forward by Mol is that medicine should be considered as an ongoing, complex task of living with illness; with the patient and practitioner on the same side, allowing the patient to be passive or active as appropriate to their health or needs. The ‘Logic of Care’ is more accommodative of irrational, inconsistent health behavior that can often be the case when people are chronically sick or confused. It is this ethos perhaps that practitioners should be mindful of during their consultations with patients, fostering a consultation style that allows for those people who wish to be more proactive in their own care and those who cannot be, then tailoring their ongoing foot health and education needs to fit.

3.4.1: Summary

In summary, in order to achieve a judicious outcome for the person with RA and ensure the more effective implementation of clinical guidelines service managers need to implement change, audit services and ensure that staff meet the competency framework skills. This needs to be further supported through collective action by MDT’s in relation to the ‘focus on feet’.

3.5 - Future development: Considerations and implications for future research.

This final section of the critical review will address the factors that require consideration in the future development of FHE for people with RA in the context of the current evidence base and guidelines. The work conducted to date will be contextualized within the Medical Research Council (MRC) Framework for conducting and evaluating research for complex interventions (Craig et al, 2013) and recommendations for the future development of an educational needs analysis tool, with a focus on the foot affected by RA, will be described. Issues of health literacy, skills competency, clinical and cost-effectiveness will be considered.

Current NICE guidance (NICE, 2009) stresses the importance of the provision of patient education in the management of people with RA. EULAR's more recent eight evidence and consensus-based recommendations for Patient Education for people with inflammatory arthritis (2015), emphasizes the specific areas that should be targeted. (Table 11) Further to this EULAR have also developed an extensive research and an educational agenda in support of providers of patient education.

Table (11): EULAR recommendations for patient education for people with inflammatory arthritis (Zangi et al, 2015).

EULAR Recommendations:

1. Patient education should be provided for people with inflammatory arthritis as an integral part of standard care in order to increase patient involvement in disease management and health promotion
2. All people with inflammatory arthritis should have access to and be offered patient education throughout the course of their disease including as a minimum; at diagnosis, at pharmacological treatment change and when required by the patient's physical or psychological condition
3. The content and delivery of patient education should be individually tailored and needs-based for people with inflammatory arthritis
4. Patient education in inflammatory arthritis should include individual and/or group sessions, which can be provided through face-to-face or online interactions, and supplemented by phone calls, written or multimedia material
5. Patient education programmes in inflammatory arthritis should have a theoretical framework and be evidence-based, such as self-management, cognitive behavioural therapy or stress management
6. The effectiveness of patient education in inflammatory arthritis should be evaluated and outcomes used must reflect the objectives of the patient education programme
7. Patient education in inflammatory arthritis should be delivered by competent health professionals and/or by trained patients, if appropriate, in a multidisciplinary team
8. Providers of patient education in inflammatory arthritis should have access to and undertake specific training in order to obtain and maintain knowledge and skills.

The variation that exists across European countries (Zangi et al, 2014) and national domestic boundaries here in the UK (Ndosi et al, 2017), in both health care and health education provision for people with RA, has proven to be a key driver in the agenda for the development and standardisation of targeted PE. This is further bolstered by the relatively recent increase in momentum for Shared Decision Making (SDM) strategies in managing patients with complex and chronic conditions such as RA and Diabetes (Coulter, Roberts and Dixon, 2013. The far-reaching research agenda developed by EULAR indicates that there is a significant amount of work to be done before relevant and effective PE strategies can be implemented, although dissemination and integration of the eight recommendations provides practitioners with robust guidance and a clear framework within which to work.

The key findings articulated within this body of published works are strongly aligned with EULAR recommendations 1-4. Further work is now required to develop a mechanism by which FHE interventions can be developed, implemented and evaluated by appropriately trained health practitioners in line with EULAR recommendations 5-8 and in respect of the Medical Research Council (MRC) guidance for conducting and evaluating research on complex interventions. Figure (9) outlines the key elements of the MRC development and evaluation of complex interventions framework (Campbell et al, 2000).

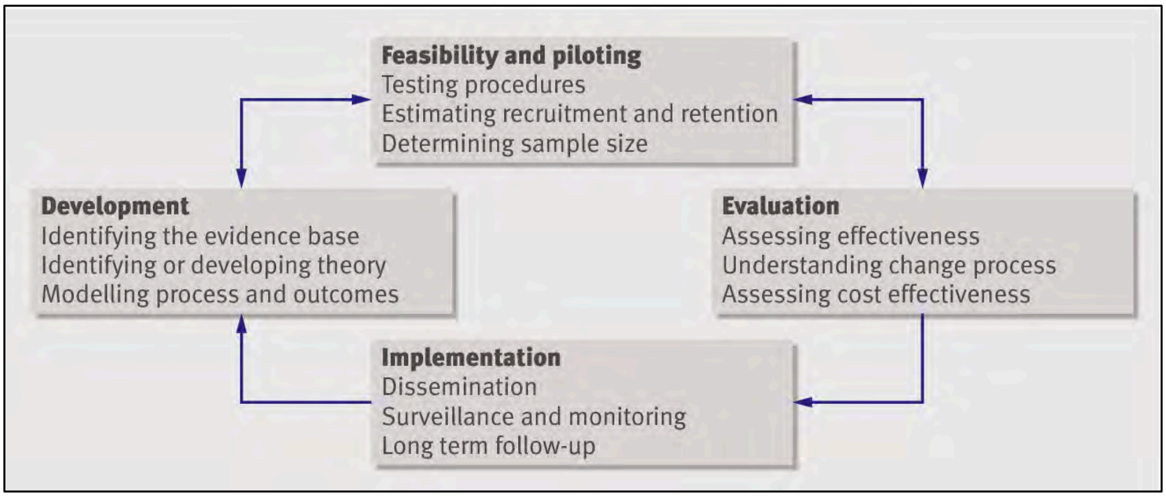


Figure (9): The key elements of the MRC development and evaluation of complex interventions framework (Campbell et al, 2000).

The work that forms the basis of this thesis is aligned within the ‘development’ phase of the MRC framework. Currently, there are no specific FHE interventions for people with RA. In order to develop and evaluate the potential effectiveness of FHE as a definable intervention, an understanding of its' possible key components, how it could be operationalized and any related causal assumptions, is required. The research undertaken within this body of publications has revealed what people with RA value and require in respect of the potential content, timing and mode of future foot health educational intervention delivery. In addition, the statistical significance of factors that have the potential to influence PE engagement such as, patient/practitioner gender, the patients' disease duration and the level of practitioner experience, has been identified (Graham et al 2015; Graham et al 2016; Graham et al 2017). One of the most significant key findings from these publications is the need to facilitate the timely identification of FHE needs of people with RA. Time and systematic constraints limit podiatry practitioners in their ability to deliver effective FHE during the consultation. Finding a mechanism to enable people with RA and health care practitioners to collaboratively and efficiently identify FHE needs, could ensure that the FHE needs of people with RA are met in a timely and individualized manner. The development and implementation of a foot health-specific needs analysis tool could facilitate that process.

A framework for the education of patients with diabetes at low risk of lower limb complications was developed through an expert consensus approach in 2011 by McInnes et al, as this group of patients had been identified as being 'vulnerable'. No such framework exists or is in development for people with RA, who can be considered to be an equally vulnerable group of patients. Certain parallels can be drawn with the situation that people in a 'low-risk' category of diabetes and people with RA experience in respect of FHE provision, with a lack of foot care advice being provided to either group. Although the North West CEG guidelines (2014) include key points that should be included as part of foot health education provision for people with RA, the findings of the studies within this body of work show that, unlike in diabetes, foot care education is not generally, an integral part of the RA 'information package' that patients receive and that awareness of the RA related management guidelines is poor amongst the podiatry profession (Williams et al, 2013).

The use of educational needs assessment tools within the RA population is well documented within the published literature; an Educational Needs Assessment Tool (ENAT) to help people with RA decide their priorities for education based on their own needs, was originally developed by Hardware et al, in 2004. This tool has since been translated and validated for use in 9 countries and in patients with other rheumatic diseases including; Systemic Sclerosis, Ankylosing Spondylitis, Psoriatic Arthritis, Systemic Lupus Erythematosus, Osteoarthritis and Fibromyalgia (Ndosi et al 2011, 2014; Sierakowska et al, 2015). Further to this, the usability of the ENAT in clinical practice has been demonstrated through the collection and analysis of both quantitative and qualitative data (Hardware et al 2014; Ndosi et al, 2015). The qualitative study demonstrated that the ENAT works within clinical practice and that it is reflective of patients' needs and although participants recruited from within the control group perceived that they had an equally adequate experience of educational provision, the ENAT served as a prompt for questions that those in the experimental group may not have considered without it (Hardware et al, 2014). The RCT demonstrated that the use of the ENAT significantly improved self-efficacy and some other aspects of health status (AIMS2-SF- symptoms and affect domain scores), when compared with the control group at 32 weeks (Ndosi et al, 2015). Overall the results of this needs based approach to patient education for people with RA would suggest that their individual educational needs are being met and significantly, this has been shown to positively influence their levels of self-efficacy. These findings are of significant importance in the future development of any foot-based educational needs analysis tool, because they show that it is feasible to employ an approach to the identification of patients educational needs within clinical practice that is accepted and valued by both patients and practitioners.

The seven domains of the original ENAT (Hardware et al, 2004); management of pain, movement, feelings, the arthritis process, treatments, self-help measures and support systems, could be built upon or modified to include items with a focus on foot health. Alternatively, a separate foot health ENAT could be developed as an appendix to the original. In this way, the 'foot ENAT' could be used to help people with RA decide their foot health education priorities and health care practitioners to identify the aspects of foot health education they can provide themselves or to prompt timely referral to specialist foot health services.

The research process to enable the creation of a foot ENAT would require an item development phase, to identify those items most relevant in the identification of FHE needs for people with RA. Resources that could be used in the generation of item development are the 'content' and 'methods of delivery' section items that were included within the patient and podiatrist online surveys used within Papers 5, 6 and 7. These items could be used as the basis for statements to be subject to Expert consensus through the use of a Delphi technique and semi-structured interviews with people with RA. The modelling process and subsequent determination of outcomes that could be used to measure the potential effectiveness of a foot-focused ENAT would still remain within the ‘development’ phase of the MRC (2000) framework, further work would be required to determine the feasibility and cost effectiveness of its’ use in practice through future pilot and evaluation phases.

In addition to the need to develop a foot focused ENAT, there are other factors that require consideration in the development and delivery of FHE for people with RA. This body of work has shown that a number of barriers exist that prevent or deter people from engaging with patient educational resources, including; a lack of awareness, time and financial restraints (Graham et al 2015; 2016; 2017). A reduced physical ability to undertake self-care and lower levels of literacy are further factors that influence a persons’ level of engagement with patient education strategies.

Health literacy describes the; *“degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health choices.”* (Nielsen et al, 2004). According to Adams (2010), adults with limited literacy are less likely to ask questions of clinicians during the medical consultation and those with a less than university level of education are unlikely to classify themselves as ‘education seekers’. Communication needs to be tailored to take into account the patient preferences for the type of patient education media, the frequency of its’ delivery and the skills competencies of the individual patient (Adams, 2010). Recent research that investigated the accessibility of patient support websites for Osteoarthritis self-management, recommended that health care literature should be written at a reading level that is pitched at a reading age of 11years or under. This study identified that half of the websites surveyed failed to include relevant visual information to support the text and concluded that many of those websites were too complex, too text heavy and rarely used video content (Chapman et al, 2017). They stated that lower levels of literacy are associated with poor clinical outcomes and a reduced ability to self-manage their condition, this is further reinforced by Adams (2017) who found that many MSK educational programmes have failed to meet the needs of individuals with lower levels of literacy.

Heron et al, (2017) showed that the factors that most facilitated the accessible use of patient support websites for people with arthritis included; site aesthetics, size of text, use of icons, pictures, types of graphics and colour, content, interactiveness, ease of physical access and trustworthiness of information.

The majority of patients with RA that need FHE will be adult learners and will have individual learning preferences. Quantitative results from the patient and practitioner surveys conducted as part of this portfolio of work show that, for this group of patients, verbal, written and web-site information provision are the most commonly used methods of FHE delivery (Graham and Williams 2015; Graham, Stephenson and Williams, 2017). This is typical of FHE delivery within the podiatry profession, but may not adequately address the needs of patients who are visual or kinaesthetic learners (Bullen et al, 2017). Identification of learning style preferences may be approached with the use of simple questions such as: "*Do you prefer to read a book or watch a film?*" or "*Would you like me to draw a diagram?*" (Hillier, 2005), such questions could be considered within the developmental design of the foot ENAT. Addressing the health literacy needs, learning preferences; use of visual and kinaesthetic learning strategies that support and compliment traditional verbal and written information and skills competencies may encourage a deeper, rather than surface learning approach and result in improved clinical outcomes for the patients that we manage (Bullen et al, 2017).

It has already been shown that foot health self-management strategies can be used within this population of patients, but that a comprehensive assessment of the functional ability of the individual is needed to ensure that they can safely undertake routine self-care such as nail cutting and filing (Semple et al, 2009). In this particular study to assess the individuals' ability to participate in a self-management foot health programme, the main factor that restricted participation was hand-grip strength, followed by the persons' ability to reach their feet. In this circumstance the recommendation was that those individuals should receive Occupational Therapy to address hand function and/or train a relative or carer to undertake those tasks for them. This factor should be a significant consideration in the identification of the FHE needs of any individual, if the intention is to refer the patient into a self-management programme or provide one-to-one advice about how to undertake aspects of self-care for feet. Therefore, the development of a foot related ENAT should allow for identification of any physical impediment that could prove to be a barrier to self-management; such as hand, back or hip related pathology.

Research to investigate the effectiveness of self-management programmes in patients with diabetes and foot pathology have had variable results in respect of their impact on measures of clinical and cost-effectiveness. Vatankhah et al (2009) showed that short, 20 minute education sessions resulted in some improvement in patient knowledge about foot health and in their foot health related behaviour, with improvements in self-efficacy outcomes being found in a study by Seyyeddrasooli et al (2015) and written information proving more effective than interactive (group) education in improving foot health (Baba et al, 2015). Seyyeddrasooli et al (2015) found that group education was more cost-effective than individual PE and Baba et al (2015) found that interactive (group) education resulted in participants having greater confidence in undertaking preventative foot health measures. None of these studies were more than 6 months in duration and therefore the longer term positive influence of such self-management strategies cannot be assumed and it should also be considered that, in the case of patients who have a complex and chronic disease profile such as people with diabetes and inflammatory arthropathy, self-management programmes maybe insufficient to prevent significant pathology such as foot ulceration (Chin et al, 2014). Factors such as variations in 'illness schemata' – how people 'view' their illness – have been shown to be influential in self-reported foot care behaviour in patients with peripheral neuropathy and diabetes (Perrin et al, 2014), further reinforcing the need for FHE that is tailored to the individual within the context of their own perceptions of their foot health. Finally, Bus and Van Netten (2016) argue that the priority of foot care research for patients with diabetes is disproportionately skewed towards reducing ulcer recurrence and improving healing rates. Their review of the literature revealed that for every RCT conducted on diabetic foot ulcer prevention there were 10 RCTs to investigate ulcer healing rates; for every Euro spent on prevention strategies 10 Euros are spent on diabetic foot ulcer care. Studies on patient education in people with diabetes show that while knowledge of problems and foot care behaviour can be improved, ulcer recurrence is not prevented. Bus and Van Netten state that the most effective way for reducing the patient and economic burden that diabetic foot pathology places upon health care systems, is to focus research upon prevention, developing advice and education sessions that patients will adhere to.

Semple et al (2009) and the original FOOTSTEP study by Waxman et al, (2003) highlighted the potential cost-effectiveness of foot health self-management programmes. Farndon et al (2009) have shown that core podiatry can improve or sustain foot health and pain in 75% of their audit participants with mild to moderate foot pathology, although cost-effectiveness was not an outcome measured within this particular study and so the cost-effectiveness of core podiatry interventions are, to date, unknown. The economic evaluation undertaken as part of the REFORM study (Cockayne et al, 2017) suggests that the podiatry based falls-interventions (of which foot health and foot wear advice were a component) could be cost-effective. Research has shown that the use of the ENAT in patients with RA improves self-efficacy and guides individualised patient education, thereby reducing the risk of referring patients to educational resources/programmes that would prove costly and clinically ineffective for the individual (Ndosi et al, 2014). Podiatric interventions, notably foot orthoses (Hennessey et al 2012; Rome et al, 2017) are known to be clinically and cost effective for people with RA. However, a recent study by Wilson et al (2017) has reinforced the need for more research to identify the level to which foot pathology is responsible for participation restriction and its' subsequent economic burden, in this patient population. This groundswell of evidence should indicate to Clinical Commissioning Groups wishing to develop a clinical and cost-effective foot health service, the positive outcomes that guiding patients to foot health services and implementing foot health-self management programmes can herald.

Using the findings of research in the self - management of the diabetic foot, the elderly (Waxman et al), the results from feasibility studies such as conducted by Semple et al (2009) and understanding issues of health literacy can help to refine the development of a foot ENAT for people with RA. Further to this, it could illustrate to clinical commissioners the potential clinical and cost-effectiveness that the adoption of foot-related educational needs analysis tools could bring.

Chapter 4: concluding summary of the body of works and critical review.

Chapter 4: Conclusion

A total of seven publications have been presented within this thesis for PhD by Published Works, as evidence of a sustained development portfolio over the last seven years (2010-2017). The publications within this body of work, whilst generating subsidiary publications in relation to foot health guidelines, have been selected as they demonstrate the range and scope of the authors' developing research skills. The range of publications demonstrates that the stated research aims and objectives below, have been achieved:

Aim: I have investigated both the patients' and podiatrists' perspectives of current foot health education provision for people with RA in the UK.

Objectives:

From the practitioners' perspective I have

Identified the nature of the current provision of FHE to people with RA.
Explored the content of the current provision of FHE to people with RA.
Gained insight into the current barriers to the provision of FHE to people with RA.

From the perspective of the person with RA I have:
Gained insight into patient experiences of FHE in respect of its' nature.
Explored patient experiences' of FHE in respect of its' content.
Gained insight into patient experiences' of FHE in respect of its' accessibility.

Critically reviewing this body of work in the context of its' impact, methodological approach, knowledge translation and the potential for future development, demonstrates the originality, innovative approaches to research design and how the body of work is contextualized within the broader areas of both FHE and the management of patients with RA. Through reflecting on my personal journey, the completion of the research has significantly contributed to my greater understanding of the research process and a range of research methodologies, most significantly the use of qualitative approaches to data collection and analysis and online survey development. The use of these 'new' research skills has already been built upon during the last three years (2014-2017) through the author being the lead developer for a national survey of the use of foot orthoses (Nester et al, 2017). I have also had an increasing number of invitations to review new research across a number of peer-reviewed journals; the Journal of Foot and Ankle Research, Clinical Rehabilitation and BMJ Open Musculoskeletal Disorders, indicating an increased professional profile and national recognition as a specialist in patient education.

A number of recommendations for future research have been presented with the aim of ensuring that FHE for people with RA continues to develop within the health care professions in a manner that is timely, clinically effective and cost-effective for both patients and practitioners alike. A summary of the key recommendations that have emerged from the body of work are outlined in Figure 10, together with a summary of key innovations (Fig 11) that have contributed to knowledge and impact within the field.

Figure 10: A summary of key recommendations from the body of work.

Summary of Key Recommendations

- We need to start to change established FHE provision habits by the implementation of competency based professional development such as those developed by the NWCEG (2017) to benchmark existing services.
- ‘Grass roots’ changes in the attitudes of health practitioners are needed towards the provision of FHE by making sure that the UG training reflects the need for skills in developing strong therapeutic relationships, which is key to the provision of FHE that can foster positive health behaviour change. UG curriculums should include the Level C competencies as part of their training of new podiatry graduates.
- Audit of rheumatology service provision in respect of current foot health management guidelines for people with RA should be used as a mechanism to drive change and raise awareness in relation to current guidelines. This requirement should be included within local/National NHS audit policies.
- The specialist role of the podiatry practitioner within the rheumatology team remains essential to the effective care of patients with rheumatological disease and also to help raise the awareness of the podiatrist’s scope of practice to other AHP’s/Medical staff.
- As a MINIMUM people with RA should be provided with the opportunity to voice their foot health concerns during the medical consultation. This minimum standard should be included within local and national guidelines.
- Development of a Foot ENAT for people with RA that acknowledges literacy levels and learning preferences of the individual to enable effective, tailored and timely recognition of FHE needs.

Figure 11: A summary of key innovations from the body of work.

Summary of Key Innovations

- Identification for the first time that FHE for people with RA should be targeted to the individual and should be used to inform future clinical protocols for the management of people with RA and foot-related pathology.
- Insight into the perspective of the person with RA about foot health and the profound physical, psychological and emotional impact that it has upon the individual.
- The identification of the importance of the therapeutic relationship, the influence of age and gender in the effective delivery of FHE.
- The identification of the high value placed upon written foot health information provided within the context of the medical consultation, by people with RA.
- This body of work has given a voice to the participants about how they perceive the current status of FHE in the UK and its future development.
- People with RA want to and should be able to have the chance to voice their foot health/education concerns during their medical consultations, an opportunity that is currently not available to many people with RA.

Chapter 5: Appendices

5.1 Appendix A: Co-Authors statements of contributed work.

Congratulations on progressing to this point.
I confirm,to my knowledge, , your statement reflects he work you have undertaken
Kind regards
Alison

Sent from my iPad

On 19 Aug 2016, at 15:32, Graham Andrea <A.S.Graham@salford.ac.uk> wrote:

Dear all, as part of the Prima Fascie assessment process for PhD by Published works I need to obtain a confirmatory statement from all my co-authors in relation to their contribution to my work. I have attached a draft table which outlines the contributions to the work i have published (the last paper is in review)... Would you mind sending me a statement to indicate your agreement with the paper number (s) contained in the table to which you have contributed - and/or add in any other details that you would like me to include in relation to your contributions.

May I take this chance to thank each of you for your help, guidance and support along the way- all of it invaluable and greatly appreciated.

Kindest Regards, Andrea.
<Prima Facie -Draft statements of candidates' independent work and contributory authors by publication number.docx>

Hi Andrea

I can confirm that the information provided in the table is a true reflection of contributions.

Please note that my last name is spelt incorrectly in the table.

Many thanks

John

From: Graham Andrea [mailto:A.S.Graham@salford.ac.uk]
Sent: 19 August 2016 15:32
To: John Stephenson <J.Stephenson@hud.ac.uk>; Williams Anita <A.E.Williams1@salford.ac.uk>; Hammond Alison <A.Hammond@salford.ac.uk>; S.Walmsley@westernsydney.edu.au
Subject: PhD by Published works - confirmatory statement of authors contribution

Dear all, as part of the Prima Fascie assessment process for PhD by Published works I need to obtain a confirmatory statement from all my co-authors in relation to their contribution to my work. I have attached a draft table which outlines the contributions to the work i have published (the last paper is in review)... Would you mind sending me a statement to indicate your agreement with the paper number (s) contained in the table to which you have contributed - and/or add in any other details that you would like me to include in relation to your contributions.

May I take this chance to thank each of you for your help, guidance and support along the way- all of it invaluable and greatly appreciated.

Kindest Regards, Andrea.

University of Huddersfield inspiring tomorrow's professionals.

Hi Andrea,

I can confirm that your table is an accurate reflection. I wish you all the best with the completion of your PhD.

Kindest regards,

Steven Walmsley

From: Williams Anita [A.E.Williams1@salford.ac.uk]
Sent: Saturday, August 20, 2016 7:42 PM
To: Graham Andrea; j.stephenson@hud.ac.uk; Hammond Alison; Steven Walmsley
Subject: RE: PhD by Published works - confirmatory statement of authors contribution

Hi Andrea
This a true reflection of your contribution and I am happy that this reflection your learning and development to being an independent researcher.

Also as Andreas mentor can I take this opportunity to thank you all for your contributions, not only to Andreas work but to a significant range of publications that have already had an impact.

I look forward to future work in this area post PhD completion. Andrea, thank you for being such a diligent 'student'.I am sure the final thesis will be one to be proud of.

Regards
Anita

Dr Anita Williams PhD, BSc (hons) FCPodM,FFPM.RCPS(Glsg)
Reader I Post Graduate Research Studies Director
School of Health Science I Office PO29 I Brian Blatchford Building
University of Salford M6 6PU
Tel 0161 295 7027 I Mob 07803002497

View my profile at: http://www.seek.salford.ac.uk/profile/WILLIAMS1012.jsp

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From: Graham Andrea
Sent: 19 August 2016 15:32
To: j.stephenson@hud.ac.uk; Williams Anita; Hammond Alison; S.Walmsley@westernsydney.edu.au
Subject: PhD by Published works - confirmatory statement of authors contribution

Dear all, as part of the Prima Fascie assessment process for PhD by Published works I need to obtain a confirmatory statement from all my co-authors in relation to their contribution to my work. I have attached a draft table which outlines the contributions to the work i have published (the last paper is in review)... Would you mind sending me a statement to indicate your agreement with the paper number (s) contained in the table to which you have contributed - and/or add in any other details that you would like me to include in relation to your contributions.

May I take this chance to thank each of you for your help, guidance and support along the way- all of it invaluable and greatly appreciated.

Kindest Regards, Andrea.

5.2 Appendix: B

Patient and Practitioner Focus Group University Ethical Approval documentation:

University of Salford
MANCHESTER

24 October 2011

Dear Anita,

RE: ETHICS APPLICATION HSCR12/62 –
RA Patient experiences of foot health and foot care

Following your responses to the Panel's queries, based on the information you provided, I am pleased to inform you that application HSCR12/62 has now been approved.
If there are any changes to the project and/ or its methodology, please inform the Panel as soon as possible.

Yours sincerely,

Rachel Shuttleworth

Rachel Shuttleworth
College Support Officer (R&I)

Research, Innovation and Academic
Engagement Ethical Approval Panel
College of Health & Social Care
AD 101 Allerton Building
University of Salford
M6 6PU
T +44(0)161 295 7016
r.shuttleworth@salford.ac.uk
www.salford.ac.uk/

Academic Audit and Governance Committee

Research Ethics Panel
(REP)

THE UNIVERSITY OF SALFORD

MEMORANDUM

To Andrea Graham

cc: Ms Sue Braid

From M Pilotti, Contracts Officer

Date 4th December 2009

Subject: **Approval of your Project by REP**

Project Title: **Podiatrists' Perceptions of Foot Health Education provision for people with Rheumatoid Arthritis.**

RGEC Reference: **REPN09/119**

Following your responses to the committee's queries, based on the information you provided, I can confirm that they have no objections on ethical grounds. The Chair of the REP has asked me to pass on the following comment regarding your ethical approval application:

- There is a risk that if any participant in a focus group withdraws consent the information from an entire focus group could be unusable. The PI should consider accepting this risk; otherwise give further thought to the wording of the third guarantee on the consent form.

If there are any changes to the project and/or its methodology, please inform the committee as soon as possible.

Regards,

pp
T. Clements

Max Pilotti
Contracts Officer
MP/JH

Tim Clements

For enquiries please contact
M U Pilotti, Contracts Officer
Contracts Office for Research and Enterprise
Enterprise & Development Division
Faraday Building
Telephone 0161 295 2654 Facsimile 0161 295 5494
E-mail m.u.pilotti@salford.ac.uk

Academic Audit and Governance Committee

Research Ethics Panel
(REP)

THE UNIVERSITY OF SALFORD

MEMORANDUM

To Andrea Graham

cc: Ms Sue Braid

From Tim Clements, Contracts Administrator

Date 25th February 2010

Subject: **Approval of your Project by REP**

Project Title: **Patients' Perceptions of Foot Health Education provision for people with Rheumatoid Arthritis.**

RGEC Reference: **REPN09/171**

Following your responses to the Panel's queries, based on the information you provided, I can confirm that they have no objections on ethical grounds to your project.

If there are any changes to the project and/or its methodology, please inform the Panel as soon as possible.

Regards,

T. Clements

Tim Clements
Contracts Administrator
TC/JH

For enquiries please contact
Tim Clements
Contracts Administrator
Contracts Office
Enterprise Division
Faraday House
Telephone 0161 295 6907, Facsimile 0161 295 5494
E-mail: t.w.clements@salford.ac.uk

University of Salford MANCHESTER

Research, Innovation and Academic Engagement Ethical Approval Panel

College of Health & Social Care
AD 101 Allerton Building
University of Salford
M6 6PU

T +44(0)161 295 7016
r.shuttleworth@salford.ac.uk

www.salford.ac.uk/

15 June 2012

Dear Andrea,

RE: ETHICS APPLICATION HSCR12/35 – A survey of current foot health education provision for people with rheumatoid arthritis (RA) - patients' and podiatrists' perspectives

Following your responses to the Panel's queries, based on the information you provided, I am pleased to inform you that application HSCR12/35 has now been approved.

If there are any changes to the project and/ or its methodology, please inform the Panel as soon as possible.

Yours sincerely,

Rachel Shuttleworth

Rachel Shuttleworth
College Support Officer (R&I)

5.3 Appendix C: Patient and Practitioner Focus Group Participant Information Sheets and Consent forms.

School of Health, Sports and Rehabilitation Sciences
Allerton Building
Salford University

Tel: 0161 295 6416
E-mail: a.s.graham@salford.ac.uk

Date:.24-03-2010

Dear NRAS member

Re: Patient Education for People with Rheumatoid Arthritis related Foot Health Problems

You are being invited to take part in this research study that requires your involvement for one morning/afternoon in a focus (discussion) group. This study aims to identify what you, as patients with Rheumatoid Arthritis (RA), feel is the current provision of patient education for people with foot problems related to (RA). There is no evidence base to support this essential aspect to the management of people with RA and thus was not considered for recommendation within the recently published NICE guidelines for Management of RA in Adults (2009).

The provision of patient education is a key part of the role of podiatrists when treating people with RA and an aspect of care that patients value highly. As such this area of practice requires high quality research that aims to support it's development and appropriate implementation.

You will join bewteen 5 -10 other people with RA in this group and discussions will be hosted by myself and a colleague. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information sheet carefully and discuss it with others if you wish. Please contact me if there is anything that is not clear or if you would like more information. Take time to consider your involvement in this research and decide whether or not you wish to take part. It would be helpful if you would complete and return the reply form attached within two weeks from the date you receive this letter to let me know whether you will be able to take part or not.

The focus group is planned to take place on:
Date – 14th April, 2010 3.30pm-4.30pm
Venue – Lever Chambers Room S30.
Thank you for reading the attached information.

Yours Faithfully

Andrea Graham, lecturer in Podiatry. Msc, BSc (hons), PG cert in HE.

Tel: 0161 295 6416 : e-mail: a.s.graham@salford.ac.uk

PARTICIPANT INFORMATION SHEET

Study title:

Patient Perceptions of Foot Health Education provision for people with Rheumatoid Arthritis.

Part One: Introduction

We would like to invite you to take part in a PhD research study. Before you decide, you need to understand why the research is being done and what it will involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear to you or if you would like more information. We can be contacted on the telephone numbers at the end of this sheet. Take time to decide whether or not you wish to take part.

This part of the study will involve your participation in a Focus Group. The aim of the focus group will be to generate discussion regarding your views of the current provision of foot health related patient education for people with R.A. including the type of information given (content), when it is given (timing) and how it is provided (mode of delivery). It will also explore your views regarding barriers to the provision of patient education. The discussion will be audio-taped so that it can be transcribed and subject to thematic analysis. The results of this part of the study will form the basis of a report to be presented at conference and a journal publication to be submitted as part of the requirements of PhD by Publication. The raw data will be stored as a digital file on University password protected P.C, to which only A.G has access. In addition, any transcribed documentation will be coded and anonymised so that no individuals may be identified. All participants will remain anonymous within the text of any publication or conference presentation. You will have the opportunity to read the transcribed discussion and thematic analysis to verify it's content and make comment if you so wish. At the end of the period of the PhD (approx 5 years), all data will be destroyed.

1. **What is the purpose of the study?**

The majority (80-90%) of people with rheumatoid arthritis (RA) will have foot problems, if not preceding their diagnosis then within five years of it. Podiatrists are potentially well placed to provide tailored foot health education using a flexible approach, as they are likely to have long term and regular consultations with this patient group due to the nature of the interventions they provide. This area of rheumatology podiatric practice is currently under-evaluated. Because of the lack of research,, podiatry provision of foot health education could not be recommended within the recent NICE guidelines for the management of RA, despite their recognition that Podiatry is insufficiently available within Health Service provision for people with RA. Research is therefore essential to identify the nature and role of foot health education for people with RA and to inform future development of appropriate educational methods.

The purpose of the study is to explore what you perceive the patient education needs are of people, such as yourselves who may have or go on to develop foot problems related to rheumatoid arthritis. The data from the focus group will be used to develop a framework of questions that can used for more in-depth, individual patient interviews. The overall aim is to identify the most appropriate format, timing and information content with which to develop 'package' of education tailored to the needs of the individual. A similar process will be used to explore the Podiatrists perspective.

The researcher (A.G) is a lecturer and PhD student at the University of Salford. She has worked for the NHS previously within the specialist area of Rheumatology. Her colleague, AW has 25 years of clinical experience working with people with rheumatoid arthritis and is a renowned researcher, both nationally and internationally in the area of Footwear.

2. **Why have I been invited?**
   You have been invited because you are a person with Rheumatoid Arthritis and you are a member of the National Rheumatoid Arthritis Society (NRAS).

3. **Do I have to take part?**
   Taking part in the research is entirely voluntary. It is up to you to decide whether or not to take part. If you do decide to take part please retain this information sheet and we will then ask you to sign a consent form on the day you attend the focus group. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

4. **What will happen to me if I take part?**
   I will attend one of your local support group meetings and the focus group will take place as part of that.. The routine business of your meeting will take place followed by the Focus group, thus if you do not wish to participate in the focus group, you will not be excluded from the meeting. There will be a short presentation by A.G detailing the

purpose and objectives of the focus group. The group work will take a maximum of 2 hours. The focus group work will be recorded on a digital recorder. Once the information from the focus group work has been analysed, a
short report will be sent to you for you to add any further comments if you wish.

5. **What are the possible disadvantages and risks of taking part?**

We do not expect there to be any disadvantages or risks to you in participating. We are interested in your views as people with R.A on this matter and there is thus likely to be a range of opinions expressed within the group. We are interested in hearing your views. Please be assured that all information will be anonymised in future reports. We are also requesting that all participants consider the discussion in the group as confidential.

6. **What are the possible benefits of taking part?**
The benefits may be that the study will ultimately improve the experience of being provided with timely and appropriate education for people with R.A.

7. **Will my taking part in this study be kept confidential?**
All information, which is collected during the focus group work, will be kept strictly confidential. Any information about you will be anonymised so that you cannot be recognised from it.

8. **What will happen to the results of the research study?**
Once the research is complete the work will be published in a professional journals, potentially presented at a professional Conference and will form part of the researchers' (Andrea Graham) PhD thesis. A summary of the focus group report will be sent to you for your information. The people who have contributed to the study will not be mentioned by name in any paper, report or presentation at conferences.

Who is organising and funding this research?
This study has been reviewed by the University of Salford Research Ethics Panel. It is funded by the University of Salford and organised by A.G

9. **Contact for Further Information**

Andrea Graham, lecturer in Podiatry
Tel: 0161 295 6416 : e-mail: a.s.graham@salford.ac.uk

If you agree to take part in the study you will be asked to sign a form (example attached) where you give your consent (written agreement) to taking part in the study. This does not mean than you cannot withdraw at any time if you so wish. You will be provided with a copy of the consent form to sign. Thank you for reading this Information sheet and considering your inclusion in this study. If you should have any queries regarding the way this study will run or wish to seek further clarification, please contact me using the contact details above.

Andrea Graham
Lecturer in Podiatry
Directorate of Prosthetics & Orthotics and Podiatry
School of Health, Sports and Rehabilitation Sciences
Allerton Building
Salford University

Tel: 0161 295 6416
E-mail: a.s.graham@salford.ac.uk

Date: August, 2010.

Project Title: Patient's Perceptions of Foot Health Education provision for people with Rheumatoid Arthritis: a focus group study.

Name of Researcher: Andrea Graham

I guarantee that the following conditions will be met:

- Your real name will not be used at any point of information collection or within any written report. You and all participants will be given pseudonyms that will be used in all verbal and written records/reports.
- If you grant permission for audio-taping the data will be used solely for the purpose of this study and will not be played for any other reason than those related to this study. At the end of the study period (of the PhD, approx 5 years) this data will be destroyed.
- Your participation in this research is voluntary; you have the right to withdraw at any point, for any reason and without prejudice. The information provided by you will not be used within the study or within subsequent publication. Any information and reports that relate to you will be either destroyed or turned over to you at your discretion.
- You will receive a copy of the transcribed data for your verification and suggestions if you feel it does not represent a true account of the proceedings.

Please INITIAL the boxes below

1. I confirm that I have read and understand the information sheet dated (March, 2010 version) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐

3. I agree to the interview/ focus group being tape recorded and that anonymous quotes may be given verbatim in reports ☐

4. I agree to take part in the above study ☐

Name of participant	Date	Signature
Name of researcher taking consent	Date	Signature

When completed: 1 for participant: 1 for researcher;.

Podiatry focus group study consent form date/ ve

Directorate of Prosthetics & Orthotics and Podiatry
School of Health, Sports and Rehabilitation Sciences
Allerton Building
Salford University

Tel: 0161 295 6416
E-mail: xxxxxxxx@salford.ac.uk

Date:.

Dear

Re: Patient Education for People with Rheumatoid Arthritis related Foot Health Problems

You are being invited to take part in this research study that requires your involvement for one morning/afternoon in a focus (discussion) group. This study aims to identify what you, as podiatrists who are involved in the management of people with Rheumatoid Arthritis (RA), feel is the current provision of patient education for people with foot problems related to (RA). There is no evidence base to support this essential aspect to the management of people with RA and thus was not considered for recommendation within the recently published NICE guidelines for Management of RA in Adults (2009). The provision of patient education is part of the key role of podiatrists when managing people with RA related foot problems. As such this area of practice requires high quality research that aims to support its development and appropriate implementation. You will join 5-10 other Podiatrists in this group and discussions will be facilitated by myself and a colleague. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information sheet carefully and discuss it with others if you wish. Please contact me if there is anything that is not clear or if you would like more information. Take time to consider your involvement in this research and decide whether or not you wish to take part. It would be helpful if you would complete and return the reply form attached within two weeks from the date you receive this letter to let me know whether you will be able to take part or not.

The focus group is planned to take place on:
Date - TBC
Venue – TBC
Thank you for reading the attached information.
Yours Faithfully
Andrea Graham, lecturer in Podiatry. Msc, BSc (hons), PG cert in HE.

Tel: 0161 295 6416 : e-mail: a.s.graham@salford.ac.uk

PARTICIPANT INFORMATION SHEET

Study title:

Podiatrists Perceptions of Foot Health Education provision for people with Rheumatoid Arthritis.

Part One: Introduction

We would like to invite you to take part in a research study. Before you decide, you need to understand why the research is being done and what it will involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear to you or if you would like more information. We can be contacted on the telephone numbers at the end of this sheet. Take time to decide whether or not you wish to take part.

This part of the study will involve your participation in a Focus Group. The aim of the focus group will be to generate discussion regarding your views of the current provision of foot health related patient education for people with R.A. including the type of information given (content), when it is given (timing) and how it is provided (mode of delivery). It will also explore your views regarding barriers to the provision of patient education. The discussion will be audio-taped so that it can be transcribed and subject to thematic analysis. The results of this part of the study will form the basis of a report to be presented at conference and a journal publication to be submitted as part of the requirements of PhD by Publication. The raw data will be stored as a digital file on University password protected P.C, to which only A.G has access. In addition, any transcribed documentation will be coded and anonymised so that no individuals may be identified. All participants will remain anonymous within the text of any publication or conference presentation. You will have the opportunity to read the transcribed discussion and thematic analysis to verify it's content and make comment if you so wish. At the end of the period of the PhD (approx 5 years), all data will be destroyed.

1. **What is the purpose of the study?**

The majority (80-90%) of people with rheumatoid arthritis (RA) will have foot problems, if not preceding their diagnosis then within five years of it. Podiatrists are potentially well placed to provide tailored foot health education using a flexible approach, as they are likely to have long term and regular consultations with this patient group due to the nature of the interventions they provide. This area of rheumatology podiatric practice is currently under-evaluated. Because of the lack of research,, podiatry provision of foot health education could not be recommended within the recent NICE guidelines for the management of RA, despite their recognition that Podiatry is insufficiently available within Health Service provision for people with RA. Research is therefore essential to identify the nature and role of foot health education for people with RA and to inform future development of appropriate educational methods.

The purpose of the study is to explore what you perceive the patient education needs are of people with foot problems related to rheumatoid arthritis. The data from the focus group will be used to develop a framework of questions that can used for the development of an online survey.. The overal aim is to identify the most appropriate format, timing and information content with which to develop ‘package’ of education tailored to the needs of the patient. A similar process will be used to explore the Patients perspective.

The researcher (A.G) is a lecturer and PhD student at the University of Salford. She has worked for the NHS previously within the specialist area of Rheumatology. Her colleague, AW has 25 years o clinical experience working with people with rheumatoid arthritis and is a renowned researcher, both nationally and internationally in the area of Footwear.

2. **Why have I been invited?**

   You have been invited because you currently work within the specialist area of Rheumatology, have an interest in this particular aspect of podiatry and have expressed an interest via the Northwest Podiatry Clinical Effectiveness Group (CEG) for Rheumatology.

3. **Do I have to take part?**

   Taking part in the research is entirely voluntary. It is up to you to decide whether or not to take part. If you do decide to take part please retain this information sheet and we will then ask you to sign a consent form on the day you attend the University for the focus group. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

4. **What will happen to me if I take part?**

   You will attend the University of Salford, Directorate of Podiatry and the focus group will take place as part of the North West Podiatry CEG meeting held on 16th December 2009. The routine business of the CEG meeting will take place followed by the Focus group, thus if you do not wish to participate in the focus group, you will not be excluded from the meeting. There will be a short presentation by A.G detailing the purpose and objectives of the focus group. The group work will take a maximum of 2 hours. The focus group work will be recorded on a digital recorder. Once the information from the focus group work has been analysed, a short report will be sent to you for you to add any further comments if you wish.

5. **What are the possible disadvantages and risks of taking part?**

We do not expect there to be any disadvantages or risks to you in participating. We are interested in your professional views on this matter and there is thus likely to be a range of opinions expressed within the group. We are interested in hearing your views. Please be assured that all information will be anonymised in future reports. We are also requesting that all participants consider the discussion in the group as confidential.

6. **What are the possible benefits of taking part?**

The benefits may be that the study will ultimately improve the patient's experience of being provided with timely and appropriate education.

7. **Will my taking part in this study be kept confidential?**

All information which is collected during the focus group work will be kept strictly confidential. Any information about you will be anonymised so that you cannot be recognised from it.

8. **What will happen to the results of the research study?**

Once the research is complete the work will be published in a professional journals, potentially presented at a professional Conference and will form part of the researchers' (Andrea Graham) PhD thesis. A summary of the focus group report will be sent to you for your information. The people who have contributed to the study will not be mentioned by name in any paper, report or presentation at conferences.

Who is organising and funding this research?

This study has been reviewed by the University of Salford Research Ethics Panel. It is funded by the University of Salford and organised by A.G

9. **Contact for Further Information**

Andrea Graham, lecturer in Podiatry
Tel: 0161 295 6416 : e-mail: a.s.graham@salford.ac.uk

If you agree to take part in the study you will be asked to sign a form (example attached) where you give your consent (written agreement) to taking part in the study. This does not mean than you cannot withdraw at any time if you so wish. You will be provided with a copy of the consent form to sign. Thank you for reading this Information sheet and considering your inclusion in this study. If you should have any queries regarding the way this study will run or wish to seek further clarification, please contact me using the contact details above.

Andrea Graham
Lecturer in Podiatry
Directorate of Prosthetics & Orthotics and Podiatry
School of Health, Sports and Rehabilitation Sciences
Allerton Building
Salford University

Tel: 0161 295 6416
E-mail: a.s.graham@salford.ac.uk

Date: October 2009.

Project Title: Podiatrists' Perceptions of Foot Health Education provision for people with Rheumatoid Arthritis: a focus group study.

Name of Researcher: Andrea Graham

I guarantee that the following conditions will be met:

- Your real name will not be used at any point of information collection or within any written report. You and all participants will be given pseudonyms that will be used in all verbal and written records/reports.
- If you grant permission for audio-taping the data will be used solely for the purpose of this study and will not be played for any other reason than those related to this study. At the end of the study period this data will be destroyed.
- Your participation in this research is voluntary; you have the right to withdraw at any point, for any reason and without prejudice. Any information and reports that relate to you will be either destroyed or turned over to you at your discretion.
- You will receive a copy of the transcribed data for your verification and suggestions if you feel it does not represent a true account of the proceedings.

<u>Please INITIAL the boxes below</u>

1. I confirm that I have read and understand the information sheet dated (October, 2009 version) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐

3. I agree to the interview/ focus group being tape recorded and that anonymous quotes may be given verbatim in reports ☐

4. I agree to take part in the above study ☐

Name of participant Date Signature

Name of researcher
taking consent Date Signature

When completed: 1 for participant: 1 for researcher;
Podiatry focus group study consent form date/ version

5.4 Appendix D: Draft versions of the Foot Health Surveys for People with RA and Practitioners.

5.4.1 Appendix D: Foot Health Education Survey for People with Rheumatoid Arthritis – Patient Version

This is a draft version of questions to be used within the online survey

Rheumatoid Arthritis (RA) is a chronic, inflammatory joint disease. For many people the feet are the first part of the body affected. Many can expect some foot involvement later on. Some people may also have problems caring for their feet because their hands are painful or it is difficult to reach their feet. We have run focus groups with people who have RA and with podiatrists who treat people with RA. The results of these focus groups indicated that people with RA require foot health education relating to RA and has led to the development of this survey.

The aim of this survey is to find out your views of current foot health education for people with Rheumatoid Arthritis. There are 13 questions and it should take no longer than 10 minutes to complete.

Section 1 asks about you. Your responses are completely anonymous. Therefore we do not ask for any details that will identify you as an individual.

Sections 2 - 6 then ask what you think about:

- Aims of foot health education
- The best ways to provide foot health education
- What should be included in foot health education
- When is the best time for you to be provided with foot health education
- What prevents you from accessing foot health education

Some questions ask for more than one response. Some ask you to rate your answers. Some have boxes for you to add your own comments so we can understand your views in more detail. Please consider the questions carefully and answer as honestly as possible.

Thank you for taking the time to complete this survey.

Section 1. About you:

1. Are you Male

Female

2. What is your Date of Birth?

….(day)….(month)……(year)

3. How long ago were you diagnosed with RA, approximately? ……(years)…….(months)

4. Do you live:

alone

with a partner/spouse

with another family member or carer

5. Which part of the UK do you mainly live in?

South East England

North West England

South West England

Greater London

West Midlands

East Anglia

Yorkshire & North Humber

East Midlands

South Central England

North East England

Wales

Scotland

Northern Ireland

6. Do you currently receive Podiatry/Chiropody treatment?

Yes

No

7. If you answered ‘Yes’ to question 6: does your Podiatrist/Chiropodist work in the (tick one):

NHS

Private Practice

I see both NHS and private

Section 2: The aims of Foot Health education

- **Which aims of Foot Health Education for people with RA do you consider to be most important? (please rank the 5 items below in order of importance from 1-5 with 5 being the most important)**

To allow informed consent before treatment

To allow me to make informed choices about my treatment options

To enable me to manage my own foot health

To educate me about how RA can affect my feet

To inform me about information & resources I can access such as
Web sites or support groups (including the National Rheumatoid Arthritis
Society (NRAS), Arthritis Care or Arthritis Research UK).

Other: Please specify in the text box below:

Section 3: The best ways of providing foot health education:

The following questions will let us know which methods of education you have experienced, who provided them, which you think are the most effective and why.
Have you ever received education about how to care for your feet because of your RA? Yes No

If you have received any form of foot health information/education, please indicate which ones and from whom below. Tick all that apply.

	Tick the boxes below for each type of education you have received and please indicate who you received it from according to the options in the right hand columns.	Podiatrist or chiropodist	Physiotherapist	Occupational Therapist	Specialist Nurse	Orthotist	Rheumatologist	Don't Know
Written Information								
One-to-one sessions								
Group Education sessions								
Audiovisual aids such as short videos or DVD's								
Audiovisual aids such as demonstrations of how to look after your feet								
Audiovisual aids such as pictures of footwear, insoles or images of feet								
Use of websites								

Any other methods:

2. Please let us know how effective or not you think this foot health education was by placing a tick the boxes below:

	Very Effective	**Effective**	**Not very Effective**	**Not at all effective**	**Don’t know**	**Never received**
Verbal Information						
Written Information						
One-to-one sessions						
Group Education sessions						
Audiovisual aids such as short videos/demonstrations/pictures						
Web Sites						
Other methods (give details here)						

Please use the box below to comment upon the reasons you thought one method worked more than another:

Section 4: What should be included in Foot Health Education?

These questions will tell us what you think are the most important areas of content for people with RA to be informed/educated about in relation to their feet.

How important or not, do you think it is to know about the following areas of foot health education? Place a tick in the box according to your answer. They are in no particular order.

	Very Important	Important	Not Important
The role of the Podiatrist/Chiropodist in managing my foot health			
General disease related information (E.g. what RA is, causes etc...)			
Information about how the medication I take can affect my feet			
How RA affects the feet			
When to contact the Podiatrist as an emergency			
Contact details for Podiatry services (when, how and who to contact)			
The different kinds of podiatry/chiropody treatment I can have to help me with my foot problems			
How to look after my own foot health (foot wear advice, use of moisturisers, safe nail cutting.)			
What happens if I don't look after my feet			
The role of other health professions in managing my foot health (such as Physiotherapists, Occupational Therapists, Specialist Rheumatology Nurses, Orthotists).			
Use of websites (e.g: NRAS, Arthritis Care, Arthritis Research UK)			

Other information you feel is important about foot care but not included above:

Section 5: When is the best time to receive foot health education?

The responses to these questions will give us some information about **WHEN** you think foot health education relating to RA ought to be provided.

When do you think is the most appropriate time for you to receive foot health education relating to RA? Tick all that you think apply.

When you are diagnosed with RA

When you ask for it

When/if you develop foot related symptoms

At every available opportunity

Other (please specify)

Section 6. Accessing foot health education

This section will give us some information about the factors that may prevent you from accessing foot health education/information relating to RA.

How strongly do you agree or disagree with the following statements:

	Strongly agree	Agree	Disagree	Strongly disagree	Don't know
I do not know what questions to ask my Podiatrist/Chiropodist or other Health Professional about my foot health					
There is not enough time during my appointments with any Health Professionals to talk about foot health					
My Podiatrist/Chiropodist does not ask about my foot health concerns during the consultation					
Other Health Professionals (Specialist nurse, Physiotherapist, Occupational Therapist, Orthotist, Rheumatologist) do not ask about my feet during the consultation					
I have not been provided with any written foot health information from my Podiatrist/Chiropodist or other Health Professional					
I have received or found information myself relating to RA and foot health but found it difficult to understand					
I have received or found information myself relating to RA and foot health but it made me feel worried about my future foot health.					
I do not know where to get written foot health information (such as a leaflet or from web sites such as NRAS)					
I am unable to access the Internet someone does it for me.					
I cannot afford to attend patient support group meetings					

Other factors you wish to include but that are not mentioned above:

This concludes the survey. Thank you for taking the time to complete this questionnaire.

5.4.2 Appendix D: Foot Health Education Survey for People with Rheumatoid Arthritis –Podiatrist Version

This is a draft version of questions to be used within an online survey:

Rheumatoid Arthritis is a chronic, inflammatory joint disease. For many people the feet are the first part of the body that is affected. Many can expect some foot involvement later on. Some people may have problems caring for their own foot care because their hands are painful or because it is difficult to reach their feet. We have run focus groups with people who have RA and with podiatrists who treat people with RA. The results of these focus groups indicated that people with RA require foot health education relating to RA and has led to the development of this survey.

The aim of this survey is to find out your views of current foot health education for people with Rheumatoid Arthritis. There are 15 questions and it should take no longer than 10 minutes to complete.

Section 1 asks about you. Your responses are completely anonymous. Therefore we do not ask for any details that will identify you as an individual.

Sections 2 – 6 then ask what you think about:

- Aims of foot health education
    - The best ways to provide foot health education
    - What should be included in foot health education
    - When is the best time to provide people with foot health education
    - What prevents you from providing foot health education

Some questions ask for more than one response. Some ask you to rate your answers. Some have boxes for you to add your own comments so we can understand your views in more detail. Please consider the questions carefully and answer as honestly as possible.

Thank you for taking the time to complete this survey.

Section 1. About you:

1. Are you Male

Female

2. What is your date of birth?

…(day)…….(month)……..(year)

3. Please select the length of time since you qualified as a Podiatrist:

Up to 1 year

A year or more, but less than2 years

2 years or more, but less than5 years

5 years or more, but less than10 years

10 years – 20 years

20 years – 30 years

30 years – 40 years

4. Are you registered with the Health Professions Council (HPC):

Yes

No.

5. Please select where you practice for the MAJORITY of the time:

In Primary Care
In Secondary Care
It is an equal split

6. Do you work in the UK or elsewhere?

In the UK

Elsewhere (if you work elsewhere please do not continue to complete the survey as it is for UK practitioners only. Thank you for your interest in this survey)

7. Which UK geographic location do you work within?

South East England

North West England

South West England

Greater London

West Midlands

East Anglia

Yorkshire & North Humber

East Midlands

South Central England

North East England

Wales

Scotland

Northern Ireland

Section 2: The aims of Foot Health education

Which aims of foot health education for people with RA do you consider the most important? Please rank the 5 items below in the order you consider to be most important from 1-5, with 5 being the most important:

To allow informed consent before treatment

To allow them to make informed choices about their treatment options

To enable them to manage their own foot health

To educate them about how RA can affect their feet

To inform them about information & resources they can access such as web-sites or support groups

Other: Please specify in the text box below:

Section 3: Methods of Providing Foot Health Education:

These questions will tell us which methods of education you have experience of providing, which you think are the most effective and why.

- **If you have provided any form of foot health information/education to people with RA please indicate below. Tick all that apply.**

	Please tick those that apply.
Verbal Information	
Written Information	
One-to-one sessions	
Group Education sessions	
Audiovisual aids such as short videos/demonstrations/pictures	
Web Sites	

Any other methods you would like to state here that are not mentioned above:

2 . From the options given, please rank the methods of delivering Foot Health education in terms of how effective YOU think they are.

	Very Effective	**Effective**	**Not very Effective**	**Not at all effective**	**Don't know**
Verbal Information					
Written Information					
One-to-one sessions					
Group Education sessions					
Audiovisual aids such as short videos/demonstrations/ pictures					
Web Sites					

Any other methods you would like to state here that are not mentioned above

Section 4: Content of Foot Health Education:

These questions will tell us what you think are the most important areas of content for people with RA to be informed/educated about in relation to their feet.

- **How important or not, do you think it is for people with RA to know about the following areas of foot health education? Place a tick in the box according to your answer. They are in no particular order.**

	Very Important	**Important**	**Not Important**
The role of the Podiatrist in managing foot health			
General disease related information (e.g what RA is, causes etc..)			
Information relating to the medication taken for RA and how it affects their feet			
Signs and symptoms of foot problems related to RA			
When to contact the Podiatrist as an emergency			
Contact details for Podiatry services (when, how and who to contact)			

Management options relating to foot health			
How to manage their own foot health (foot wear advice, use of moisturisers, safe nail cutting..)			
The consequences of not looking after their feet			
The role of other professions in managing foot health			
Information relating to Patient Support groups/resources such as websites.			

Other information you feel is important but not included above:

Section 5: Timing of Foot Health Education

The responses to these questions will tell us WHEN you think foot health education relating to RA ought to be provided.

- **When do you think is the most appropriate time for you to provide foot health education relating to RA? Tick all that you think apply.**

At the point of diagnosis of RA

When you are asked for it

When/if the person develops foot related symptoms

At every available opportunity

Other (please specify)

Section 6. Barriers to providing foot health education

This section will allow us to gauge what you feel are the barriers to providing foot health education/information relating to RA.

- How strongly do you agree or disagree with the following statements:

	Strongly agree	**Agree**	**Disagree**	**Strongly disagree**	**Don't know**
There is not enough time during consultations to provide Foot Health Education					
You have do not have access to RA- specific foot health information such as leaflets provided by your Trust or from organisations such as NRAS/ Arthritis Research UK					
You are not aware of any Group Education Programmes that you could refer people with RA to, within your Trust					
You do not think that you have enough knowledge about how RA effects the feet in order to provide effective foot health education					
The people with RA that you manage do not engage with your foot health education					

Other factors you wish to include but that are not mentioned above:

2. If people with RA do not engage with the foot health education that you provide is this because (please tick all that apply):

They tend to be well educated about RA already, before they come to see you.

They cannot afford financially to engage in positive foot health behaviours, such as purchasing new footwear or moisturising foot cream.

They do not perceive that foot health education is relevant to them.

Other factors you wish to include but that are not mentioned above:

That concludes the survey.
Thank you for taking the time to complete this questionnaire.

5.5 Appendix E: Copies of Email permission to access JISCMail and NRAS membership, Email Invites to participants and FHE survey Participant Information Sheets.

5.5.1 Appendix E: Email permission to access JISCMail and NRAS membership

-----Original Message-----
From: Anthony Redmond [mailto:A.Redmond@leeds.ac.uk]
Sent: Mon 5/9/2011 10:27 AM
To: Graham A
Subject: RE: JISC mail group numbers

Hi Andrea

Re: your query: the two JISC mail lists are podiatry, the general list; and rheum-foot, which is the rheumatology specific list.
Podiatry has 351 recipients and rheum-foot has 78. Rheum-foot has about a dozen non- pods (rheumatologists, GPs etc).
There is some overlap between the two also.

You are welcome to use either as long as it is line with the JISC mail ways of working.
Let me know once you have a clearer idea and I'll do what I can to help
Best wishes
Tony

-----Original Message-----
From: Andrea Graham [mailto:A.S.Graham@salford.ac.uk]
Sent: 06 May 2011 14:55
To: Anthony Redmond
Subject: JISC mail group numbers

Hi Tony, hope all is well with you and yours? Was good to see you, all be it briefly, at BSR!

Just a quickie...

Part of my PhD project will be to survey Podiatrists regarding current Foot Health Education provision for people with RA and I'm just working out the logistics of contacting large groups of Pods...I want the survey to be distributed online and wondered how many Pods are on the JISC mail list that you use to send out information? Are all these Pod's specialising in MSK/Rheumatology or are some generalists too? I want to capture responses from more than just the Northwest if I can and thus seems to be the best way to capture a large group of people without having to post out hard copy...

Kind regards, Andrea.

Hi Andrea

I'm good thanks, unbelievably busy (as always!) - did you see our live webchat with the Minister Paul Burstow for World Arthritis Day yesterday? http://webchat.dh.gov.uk/

In regard to your PhD project, we'd be happy to help but I wonder if there is any funding support for the work/resource involved here in doing this for you? We are requested to do this kind of thing on a regular basis and the reality is that the workload involved has become such that we cannot sustain the support we are providing to UK academic research without it being properly funded. I am working with Sarah Hewlett/Alan Silman/BSR and others to try and structure this going forward as all our staff are flat out providing the services we offer to people and so we have to pull people off other work in order to provide the kind of database searching, emailing etc. that you describe. I think I have something like 25 research project folders on the go at the moment! In the event that as this is your PhD there is no funding available, we will of course do it anyway as you have been very supportive of NRAS with our new web area.

BW
Ailsa

Ailsa Bosworth
Chief Executive
NRAS
Joint Chair, Rheumatology Futures Group Project

NRAS Christmas Cards and gift wrap are now available to buy.
To buy online please visit http://stores.ebay.co.uk/NRAS-Charity-Shop
or contact Val on 01628 501547 or visit our website at www.nras.org.uk

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-----Original Message-----
From: Andrea Graham [mailto:A.S.Graham@salford.ac.uk]
Sent: 13 October 2011 09:48
To: Ailsa Bosworth
Cc: Williams Anita; Hammond Alison
Subject: Foot Health Education - Online Survey of people with RA
Importance: High

Dear Ailsa,

Hope you are ok and not too busy at the moment?

As you know my PhD project is focused upon the Foot Health Education of People with RA - I am in the process of developing an online survey that will investigate the perceptions and foot health education needs and wondered if you would be amenable to sending a link to the survey within an e-mail and then a 'reminder' email to your members, once we have received ethical approval from the University? I will of course provide you with draft copies of the survey and participant information sheet for your comment, prior to the survey going 'live' in the new year.

A similar survey will be sent to Podiatrists across the UK who work with or who have an interest in managing people with foot health problems relating to RA.

On another note - I hope the website development is going well, please do let me know if there is any more information or amends you need in relation to that.

I hope this email finds you well and hope to hear from you soon,

Kindest Regards, Andrea.

Andrea Graham.
Lecturer in Podiatry.
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Directorate of Prosthetics & Orthotics and Podiatry,
School of Health Science
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Allerton Building,
Frederick Road,
Salford. M6 6PU.

a.s.graham@salford.ac.uk

5.5.2 Appendix E: Draft E-mail invite to NRAS member participants for foot health education survey:

Dear NRAS member,

You are being invited to participate in a survey about your views of foot health education for people with Rheumatoid Arthritis (RA). Foot health education may be provided by any health care professional including podiatrists/chiropodists, Specialists Nurses, Rheumatologists, Physiotherapists, Occupational Therapists and Orthotists or it may be that you have found out information for yourself. It can include foot health advice and how to look after your own feet, as well as how RA and your medication might affect your feet in the future.

The aim of the survey is to investigate if people with RA receive foot health education, who from, what kind of things you want to know about your foot health, when you want to receive foot health education and what kind of things stop you from accessing foot health information/education.

The study requires you to complete an online survey. The link to the survey is highlighted below. The survey is completely anonymous and does not ask for any information that will identify you as an individual. Your participation is entirely voluntary, but your views as a person with RA are valuable to us. Instructions for how to complete the survey are provided once you click on the link. It should take no longer than ten minutes to complete. Completion of the survey implies that your consent has been given. The time frame for completion of the survey is within four weeks of the date of this e-mail. You will also receive an e-mail reminder in two weeks.

Attached to this e-mail is a Participant Information Sheet, which will give you full details regarding this survey and what will happen to the results. It also contains the contact details for xxxxxxxxxxx, who is running the study, if you would like more information before you complete the survey.

This survey is aimed at people with RA only – if you are a health care professional or a carer/partner of a person with RA, then please do not complete this survey.

Thank you for your participation and time,

Yours faithfully,

xxxxxxxxxxx, Lecturer in Podiatry, Directorate of Prosthetics, Orthotics and Podiatry, School of Health Science, Allerton Building, University of Salford, M6 6PU.

Tel: 0161 295 xxxx   Email: xxxxxxxxx@salford.ac.uk

Draft E-mail invite to podiatry JISCmail member participants for foot health education survey:

Dear Podiatrist,

You are invited to participate in a survey regarding your views of foot health education for people with Rheumatoid Arthritis (RA). Foot health education may be provided by any health care professional including podiatrists/chiropodists, Specialists Nurses, Rheumatologists, Physiotherapists, Occupational Therapists and Orthotists or it patients may access it for themselves. It can include simple foot health advice and how to look after feet, as well as how RA and medication used in its management might affect patients' feet in the future.

The aim of the survey is to investigate if people with RA receive foot health education, who from, what kind of things you think people with RA need to know about foot health, when they should receive foot health education and what kind of things are a barrier to your provision of foot health information/education.

The study requires you to complete an online survey. The link to the survey is highlighted below. The survey is completely anonymous and does not ask for any information that will identify you as an individual. Your participation is entirely voluntary, but your views as a podiatrist are important to us. Instructions for how to complete the survey are provided once you click on the link. It should take no longer than ten minutes to complete. Completion of the survey implies that your consent has been given. The time frame for completion of the survey is within four weeks of the date of this e-mail. You will also receive an e-mail reminder in two weeks.

Attached to this e-mail is a Participant Information Sheet, which will give you full details regarding this survey and what will happen to the results. It also contains the contact details for xxxxxxxxx, who is running the study, if you would like more information before you complete the survey.

This survey is aimed at UK –BASED PODIATRISTS ONLY if you are not a Podiatrist and/or you are based outside of the UK then please do not complete this survey.

Thank you for your participation and time,

Yours faithfully,

xxxxxxxxxx, Lecturer in Podiatry, Directorate of Prosthetics, Orthotics and Podiatry, School of Health Science, Allerton Building, University of Salford, M6 6PU.

Tel: 0161 295 xxxx   Email: xxxxxxxxx@salford.ac.uk

5.5.3 Appendix E: Patient Survey – Invitation to participate in pilot of survey and participant information sheet.

XXXXXXXXXXXXXX (name)
Directorate of Prosthetics & Orthotics and Podiatry
School of Health Sciences
Allerton Building
Salford University

Tel: 0161 295 XXXX
E-mail: xxxxxxxx@salford.ac.uk

Date:.

Dear

Re: **Foot Health Education Survey for People with Rheumatoid Arthritis (RA) (Patient Version) – Pilot Study**

You are being invited to take part in this research study that requests your involvement in a one-to-one interview for approximately 40 minutes. This study aims to identify any issues relating to the clarity and wording of a draft foot health education survey for people with RA (Patient version). It is intended that this draft survey will be used within a larger study of people with RA across the UK.

There is no evidence to support the use of structured foot health education in the management of people with RA and thus it was not considered for recommendation within the recently published NICE guidelines for Management of RA in Adults (2009). The provision of patient education is a key part of the role of podiatrists when treating people with RA and an aspect of care that patients value highly. As such this area of practice requires high quality research that aims to support it's' development and appropriate implementation. We are in the process of developing a questionnaire for people with RA to complete and would like your views, as a person with RA and foot problems, about the draft questionnaire that we have developed.

We are asking five people with RA for their views. The interview will involve you attending the University of Salford to complete the draft questionnaire and for a one-to-one interview. We will ask you about how the questions are worded, if they make sense to you and if you would suggest any changes to the questions, as you complete the questionnaire. We will pay your travel expenses and could offer you a free podiatry treatment on the day of your interview. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information sheet carefully and discuss it with others if you wish.

Please contact me if there is anything that is not clear or if you would like more information. Take time to consider your involvement in this research and decide whether or not you wish to take part. It would be helpful if you would complete and return the reply form attached within two weeks from the date you receive this letter to let me know whether you will be able to take part or not.

Date – To be arranged for date and time that suits you.
Venue –University of Salford, Directorate of Prosthetics, Orthotics and Podiatry
Thank you for reading the attached information.
Yours Faithfully

xxxxxxxxxxxx, lecturer in Podiatry. Msc, BSc (hons), PG cert in HE.

Tel: 0161 295 xxxx : e-mail: xxxxxxx@salford.ac.uk

PARTICIPANT INFORMATION SHEET

Study title: Foot Health Education Survey for People with Rheumatoid Arthritis (RA) (Patient Version) – Pilot Study

Part One: Introduction

We would like to invite you to take part in a research study. Before you decide, you need to understand why the research is being done and what it will involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear to you or if you would like more information. We can be contacted on the telephone numbers at the end of this sheet. Take time to decide whether or not you wish to take part.

This part of the study will involve your completion of a draft questionnaire about the foot health education of people with rheumatoid arthritis during a one-to-one interview.The aim of the interview is for you to comment on whether the questionnaire is worded in a clear and simple way as you complete it. Therefore, as you are completing each question, we will ask you to say out loud what you are thinking in response to the questions. The interview will be audio-taped so that it can be transcribed, analysed and compared with interviews of other participants.

The results of this part of the study will help us to decide if the questionnaire needs to be changed in anyway before it is completed by a larger number of people. Following on from this, the results of the larger study will help to develop a programme of foot health education for people with RA. The taped interview will be stored as a digital file on University password protected file-store, to which only (XX) has access. In addition, any transcribed documentation will be coded and anonymised so that no individuals may be identified. All participants will remain anonymous within the text of any publication or conference presentation. You will have the opportunity to read the transcribed interview and analysis to verify its content and make comment if you so wish. All data will be destroyed within 2 years of the completion of the study.

1. What is the purpose of the study?

The majority (80-90%) of people with rheumatoid arthritis (RA) will have foot problems, if not before their diagnosis then within five years of it. Podiatrists are potentially well placed to provide tailored foot health education using a flexible approach, as they are likely to have long term and regular consultations with this patient group due to the types of treatment they can offer. This area of rheumatology podiatric practice is currently under-evaluated. Because of the lack of research, podiatry provision of foot health education could not be recommended within the recent NICE guidelines for the management of RA, despite their recognition that Podiatry is insufficiently available within Health Service provision for people with RA. Research is therefore essential to identify the nature and role of foot health education for people with RA and to inform future development of appropriate educational methods.

The purpose of the interview is for you to comment on whether the draft questionnaire is worded in a clear and simple way as you complete it. Therefore, as you are completing each question, we will ask you to say out loud what you are thinking in response to the questions. The interview will be audio-taped so that it can be transcribed, analysed and compared with interviews of other participants. The overall aim is to identify any problems with the wording of the questionnaire, to make sure that it is clear and easy to follow before it is used on a larger number of people with RA.

The researcher (XX) is a lecturer and PhD student at the University of Salford. XX has worked for the NHS previously within the specialist area of Rheumatology.

2. Why have I been invited?

You have been invited because you are a person with Rheumatoid Arthritis and you are patient of the University of Salford Podiatry Clinic.

3. Do I have to take part?

Taking part in the research is entirely voluntary. It is up to you to decide whether or not to take part. If you do decide to take part please retain this information sheet and we will then ask you to sign a consent form on the day you attend the interview. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

4. **What will happen to me if I take part?**

   You will be required to attend the University of Salford, Directorate of Prosthetics, Orthotics and Podiatry at an agreed date and time. The interview will take approximately 40 minutes and will be recorded on a digital recorder. Once the information from the interviews with all the patients have been analysed, a short report of your interview will be sent to you for you to add any further comments if you wish.

5. **What are the possible disadvantages and risks of taking part?**

   We do not expect there to be any disadvantages or risks to you in participating. We are interested in your views as people with R.A on this matter.We are interested in hearing your views. Please be assured that all information will be anonymised in future reports.

6. **What are the possible benefits of taking part?**

   The benefits may be that the study will ultimately improve the experience of being provided with timely and appropriate education for people with R.A.

7. **Will my taking part in this study be kept confidential?**

   All information collected during the interview will be kept strictly confidential.
   Any information about you will be anonymised so that you cannot be recognised from it.

8. **What will happen to the results of the research study?**

   Once the research is complete the work will be published in a professional journals, potentially presented at a professional Conference and will form part of the researchers' (XX) PhD thesis. A summary of the interview report will be sent to you for your information. The people who have contributed to the study will not be mentioned by name in any paper, report or presentation at conferences.

   Who is organising and funding this research? This study has been reviewed by the University of Salford Research Ethics Panel. It is funded by the University of Salford and organised by XX

9. **Contact for Further Information**

XXXXXXX, Lecturer in Podiatry
Tel: 0161 295 XXXX : E-mail: XXXXXXXX@salford.ac.uk

If you agree to take part in the study you will be asked to sign a form (example attached) where you give your consent (written agreement) to taking part in the study. This does not mean than you cannot withdraw at any time if you so wish. You will be provided with a copy of the consent form to sign. Thank you for reading this Information sheet and considering your inclusion in this study. If you should have any queries regarding the way this study will run or wish to seek further clarification, please contact me using the contact details above.

Participant consent form (patient) for Pilot study.

Andrea Graham
Lecturer in Podiatry
Directorate of Prosthetics & Orthotics and Podiatry
School of Health Sciences
Allerton Building
Salford University

Tel: 0161 295 xxxx
E-mail: a.s.graham@salford.ac.uk

Date:.

Project Title: Foot Health Education Survey for People with Rheumatoid Arthritis (Patient Version) – Pilot study

Name of Researcher: xxxxxxxxxxxxx

Please INITIAL the boxes below

1. I confirm that I have read and understand the information sheet dated April, 2012, Version 2.0 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
3. I agree to the interview being tape recorded and that anonymous quotes may be given verbatim in reports ☐
4. I agree to take part in the above study ☐

Name of participant	Date	Signature
Name of researcher taking consent	Date	Signature

When completed: 1 for participant: 1 for researcher;.
Patient cognitive debrief interview consent form date: 24-11-11 version 1.0

5.5.3 Appendix E: Participant (podiatrist) Invite letter and participant information sheet to take part in online survey.

xxxxxxxxxxxxx
Lecturer in Podiatry
Directorate of Prosthetics & Orthotics and Podiatry
School of Health Sciences
Allerton Building
Salford University

Tel: 0161 295 xxxx
E-mail:xxxxxxx@salford.ac.uk
Date: ***** .

Re: A survey of current foot health education provision for people with rheumatoid arthritis – patient and podiatrists' perspectives.

You are being invited to take part in this research study that involves you completing an online survey. This study aims to identify what your views are, as Podiatrists, about foot health education provision for people with RA. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information sheet carefully and discuss it with others if you wish. Please contact xxxxxxxxx if there is anything that is not clear or if you would like more information. This survey is completely anonymous. Take time to consider your involvement in this research and decide whether or not you wish to take part.

The online survey is planned to be available from:………….and I would be grateful if you could complete it within two weeks of that date.
Thank you for reading the attached information.

Yours Faithfully

xxxxxxxxxxxxxx, Lecturer in Podiatry, BSc (hons) Podiatry, MSc, P.G Cert.
xxxxxxxxxxxxx@salford.ac.uk

PARTICIPANT INFORMATION SHEET

Study title:

A survey of current foot health education provision for people with rheumatoid arthritis – patient and podiatrists' perspectives.

Part One: Introduction

We would like to invite you to take part in a research study. Before you decide, you need to understand why the research is being done and what it will involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear to you or if you would like more information. We can be contacted on the telephone numbers/e-mail addresses at the end of this sheet. Take time to decide whether or not you wish to take part.

4. **What is the purpose of the study?**

The aim of this study is to explore the views of podiatrists with regards the provision of foot health education for people with RA in terms of:

- The aims of foot health education
- Methods of delivering foot health education
- Content that should be included within the provision of foot health education for people with RA.
- Timing of delivery
- Barriers to the delivery of foot health education.

We have run focus groups with people who have RA and with podiatrists who treat people with RA. The results of these focus groups indicated that people with RA require foot health education relating to RA and has led to the development of this survey.

5. **Why have I been invited?**

You have been invited because you are a Podiatrist who works within the NHS and are likely to manage people with Rheumatoid Arthritis and associated foot problems.

6. Do I have to take part?

Taking part in the research is entirely voluntary. It is up to you to decide whether or not to take part.

7. **What will happen to me if I take part?**

   You have the web link to an online questionnaire survey in the content of this e-mail. You should complete the survey and submit your responses within two weeks. No personal data that can identify you, as an individual will be requested. Your responses will be entirely anonymous. Once the data from the survey has been collected and analysed it will be used to develop a package of foot health education for people with RA. This will be piloted and evaluated with people who have RA.

8. **What are the possible disadvantages and risks of taking part?**

   We do not expect there to be any disadvantages or risks to you in participating. We are interested in your professional views on this matter. There is likely to be a range of opinions expressed within the participants. We are interested in hearing your views. Please be assured that all information will be anonymised in future reports.

9. **What are the possible benefits of taking part?**

   The benefits may be that the study will ultimately improve the patient's experience of being provided with timely and appropriate structured foot health education.

10. **Will my taking part in this study be kept confidential?**

    All information that is collected from the online survey will be kept strictly confidential. NO information that can identify you, as an individual will be requested so you cannot be recognised from it. The results from the survey will be stored as a digital file on University the main server, which is password protected. Transcribed data will be coded. All data will be destroyed within 2 years of the end of the study.

11. **What will happen to the results of the research study?**

    Once the research is complete the work will be published in a professional journal, potentially presented at a professional Conference and will form part of the researchers' (xxxxxxxxx) PhD thesis.

Who is organising and funding this research?

It is funded by the University of Salford and organised by xxxxxxxxxxxx

12. **Contact for Further Information**

XXXXXXXXXXX
University of Salford,
Directorate of Prosthetics & Orthotics and Podiatry,
School of Health Sciences
Allerton Building
Frederick Road,
Salford M6 6PU Tel: 0161 296 xxxx E-mail: xxxxxxxxxxx@salford.ac.uk

If you agree to take part in the study your consent will be implied by your completion of the online survey. Thank you for reading this Information sheet and considering your inclusion in this study. If you should have any queries regarding the way this study will run or wish to seek further clarification, please contact us using the contact details above.

Thank you, xxxxxxxxxxxxxx

5.6 Appendix F

Rheumatology 2016
26-28 April 2016 | SECC Glasgow, UK

Foot health education for people with rheumatoid arthritis: A game of chance: A survey of patients experiences – Andrea Graham, Lecturer in Podiatry, University of Salford.

Summary of presentation for delegates:

Background: up to 90% of people with rheumatoid arthritis (RA) experience painful foot problems by the time the disease is well established. This results in restricted activity (social and work-related) and reduced quality of life. Foot health education (FHE) should be recognised as an essential part of the way foot health problems are managed. Additionally, FHE could help to increase awareness of the potential for foot problems related to RA to develop. Increasing this awareness could allow people with RA to better understand what can be done to help reduce the risk of foot problems developing or getting worse. The provision of FHE is advocated in management guidelines for foot health problems in RA, although despite this there remains a lack of understanding and awareness about foot problems, how to access foot health services and what foot health education 'is' amongst both health professionals and people with RA.

Andrea's research into FHE constitutes her PhD project and aimed to uncover the status of foot health education provision from both the patient and practitioner (podiatrist/chiropodist) viewpoint, in order to understand how we can effectively provide FHE in the future for people with RA.

This short presentation outlines some of the findings of an online survey of 543 people with RA in relation to how they currently perceive FHE provision and presents some suggestions as to how the results could influence the future practice of health professionals and what could be the 'next step' in building on this research.

The presentation covers the 'qualitative' data from the survey – analysis of the additional comments provided by the study participants, that showed how deeply and strongly these participants felt about their foot health and the impact it had on their lives in the context of their disease.

References:

Adams, J. (2017). *Supporting people with lower health literacy to engage with MSK patient education.* Paper presented at the British Society for Rheumatology conference, Birmingham.

Adams, RJ. (2010). Improving health outcomes with better patient understanding and education. *Risk Management and Health Care Policy, 3*, 11. doi:10.2147/RMHP.S7500

Albano, M. G. Giraudet-Le Quintrec, J. S., Crozet, C., & d'Ivernois, J. F. (2010). Characteristics and development of therapeutic patient education in rheumatoid arthritis: analysis of the 2003-2008 literature. *Joint Bone Spine, 77*(5), 405-410. doi:10.1016/j.jbspin.2010.01.010

Allen, & BL. (1996). *Information Tasks: Towards a User-Centred Approach to Information Systems.* San Diego CA: Academic Press.

Arthritis and Musculoskeletal Alliance (ARMA).(2004).Standards of Care for People with Inflammatory Arthritis. Retrieved from http://arma.uk.net/resources/standards-of-care/ [accessed August, 2017]

Baba, M.,Duff, J., Foley, L., Davis, W. A., & Davis, T. M. (2015). A comparison of two methods of foot health education: the Fremantle Diabetes Study Phase II. *Prim Care Diabetes, 9*(2), 155-162. doi:10.1016/j.pcd.2014.05.004

Bacon, D., & Borthwick, A. M. (2013). Charismatic authority in modern healthcare: the case of the 'diabetes specialist podiatrist'. *Sociol Health Illn, 35*(7), 1080-1094. doi:10.1111/1467-9566.12024

Bakkalbasi, N., Bauer, K., Glover, J., & Wang, L. (2006). Three options for citation tracking: Google Scholar, Scopus and Web of Science. *Biomed Digit Libr, 3*, 7. doi:10.1186/1742-5581-3-7

Barnett, S.,Campbell, R., & Harvey, I. (2005). The Bristol Foot Score: developing a patient-based foot-health measure. *J Am Podiatr Med Assoc, 95*(3), 264-272.

Barton, CJ, Bonanno, DR, Carr, J, Neale, BS, Malliaras, P, Franklyn-Miller, A, & Menz, HB. (2016). Running retraining to treat lower limb injuries: A mixed methods study of current evidence synthesized with expert opinion. *British Journal of Sports Medicine., 50*, 13. doi:10.1136/bjsports-2015-095278

Beck, A. (2004). The Flexner report and the standardization of American Medical Education. *The Journal of the American Medical Association, 5*(291), 2.

Beischer, A. D., Clarke, A., de Steiger, R. N., Donnan, L., Ibuki, A., & Unglik, R. (2008). The practical application of multimedia technology to facilitate the education and treatment of patients with plantar fasciitis: a pilot study. *Foot Ankle Spec, 1*(1), 30-38. doi:10.1177/1938640007312299.

Blake, A., Mandy, P. J., & Stew, G. (2013). Factors influencing the patient with rheumatoid arthritis in their decision to seek podiatry. *Musculoskeletal Care, 11*(4), 218-228. doi:10.1002/msc.1044

Borthwick, A. M., Nancarrow, S. A.,Vernon, W., & Walker, J. (2009). Achieving professional status: Australian podiatrists' perceptions. *J Foot Ankle Res, 2*, 4. doi:10.1186/1757-1146-2-4

Boynton, P. M., & Greenhalgh, T. (2004). Selecting, designing and developing your questionnaire. *BMJ, 328*(7451), 1312-1315. doi:10.1136/bmj.328.7451.1312

Bullen, B, Young, M, McArdle, C, & Ellis, M. (2017). Visual and kinaesthetic approaches to pragmatic, person-centred diabetic foot education. *The Diabetic Foot Journal, 20*(1), 5.

Burford, B., Morrow, G.,Rothwell, C.,Carter, M., & Illing, J. (2014). Professionalism education should reflect reality: findings from three health professions. *Med Educ, 48*(4), 361-374. doi:10.1111/medu.12368

Bus, S. A., & van Netten, J. J. (2016). A shift in priority in diabetic foot care and research: 75% of foot ulcers are preventable. *Diabetes Metab Res Rev, 32 Suppl 1*, 195-200. doi:10.1002/dmrr.2738

Calle-Pascual, AL, Durán, A, Benedí, A, Calvo, MI, Charro, A, Diaz, JA, Cabezas-Cerrato, J. (2002). A preventative foot care programme for people with diabetes with different stages of neuropathy. *Diabetes Res Clin Pract, 57*(2), 111-117. doi:S0168822702000244 [pii]

Campbell, N. C.,Murray, E., Darbyshire, J., Emery, J., Farmer, A., Griffiths, F., Kinmonth, A. L. (2007). Designing and evaluating complex interventions to improve health care. *BMJ, 334*(7591), 455-459. doi:10.1136/bmj.39108.379965.BE

Caruth, GD. (2013). Demystifying Mixed Methods Research Design: A Review of the Literature. *Mevlana International Journal of Education., 3*(2).

Chapman, L, Lawson, J, Russell, C, Brookes, L, & Adams, J. (2017). *OS 23 - An investigation into the accessibility of online self-management websites for people with chronic joint pain.* Paper presented at the British Society for Rheumatology conference, Birmingham.

Chapman, S. (2017). Foot care for people with diabetes: prevention of complications and treatment. *British Journal of Community Nursing, 22*(5), 3.

Chin, Y. F., Liang, J., Wang, W. S., Hsu, B. R., & Huang, T. T. (2014). The role of foot self-care behavior on developing foot ulcers in diabetic patients with peripheral neuropathy: a prospective study. *Int J Nurs Stud, 51*(12), 1568-1574. doi:10.1016/j.ijnurstu.2014.05.001

Clark, J. (2008). Philosophy, understanding and the consultation: a fusion of horizons. *Br J Gen Pract, 58*(546), 58-60. doi:10.3399/bjgp08X263929

Cockayne, S., Adamson, J.,Corbacho Martin, B., Fairhurst, C., Hewitt, C., Hicks, K. (2014). The REFORM study protocol: a cohort randomised controlled trial of a multifaceted podiatry intervention for the prevention of falls in older people. *BMJ Open, 4*(12), e006977. doi:10.1136/bmjopen-2014-006977

Cockayne, S., Rodgers, S., Green, L., Fairhurst, C., Adamson, J., Scantlebury, A., . . . Torgerson, D. J. (2017). Clinical effectiveness and cost-effectiveness of a multifaceted podiatry intervention for falls prevention in older people: a multicentre cohort randomised controlled trial (the REducing Falls with ORthoses and a Multifaceted podiatry intervention trial). *Health Technol Assess, 21*(24), 1-198. doi:10.3310/hta21240

Coulter, A, Roberts, S, & Dixon, A. (2013). *Delivering Better Services for People with Long Term Conditions: Building the House of Care.* Retrieved from https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/delivering-better-services-for-people-with-long-term-conditions.pdf [accessed August, 2017]

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2013). Developing and evaluating complex interventions: the new Medical Research Council guidance. *Int J Nurs Stud, 50*(5), 587-592. doi:10.1016/j.ijnurstu.2012.09.010

Creswell, JW. (2002). A Framework for Design. In JW Creswell (Ed.), *Research Design: Qualitative, Quantitative and Mixed Method Approaches.* (2nd ed). Thousand Oaks, CA.: SAGE.

Crotty, MJ. (1998). *The Foundations of Social Research: Meaning and perspective in the research process* (1st ed.). London: Sage Publications.

Darlington, Y, & Scott, D. (2002). In-Depth Interviewing. In *Qualitative Research in Practice: Stories from the field.* (1st ed., pp. 61-65). NSW, Australia: Allen and Unwin.

Denscombe, M. (2007). *The Good Research Guide: for small-scale social research projects.* (3rded.). McGraw Hill: Open University Press.

de Ridder, D., Geenen, R., Kuijer, R., & van Middendorp, H. (2008). Psychological adjustment to chronic disease. *Lancet, 372*(9634), 246-255. doi:10.1016/S0140-6736(08)61078-8

de Souza, S., Williams, R., & Lempp, H. (2016). Patient and clinician views on the quality of foot health care for rheumatoid arthritis outpatients: a mixed methods service evaluation. *J Foot Ankle Res, 9*, 1. doi:10.1186/s13047-015-0133-2

Dragoi RG, Ndosi M, Sadlonova M, Hill J, Duer M, Graininger W, Smolen J & Stamm TA (2013). Patient education, disease activity and physical function; can we be more targeted. A cross-sectional study among people with rheumatoid arthritis, psoriatic arthritis and hand osteoarthritis. *Arthritis Res Ther,* 15, R156. doi:10.1186/ar4339.

Dorresteijn, J. A., Kriegsman, D. M., Assendelft, W. J., & Valk, G. D. (2010). Patient education for preventing diabetic foot ulceration. *Cochrane Database Syst Rev*(5), CD001488. doi:10.1002/14651858.CD001488.pub3

Drahota, A., Galloway, E., Stores, R., Ward, D., Severs, M.,& Dean, T. (2008). Audiovisual distraction as an adjunct to pain and anxiety relief during minor surgery. *Foot (Edinb), 18*(4), 211-219. doi:10.1016/j.foot.2008.06.001

Estape, E. S., Mays, M. H., Harrigan, R., & Mayberry, R. (2014). Incorporating translational research with clinical research to increase effectiveness in healthcare for better health. *Clin Transl Med, 3*, 20. doi:10.1186/2001-1326-3-20

Farndon, L Vernon, W & Parry, A. (2006). What is the evidence for the continuation of core podiatry services in the NHS? A review of foot surveys. *British Journal of Podiatry, 9*, 89-94.

Gadamer, HG. (2004). *Truth and Method* (2nd ed.). London: Continuum International Publishing Group.

Giddens, A. (1971). *Capitalism and Social Theory: an analysis of the writings of Marx, Durkheim and Max Weber.* Cambridge: Cambridge University Press.

Gough, D., Thomas, J., & Oliver, S. (2012). Clarifying differences between review designs and methods. *Syst Rev, 1*, 28. doi:10.1186/2046-4053-1-28

Graham A (2006), A critical review of interventions for the rheumatoid arthritic foot: foot orthoses and therapeutic footwear. Master of Clinical Practice for Health Care Practitioners dissertation. The University of Salford, Faculty of Health and Social Care.

Graham, A., Hammond, A., & Williams, A. (2011). Therapeutic foot health education for patients with rheumatoid arthritis: a narrative review. *Musculoskeletal Care, 9*(3), 141-151. doi:10.1002/msc.205

Graham, A. S., Hammond, A.,Walmsley, S., & Williams, A. E. (2012). Foot health education for people with rheumatoid arthritis - some patient perspectives. *J Foot Ankle Res, 5*(1), 23. doi:10.1186/1757-1146-5-23

Graham, A. S., Hammond, A., & Williams, A. E. (2012). Foot health education for people with rheumatoid arthritis: the practitioner's perspective. *J Foot Ankle Res, 5*(1), 2. doi:10.1186/1757-1146-5-2

Graham, A. S., & Williams, A. E. (2015). Foot Health Education for People with Rheumatoid Arthritis: '…. A Game of Chance…' - A Survey of Patients' Experiences. *Musculoskeletal Care*. doi:10.1002/msc.1111

Graham, A. S., & Williams, A. E. (2016). Foot health education provision for people with rheumatoid arthritis-an online survey of UK podiatrists' perceptions. *J Foot Ankle Res, 9*, 13. doi:10.1186/s13047-016-0145-6

Graham, A. S., Stephenson, J., & Williams, A. E. (2017). A survey of people with foot problems related to rheumatoid arthritis and their educational needs. *J Foot Ankle Res, 10*, 12. doi:10.1186/s13047-017-0193-6

Greenhalgh, T, & Heath, I. (2010). *Measuring Quality in the Therapeutic Relationship. An Inquiry into the Quality of GP Practice in England.* Retrieved from: https://www.kingsfund.org.uk/sites/default/files/field/field_document/quality-therapeutic-relationship-gp-inquiry-discussion-paper-mar11.pdf

Grimshaw, J. M., Eccles, M. P., Lavis, J. N., Hill, S. J., & Squires, J. E. (2012). Knowledge translation of research findings. *Implement Sci, 7*, 50. doi:10.1186/1748-5908-7-50

Guba, E, & Lincoln, Y. (2005). Paradigmatic controversies, contradictions and emerging confluences. In N Denzin & Y Lincoln (Eds.), *Handbook of Qualitative Research.* (3rd ed., pp. 191-215). Thousand Oaks, CA.: SAGE.

Habermas, J. (1987). *The Theory of Communicative Action.* Boston. Beacon.

Haq, M. (2014). *A comparative analysis of qualitative and quantitative research methods and a justification for use of mixed methods in social research.* (PhD), University of Bradford, Bradford. Retrieved from http://hdl.handle.net/10454/7389 [accessed June, 2017]

Hardware, B, Lacey, E, & Shewan, J. (2004). Towards the development of a tool to assess educational needs in patients with arthritis. *Clinical Effectiveness in Nursing, 8*, 111-117.

Hardware, B., Johnson, D., Hale, C., Ndosi, M., & Adebajo, A. (2015). Patients and nursing staff views of using the education needs assessment tool in rheumatology clinics: a qualitative study. *J Clin Nurs, 24*(7-8), 1048-1058. doi:10.1111/jocn.12733

Harrison-Blount, M., Cullen, M., Nester, C. J., & Williams, A. E. (2014). The assessment and management of diabetes related lower limb problems in India-an action research approach to integrating best practice. *J Foot Ankle Res, 7*, 30. doi:10.1186/1757-1146-7-30

Health and Care Professions Council (HCPC). (2013). Standards of Proficiency: Chiropodists and Podiatrists. Retrieved from http://www.hpc-uk.org/assets/documents/10000DBBStandards_of_Proficiency_Chiropodists.pdf [accessed August, 2017]

Hendry, G. J., Gibson, K. A., Pile, K., Taylor, L., du Toit, V., Burns, J., & Rome, K. (2013). Provision of foot health services for people with rheumatoid arthritis in

New South Wales: a web-based survey of local podiatrists. *J Foot Ankle Res, 6*(1), 35. doi:10.1186/1757-1146-6-35

Hennessy, K., Woodburn, J., & Steultjens, M. P. (2012). Custom foot orthoses for rheumatoid arthritis: A systematic review. *Arthritis Care Res (Hoboken), 64*(3), 311-320. doi:10.1002/acr.21559

Heron, E, Winchcombe, M, Cobbledick, J, & Adams, J. (2017). *Poster 132 - Working with*
service users to design an accessible health website for people with arthritis and lower levels of digital literacy. Paper presented at the British Society for Rheumatology conference, Birmingham.

Higher Education Academy (HEA). (2015). Framework for flexible learning in higher education. Retrieved from https://www.heacademy.ac.uk/knowledge-hub/framework-flexible-learning-higher-education

Hill, J., Tennant, A., & Adebajo, A. (2004). *Further development of an educational needs assessment tool (ENAT) for patients with rheumatoid arthritis.* Paper presented at the Arthritis Rheum.

Hillier, Y. (2005). *Reflective Teaching in Further and Adult Education.* (2nd. ed.). London. Continuum.

Hjelm K, Nyberg P, Apelqvist J. (2002) Gender influences beliefs about illness in diabetic subjects with severe foot lesions. *J Adv Nurs.* 40; 673-84

Hymes, L, & Hymes, GS. (1975). How long shall I keep these pads on? *Journal of the American Podiatric Association, 65*(10), 2. doi:https://doi.org/10.7547/87507315-65-10-1023

Johnson, MJ and May, CR (2015). Promoting professional behaviour change in healthcare: what interventions work, and why? A theory-led overview of systematic reviews. In *British Medical Journal Open* (Vol. 5, pp. 14). Retrieved from http://bmjopen.bmj.com/content/5/9/e008592 [accessed August, 2017]

Jotterand, F., Amodio, A., & Elger, B. S. (2016). Patient education as empowerment and self-rebiasing. *Med Health Care Philos, 19*(4), 553-561. doi:10.1007/s11019-016-9702-9

Launer, J. (2003). Uniqueness and conformity. *QJM, 96*(8), 615-616.

Lefevre-Colau, MM, Buchbinder, R, Regnaux, JP, Roren, A, Poiradeau, S, & Boutron, I. (2014). Self-management education programmes for rheumatoid arthritis. (Publication no. 10. 1002/146511858.CD011338). Retrieved June, 2017, from Cochrane Database of Sytematic Reviews. Retrieved from http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD011338/full [accessed June, 2017]

Liberati, A, Altman, DG, Tetzlaff, J, Mulrow, C, Gøtzsche, PC, Ioannidis, JP, . . . Moher, D. (2009). The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. *J Clin Epidemiol, 62*(10), e1-34. doi:S0895-4356(09)00180-2 [pii]10.1016/j.jclinepi.2009.06.006

Mata, HJ, & Davis, S. (2012). Translational Health Research: Perspectives from health education specialists. *Clinical and Translational Medicine, 1*(27). doi:10.1186/2001-1326-1-27

McGartland-Rubio, D, Schoenbaum, EE, Lee, LS, Schteingart, DE, Marantz, PR, Anderson, KE, . . . Esposito, K. (2010). Defining Translational Research: implications for training. *Academic Medicine, 85*(3), 5. doi:10.1097/ACM.0b013e3181ccd618.

McInnes, A., Jeffcoate, W., Vileikyte, L., Game, F., Lucas, K., Higson, N., . . . Anders, J. (2011). Foot care education in patients with diabetes at low risk of complications: a consensus statement. *Diabet Med, 28*(2), 162-167. doi:10.1111/j.1464-5491.2010.03206.x

Mol, A. (2008). *The Logic of Care: Health and the Problem of Patient Choice.* London. Routledge.

Moran, A. M., Nancarrow, S. A., Wiseman, L., Maher, K., Boyce, R. A., Borthwick, A. M., & Murphy, K. (2012). Assisting role redesign: a qualitative evaluation of the implementation of a podiatry assistant role to a community health setting utilising a traineeship approach. *J Foot Ankle Res, 5*(1), 30. doi:10.1186/1757-1146-5-30

Morgan, DL. (1996). Focus Groups. *Annu Rev Social*.22, 129-152.

Morgan, DL. (2014). Pragmatism as a Paradigm for Social Research. *Qualitative Inquiry.* 20(8), 9. doi:10.1177/1077800413513733

Mäkeläinen, P, Vehviläinen-Julkunen, K, & Pietilä, AM. (2007). Rheumatoid arthritis patients' education - contents and methods. *J Clin Nurs, 16*(11C), 258-267. doi:JCN1953 [pii]10.1111/j.1365-2702.2007.01953.x

Mäkeläinen, P, Vehviläinen-Julkunen, K, & Pietilä, AM. (2009a). Rheumatoid arthritis patient education: RA patients' experience. *J Clin Nurs, 18*(14), 2058-2065. doi:JCN2763 [pii]10.1111/j.1365-2702.2008.02763.x

Mäkeläinen, P, Vehviläinen-Julkunen, K, & Pietilä, AM. (2009b). Rheumatoid arthritis patients' knowledge of the disease and its treatments: a descriptive study. *Musculoskeletal Care, 7*(1), 31-44. doi:10.1002/msc.138

National Audit Office. (2009). Services for people with rheumatoid arthritis. In. London: The Stationery Office. Retrieved from https://www.nao.org.uk/report/services-for-people-with-rheumatoid-arthritis/ [accessed August, 2017]

National Institute for Health and Clinical Excellence. (NICE) (2007). How to change practice: understand, identify and overcome barriers to change. Holborn, London. Retrieved from https://www.nice.org.uk/media/default/about/what-we-do/into-practice/support-for-service-improvement-and-audit/how-to-change-practice-barriers-to-change.pdf [accessed August, 2017]

National Institute for Clinical Excellence. (NICE). (2009). Rheumatoid arthritis: the management of rheumatoid arthritis in adults. Retrieved from https://www.nice.org.uk/Guidance/CG79 [accessed August, 2017]

National Rheumatoid Arthritis Society. Retrieved from http://www.nras.org.uk/our-articles-on-foot-health [accessed August, 2017]

Navarro-Flores, E., Morales-Asencio, J. M., Cervera-Marín, J. A., Labajos-Manzanares, M. T., & Gijon-Nogueron, G. (2015). Development, validation and psychometric analysis of the diabetic foot self-care questionnaire of the University of Malaga, Spain (DFSQ-UMA). *J Tissue Viability, 24*(1), 24-34. doi:10.1016/j.jtv.2014.11.001

Ndosi, M., & Adebajo, A. (2015). Patient education in rheumatoid arthritis: is the needs-based approach the way forward? *Clin Rheumatol, 34*(11), 1827-1829. doi:10.1007/s10067-015-3063-2

Ndosi, M., Bremander, A., Hamnes, B., Horton, M., Kukkurainen, M. L.,Machado, P., Hill, J. (2014). Validation of the educational needs assessment tool as a generic instrument for rheumatic diseases in seven European countries. *Ann Rheum Dis, 73*(12), 2122-2129. doi:10.1136/annrheumdis-2013-203461

Ndosi, M., Ferguson, R., Backhouse, M. R., Bearne, L., Ainsworth, P., Roach, A., Cherry, L. (2017). National variation in the composition of rheumatology multidisciplinary teams: a cross-sectional study. *Rheumatol Int*. doi:10.1007/s00296-017-3751-0

Ndosi, M., Johnson, D., Young, T., Hardware, B., Hill, J., Hale, C., Adebajo, A. (2016). Effects of needs-based patient education on self-efficacy and health outcomes in people with rheumatoid arthritis: a multicentre, single blind, randomised controlled trial. *Ann Rheum Dis, 75*(6), 1126-1132. doi:10.1136/annrheumdis-2014-207171

Ndosi, M., Lewis, M., Hale, C., Quinn, H., Ryan, S., Emery, P., Hill, J. (2014). The outcome and cost-effectiveness of nurse-led care in people with rheumatoid arthritis: a multicentre randomised controlled trial. *Ann Rheum Dis, 73*(11), 1975-1982. doi:10.1136/annrheumdis-2013-203403

Ndosi, M., Tennant, A., Bergsten, U., Kukkurainen, M. L., Machado, P., de la Torre-Aboki, J., Hill, J. (2011). Cross-cultural validation of the Educational Needs Assessment Tool in RA in 7 European countries. *BMC Musculoskelet Disord, 12*, 110. doi:10.1186/1471-2474-12-110

Nester, C. J., Graham, A., Martinez-Santos, A., Williams, A. E., McAdam, J., & Newton, V. (2017). National profile of foot orthotic provision in the United Kingdom, part 1: practitioners and scope of practice. *J Foot Ankle Res, 10*, 35. doi:10.1186/s13047-017-0215-4

Newman, S., Steed, L., & Mulligan, K. (2004). Self-management interventions for chronic illness. *Lancet, 364*(9444), 1523-1537. doi:10.1016/S0140-6736(04)17277-2

Nielsen-Bohman, L, Polzer, A, & Kendig, A. (2004). *Health Literacy: a prescription to end confusion.* Washington DC. National Academics Press.

North West Podiatry Clinical Effectiveness Group, (NWCEG). (2014). Guidelines for the management of foothealth for people with rheumatoid arthritis. (pp. 19,20).

Northwest Podiatry Services Clinical Effectiveness Group for Rheumatology. (2017). *Podiatry Skills and Knowledge Framework for the Integrated Care of the Foot in Inflammatory Joint Disease and Connective Tissue Disorders.* National Health Service.

O' Cathian, A., & Thomas, K.J. (2004). Any other comments? Open questions on questionnaires - a bane or bonus to research? *BMC Medical Research Methodology, 4*(25).

Palmer, RE. (1969). *Hermeneutics: Interpretation Theory in Schleiermacher, Dilthey, Heidegger and Gadamer.* Evanston: Northwestern University Press.

Pawson, R., Greenhalgh, T., Harvey, G., & Walshe, K. (2005). Realist review--a new method of systematic review designed for complex policy interventions. *J Health Serv Res Policy, 10 Suppl 1*, 21-34. doi:10.1258/1355819054308530

Perrin, B. M., Swerissen, H., Payne, C. B., & Skinner, T. C. (2014). Cognitive representations of peripheral neuropathy and self-reported foot-care behaviour of people at high risk of diabetes-related foot complications. *Diabet Med, 31*(1), 102-106. doi:10.1111/dme.12287

Podiatric Rheumatic Care Association (PRCA) (2008). Standards of care for people with musculoskeletal foot health problems. Retrieved from http://arma.uk.net/wp-content/uploads/pdfs/musculoskeletalfoothealthproblems.pdf [accessed August, 2017]

Powell, R. A., & Single, H. M. (1996). Focus groups. *Int J Qual Health Care, 8*(5), 499-504.

Quality Assurance Agency (QAA). (2001). Benchmark Statement: Health Care Programmes: Podiatry (Chiropody). Quality Assurance Agency for Higher Education. Gloucester.

Rabiee, F. (2004). Focus-group interview and data analysis. *Proc Nutr Soc, 63*(4), 655-660.

Redmond, A. C., Waxman, R., & Helliwell, P. S. (2006). Provision of foot health services in rheumatology in the UK. *Rheumatology (Oxford), 45*(5), 571-576. doi:10.1093/rheumatology/kei205

Riemsma, R.P, Kirwan, J.R, Taal, E, Rasker, H.J.J. (2003). Patient Education for Adults with Rheumatoid Arthritis. *Cochrane Database of Systematic Reviews* 2003, Issue 2. Art. No.: CD003688. DOI: 10.1002/14651858.CD003688.

Riiskjær, E., Ammentorp, J., & Kofoed, P. E. (2012). The value of open-ended questions in surveys on patient experience: number of comments and perceived usefulness from a hospital perspective. *Int J Qual Health Care, 24*(5), 509-516. doi:10.1093/intqhc/mzs039

Rizzo, M, Migneco, A, Mansueto, P, & Tringali, G. (2007). Therapeutic patient education in oncolgy: pedagogical notions for women's health and prevention. *European Journal of Cancer Care, 16*, 3.

Rome, K., Clark, H., Gray, J., McMeekin, P., Plant, M., & Dixon, J. (2017). Clinical effectiveness and cost-effectiveness of foot orthoses for people with established rheumatoid arthritis: an exploratory clinical trial. *Scand J Rheumatol, 46*(3), 187-193. doi:10.1080/03009742.2016.1196500

Rosenbaum, A. J., & Ellis, S. J. (2016). The Internet for Patient Education: A Friend or Foe? *Foot Ankle Int, 37*(3), 346-347. doi:10.1177/1071100716629133

Scarlett, JJ, Conner, JC, & Monastersky, C. (1976). Diabetic foot care education in a podiatry clinic: a pilot study. *Journal of the American Podiatric Medical Association, 66*(10), 2. doi:https://doi.org/10.7547/87507315-66-10-798

Semple, R, Newcombe, LW, Finlayson, GL, Hutchison, CR, Forlow, JH, & Woodburn, J. (2009). The FOOTSTEP self-management foot care programme: are rheumatoid arthritis patients physically able to participate? *Musculoskeletal Care, 7*(1), 57-65. doi:10.1002/msc.142

Seyyedrasooli, A., Parvan, K., Valizadeh, L., Rahmani, A., Zare, M., & Izadi, T. (2015). Self-efficacy in foot-care and effect of training: a single-blinded randomized controlled clinical trial. *Int J Community Based Nurs Midwifery, 3*(2), 141-149.

Sheppard, E. D., Hyde, Z., Florence, M. N., McGwin, G., Kirchner, J. S., & Ponce, B. A. (2014). Improving the readability of online foot and ankle patient education materials. *Foot Ankle Int, 35*(12), 1282-1286. doi:10.1177/1071100714550650

Sierakowska, M, Krajewska-Kułak, E, Lewko, J, Przeorska-Najgebauer, T, Jankowiak, B, Rolka, H, & Szyszko-Perłowska, A. (2005). The education of patients with rheumatoid arthritis--the knowledge and expectation of patients-the opinions of rheumatology nurses. *Rocz Akad Med Bialymst, 50 Suppl 1*, 107-110.

Stressing, S. J., & Borthwick, A. M. (2014). The impact of workforce redesign policies on role boundaries in 'generalist' podiatry practice: expert views within the professional body. *J Foot Ankle Res, 7*(1), 52. doi:10.1186/s13047-014-0052-7

Tariq, S, & Woodman, J. (2010). Using mixed methods in health research. *Journal of the Royal Society of Medicine Short Reports, 0*, 8. doi:10.1177/2042533313479197

Thomas, LH, Mc Coll, E, Priest, J, & Bond, S. (1996). Open-ended questions: do they add anything to a quantitative patient satisfaction scale? *Social Sciences in Health., 2*, 12.

Torangeau, R. (1984). Cognitive Science and Survey Methods: A cognitive perspective. In T Jabine, M Straf, J Tanur, & R Torangeau (Eds.), *Cognitive Aspects of Survey Design: Building a bridge between disciplines.* Washington DC. National Academic Press.

van der Zwaard, B. C., Poppe, E., Vanwanseele, B., van der Horst, H. E., & Elders, P. J. (2014). Development and evaluation of a leaflet containing shoe advice: a randomized controlled trial. *Fam Pract, 31*(3), 267-272. doi:10.1093/fampra/cmt084

Vatankhah, N., Khamseh, M. E., Noudeh, Y. J., Aghili, R., Baradaran, H. R., & Haeri, N. S. (2009). The effectiveness of foot care education on people with type 2 diabetes in Tehran, Iran. *Prim Care Diabetes, 3*(2), 73-77. doi:10.1016/j.pcd.2009.05.003

Walmsley, S., Ravey, M., Graham, A., Teh, L. S., & Williams, A. E. (2012). Development of a patient-reported outcome measure for the foot affected by rheumatoid arthritis. *J Clin Epidemiol, 65*(4), 413-422. doi:10.1016/j.jclinepi.2011.11.005

Waxman, R, Woodburn, H, Powell, M, Woodburn, J, Blackburn, S, & Helliwell, P. (2003). FOOTSTEP: a randomized controlled trial investigating the clinical and cost effectiveness of a patient self-management program for basic foot care in the elderly. *J Clin Epidemiol, 56*(11), 1092-1099. doi:S0895435603001975 [pii]

West, R, & Stenius, K. (2008). The use and abuse of citations. In TF Babor, K Stenius, S Savva, & J O'Reilly (Eds.), *Publishing Addiction Science: A guide for the perplexed.* (2nd ed., pp. 98-109): International Society of Addiction Journal Editors.

Westfall, J. M., Mold, J., & Fagnan, L. (2007). Practice-based research--"Blue Highways" on the NIH roadmap. *JAMA, 297*(4), 403-406. doi:10.1001/jama.297.4.403

Williams, A. E., Cherry, L., Blake, A., Alcacer-Pitarch, B., Edwards, C., Hopkinson, N.,Teh, L. S. (2016). An Investigation into the Scale and Impact of Self-Reported Foot Problems Associated with Systemic Lupus Erythematosus: A Study Protocol and Survey Questionnaire Development. *Musculoskeletal Care, 14*(2), 110-115. doi:10.1002/msc.1119

Williams, A. E., Davies, S., Graham, A., Dagg, A., Longrigg, K., Lyons, C. North West Clinical Effectiveness Group for the Foot in Rheumatic Diseases.(NWCEG), (2011). Guidelines for the management of the foot health problems associated with rheumatoid arthritis. *Musculoskeletal Care, 9*(2), 86-92. doi:10.1002/msc.200

Williams, A. E., & Graham, A. S. (2012). 'My feet: visible, but ignored . . .' A qualitative study of foot care for people with rheumatoid arthritis. *Clin Rehabil, 26*(10), 952-959. doi:10.1177/0269215511434995

Williams, A. E., Graham, A. S., Davies, S., & Bowen, C. J. (2013). Guidelines for the management of people with foot health problems related to rheumatoid arthritis: a survey of their use in podiatry practice. *J Foot Ankle Res, 6*(1), 23. doi:10.1186/1757-1146-6-23

Williams, C. M., Penkala, S., Smith, P., Haines, T., & Bowles, K. A. (2017). Exploring musculoskeletal injuries in the podiatry profession: an international cross sectional study. *J Foot Ankle Res, 10*, 3. doi:10.1186/s13047-016-0185-y

Willis, G. (2005). *Cognitive Interviewing: A Tool for Improving Questionnaire Design*: Sage Publishing Inc.

Wilson, O., Kirwan, J., Dures, E., Quest, E., & Hewlett, S. (2017). The experience of foot problems and decisions to access foot care in patients with rheumatoid arthritis: a qualitative study. *J Foot Ankle Res, 10*, 4. doi:10.1186/s13047-017-0188-3

World Health Organisation (WHO). (1998). *Therapeutic Patient Education. Continuing educational programmes for health care providers in the field of prevention of chronic disease: A report of a WHO working group.* Retrieved from

World Health Organization (WHO). (2005). *Bridging the Know-Do Gap.* Paper presented at the Meeting on Knowledge Translation in Global Health. Geneva. Retrieved from https://www.measureevaluation.org/resources/training/capacity-building-resources/high-impact-research-training-curricula/bridging-the-know-do-gap.pdf [accessed August, 2017]

www.everydayhealth.com. Retrieved from https://www.everydayhealth.com

www.gov.scot. (2011). Curriculum for Excellence. Retrieved from http://www.gov.scot/resource/doc/920/0121215.pdf

Zangi, H. A., Ndosi, M., Adams, J., Andersen, L., Bode, C., Boström, C., . . . (EULAR), European League Against Rheumatism. (2015). EULAR recommendations for patient education for people with inflammatory arthritis. *Ann Rheum Dis, 74*(6), 954-962. doi:10.1136/annrheumdis-2014-206807