Recognising Foot Health Needs in Rheumatoid Arthritis

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ABSTRACT

Recognising Foot Health Needs in Rheumatoid Arthritis.

The aim of the study was to describe how patient understanding and attitude to the effects of rheumatoid arthritis on the foot, and the services available to help limit this, influences self reporting of foot problems. Referral to podiatry was occurring at a stage in the disease process too late to instigate certain preventative interventions. Preliminary fieldwork highlighted that the responsibility for the instigation of this locally lay with the patient. Literature supports the inclusion of podiatry within the multidisciplinary rheumatology team and early foot assessment with regular monitoring. There was a gap in the literature relating to the effectiveness of patient self-reporting in terms of foot health and the implications of relying on this approach.

A qualitative case study methodology was employed underpinned by a constructivist realism stance. Nine patients attending the out-patient rheumatology department participated in the study and data was gathered through semi-structured interviews. This information was analysed using a framework approach.

The key themes derived from the data suggested that there are a variety of factors influencing the patient’s decision to self report foot concerns. Some will act to encourage the action (perceived benefits for the patient, knowledge and understanding of the rheumatoid foot and podiatry services, the foot being the primary concern at the time) and others will act to oppose it (perceived costs to the patient, misunderstandings regarding podiatry services, the foot as a secondary concern to other factors). Other factors can influence the decision either way depending on the individual patient (psychological state, previous experience, body image changes). In addition, age, gender, cultural and social aspects are also significant.

This study has generated new knowledge by proposing that, due to the multitude of factors influencing the individual’s decision to seek help, the patient cannot be given sole responsibility for their foot health if we wish to achieve timely and appropriate foot care as recommended in the literature. This responsibility should be returned to the health professionals.
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I am so grateful to the local rheumatology team or allowing me the chance to conduct this research and finally, to the patients who consented to participate with the interviews. They have provided such an important insight into the often neglected area of rheumatoid foot care provision.

I dedicate this thesis to my sister, Debbie James, who died before its completion but who had always been so supportive of my studies.
DECLARATION.

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree, and does not incorporate any material already submitted for a degree.

Signed:

Dated:
Chapter 1: INTRODUCTION.

Introduction.

This thesis reports a study investigating the provision of footcare services for patients with rheumatoid arthritis (RA). At the local District General Hospital no specialist podiatrist is currently in post within the rheumatology team. If patients require podiatric assessment they are referred to the community clinics either directly or via their GP. Twice a month, a podiatrist joins the rheumatology consultant and an orthotist to run the Lower Limb Clinic providing footwear and orthoses for those with marked foot deformity. As a lead podiatrist within the community podiatry department, I noted how the individual local services for patients with RA did not appear to work as closely as observed in other regions. This comparison was based on attendance at conferences and other fora where dissemination of work in support of current best practice brings an awareness of the ways in which an integrated team can provide care for patients with rheumatoid arthritis especially in relation to the effects of the disease on the foot. As a member of the British Health Professionals in Rheumatology (BHPR) and the Podiatry Rheumatic Care Association (PRCA), the frequent opportunity arises to network with colleagues who specialise in podiatric rheumatology. These professionals provide an insight into the positive effect their inclusion in the rheumatology team can have on patient care.

Rationale.

The investigation was prompted by the clinical observation that patients with rheumatoid arthritis seemed to be referred for podiatric assessment at an advanced stage in their disease. This raised the concern that intervention by podiatry was then too late to protect foot function in some individuals. The significance of this is confirmed by evidence in the literature suggesting that, in order to minimise the effect of the disease on joint deformity and subsequent foot function, podiatric biomechanic interventions should be implemented within two years of diagnosis (Woodburn, 2000; Aletaha & Smolen, 2006). After this time, intervention with orthoses is concerned with reducing pain, maintaining function and tissue viability, accommodating existing deformity, and prevention of further deformity (Helliwell et al, 2007). Recommendations in clinical
guidelines and standards of care documents for RA also support the need for early podiatric intervention for patients with RA and are discussed in chapter 2 (SIGN, 2000; ARMA, 2004).

Preliminary fieldwork confirmed the clinical observation and quantified the shortfall in service provision for both orthoses use and tissue viability care. It indicated that the patients were not receiving the level of podiatric intervention required to minimise the effects of rheumatoid arthritis on the foot and so recognised the lack of equity in podiatry services consistent with reports in the literature. In addition, it revealed the responsibility of the patient to self-report foot problems in the absence of routine foot screening by an appropriate health care professional (see chapter 3, p.47).

There is a gap in the literature regarding the effectiveness of patient self-reporting in ensuring good foot health. No reports were available on the application of patient empowerment in this area. As the local rheumatoid patient population received no formal education sessions or self-management programme involvement, it was feared that their level of knowledge regarding the foot and its involvement in RA would be insufficient to promote timely and appropriate referral to podiatry services. This may be contributing to the lack of early uptake of podiatry services.

Research was needed to increase understanding of this current system of recognising foot health in RA with a view to improving podiatric service provision in line with national recommendations and to reduce inequity in delivery of foot health care.

**Aim and Scope.**

The overall aim of the study was to increase our understanding of the provision of footcare services for patients with rheumatoid arthritis with a view to suggesting a way forward to improve this service.

The audit work had shown that no formal screening for foot problems was included at the patient’s rheumatology review appointments as patients were expected to self-report foot issues as they deemed necessary. This prompted the need to design a qualitative
study, using a case study approach, to increase our understanding of whether this policy contributes to the failure in appropriate and timely referral to podiatry services.

This study concludes with suggestions for improving foot care service provision in line with published recommendations.

Research Question.

How does patient understanding and attitude to the effects of rheumatoid arthritis on the foot, and the services available to help limit this, influence self reporting of foot problems?

Research Objectives.

- To explore patient understanding about the effects that rheumatoid arthritis can have on their feet.
- To explore what patients understand about podiatry services and the help that is available for their rheumatoid foot problems.
- To establish the views of the patient as to who is responsible for ensuring the health of their feet.
- To establish the existence of any barriers (real/perceived) to accessing this care.
- To offer an insight into the appropriateness of the current policy of patient responsibility for foot health in terms of foot screening.

Scope of the research.

There are limits to the type and scale of the improvements which can be made locally. As there will be no funding available from either the podiatry or rheumatology department budgets, any improvements would have to be achieved using current resources. This scope, as applied to the planned improvements in clinical practice, was echoed in a recent Westminster Hall Debate (2010). Paul Rowen (Member of Parliament for Rochdale) made the clear point that strategic proposals set out by the Arthritis and Musculoskeletal Alliance (ARMA, 2009a) to address the need for greater awareness, improved delivery of service and better outcomes for musculoskeletal
conditions is not about additional resources but about using (and better co-ordination of) what is currently available.

**Research Method.**

A qualitative research approach was used to gather information about this specific setting. A case study strategy allowed for semi-structured interviews of nine patients. These were individuals with rheumatoid arthritis attending the local district general hospital rheumatology department. A framework approach was employed to analyse the data.

**Structure of the thesis.**

The thesis consists of nine chapters. A summary of the remaining eight has been provided to signpost the thesis structure for the reader.

**Chapter 2: BACKGROUND**- discusses and critically evaluates the background literature in support of the research and the rationale for the audit is introduced. Further details are provided regarding the disease itself and its specific effects on the foot, the team delivery of care for people with rheumatoid arthritis, and the role of the podiatrist within this team is clarified to provide context for the research.

**Chapter 3: PRELIMINARY FIELDWORK**- provides a report on the preliminary fieldwork which took the form of the audit to assess and quantify the need for podiatry services locally. It was used to establish the ways in which local foot care provision differed from that recommended in the published clinical guidelines. The way in which this work informed the qualitative research question is explained.

**Chapter 4: THE RESEARCH FOCUS**- goes on to explain the rationale for the qualitative research that followed. Further literature is discussed to support this and the move towards a patient centred study.

**Chapter 5: THE RESEARCH DESIGN**- describes the decision making process for choosing and justifying an appropriate methodology to address the research question in
the context of its philosophical underpinnings. The specific choice of strategy for conducting the study is set out and a description of the process of analysing the findings is presented. Ethical issues and a debate on rigour in qualitative designs are discussed here.

Chapter 6: FINDINGS- will provide information about the participants and present the findings of the qualitative research interviews with quotes to illustrate important issues discovered.

Chapter 7: DISCUSSION- will discuss what the findings say about the research question and how this correlates with other work. How the findings can be generalised will also be explained here along with their contribution to the literature in this field.

Chapter 8: REFLECTION- will provide a reflection on the process of both conducting the research and writing the thesis. The influence I had, as researcher, on the study will be acknowledged as well as a reflection on the assumptions made at the commencement of the work.

Chapter 9: CONCLUSION & SUMMARY- will explain the impact of this study in terms of how the aims and objectives were met. The implications of the study findings on clinical practice will be made clear and the need for further research is introduced. The original contribution of this work will be made explicit at this stage.
Chapter 2: BACKGROUND.

Introduction.

The overall aim of the study was to increase understanding of the provision of footcare services for patients with rheumatoid arthritis and specifically to discover the reasons for any failure in timely and appropriate referral for podiatric management. From a local podiatry perspective, preventative interventions are limited for the majority of rheumatoid patient referrals received because the disease is well established by this stage. Individuals need to be assessed by a podiatrist as soon as possible after diagnosis in order to intervene earlier and minimise joint and tissue damage. Therefore, evidence from the literature was needed to confirm best practice models for rheumatoid foot health provision and the role of the podiatrist within this.

Once this had been established, any specific areas of discrepancy between this model and the clinical situation in practice would assist the focus for investigation. Whilst assumptions had been made that a need for education regarding the potential role of the podiatrist in the management of the rheumatoid foot and the absence of a hospital based specialist podiatrist were issues at the heart of the failure of uptake in podiatry services, the specific focus of any potential investigation had not been specified at the time of the review. From this subsequent investigation, evidence could be discovered to either justify a change in practice for the podiatric management of people with rheumatoid arthritis or defend the continuation of the service provision in its current form.

This chapter will present the initial literature review, the specific intention of which is to explain why this subject area is of importance, to support the rationale for the need to explore this area of clinical practice further and to explain the subsequent development of the research focus. It will set the research in context and demonstrate its relevance to other studies. Further literature reviews were conducted after the preliminary fieldwork (chapter 4), as additional information was revealed to direct the focus of the study, and during the discussion of the research findings (chapter 7) to expand on the correlation between this study and previous work.
Rheumatoid Arthritis.

“Musculoskeletal disorders affect one in four of the adult population or more than 10 million people. The economic and social costs are huge and set to grow without improvement in the delivery of services and outcomes. Despite their importance in every constituency, musculoskeletal services have failed to get the attention they deserve.”

(ARMA, 2009a, p.1)

Rheumatoid Arthritis is a chronic and progressive auto-immune disease which affects 0.8% of the UK adult population (Symmons et al, 1994). It can be an incredibly painful condition with the potential to cause severe disability which may influence a person’s ability to carry out everyday tasks. It affects approximately 3 times more women than men and onset is generally between 40 - 60 years of age although the disease can manifest itself at any age (Steward & Land, 2009). The cause is unknown and, to date, a cure is not available, but much is now known about the inflammatory process and how to manage it. RA and its effects are not well publicised so there is a lack of awareness about the disease amongst the public, health professionals and commissioners (National Audit Office, 2009).

There is no specific test which can be used to diagnose this condition. A patient is said to have RA if they have met at least four of the seven criteria (defined by the American College of Rheumatology) summarised below:

1. **Morning stiffness**- in and around joints lasting at least one hour before maximal improvement.

2. **Arthritis of 3 or more joint areas**- at least 3 joint areas simultaneously have had soft tissue swelling or fluid (not bony overgrowth alone) observed by a physician.

3. **Arthritis of the hand joints**- at least one swollen area in the wrist, metacarpophalangeal joints or proximal interphalangeal joints.

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4. **Symmetric Arthritis** - simultaneous involvement of the same joint areas on both sides of the body (except the joints of the hand mentioned above).

5. **Rheumatoid nodules** - subcutaneous nodules over bony prominences, or extensor surfaces, or in juxta-articular regions, observed by a physician.

6. **Serum Rheumatoid Factor** - using a method for which the result has been positive in <5% of normal control subjects.

7. **Radiographic changes** - typical RA changes on posterior-anterior hand and wrist radiographs which must include erosions or unequivocal bony decalcification localised adjacent to the involved joint.

In the case of the first four criteria, each must have been present for at least six weeks (Arnett et al., 1988).

The disease can progress rapidly, causing swelling and damaging cartilage and bone around the joints initiated by synovitis. Any joint may be affected but it is commonly the peripheral joints of the hands, feet and wrists. It is a systemic disease with the potential to affect the whole body and internal organs. These extra-articular features include:

- Anaemia which normally resolves as the disease abates,
- Entrapment neuropathies (e.g. carpal tunnel syndrome),
- Felty’s syndrome causing splenomegaly,
- Fibrosing alveolitis and pleural effusions,
- Hepatomegaly caused by amyloid deposits,
- Lymphadenopathy resulting in diffuse pitting oedema of the ankles,
- Muscle wasting around the inflamed joints,
- Osteoporosis leading to fractures of the spine, hip and wrist,
- Pericarditis, pericardial effusions and amyloidosis,
- Rheumatoid nodules (occurring on elbows, occiput, sacrum, scapulae, Achilles tendon, lungs and myocardium).
- Sjögren’s syndrome (dry eyes and mouth),
- Vasculitis causing nail fold infarcts and leg ulcers.

(adapted from Hill & Hale, 2004)

Rheumatoid arthritis is an economically costly disease. In fact, the total UK costs, including NHS expenses, carer fees, nursing homes, private expenditure, sick leave and work related disability, are estimated to be approximately £3.8 - £4.75 billion per year (National Institute for Clinical Excellence (NICE), 2009). Of these costs, the NHS figure amounts to some £560 million each year (National Audit Office, 2009). Within two years of diagnosis it is reported that one third of people will have given up working and this figure increases to half within ten years (Yelin, 1987). Unremitting aggressive disease can lead to disability within twenty years (Buckley, 1997).

Although rheumatoid arthritis is accepted as a serious disease it is not thought to have a direct effect on mortality rates. Having said that, there is evidence to demonstrate a significant reduction in life expectancy for this patient group (Wolfe et al, 1994). This effect is thought to be equivalent to malignancy and triple vessel coronary disease (Pincus, 1995) making this a significant factor. We now know that uncontrolled rheumatoid arthritis does increase risk of cardiovascular disease; again the need for early treatment is emphasised. Today, if diagnosed and treated early, the prognosis is significantly better than it was 20-30 years ago with many people experiencing a much better quality of life in spite of having RA. This is in part due to developments in drug management of the disease.

The impact of long-term consequences for the patient and the health services cannot be denied. Within this concern there are multiple and specific areas of interest for the podiatrist.
Foot involvement in rheumatoid arthritis.

Most of the caseload of the general rheumatologist consists of patients with rheumatoid arthritis and this is the commonest condition for referral from rheumatology to podiatry (Helliwell et al, 2007). Foot involvement in rheumatoid arthritis has been reported to occur in 50-92% of patients, with progressive disability occurring over time (Michelson et al, 1994; Kerry et al, 1994; Balint et al, 2003).

Sixteen percent of patients report their first disease symptoms in the foot, with metatarsalgia, mild hallux valgus and plantar callosities being common early problems (Arnett et al, 1988). Literature published after the commencement of this study has indicated that this figure may be higher (Otter et al, 2010). As early disease typically presents as symmetrical small joint polyarthritis, it is not surprising that patients complain of “painful toes” when the metatarsophalangeal (MTP) and proximal interphalangeal (PIP) joints are involved. However, in the absence of reported symptoms, synovitis can be difficult to detect in the MTP joints and in the rearfoot (Maillefert et al, 2003). Occasionally, the daylight sign can be seen where the toes appear to splay apart due to inflammation of the intermetatarsal bursa (Dedrick et al, 1990). Radiographically, the foot joints show damage more often and earlier than those in the hand. Studies show that, in patients with a diagnosis less than 12 months, oedema, synovitis and erosion can be detected using magnetic resonance imaging (MRI) at the MTP joints when their hands are normal (Ostendorf et al, 2004). This may give an indication of why diagnosis can sometimes be delayed in patients presenting with foot signs. Turner et al, (2006) reported on their detection of small but clinically important changes in foot function, accompanied by active joint disease and disability, in RA patients with a diagnosis of under 2 years. The authors concur with the view that early detection of foot changes is imperative due to the possibility of a missed opportunity to intervene with orthotic and footwear management in an attempt to maximise structure and function over time.

Fifty percent of patients will have foot involvement by three years. Forefoot involvement can progressively extend to subluxation of the metatarsal heads, hammer toes and more severe hallux valgus. Even taking into account the prevalence of forefoot
deformity in the general population, the incidence is significant in the RA population, with hallux abductovalgus occurring in 80% of patients with established disease (Spiegel & Spiegel, 1982). In clinic we tend to see fibular drift of the toes and inflammation of the forefoot, involving the deep transverse ligament, allows the MTP joints to drift apart leading to forefoot spread (Stainsby, 1997). The disease can extend proximally to involve the talonavicular joint involvement and ankle (Wollheim, 1993; Balint et al, 2003). Rheumatoid foot changes are thought to result from active synovitis combined with mechanical stresses (Spiegel & Spiegel, 1982). As well as joint involvement more proximally, other structures can be affected, particularly the tendon of tibialis posterior. Tenosynovitis, tears or complete rupture of this structure may give rise to longitudinal arch collapse and valgus hind foot (Jernberg et al, 1999). This incidence of pesplanovalgus deformity increases with disease duration and is also linked to the severity of the disease (Shi et al, 2000). This indicates a need for orthotic management to stabilise the rearfoot and maximise foot function.

Other reported rearfoot problems include Achilles bursitis, calcaneal spurs (which may be due to mechanical stresses with age rather than inflammation) and painful rheumatoid nodules in the heel pad (Bouysset et al, 1989; Vainio, 1991). All of these pathologies may be managed by the podiatrist with functional and/or accommodative devices to ease strain on the structures involved and reduce accompanying discomfort.

Inflammation of the joints and the subsequent deformities can cause foot pain and reduced mobility, with associated callus formation. Foot ulceration can develop if tissue viability is compromised due to vascular, neurological or immunological complications both from the disease and its management with medication as will be discussed next. It is clear that the extent of foot involvement in this patient group substantiates the need for a range of specialist footcare interventions, including orthotic management and tissue viability care. The “Standards of Care for People with Musculoskeletal Foot Health Problems” recommends that foot assessment should occur from diagnosis and continue, with regular reviews, to track the progression of the disease and manage individual needs appropriately (PRCA, 2008). This is based on best practice guidelines rather than research evidence. It must be remembered that adequate medical management of the patient’s general disease is paramount to support this. Van der Leeden et al (2008) reported that pain and swelling in more than one MTP joint reduces
from 70% prevalence at baseline to around 40% after two years diagnosis due to the introduction of disease modifying anti-rheumatic drugs (DMARD’s).

**Drug management for RA and its implications for podiatry.**

The aim of drug management in rheumatoid arthritis is to alleviate the symptoms of the disease and, where possible, modify the disease process. Controlling the inflammatory processes is essential to these aims. Several categories of drugs can be used to achieve this including analgesics, non-steroidal anti-inflammatory drugs (NSAID’s), steroids, DMARD’s and the relatively new biologic therapies, for example anti-Tumour Necrosis Factor Alpha (anti-TNFα) (Hill and Reay, 2002a). These days, the DMARD’s are commenced on diagnosis as, in order to prevent disability, rapid suppression of the disease is crucial (Emery, 1994). These drugs can take up to 12 weeks to show any benefit so the use of intra-muscular or intra-articular injection of corticosteroid and/or analgesics is frequently used to manage symptoms during this period. Effective symptom control is difficult to achieve. Methotrexate and similar drugs have potentially serious side effects and require constant monitoring.

The identification of the role of the pro-inflammatory cytokine tumour necrosis factor alpha (TNF-α) to mediate many of the pathogenic features of RA has enabled the development of drugs to target this, thus blocking an important part of the inflammatory disease process (Maini, 2001). The efficacy of anti-TNFα drugs is demonstrated in their ability to dramatically reduce the severity of both clinical and laboratory markers of rheumatoid arthritis (Dinarello & Moldawer, 2001). They are administered either by infusion (in hospital) or subcutaneously by the patient. The reported problem of infection with use of these agents makes it imperative that the podiatrist is on the alert. Monitoring of these patients can limit the development of foot ulceration and the accompanying threat of infection. One third of those RA patients presenting with foot ulceration will be on biologic therapies to manage their disease (Davys et al, 2006). Infection is also a consideration when nail surgery for ingrowing toe nails is considered and close communication with the consultant rheumatologist is necessary to ensure the continuation of the anti-TNFα agent is appropriately managed during this intervention.
Once infection has been noted, the role of the podiatrist is then to ensure the consultant rheumatologist is aware as withdrawal of the anti-TNF agent may be necessary (Pisetsky, 2000). Evaluations of these drugs are encouraging but they are not a panacea for the management of RA due to this increased risk of infection for the patient (Otter et al, 2004). Opportunistic infections leading to foot problems are also more common if the patient’s disease is managed with any of the immunosuppressant drugs (Wilski, 1993; Jones, 1997). Other podiatric implications from drug management of RA are listed in table 1 below:

<table>
<thead>
<tr>
<th>Drug Management</th>
<th>Implications for Podiatry</th>
</tr>
</thead>
<tbody>
<tr>
<td>Analgesics</td>
<td>In early arthritis high doses are indicative of a failure of treatment. In late disease, they control the symptoms of joint damage.</td>
</tr>
<tr>
<td>Non-steroidal anti-inflammatory drugs</td>
<td>Awareness of side effects which may be reported by the patient including Gastro-intestinal (GI) symptoms (including ulcers), fluid retention, hypertension, deterioration of renal function. COX-2 drugs (specific to certain prostaglandins) reduce the GI side effects but may be associated with adverse cardiac risk profile.</td>
</tr>
<tr>
<td>Disease modifying, anti-rheumatic</td>
<td>Gold/D-penicillamine- rash may be noted. Anti-malarials- may cause retinopathy. Sulphasalazine- agranulocytosis. Methotrexate- bone marrow suppression, liver and pulmonary side effects. All potentially increase risk of infection due to effect on immune system (Edwards et al, 2004; Olsen &amp; Stein, 2004)</td>
</tr>
<tr>
<td>drugs (DMARD’s)</td>
<td></td>
</tr>
<tr>
<td>Biologic drugs</td>
<td>Increased susceptibility to infection with the usual signs of infection (e.g. pain, fever) being masked. Recrudescence of dormant tuberculous lesions. Hypersensitivity reactions.</td>
</tr>
<tr>
<td>i.e. anti-TNFα</td>
<td></td>
</tr>
<tr>
<td>Steroids</td>
<td>Side effects of weight gain, diabetes and osteoporosis and effects on skin healing.</td>
</tr>
<tr>
<td>-------------------</td>
<td>-----------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>

(Adapted from Helliwell et al, 2007).

Table 1: The Implications for Podiatry of Drug Management in RA.

The effects of drug management in RA not only add to the validation of the role of the podiatrist due to the increased tissue viability and immunological risks, but suggests a screening role too as the rapport emerging between practitioner and patients due to regular consultations over a prolonged period often mean the podiatrist is likely to be the first to hear of developing complications and side effects concerning the disease and its management (Mandy et al, 2003). In this way, the podiatrist echoes the nursing facilitator role of guiding, supporting and empowering the patient (Ryan, 1998). They then provide a useful link between the patient, their rheumatology team and the GP.

**The role of the podiatrist in the management of the rheumatoid foot.**

Having made the claim that local podiatry services for patients with rheumatoid arthritis could be better utilised, it was necessary to examine the evidence available in support of the role of podiatry in this specialist area. The above sections have established the general areas in which the disease and its management can affect the foot, and thus when it may be appropriate for a podiatrist to intervene. However, the following section expands on this with evidence to support specific podiatry intervention.

Woodburn and Helliwell (1997) report that the goals of foot care in this patient group are to:

- Relieve pain,
- Maintain function,
- Improve quality of life using safe and cost effective treatments:
  - Provide palliative foot care
  - Provide prescribed foot orthoses,
  - Provide prescribed footwear.
There is evidence to support the effectiveness of podiatry intervention in most of these areas and a series of validated outcome measures (assessing pain, disability, deformity, etc) are routinely used in practice to monitor this where appropriate (Macran et al, 2003; Platto et al, 1991; Nancarrow, 1999; Garrow et al, 2000; Bennett et al, 1998).

Woodburn et al (2000) conducted a preliminary investigation that showed a substantial reduction in pain following the debridement of callus in RA patients. However, this benefit was short lived. They also discovered that peak pressures under the foot are increased following callus treatment that could contribute to the increased risk of ulceration. Davys et al (2005) executed a study comparing sham treatment with scalpel debridement of callus that showed that the latter had no greater benefit. The authors suspected that the pain was not directly due to the callus but attributed to the fact that the metatarsophalangeal joints beneath the callus were more eroded than those with no callus associated with them. The indications for podiatric practice recommended from the outcomes of both the above studies is that callus should be debrided because it can lead to ulceration if it develops but it ought not to be attempted without conjunction with other treatment modalities (i.e. insoles, orthoses, footwear provision) to reduce the peak pressures in these areas.

There is evidence that semi-rigid foot orthoses can help reduce metatarsalgia (Chalmers et al, 2000) and orthopaedic footwear, combined with moulded insoles, can reduce foot pain and improve lower limb function and gait (Woodburn et al, 2002; Egan et al, 2003). Most of the research in the area of podiatrist management of the RA patients is concerned with the provision of evidence in support of the use of orthotic management in this patient group. Locke et al (1984), Hunt et al (1987), MacSween et al (1999), Chalmers et al. (2000), Woodburn et al (2002), Kavlak et al (2003) and others have added to this body of evidence. It must be remembered that efficacy in these studies is measured only in terms of pain relief, improvement in gait pattern and pressure management. Not all are randomised control trials and the number of subjects varying from eight to ninety eight. Some measurements were recorded during one visit only and, where there was a follow-up period, it ranged from 3 months to 36 months. Budiman-Mak et al (1995) conducted a randomised control trial assessing 102 subjects over a 3 year period which concluded that orthotics do not stop the progression of Hallux Valgus deformity. Thus, the individual studies are very specific about what can and cannot be
achieved depending on the outcome measures employed. Few provide information on the use of these devices alongside palliative podiatric care. The research on orthotic management can be considered to be in support of their use to positive effect in this patient group in terms of rearfoot control especially. However, they are only fully effective for forefoot management when coupled with appropriate management of any lesions present (Davys, et al, 2005). The aim of this is to reduce peak pressures at the lesion site, reduce pain and prevent ulceration (Helliwell, et al, 2007). Locally, the devices may be issued by the orthotics department in which case the lesion management may not automatically be forthcoming as this may require a further referral to the podiatry department. In addition, review appointments may not be offered by the orthotics department to assess the effectiveness of the orthoses in the management of the forefoot problem.

The local rheumatology department manages the aforementioned Lower Limb Clinic involving the collaborated assessment by the podiatrist, consultant rheumatologist and the orthotist in accordance with the reported research findings. In recent years, this clinic has been downsized as demands on consultant time elsewhere means he is frequently unable to attend. When the consultant is not present the clinic is cancelled. Also, the other rheumatologists tend not to send patients requiring orthotics to this clinic, choosing to send them directly to the orthotics department, as there are cost implications of referring the patient to another consultant led clinic. This means that an opportunity for podiatry input may be bypassed for this patient group.

In her article on tissue viability in rheumatoid arthritis, Firth (2005) explores the evidence to support the increased prevalence (9.7%) of pressure ulcers, lower limb ulceration and delayed wound healing in RA patients when compared to the general population. This is multifactorial in nature but is thought to be associated with reduced mobility and self care capacity, poor nutrition, the side effects of some medication, foot deformities, extra-articular manifestations of the disease and peripheral vascular disease. In addition to the management of ulceration once it occurs, the podiatrist can also have an input into prevention by orthotic and footwear management. Again, locally, this would support the need for protecting the Lower Limb Clinic and expanding the service to include tissue support.
As well as the role of the podiatrist in the management of foot lesions and abnormal biomechanics, the value of podiatrists in the assessment of patients for prescription footwear has been highlighted in the literature. A study by Williams and Meacher (2001) compared the satisfaction and compliance with hospital provision of footwear between patients who attended a multidisciplinary footwear clinic (with podiatry input) and a surgical appliance department. With the podiatrist involved, a discussion took place before the prescription regarding the footwear and what to do if problems occurred. In this situation, only 7.2% of the patients failed to wear the prescribed shoes compared to 48.1% in the comparison clinic. If the podiatrist leads this process, patients show improved compliance. This highlights the importance of the rapport between the podiatrist and the patient which is often noted as a consequence of ongoing management over years.

Whilst the importance of the combination of appropriate foot management strategies is paramount in effective foot care in RA, literature indicates that the timing of this management is imperative with early podiatric intervention needed to minimise joint damage, pain and loss of function which can be associated with a chronic disease (Williams, 1997). This was a particular concern for the local podiatry department as it appeared that it was largely receiving referrals of patients with established disease at a point when it would be too late for certain orthotic interventions to maintain optimum foot structure and function. Once foot deformity is established, the aim of management is limited to accommodating the deformity and providing comfort with little hope of improving structure and function. Woodburn (2000) suggests that, in early disease, using orthoses to minimise soft tissue and joint involvement can maximise mobility and maintain many physical capabilities. Woodburn et al (2002) also show that there is a window of opportunity for this effect to be achieved, after which the podiatrist “would be looking to achieve rehabilitation rather than prevention of deformity. Aletaha et al (2006) reported that early intervention reduces the percentage of irreversible effects on the foot. Timely intervention by the podiatrist as a member of the rheumatology team is further emphasised in papers by Beeson (1995) and Jacobs (1984).

The literature has produced evidence to support the work of the podiatrist for the RA patient group in terms of tissue viability and palliative footcare, maintenance of structure and function utilising orthoses and therapeutic footwear and pain relief leading
to improved quality of life. This adds weight to the recommendations of Woodburn & Helliwell (1997) outlined at the beginning of this section. The publications began to indicate the areas in which the local footcare service needed to be brought in line with this evidence, namely in the timing of the initial contact with podiatry services, to provide a better service for the patients.

**Published Guidelines for Foot Health in RA.**

In addition to evidence in support of the use of the podiatrist in the management of the rheumatoid foot, a search was then conducted to find supporting documentation to promote the role of the podiatrist within the rheumatology team. Information was gathered on the clinical guidelines produced with regard to podiatry provision for RA patients. The reason behind this was to give further support to the justification of the importance of podiatric intervention in this field.

The North West Podiatry Services Clinical Effectiveness Group (2003) produced a comprehensive piece of work developing guidelines for the management of the rheumatoid foot in rheumatic diseases. Its aim was to support the global goal of improving the care of patients with musculo-skeletal and rheumatic diseases (Harris, 2001).

The North West Group document set out to:

- Provide a framework for podiatrists, using improved knowledge and confidence, to develop and/or enhance podiatry services to patients with rheumatic diseases.
- Provide clear guidelines for consultants and members of the rheumatology team to facilitate appropriate referral,
- Ensure management of foot problems in this patient group will be based on available evidence and best practice,
- Ensure outcome of podiatry management for this patient group will be readily audited.

Included in the document are details of what treatments/services should be provided by podiatry departments, what tools are available for screening and monitoring progress
and at what stage patients should be referred to other health professionals. In the summary, the group provides a foot screening referral pathway for new and existing patients. An annual screening/review with a podiatrist is also recommended which would help to ensure that, if a patient’s situation alters, the system still ensures that they receive appropriate care. This document is seen within the podiatry profession as the current “Gold Standard”, with evidence to support its claims. It reinforces the concern that the local podiatry department is not providing the full range of podiatric interventions ideally required by this patient group. Whilst it is accepted that the “Gold Standard” would be difficult to achieve in all departments due to the variation in resources, there are some aspects of the document which, if not implemented, would have a detrimental effect on the foot health of this patient group according to the evidence. This includes the encouragement of early orthotic intervention mentioned earlier in this chapter.

Since the commencement of this research the above document has been advanced by the Podiatry Rheumatic Care Association (PRCA), with funding from the Arthritis Research Campaign, into “The Standards of Care for people with Musculoskeletal Foot Health Problems” (PRCA, 2008). With the backing of the Society of Chiropodists and Podiatrists, along with the Arthritis and Musculoskeletal Alliance (ARMA), it is hoped that this practical and informative document will reach a wider audience and be put to use as a tool for improvement in RA foot health services nationally. Its recommendations are considered to be “Gold Standard” by the podiatry profession and are evidence based wherever possible with the remaining standards based on “best practice” models. The preliminary document was intended to be a guide for podiatry departments as to the range of treatment and screening interventions needed for RA patients. The subsequent document has expanded this function in an attempt to empower podiatry managers to expand services to envelope the full range of interventions and to give information to health care professionals beyond podiatry regarding the foot care requirements of this patient group. Although this document adds weight to the need for a podiatrist in the rheumatology team, it does not give a clear indication regarding the responsibility for initiating this care.

Further literature along these lines was available as published work by several sources in the form of rheumatology clinical guidelines. It should be remembered that clinical
guidelines are systemically developed statements to assist the practitioner and patient to make decisions regarding health care for specific clinical circumstances and are not a prescriptive document. A summary of the key implications for podiatry are reported below.

Arthritis Care, an organisation that represents people with arthritis, produced a guidelines document aimed at GP’s in which it was suggested that all surgeries should provide a chiropodist to give footcare services to arthritic patients (Arthritis Care, 1997). It went on to say that, if this service could not be provided in-house, “prompt and timely” referrals should be made to ensure the patient receives this care. Despite this the British League Against Rheumatism (BLAR) Standards of Care (1997) report found that only 45% of RA patients are informed about the podiatry service and the help that it can provide. Locally, no specific communication from General Practitioners (G.P.s) was received following publication of the Arthritis Care paper to ensure that the recommendations were possible for their patients. From our experiences in clinic, we know that few local G.P.s refer their arthritic patients directly to us. However, these particular guidelines make it clear that GP’s are expected to lead this.

The Scottish Intercollegiate Guidelines Network (SIGN) is a group consisting of medical specialities, other health care professionals, patients, managers, social services and researchers. Its objective is to reduce the variation in practice and outcome through the dissemination of national clinical guidelines containing recommendations for effective practice based on evidence. Their work is quoted in papers nationwide and is not specific to Scotland. In 2000, they produced a document entitled “The management of early rheumatoid arthritis” in which they recommend that all patients with early arthritis have access to a range of health professionals including podiatry and that podiatry referral should be offered to all patients. SIGN also remark that, as the foot function of patients with RA is likely to decline over time, the goals of treatment must be symptom control, reduction of joint damage and disability and maintenance or improvement of quality of life. In particular it recognises the efficacy of foot orthoses and the provision of appropriate footwear.

Some confusion arises from guidelines produced by The Primary Care Rheumatology Society in the same year (2000). This states that early referral for disease-modifying
anti-rheumatic drugs will introduce patients to other therapies, including chiropody/podiatry. This is seen as the primary reason for this referral along with the prevention of long-term damage. This would suggest that GP’s are not responsible for referring the patient directly to individual services required but, by referral to rheumatology for DMARD therapy, this makes the assumption that referral to other services will automatically result from this. The assumption is made that consultants will have access to these guidelines and realise the implications as outlined. This gives an indication of where a misunderstanding of the process occurs. If G.P’s assume that by making a referral of a RA patient to the rheumatology department they will have access to all the other health professionals they need, they may be mistaken, but from this document it is possible to assume that their obligation is covered.

Moving the focus away from G.Ps, other clear guidelines for providing effective pediatric management of patients with rheumatoid arthritis exist that are targeted towards rheumatologists. The British Society for Rheumatology (BSR) guidelines on standards of care for persons with rheumatoid arthritis (Kennedy et al, 2004) report that all persons with RA should have access to a multidisciplinary team of health care professionals and that these should include podiatry. This professional organisation is concerned with developing efficient, cost-effective and evidenced-based clinical care for persons with RA. However, if the rheumatology team does not have direct podiatry input on site, no mention is made of the need to refer elsewhere, for example, to a community setting. These guidelines are produced for rheumatologists so, with this omission, any GP’s who have assumed the referral of the patient to podiatry via this third party could be disappointed. Standards of care should be made available to all parties mentioned, both in terms of those making the referral and those receiving them in order that each member can weigh up the implications for their practice.

The aforementioned ARMA is a registered charity and the user-centred umbrella organisation for the UK musculoskeletal community. As such it reaches a wide audience across healthcare team members, managers, patients and other agencies. In 2004, they brought together existing evidence and examples of best practice to produce their standards of care document. In this they acknowledge that those planning and delivering services around the UK face differing demographic, geographic and economic factors which affect how standards of care are implemented locally. Practical
examples are included on how to improve practice. This is the first document to mention of the importance of information available to patients. This information should explain the services available to the patient with advice on when and how they should seek help. Whilst introducing this guidance for the patient, the document still indicates that, on diagnosis, a full rheumatology multidisciplinary team (MDT) assessment should be carried out and any necessary referrals made at this point. They also accept that ongoing access to the MDT should also be available but that this may be in secondary care or in a community setting. Along with their general statements it is suggested that access to a healthcare professional trained in footwear assessment should be considered.

Despite being based on research evidence, and published by a number of different bodies which target different professional groups within the team, clinical observation noted that some patients are still not receiving the total package of care that these documents suggest they need. Representatives of several arthritis groups who have involvement in the production of guidelines/standards of care have been approached to discuss the process of dissemination for these documents. Generally speaking, the final documents are sent to service providers and those professionals who are thought to be responsible for the implementation of the suggested guidelines. It is assumed that the information will be disseminated to all those services mentioned in the document. Locally, experience tells us that this is not always the case. When the existence of new documents comes to light, which may have implications for podiatry services, we do not receive any official notification of this information.

Although the standards documents show that much has been done to provide guidance to professionals on what they should be offering, it is not known the extent to which patients are aware of their entitlement with regard to rheumatology service provision. One would assume that, if a patient were a member of a group such as Arthritis Care then they would be advised of the guidelines. However, not all patients are members of these groups and those who participate may not be representative of the RA population as a whole. The Arthritis and Rheumatism Council for Research in 1997 (now Arthritis Research UK) produced a leaflet for patients entitled “Your Rheumatology Department-what you can expect”. It explains the healthcare professionals likely to be encountered by the patient and their roles. The drawback is that, as it is usually to be found in out-
patient waiting rooms, it is only likely to be seen by those patients who have already been referred to the rheumatology department.

With so many bodies and other professions recognising the need and value of podiatry intervention, it was perhaps surprising that there was still a poor referral rate. There appeared to be no clear guidelines on who has overall responsibility for the health of feet affected by RA. The problem of motivation to implement a change in practice is seen when new standards of care or clinical guidelines are published. A recent audit from the Arthritis and Musculoskeletal Alliance (ARMA, 2009b) reported on the progress of the implementation of the “Musculoskeletal Services Framework” (Department of Health, 2006a). This framework was developed to address some common concerns with musculoskeletal services, namely that:

- Services are fragmented and incoherent,
- The skills of healthcare professionals are poorly exploited,
- Services are hampered by a lack of strategic planning.

Each of these points can certainly be identified locally as stated previously. The implementation of this framework nationally was found to be compromised by three inherent limitations:

1. No set formal standards for NHS service delivery which the NHS was required to meet (like National Service Frameworks).
2. No requirement to ring fence formal funding to develop and improve capacity in musculoskeletal services.
3. Not led by a “National Clinical Director” unlike other areas such as diabetes and cancer.

We begin to understand the reasons why guidelines and other evidence-based changes in practice (including foot screening in RA) have not been fully addressed despite the numerous mentions of their importance in the literature. Unless there is a clear driver for the alteration, the resources allocated to make this adjustment and a leader appointed to oversee the change, it may not occur. For this to be so, the changes would need to be enforceable which is unlikely to be the case in the current NHS system.
Podiatry within the Rheumatology Team.

At the commencement of the literature review, the supposition had been made that local podiatry services may be underused because they are not hospital based and therefore not included within the on-site multidisciplinary team. Literature was therefore, examined to determine the importance of this approach to service provision.

National policy clearly supports the development of interprofessional teams in order to provide flexible and responsive health care (Department of Health, 2000, 2002). Miller et al (2001), in their book on interprofessional practice, explain how new legislation to encourage the rationalisation of resources, reduction of duplication and provision of a more effectively integrated service has come about due to the growth of health services, increasing costs and the expected increase in demands by an ageing population. There have been moves to increase care in the community (Department of Health, 1997) which rely on interprofessional care. This in turn will require changes in the management of integrated care.

Soothill et al (1995) write about the reasons for the need for multidisciplinary care as being:

- Avoid failure of communication leading to patient suffering,
- Improving quality of care,
- Improving the effective use of resources.

Certainly, from a local point of view, podiatry resources have been cut dramatically over recent years and thus any system that could help to make the best of that which remains should be welcomed.

During initial reading for this programme of study consideration was given to the difference between multidisciplinary and interprofessional working. In his article Mandy (1996, p.110) explains these differences as:

- Multidisciplinary- requires everyone to do their own thing without great awareness of the work of other disciplines. The individual efforts may be moulded into an end result by a team leader (Temkin-Greener, 1983),
- Interdisciplinary- requires integration or modification of efforts with continuous communication and re-examination amongst all professional involved in order to have group responsibility for the final product (Luski, 1958).

Comparing again to the local situation, based on the above definitions, it would seem the department currently employs multidisciplinary approaches when working with other professionals. It is possible that a more interdisciplinary approach may help to improve the current position. A diabetes foot care pathway was recently implemented by the local podiatry department, one of the aims of which was to avoid duplication of tasks by more than one health care professional. Patients reported that they welcomed the new system as it meant that they did not have to attend for so many appointments and one department was responsible for orchestrating their care. This is an example of the advantage of interdisciplinary over multidisciplinary care and may indicate that a new podiatry referral protocol is needed rather than the need to change the position of the podiatrist within the hospital rheumatology team.

Miller et al (2001) identifies three types of multiprofessional interactions, one of which is core and periphery team working. An example of this occurs when an established team may work together solely in the hospital setting but additional members of the team have other commitments in the community setting and are therefore, removed from the hospital for much of the time. Generally a team approach of this nature can work well but dislocation of the peripheral group constrains communication leading to a lack of understanding of the roles of others and how professionals could come together to provide more comprehensive care. This definition seems to best describe the local situation. As a community-based service, when local podiatrists do visit the hospital to participate in the Lower Limb Clinic, things work well. When away from the site anecdotal comments suggest that rheumatologists have little idea of what else podiatrists can offer and this was certainly the case as discovered when approaching the consultants with regard to the study implementation.

Work done by Bateman et al (2003) showed that teams offer great potential but represent a complex structure of individuals with professional commitments and expectations within and beyond the group. Although an integrated team approach may improve the use of existing resources, changes to adopt this approach may require
additional resources and the cost implications of this, perceived or actual, are often considered as a barrier to changes in working practice. It is also assumed that, once a professional is made aware of the benefits of a certain style of practice that they will be willing/able to agree to change to this way of thinking. This cannot be assumed to be the case. Some individuals do not welcome change as it may not fit in with their beliefs or they may feel too pressured with current commitments to consider change.

**Podiatric Rheumatology-The National Picture.**

Literature was found to describe the national situation with regard to podiatric rheumatology service provision with a view to establishing the position of the local podiatry department within the national picture. There is evidence to show that there is lack of equity in podiatric rheumatology provision nationwide. Redmond et al (2006) reported that only half of all rheumatology departments in the UK say that they have access to adequate basic podiatry services for their patients and less than 1 in 10 have a formal mechanism for referral to foot care services. This assumes that all rheumatology services are aware of the range of podiatric interventions available for their patient group. If this is not so, this number could be higher. This inequality of podiatry services for RA patients nationally has been reported by several other authors (Helliwell, 2003; Michelson et al, 1994). The literature therefore suggests that the local podiatric rheumatology service was not unique in its lack of involvement in rheumatoid foot care but there has been no mention of whether this had any negative effect on foot health in this patient group. The gap between policy and practice in podiatric services for inflammatory arthritis is wider than for other diseases, in particular diabetes. This comparison will be raised again in chapter 9.

Williams & Bowden (2004) conducted an audit of foot health in patients with rheumatic diseases at Rochdale Infirmary that involved a convenience sample of 139 patients (100 female and 39 male) attending a rheumatology outpatient follow up clinic who agreed to participate when asked by the rheumatology nurse. Of these patients 74 had RA, 24 osteoarthritis, 10 systemic lupus erythematosi, 6 seronegative polyarthritis, 4 psoriatic arthritis, 5 ankylosing spondylitis, 3 each of fibromyalgia, polymyalgia and gout, 2 each of reactive arthritis and Reynaud’s and 1 each of mixed connective tissue disorder (CTD), Paget’s disease and undifferentiated CTD. These patients had their feet
examined with validated assessment tools used to measure foot deformity and foot pain. This audit found that 83 patients (60%) had no foot care at all and that 26 patients who did receive care had to use private podiatry services due to inaccessibility to NHS clinics. The remainder received NHS foot care at their local clinic. There was evidence that foot pain caused by both joint and skin problems were present but there was a low prescription of foot orthoses and specialist footwear. Only 8% of patients required no intervention at all. Over half of them had poor tissue viability and moderate to severe foot deformity placing them at risk from foot ulceration.

Overall, the authors stated that they found evidence of poor foot health and pain (self-reported in 21%) being highly prevalent in this patient group (when compared to a similar study that looked at the foot health needs of older people) although the explanation for this was not clear. This may lead to functional limitation and disability. Where foot care had been provided to individuals as suggested by the North West Clinical Effectiveness Group Guidelines, the authors claim benefits appear to be improved foot health, reduction of pain and a perceived improvement in general well being. The findings supported the case for dedicated podiatry services within rheumatology clinics in hospitals.

It appears therefore that a lack of equity is a national issue and local RA services are not alone in their variance from the recommended standards of care for foot health in this patient group.

**Summary**

The literature has highlighted the importance of the foot in rheumatoid arthritis in terms of the significant costs to the patient’s quality of life and the demands on health service resources. Evidence has been provided to show details of the effects of the disease and its management on the foot, the services a podiatrist can offer to minimise the negative effects of this (whilst keeping the patient comfortable and mobile) and an indication of the effectiveness of this intervention. These published documents substantiate the assumption that the local podiatry service could provide more for its RA population if these patients were referred in a timely and appropriate manner. Alongside this, the lack
of equity in podiatry service provision has been reported as a national concern. This being so, there is justification for further investigation in this subject.

On balance, the literature suggests that the podiatrist should be an integral part of the rheumatology department, however, this is unlikely to be achievable locally because of resource issues arising from the current relationship between the Acute Hospital Trust and the local Primary Care Trust (the current employers of podiatry services). The scope of this research set out in chapter 1 clearly states that any change in clinical practice recommended as a result of this literature should remain within current resources. The intention was solely to increase uptake of a service currently available in a community setting with no further budgetary implications. The focus for the research would not therefore be on multidisciplinary rheumatology services provision. This decision is explained further in chapter 4.

Whilst the local podiatry provision falls short of that recommended in the literature, very little work has been done to explore the reasons why this may be so despite this being reported as a national problem. Resource issues are sometimes quoted as an obstacle but this does not account for the local situation where more patients could be seen by podiatry if they were referred. This exposed a potential gap in the literature which would serve as a focus for the investigation. However, the literature review revealed no firm direction for the research.

At this stage of the research planning process the decision was made to conduct an audit to assess the extent of the mismatch between the level of podiatry services recommended in the literature and current clinical practice. The audit would give a quantifiable indication of how the rheumatoid foot care provision locally fitted with the picture nationally in terms of adherence to published guidelines, thus substantiating the need for investigation, and would further assist in the design of the research by seeking out the elusive focus for inquiry. The audit will now be described in chapter 3.
Chapter 3: PRELIMINARY FIELDWORK.

Introduction.

Preliminary fieldwork was undertaken to add a quantitative value to the subject under investigation, further endorse the need for the research, and to identify areas of particular focus for the qualitative work which was to follow. It was consistent with the overarching aim of increasing understanding of the provision of footcare services for patients with rheumatoid arthritis with a view to suggesting a way forward to improve this service. This work, in the form of an audit, was supported by the Chair of the Ethics Committee as evidence to show that patients were currently disadvantaged. This would give good reason for the commencement of a study in this subject area at a politically sensitive time.

The specific aims of the audit were:

- To establish the need for further research and to provide a focus for this proposed research project.
- To identify the foot health needs of people with rheumatoid arthritis attending the local District General Hospital Rheumatology Department.
- To compare the foot care being received with that which is recommended in published guidelines for this patient group.
- To enable targeting of podiatry resources to best effect.

Recruitment.

No Ethics Committee approval was required as the audit was considered to be a service evaluation. The work was registered with the Clinical Audit Department which was consulted prior to the commencement of the collection of data. Its approval for the method for the audit, which included a verbal explanation of the audit to the participants and non-written consent, was gained. The consent of the Consultant Rheumatologist to access his patients was obtained during this planning process.
The audit recruited people with rheumatoid arthritis who were attending the local small Rheumatology Unit in a medium-sized District General Hospital (DGH) over a period of ten sessions. All RA patients attending the department during these sessions were invited to undergo a 15 minute foot screening session with a podiatrist at the end of their planned consultation. There was no obligation to participate should they prefer not to and their decision did not affect their future treatment. Unfortunately, only ten half days (one per week for 10 weeks) were available due to time constraints and several patients attending the sessions did not participate for a variety of reasons. These included not having RA (as diagnosed in the hospital notes), not wishing to delay the consultant by participating first or not wishing to remain once the consultant appointment was completed. Therefore the response rate was approximately 12.5%. This did, however, provide sufficient information to meet the aims. In particular, it offered a flavour of the current foot care activity and the focus for the research, as well as providing an opportunity to discover and address access issues with the rheumatology department.

Data Collection.

The audit tools used in the paper by Williams and Bowden (2004) (discussed in chapter 2, p.35) were mirrored in the local audit as the information generated from them was similar to that used for local podiatric foot assessment and would thus be representative of information captured in normal clinical circumstances. The authors also set out with the same initial aims. Standard new patient podiatric assessment locally would normally include the points listed in the North West Guidelines (chapter 2, p.27) which are then translated into a score, incorporating a grade for vascular, neurological and deformity assessments, with patients eligibility for care being determined by a total greater than 32. Including this scoring information along with the audit tool would give an indication of whether the local podiatry department’s eligibility criteria would allow patients in need of treatment according to the national guidelines to receive it through the local NHS podiatry department. The audit tools and scoring form are provided in appendix 1. The suitability of these audit tools would be reviewed at the re-audit stage.
A general foot examination was carried out by an experienced podiatrist as set out by the North West Clinical Effectiveness Group guidelines mentioned above with data recorded in the following ways:

- The participants were asked for information regarding their general health (co-morbidities, surgical history, social history, and medication) and any current or previous foot care intervention.
- The podiatry department’s criteria to determine “at risk” patients are based on the presence and quality of pulses (dorsalis pedis and posterior tibial using Doppler Ultrasound) and presence/absence of neuropathy (established using a 10g monofilament over ten sites on the foot). These test results were recorded and used to indicate risk in terms of tissue viability.
- The Foot Structure Index was employed to score the degree of foot deformity which may be present (Platto et al, 1991). The greater the score the greater the degree of deformity noted. A rearfoot score of greater than or equal to five would indicate the need for orthotic intervention to help stabilise the foot.
- The Foot Function Index used by Williams & Bowden gave a score for foot pain and disability (Budiman-Mak et al, 1991). However, this was superseded by the Manchester Foot Pain and Disability Questionnaire (Garrow et al, 2000) for the purposes of the local audit.
- A self-administered questionnaire was used to assess footwear suitability for the needs of the rheumatoid foot in terms of support of the rearfoot and accommodation of forefoot deformity (Nancarrow, 1999). The information was used to identify features of the shoe that could be improved upon to ensure the footwear could support and help to stabilise the foot position.

To simplify the data collection, forms were used as devised in Bournemouth Foundation NHS Trust (Field & Dewson, 2005) to capture the information presented above. These too were developed using the guidelines suggested by the North West Podiatry Clinical Effectiveness Group (2003).

The audit was piloted with 4 patients to judge the time taken to conduct the foot screening. During the pilot, the Manchester Foot Pain and Disability Questionnaire
(Garrow et al, 2000), provided very little supporting data for this audit but was still included as we were also evaluating the tool for local use.

**Results.**

The total number of patients recruited was twenty four (11 males and 13 females). The mean age was 64 years (range being 40-87). Of these 24 participants, 13 had late RA having been diagnosed for over ten years, and 6 had early RA with a diagnosis less than 5 years. Whilst the literature would suggest that early diagnosis is considered to be less than 2 years, this audit followed the method used by Williams & Bowden (2004) and thus used the 5 year criteria. Fourteen were on methotrexate, with 9 on other DMARD’s (singly or in combination with methotrexate), 2 were taking oral steroids only and 3 were managed with biologics therapy and methotrexate. The podiatric implications of this have been explained in chapter 2 (pp.21-23) and indicate that several patients would be eligible for NHS podiatry treatment due to the “high risk” status associated with their drug therapies alone.

The figures revealed an actual shortfall in the number of patients who were receiving timely and appropriate podiatry services as set out in the literature, providing a quantitative foundation for the original practice observation of late referral to podiatry services. Several patients received some foot care input but not the full range of interventions recommended in the guidelines.

**Deformity.**

The Foot Structure Index findings were in keeping with the literature described in chapter 2, which signifies that deformity increases with duration of disease (Speigel & Spiegel, 1982; Wollheim, 1993 and Balint et al, 2003).

Due to time constraints, one assessor was used to collect the data for the audit. Therefore, no measure of inter-professional reliability could be evaluated. This may have had an effect on the validity but the results serve to provide an indication of the situation present at the time.
Relating the findings in table 2 (below) with disease duration, ten out of the eleven patients with severe or maximal foot deformity had been diagnosed with RA for over 10 years. Forefoot deformity predisposes to altered pressure distribution and the formation of corns/callus and pain. Twenty patients had significant rearfoot involvement requiring orthotic control to prevent further deformity and loss of function. The forefoot deformities also present may require management and advice to reduce the risk of tissue damage due to the pressures placed upon them. Considering the number of patients with foot involvement of this type, it was of concern that the orthotic management required was either not being received or not reviewed to assess its appropriate use.

<table>
<thead>
<tr>
<th>FOREFOOT</th>
<th>NUMBER OF PATIENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-10 Minimal deformity</td>
<td>15</td>
</tr>
<tr>
<td>11-20 Moderate deformity</td>
<td>7</td>
</tr>
<tr>
<td>21-32 Severe deformity</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>REARFOOT</th>
<th>NUMBER OF PATIENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-4 Minimal deformity</td>
<td>4</td>
</tr>
<tr>
<td>5-8 Moderate deformity</td>
<td>10</td>
</tr>
<tr>
<td>9+ Severe deformity</td>
<td>10</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TOTAL SCORE</th>
<th>NUMBER OF PATIENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-10 Minimal deformity</td>
<td>6</td>
</tr>
<tr>
<td>11-20 Moderate deformity</td>
<td>7</td>
</tr>
<tr>
<td>21-30 Severe deformity</td>
<td>9</td>
</tr>
<tr>
<td>31-46 Maximum deformity</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 2: The Foot Structure Index Scores.

Biomechanic/orthotic management.

Thirteen of the participants reported that they had orthoses. Eight had casted functional devices. The remaining five did not bring their orthoses to clinic and could not adequately describe them. Only one third of those screened had devices that they were using, with only one quarter of the devices achieving adequate or good support.
Of the twenty patients requiring long term orthoses for stabilisation of rearfoot deformity, only three were receiving adequate treatment. Some patients had never received orthoses and others were issued devices only when they were experiencing foot symptoms which can be too late to limit some deformities (as reported in chapter 2, p.26). From anecdotal comments, several participants stated they were not aware that continued use of the orthoses beyond symptom resolution may be required to limit recurrence of the initial problem and to maintain the structure and function of the foot. Of the five patients who had not continued with their devices, all should have been advised to do so for this reason and not one of these five reported an awareness of this need.

Most of the orthoses were provided through the orthotics department directly and not via the Lower Limb Clinic which would have provided additional podiatry input. This was due to the potential cost implications of sending the patient through this additional consultant-led service.

When orthoses were deemed to be inadequate for the purposes of this audit it was because they addressed one foot problem (forefoot or rearfoot) but not all. Footwear was also deemed inadequate in that it was unsupportive and would not assist in limiting foot deformity or poor function. Ten participants were affected in this way.

<table>
<thead>
<tr>
<th>SCORE</th>
<th>NUMBER OF PATIENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not being used</td>
<td>5</td>
</tr>
<tr>
<td>Inadequate (not fully controlling)</td>
<td>5</td>
</tr>
<tr>
<td>Adequate</td>
<td>2</td>
</tr>
<tr>
<td>Good</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 3: Evaluation of orthoses issued.
Tissue Viability.

<table>
<thead>
<tr>
<th>SCORE</th>
<th>NUMBER OF PATIENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good</td>
<td>16</td>
</tr>
<tr>
<td>Vulnerable</td>
<td>7</td>
</tr>
<tr>
<td>Pre-ulcerative</td>
<td>1</td>
</tr>
<tr>
<td>Ulcerated</td>
<td>0</td>
</tr>
</tbody>
</table>

Table 4: Assessment of tissue “At Risk” status.

One third (eight) of participants would have been eligible for NHS podiatric care purely on their tissue viability risk status alone but only three were receiving this. This “at risk” group were recorded as “pre-ulcerative” or “vulnerable” based on the presence/absence and quality of pulses and the assessment of neuropathy.

Footwear Evaluation.

Ten of the patients were wearing inadequate footwear in that it was unsupportive and would not help to limit future foot deformity or poor function.

<table>
<thead>
<tr>
<th>SCORE</th>
<th>NUMBER OF PATIENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ideal</td>
<td>8</td>
</tr>
<tr>
<td>Adequate</td>
<td>6</td>
</tr>
<tr>
<td>Inadequate</td>
<td>10</td>
</tr>
</tbody>
</table>

Table 5: Evaluation of footwear.

Podiatric Management.

The presence of the following pathologies was noted in the participants but no tool was used to assess severity.

<table>
<thead>
<tr>
<th>TYPE OF FOOT PROBLEM</th>
<th>NUMBER OF PATIENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Callus under forefoot</td>
<td>7</td>
</tr>
<tr>
<td>Callus on toes</td>
<td>5</td>
</tr>
</tbody>
</table>
Table 6: Assessment of foot pathology present.

Over a third of the participants had callus formation at some forefoot site. This reflects the shift in pressure due to typical foot deformities seen in RA. Based on these observations and the summary of the screening as a whole, a note was made of the type of footcare appropriate for each individual, whether this was in place or referral required.

<table>
<thead>
<tr>
<th>TYPE OF INTERVENTION</th>
<th>NUMBER OF PATIENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Immediate referral to podiatry</td>
<td>1</td>
</tr>
<tr>
<td>Referral for routine podiatric care</td>
<td>6</td>
</tr>
<tr>
<td>No footcare required</td>
<td>5</td>
</tr>
<tr>
<td>Podiatry already being received</td>
<td>5</td>
</tr>
<tr>
<td>Footwear advice needed</td>
<td>2</td>
</tr>
<tr>
<td>Foot orthoses required</td>
<td>4</td>
</tr>
<tr>
<td>Prescription footwear needed</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 7: Foot care intervention required.

Only five patients did not need podiatric intervention at this time. Of the remaining nineteen who did, only five already had this care in place. This relates to intervention only and does not take into account regular screening and advice as suggested in the literature.

The primary referral recommendation was recorded during the audit but some patients also required a secondary referral in addition to this (i.e. orthoses and routine care)
which was not noted because the audit tool did not allow for this. Six patients required advice beyond general good hygiene guidance, which was necessary for their ongoing foot health but which they would not have sought outside this screening session. These figures are based on need according to guidelines but it is possible that some patients may require practical help with nail care/routine foot health care (possibly due to hand or eye disease involvement) that would cause them to seek podiatry services.

Eight (a third) of those seen qualified for NHS Podiatry and were considered “at risk” in accordance with the eligibility criteria. However, only six (a quarter) had ever received NHS care and, even when private provision was accounted for, some “at risk” patients were not receiving care from Health Professions Council registered practitioners. This may be the choice of the patient based on practical reasons (e.g. location of clinic, cost). However, whilst not officially recorded as part of the audit, some patients stated they were ignorant of their eligibility for podiatry referral, their GP’s reported problems with access to NHS Podiatry service, or they had previously been discharged from the podiatry department and were unaware they could be re-referred.

On occasion, when certain managements are instigated (i.e. orthotics, routine palliative podiatry) a lack of adequate follow up can lead to a misunderstanding of the expected outcome and further review to ascertain the effectiveness of the treatment.

**Conclusion.**

Prior to the audit, there were no separate guidelines used by the local podiatry department for the assessment of patients with inflammatory arthritis despite the literature indicating a need. This preliminary work helped to provide baseline information from which to develop departmental guidelines for the specific management of this patient group. The aims of the audit with regard to research planning were also met. Having shown that a considerable number of patients were not receiving the full range of podiatry services available to them, the audit confirmed the validity of the clinical concerns which prompted this research. The data collected identified the range of foot health needs for RA patients attending the DGH Rheumatology Department some of which were being met to a certain extent (i.e. basic help with nail care and lesion symptom relief) and others were falling short of the
suggested guidelines (i.e. provision and review of orthoses, annual screening for foot changes, etc). The comparison of the care currently being received with the recommended national and local guidelines indicated several fields where a lack of parity needed to be investigated further.

The results also gave the podiatry department a number of areas within its current service to target change with a view to improvement of clinical effectiveness. The standard new patient assessment was a snapshot of the patient’s foot health on the day and took no account of the progressive nature of the disease by offering a review at a later date. If the patient scored under 32 at assessment, they would be discharged from the podiatry department with the responsibility of contacting their GP for re-referral should their medical situation change. This indicated a potential loophole where patients who may soon become “high risk” would be lost to foot care services. These findings resulted in an immediate change in podiatry department procedure which will be explained in chapter 9 (p.181) along with the other changes in practice resulting from the main qualitative work which followed.

Theaudit revealed another important point which changed the course of the study. Several member of the local rheumatology department (including consultants, registrars and allied health professionals) stated that there is no routine screening for foot involvement in the RA patient during their usual assessments and subsequent consultations. These reviews are routinely at six month intervals but the proforma used to assess disease activity did not record information relating to the foot and questions on foot symptoms were not routinely asked. Patients are relied upon to self-report any foot problems that they believe to be relevant. However, the observation was noted that patients fail to flag up specific foot care issues to the health professionals involved in their care. The results touched anecdotally on some of the reasons why this happens. As most patients would wait until they experience foot symptoms before seeking help, they would generally not be aware that they could and should seek early advice before deformity takes place. Most individuals with the condition live with a constant degree of pain and so do not always report an additional site of involvement or individual locations of pain. Patients used the opportunity during the audit consultation to ask a podiatrist questions regarding their feet. However, they did not feel they could have
initiated a formal referral to podiatry solely to receive this advice. These comments proved significant in light of the views expressed by the rheumatology team.

Summary.

The aims of the preliminary fieldwork were met in that numerical data was provided to illustrate the clinical practice observation and support the assumption of a shortfall in the provision of a complete package of foot care services. It also identified specific areas in which the podiatry department could improve its service for patients with rheumatoid arthritis. In addition to the quantitative findings, the work identified that a patient centred approach for the qualitative investigation to follow would be appropriate. The patient’s understanding of, and attitude to, the effect of the disease on the foot and the services available to help limit this became the focus of inquiry to address the clinical concern. It was therefore proposed to conduct a qualitative research project which would focus on the role of the patient in ensuring rheumatoid footcare needs are met. The next chapter will further explore the decision-making process behind this.
Chapter 4: THE RESEARCH FOCUS.

Introduction.

When embarking on the initial literature review to support this work it was anticipated that the change in practice required to address the original clinical concern might involve a revision of service delivery or organisational structure. Ideally this action would attempt to improve the foot health care delivered to patients with rheumatoid arthritis by reviewing and improving the links between the rheumatology and podiatry teams. Conducting the preliminary fieldwork and initial consultation with stakeholders exposed the realisation that this direction was unlikely to be achievable due to political, financial and inter-professional communication issues. It had been made clear that resources would not be made available to enable a service delivery change of this nature and so an alternative approach to improving the podiatric referral circumstances was needed. Hence the reason behind the scope set out in chapter 1. Chapter 4 will further explain the rationale behind this decision and the choice of a patient-focused investigation.

A Patient-Centred Focus.

To follow the recommendations outlined in the literature (see chapter 2, p.32) and effect a change in provision of podiatry services from its current community based setting to inclusion within the hospital based rheumatology team, would involve significant changes to the current administration. This would be in line with the models of team delivery of care which are reported to be ideal (Miller et al, 2001; Embling, 1995; Hornby, 1993). It was during the preliminary fieldwork exercise that it became evident that the funding implications of this change would not have been welcomed by those who would be expected to finance it locally. Whilst early intervention could save money with improved quality of care, the situation was such that minimising expenditure in the short-term was seen as more important that a longer-term investment when the potential saving figures were unknown. In addition to the stumbling block of finance, the changing national situation at the time supported a move towards transferring rheumatology services into primary care settings (Department of Health, 2006a). This would mean that the model situation would be physically difficult to
achieve, not solely because of the financial implications but also as the logistical factors involved in housing a similar team structure in the community setting would be challenging. This was one reason why a more appropriate focus for the research was considered.

Whilst the provision of rheumatoid foot care, and the mix of disciplines involved in this care, may be variable in nature according to the national picture, the reported need for foot care by this patient group remains constant. Research which approaches the neglected area of practice from the point of view of influencing the patient’s response to the issue could have the desired influence on access to podiatric services without the need to alter the position of the podiatrist within the rheumatology team. Therefore a change in practice via a patient focussed route could be achieved without the major funding implications, or policy changes, previously mentioned. The Chair of the Ethics Committee also expressed the opinion that the panel would feel more comfortable in approving a patient-centred study. The reason for this was that to examine the views of individual members of the rheumatology team and its operational systems may involve problems with perceived coercion. The researcher could be considered as a colleague to those research participants leading to the potential to feel under pressure to assist with the study.

At the same time as this realisation occurred, the audit revealed the anecdotal comment that the rheumatology team regard the patient to be responsible for highlighting their foot problems and initiating foot care. These combined factors altered the focus of the inquiry. The local healthcare professionals reported that they do not routinely screen for effects of the disease and its management on the foot but wait until symptoms or concerns are reported by the patient. Helliwell (2003) reiterated the view that foot problems in rheumatoid arthritis are under-researched and frequently neglected. He supports the anecdotal comments found locally with his report that rheumatology trainees receive little instruction in the problems associated with the rheumatoid foot and, as they become consultants, he hypothesises they are poorly equipped to assess the foot and make appropriate recommendations following this assessment. This problem is reported to be perpetuated by a lack of postgraduate courses on the subject. Little wonder then that the foot is frequently missed in evaluation of the effect of the disease
on the patient. It appears this attitude has shifted the responsibility for foot health monitoring to the patient.

Patients may see their G.P. with a foot concern rather than their rheumatology team. Survey results show that only three quarters of G.P.’s have received pre-registration training which covered rheumatoid arthritis with two thirds of these reporting that this training was brief (National Audit Office, 2009). It is due to this lack of specific training that a further delay in referral to podiatry services could be encountered. Unless patients knew that the symptom was as a result of their arthritis, the doctor would not necessarily recognise it.

It was not certain whether the local RA patients currently had sufficient skills and resources available to them to achieve appropriate self-reporting of foot problems. Relating these thoughts to local clinical practice, the indication at this stage was that, in order to achieve a change in procedure ensuring timely and appropriate podiatric management for RA patients, it would be necessary within the current organisation to explore the ability of this patient population to adequately seek this assistance and to discover ways in which this process may need to be facilitated. For this patient group to achieve effective self-reporting of foot health issues the assumption was made that they must have adequate knowledge and understanding of the effects that the disease, and its management, can have on the foot and an idea of what can be done to limit the negative effects of this so that the most appropriate health professional is approached when required.

The belief at this stage was that a lack of this knowledge base was likely to be at the heart of the problem under investigation. Looking ahead to potential clinical solutions, intervention in the form of patient education could be used to ensure patients achieve the foot health goals indicated in the literature and standards of care documents. This being the case, education sessions could prove to be the route for achieving the necessary change in practice to achieve the required effect of more efficient footcare services for local RA patients. An exploration of patients’ knowledge about the foot care services they should receive, how to access help and any issues around self-reporting foot problems at the appropriate stage in the disease would give an indication of whether it was appropriate to continue to assume that the current route of self-referral
is suitable. The research would go on to establish any barriers which may exist to achieving this. By means of this research it was hoped that we would attain an improved picture of the provision of local rheumatoid foot care in the event of a re-audit.

**Inequalities in health.**

Mention should be made regarding the position of the government in this argument to provide further context to the research. Ewles & Simnett (2003) summarised the Government and World Health Organisation (WHO) targets for health promotion from the 1980’s onwards. They outline inequalities in health, promoting positive wellbeing and supporting patients to take a positive stance regarding their welfare (WHO, 1981). In 1986 the organisation further published the “Ottawa Charter” which emphasised the need for a change in service provision to create supportive environments and re-orientate towards preventative approaches and health promotion. These principals were further translated into the “Jakarta Declaration” (1997). The initial targets were reviewed in 2000 and, although progress had been made, the report indicated there was still room for improvement. Whilst this adds weight to the justification for more resources to be allocated to areas where health inequalities are observed, we have seen that this does not always apply in practice mainly due to political reasons. These documents highlight the international recognition of the long-term goal for a need to eradicate health inequalities and promote good health which relates sympathetically to the underlying goal of this local project.

On a national level, these sentiments are echoed by the Department of Health. “The Health of the Nation” strategy (1998) was the first to focus on health gain rather than illnesses and health services. It was in 2001 that targets were published to reduce national health inequalities. Although the emphasis for these was on infant mortality and life expectancy at birth, they indicated the importance of equity in health across the country. In the same year, the paper “Saving Lives: Our Healthier Nation” set targets to promote a wider understanding of health and increased health protection alongside an emphasis on better partnership working. Ewles & Simnett conclude their summary saying that today there is a stronger national and local emphasis on prevention, health
improvement and reducing inequalities and yet, although frequently alluded to in the literature, this is still not fully integrated into clinical practice nationwide.

Remaining mindful of the Department of Health’s suggestions, the preliminary fieldwork established the lack of equity in the local rheumatoid foot service when compared to national guidelines. This was endorsed by the clinical experiences of those in other rheumatology departments (Redmond et al, 2006). Locally, the responsibility for foot health lay primarily with the patient which, despite appearing to encourage empowerment, lacks the partnership approach to health promotion encouraged in the documentation. As a consequence, the focus of the research was to identify whether a lack of delivery of foot health advice contributed to the inability to self report foot problems amongst the local RA patient group where uptake of podiatric services was poor. This was to be achieved by establishing the current level of knowledge and understanding of foot issues within this population and relating this to their motivation to seek appropriate help. It was anticipated that the patients’ knowledge base would be the key factor behind their ability to self-report foot problems in a timely and suitable manner in accordance with good health promotion tactics.

**Patient Education and Empowerment.**

The picture was now becoming one of patient empowerment in healthcare, a subject about which much has already been published. A review of this literature was undertaken at this stage in an attempt to establish whether the patient as the instigator of their own foot health could be considered a feasible possibility.

The Department of Health document in support of the patient as an expert in the field of his/her disease (2001) states that the better health service providers are those who give people good advice and information regarding their disease and its management, and answer the patient’s questions regarding their concerns. However, few then go beyond this to ensure the patient’s growing knowledge develops to a level whereby self-management becomes a real option. This document goes on to say that patients with chronic diseases are effective in appropriately accessing health and social care services, assuming that they have developed the knowledge base to do so. Relating this to the patient’s foot health needs, in order that an individual can take steps to seek advice for
foot concerns, they require sufficient knowledge regarding the potential foot problems in RA so as to judge when they need to obtain this help. The education of the patient is thus essential to achieving this aim.

Burckhardt (1994) defined patient education as a planned organised learning experience designed to facilitate voluntary adoption of behaviours and/or beliefs conducive to health. Several papers have reported the benefits of patient education sessions on symptom reporting and psychological status in the short term (Riemsma et al, 2002) and the longer term benefit in terms of pain and functional ability (Superio-Cabuslay et al, 1996). Education groups, as well as providing knowledge on disease progression and its management, can also inform patients on how they can help themselves. The benefits of self help groups as reported by Matzat (1993) are:

- Reduced depression,
- Increased self-esteem,
- More personal contact,
- Increased skills in conflict management,
- A comparative perspective on one’s own problems,
- A more selective use of the formal care system.

Successful education has been achieved via a variety of approaches. It can be delivered on an individual basis (both planned and opportunistic in nature) with the patient and their carers (Knudson, Speigel & Furst, 1981), as a group education session (Udelman & Udelman, 1978) or through computer based learning (mostly self sought information). Each mode of delivery has its benefits and problems. For example, information sourced by the patient using the internet may not be suitably applied to their individual circumstances and the healthcare team have no influence over what information is accessed and whether it is appropriate for their patient. Some individuals can find a group session daunting and may not feel comfortable discussing personal issues in front of others. However, this situation can be useful as subjects may arise from the experience of others which may not have been recalled in other settings but could provide useful information to other members of the group.
Education programmes in rheumatology have already proved to be valuable in empowering patients to change their lives (Gutch, 2000). Powers & Bendall (2003) explain that the concept of empowerment through education can positively influence patient participation and compliance with their treatment programme. Patient empowerment is also included as a recommendation in standards of care documents (ARMA, 2004). Hill & Reay (2002) list amongst the aims of RA disease management that of empowering the patient by providing patient education.

The Expert Patient programme endorsed by the Department of Health is well established in rheumatology. It was developed to acknowledge that, as the population is living longer, the effect of chronic conditions becomes an increased burden for them. The programme aims to tap into the patient resource, as their personal knowledge of their disease should empower them to take an active role in the management of their condition. Programmes are designed to link with NICE guidelines and similar documents so those patients are aware of what they should expect from their health services. Arthritis Care has developed an Expert Patient programme for rheumatology known as “Challenging Arthritis”. This has been largely based on the evidence supplied by Lorig et al (1993) which shows that this type of health education for self-management in patients with chronic arthritis has sustained health benefits as well as the advantage of reducing health care costs by increasing self-efficacy.

Having presented the view that patient education is regarded as desirable, it should be noted that its use is not as straightforward as it may at first appear. Research by DiMatteo and DiDicola (1982) suggested that people seek help and comply with advice only under certain circumstances as set out in the health belief model described by Rosenstock (1974). The significance of the health beliefs of the individual will be further explored in chapter 7 (p.136 & p.157). The indications from this were that, for education and adherence to advice to be successful, the perceived threats and benefits of compliance for the individual patient must be known and targeted. Dooher & Byrt (2002) also report that contrary to the perceived benefits of health education, there is evidence to suggest that seeking medical help may be seen as disempowering (as it may be viewed as giving up control), financially costly and generally unwelcome to patients. This being the case, it would again be necessary to discover the particular beliefs and health attitudes of the individual patient.
Coulter (1997) reflects on the importance of patient empowerment stating that patients should be provided with information of good quality and healthcare professionals should be trained to provide this information in a way that ensures the patient has understood the implications of the advice. This again implies that it is not sufficient simply to provide the same general information to each patient. Funnell (2000) also suggests that professionals need skills in asking questions in order to understand the patient’s fears, concerns and priorities to enable that professional to educate and support those patients in on-going self-management on an individual basis. In this way, education is also considered an important aspect of informed consent.

As well as providing information about a disease and its management, to achieve a positive health behaviour change from that education, an appropriate level of psychomotor skill is required (Redman, 1993). Again, the individual requirements for each patient have to be taken into consideration and skills to translate this information into a change in behaviour (even if this behaviour is simply appropriate self-referral of problems) need to be taught. It might be supposed that a patient’s level of knowledge about his/her disease increases with its duration but this may not always be the case as it is a generalisation (Coulter, 1997).

If knowledge is to be gained through expert patient programmes or group education sessions, there is a potential problem in ensuring equity for all patients. In addition to the problem of geographical variation in the range of rheumatology services available, it appears that these self-help programmes appeal to certain patients and the fear is that other members of the RA patient population, whose personal circumstances or psychosocial skills prevent them from engaging fully with the process, will be disadvantaged.

It would seem therefore that, although educating the patient on the facts surrounding RA is seen as desirable and of benefit in terms of understanding and adherence to disease management plans, for health behaviour to change, the patient’s attitude and beliefs as an individual must be taken into account. Time should be spent with each patient to establish the skills they need to translate knowledge into change in approach to their RA management. The literature supports the importance of patient education
and subsequent empowerment if these considerations are addressed. Developing the investigation to examine this subject further as a potential solution to the local clinical problem could therefore justified.

**Summary.**

This chapter has provided further information on why this study is necessary in terms of the importance of the patient in the management of their disease. Whilst literature exists to show the value of patient empowerment on their general wellbeing, a gap in the knowledge exists regarding the specific application of empowerment on foot health. This is especially important as it has become apparent that patients are given the responsibility for reporting rheumatoid foot problems as they occur.

The aim of this work was then to discover the patient’s understanding and attitude towards the effect of RA on the foot and the rheumatoid foot care services available to help limit this. This would establish if sufficient knowledge is currently provided for patients to make the decision when and how to seek foot care help in a timely and appropriate manner as laid out in the guidelines. It was envisaged that the results would enhance the professions understanding of what further educational help could be offered to our patients in order to prompt them to seek appropriate care. Patient empowerment and self-efficacy groups will be revisited in chapter 7 (p.129) when the literature will be cross referenced with the outcome of the qualitative stage of the research which follows.

There was an assumption made that, if a greater understanding was known regarding the patient’s viewpoint, new education sessions could be targeted to greater effect and potentially achieve optimum timing and appropriateness of self-reporting of foot symptoms. The results of the study (reported in chapter 6) serve to explain why this was not going to be the complete answer to the problem.

The remaining chapters will document the qualitative research subsequently undertaken which explored the idea of patients self reporting of foot problems in RA and examined the suitability of this approach as it is used locally. Chapter 5 will now detail the specific design of this research.
Chapter 5: RESEARCH DESIGN

Introduction.

This chapter will summarise how the research question, generated from a combination of a review of current literature and the results of preliminary work generated by the audit, was translated into a qualitative study strategy. It is divided into two parts. The methodology section will discuss the approach to the research design along with its philosophical underpinning. The manner in which this informs the investigation will be described. The research process section will then go on to explain the mode of data collection and its analysis. By the end of this chapter, a clear account of the decision-making process behind the design will have been given and the process carried out to obtain the conclusions from the work will be apparent.

Methodology

Philosophical Position of Researcher and Study.

“It is the uncomplicated style and innocent way of questioning, which produces confusion and instability in our assumptions and ideas about the world that makes the study of philosophy of special benefit (Smith, 1998)”

(Crossan, 2003, p46)

When considering the research subject area, based on previous research experience, the immediate thought was to embark upon a study design which would be quantitative in nature. The previous studies had been grounded in a positivist philosophical position, where the research involved testing a hypothesis with a view to generalising the findings to other possible applications (Holloway, 1997). The quest for objectivity was fundamental and the aim was to minimise personal biases by placing the emphasis on neutrality. The basis for this positivist position had to a certain extent been due to the working environment, the mind-set of the people working within it and the familiarity with this position over alternatives. I had not been required to formally reflect upon my own beliefs, assumptions and their effect on areas to be studied.
A quantitative approach could have been applied to further investigate the provision of foot care services locally. For example, a comparison of the podiatry interventions received compared to that proposed in the published guidelines would have provided a measure of how the service measured up to the recommendations. However, if adopted, and not explored further, this approach would simply provide evidence of the disparity in service provision. No explanation of the reasons for this discrepancy or potential recommendations to improve uptake of podiatry services would be offered. For the current study question, a research position was needed which would describe the local situation with regard to rheumatoid footcare and provide an understanding as to why it functions as it does. A qualitative approach was considered to be a more appropriate way to meet this aim.

It was during the quantitative preliminary fieldwork that the need to consider reality as subjective and multiple became apparent. The anecdotal comments made by both health professionals and patients sparked the realisation that individuals described their perceptions of healthcare provision in a number of different ways. This reflected their beliefs on health priorities and expected treatment outcomes. This was despite being influenced by the same organisational and policy procedures. With this realisation, there was a need to reconsider my philosophical position as researcher to establish the effect this stance would have on the study and the approach to the work. All researchers have their own life experiences which influence the design of their inquiry and the way in which the results from their work are interpreted. This consideration was also necessary because the choice of a qualitative research approach is not considered congruent with positivism. Qualitative work is considered constructivist, naturalistic, interpretative and post positivist/postmodernist (Cresswell, 1998). Additionally, Proctor (1998) reminds us that a hospital is not a stable or value free environment as a positivist approach would demand.

Clough & Nutbrown (2002) make the statement that all social research sets out with specific purposes from a particular position, and aims to persuade readers of the significance of its claims. This “particular position” is described in terms of ontology and epistemology. Ontology is concerned with the nature of being and existence (Holloway, 1997). It explains what the researcher considers to be reality. Epistemology
Hitchcock & Hughes (1995) suggest that forms of knowledge, access to knowledge and ways of acquiring knowledge are epistemological issues. Easterby-Smith et al. (1997) explain that exploring philosophy is significant in relation to research methodology because it helps to refine, specify and evaluate different methodologies and methods in order to avoid inappropriate use and unnecessary work by the identification of limitations early on. The research methods are then grounded within an accepted epistemological paradigm. Houldsworth (1997) goes on to say that this is what differentiates academic work from lay knowledge by increasing its authority. By disclosing the researcher’s philosophical stance within this report, the reader can judge the conclusions reached against their own standpoint.

I have come to believe that what we know of reality is what we interpret from personal experience and perceptions. This is therefore individual and unique. I also hold with the view that a universal reality is achieved when people sharing the same experience shape their realities to fit each other by reaching a consensus. The aim of research would therefore be to construct a clearer reality rather than to discover an absolute one (with “objectivity” viewed as a social phenomenon based on triangulation of multiple imperfect perspectives). I believe that no objective truth can be reached in a study that involves people which is independent of those participants within the context of their lives. My ontological stance would therefore be considered as constructivist in nature (Stake, 1995; Trochim, 2006).

The movement of social research towards the belief that knowledge is constructed rather than discovered has been led by Guba & Lincoln (1989). From childhood we believe what we are told about the world and this is then tailored by experience, but it can vary according to the culture in which we are reared. Crotty (2003) illustrates this with the example of trees. They can be considered a source of livelihood or aesthetic pleasure dependant on whether one lives in a lumberjack or artist community. A constructivist believes that each individual’s account of making sense of the world is valid and worthy of respect. Therefore, constructivist research invites us to “approach the object in a radical spirit of openness to its potential for new or richer meaning” (Crotty, 3003, p. 51). It is considered to be a critique of positivism (Denzin & Lincoln, 1998).
However, the positivist values which supported the previous research history were proving difficult to dismiss. Whilst embracing the constructivist position, the importance of empiricism was still acknowledged. Fortunately, Cupchick (2001) puts forward the view that positivist and constructivist approaches in social science can work well together. He describes this ontology as Constructivist Realism. Many authors have argued that positivism and constructivism are incongruous and so cannot be made compatible (Lincoln & Guba, 1985; Smith & Heshusius, 1986). Despite this, Cupchick argues that each of these two ontologies has an important role to play and when used in conjunction can enhance the research process.

Instead of looking at the differences between qualitative and quantitative approaches, Cupchick (2001, p.2) emphasises the similarities stating that “both begin with a concrete world and step into another world of abstraction”. He suggests that positivist scientists cannot be fully neutral in their research as, like constructivists, they select their facts and by doing so engage in construction. Also, there are principals accepted by the positivist scientific community which illustrate that the researcher can have an effect on the phenomenon being studied. For example, Heisenberg’s uncertainty principal in physics states that it is not possible to simultaneously determine the position and momentum of a particle. In fact, the better the position is known, the less well the momentum is known (Heisenberg, 1927). Hence, both approaches are subject to the same potential biases. Once this is recognised, the ability to work together is possible.

The richness provided by qualitative studies and the precision of quantitative research can complement each other if the former is used to clarify processes and shape a hypothesis to be tested by the latter. Also, empirical findings which relate to processes can be used to suggest issues which would benefit from more detailed qualitative inquiry. A greater level of clarity is then achieved in the account of the phenomenon under investigation. The acceptance of this advantage is also acknowledged outside of the social sciences. Cole (1997) reports on the conflict between these two research approaches in terms of choosing a framework for educational research. The conclusion is again that each is important and can be justified in having a place in this field. Shuurman (2002) applies this to geographic information science and reports on the rewards from the appreciation of both views.
Miles & Huberman (1994) suggest four basic ways in which qualitative and quantitative designs can be integrated. One of these suggests that quantitative data, in the form of survey or audit can be used to inform a qualitative field study. This latter work may then lead to further quantitative work which may be experimental in design.

“It is important to note that while the quantitative research methods (or positive philosophies) and qualitative methods (or post-positive philosophies) are often seen as opposing and polarised views they are frequently used in conjunction. The distinction between the philosophies is overstated (Webb, 1989) and triangulation of methods in current day research is common (Polit et al, 2001).”

(Crossan, 2003, p.46)

Whilst it is unclear as to whether constructivist realism is a separate ontology, or an acceptance that two seemingly opposing views can be used together to enhance the research process, it is with this stance that I embarked on this research. The quantitative preliminary fieldwork was used to provide both the numerical evidence to support the initial assumptions regarding rheumatoid patient foot care and suggested the benefit from qualitative follow-up to further clarify the situation with regard to patient self-reporting of foot problems.

**Qualitative Research Design.**

Having accepted that a positivist quantitative position would not be the most appropriate approach to answer a question relating to the patient’s understanding of the rheumatoid foot issues under investigation, the focus for the next stage of the research design became qualitative in nature.

“Qualitative methods should be used when there is little known about a domain, when the investigator suspects that the present knowledge or theories may be biased or when the research question pertains to understanding or describing a particular phenomenon or event about which little is known.”

(Field & Morse, 1985, p.11)
The above quotation further substantiates the suitability of a qualitative study for this work in that little is known as to patient understanding of foot issues in RA and the original preliminary audit raised the query as to whether the present theory in support of patient self reporting of foot symptoms is biased in favour of preserving clinician time. The decision had then to be made on the specific qualitative strategy to employ in order to avoid “method slurring” which is the muddling of different procedures in a single piece of research (where each has its own underlying principles, assumptions and procedures) such that they do not “fit” together (Baker at al, 1992). Various methodological approaches were considered and discounted for this work. Qualitative questions seek to discover (grounded theory), explain or seek to understand (ethnography), explore a process (case study) or describe personal experiences (phenomenology) (Creswell, 1998). Whilst the appropriateness of the underlying philosophy for each had to be deliberated, the ability of the methodology to provide the clearest answer to the specific research question was the major objective.

Grounded theory attempts to generate theory by multiple stages of data collection and refinement. It uses constant comparison of data with emerging categories and theoretical sampling of different groups to maximise the similarities and differences (Glaser and Strauss, 1967; Creswell, 1994; Holloway, 1997). This approach was not considered suitable for the aim of the work under investigation as the development of a theory was not the intended outcome. In addition, grounded theory is criticised for its affinity with positivism and so was not considered congruent with the stance outlined for this study (Roman, 1992).

Whilst an ethnographical approach can adopt a variety of paradigms (including positivist and interpretivist viewpoints), it was also discounted for the proposed research as it is concerned with the study of culture (Hammersley & Atkinson, 1995; Holloway, 1997; Grbich, 1999). The local study aim was not to examine the cultural determinants of human behaviour, although this was to be seen within the findings. Moreover, it was trying to understand processes within and beyond this group and how that may impact on care delivery systems. Also, ethnography relies predominantly on immersion in the field and observations for data collection which would not provide the information required to answer a research question regarding patient’s understanding.
A possible approach for the intended investigation was that of phenomenology (Husserl, 1960; Merleau-Ponty, 1962; Heidegger, 1962). As the study of “phenomena” and human experience, phenomenology could be applied to the local study with the phenomenon under investigation being the acquisition and rationalization of RA foot knowledge to achieve timely and appropriate help in the local patient population. Phenomenological studies look at human experiences examined through detailed descriptions of people being studied (Creswell, 1994). In this way they provide an understanding of the lived experience. The experience of the individual, with regard to RA foot health, and their use and interpretation of this information is the point of interest for the local research. Phenomenology lies firmly in the interpretivist stance which again confirms its position as a possible approach for this study. However, a greater flexibility in the research approach was required to:

- allow for the possibility of providing an explanatory theory in the conclusion, which does not fit with the aims of phenomenology,
- allow the previous experiences and assumptions of the researcher to be acknowledged as a potential influence on the interpretation of the findings.

Descriptive phenomenology in the Husserlian tradition advocates the suspension of these influences.

However, the aims of the research are broader than simply exploring the individual’s experience of footcare services. It aims to examine the participant’s knowledge and subsequent behaviour. This being so, a case study approach provides a better match with the particular research question and allows for the wider investigation.

As the overarching aim of this research was to increase our understanding of the provision of footcare services for patients with rheumatoid arthritis (a process), case study was deemed a suitable approach for consideration. A case study is an entity which is studied as a single unit and has clear boundaries (Merriam, 1988). These boundaries are determined in terms of the questions asked, the data sources used and the setting and persons involved (Holloway, 1997). This can therefore be applied to the research aim of discovering how the patient’s understanding of the effects of RA on the foot, and the services available to help, influence self-reporting of foot problems. In this study, the case is particularly related to the local rheumatoid foot health situation. Case studies
have a greater flexibility than some of the aforementioned methodologies in that, although not the primary aim of the work, case studies can be employed as a first step towards building theory (Yin, 1994). This was the aspiration, if not the aim, of the study in that its findings would provide information on how to improve the current rheumatoid foot health situation. Evans & Gruba (2002) assert that case study design seeks to argue your point within an overall conceptual framework. They go on to say that research that starts as the study of a phenomenon often develops into a case study as the researcher realises that the findings can become generalisable to situations beyond the specific entity under investigation. Whilst the research focus was very much on local clinical practice, there was an intention of illuminating the situation regarding podiatric provision in a broader context thus supporting the view of the above authors.

Case study research has been described as “transparadigmatic” in that it is relevant regardless of the researcher’s philosophical position (VanWynsberghe & Khan, 2007, p.2). Yin (1994) takes this a stage further and warns that there should be no attempt to associate case study with a particular paradigmatic position. While it can be argued that the choice of design should reflect the epistemological beliefs of the researcher (Woods, 1997), we are constantly reminded that the main guide in choosing a design should be its suitability to answer the research question (Sackett and Wennberg, 1997). However, some authors argue that case study can be strongly associated with qualitative research, because of its emphasis on ‘real’ situations and their inherent descriptive qualities (Lincoln and Guba, 1985). This being so, it must be considered broadly post-positivist in nature and thus congruent with the philosophical stance influencing this study. With the move away from the positivist stance and, having accepted that different parties bring their own social constructions to the table, it would be impossible for me as researcher to be totally independent of the study. The flexible nature of a case study approach allows for any researcher effects on the data and its interpretation providing this is made transparent and explained throughout the thesis.

Having established case study as the research approach of choice for this study, its suitability will now be examined in greater depth.
Case Study.

Although it has a variety of meanings relative to its setting, in research case study is taken to be the examination of an entity as a single unit which has clear boundaries (Holloway, 1997, p.30). The term “case study” itself can be used to describe both a process of inquiry and its end product (Gray, 1998, p. 15). A distinguishing feature of case study research is that although the number of cases may be small (or even one) the number of variables involved is large (Burns and Groves, 1997; Yin, 1994). Historically, case study research in the health professions had received less attention due to the potential confusion between case study as a research approach and its use as a learning tool in education (Bryar, 2000). For the latter, the case study need not contain a complete and accurate account of actual events as its aim to establish a framework for discussion (Yin, 2009). This would obviously be inappropriate for research purposes. Evans and Gruba (2002) report the suitability of a case study approach when examining the consequences of a decision and challenging the existing way of thinking. Case study as a research design choice is now considered an essential option for social science and is used extensively for practice-orientated professions. Indeed, there has been an increase in the number of case studies conducted in nursing which is attributed to a greater acceptability of the process as a research strategy and a way of addressing the holistic nature of treatment in the caring professions (Sandelowski, 1996).

In the past, case studies have been criticised for being unscientific and anecdotal. The Centre for Reviews and Dissemination placed the case study in a very inferior position in their hierarchy of research evidence (CRD, 1996). However, the approach comes into its own when used to translate scientific knowledge into clinical practice thus bridging the gap between theory and patient care (Green, 1998). When conducting patient-centered research, findings are often unpredictable and an accommodating research approach, like case study design, would help provide the necessary flexibility to encompass any required change as the research progresses. In addition, Yin (1994) argues that when process issues are involved, multiple sources of evidence used with case studies offer a holistic perspective facilitating a fuller exploration of the issues in question. The complex nature of studying health care and its provision means the importance of choosing the most appropriate research design for the aim is a priority.
over choosing an approach deemed to be more acceptable to the scientific community (Jones & Lyons, 2005).

Confusion further surrounds case study with regard to lack of clarity over its classification as research design or a method (Jones & Lyons, 2005). Stake (1995) detached case study from methodology by describing a choice of what is to be studied rather than a methodological choice. VanWynsberghe & Khan (2007, p.9) suggest that case study is not a method, methodology, or research design. Their proposed definition of case study is that of a “transparadigmatic heuristic that enables the circumscription of the unit of analysis”. However, this definition does still suggest an element of strategic intent. Indeed, the consensus among authors is that case study is a research strategy that makes use of multiple methods of data collection as appropriate in relation to the questions being examined (Bryar, 2000). DeVaus (2001) describes a research design as the planning process which ensures the evidence obtained will answer the research question as unambiguously as possible. This implies the need for design to involve careful consideration and planning before embarking on any collection of data. This would, therefore, certainly indicate that case study is a research design or strategy. To achieve its aim, the case study design can make use of methods from both the qualitative and quantitative traditions which are considered harmonious with the constructivist realism argument.

Whilst case studies can be used to investigate a single case, that case may be considered as an individual, an organisation, event or process (Meiher and Pugh, 1986). Miles and Huberman (1994) acknowledge that the process of defining what forms the basis of a ‘case’ can prove to be a problem for many qualitative researchers. They suggest that it should be considered as the issue which is at the heart of the study. The “case” for this research is the patients understanding of RA foot health issues and the influence this has on self reporting foot problems. This also fits with the view that the phenomenon under investigation should be contemporary in nature (Yin, 1994). VanWynsberghe & Khan (2007, p.9) suggest that case study is not exclusively about the case revealing itself as it is about the unit of analysis being discovered or constructed. The unit of analysis is defined as the major entity that is being analysed in the study (Trochim, 2006, p.1). VanWynsberge & Khan (2007) propose that circumscription of the unit of analysis is accomplished by:
• providing detailed descriptions obtained from immersion in the context of the case,
• bounding the case temporally and spatially, and
• frequent engagement between the case itself and the unit of analysis.
This view is an important development because it suggests that researchers cannot definitively state the unit of analysis at the outset of the research as it must emerge as the research progresses. This being so, the unit of analysis for this study will become apparent in later chapters.

Hakim (1987, p61) describes the case study as being like a spotlight or microscope but warns that its value depends on how well the study is focused, with this focus lying anywhere on a continuum from the descriptive to the experimental. In between these two extremes there is an extended range of case studies combining exploratory work, description and the testing of hypothesis, in varying combinations. Other authors have described this research strategy in terms of different stages. Yin (2009, p7) describes these as:

• Descriptive- used to describe the phenomenon under investigation,
• Exploratory- which debates the value of further research into this subject,
• Explanatory- which explains the arguments highlighted by the descriptive work.

These stages are not mutually exclusive. Stake (1995, p3) also identifies three categories that are similar to those of Yin and are described as follows:

• Intrinsic- used to understand a particular case without trying to establish that other cases may be similar.
• Collective- to compare a number of similar cases.
• Instrumental- used with a view to theory building.

It can, therefore, be seen how, as well as being used to provide a clearer understanding of the nature and extent of a problem, case studies are frequently employed as the first step towards developing theory (Jones & Lyons, 2005). This research was designed as a descriptive or intrinsic case with the aim of understanding more about the specific process of footcare provision for our local rheumatoid patient population. It later developed into an exploratory case when issues arose which would be used to define research questions for future work.
Yin (1994, p.40) supports the use of a single case of this type when it is “revelatory” in nature. He goes on to say that case study research is appropriate when socialisation has previously occurred. In this study, the case has been “socialised” regarding the patients understanding about rheumatoid foot issues. The knowledge generated from the research will be description in the first instance. The “bounded system” is focused on answering the question of how rheumatoid foot problems and their management are viewed by this patient group. As the research progresses into an exploratory case study, the bounded system of the case would be concerned with the issues to be discovered. The research may also be considered evaluative in that we are evaluating the current local situation with national standards of care.

The idea of generalisability in case study research needs further explanation. There has been criticism of the lack of generalisability in case study but it can be argued that the development of theory mentioned above can come from the ability to produce findings which are relevant beyond the case in question. Within qualitative research, the term ‘transferability’ may be preferred (Lincoln and Guba, 1985) as generalisation in quantitative research implies the findings can be applied to a larger population whereas, in qualitative work, the translatability applies more to similar situations which may not necessarily be larger. This is because the case study does not represent a sample as such. Yin (1994, p.30) argues that case study is concerned with analytical generalisation and not statistical generalisation as the aim of this approach is to generalise and develop theories not frequencies or statistical generalisations to a wider population. Stake (1995, p.7) also acknowledges that case study is inappropriate as a basis for generalisation in a statistical sense. He goes on to refine his belief that there are ‘petite generalisations’ that occur throughout a particular case, factors which lead to the refinement of a generalisation (by observing that something happens in a variety of ways, such as social interaction, for example) and that these can lead to ‘grand generalisations’. The transferability in qualitative study is achieved through attention to detail in describing the research design. In doing so, it becomes the responsibility of the reader to decide if the results are transferable or not (Lincoln and Guba, 1985). Whilst the focus of this work was on the local situation, implications for national changes in foot screening protocols have been suggested as a response to the findings which may be considered by the reader as transferable to their clinical practice.
Gray (1998, p.17) listed ten uses for case study research. These were compared with the goals of this study with the intention of further assessing the suitability of continuing with this approach. Seven of the ten uses were relevant to this study as it provides:

- An in-depth study of a phenomenon in its context by increasing the understanding of how the patient’s beliefs and knowledge of rheumatoid foot health impacts on their ability to seek appropriate help.
- An investigation of a person-centred clinical problem.
- An illustration of a specific element of a project, namely the issue of patient responsibility for foot health within the overall aim of increasing our understanding of the provision of foot care services for patients with rheumatoid arthritis.
- Findings which can lead to the generation of a new hypothesis as will be explained in chapters 7 and 9.
- A pilot which can be used for a larger study.
- A pilot which could lead to a quantitative study but taking the findings and translating them into a questionnaire to reach a larger patient group.

In summary, case study approach was deemed the most suitable strategy for this research in that it aimed to describe a phenomenon but also required the flexibility to translate findings to broader healthcare settings and produce recommendations with regard to changes in service provision. This is achieved in a way consistent with the view of constructivist realism. In this way, it enables the gap between theory and patient care to be bridged.

**Research process.**

**Data Collection Method.**

The next stage of the research design was to state how the choice of data collection method adds to the validity of the study (Jones & Lyons, 2005). A variety of data collection tools are deemed to be appropriate for case study inquiries (Holloway, 1997; Yin, 2009; Stake, 1995). These include interviewing, observation and examining
documentation. Observations were considered and discounted as the information needed to meet the research objectives could not be obtained in this way. The clinical consultation would be the only opportunity to observe the patient and this situation would be unlikely to reveal the individual’s attitudes and beliefs towards the foot unless foot symptoms were specifically raised at the time. Thus, the views of the patient could not be ascertained by this data collection method. Indeed, Morse (1994) suggested that observations were best suited to ethnographic studies. The same applied to the investigation of documents. There would be no relevant occasion presenting itself which would offer the required information in sufficient depth to fulfil the aims of the research. In addition, the information from documents is historical and Yin (2009) emphasises the contemporary nature of the phenomenon in a case study. The decision was taken to collect data from direct contact with the patient.

When interacting with the patient, the choice of technique can involve interview or a survey questionnaire dependent on the selected procedure's ability to give maximum opportunity for complete and accurate communication between the researcher and the respondent (Cannell & Kahn, 1968, p.554). Questionnaires were excluded as a data collection method due to the need to make certain assumptions related to the subject in order to set the questions (Oppenheim, 1992). This being so, questionnaires would not allow the flexibility required to gain the depth of information that would be generated. Although assumptions had been made as to the underlying issues surrounding the subject, an active attempt was made to ensure minimal impact of this on information presented to the participant during the data collection phase of the investigation. This supported the aim of generation of new knowledge as a result of the data collection process. The flexibility of the interview method allows the inquiry to be modified as it progresses ensuring that as much information as possible is gained and at a greater depth.

“Interviews allow the researcher to fine-tune the explanation and satisfy themselves that respondents have sufficient understanding to reach considered views.”

(Fielding, 1994, p7)
Interviews are considered a particularly useful tool for collecting data when information is required on understanding the perceptions of subjects, or learning how participants come to attach meanings to phenomena or events (Taylor & Bogdan, 1998, p.98). Interviews were therefore chosen as the data collection method for this study.

Creswell (1994) describes two limitations of the interview relating to the patient. Firstly, the author reports that the technique provides “indirect” information filtered through the views of the participant. This may be seen as an advantage in case study as this helps to show how meaning is attached to the topic under discussion. Another limitation is reported to be the lack of equality in ability of the participants to be articulate and perceptive. For the local population with rheumatoid arthritis, the views of a range of people would be considered valuable and important to the subject regardless of the manner in which this is presented.

Having made the decision that interviews were the data collection method of choice, the specific form then had to be confirmed. The range can include face-to-face, telephone and group interviews. Group interviews were considered when designing the project but would have been difficult to arrange these locally as several practical barriers existed to arranging such an event. On reflection, a focus group exercise for future expansion of the findings would be valuable as the issues raised here could be explored amongst a wider audience. Had groups been used for the main research inquiry, the respondents may not have been so open about their individual reasons for choosing whether and when to seek medical advice. Data collected in this way is reported to be “patchy and incomplete” (Gillham, 2005). As the findings from a focus group are often used as a basis for action (Holloway, 1997) it would be more appropriate for future validation of this subject rather than the initial exploration of the topic.

The decision was made to use face-to-face interviews rather than via telephone for reasons of practicality in that the amount of time available to spend using the telephone might be limited. In addition, the ability to assess non-verbal elements would be lost (Gillham, 2005). Having established that face-to-face, individual interviews were to be used for data collection, the choice was then to decide which type of interview would be considered most appropriate for the aim and the methodology employed. Fielding (1994) suggests that structured interviews be used mainly in quantitative studies as they
are standardised in their approach and thus are easier to code and quantify. They again assume that you have some ideas/assumptions about the research topic and are used in those circumstances when a questionnaire would be suitable but an interview reduces the number of non-responders. However, this is not applicable to qualitative work where these assumptions are kept to a minimum.

Rose (1994) suggests that semi-structured and unstructured interviews are the most commonly used in qualitative research with the purpose of understanding and/or interpreting the meaning of experiences/events for individuals. A semi-structured interview technique was considered appropriate for this study as the tighter structure of this technique enables collection of all important information while still allowing an opportunity for participants to report their own thoughts (Holloway, 1997). Certain standard questions (developed from the literature) were asked at each interview to ensure that the central topics were covered, but flexibility to probe deeper was also possible. The unstructured interview also allows this flexibility with greater depth but the ability to generalise is reduced. As stated earlier, this translatability of the findings is a feature of the case study approach. Therefore, the method chosen avoided the unstructured approach for this stage in the inquiry.

To summarise, face-to-face, semi-structured, individual interviews were deemed to be the most appropriate approach for this study. The choice is congruent with the philosophical stance of the researcher and the methodology. The interviews were conducted by me as the researcher in order to fully appreciate the non-verbal communication, assess the accuracy of the transcript based on the interview experience and to ensure evolution of subsequent interview questions based on the responses from previous interviews. Audio tape recordings of the interviews were made to limit the distraction of taking copious notes and to ensure accuracy of the transcript as the tape can be played over again to catch the exact phrase etc.

The Interview Guide.

Although at the commencement of the study it would not have been appropriate to anticipate the content of the interviews, the initial assumptions gained from the literature were used to produce a flexible framework for the semi-structured questioning. The aim
of the schedule was to ensure information was collected on the following topics:

- What do patients understand about the effect that RA can have on their feet?
- What do patients understand about podiatry services and the help a podiatrist can offer to help their rheumatoid foot problems?
- What is the patient's experience of podiatry services to date (if any)?
- What barriers exist (real/perceived) to accessing this care?

These subjects were then used to develop the themes during analysis of the data.

The schedule took the form of the following questions:

- **How long have you had rheumatoid arthritis?**
  A question used to “break the ice” and to provide general background. An indication of the extent of the disease and the exposure to a range of health professionals (and consequently potential sources of information) was gained.

- **How does it affect you generally?**
  This was to provide further information on the severity of the disease and the joints which may be involved. To ascertain whether the foot is involved and how this is perceived within the context of the condition as a whole.

- **What can you tell me about the ways in which rheumatoid arthritis can affect/have affected your feet?**
  The response provided details of any foot involvement due to the disease process and to assess the extent of RA foot knowledge. The participants were asked directly if they had received any formal information or advice regarding the rheumatoid foot.

- **How do you feel about this?**
  This was used to gain an understanding of the importance of foot involvement to the patient.

- **Who do you consider is responsible for your foot care needs?**
  To gain the opinion of the patient regarding who they believe is responsible for ensuring their foot health and whether they are aware that the rheumatology team consider that this responsibility sits with the patient.

- **What does Podiatry mean to you?**
  This gave an indication of what the patient understands with regard to the role of the podiatrist in the management of the rheumatoid foot.

- **How do you think that a podiatrist could help people with rheumatoid arthritis?**
This provided more information regarding knowledge concerning the profession of podiatry.

- **Do you know how/when to access Podiatry Services?**
  To establish whether the patient would know where to seek help should they need to instigate it themselves.
- **If so, what is your experience of Podiatry services?**
  To understand better the opinions on the podiatry service based on any previous experience.
- **Are there any reasons why you wouldn’t attend the podiatry clinic?**
  To ascertain potential barriers to self-reporting of foot health issues.

To clarify or develop an answer the following questions were used:

- **Can you develop your thoughts further?**
- **Could you describe that in more detail?**

**Ethical considerations.**

Before commencement of the research, approval was sought and obtained from the local research ethics and the research governance committees (REC reference number 06/Q2008/45). Letters confirming approval are contained in appendix 2. This process ensured adherence to the following points which relate to ethical standards in professional practice:

- Accuracy in data gathering and data processing.
- Relevant research methodology.
- Appropriate interpretation of the data.
- Accurate reporting.
- Fabrication of data is misconduct.

(Adapted from Sarantakos, 1998, p.22)

Before embarking on the study, consideration was given to the possibility of discoveries relating to under-performance in delivery of patient care for patients with rheumatoid arthritis when compared to the national standards. There was a need to be diplomatic in how findings would be presented in order not to be seen to criticise the team and have a
negative effect on morale. At the same time, if issues needed to be addressed, the relevant stakeholders would need to be informed in line with the requirements of the Primary Care Trusts “Raising Significant Concerns” policy (Wiltshire PCT, 2008). Other particular areas of consideration required by the ethics committee will now be explained.

**Data Protection/Confidentiality Issues.**

Tapes and transcripts were coded to keep the identity of the individual confidential. No recognisable patient information was recorded on either form of data. They were stored in a locked cupboard on NHS premises, which was only accessible to me as the researcher. Patient’s details used to provide the codes for the tapes and the transcribed interviews were stored on a password protected NHS computer. The raw data will only be stored for seven years after which time it will be destroyed. This was in line with Caldicott Principles and the Data Protection Act (1998).

Advice had been sought regarding data protection issues to ensure the project was fully compliant.

*Consent.*

Written participant information explaining the study, why they were being invited to take part and the nature of their involvement was submitted for the local Ethics Committee to examine and was approved. This document included specific mention that the interviews would be tape-recorded. Great care was taken with the wording at this stage to ensure adequate informed consent would be achieved. It was made clear, both in writing and verbally, that potential interviewees were not obliged to participate and would not be disadvantaged with either decision. The right to withdraw their data at any stage and to withdraw from the study itself (without effect on subsequent service access) was also made clear. Written, informed consent was obtained from each participant once all this was explained. The timing of consent will be explained in the recruitment section. A copy of the patient information and consent forms approved by the ethics committee is included in Appendix 3.
Consent from the consultant rheumatologist was sought and agreed before approaching patients from the rheumatology department.

**Other Issues.**

The Ethics Committee required that the possibility of providing counselling following the interview was considered and could be made available if required. However, upset caused by the topics covered was not anticipated, due to the nature of the research subject, nor did it occur in practice. As the ethics committee needed to see that this service has been considered, the Patient Advocacy and Liaison Service (PALS) were approached and confirmed that this service could be provided through their office if necessary. The PALS service can also provide interpreters if English is not the first language of one of the participants.

Participants were given the opportunity to read a transcript of their interview to ensure that it was an accurate representation of their views and were encouraged to feel free to add further information at this stage. Respect for the individual's point of view was maintained throughout and reassurance issued that any information published/presented as a result of this work will be anonymised.

The interviews were held at the community-based headquarters of the podiatry department in order to avoid the need for an honorary contract by the researcher who is employed by the local Primary Care Trust and not the Acute Hospital Trust, from where the participants were recruited. This was suggested by the ethics committee and verified by the Research and Development Support Unit. This setting was also chosen for its convenient location in the centre of the city.

**Recruitment.**

Suitable patients for this study were selected as those who had a diagnosis of rheumatoid arthritis (established from the patient records) and were attending the local District General Hospital rheumatology outpatient department. A purposive, stratified sampling technique (LeCompte & Preissle, 1993) was used to ensure that views were obtained from those who had early disease (diagnosis less than two years), intermediate
disease and chronic established disease. This was partly because the level of foot involvement varies over time as discussed in chapter 2, p.19 (Michelson et al, 1994; Kerry at al, 1994) and thus the podiatric needs of the patient may be different during these stages, but also the patients will have had differing exposure to rheumatology health care professionals (which may or may not include podiatrists) and thus, varied potential access to information regarding their disease. The duration of the disease as an indicator of the severity of its effects on the joints within the foot has been justified in several papers, the main authors being Spiegel & Spiegel (1982) and Shi et al (2000). Some of the patients interviewed had previous experience of podiatry services and some had not. This was part of the sampling process to ensure information on their experiences of the service and also their beliefs on the benefits and scope of podiatric care were captured in both circumstances.

When considering exclusion criteria, the potential problems of co-morbidities were discussed. In quantitative research it would be usual to exclude those patients who suffer co-morbidities that may influence the findings of the study. However, in this work, it was felt that the opinion of all would be welcome as all patients would still need to have the information and skills to empower themselves to seek timely and appropriate care regardless of the effect on the feet of other concurrent disease processes. Indeed, this is perhaps more important for those with multiple pathology as their other health problems may increase their need for timely foot care. The experiences of all individuals selected by duration and previous podiatric experience was considered important. Patients who had been, or were at the time of interview, under the care of the researcher were excluded from the study as this relationship could lead to bias in the responses. There is no local paediatric rheumatology service and so the involvement of minors in this study was not relevant in this case.

Individual packages were created containing written information regarding the nature of the study, a formal letter of invitation to participate and a stamped addressed envelope for return of a slip indicating an interest in involvement. These were then given to the rheumatology practitioner who received advice as to potential suitable subjects. When these had been identified, she was instructed to hand the packages to the individuals with the direction to take them and read the contents in their own time having first given a brief explanation of the nature of the study. There may have been potential for bias in
the selection process because of the use of the practitioner as sole gate keeper and her reasons for choosing individual subjects. The extent of this potential source of bias is unknown. The reply slip at the bottom of the letter of invitation was then returned by the patient in the stamped addressed envelope to the researcher if they expressed an interest in taking part in the study. The researcher was then able to contact the patient directly to arrange a suitable time for interview. This arrangement satisfied the ethics committee in terms of minimising the risk of coercing the patient by removing the researcher from the initial contact with the patient.

The patients were given an appointment to attend a Health Centre in the centre of the city (well-located for access by public transport and car parking which was more convenient than using the hospital site) and at this time they were given more information regarding the study and an opportunity to ask questions. The interview then followed. Formal written consent to be interviewed and for this to be tape-recorded took place at the time of the interview.

Participant Details.

The first part of the interview provided a general discussion to ascertain the patients disease history, when and how it was diagnosed, which joints were affected then and since, and which healthcare professionals they had met since diagnosis. General disease management was also discussed. The interviewees provided information regarding age, gender and employment details. These general questions helped to establish a rapport during the interview and determined the patient’s attitude to their disease and its effect on them personally and in relation to their social roles. The importance of this will be reported later in chapter 7.
<table>
<thead>
<tr>
<th>Patient Code/Gender</th>
<th>Age</th>
<th>Geographic details</th>
<th>Duration of RA from diagnosis</th>
<th>Current Footcare provision</th>
<th>Current Drug Therapy</th>
<th>Employment/socail concerns</th>
</tr>
</thead>
<tbody>
<tr>
<td>001 Female</td>
<td>40’s</td>
<td>Rural village location on western edge of catchment area.</td>
<td>3years</td>
<td>family</td>
<td>Sulphasalazine, Hydroxychloroquine, Methotrexate, Etanercept Injection.</td>
<td>None Dog owner</td>
</tr>
<tr>
<td>002 Male</td>
<td>60’s</td>
<td>Small town north of the city.</td>
<td>24years</td>
<td>Regular, NHS podiatry</td>
<td>Co-codamol, Calcichew, Alendronic Acid.</td>
<td>Retired</td>
</tr>
<tr>
<td>003 Male</td>
<td>50’s</td>
<td>Small town north of the city.</td>
<td>7years</td>
<td>Regular, Non-HPC-reg ex-podiatry assistant</td>
<td>Prednisolone, Ametrazole, Quinine</td>
<td>Part Time Employed</td>
</tr>
<tr>
<td>004 Female</td>
<td>72</td>
<td>Housing estate on edge of City centre.</td>
<td>4years</td>
<td>Discharged, NHS Podiatry</td>
<td>Amitryptiline, Calcium</td>
<td>Retired Dog owner</td>
</tr>
<tr>
<td>005 Male</td>
<td>68</td>
<td>Rural village west of city.</td>
<td>25years</td>
<td>None</td>
<td>Infliximab, Methotrexate</td>
<td>Retired Forces Children in private education</td>
</tr>
<tr>
<td>006 Female</td>
<td>45</td>
<td>Village north of city.</td>
<td>18years</td>
<td>Irregular, NHS Podiatry</td>
<td>Steroids, Etanercept</td>
<td>Part Time Self-employed due to RA</td>
</tr>
</tbody>
</table>
The participant group was a representative sample of the local clinic caseload as a whole in terms of age and gender. This was established by discussion with the rheumatology team following the recruitment stage. Nine patients were interviewed in total. Four were female and five were male. The mean age was 58 with the youngest being 40 and the oldest being 72 years old. The mean duration of disease was 12.6 years with the longest duration being 30 years and the shortest 1 year. Three interviewees had been diagnosed less than three years suggesting that, according to the literature already discussed in chapter 1, the window of opportunity for orthotic management to prevent deformity would still be available to them should it be required (Woodburn, 2000). The implication being that a foot assessment should have been received at this stage if it were to achieve optimal intervention. Three participants received a diagnosis of RA over 20 years ago and, referring to this same literature, some of the orthotic management options may no longer be of benefit to them if not already suggested by

Table 8: Participant details.

<table>
<thead>
<tr>
<th>ID</th>
<th>Age</th>
<th>Gender</th>
<th>Location</th>
<th>Duration</th>
<th>Disease Type</th>
<th>Medications</th>
<th>Occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td>007</td>
<td>65</td>
<td>Male</td>
<td>Village north of city, associated with the army.</td>
<td>1 year</td>
<td>Occasional, Private Podiatry</td>
<td>Sulphasalazine, Steroids</td>
<td>Retired, Voluntary Committee Work</td>
</tr>
<tr>
<td>008</td>
<td>70’s</td>
<td>Male</td>
<td>Village north of city, associated with the army.</td>
<td>30 years</td>
<td>Occasional, Private Podiatrist</td>
<td>Warfarin, Co-proxamol</td>
<td>Retired</td>
</tr>
<tr>
<td>009</td>
<td>40</td>
<td>Female</td>
<td>Village on city periphery.</td>
<td>18 months</td>
<td>Occasional, Private podiatrist and NHS orthotics</td>
<td>Methotrexate, Codeine, Paracetamol.</td>
<td>Housewife Small child at school</td>
</tr>
</tbody>
</table>

The participant group was a representative sample of the local clinic caseload as a whole in terms of age and gender. This was established by discussion with the rheumatology team following the recruitment stage. Nine patients were interviewed in total. Four were female and five were male. The mean age was 58 with the youngest being 40 and the oldest being 72 years old. The mean duration of disease was 12.6 years with the longest duration being 30 years and the shortest 1 year. Three interviewees had been diagnosed less than three years suggesting that, according to the literature already discussed in chapter 1, the window of opportunity for orthotic management to prevent deformity would still be available to them should it be required (Woodburn, 2000). The implication being that a foot assessment should have been received at this stage if it were to achieve optimal intervention. Three participants received a diagnosis of RA over 20 years ago and, referring to this same literature, some of the orthotic management options may no longer be of benefit to them if not already suggested by
this stage in the disease process. Ideally, these participants ought to have been able to provide a good account of exposure to foot assessment and management with a report of long term orthotic use if indicated. Consequently the participants covered the range of subjects required for the purposive sample mentioned earlier although it is though that this was actually achieved randomly. The audit results indicated that orthoses management locally did not reflect the early interventions recommended in the national guidelines. The comments which follow from the interviews regarding lack of knowledge with respect to foot health services and the use of orthoses are not therefore surprising.

The disease duration also provided an indication of potential exposure to foot advice from the rheumatology healthcare team. Each of the participants reported regular visits to the rheumatology department including a minimum contact with the consultant every six months and the rheumatology practitioner at alternate appointments also every six months. Patients therefore have review appointments every three months rotating between the healthcare professionals. This is the pattern from diagnosis with the appointments being more frequently if the patient has flare-up of the disease or other acute episodes. In theory, this affords plenty of opportunity for patients to access advice regarding all aspects of RA management including foot problems and their care.

The literature forming the background to this study also gave an indication of the percentages of foot problems likely to be seen in the RA patient population (Michelson et al, 1994; Kerry et al, 1994; Balint et al, 2003 and subsequently Otter et al, 2010). Taking into account the long disease duration of the majority of the participants interviewed, it was considered probable that most would have some foot involvement at this point in the course of their RA but may not report this if they were unaware of its specific manifestation. This was illustrated in the audit data and is one of the points to be discussed in chapter 7 (p.129).

All the participants mentioned the desire to have some kind of help with their routine foot care needs as the practicalities of reaching their feet or using instruments (due to the effects of joint damage in the hand) was proving increasingly difficult. Surprising then that only one of the nine participants was receiving regular NHS podiatry care. One received NHS footcare on an irregular basis and one participant received regular care
but from a non-HPC registered retired podiatry assistant. Three interviewees sought occasional private podiatry treatment but only when discomfort forced them to do so because of issues of cost. Reasons for this lack of uptake of podiatry services will be discussed later.

Three interviewees were currently managed for their RA using biologic therapies. The implications for the footcare needs when on these medications have been explained in chapter 2, p.21 (Firth, 2005; Otter et al, 2004, etc). One would expect these patients to receive regular foot monitoring because of the increased risk of foot infection. Other participants had previously been on similar management but had been withdrawn due to adverse effects. Three patients were prescribed DMARD’s, which may have immunosuppressant effects, and three individuals had other drug management of their RA and co-morbidities (including steroids and warfarin) which are considered to have tissue viability issues for their feet. For all the above mentioned patients, the standards of care and clinical guideline documents discussed in chapter 2 (p.26) suggest that, for reasons of tissue viability alone, they should have access to a podiatric assessment and subsequent appropriate management. The interviews and audit results show that this does not happen in every case and are indicative of the view that patients do not self report the type of potentially preventative footcare issue. The interview findings go on to propose possible reasons for this.

On commencement of the study, although it was assumed that the findings would indicate a deficit in the foot care knowledge requirement, there were no preconceived ideas regarding the range of factors beyond understanding which would influence the patients' ability and/or choice to initiate appropriate referral for foot care. The decision was made to stop interviewing after nine participants had been recruited. Answers to the research question had been found at this point and the data needed to be analysed. As this had been a descriptive case study, the wide variety of issues found needed to be considered within the context of the research topic and ideas for further exploratory and explanatory case studied developed.
Rigour and Validity.

Establishing consensus regarding rigour in qualitative research has been under debate for some time as there is no integrated body of theory, methodology or method that can be described as qualitative research (Rolfe, 2006). Some authors have tried to impose the use of validity criteria on qualitative work adopting the concepts and terminology of positivist research in their attempts to establish if research findings approach the truth (Morse et al, 2002). This is an endeavour to view qualitative research as more “scientific”, and therefore more acceptable to the conventional academic community, such that its results are more likely to be integrated into our knowledge base. However, it was Sandelowski (1993) who argued that the issue with quality in qualitative research is not associated with its “truth” or “value” but with its “trustworthiness”. This returns to the interpretive nature of the research rather than “aspiring” to the realist stance.

Whilst it was not felt to be appropriate to adopt a positivist style of validity check to this research, some form of criteria was necessary to ensure concepts were not fabricated by the researcher that could not be authenticated (Hammersley, 1992; Lincoln & Guba, 1985).

Internal validity is reported to be the most important aspect of trustworthiness in qualitative research as it demonstrates that the work presents the reality of the participants (Holloway, 1997). This can be achieved through a coherent storyline and the inclusion of excerpts from interviews (as shown throughout the findings in chapter 6). Using a clear rationale for decisions made and field notes, the researcher provides evidence that they have represented the participants and the setting truthfully. In addition to this, Burnard (1994) and Lincoln & Guba (1985) advocate the use of member checking where the participants are asked to validate either the interview transcript or a summary in order to confirm that the information is an accurate record of their experience.

For this research, each interviewee was asked if they would like to receive a copy of the transcript to ensure that they agreed that it was an accurate representation of their views. They were given a stamped addressed reply envelope and a deadline of two weeks after
receipt to return any comments to the researcher. Only two accepted this offer and neither provided feedback. All participants were reluctant to be involved in this saying that they would be happy to trust the researcher. This process was therefore thought to add little value to this particular work. Ashworth (1993) also found that member checks do not necessarily provide evidence of trustworthiness because the participants might not wish to disagree with the researcher.

As a further attempt to ensure internal validity, Lincoln & Guba (1985) suggest peer debriefing be employed to establish whether colleagues arrive at the same interpretations of the data. Podiatry colleagues with an interest in rheumatology were asked for their interpretations of the data generated to discover whether their findings were similar to those originally stimulated. It was not surprising that, as the themes were deduced from the research aims and questions, the same points of interest were raised by the peer group. Sandelowski (1993) questions the use of both member checking and peer review stating that, as reality in qualitative research is generally assumed to be multiple and constructed, then repeatability is not an essential, necessary or sufficient property of the work itself. This is not the only criticism of inter-rater analysis in that although it often shows agreement on the basic themes individual analysts interpret the themes differently (Armstrong et al, 1997).

The use of “triangulation” at some stage in the research design is also considered to enhance the trustworthiness and internal validity of the study. Triangulation is a process by which the same problem is investigated from different perspectives to overcome the biases inevitable with a single viewpoint (Becker et al, 1961).

“The extent of your data-collecting will be influenced by the amount of time you have...Even so, if possible, efforts should be made to cross-check findings, and in a more extensive study, to use more than one method of data-collecting. This multi-method approach is known as triangulation”

(Bell, 1999, p. 102).

Once again, care has to be taken when employing triangulation as multiple methods can have their origins in different world views which may not be harmonious at the same
time and can lead to method slurring (Leininger, 1985). Triangulation has been achieved during this research in that the case study was designed for qualitative follow up of factual issues which emerged from the audit. This is an example of data triangulation using mixed methods (Holloway, 1997). Used in this way, triangulation is consistent with the constructivist realism stance taken.

The external validity of qualitative research is related to the extent to which findings are transferable to other situations (Conway, 1998). Qualitative research is frequently considered weak in its ability to generalise (Johnson, 1997) particularly as participants are often, as in the case of this study, selected purposively to fulfil the needs of the research (Priest, 2001). However, having provided a description of the setting, and the organisational approach to the foot care management for our local rheumatology patient population, the reader has been presented with the information necessary to make a decision as to whether the findings from this study may be applicable to their own situation. As discussed earlier, transferability is an integral part of case study research. It could be argued that nine is a small number of participants and transferability would therefore be limited. However, as case study is concerned with analytical generalisation and not statistical generalisation (Yin, 1994; Stake 1995) external validity for this research is considered high as the rheumatoid foot is a contemporary phenomenon and thus similar cases exist. Therefore, practitioners with similar patients could use the findings to criticise their own practice. In addition, if the findings can be shown to mirror those in other studies, the external validity is said to be high. This has been the case and will be discussed in chapter 7.

From the practical application of the above validity checks to the data, and the concern regarding their philosophical underpinnings, it is seen that their merit for this study is questionable. For this reason I have chosen to follow the following approach to ensuring trustworthiness. Sandelowski (1993) introduces the idea of the decision or audit trail where the reader can clearly follow the practices of the researcher and the process leading to the study evaluation is transparent. This is echoed by Koch (1994) who suggests that research rigour for qualitative studies can be achieved by addressing issues of reflexivity, offering authenticity and an audit trail. Rolfe (2006) explains that the quality of qualitative studies cannot be assured by a set of previously agreed strategies stating that it is revealed in the writing up of the research and is assessed by the reader.
De Witt and Ploeg (2006, p.215) review the arguments surrounding the issue of quality and rigour in qualitative research and summarise by the development of their own proposed framework. These are an extension of the standard issues reported as important in most literature on the subject (Lincoln & Guba, 1985; Long & Johnson, 2000). They suggest evidence should be readily available to support the following criteria:

- Balanced integration
  An explanation of the philosophical underpinning applied to the study, its appropriateness to the question and how this relates to each research process.

- Openness.
  A decision/audit trail should be easy to follow throughout the report.

- Concreteness.
  Study findings are written in such a way that the reader is situated concretely in the context of the phenomenon.

- Resonance.
  The effect that is felt by the reader on reading the study report

- Actualisation.
  The work should continue to be interpreted by readers in the future. This effect cannot be recorded.

For this research I have made every effort to be transparent in the approach to the research methodology, data collection and analysis such that future researchers wishing to repeat the process could do so. Where decisions regarding the research have been, a rationale for this is reported. Excerpts from the transcripts have been included to illustrate and validate the findings. By adopting the decision trail approach, the reader can make the decision as to the extent to which they can place confidence in the outcomes of the work.

Pilot Interviews.

The first two interviews served as a pilot for the main study as recommended by Oppenheim (1992). The purpose of the pilot was to ensure that the style of the interview
was correct for the information that was to be collected, that the interview schedule flowed well and the content was appropriate. It would also help to iron out any practical difficulties. Once the data was collected it would give some idea of the effectiveness of the technique in answering the research question.

Denzin & Lincoln (1998) state that the pilot exercise allows for development and solidification of rapport with participants as well as establishing effective communication patterns. Therefore, trial interviews should be performed on as near to target subjects as possible. In addition, they can provide important information on the administration of the study as well as the method itself. The trial interview can save time and money at a later date as it should avoid the production of uninterpretable responses which have implications on the quality of the work.

During the trial interviews, Berg’s (2001) guidelines for pre-testing the interview schedule was employed which asks the following questions:
1. Have you included all the questions necessary to answer the research question?
2. Do the questions elicit the types of responses that were anticipated?
3. Is the language used meaningful to the respondent?
4. Are there other problems with the questions (double meanings, multiple issues)?
5. Does the interview guide motivate subjects to participate in the study?

Robson (2002) confirms that the role of the pilot is to bring to light the inevitable problems of converting your design into reality. It also provides an opportunity to discover if things are likely to go very wrong, in which case it is suggested that it is better to transfer your efforts elsewhere.

Following these interviews, no changes were made to the original interview schedule as the responses yielded a plethora of information which provided a variety of answers to the research questions. However, because of the emergence of additional information, a further question was added to the schedule adopted for the subsequent interviews. The main unanticipated issue concerned the attitude towards self-image and the importance attached to the appearance of the foot. The issue of appearance over function was seen to be a driver for seeking help for some individuals. This point was raised by the first interviewee and all subsequent participants were asked for their opinions regarding this.
Several practical issues needed to be addressed following the pilot. There had been a problem with interruption during one interview. Although a notice had been placed on the door of the interview room, it was a clinic room and a colleague automatically entered to find dressing materials. This upset both the tape recording and the flow of the interview. The importance of not being disturbed during the data collection was raised with staff using the clinic space and was acknowledged. Some positioning of the chairs had to be reconsidered in order to maximise the quality of the recording. Placing them at right angles to each other on one side of the room did improve the quality of the tape recording significantly without making the patient feel uncomfortably close to the researcher.

Fortunately, having already conducted the audit, many of the issues surrounding access to the rheumatology department and its patients had already been addressed. As mentioned earlier in this chapter (p.77), participants were recruited via the assistance of the rheumatology practitioner to eliminate coercion by the researcher. It became apparent in the pilot that the practitioner had not fully appreciated the inclusion criteria for interview. This accounted for the slow receipt of responses as the practitioner thought she had to wait for those patients who reported foot problems. In fact, any patient with a diagnosis of RA regardless of current foot symptoms was considered suitable for invitation as the view of participants with or without current problems or previous podiatric experience was desirable to obtain as broad a view of circumstances as possible. With the interviews being removed from the hospital site (as agreed at the ethics committee meeting), the research appeared at times to be “out of sight, out of mind” and therefore neglected by the rheumatology team. This again contributed to the slow recruitment. In an attempt to rectify this, a regular email update to the rheumatology practitioner prompted resumption of invitations to participate. This achieved an improved response and ensured a steady flow of consenters but the recruitment rate remained slow throughout the study. It is not known how many potential recruits attended the department during the study period or how many of these were offered information but did not take part. From the number of packs returned at the end of the recruitment phase, it would seem that all those who expressed enough interest in the research to take the information were subsequently recruited.
The pilot transcripts were included in the study as no major changes were required for the main study interviews following this exercise and it was felt that the opinion of these recruits was important and should be retained.

**Data Analysis.**

Yin (2009, p.126) admits that case study data is difficult to analyse because the specific techniques for this are not well defined. In order to overcome this Yin suggests that every case study should employ a general analytical strategy with definition of what is being analysed and why. Whilst Stake (1995) writes that we automatically start to dissect and relate the data without a protocol, the purpose of a strategy is to ensure the data is treated equitably, provide convincing conclusions and rule out alternative interpretations. Holloway (1997) states that, although case studies have no specific strategy for data analysis, they can adopt any of those protocols employed for other qualitative methodologies.

Whilst case study literature supports this flexibility in choice of analytical approach, the decision was made not to choose a strategy which was too closely associated with any other specific methodology as the particular focus of these may detract from the case study objectives. Examples of these include the constant comparison technique used in grounded theory (Corbin & Strauss, 1990) or the essentially inductive style used in phenomenology (Colaizzi, 1978; van Manen, 1984). Also discounted were Spiegelberg’s (1982) framework which was based on Husserl’s original phenomenological work but specifically excluded interviews and Van Kaam (1966) who advocated that a large sample population should be drawn on and this has not been the case for this study.

Stake (1995) relates the choice of the analytical approach to the aim of the case study. With an intrinsic case study, when understanding of the case is required, direct interpretation is employed to comprehend the case. With instrumental case studies, where the aim is to gain understanding of the phenomenon and the relationships within it, a categorical aggregation is the preferred choice to concentrate on the associations identified in the research question. As this case study research was designed to be
intrinsic in nature, the direct interpretation provided by content analysis was deemed appropriate.

Thematic analysis is used for most qualitative studies as the researcher searches for patterns and themes in the transcripts of interviews (Holloway, 1997). It involves searching the data for related categories with similar meaning. These categories are then grouped together and thus themes are generated from the data. To achieve this, coding is employed to identify and label concepts and phrases in the transcripts. The importance of this is described by Ryan and Bernard (2000, p.780) who maintain that “coding forces the researcher to make judgements about the meanings of contiguous blocks”. Mayring (2000, p1) describes an analytical strategy which developed from a quantitative content analysis background and as such, was structured in its approach. Despite this it included the flexibility to adopt either an “inductive” or “deductive” approach to category development in that the production of themes can emerge from the data itself or be based on the original aims of the research (Ryan & Bernard, 2000). Kohlbacher (2005) advocates the application of Mayring’s approach specifically to case study research due to its ability to synthesise the openness required of qualitative research with the theory-guided investigation consistent with a hypothetical-deductive paradigm. From this, a decision was made to employ a structured, thematic analytical approach.

The specific process of analysis employed for this case study was the framework approach as described by Ritchie & Spencer (1994, p.178). There are five stages involved in this process:

1. Familiarisation- where the transcript is read a number of times to gain an overview of the data, its range and the diversity.
2. Identification of a thematic framework- this was developed from the research questions, the interview schedule and the familiarisation process.
3. Indexing- the above framework is systematically applied to the transcript of the interviews. This is a form of coding.
4. Charting- Headings and sub-headings from the thematic framework represent themes for each respondent. Indexed data is lifted from its context and rearranged according to the appropriate thematic reference.
5. Mapping & Interpretation- once charted into core themes, the data is analysed to define concepts, find associations and provide explanations for the data.

With this approach to thematic analysis, the framework is based on the original aims of this case study research and guided by the interview schedule. Themes and sub-themes are then assigned from indexing the text in relation to the framework (Farndon & Borthwick, 2007). This being so, the framework approach starts deductively but still reflects the original accounts of the participants in the production of the themes and sub-themes, thus remaining grounded and inductive (Pope et al, 2000). This approach can also be termed “theoretical” thematic analysis in that it is driven by the theoretical and analytical interests of the researcher (Braun & Clarke, 2006). This selection maintained the congruency with the aim of the research and the choice of an intrinsic case study approach. The literature further confirms its suitability as thematic analysis is reported to be a suitable choice for data generated by the different research methods and regardless of the underpinning philosophical stance (Boyatzis, 1998; Braun & Clarke, 2006).

With reference to the research aims and objectives, the following framework subjects were applied to the data:

- Patients understanding of the potential foot effects of RA,
- Patients attitude to foot problems in RA,
- Patients understanding of who is responsible for their foot health,
- Patients attitude to seeking help,
- Patient’s attitude to podiatry services.
- Barriers to attending appointments,

Having gained a general familiarisation with the transcripts, an idea of the relevant issues pertaining to each of these subjects was known. From this point, the transcripts were systematically checked to index the text in relation to the above list. These indexed areas of text were then lifted from the transcript and placed in a chart which grouped together quotes with similar issues in the same column thus developing the sub-themes. These sub-themes were then given a title. For example, with regard to patient attitude to
seeking help, areas of the transcript were highlighted where they related to this subject. These were then grouped into the following themes:

Attitude to seeking help:

- Perceived benefits,
  - Pain relief,
  - Reassurance.
- Perceived costs,
  - To social role,
  - To disease control,
  - Material costs.

An example of the charting process is shown in Appendix 4. The themes and subthemes are listed throughout chapter 6 along with quotes used to illustrate them. These are then cross referenced with the literature to provide an account of the findings, suggest an explanation for the local situation, and find associations with previous work (chapter 7).

When indexing the transcripts, initially the process described by Wax (1971) was employed. This report describes how file cards can be used to organise the data and produce unitisation of this data. This breaking down into units of data then allows them to be sorted under headings as different categories of information come to light. Lincoln & Guba (1985) recommend this type of data card analysis. The “discovery” process then begins where you begin to search for the important meanings in what people have reported to you (Taylor & Bogdan, 1998). It was when these snippets were entered into the framework charts that I could see the themes and the association between them beginning to take shape. An example of a transcript is shown in Appendix 5.

Although a number of software packages are available to help organise qualitative data, the researcher still has to provide an explanation of the themes derived from the data and thus these packages cannot be considered a shortcut (Pope et al, 2000; Farndon & Borthwick, 2007). The decision was taken not to use a software package to help with coding and analysis of the data because limited time was available to learn how to use and become familiar with the system and the experience of handling the data entirely by
hand was viewed as beneficial to the understanding of the findings. In addition, software packages are concerned with statistical generalisability which, as mentioned earlier in this chapter, is not the intention of case study research.

Notes were kept throughout the research in the form of a journal. The purpose of this was to record areas in which my own interests and viewpoints impacted on the research and to document field notes capturing interesting points regarding the individual interviewees and their approach to the interviews not captured on the tapes (Holloway, 1997). This was used in the writing of this thesis to recall decisions made regarding the planning and execution of the research and form the basis for my reflection (see chapter 8). In addition, excerpts from the research diary itself and included in Appendix 6.

**Summary.**

In this chapter I have explained my philosophical position as that of a constructivist realist. With this in mind, a rationale has been reported for the choice of a qualitative approach to the research question and specifically to the selection of an intrinsic case study strategy. From this position, a research design has been created to facilitate data collection and analysis which are appropriate for this approach. The data collection method therefore involved nine semi-structured interviews analysed using a framework approach to content analysis.

Chapter 6 presents the findings within the framework, illustrated with quotes from the participants. The sub-themes for the framework established from the data will be revealed.
Chapter 6: FINDINGS.

Introduction.

This chapter will present the findings from the interviews as they relate to the question “How does patient understanding and attitude to the effects of rheumatoid arthritis on the foot, and the services available to help limit this, influence self reporting of foot problems?” with quotes to illustrate the issues raised. The responses will be categorised into three main themes relating to the framework initially provided by the research question and the interview guide, with sub-themes emerging from the transcripts. Each theme includes information concerning how these opinions were formed based on supplementary findings within the data.

Themes.

1. Patients attitude to foot problems in rheumatoid arthritis.

The assumption was made that the patient must have an adequate understanding of the potential foot problems associated with rheumatoid arthritis, and how these manifest themselves, in order to be able to recognise the development of these problems and seek the necessary help for them. This was backed up by the literature on patient education and empowerment discussed in chapter 4 (p.52). When asked to describe the foot problems associated with RA, the responses from the participants were vague.

“you get distortion of the bones and that sort of thing and you can grow nodules which some people grow on their fingers but I don’t.”

T/003-3

“I have had bursas removed”

T/004-2

No interviewee was deemed able to report the level of understanding assumed to be needed for self-reporting. To achieve this outcome they would need to report an understanding of how the structure, and consequently function, of the foot may be affected by disease activity and the effect drug management may have on tissue
viability in terms of ulceration and infection as recommended by Hill in her report on patient education in rheumatoid arthritis (1998). Information was then gleaned to describe how patients currently feel in regard to their feet and how they respond to foot symptoms as they experience them. The intention was to establish the importance of this anatomical structure to the individual and whether the attitude to their feet would influence their decision to seek help with specific foot problems. From this data, the following two categories were described.

1.1. The foot as primary source of concern.

Often, unless there had been previous experience of foot discomfort, patients hadn’t considered the structure at all.

“I’ve never really thought about them much”

T/004-3

When the foot has previously been a primary source of significant discomfort, their importance was unmistakable.

“you see I was housebound because of my feet”.

T/002-1

Participant 002 was a retired man who attended the interview with the sole aim of putting his case for reducing the interval between his podiatry appointments. Although he lived a distance north of the city centre, he repeatedly said that he would be happy to travel to any of the podiatry clinics in order to have podiatry treatment more regularly. His enthusiasm was based on the comfort he associated with this regular foot care but despite this, his knowledge of specific foot complications associated with RA was limited to his personal experience of joint deformity and related callus formation. This interviewee explained that his foot pain, if not kept under control by regular podiatry intervention, had an effect on his gait which led to further soreness in knees and hips. He therefore saw his feet as a concern due to their influence on his body as a whole. This concern was expressed as an anxiety in regard to increasing intervals between his podiatry appointments.
“If they take the appointment over a long period my health will deteriorate”

T/002-5

He continued to raise this concern throughout the interview.

“...they keep making the insoles but when the corn is big I can’t wear the insoles.”

T/002-2, 3.

For another older gentleman, the concern associated with deformity of the toe joints was that of potential surgery.

“As long as they didn’t want to break it to sort it out, not at my age, I don’t mend very well.”

T/007-4

Participant 007 was a retired man who remained active in the voluntary sector and represented patient groups at his local GP surgery. Maintaining his role as a valued member of his local community was of great importance to him. He had helped to form a patient self-help group with a member of the rheumatology team and considered himself well-informed regarding the health service. However, this was for another medical condition and had no influence on RA foot knowledge. There is no local self-help group specific to inflammatory arthritis patients.

Two of the younger, female participants mentioned their concern was regarding the appearance of their feet.

“...I like my bare feet...if I go out and wear sandals in the summer [the hard skin] is not really very nice.”

T/001-3
“Because I was on Inflixamab and they didn’t want to give [lamisil] to me...[GP] thought [fungal toe nail] was purely cosmetic and I said “well it’s alright for you, you wear socks and shoes but I don’t wear socks and shoes all the time- in the summer I want to wear some sort of sandal.”

T/006-4

Whilst appearance is important to certain participants, comfort and maintaining function are important to every member of our patient group. The older interviewees reported that appearance was not the concern that it had been when younger. Attitude to foot cosmesis does seem to vary with the age of the respondent as priorities change.

“I’ve gone past how they look now. Everything’s dropped or drooped! So now I go for comfort.”

“They are ugly feet... I went for looks not comfort.”

T/004-6,7.

As far as the male participants were concerned, they were more anxious about keeping their feet pain free and maintaining good function. Relating this information to the aim of this study, the implication was that a person might be more inclined to seek help if the foot symptom had an effect on their ability to participate in a particular activity. This may be the ability to wear opened toed shoes or to continue in employment.

“...I depend on my feet a lot”

“I would have to drive an automatic not a manual car because of changing gears and all the rest of it.”

“It’s pain and how they feel rather than how they look. I’m not bothered how they look as long as they work.”

“How they function, to me that’s the most important thing.”

T/003-4, 5

The concern for foot comfort is echoed in the choice of footwear. These interviewees explain how the need for comfort has led to compromise in their choice of shoes.
“I need width, which these have got and I need depth, which these have got. I can’t wear fashionable things...even the shoes I wear with my dinner jacket!”

T/005-11

“Well, I don’t get any problems. I wear these slip-on shoes all the time. They’re easy to get on and off.”

T/008-4

Instead of being an instigator to seek help, there is an indication from these quotes that the patient seeks their own methods of keeping comfortable rather than seeking advice. Accommodating foot problems in different shoes without an expert opinion may help comfort but may delay assessment of the underlying problems calling for the need to make these changes in the first instance.

To summarise, the foot as a source of concern encompasses the potential effects on mobility, appearance and the body as a whole. However, the participant group showed little overall concern regarding the primary importance of the foot in relation to their general health.

1.2. The foot as a secondary concern.

More frequently the interviewees reported the foot as a concern secondary to other aspects of the disease. It is common for RA patients to report more than one painful area to deal with at any given time. In these circumstances, the tendency is to concentrate on the worst pain at the time and not to focus on the lesser areas. The importance of the foot to the patient is, therefore, relative to other concurrent disease symptoms. The implication being that if foot problems develop in isolation, the patient may seek help for it without delay.

“...sometimes [feet] hurt a bit but when you’ve got big pain, like the one in my back at the moment, it really takes over, and um, you don’t notice. If you have other pain then..[shrug].”

“Whatever the worst pain is, that’s what you remember I think.”

T/004-3, 4
“And my shoulders and sometimes it’s, um...your whole body, a feeling of malaise, I think is the, um, word. It’s always too...[sighs] everything is too much.”

T/005-5

“Some of my toes are a bit [deformed] but I don’t think they’re that bad. Not on a par with my hands.”

T/006-4

This value of the foot when ranked against other concerns was particularly evident for one interviewee. This gentleman explained that he had taken the decision to sacrifice a toe that had developed a chronic wound in order to reduce the risk of recurrent infection. This would ensure that he could continue to use the biologic drugs that he found so beneficial in the management of his rheumatoid arthritis. These drugs would have been contra-indicated if the infection risk had continued (Otter et al, 2004).

“...when I got back it still hadn’t healed and I couldn’t stay on the Infliximab if you’ve got an unhealed wound...so I said to [rheumatologist] “this is ridiculous, I need..., I mean I’m ill now” and I said “can’t you cut it off” and she said “yes if you like”. So I said “Yes, let’s get rid of it”.”

T/005-7

In this example, it is easy to understand why the consultant was correct in the support of the amputation. This was appropriate in this specific circumstance.

As it appeared that most of the participants considered foot symptoms to be simply a secondary concern within their general arthritic condition, the common belief was that drug management of the underlying complaint with DMARD’s and other holistic/systemic interventions would assist in controlling foot pain and this would be considered sufficient management.
“I went to the doctors this morning and he gave me some stuff to put on the ankles...it actually has some sort of medicinal properties...in other words, if I get trouble with my toe nail as well, it will calm that down as well.”

T/007-3

This concept of seeing foot problems as a symptom of RA generally is an important and recurring one both in regard to recognition and management of foot problems. The idea was raised when asked about rheumatoid foot advice received (p.101) and again when questioned on who was considered to have responsibility for foot health in RA (p.118). Due to this attitude, patients may delay seeking help for foot problems either because they are coping with a bigger issue or they assume that treatment for the disease as a whole will fully manage their foot symptoms.

1.3. Factors informing patient’s attitude to RA foot problems.

Having established the patients’ attitude towards their feet, the transcripts also revealed some ways in which patients may have formed this opinion based on previous knowledge received or experience gained. Despite the number of ways it was possible to elicit this information, the report provided was vague.

1.3.1. Knowledge and experience.

Information shaping attitudes to feet may be gained through advice delivered by healthcare professionals, from previous experience or a number of other sources including leaflets. Although at the commencement of the study the rheumatology practitioner was trying to establish a regular series of education sessions for RA patients, these had not yet become part of the mainstream management for the patients interviewed. As previously mentioned, it was assumed that those with longer disease duration would have accessed the rheumatology department for a longer period and would thus have been exposed to greater opportunities for receipt of advice or previous experience. The opposite would be true of those more recently diagnosed. The findings did not reflect this relationship.
Each participant was asked directly whether they had received advice regarding their feet and RA. The intention was to establish if patients had been told of the signs and symptoms they need to be aware of in order to effectively self-report RA foot problems.

1.3.1.1. Formal Education.

When asked if they had received any formal advice or education regarding the effects RA can have on the foot, all of the interviewees replied that they had not. Most replied with a direct “no”. Even though they had attended the rheumatology department at least every three months, and some had been doing so for twenty years, formal education sessions could not be recalled, which is not surprising as the programme had only recently been initiated, and neither could they recall one to one advice sessions during consultation with members of the health care team which was rather more surprising. The responses were very definite.

AB “ever given you advice on how RA can affect your feet?”
001 “No”
AB “…what sort of problems [can affect the foot]?”
001 “No”
AB “You’ve not had any education sessions.”
001 “No”
AB “So they’ve just sort of talked about the problems that you’ve reported”
001 “Yes, I mean, they’ve just taken that as part of everything else”

T/001-3

AB “…any formal advice or education sessions on your feet and how they are affected by RA?”
002 “No, just…like...exercises”

T/002-3

Several interviewees went on to qualify their answer to the question of foot knowledge by adding that their feet were examined by a health care professional.
“No I just got referred to [local] podiatry...They did check all your toes and everything.”

T/006-4

“Well, no. Originally they [rheumatology] checked fingers and everything...”

T/007-3

The inference from this response was that advice received was not considered important to them because their expectation was that the rheumatology team would screen for any problems and act accordingly. This response was revealing as it was the opposite idea to that raised in the anecdotal comments from the health professionals during the audit which prompted this research. The idea of the foot as being of little significance, when viewed from within rheumatology, was reported by an interviewee.

“I said “you’re not going to do my toes?” [rheumatologist] says
“No, toes don’t come into it.””

T/005-4

The rheumatology team may be seen as endorsing the idea of foot symptoms as simply a part of the general disease. This attitude, without explanation of its context, could lead the patient to assume that feet are unimportant in rheumatoid arthritis.

007 The ankles and the feet, generally it’s burning.
AB Who have you mentioned this to?
007 [rheumatology practitioner]. I think its symptomatic of whatever it is [general flare-up] and I see [consultant rheumatologist] again in November...So it’s literally six months unless anything crops up.
AB OK. And [rheumatology practitioner] said it was basically part of your arthritis did she?
007 That’s right yes. She has to do a big questionnaire and, you know, it all comes out of that.
AB Apart from arranging your appointment with [consultant rheumatologist], she hasn’t done anything specific for the foot following that?

007 No no.

T/007-2

“Well it’s part and parcel of the same thing”

“...I mean they’ve just taken [feet] as part of everything else...”

T/001-2, 3

“I’d deal with it if my toes went crooked. I’d just think, well that’s just part of [RA] but I don’t really want them to get that unsightly. Your toes aren’t the nicest things.”

T/006-4

Participant 006 was a younger woman who had suffered with RA for many years and had undergone a number of joint replacement operations. The disease had affected several members of her family, including her father and brother, and she appeared resigned to living with her symptoms and the many hospital visits. She had even altered her employment circumstances and become self-employed to accommodate her medical needs and frequent appointments.

One participant intimated that there had been a discussion with their rheumatology practitioner regarding the potential effects their disease could have on the foot but the details of this conversation could not be recalled and this lady did not pursue the referral for podiatry assessment following the initial conversation.

“Once [rheumatology practitioner] said about coming to the clinic to do with how [RA] may affect my feet in the future.”

T/004-2

In a further attempt to detract from the lack of specific foot knowledge, two of the respondents related the question back to their rheumatoid disease generally. Again the inability to separate foot problems from the disease as a whole became evident.
AB “Have you picked up information from anywhere else?”
001 “No, not particularly. Only generally on arthritis rather than opposed to on that specifically”

T/001-3

All participants were keen to state how pleased they had been with their treatment to date and were defensive of their healthcare team. When asked if they had received any specific RA foot information, one interviewee replied:

“No, I did get physiotherapy”

T/002-3

The interviewees went on to emphasise the positive aspects of the health care they had received and often changed the subject or altered its emphasis to achieve this. Concern that their comments may be reported back to those professionals involved in their care may have been one reason for this. Another could be fear of disclosing an ignorance of the other management options which may have been appropriate thus showing themselves to be uninformed.

During the course of the conversation, one participant did eventually recall that she attended one of the newly presented education sessions involving a number of health care professionals. She could not recall any of the information presented by the podiatrist because she did not have any foot problems at that particular time.

009 “I do remember we had this session. We had a couple of group sessions at the hospital and one of them was on podiatry but I didn’t take a lot of it in, well, you do and you don’t. I’ve got lots of booklets and leaflets but I haven’t read them...because I haven’t got pain in my feet at the moment”
AB “So he probably would have mentioned how RA affects your feet.”
Participant 009 was a housewife who had initially been overwhelmed at the possible consequences of living with a chronic disease following exposure to other people attending the education session. This appeared to be the only learning outcome for her at this session.

“I couldn’t believe it ‘cos in walked all of these people and some of them could barely walk and I was thinking “Oh God, I’ve got this coming””.

The use of written advice without adequate verbal support can also be counter-productive. The same participant admitted to a failure to read leaflets when they were issued at diagnosis because the timing was wrong for her. At this point she needed an opportunity to discuss specific individual questions.

“[GP] said “yes, you’ve got rheumatoid arthritis”. I said “ok, what’s that?” So I just got loads of bumf to read and then started going to the hospital.”

This poses several issues regarding the content and timing of education sessions which is quoted frequently in the literature and will be discussed further in chapter 7 (p.132).

1.3.1.2. Informal Education.

Having received reports that an appropriate level of rheumatoid foot knowledge had not been gained via formal advice directly from the appropriate healthcare professional, other possible sources of information were then explored during the interviews. Although the literature introduced in chapter 4 (p.52) indicated that the quality of
patient information is as important as quantity, it was acknowledged that patients could
glean information from a number of informal sources to add to their knowledge base
and this could be sufficient to inform their decision to seek foot advice. These facts
could be gained from leaflets, television, internet and experience (their own and that of
others). For the participants in this study, any informal knowledge was provided mostly
from either personal experience or that of friends and family.

“The other thing I know is that, I don’t know how I...I can’t
remember how I came to go and see [podiatric surgeon]...it was
then he told me that I’d got a bursa.”

T/004-7

Participant 004 drew upon the experiences of other RA sufferers for her knowledge of
foot problems as she had been exposed to this as part of a previous job as a warden at a
sheltered housing complex. She considered herself to be well informed. However, on
further questioning, the depth of knowledge appeared insufficient to inform a decision
as to when to initiate professional help. She was a lady whose social life was largely
dependent on the people she met regularly whilst dog-walking. Keeping mobile and
appearing to cope without complaint were important factors for her.

“I do know a bit of everything because I was a warden in sheltered
housing for years”

T/004-3

Another interviewee had received information that her medication could affect her foot
condition, in terms of increasing the risk of infection, but seemed more concerned with
reporting her inappropriate treatment of a painful (“pulling”) ingrowing toe nail rather
than seeking professional advice regarding future prevention of her nail problem and the
safety of continuing on her medication whilst suffering an infected wound.

“I get a lot of pain in the sides of my feet...I constantly get nail
infections because of the steroids and embril and if I have a
problem then it pulls so I pick it out...”

T/006-2
It became evident that very little information is gathered through any route and that the little knowledge which is gained is insufficient in detail and sometimes misconstrued. None of the interviewees demonstrated sufficient awareness of the potential effects of RA on the foot to seek timely help when required.

1.3.1.3. Self diagnosis.

Despite the lack of formal or informal education regarding the foot problems associated with RA, there were occasions during the interviews when patients explained their own attempts to diagnose their health problems. This could be based on previous experience of similar problems, the experience of others or expectations associated with the aging process. Sometimes the conclusions reached by the individual were logically deduced and quite probable. However, other patients reported a construed diagnosis which was far from being a correct judgment. The indication was that only when a patient could not provide their own explanation for the symptoms would they take the decision to seek help. In either case confirmation by a healthcare professional is essential to avoid misdiagnosis and a delay in receiving appropriate treatment.

The following quotes illustrate these concerns and show how experiences may be accepted as inevitable and thus not to be pursued.

“I mean... is it the rheumatoid that’s doing that [changing foot shape] or is it the way I’m walking? Is it just me?”

“... it’s your joints again, the same as your fingers and hands.”

T/009-3, 4

“It makes my feet ache and, because big feet run in the family, they’ve always been difficult”

“I’ve never really thought about them much.”

T/004-3

The respondents frequently explain away foot symptoms by relating them to similar problems in the hands. As hands do not have the same weight-bearing issues as the foot they are consequently managed in a different way. This may further result in a delay in
receipt of appropriate foot-specific intervention. The common view that foot problems are considered as part of a more general disease problem confirms the hypothesis that RA patients would not distinguish those symptoms or preventative issues which would require them to instigate referral to podiatry.

AB so you say you’ve had the pain in your ankle and you’ve had it in the ball of your feet.
001 Right.
AB Is there anything specific that has been done about that?
001 Well, it’s part and parcel of the same thing [general RA symptoms] so...

T/001-2

In addition to the failure to report understanding of the rheumatoid foot, there was also little reported evidence of education and advice gained, either formally or informally, through knowledge or experience. Whether this is related to failure of information retention or lack of ability to apply the advice is unknown.

2. **Patients attitude to seeking help.**

This theme came not from the direct line of questioning but emerged from the data. When considering the decision to seek help, the participants appear to assess the benefits and costs associated with this action. The factor that weighs heaviest at the time, informs the action taken. These benefits and costs take multiple forms and are particular to that individual.

2.1. **Perceived Benefits.**

2.1.1. **Pain Relief.**

Those participants who had experience of attending podiatry services in the NHS or private sector reported perceived healthcare benefit. Pain relief is experienced when related to the treatment of corns, callus and nail care (i.e.: routine footcare services) and
this effect is immediate. The following comments were made by patients and illustrate this point.

“When my feet are done it’s fine”

T/002-1

“And the [private podiatrist] there just whipped [the corn] out and I’ve never had the problem since.”

“So after [private podiatrist] took the corn away I had no problems at all.”

“I tried everything with [the corn] but I couldn’t get it out… [private podiatrist] whipped it out and I came out of there like a ballerina!”

T/008-3, 6

The benefit of symptom relief was also acknowledged following the provision of insoles to manage pain associated with biomechanical foot problems.

“Yes [podiatry] was brilliant!”

T/009-6

2.1.2. Reassurance.

In addition to the feeling of physical relief, our interviewees reported a sense of reassurance, knowing that a specialist was keeping an eye on their feet for developing problems. The following quotes are from male and female interviewees, two of whom are retired but remain very active either in voluntary work or caring for their dog with regular long walks.

...it would be rather nice to have a six monthly sort of check-up if that was possible”

“Preventative treatment rather than wait ‘til something really happens, you know?”

T/007-7, 6
“I used to like going to see [the podiatrist] because I felt that, what I didn’t know about feet, he’d know about feet and it nipped it in the bud, you know?”

“I liked going to him ‘cos I thought at least my feet are ok”

T/004-7

“They did check all your toes and everything.”

T/006-4

A point to note here is that the quotes report this experience in the past tense as cuts in the podiatry service budget some years ago led to the discharge of many patients with no immediate “high risk” status. This was reported in chapter 3 and has subsequently been addressed to ensure this perceived benefit is not lost.

2.2. Perceived costs.

Whilst these benefits of seeking help were of great importance to our participants, the reported costs in doing so outweighed this in number and thus, may contribute to the lack of uptake of podiatry services. These costs were grouped into three categories.

2.2.1. Cost to social role.

Patients with chronic diseases often have to endure a constant degree of discomfort or disability throughout their daily activities. Their ability to cope with this was reported as of great importance to the interviewees. The reasons for this were explained as the wish to avoid being viewed as a nuisance by their healthcare team and also because of the burden of appointments on the rest of their life.

“Joints are sore, it’s playing up but I manage”

“...I wouldn’t like to impose on [private Foot Care Assistant]”

“I do have a lot of appointments which does get a bit overbearing at times”

T/003-2, 6, 7
Participant 003, although a retired man, had a part-time job at a local DIY superstore. He was pleased with treatment received to date but, as he appeared largely unaware of the range of help which should be available to him, he had little on which to base this opinion. As long as he was able to continue with his current quality of life he seemed content. This man was also receiving his basic nail care from a friend who was a retired NHS podiatry assistant. He was very defensive of her care because he knew that she was not qualified to treat all his potential foot care requirements. This care was probably costing very little and economic concerns were another reason why this man would not wish to jeopardise his current arrangements.

For one interviewee, her General Practitioner was reported as a barrier to seeking a re-referral to podiatry services because she felt he perceived her as a difficult case.

“And now to get back [to podiatry] again I’ve got to um, get referred from my doctor...I never go to my GP because my GP hates me...he just doesn’t know what to do with me anymore. So ‘course I haven’t got round to it.”

T/006-3

The importance of a good relationship with ones GP is essential for gaining access to all appropriate services as recorded in published Primary Care Guidelines mentioned in chapter 2 (p.29).

Although it was reported as important to patients that their healthcare team viewed them as someone able to cope with their illness, it was as important that the patient’s family noted this too. One participant indicated that she didn’t want her family to feel that she was always complaining about aches and pains.

“I don’t want to make [family] miserable thinking mum’s not well”

T/004-4

In general our participants tried to play down the disabling effects of their chronic illness. Those individuals in employment did not want employers to think the arthritis and its management impacted on their ability to work. For this reason, the
aforementioned appointment overload, the effect of this on work and other commitments, were of concern to participants.

“And luckily, I was a fairly senior sort of person [army] so I managed to hide it for ages and ages.”
“normally people with rheumatoid arthritis should be medically discharged”
“...at the time I had two children at boarding school and I really didn’t want to leave the army”.

“I have nasty bumps on each side of my big toe, which, um, to be quite honest, I think I had rheumatoid arthritis a long time ago...I used to hide it”

T/005-1, 8

“So [foot problems] would certainly restrict me and I also go to work part time, 15 hours a week so I would have to pack that up as I am dependent on walking in my job”

T/003-4

Participant 005 was a retired army officer who freely admitted to having purposely ignored his RA symptoms for years because of the negative affect it may have had on his career. He had children in private education and could not afford to leave the army. This introduced the importance of concealment of symptoms for some individuals.

Podiatry services were frequently viewed by the interviewees as only being needed when one is no longer able to manage one’s own footcare. This, coupled with the generally stoic nature of this patient group, suggested that they were proud to put off seeking footcare help until absolutely necessary.

“Well I’m 80 now and I was nearly 80 before I saw a chiropodist for the first time.”

T/008-6
“...let’s just say if you can’t get down to cut your toe nails or if I get a corn, [podiatrist] would get my corn out...I just think [podiatry] can sort things out like that or people that have got verrucas and people who can’t get down there.”

T/009-5

The above quote was from a lady who, according to the published guidelines should have accessed podiatric assessment partly because of the tissue viability implications of the drug management of her arthritis but also because of the presence of foot deformity. She had not received a referral for NHS podiatry and the attitude that the service was purely for those who cannot manage their own foot care would be unlikely to assist her in a decision to seek this assessment for herself. This may be associated with how the individual is viewed by their social peers in terms of influences on their independence.

2.2.2. Costs to disease control.

As well as playing down the effects of their arthritis to maintain a social role, participants appeared to do so as a means of maintaining control over the disease itself. The following quotes show how the participants described their stoic approach to pain and how seeking help was viewed as a failure to cope with the disease. The notion seems to be that a certain level of pain is to be expected and to be endured and pain has to reach a certain level before action is taken.

“I’ve had it for years. About 10 years. And the ball of my foot swelled up. It didn’t hurt so they say if it’s not broke don’t fix it!”

T/008-2

“It’s not too bad. I’ve got quite a strong pain barrier actually.”

“I wait till the pain gets that bad and then I feel I must do something.”

T/009-2, 5
“I’m one of those people who carries on regardless. I just get up and get on with it because most of what happens in your life is what you make it.”

T/006-3

“It’s just something you’ve got to put up with.”

T/004-4

This does influence the decision to delay initiating help as one interviewee indicated that they viewed seeking advice outside their regular appointment schedule as a sign of their inability to cope with the illness and its effects.

“I don’t do doctors! So I thought right, just leave it. So I left that [shoulder pain] and then got it in my wrists, the pain was so bad I went to hospital at 1 o’clock in the morning.”

T/009-1

Patients will wait until desperate at times before finding help.

“Once it got to that stage [discomfort], I was keen to get something done about it.”

T/008-4

What is not known is the reason for this attitude. We have seen that it may be because of the concern about being viewed as a nuisance or because they do not want to admit to themselves that their disease may be worsening. The findings from the interviews indicate that, due to this attitude to a chronic condition, signs do not prompt a response to seek assistance in the same way as symptoms, especially pain, would do.

2.2.3. Material Costs.

Patients reported a number of practical considerations which may prevent them from initiating a podiatry assessment. The responses returned to the number of appointments an individual can be faced with when suffering from a chronic disease. We have already noted the concern regarding the effect of time off for those interviewees who were
employed. There seems to be a temptation to attend only those which are considered to be of most importance to the individual.

“I do have a lot of appointments which does get a bit overbearing at times”

“Like, I’ve got one...I’m supposed to see Dr K next week at 9.30am but now I’ve got a letter to say I’ve got to see him at 1.45pm. I start work at 1pm, so I can’t do it. I don’t want to mess them up at work with only 16 hours a week.”

T/003-7

001 “No, they made me an appointment once but it clashed with something else, and I forgot and…”

AB “It just didn’t happen”

001 “No. Frankly, I live so far away, it’s a big thing to come this far. I have to make sure I have someone with me because I have a dog in the car, I can’t leave him alone.”

T/001-2

Participant 001 was a middle-aged woman who lived on the edge of the catchment area for both the Hospital Trust and Primary Care Trust. Because of this it seemed she often missed out on the offer of referral to other services as there were queries over her entitlement to the local podiatry department due to geographical border issues. She also had a dog requiring much attention, so she frequently avoided trips into the city as this involved finding someone willing to dog sit. She enjoyed the isolation of her country situation and did not relish the idea of coming into the city more than she considered necessary. She therefore did not instigate appointments unless deemed by her to be essential. Her knowledge of foot issues was limited to the appearance of her feet when affected by hard skin and the practical considerations of nail cutting.

This last quote indicates that distance to the clinic is also a concern for our patients and could be a reason for failure to attend or accept the offer of an appointment. Ideally local clinic appointments should be offered but lack of resources frequently prevents this option. The material cost here is in terms of time.
Until now, it had been assumed within the podiatry department that, due to the morning stiffness traditionally attributed to inflammatory arthritis (Arnett et al., 1988), patients would prefer a later appointment. However, the quote below indicates that the effect of the disease on the patient is more individual than assumed (possibly due to the effects of new drug regimes) and, if practical, should be taken into account when timing appointments.

“The only thing is I like to be early...I deteriorate as I go through the day”

T/004-8

In addition to this, having to arrange appointments around family and work commitments will influence an individual’s ability or reluctance to attend.

“It’s just the timetable, obviously with working I’d like to fit in.”

T/003-6

“The only problem I have as I say is that I work for myself, so I can sort that out but it’s my little boy. Getting into school and coming out of school. I’ve got to make arrangements”

T/009-6

Some of the interviewees had chosen to seek private foot care. However, the financial cost of this determined the frequency of visits and not one of these participants received podiatry care as recommended in the guidelines.

“When this toe [nail] was playing up and getting too long I thought I’d get someone in and bite the bullet and just pay up this time. If I got on the system I might have to wait so many months.”

T/007-6

007 “If it can be done on the National Health it would be a great saving. It costs £28 a time to do them.”
AB “Have you been seeing someone privately regularly or just as and when?”

007 “Well, only when this nail causes trouble.”

T/007-2

“My wife does my toe nails and she does it very well. I’m not going to spend £20 on the lady in the village who does her feet.”

T/005-9

These comments are relevant as contributing factors to the complete picture of the research question. They have, according to some interviewees, been important concerns in the patients’ decision not to pursue a podiatry referral. There is an assumption that they base the decision to seek help on the greatest perceived benefit or cost at that time.

2.3. Factors informing attitudes to seeking help.

The dialogues indicated that the participants’ attitude to seeking help (both generally and with specific regard to podiatry) was largely dependent on previous experience. If they had received an intervention which had worked for them, they remembered it and sought the same intervention for a similar problem at a later date. The feeling was that this saved time in finding the correct source of aid.

“Because when you’ve had something and somebody helps you with some medication, you’re more likely to find out things...You know who to go to and that’s a bonus see”

T/004-6

“I know what [a corn] is like and I know it’s treatable and it’s like, I don’t want to waste their time at the hospital on something that I know what to do with. “

T/009-5

The idea that patients are happy to arrange help for themselves based on a positive previous experience is encouraging as it supports the idea that patients will under certain
circumstances self report problems. Whilst this system works well when the new
symptom involves the same issue as previously treated, concerns arise when a positive
experience on one part of the body is translated to a different anatomical structure as in
the recurring issue of relating hands and feet. A previous positive experience with the
occupational therapist for a hand condition led two of the interviewees to consider this
option for management of a foot problem. Although the way in which RA affects the
joints of the hands and feet involves the same pathological processes, because of the
differences in function of these joints and the weight bearing nature of feet, the
management principles are quite different. Seeking help from an occupational therapist
in this way may delay the most appropriate treatment but would at least lead to a
problem being recognised and hopefully the referral to podiatry services would follow.

This finding prompted the question of who the patient would approach to seek help for
foot problems.

2.4. Patients understanding of who is responsible for their health.

As one element of the research question was to ascertain what our participants knew
about the help available for foot problems once the decision had been made to seek
help, they were asked who they would approach for help if needed. Those participants
who had not attended podiatry services were asked if they would know how to gain
access to the service should they feel the need. The correct route of referral is via the
patients’ G.P. or directly from the rheumatology department. Surprisingly, although two
of the respondents were aware of this, most patients said they would expect the
rheumatology practitioner to make any necessary referrals for them. It was from this
line of questioning that the patients were asked to consider who was thought to be
responsible for their RA foot health generally.

In the first instance most interviewees mentioned one or two health care professionals
whom they felt would be answerable for their foot health needs. However, after greater
deliberation, the majority of the respondents again reported that they would consider the
rheumatology practitioner would be the person responsible for their foot health as she
was believed to have overall responsibility for their general wellbeing whilst under the
care of the rheumatology department. This echoes the sentiments from earlier findings
that problems of the foot are not considered separate to those aspects of the disease as a whole. The rheumatology practitioner was not aware of the full extent of the responsibility placed upon her at the time of the interviews.

“I would see [Rheumatology Practitioner] and she would recommend that I see [Occupational Therapist] or I would see my doctor and he would chase it up for me.”

T/003-4

Four of the participants immediately stated when questioned that they would contact the rheumatology practitioner in the first instance even if this was only to assist a re-referral to podiatry.

“If I had a problem with my feet I’d see [rheumatology practitioner] and say “I think I’d like to go down to podiatry ‘cos this has happened or that has happened.””

T/004-5

“I would initially go through [rheumatology practitioner] if something drastic happened.”

T/007-5

As patients with a chronic condition often build up a rapport with the health care professionals that they see on a regular basis over a number of years, there is a tendency to think that the favourable attention they receive is only because they have become a “friend”. The implication is that this interest in their care would not be achieved by approaching a health professional with whom they have less frequent contact.

“[Private Foot Care Assistant] does it for us as a favour more than anything else. She’s a kind friend.”

T/003-6

Two respondents did not know who to contact initially but, when pushed, felt that the responsibility would be with the rheumatology practitioner. One interviewee would...
contact his chiropodist directly and one would contact his Occupational Therapist (OT), within the rheumatology team, as she had assisted him with a hand problem and again there was an assumption that a foot problem would be similarly managed. As previously stated, two participants reported that they would contact their GP to facilitate any necessary referral. This was partly due to the perceived speed of access. One of these patients expected this course of action to take them back to their rheumatology practitioner for help.

“Um, go to my GP and he would refer me to [rheumatology practitioner].”

T/008-3

“Oh I’d go to my GP first because I can’t come to [podiatry] and I can’t get to [rheumatology practitioner] so I can’t just ring up [practitioner] and say I’m coming in, um...”

T/005-10

The additional point raised by participant 008 is that, due to his RA and a number of co-morbidities, he relies on his wife as his carer. This being so, she was reported to be the person currently providing basic foot care and would potentially be the person recognising any changes in foot health. Interviewee 005, after giving further thought, felt that contacting his consultant rheumatologist directly would be best:

“Well it must be Rheumatology I would have thought...
The consultant rheumatologist not [Rheumatology Practitioner]”

T/005-10

The above quote was from the patient who had been in the army. He attributed the success of his arthritis treatment to his army contacts who had, in his opinion, directed him towards the right members of the medical team. This again implies an element of chance in the care received depending upon rapport. The anecdotal comments from the audit showed that, with the current local situation, this would delay referral to the podiatry department as the consultant would write to the GP to make the referral as
there would be cost implications for his budget should he choose to refer directly to podiatry.

Of those participants who received some level of foot care management from a podiatrist, only one would not consider seeking help from them in the first instance if a new foot symptom should develop. This would yet again lead to a delay in obtaining the most appropriate care according to the standards of care documents because the patient recognises the symptom as associated with the disease first and the anatomy second.

Not one of the interviewees indicated without prompting that looking after their foot health should be considered their own responsibility. However, they were not specifically asked if they believed this should be the case and, in retrospect, the questioning could have guided them to reflect on a healthcare professional only. When asked directly if they would be comfortable with the responsibility for self-reporting foot problems (if adequate education on what to report was given to them) the interviewees responded that they would be more than happy to do this.

3. Patient’s attitude towards podiatry services.

Interview responses indicated that our local rheumatoid population had an inconsistent understanding of foot involvement in the disease. None of the participants reported a complete description of the effects that the disease can have on the foot in a way that would seem satisfactory to achieve prompt appropriate and timely help. The interview guide progressed to discover what the participants knew about podiatry services and what footcare management options were available to help them. The idea behind this being that, if the interviewees were aware of the range of podiatric interventions available to them, viewing the problem from this angle may make them more likely to seek help if it were to become necessary. In this way, knowledge of intervention rather than signs and symptoms could provide another route to enable the patient to self-report foot problems.

Only one of the participants had actually never experienced podiatry services. This was initially thought to apply to others but this was because they used to attend clinic, but no longer did so, or they were vague about the experience.
AB “have you got any idea of what [podiatrists] do?”

001 “No

AB “So apart from skin and nails you wouldn’t really know?”

001 “I wouldn’t know what you do, no.”

AB “So if you came along to an appointment you wouldn’t really know what to expect.”

001 “No.”

This participant then went on to indicate that this lack of knowledge as to the scope of practice of podiatrists would be a deterrent to seeking help because of a fear of the unknown. An appointment had been made for her to attend for podiatric assessment, although she was unable to recall the reason for this, but she had cancelled due to the difficulties of leaving her puppy unattended. The importance of the appointment had not been stressed to her and the failure to attend had not been followed up. She had not pushed for another appointment herself because of the above mentioned issues and the distance to the clinic.

All participants were aware, when pushed, that podiatrists can help with nail cutting and the management of corns and hard skin. There was an assumption that podiatry was a service for people who could no longer cope with their own foot care.

“I know [podiatrists] do nails”

“[podiatrists] just literally cut the nails, hard skin...’cos you do get a lot because you walk funny.”

Two patients were aware of the nature of the specialist in podiatric surgery. The first had witnessed the positive effect bunion surgery had had on his wife’s feet and the second had received successful surgery for removal of bursae. Therefore, the two extremes of podiatric practice were recognised but very little was reported about the range of interventions associated with tissue viability and biomechanical foot management. A
reason for this may be that these interventions can be provided by health professionals other than podiatrists. However, seeing others for these actions may rule out a foot screening opportunity.

With regard to biomechanics intervention, there is confusion amongst the local RA patient group as to why this intervention is required and who should be providing it. As the literature presented in chapter 2 emphasises the importance of orthotics management to reduce pain and limit deformity in this patient group, it is imperative that patients understand the structural and functional problems which can occur in rheumatoid arthritis if they are to be the instigators of any help required. In those cases where the interviewee had received orthotic management for biomechanical foot problems, the care had almost exclusively been provided by the orthotics department alone without the advice of the podiatrist. This frequently resulted in confusion over how to use the devices or failure to persevere with them at all. A lack of review appointments when this route is followed may account for this as the patients have no formal opportunity to ask questions or report areas requiring alteration. These issues are commonly picked up in podiatry clinics if the patient is receiving regular care for other aspects of their foot health.

“and then they built them up inside but they were so wide they fell off my feet so they never got worn, just a couple of times and that was it. That was a waste of money.”

T/006-6

“[orthotist] said “oh, we’ll get you some thinner ones” but I’d never heard anything in 2 months so when I was in the hospital I called in. He said “Oh I can’t find any trace of that, I’ll see what I can do’’”.

T/007-5

3.1. Factors informing patient’s attitude to podiatry services.

The interviews highlighted an unforeseen implication for the podiatry team. Although related to the original practice observation of insufficient uptake of podiatry services, it viewed the problem from concerns within the podiatry department rather than as an issue
of failure to receive appropriate referrals. The patients’ experiences of podiatry were not always positive and some changes in the podiatric approach to the management of patients with RA would have to be addressed before the original question of promoting access of this patient group to foot services could be enhanced.

In addition to the perceived benefits and costs reported under attitudes to seeking help, there were some issues directly linked with the podiatry service which influenced the patient’s opinion of that department and consequently might affect their decision to refer to it.

3.1.1. Communication.

Apart from the inadequate communication between the patient and the orthotics department mentioned above, the participants also reported areas for improvement for communication with the podiatry department. Inadequate information, with regard to explaining why treatment was necessary and what to expect from podiatric intervention, could lead to misunderstandings. For example, comments from the audit suggest that patients assume their orthotic devices need only be worn for the duration of symptom management and thus discontinue their use once the original problem had subsided. It is usual for orthoses to be used long-term to prevent recurrence of the symptoms whilst maintaining optimal foot structure and function. Even in cases where the podiatrist was involved, patients reported mixed responses regarding satisfaction from this intervention. This is usually associated with a lack of communication with regard to management expectations.

“She gave me an insole…it didn’t really do a lot.”

T/008-5

“So I just went to see a foot person [private practitioner] and got some build-ups made and I’ve been wearing them and I have to get them repaired every so often.”

T/009-2
Participant 008 was an elderly gentleman of few words. He was in a wheelchair and was brought to the interview by his wife who acts as his carer. He had suffered three strokes leading to slow and deliberate speech. He would require more time with healthcare professionals to ensure he fully understood any advice given. Also, his wife should be present to ensure any advice was adhered to. The reason for attending the interview was a desire to please the rheumatology practitioner.

Even when participants had reported a previous referral to podiatry, they seemed unsure as to the role of this particular healthcare professional within the team management of their RA footcare needs as a whole. Patients reported some uncertainty as to why they have been sent to podiatry in the first instance. Also, the difference between podiatry and chiropody is still causing confusion for most patients. Their expectation of the service was unknown.

“I went to see a podiatrist...when I had my toe cut off and I can’t remember why I went to see a chap...and I thought I was going to get a good toe nail cutting”

“I don’t really know the difference between a chiropodist and a podiatrist”.

T/005-8

An additional communication concern related to the discharge policy previously mentioned in chapter 3. If patients were not deemed to be of “at risk” status on the day of assessment they were discharged with no clarification given on how to return if their situation changed. The podiatry department did not give the patient adequate information to support them in the event of a change in their health or a recurrence of original symptoms requiring further assistance. A female, retired patient had summarised her last encounter with the podiatry service as:

“I think I was just told not to come back anymore”

T/004-7

This message was reiterated by a retired man:
“But I could tell she [NHS Podiatrist] wasn’t keen for me to come back”

As stated earlier, all the participants in the study reported that they had received no specific advice or education regarding the effects of rheumatoid arthritis on the foot. This applies to those individuals who attend, or who have attended the local NHS podiatry service, as well as those with no previous exposure. The information should include how the disease affects the foot and what symptoms to report, as well as information on the management plan and the outcomes to expect from intervention. The findings of this study do not tell us whether the podiatry service is failing to provide such information or, if it is being delivered in such a way that the recipients are not able to recall it. It may be that insufficient time is spent on a full explanation of these points to the patient. Written information leaflets are not currently used and this may be the reason for this misunderstanding. Either way, the patient does not fully appreciate the expectations of the foot management and an education opportunity is lost.

Communication factors informing attitude towards podiatry services includes information received from those outside podiatry. Misconceptions surrounding the podiatry referral and appointment system were preventing our interviewees from seeking a referral. These misunderstandings were sometimes based on the experiences of others in different parts of the country.

“I had a Father who lived in Worthing, there’s a lot of old people in Worthing, and they had such a long waiting list that he had to get a [private] chiropodist in”

“If I got on the [NHS Podiatry] system, I might have to wait so many months.”

The latter comment was made by a male aged 65 so it is possible that some time may have elapsed since his father experienced the access issue. As mentioned in chapter 2 (p.34) the national picture for podiatry services is not equitable and comparisons with
other podiatry departments would not provide information relevant to the local service. Certainly, at the time of interview, the waiting time for local podiatry assessment was short.

When asked if NHS podiatry treatment had been offered:

“No. They said it was too...I went to my doctor and he said it was too busy. There’s a huge waiting list.”
T/008-4

 “[Rheumatology practitioner] did say she didn’t know whether [podiatry] would take me or not because I live so far out...”
T/001-3

From these examples it seems that health care practitioners hold some responsibility for misrepresenting the podiatry service to the patient.

3.1.2. Organisational Issues.

The increase in interval between appointments, as well as being of direct concern to the patient’s health, also influences the patient’s attitude towards the value of the podiatry department in terms of symptom relief for that individual. In addition to this, access to the department in general is seen as problematic. A female patient, who is self employed, reported the following in regard to trying to rebook a cancelled appointment.

“First of all they cancelled me, just cancelled, then they made me another appointment which came with about 2 days notice but I was away and my mother opened it. So she rang up and cancelled it...and I’ve never got another appointment since. They just looked at it and thought, “she hasn’t come twice so that’s it””.

T/006-2

“I was...being seen every 10 weeks but it’s gone up to 20 weeks so, it’s a waste of time.”

T/006-2
There was an indication from the comments that, even when advised to contact the clinic for an urgent appointment if considered by the patient to be necessary, the implied help was not forthcoming. This comment was made by the retired man who was very upset by the effect on his feet of the lengthening appointment interval:

“[The podiatrist] said that if you’ve got problems that you can ring and that’s what I did but it didn’t help.”
“she always says ring if you’ve got problems with your toe but I’ve tried it, you know but...No”

T/002-4

These potential problems related directly to the podiatry service have subsequently been addressed and are reported in the conclusion (chapter 9).

Summary

The findings have been presented in terms of:

- Patient’s attitude to foot problems in RA,
- Patient’s attitude to seeking help,
- Patient’s attitude towards podiatry services.

For each of these categories, factors influencing the patient’s attitude have been reported.

Chapter 7 will now discuss the implications of these findings as they relate to the research aims. In order to address the research question, these findings will be discussed in terms of their impact on the self-reporting of rheumatoid arthritis foot problems. The referral pathway to podiatry services can be influenced at a number of points and the discussion will look at the findings from this aspect.

The chapter will go on to explain the associations between the themes and their relationship to the literature examined. It will go on to cover the final stage of framework analysis, involving mapping and interpretation of the findings, to develop concepts which offer an explanation of the research outcomes.
Chapter 7: DISCUSSION.

Introduction.

This chapter will discuss the findings from the interviews in relation to their impact on the patient’s decision to seek appropriate and timely referral for RA foot problems. Charting the data from the transcripts revealed categories of information which link to the various stages within the referral process. From these categories, key characteristics from the data have been pulled together. The patients understanding and attitude towards the potential effects of rheumatoid arthritis on the foot, and the services available to help with these, will be presented within the context of the stage of the referral process affected by each topic. In this way, the data categories have been mapped and interpreted as is consistent with framework analysis. Therefore, the findings will be divided into sections which explore:

- the process of informing the patient in regard to their foot health,
- the influences on their decision to seek help, and
- communication with the healthcare professional approached to provide this assistance.

As the overarching aim of the study was to increase understanding of the provision of footcare services this chapter will also suggest how the findings inform the referral process beyond this point to address:

- communication between the source of referral and the podiatry department,

The preliminary fieldwork revealed the local expectation on behalf of the healthcare professionals that patients will self-report emerging foot issues but the interviews revealed diverse reasons to explain why this has not been happening in practice. These arguments will be explained further in terms of the influence both directly, from the patient, or indirectly, via the organisations effect on the patient, in relation to the clinical practice observations and current literature.

Thus a picture will be described to explain the current situation with regard to local provision of footcare services with particular reference to the role of patient self-reporting of foot problems within this.
Patient knowledge and understanding.

Before the patient thinks about the decision to seek help, they have to be aware of the circumstances that would inform this decision in terms of what signs and symptoms need to be conscious of. For this to occur, the individual needs to be well informed as to what foot problems to refer and when. The findings have indicated that this understanding not only comes from direct information received but also from beliefs based on previous experience.

Formal education.

As well as recommendations from international and government health bodies (see chapter 4, p.51), other literature recognises that patients require current and accurate knowledge about their disease and its management in order to encourage health promotion and enable them to make decisions about their medical condition and its management (Gray, 2002). The two main areas of focus regarding patients’ knowledge of footcare in rheumatoid arthritis (based on the literature reviewed in chapter 2) are:

- Knowledge for preventative screening.
  - understanding issues around tissue viability care especially when linked to RA drug management and the importance of biomechanical assessment on a regular basis to assure early intervention to prevent deformities wherever possible.

- Knowledge for symptom recognition.
  - to identifying symptoms/signs of potential foot pathology and recognising their distinction from the disease as a whole (i.e.: requiring more specific help than holistic drug therapy alone).

To empower our patients to self-report foot problems as recommended in the literature, sufficient understanding in both areas listed would be necessary. The participants in this study did not report sufficient appreciation of the foot in RA to fully recognise and assess problems that may result from their chronic disease process. Whilst this was an anticipated finding of this study, based on the assumptions that formed part of the rationale, we now have evidence to support this. However, the subject proved more complicated in nature than initially expected.
From Table 8 (p.78) one can see that each participant, by nature of disease duration, had repeated exposure to various members of the rheumatology team. Routine practice consisted of alternating six-monthly appointments between the consultant and the rheumatology practitioner. Despite this opportunity for the delivery of a variety of advice, each of the interviewees reported that they had received no information on the foot in RA at all. Patients locally are not routinely receiving formal education sessions which current published guidelines state are important and it seems they do not glean sufficient advice informally from consultations to inform their decision-making process. Neither do they appear to have an adequate awareness of the preventive footcare issues needed to ensure minimal effect from the disease on their joints. The implications of drug management have also been under reported which may indicate that patients under-estimate these effects. These concerns arise regardless of any previous exposure to podiatry services. This was also the response of the one interviewee who had attended the recently instigated foot health education session. This is not to say that the foot health advice was not given, merely that none could be recalled at the time of interview and this recall of information is vital to timely action. These sessions have now been disbanded due to failure of uptake. This may in part be due to the limited advertising (consisting of posters in the out-patient waiting room and word of mouth only) or the timing of sessions. They were scheduled in the evening to suit the consultant’s timetable. They were aimed at anyone with RA and were not specific to certain stages in the disease or particular drug management groups. Advice on certain aspects of the disease may only be discussed if the subject is raised during the course of the consultation. This may not be recognised by the patient as “formal advice” and also allows the possibility of preventative advice being overlooked.

When the subject of information was approached from another angle and participants were questioned regarding podiatrists’ scope of practice in respect to RA footcare, responses remained unclear. In general, there was an awareness of the palliative care provided in terms of toenail cutting and treatment of corns and callus but this was thought to be mainly for those people unable to self-manage this. Little mention was made of orthoses and footwear in relation to podiatry. Several patients were aware of podiatric surgical interventions, based on their own experiences or that of family and friends. However, in the main responses remained vague. This supports the fundamental
concern guiding this study. If patients are expected to self-report foot problems, and these foot problems will not otherwise be discovered due to the lack of screening, there is a need for the individual to understand the effect the disease can have on the foot and what help is available to assist with this in terms of podiatry if referrals to this service are to be as recommended in the guidelines. There has been little evidence to support sufficient understanding of the role of the podiatrist in the management of the rheumatoid foot within the participants of this study.

Whilst emphasis has been placed on the importance of the well informed patient, the literature suggests that providing knowledge to patients is not considered sufficient on its own (Gray, 2002). This literature recommends that patients need access to high-quality information pitched at an appropriate level in order to ensure the accuracy of the information acquired. Skills for appraisal of information, especially when gleaned from web-sites are essential. An adequate knowledge base is fundamental to the principles of the Department of Health “Expert Patient” programme (2001). As mentioned in chapter 4 (p.54), this scheme relies on using the patient as a resource with their personal knowledge of their disease being enhanced to empower them to take an active role in the management of their condition. In areas where such programmes exist they have proved to be successful in term of appropriate self-referral and with patient satisfaction but little evidence is reported on specific outcomes. Thus, self-management strategies are considered more effective than education sessions alone. With no such programme locally the patient knowledge base lacks the opportunity to develop, through use of the patient group as a resource, to the stage where the individual can achieve this empowerment. Without a formal disease self-management programme the “expert patient” will remain an untapped resource.

Recall of information given at a consultation has been reported in the literature as questionable. Several earlier studies report this phenomenon as a concern (Bain, 1977; Crichton et al, 1978). The implications locally are that even if sufficient education regarding the effects of RA on the foot and the flags for referral had been recalled by the patient, this alone may still have been insufficient to ensure timely and appropriate self-reporting to podiatry services. Information should be targeted to individuals at various stages in the disease with monitoring for evidence of retained understanding of the information given. Patients have to be receptive to the information.
Hill & Hale (2004) expand on the literature in support of patient empowerment (chapter 4, p.52) by stating that the self-management education approach should enable patients to become partners in their disease management rather than passive recipients. Those people who take an active role in helping themselves believe that they have a positive effect on their health and thus may be able to alter the course of rheumatoid foot problems. This would echo the desire reported by the local interviewees who expressed a need to remain in control of their condition and fulfil a functional role in society. However, the authors admit that, although there are a number of ways in which the health education can be delivered to patients (i.e. one to one, group education, self-management courses and opportunistic), there are advantages and disadvantages with each.

Hammond (2003) states that, to be effective, patient education needs to be timely and pertinent to the patient which was illustrated by the interviewee in this study who indicated she was too busy to remember the advice. She had kept, but not read, the leaflets given to her at each education session and, implied that she would refer to them only if a problem occurred. Her overwhelming reflection on the session was that her RA was inevitably going to get worse based on the condition of the people around her as the session included individuals at all stages of disease activity. The timing of the session was perhaps inappropriate for this individual and the education session would not have achieved its aim of a proactive stance on foot health.

Hammond (1999) again showed that education sessions alone are not enough to change the behaviour of patients to achieve adherence to management regimes. An individual approach, recognising and working with the patients beliefs is necessary. In order that the patient should observe any advice, steps have to be taken to ensure they understand both the knowledge regarding the nature of their disease and how the advice given will impact on this. This point had been previously made by Boyle (1970) who investigated patients’ understanding of definitions of diseases and discovered a lack of patient understanding which was considered likely to affect adherence to treatment regimes.
Self-diagnosis.

Williams (1984) describes the way in which people with RA make sense of the onset of a chronic illness in their lives. He terms this “narrative reconstruction” as it records the changing relationship to the world in which the individual lives and the mode of generation of the illness within it. When the science and the medical models do not fully address the cause of rheumatoid arthritis to the satisfaction of the individual, they draw upon other factors to explain the cause of the disease. These factors include moral, religious, political and sociological issues which are personal to that patient and based on their experiences. In this way the person renders comprehensible the biographical disruption to which the disease has given rise.

The lack of formal education does not prevent the individuals from attempting to make sense of the effects of the arthritis on their body based on their beliefs. In this way, they attempt to inform themselves regarding their disease and its consequences. One participant remarked that big feet run in her family and she explains her foot symptoms in view of this. Another interviewee offered the explanation of her changing foot shape as being attributed simply to the way she walked and symptoms as a result of osteoarthritis. This became an important factor as, if the interviewees could find a reassuring explanation for the problem currently experienced, they would wait until the next scheduled consultation to report it.

A study by Lempp et al (2006) exploring the patients’ view on the quality of health care for rheumatoid arthritis reinforces the opinion that patients do make their own decisions regarding treatment choices based on their beliefs. They found almost half of patients interviewed said they sometimes resorted to taking their own decisions about medication, dose and frequency. They linked this with their perception of feeling unwell and what, in their opinion, “was good for them”. This could potentially lead to a delay in receiving the appropriate care.

The reported patient behaviour of self-diagnosis is of concern when the conclusions reached are incorrect and potentially lead to the failure to report problems requiring more urgent attention. Besides the importance of knowledge and understanding, we
begin to see that patient’s individual characteristics, and the influence of others, has an effect on their behaviour with regard to reporting health needs.

Reports have highlighted the recommendation that education is important in the patient-centred management of rheumatoid arthritis but the findings from this study have shown that this information is not being recalled by the patient. However, the data relating to patient knowledge and understanding has agreed with the literature in so much as it would seem information alone is not sufficient to empower patients to take responsibility to report foot health issues.

**The decision to seek help.**

Once the patient has identified a problem requiring attention, there are a number of factors which then influence the decision to seek help. These will be discussed below but it should be remembered that it may be the individual’s carer who has to make this decision which introduces another tier of variables to be addressed in future research.

**Disease control.**

Chronic disease can have a negative effect on patients’ perceptions of control (Ryan et al, 2003) in that they may feel unable to influence events affecting their health which can lead to depression and inability to cope efficiently with the disease. Certainly that was the view of one interviewee who expressed concern when she was first faced with a room of RA people who exhibited marked visual signs of deformity as a result of RA. She believed that these consequences were an inevitable part of the disease over which she would have little influence. The ability to keep control of the consequences of ill health is extremely important to the individual and links with the health psychologists’ view of the patients’ “Health Locus of Control” where an individual is felt to have an internal locus if events are felt to be controllable by the individual or an external locus if they are not (Ogden, 2007).

Coping has been defined as “efforts to manage …environmental and internal demands” (Lazarus and Launier, 1978). This may be problem-focused coping, which involves taking action to reduce the setback itself or increase the resources available to manage
it, or emotion-focused coping, which attempts to manage the emotions evoked by the source of stress. Tennen et al (2000) examined daily coping in people with RA and found that problem-focused and emotion-focused coping usually occurred together. Ogden (2007) reported a number of factors which are thought to influence the coping strategy used:

- **Type of problem**: problems with health tend to evoke more emotion-focused coping.
- **Age**: middle-aged people tend to use problem-focused coping whereas the elderly tend toward to more emotion-focused help.
- **Gender**: Although not found in all studies, it may be that women tend to adopt more emotion-focused coping and men a more problem solving approach.
- **Controllability**: If it is believed that a problem can be changed, problem-focused coping is employed. When a problem is perceived to be out of the individual’s control, emotion-focused techniques are employed.
- **Available resources**: Problem-focused coping is more likely if external resources are felt to be available to help control the problem.

As an example of this we find one participant, an older woman, exhibiting emotion focused coping in her relationship with the family in that she chooses to play down the extent of her symptoms. Another participant chooses to become self employed as a problem-focused approach to her changing situation. This can also be linked with the patients self-diagnosis reports in that there may be an attempt here to remain in control of events.

A study by Affleck et al, (1992) also found a difference in coping strategies for pain in RA patients in which more disabled and female patients were drawing on a wide range of tactics and waiting longer before seeking help. Yong et al, (2001) reported that older people exhibit an increase in degree of reticence to pain, self-doubt and reluctance to label a sensation as painful. They recommend caution when accessing pain in the older age group as they tend to under-report. In addition, work carried out by Sollner et al (1999) supported the existence of different patterns of interaction between individual coping style and social support which calls for different clinical interventions. This adds weight to the findings of the interviews in this study which imply that individual
characteristics (i.e. gender, age) affect the attitude of the patient to seeking help. The implications from this are that, if relied upon to self report foot pain, some patients wait longer than others. This is of concern as the literature indicates that intervention needs to be early to attempt to prevent progressive foot deformity.

The timing of the problem also makes a difference in that, if a problem arose near the time of a scheduled appointment, they would wait until that appointment to raise it. If it did not, they would make the decision about who best to approach for advice between consultations at the hospital. These are all issues related to the control of the disease and its management.

Effect on social role.

Reports from the interviews suggest that the consequences of the illness on friends, work colleagues and family are considered by the patient when they plan the approach to their health care needs. This relates to the many factors affecting the patient’s comprehension and reaction to illness as expressed in the biopsychosocial model (based on Engel, 1980) below:

![Biopsychosocial Model of Health & Illness](image)

**Figure 1. The Biopsychosocial Model of Health & Illness.**

An ailing person is surrounded by social expectations and evaluations which influence their understanding and behaviour. This view of illness as a social state originated with the description of the “Sick Role” (Parsons, 1951) which emphasised the need for patients to be motivated to seek help from appropriately competent agents in order to get well as soon as possible. Its aim was to control the disruptive effects of illness on society. The Sick Role also allows for the exemption of the patient from their normal
social role obligations whilst accepting that the expectations of the sick role are affected by age, social class, race etc (Morgan et al, 1985). This release can be seen as an advantage of sickness for some people and a detriment for others. The problem with this model is its focus on conditions which are curable and so it does not translate readily to chronic diseases where cure may not be achievable. However, Kassebaum and Baumann (1965) reported that maximum function occurs if patients with long-term medical conditions are allowed to continue in their normal social role. This supports the intention of the Sick Role when applied to ongoing disease.

Relating this to the interviews, the issue of appearing to be able to cope with the disease itself extends to the importance of remaining able to fulfil a role in society and was a recurrent theme raised. Participants indicated a need to tolerate as much discomfort and disability as possible in an attempt not to burden the family, to limit the effect of health problems on work and to uphold a generally stoic attitude. One interviewee explained that she likes to put on a brave face in front of her family as she wants to be viewed as a “normal” mother and grandmother and not a “whinger”. Returning to the study by Lempp et al (2006), half their patients reported presenting themselves to secondary care staff as a “coper” and a third said that they tried to please staff by “not being a nuisance”.

**Personality traits in rheumatoid arthritis.**

As well as general health behaviour models, a report by Labhardt (1979) relating specifically to the personality of the rheumatism patient suggested that, because of the vicious cycle of emotion, muscle tension and pain experienced by these patients, certain personality traits have been developed. These are suggested as perfectionism, self-control and masked-rebellion, together with an urge for physical activity. He goes on to state that patients with RA often show a mixture of tolerance and aggression and that their management should be mindful of these factors. Hill and Hale (2004) also describe the psychological problems associated with RA in that people react to their disease by acceptance, grief or denial. This confirms that the psychological state attained by the patient at the time of requiring foot health assistance may influence their attitude towards seeking help. This indicates that, although the general implications of
Biopsychosocial actions are observed in this patient group, the illness behaviour is unpredictable subject to their stage in the disease process. One participant exhibited grief for the loss of her future mobility when attending the education session and associating the visible disability of the other attendees with that she would be expected to experience in the future. Another study subject frequently expressed rebellion when talking about what he considered to be needless “poking and prodding” during consultations.

Barsky et al (1999) conducted a study which confirmed their suspicion that drug side effects are more a characteristic of the RA patient than their medication. They report that psychosocial factors make important contributions to the severity and extent of RA symptoms. Health concerns and the tendency to somatise result not only in medically unexplained complaints but also an increase in the reporting of medically based symptoms. Thus, the personality traits of the RA patient may make them more or less likely to seek help depending on their psychological state at the time of recognising the problem requiring referral.

Ehrlich (1979) wrote about the problem of adherence to the course of therapy in RA. Although this is often due to complexity of treatment regime or the lack of early reward from the interventions and the lack of appreciation of the long term effect of management, it can also be a conscious decision not to follow advice for different reasons. The author suggests that some patients deliberately non-comply with medical advice to ensure their disability benefits continue or to exploit their domestic circumstances. Whilst these reasons were not reported by the participants in this study, some evidence for concealment of symptoms for financial reasons was reported during the interviews and this will be discussed later in this section.

Experience.

Where patients had experienced podiatric intervention the results were generally positive with pain relief and reassurance being of great importance. However, patients also reported concerns regarding the manner in which the footcare service is delivered and a need for improvement in some fundamental areas.
At the time of the interviews, the podiatry eligibility score (chapter 3, p.39) did not take into account the potential disease progression of RA. It was possible that following podiatric assessment patients at an early stage in the disease, or those in remission, could be discharged. This was because the score provided a snapshot of the individual’s condition at that time with no allowance made for future screening requirements with change in the disease. The audit did not identify the number of patients who had been discharged from NHS podiatry care under these circumstances because this question was not included in the tool being used but anecdotal comments and the interviewees confirmed that this was happening regularly. Local patients with diabetes in the same situation would be offered an annual review but there was no such service offered to RA patients despite literature to recommend this.

When interviewed, those patients who had experience of NHS podiatry care expressed the concern that, during consultation with the podiatrist, advice on prognosis, both of the disease manifestations and management expectations, was not made clear. The relationship between the podiatrist and the patient should provide the ideal situation for an exchange of information partly because it is one-to-one but also as the nature of the RA patients footcare needs is such that they attend long-term and frequently giving the opportunity to build a rapport with the practitioners involved in their care (Mandy et al, 2003).

Beliefs and subsequent behaviour can be based on previous experience but not always in the most logical way. The interviews have shown that a specific foot intervention by a podiatrist, leading to a positive experience, does not automatically provoke a response to seek similar assistance in a similar situation. One interviewee had formerly seen a podiatrist privately for a biomechanical problem and reported a positive experience with regard to the subsequent orthoses provision. When a similar biomechanical issue occurred later she attended the hospital orthotist because of cost implications, even though the outcome of the second intervention was not as satisfactory as the first. This would indicate that some factors rank higher than others in the decision-making process. Additionally, the interviewee reported that she took the advice of the rheumatology practitioner on that occasion as she did not want to contradict the practitioner’s advice by mentioning the previous experience. When asked what problems would take her to the podiatrist in the first instance now, she replied that this would depend on her ability
to self-diagnose the symptom. If the patient could be sure that it was a podiatry issue she would make an appointment with the podiatrist direct but, if she was not so clear about the nature of the problem and its management, she would wait until the rheumatology consultation for advice. It is therefore important that patients understand the specific problems of the RA foot and the specific interventions for these.

Misunderstandings can arise regarding access to podiatry services which may influence the patient’s decision not to seek help from this service. This was illustrated in a number of interviews when discussing access to and the provision of podiatric care. As the findings show, the patient can misinterpret what they have been told or what has been learned from experience. Misunderstandings can also be communicated to the patient from the health professional as is discussed later in this chapter. The events were sometimes based on previous personal experience, the experiences of others or general beliefs regarding the department and access to its services. For example, a retired, male participant explained that his reason for seeking occasional private podiatry care was due to the observation of his father’s experience some years previous. He had lived in Sussex and experienced a long wait to receive NHS Podiatry treatment. Our interviewee had not wished to wait the anticipated months for an appointment. The waiting list for new patient assessment by a podiatrist locally is short. Another interviewee had not received the referral to podiatry which had initially been advised because a member of the rheumatology team was unsure as to her eligibility for treatment locally due to the possibility that she may live outside the catchment area. The practitioner had sent the referral anyway but had sown the seeds of doubt in the patient’s mind. The patient subsequently failed to attend the assessment appointment as she believed it was a long way to travel simply to be refused care. Another patient had chosen to seek occasional private foot care as he had enquired about the possibility of accessing NHS podiatry care but his GP had told him of the huge waiting list that lay ahead of him.

In general the participants regarded their foot problems as just one symptom of their general condition. They report the belief that, if the inflammatory disease itself is well managed, all symptoms would improve regardless of site thus addressing the matter of curability and control. This does not simply apply to the drug management of RA. One interviewee reported that he had recently been given antibiotic medication from his doctor which was expected to alleviate several of his symptoms including a foot
problem. As well as being based on previous experience of general RA management, the participants’ attitude towards foot care can be based on previous experience of a similar foot symptom or a comparable problem in another part of the body (i.e. the hand). This being so, foot problems are not always highlighted as a specific site of concern but at least the matter is being acknowledged.

Not only can this belief be applied to the effect from drug intervention or management but also in the form of physiotherapy or occupational therapy. Repeatedly, participants related foot concerns to those of the hand in the belief that they are similar structures. This being the case, for subsequent foot symptoms the patient may seek help from the practitioner involved in this previous hand intervention based on a positive previous experience. This may not be the most appropriate individual and, although that health care team member is likely to refer the patient onto podiatry for the intervention required, a delay in the instigation of treatment will result.

**Hierarchy of symptoms.**

The participants in this study reported their feet as either of primary or secondary concern to them depending on the impact of any foot symptoms or the severity of other symptoms at any given time. Patients describe a tendency to address only the chief problem occurring at that moment. One participant reported this when she declared her current back problem takes over other symptoms to the extent that she does not notice them. If the foot problem was not the symptom of greatest concern at the time, a delay may occur in receiving the appropriate management.

Finding out what medical concern is of most importance to the individual at that time is essential when assessing where the foot ranks in relation to this. A study by Ailinger and Schweitzer (1993) confirmed the need to consider the patient as an individual and emphasised the importance of taking time to discover what the patients’ explanation of their RA reveals about their expectations of treatment and prognosis. Their study found that the majority of patients are not particularly interested in what causes the disease but rather are concerned regarding the incapacity which may follow. Even pain management is not considered as important as maintaining function and the ability to continue with their working and social roles. This further suggests that patient’s
individual concerns and how these rank in terms of importance is influential in the decision making process to seek help.

**Body image and gender differences.**

The individual characteristics of age and gender also have an influence on the appearance of the body. The importance of cosmesis was reported in the interviews and also has a bearing on symptom self reporting. Gullette (1997) claims that it is not the body which ages us but a culture that is saturated with ideas of age and ageing which results in the negative mass of feelings and beliefs regarding the issue. Featherstone and Hepworth (1991) refer to this as the “mask of ageing” so as to describe the tension between external appearance and internal identity that can also be seen with physical disability. Age also has a practical implication in that older patients have been shown to have difficulty in undertaking basic foot care tasks such as inspection (in part due to failing eyesight) and nail care which impacts on self-screening (Thomson & Masson, 1992). In addition to this, changes in patterns of employment and relationships, neither of which are now expected to last a lifetime, mean that people feel they have to stay attractive for longer than in previous years (Twigg, 2006). It would seem therefore that it can be desirable to play down any effect of disease that could make the individual appear visibly older. This may lead to concealment of symptoms.

Conversely, this study’s findings indicate that the appearance of the feet can influence some patients to seek foot care advice at an early stage. However, this would seem to be the younger, female patients only. The first interviewee, a woman in her forties, indicated that she would like to wear open toed shoes in the summer but was uncomfortable with their appearance whereas another patient, who was an older, retired woman, explains that cosmesis is no longer a concern for her as comfort has become more important. Another younger woman reported that the appearance of her toe-nails, which were infected with a fungus, gave rise to concern but her GP was reluctant to prescribe an antifungal for cosmetic reasons only as he saw it. This emphasises again the disparity in the importance placed on the presenting signs and symptoms between the patients view and that of the health professional. She was of the opinion that her GP didn’t understand the importance of self-image when taken in the context of her condition generally. She considered there were many deformities affecting her
appearance that could not be controlled and thus believed strongly that, if a problem
could be rectified, albeit a minor thing in the eyes of the health care professions, she
would like to have treatment for it.

Whether visible signs of the disease give rise to concealment of symptoms or act as a
driver for seeking medical advice, the need to minimise them is universally
acknowledged. The literature has much to report on the importance of remaining
“normal” to illness sufferers. Social oppression is not limited to appearance but is linked
to several aspects of disability. Patients are reluctant to divulge details of personal
experiences which are difficult to discuss. Pain is stated as one of the major factors in
disability which may have a social effect on the individual (Twigg, 2006). The social
model of disability often referred to in the literature neglects to include the effects of
culture where the patient has to fight against being labelled as “other”. Historically, a
person with a disability was regarded as abnormal and sent to special, separate
institutions. The visual realm of modern society still invalidates an individual with any
visual loss of function (Hughes, 2000). Drench (1994) reported that society determines
what is considered to be normal with regard to a person’s body image and this idea is
the only view acceptable to many. This view places the emphasis on physical beauty
and perfection. It predisposes anyone with a disability or disfigurement to stigmatism
(Chandani et al, 1989). Visible disability affects not only society’s view of the
individual but also how that individual views themselves and how they think others
view them. It was Leder (1990) who said that people experience betrayal by their bodies
when the familiar appearance is replaced by the malfunctioning body of pain and
illness.

In modern society, identity and lifestyle replace the earlier emphasis on class in defining
who and what people are (Gidden, 1991). This being so, people with a disability are
oppressed both by assumptions regarding their physical capacity and also about bodily
appearance and its meaning to society. This is principally due to the influence of the
media and the visual world in post-modernity. In literature and cinema the villain is
often portrayed with a physical impairment as disability is presented in popular culture
as embodying malevolence, jealousy and hidden spite (Kriegel, 1987).
Changes in body image are extremely important to the individual. Traditionally, stigma seems to be ascribed to those conditions where the cause is unclear and the treatment ineffective (Sontag, 1977). This could be applied to rheumatoid arthritis and may help to explain why the development of biologic agents for RA management has been so popular with patients. The drugs ability to limit the development of visual deformity, whilst not evidence based as important to body image, may be an additional factor in the patient’s satisfaction with this choice of disease management. Interestingly, the biomedical model of the body does not reflect the feelings of the patient on entering the health care system when the body becomes alien from the self by becoming the object of observation and intervention by others (Twigg, 2006). This may be another influential factor in the decision not to seek help relating to body image.

Hill & Hale (2004) confirm that altered body image is a particular problem in the younger age group due to its perceived impact on relationships and leaves the patient feeling socially isolated as they are concerned regarding people’s perceptions of their appearance. Negative meanings associated with changes to body image as a result of age or disability are worse for women as they are subject to a double standard that undermines the traditional source of power which for women is evaluated as beauty and youth (Woodward, 1999). For men, this source of power is seen as money, status and social dominance. In certain circumstances it may be easier for a woman to come to terms with a physical impairment as they are more likely to accept being helped as men see assistance as a challenge to their masculinity (Connell, 1995). A disabled woman is more likely to be deserted by her partner because a man is less likely to want to take up the role of carer (Lonsdale, 1990).

Footwear is a public marker for disability (Whalley et al, 1997; Gutwenerger et al, 1999; Treharne et al, 2005). Therefore, if a patient has to wear modified footwear to accommodate RA foot problems, it may draw attention to their disabilities further. It would be understandable then if certain patients took the decision to avoid seeking help with their foot problems, and the visual consequences of this help, until they considered they were desperate. This would again jeopardise the required early intervention.

The process regarding how people in different cultures and social groups explain the causes of ill health, the types of treatment they believe in and to whom they turn for
help when they do get ill is discussed by the medical anthropology texts (Helman, 2002; Kleinman, 1980). A full explanation of this is beyond the scope of this thesis but suffice it to say that it begins to explain the individualism needed with regard to achieving success in health promotion. Body image can be associated with this as different cultures have a variety of beliefs regarding optimum body shape and the way in which it functions. This provides further weight for the argument of the need to take an individual approach to patient advice. It would be difficult to cover all these individuals’ nuances in a group education session and to assume that every patient could be given the responsibility to report foot health problems based on what we have discussed.

All the male interviewees in our local study, irrespective of age, reported that they were more concerned with relief of pain and maintenance of foot function than the appearance of their feet. This echoes the findings of Williams and Nester (2006) in their study where the male subjects were more satisfied with their hospital shoes as function was considered of primary importance to this group. Gender differences have an important role in health psychology. Reese (2000) reports men tend to avoid health screening, ignore warning signs and hide emotions due to deeply ingrained social traditions. Men are found to be less likely to seek medical advice during illness or to rest when unwell and engage in fewer health promotion activities in general (Taylor et al, 1998). Despite this, in diabetes, men have a higher belief of their self-efficacy than women (Rubin & Peyrot, 1998). Information cannot be found to support this in RA.

**Concealment of symptoms.**

The use of biologic agents to manage RA has increased rapidly. The podiatric implications are documented by Otter et al, (2004). The potential side effects of these anti-TNFα drugs may lead to an increased infection risk due to the effect on the immune system. Infections can manifest themselves in the foot and podiatrists need to report any clinical signs of this to the rheumatologist who may wish to review the choice of medication. Patients generally respond well to these medications and individuals do not wish to jeopardise the benefits experienced in terms of disease management. One interviewee mentioned he had opted to have his toe amputated, when it suffered repeated ulceration, rather than risk withdrawal from his current biologic medication.
Market research conducted on behalf of National Rheumatoid Arthritis Society (NRAS, 2007) revealed that one in five patients avoid revealing the extent of their symptoms due to concerns that their current medication will be taken away. This same report mentions that one in five patients find the language in consultations confusing and one in four find it difficult to explain their symptoms fully which compounds the communication failings mentioned previously.

The effect of a chronic illness on employment provides another explanation for concealment. One male participant admitted to hiding RA symptoms for a number of years. Being in the army, he would have faced discharge on medical grounds had he been diagnosed from the onset of the first signs. The patient had researched the problem and decided not to disclose his symptoms because he suspected RA would be a threat to his career. Another interviewee mentioned the importance to him of remaining in work and indeed the issue was raised in an episode of the television drama “Casualty” when the story revolved around a lorry driver who masked his RA for many years to avoid losing his HGV licence (BBC, 2009). The drama showed how this had led to an accident which confirmed the potential devastating consequences of his actions. This reason for concealment may be an important factor for the patient who is considering instigating a consultation to discuss a foot problem. Unless the pain they are experiencing is desperate in nature, some individuals would rather mask it than risk being seen as unfit for work and consequently unable to live a normal life which we have seen is of utmost importance.

Appointment implications.

The consequence of a chronic illness on the individuals’ ability to live their life in practical terms is clearly illustrated by the effect of appointment overload which, during the course of the year, led the patients interviewed in our study to avoid seeking further help unless it was considered absolutely necessary. A male interviewee expressed a concern over the number of appointments he has to attend with a variety of healthcare professionals. Several mentioned the problem of fitting appointments around work and other commitments including family. These appointment implications were expressed in terms of material costs in relation to time and money. Whilst there was a desire not to
bother the rheumatology team more than is considered by the patient to be necessary, the inconvenience to self and family seems to be the greater influential factor.

The practical and geographical problems associated with attending appointments can influence the decision of the patient to seek help for healthcare needs. Heenan (2006) conducted a study looking at rural Irish farmers and the problems experienced with their uptake of health services and failure to take part in preventative health measures. She discusses the attitudes and beliefs of people in rural communities, especially in the older age group, who consider seeking help as a sign of an inability to be self sufficient. They only contact health services if desperate and rarely take notice of health promotion strategies. This is partly due to the aforementioned need to be self reliant and the geographical problems of travelling to reach health services. This was a reported consideration for the participants in our study. It was noted that most of them lived outside the city area and this is representative of the RA population locally. The time taken to travel to the general hospital and the costs involved are a reported problem when attending planned consultations so would also be a consideration when being asked to attend for education sessions when a patient may not see this as essential.

In an attempt to reduce the burden of routine appointments on patients and to reduce the financial commitment for the NHS, Hewlett et al (2005) devised a six year randomised control trial looking at patient initiated outpatient follow-up in RA when compared to the standard routine rebook system. Hewlett’s report found no detriment to health or psychological status following a change in follow-up regime and patients. The direct access group had fewer appointments and reported greater satisfaction with the system. This would indicate that a system where patient self-reporting of symptoms is in place does work. However, this study was successful because the participants were given adequate written information regarding the expectations placed upon them and their G.P.s too were given written advice on the changes in the management of the patients RA follow-up in order that they were fully aware of the implications for them. This does not therefore support the shift in responsibility to self-report health problems to the patient without an adequate support network from colleagues in primary care which is not currently in place locally hence adding to the disturbance in practice.
Ideally the individual needs of each patient should be considered when issuing appointments in an attempt to take into account bus times, distance to clinic, school run commitments etc. All of these factors were of concern to the interviewees. Early morning stiffness has traditionally been considered an important impact of RA as it is a cardinal sign of inflammation used for the diagnostic classification criteria (Arnett et al, 1988). The podiatry department used to make allowances for this and sent later appointments for those patients with inflammatory arthritis. Having said this, the symptom cannot be assumed to be in evidence for all patients especially where there is established disease. In these cases drug management may have helped reduce the symptom or the stiffness does not wear off during the day. As reported by one interviewee, a morning appointment can be worse for some patients as she feels better earlier in the day, deteriorating as the day goes on. The difficulty of scheduling appointments around the individual’s practical requirements has led to some of the interviewees failing to attend podiatry appointments or to follow up referrals once they have been made. This was reported by a patient, who ignored follow-ups following a missed appointment citing distance and dog-sitting as the main reasons for this. Another patient frequently failed to attend appointments and was lost to the podiatry system because the timing interfered with work commitments. These practical considerations may prove a barrier to self-reporting foot problems.

Literature has been found to suggest solutions to the practical barriers which obstruct attendance at medical appointments. A delay in reporting symptoms before the next scheduled appointment may be overcome by the use of a rheumatology telephone helpline. Hughes et al (2002) investigated the benefit of this service and found that patients were very satisfied with the telephone advice received and the speed of response. It provides much needed reassurance for people with chronic diseases and negates the need for additional hospital appointments which had been suggested as another reason for failure to report concerns by patients. A prompt response by a rheumatology practitioner provides a more individual answer to the patient’s queries than a trip to their General Practitioner. Negative aspects of this service would be the lack of clarity on the medico legal considerations of advising the patients without seeing them and a problem of patients having to leave a message on the answering machine which is difficult for some elderly patients for a variety of reasons. Also McCabe et al (2000) compared a number of telephone help lines and reported on the disparity in
service provision nationally which led to varying degrees of success in its implementation. The grade and profession of the responder has a bearing on the level of information given and is an important consideration when providing this type of service. The shortfalls were also noted by Thwaites et al (2000) in a report which has led to the Royal College of Nursing Rheumatology Forum developing guidelines for these telephone services. Linton & Meadows (2001) describe their telephone service which addresses all the above concerns. It is available during normal work hours and is manned by staff of high grade to provide information on general rheumatology queries. Patient satisfaction with their telephone service is good. In order for a telephone helpline to assist with the problem of self-reporting concerns, it seems it ought to be provided at this level to achieve the desired outcome. The financial implications of this would prohibit its implementation locally because of the scope of the study set out in chapter 1.

Who to approach for help with foot care.

The choice of healthcare professional approached by the patient for help is reported by the study participants as being largely down to chance, being the person most accessible at the time and occasionally based on previous experience. This view is also supported by health psychologists who report that individuals are more likely to hand control of their health to medical professionals if they attribute their illness to external factors and feel they are not personally responsible for it (Ogden, 2007). This links with the previous concern over control of the disease.

A positive finding from the interviews was that the majority of patients interviewed were firm in their beliefs that the rheumatology practitioner would be the person responsible for their RA foot problems and they would contact her in the first instance should symptoms arise. The remaining patients were unsure who to deem responsible but chose the rheumatology practitioner when pressed. This choice seems to be influenced by the nature of the appointments with the practitioner indicating that she knows more about their individual disease process than other members of the rheumatology team. The individual currently holding this post locally has a nursing background. Nursing is reported to have the aim of integrating the object body of science and the lived body of individual experience making care more patient-centred.
(Twigg, 2006). The potential benefits of this approach on rapport between this professional and her patients may go some way to explaining the responses. The National Institute for Clinical Excellence guidelines (NICE, 2009) indicate that the practitioner will indeed be the person who holds responsibility for coordinating health care for the patient and thus the document follows what the patients already believe to be the case and clarifies the position for the health care professionals involved. Targeting any clinical change in practice towards improved links with this individual may help the original disturbance. At present, it is not known whether the rheumatology practitioner herself is aware of the views of her patients and thus the responsibility placed on her with regard to health care.

Two interviewees reported their GP as the person to be considered with the responsibility. One interviewee (the ex-Army man who had concealed his symptoms for years) insisted that the rheumatologist held the responsibility for all his healthcare requirements. He based this on previous experience of preferential treatment provided by officers and others in powerful positions to ensure he received the best care. It was a surprise to learn that only one patient of those interviewed would contact a podiatrist in the first instance as seven had previous experience of the services of a podiatrist at some stage. Once again this could prove to delay the onset of appropriate footcare especially as we have seen the potential for miscommunication reported above. Returning to the role of previous experience in the decision-making process, two participants went on to suggest that the occupational therapist would be responsible for their foot health as she had been the professional who had assisted them with previous hand symptoms and, as previously stated, there are times which the two situations are equated.

**The health professional-patient interface.**

Once the patient has made the decision to seek help with a concern, either general or foot related, the interviews indicated that some potential problems may occur at the health professional-patient interface.
Communication

The findings indicate that, even in those situations when the patient does report problems, the healthcare professional to whom they turn for help may not act on it. The participants reported the misunderstandings resulting from information provided from their health care team. The assumption has been made that this is due to a lack of access to the facts regarding eligibility to attend the podiatry service but the literature suggests there may be other explanations for this. The health professional may have a subconscious need to retain power during the consultation or because they are primarily concerned with the more objective signs or symptoms presented to them and may overlook any concerns presented in a subjective form.

Within the current objective and scientific biomedical concept of health, doctors are taught to filter through the patient’s subjectively viewed description, in order to objectively view the underlying medical condition (Twigg, 2006). It is at this stage in the consultation that important reports from the patient can be missed. The subjective nature of pain also underpins its inability to be shared and patients repeatedly report the reality of having their pain questioned (Kleinman, 1988). Health care professionals do not like to hear about pain, not only because they are concentrating on the more physical signs, but also because it would make their work unbearable to focus on this area (Madjar, 1997).

Patients may have to be encouraged to speak the same objective language as the medical profession in order to achieve the required outcome from the consultation. Patient’s reports of symptoms and concerns tend to be more subjective and relative to the effect on the individual. If self-management programmes are to be of maximum benefit, the patient would need to be educated as to how to present concerns at consultation to achieve a desired effect.

Relationship.

The local rheumatology patient group currently rely on their one-to-one consultations for provision of this knowledge and the medical profession itself can greatly manipulate this discussion. Variations in the approach of the doctor or health care professional (due
to training, experience, beliefs etc.) can influence their relationship with the patient and account for differences in the advice, and indeed treatment, received. The realisation that poor communication can lead to dissatisfaction and influence therapeutic outcomes and compliance (Morgan et al, 1985) has produced literature to describe the importance of the different forms of doctor-patient relationship.

In their seminal work, Szasz and Hollender described the relationship between health professional and patient as either:

- Active-passive, where the doctor does something to the patient who passively receives treatment (as in the case of surgery, trauma or coma).
- Guidance-cooperation, where the doctor tells the patient what to do and the patient complies (usually seen in acute illness).
- Mutual participation, where the doctor helps the patient to help himself and the patient uses expert advice (seen in chronic illness and psychotherapy).

(Szasz & Hollender, 1956, p586)

This view, and that of Parsons (1951), makes an assumption that the relationship is a reciprocal one with the patient accepting the doctor’s authority because of his superior knowledge and skills in order to adhere to the sick role (which has been mentioned earlier in this chapter). However, it was Bloor & Horobin (1975) who suggested that patients are sometimes viewed by doctors as far from the ideal model when they present with, in the doctor’s opinion, trivial health problems. The solution to this is to provide the patient with sufficient information to allow them to distinguish between those problems which need help and those which are seen medically as of little matter. This echoes the health promotion recommendations outlined earlier. The problem is then that, for the patient, this increased knowledge leads to increased power. This can be seen by the medical profession as a threat to their autonomy. Thus we see a further complication to the initial view that patient education is to be encouraged. Rather than helping to ensure patients receive the best possible care, it may lead to a power struggle with the professionals who hold the key to the provision of this care. Despite the acknowledgement that patient empowerment is to be encouraged, there may be additional factors in play which contribute to the inhibition of this empowerment.
The idea of the doctor’s power over the patient should not be underestimated. Foucault explains that groups of health professionals exercise authority through systems of power and knowledge and through their capacity to order and discipline the bodies of clients and patients (Rabinow, 1984). Control of knowledge maintains control of power by increasing the distance between the expert and the consumer and may be used for exploitation (Johnson, 1972; Waitzkin & Stoeckle, 1972). Stimson & Webb (1975) explain that doctors control not only information but access to themselves and possibly other services (which may include podiatry in this case). The authors also suggest that, even when patients are dissatisfied with this relationship, they rarely confront the doctor directly and so the situation is not questioned.

Freidson (1970) criticises the early relationship models as they do not consider those situations where the patient is active and the doctor passive. A “Clash of Perspectives” can occur depending on the cultural background of both parties and the context of the medical issue under discussion. In addition to this, Scheff (1968) introduced the idea of the “hidden agenda” which can apply to both contributors in the relationship and can influence the exchange during consultation.

This translates to the relationship in Primary Care as well as within the hospital team which should be considered for those cases when the patient chooses to contact their GP in the first instance as was reported by some interviewees. The recent NRAS/ King’s Fund report refers to the Department of Health paper “Our Health, Our Care, Our Say” (2006b) and highlights the variability of GP awareness and general knowledge of rheumatoid arthritis leading to a delay in referral to specialist services and subsequently podiatry. Indeed, the report states that, in the general population, there is a low level of awareness of RA which may be a reason why patients themselves delay seeking help initially. Only 35% of the 599 patients who took part in the report said that they had been offered an appointment with podiatry.

In an ideal world, a patient centred consultation is the way forward. This would attempt to minimise any patient dissatisfaction with their relationship with the healthcare provider, disclose any hidden agenda and encourage open discussion. Patient centeredness was first developed by Byrne & Long (1976) and has been expanded
further since. Although this is implemented in a variety of ways, it generally consists of three components described by Ogden (2007):

- Receptiveness by the doctor to the patient's opinions and expectations,
- Patient involvement in decision making and treatment planning,
- Attention to the affective content of the consultation in terms of the emotions of both patient and doctor.

In chronic conditions like rheumatoid arthritis the consultation can be opened up by questioning from the empowered patient who has developed ideas regarding the effects of the disease and its management through personal experience. This situation can arise following the implementation of the aforementioned Expert Patient Programme. A potential problem with this position occurs when the medical beliefs of the patient are not always correct as was found in the local interviews and will be discussed later. In this situation the doctor finds it more difficult to maintain their hold on power in the relationship and more patient dissatisfaction may be evident. It is possible that, to evade a power struggle, some patients may avoid seeking the intervention of the healthcare team in an attempt to protect their own hidden agenda. This was certainly the case for some of the interviewees when they wished to protect their employment options or to maintain the course of their preferred choice of drug therapy.

Patient-centeredness is to be encouraged beyond this one-to-one consultation and developed within the rheumatology team as a whole. Worthington (1994) suggested that patients with progressive diseases would benefit from a multidisciplinary approach because they have a need for long-term, flexible management strategies. She also says that early intervention is required to obtain active patient involvement in the management of their disease. No literature has been found to date that contradicts this for chronic conditions. This introduces the role of the patient in the team management of their disease and emphasises the importance of introducing this concept early in the management process suggesting that patient input would be less effective or their cooperation lacking if this were to be attempted later in the process. With this team approach to care, the aforementioned problems of personality clashes and power struggles are less likely as the patient would interact with more than one healthcare
professional. A favourable rapport, with at least one professional, leading to the desired open exchange of views would be more likely when a team is involved in patient care.

It can be seen, therefore, that the relationship between the doctor and patient has a bearing on the information exchanged during the consultation and any subsequent action taken as a result. The doctor may well feel he is in a position to use his expert knowledge to exercise power over the patient by control of access to services. Conversely, patients view knowledge of their disease as powerful in the relationship with their doctor and the timing of any disclosure may be used to control this relationship. Either way, a delay in the access of services required may result from this power struggle.

**Communicating with podiatry services.**

Once the patient has reported their foot concerns to a health professional, which is unlikely to be a podiatrist in the first instance, this link professional should refer onto podiatry services as recommended in the literature. Whilst not the aim of the qualitative research, problems at this level do contribute to the overarching aim of the investigation and will be mentioned briefly in relation to our understanding of the provision of foot health services.

**Communication.**

The interview findings indicate that patients tend to report foot problems to the rheumatology team in the first instance. This being so, the importance of good communication between the rheumatology and podiatry departments would seem essential to RA foot health. The different styles of team delivery in health care have been discussed in chapter 2 (pp.33-34) with the local rheumatology service falling broadly into the category of a core and periphery approach to team working. Both the preliminary fieldwork and interviews have highlighted the lack of clarity in the communication network associated with this style of care delivery. This contributes to the potential for missed opportunity to refer to podiatry as reported in chapter 6 (p.126). The main reason for this is thought to be the aforementioned misunderstandings regarding eligibility for treatment and waiting lists. This provides further confirmation
that the referral pathway between the two services is not as recommendations in the literature suggest. There may also be other reasons for this failure to refer patients to podiatry as set out below.

Inter-professional relationship.

It could be that the status of podiatry is not sufficiently regarded in some rheumatology departments for referral of patients to be recognised as a priority. Despite podiatry meeting the criteria for professional status (Goode, 1960), the public and some medical colleagues do still perceive other professions of similar standing to podiatry to be of a higher status (e.g. physiotherapy) and therefore perhaps podiatry is not viewed with the same importance (Mandy, 2000). This may in part be due to the gender balance (predominantly female) or some aspect concerning the nature of podiatric work itself (Mandy et al, 2003). Another factor may be the lack of evidence based practice seen in the discipline which is also thought to jeopardise the inclusion of podiatry in the multidisciplinary team (Cameron et al, 2009). As well as having an influence on the inter-professional relationship, this perceived lack of status within the public sector would not encourage the self-reporting directly to podiatry by the patient.

Service Provision.

Another explanation could be related to influence of resource management on referral to podiatry. With podiatry being part of the local Primary Care Trust (PCT) and not based within the Hospital Trust there may be budgetary factors which affect the referral to our service for footwear and orthotic management. As previously mentioned (Chapter 1, p.10), currently the only direct involvement of podiatry with the rheumatology team is via the consultant led lower limb clinic in which the podiatrist and orthotist join the rheumatologist. When a second consultant requires orthoses or footwear for a RA patient, they refer directly to the orthotics department. This avoids the lower limb clinic and the involvement of an additional consultant’s input. However, this also bypasses the potential for podiatric assessment. The results of the preliminary work reported in chapter 3 (p.43) indicate that lack of podiatric involvement does have a bearing on the appropriate use of subsequent orthoses by the patient. There were reported misunderstandings regarding the costs of referring to podiatry in community for foot
interventions beyond those biomechanical in nature. Referral of the patient via the GP would negate this cost implication for the rheumatology department but does rely on the GP as gatekeeper to be fully informed regarding access to podiatry services. Again, there is evidence to suggest confusion in the referral pathway.

It can be shown that, from patient’s reports of experiences, it is possible for healthcare colleagues to block both direct referral to podiatry services and in providing inaccurate information to patients, reduce their ability to make the referral for themselves. These additional factors are a concern when the interviewees indicate the rheumatology department would be their first contact for foot symptom reporting.

**The role of the patient in initiating rheumatoid foot care.**

The findings have fulfilled the aim of understanding the provision of footcare services with particular reference to the role of the patient as instigator of this. Mapping and interpretation of the data has brought together the findings of the qualitative case study in a visual representation of the role of the patient in initiating foot care.

The diagram shows the patient as a see-saw. The items stacked on the right of the see-saw are those factors which are likely to influence the patient in a positive way to seek help with foot concerns and the eventual assessment by a podiatrist. Those items stacked on the left of the see-saw are those factors which may cause the patient to delay seeking this help such that the outcome for the developing foot concern remains uncertain. It may be discovered by chance at a consultation but, at present, there would be no formal mechanism to discover it without the patients self-reporting.

The items stacked at the pivot of the see-saw are those factors which may influence the patient’s decision to seek help in either direction depending on how they are interpreted by the patient in terms of importance and in the context of the magnitude of other influences at that moment in time. The seat of the see-saw itself represents other factors individual to that patient which may also influence their decision in either direction.
Figure 2: The role of the patient in initiating foot care.

(Original in colour)

These factors mirror those cognitive dimensions described by Leventhal et al (1997) when discussing the patients’ beliefs regarding their illness:

- **Identity**: referring to the label given to the illness and the symptoms experienced,
- **The perceived cause of the illness**: may be biological and/or psychosocial,
- **Time line**: the patients belief of how long the illness will last,
- **Consequences**: the patients perception of the possible effects (physical and/or social) of the illness on their life,
- **Curability and controllability**: whether treatment or cure is available and the extent to which the outcome may be controlled by others.
At the commencement of the study, the relevance of these dimensions to the research question was not fully appreciated. They had not previously been applied to the provision of foot health care for patients with rheumatoid arthritis. This research has exposed the significance of health belief models to patients in self-reporting foot concerns. In addition, the findings relate to the work of Bury (1982) who described chronic illness as a major disruptive event in a person’s life. He suggests that there are three aspects to this disruption:

1. Once the person realises that their symptoms do not fit the normal pattern of aches and pains they can feel unsure as to whether and how to disclose the illness. There can be shock at the perceived implications that RA may have for the individual. This, and the reported practice of hiding or disguising the effects of chronic illness, can lead to a delay in referral.

2. When a diagnosis has been made, whilst it serves to provide some objective focus, this remains within a background of uncertainty. A situation arises where the incomplete medical information becomes supplemented with the patient’s own reserve of knowledge and experience as the search for answers continues. At this stage, a more reflective disruption occurs involving a fundamental re-thinking of the person’s biography in an attempt to find answers to explain what is happening to the individual and why.

3. The next stage of disruption requires the rearranging of personal and social involvements. This aims to achieve mobilisation of resources as a reaction to the altered situation but is also a response to the embarrassment of functional limitations.

Williams (2000) questions the disruption described by Bury (1982) in the light of emerging postmodern and disability perspectives. He reports that illness may not be viewed as so disruptive to the individual when hardship or experience in other aspects of life lead the disruption to be seen as expected. Indeed it may be considered a normal crisis. As such, it can be relative to class, age, gender and ethnic considerations. In this way, Williams argues that the extent of any biographical disruption is tailored by the experience and the meanings attached to it and has to be viewed in relation to timing, context, norms and expectations. Flexible working conditions and the increased tolerance to diversity in social may have also lessened the disruptive effect of chronic
disease on the individual but the author concludes that biographical disruption remains an important consideration and may well be a causative factor in perpetuating illness.

The interviews from this study have confirmed the influence of these disruptive events on the individual. Following the diagnosis of a chronic illness, health care decisions made by the patient are informed by the meanings attached to the circumstances in which they now find themselves.

The diagram indicates that, for every factor which may influence a patient towards seeking help for foot concerns, there is another which might impose the opposite effect. This being so, the findings of this study would indicate that continuing to allow the patient sole responsibility for initiating appropriate and timely podiatric assessment is problematic and unlikely to achieve the recommendations for foot health set out in the literature. Recommendations for changes in practice in light of this new information are discussed in chapter 9.

**Summary.**

The discussion has shown that the factors acting on the patient to influence their decision to seek help for RA foot concerns in a timely and appropriate manner are multiple and varied. Some will act to encourage health care seeking behaviour and others will act to discourage this. It was not known at the commencement of this study the extent to which these factors would reach beyond knowledge and understanding into health belief models. This research has shown that these complex issues add to the resulting clinical observations experienced, namely failure in early uptake of podiatry services. This new information has led to the conclusion that patients should not be given sole responsibility for the recognition of rheumatoid foot concerns as this approach is unreliable.

The following chapter will reflect upon the research process as is consistent with professional doctorate studies and qualitative research. It will discuss the effect of the researcher on the participants and gatekeepers but also the effect these individuals had on the research. Chapter 8 will report on the strengths and limitations of the study and the journey through the professional doctorate programme.
Chapter 8: REFLECTION.

Introduction.

Mention has already been made of the importance of demonstrating the trustworthiness of the researcher and the study (chapter 5, p.82). Reflection on the research process is a valuable part of the transparency required to achieve this (Alvesson & Sköldberg, 2000; Etherington, 2004). Hand (2005), emphasises the importance of reflexivity as a way of signposting the reader as to what has been going on in the research process. Whilst it is hoped that reflection is apparent throughout the thesis, this chapter provides a broader reflection on the research process as a whole.

The Influence of Others on the Research.

Pope & Mays (1995) report on the issues around gaining initial access to clinical areas and this was certainly an important factor in this study. One of the most difficult matters to address when planning the study was the attitude of others in regard to the research. I was naïve in assuming that everyone involved in rheumatoid patient care would be as enthusiastic as I to engage with this investigation. I noted in my research journal (17-05-06), when planning the preliminary fieldwork, that access to the rheumatology department would pose a challenge for me as I was viewed with suspicion. It was during this process that I developed an awareness of the insecurities of the rheumatology department. The clinicians thought that my research would be evaluating their service and may be critical of their practices thus showing them in a poor light. Those individuals with a management role were weary that this spotlight on their approach to foot health considerations may put pressure on them to include a specialist podiatrist within the team with the associated financial implications this move would bring. Whilst I could appreciate that not all rheumatology departments could maximise the use of a dedicated specialist podiatrist because of the cost implications, I assumed that, at the very least, the rheumatology team would wish to make full use of whatever level of podiatry services was currently available to them. In addition, I had heard from other sources that no research would be encouraged which would show the Hospital Trust in an unfavourable light at a time when it was looking to achieve Foundation Status.
Initially I was surprised and concerned by this view of my intentions as criticism of the department was not my objective. Having tried to explain the nature of the proposed study and its aims, I became frustrated that there were still certain key individuals with doubts as to whether I should be allowed to continue with my proposal. I regarded this attitude as the inability of others to accept that, in order to progress towards meeting published guidelines/standards of care, you have to assess your current status and acknowledge room for improvement. If no improvement were necessary, there would be no need to develop the recommendations. At this point, I considered taking the study to another department in a neighbouring NHS Trust but, as I particularly wanted to investigate the circumstances informing the local situation, the move would have meant a complete change in direction. However, by working through the access problem by repeatedly returning to the department to answer queries, I was gradually accepted. The process taught me to appreciate the opinion of others and to be aware that their attitude may be influenced by more important issues affecting them at the time. From this experience I gained an insight into others’ perspectives which became an influential factor in the appreciation of my philosophical stance.

The preliminary field work proved invaluable in planning the qualitative study. Apart from achieving its aims as explained in chapter 3, it gave an opportunity for the team to get to know me and to ask questions about the nature of the investigation. By the end of the audit stage, the staff members were comfortable with a researcher in their department and were happy to assist in a further qualitative study. In addition, they also gained a greater understanding of the work of podiatry services and how we could be of benefit to their patients. I then proceeded to formulate the qualitative research protocol and submitted it for ethic committee approval.

A valuable lesson was learned about the importance of involving the relevant gatekeepers early in the planning phase of research. Burgess (1982) reports that the tendency is to contact the most powerful person in a particular setting in order to obtain access, as was the case here. However, he goes on to say that this approach can restrict access also. When this occurs, it is suggested the researcher should ask “What right has any individual to grant or withhold access to a researcher who wants to conduct research with other informants?” (Burgess, 1982, p17). In the case of this study the consent of
the consultant to interview his patients was required by the ethics committee before approval was granted. The potential negative effect on the relationship between the rheumatology and podiatry departments would have undermined the spirit of the research aim had an amicable conclusion not been achieved.

Lack of motivation continued into the recruitment phase of the research. Whilst the rheumatology practitioner was happy to assist with this process, and I relied on her to fulfil the requirement of the ethics committee to avoid coercion, there was difficulty in maintaining this recruitment role when I was not on site to keep up momentum. In an attempt to improve this situation I engaged in a frequent email dialogue with the individual to provide a prompt in the guise of a progress report. Although it was a struggle to move the research forward with regard to access, it was certainly worthwhile and the relationship between rheumatology and podiatry was improved rather than jeopardised through this encounter.

With the benefit of hindsight I would have spent more time involving the team in the planning process to fully engage them at the start. It may have been helpful to have arranged a team meeting before any proposal had been developed to ask for thoughts on how best to design a project to answer the research question. This would have given the rheumatology department a level of ownership over the study. A team meeting approach would also have helped to avoid misinterpretation of the study information as it was cascaded from management to clinicians.

**The Effect of the Researcher.**

Clough & Nutbrown (2002) state that the research design does not guarantee that the researcher and object are distinct from each other because it is impossible to do so. Certainly in the local rheumatology department, it was difficult for me to distance myself completely from the area of study as the podiatry department does work with the rheumatology team in respect of the Lower Limb Clinic, although I am not directly involved there myself. Indeed the rationale for the research was led by my desire to work towards achieving an improved level of podiatric service provision as set out in the literature. The motivation for the investigation was also an assumption that patient foot health provision could be improved and I set out to achieve this end. At the outset, I
was convinced that it was purely a need for formal foot education which contributed to the lack of timely referral to podiatry services. If patients had been given sufficient advice regarding foot symptoms and signs that needed addressing it was assumed that they would want to seek the appropriate service to provide this care. Thus, an assumption was made that the findings would indicate inadequate understanding in this area. I had not anticipated the complexity of the situation.

Corbetta (2003) states that in quantitative research the researcher's attitude towards her subject is neutral and detached whereas in qualitative research there is empathy and identification which indicates that a degree of attachment to the subject is acceptable. This being so, I had to accept that my approach to the investigation and the assumptions I carried with me would influence my interpretation of the data and these assumptions should be made clear to the reader.

**The Research Process.**

Once the interviews were underway, I had initial concerns that my data collection would not be of sufficient depth to address the research question especially as, when asked about education received, patients merely stated that they had had none. Grbich (1999) reminds us that some people take longer to consider a response and that non-verbal cues indicate whether the question had been understood but in this case I was sure that the patients were definite in their responses. I was unsure how this closed reply would help to form any useful “themes”. Therefore, despite having an interview guide, I found myself asking more direct questions about specific individual sources of RA foot information in an attempt to glean any answer to my question. My concern then was that I was assisting with recall, thus defeating the object as recollection of information was at the heart of the research question. The literature I had referred to regarding the use of interviews had made the process sound as though it should be more unforced with the participant responding in a full and frank way.

I felt relieved when I read a report by Collins who stated that:
“There is a tendency at the outset for students to see the interview as a kind of smash and grab opportunity in which they accost some innocent bystander and relieve them of whatever useful “data” they may have”

(Collins, 1998. section.1.1)

He goes on to explain that this is, in part, due to the assumption formed from texts that implies a “model” interview during which facts are collected in an objective way. Whilst we acknowledge that the aim of qualitative research is not objectivity, I felt some literature still subliminally implied this. Following this reassurance I decided to have more faith in my interview guide, being based on my assumptions and the literature, and soon discovered emerging points of interest in the data which, whilst not always adhering to my initial assumptions, were relevant to the research question and produced a wider explanation for the issue under investigation.

Reading my transcripts, I was concerned that I frequently reassured the participants that they were telling me what I wanted to hear. Collins (1998, section 3.1) summarises that “the relationship between interviewer and interviewee is fluid and changing but always jointly constructed”. This is a recurring theme in the literature (Mason, 1996; Denzin, 1978; Burgess, 1984; Steier, 1991). It was only after reading the transcripts several times that I began to understand the significance of the information I had collected.

Collins also states, not only do we not have control over what is said during the interview, we also have little control over who we are. Referring again to Grbich (1999), I had considered my appearance to assist rapport by wearing non-clinical clothes and taking care to rearrange the interview room to appear likewise. The participants were aware that a podiatrist would be conducting the study. For some of them, the motivation for their participation was the opportunity to attempt to use me to either obtain a referral to the podiatry department or reduce their current appointment interval. In my field notes following the second interview (14-05-07) I reflected:
“This gentleman was obviously recruited for the study because he has a not-so-hidden agenda! His reason for participating today was solely due to his concerns that he does not have access to podiatry appointments as often as he feels he should. Therefore he saw me as a way of remedying this”.

Having considered this encounter, the decision was made to attempt to minimise advice in respect to individual concerns during the interview itself. I had to be clear with regard to the level of involvement I was prepared to provide in order to assist with individuals personal clinical issues. If the situation arose, the individual was advised that time would be allowed after the interview to discuss specific queries and several accepted this offer. Following this I also spoke to the rheumatology practitioner regarding the concern that recruitment was offering a platform for patients with an “axe to grind”. I decided to include this interview in the study because 002 raised valid points which were relevant to the research question. The issue of the level of involvement of the researcher in patient care or service provision is a problem reported by Gans (1982) who suggests that the potential problems should be addressed at an early stage.

Initially, some participants appeared a little guarded in their reports of care received from the rheumatology department and the personnel working within it. It was feared that information would be sent to the people involved in their health care. Despite being clear when gaining consent that anonymity would be maintained, this had to be emphasised during the conversations. Interviewee 005 exhibited the opposite traits and was open with his critical appraisal of staff. It was difficult not to become defensive of these colleagues. This influenced the interview in that I listened to all that was reported to see in what way the response may relate to the research question but I did occasionally offer up a brief explanation of why a colleague may have acted in a certain way. This was partly in defence of colleagues but also to educate the patient as to the reason for some investigations.

An enthusiasm for the subject and the responses being recorded led to the occasional concern that I, at times, allowed the process to became excessively “chatty”. In addition, I was sometimes frustrated by trying to maintain focus on the topics under discussion. I should have realised, after 23 years in clinical practice, that this is indicative of the age
group that formed the majority of my participants. Holloway (1997) reports on the effect over-rapport or under-rapport can have on a study in the form of a researcher bias. However, she goes on to say that rapport is important for the negotiating and sharing of ideas. The fact that the information gleaned was not what I originally expected or searched for in the literature and that what I did interpret from this was supported with evidence from the literature indicated to me that I found legitimate responses. It would have been easy for me to have got carried away with the responses from the interviewees and to have created an additional line of inquiry to explore further the details of individual themes raised. I needed to remain focussed on the specific aims of the research question and reserve the additional work for future projects.

I had made an assumption that each participant would have a view on each of the questions asked. This was not the case and, therefore, I had to accept that the lack of opinion could not be thematically analysed but was important to the research question in that it informed the other categories. With hindsight it is possible that a different line of questioning may have encouraged a more meaningful response to certain questions but until the data is analysed the researcher does not know what it is they do not know. Refinement of the individual factors influencing the self-reporting of foot problems in RA such that they can each be examined in greater detail is a potential future project.

It was disappointing that the participants did not want to take part in the member checking exercise. Whilst the literature does confirm limited credibility for this process, I thought I would take comfort in the feedback. My assumption from the experience was that the participants wanted to relieve themselves of their burden and simply walk away. It may have been that the interview was in some way therapeutic for the individual and that, once alleviated, they felt no wish to be reminded of the event. On reflection, I could have offered to share emerging themes, significant statements or a summary of the analysis with the participants, rather than the whole transcript (McKeganey & Bloor, 1981). However, the participants gave the impression they were not keen to receive anything further from me. Continuing on the subject of rigour, I have mentioned that the unanticipated findings from the interviews were backed up by the literature. Even though I have expressed the opinion in chapter 5 that literature suggests triangulation may not be considered valuable for every study, I found comfort in being able to demonstrate its application.
The Professional Doctorate Process.

The professional doctorate process has been long and, at times, painful. I have had to search hard within myself to discover my beliefs and attitudes regarding knowledge and the purpose of research. With no previous experience of conducting qualitative research, I underestimated the time it would take to read the literature regarding the potential choices of methodology and to appreciate their philosophical underpinnings. I tended to look at the methodology in relation to its appropriateness for the research question first but then struggled when my philosophical stance was incongruous with this fit. If starting the process again I would have spent longer exploring my beliefs about knowledge and truth long before considering research strategies.

My positivist background was one that I accepted without question. Previous quantitative research experience was focussed on achieving objectivity to the extent that an appreciation of my own beliefs was felt to be irrelevant. I have been comfortable with this detachment and the statistical approach to quantitative studies. However, on entering the realm of qualitative research I could see that my previous approach was no longer appropriate because the interpretation of the interview data would be influenced by my values and these would have to be clear to the reader. I tried to fit into the various philosophical “boxes” with little success. This was partly due to the approach I had attempted of fitting myself into a category rather than discovering my views and then finding a label to fit me. Whilst I recognised my belief that truth is constructed through the interpretation of individuals, I struggled to relinquish my positivist values because I acknowledge their importance in specific research circumstances. My new world view as a constructivist realist acknowledges both outlooks. It is congruent with my beliefs regarding truth along with an acceptance of an objective stance for use in quantitative studies. In this way there is an appreciation of how the two approaches to research can complement each other and should be encouraged to do so. This acknowledgement has provided the reassurance I needed to embrace a move to qualitative research.

Since conducting this work I have become a great advocate of qualitative research in the health care setting. However, having spent so much time reflecting on the issues
mentioned above, I find myself becoming very critical of reports professing to be qualitative in nature but with no mention or explanation of the style of methodology employed. As I review abstracts for conference presentations, it is hoped that this constructive feedback will help to strengthen qualitative work conducted by my colleagues in the future.

Having now experienced research into one’s own practice I appreciate that it is much more complicated than it first appears. Not only are there problems with access as described above but there is the possibility of seeing yourself in a way that had not been anticipated. This may be due to the response from others, patients or colleagues, or as a result of the findings as was the case with this study when the shortcomings within podiatry were uncovered. Juggling the role of the researcher with that of the clinician proved challenging at times.

As an individual I now am more willing to accept the views of others even when I feel I have evidence to suggest that their opinion is incorrect. I find myself wondering what has influenced their opinion before I pass comment. As a podiatrist, the well-being of the foot is of great importance to me but I had not appreciated that this importance would not be felt by others and, at times, this view could be justified when taken in the context of maintaining the health of the body as a whole.

Whilst the study programme was developed for “researching professionals”, it has been a challenge to juggle the demands of working in the NHS, family commitments, running a business and coping with the dramas that life can throw at you during several years of dedication to study. Whilst those undertaking full time doctoral studies must have their own obstacles to encounter, I imagine it must be an advantage to be immersed in a research and academic environment rather than having to switch in and out of this and the clinical setting. As I have developed into the role of a researching professional, my identity has changed in a number of ways. I have become a member of the Society of Chiropodists and Podiatrists Research and Development Committee. Within my own department my advice is sought before any new audits or research projects are undertaken. Whilst I am not employed as a specialist in rheumatology, I have been acknowledged as such and have been asked to review articles for journals, write book reviews and participate in teaching on a Graduate Certificate in Rheumatology Practice.
I have also been invited to present at rheumatology continuing professional development study days for podiatrists and participated in the “EFFORT” consensus exercise which was commissioned by the Arthritis Research Campaign (ARC) to explore the experiences of foot health interventions in both patients with RA and the health professionals delivering those services.

**Strengths and Limitations.**

Since finishing the study, I have considered whether the involvement of patient groups in the planning stage of the research would have improved the design. However, these patients are likely to have been highly-motivated and proactive individuals keen to be involved in a study of this kind. As this study aimed to understand the provision of foot care services in an area where patients were considered uninformed regarding foot health, the influence of these motivated individuals may have undermined this. The involvement of a patient group in the recommended future work may be of more benefit.

This study has succeeded in fulfilling its aims and objectives. In doing so, it has described a broad range of factors which may influence an individual with rheumatoid arthritis to make the decision to report foot problems in a timely and appropriate manner. Having fully analysed the data I would like to have conducted further interviews to investigate in greater depth the individual themes raised. However, this was beyond the scope of this professional doctorate programme, in that the research question would have become too big to be fully addressed in the time available. The choice of a descriptive case study approach would seem to have been appropriate but could now be expanded to inform future research (detailed in chapter 9). In this way the nine interviews were sufficient to provide a platform from which to launch a number of related studies to expand the findings further.

The findings are specific to the local situation where no education sessions are currently provided for the patient group and foot problems are not screened for. The generalisability of this research is questionable due to this specific context and the small number of participants. However, I have presented my interpretation of the data which readers of the thesis can further interpret and apply to their situation as appropriate.
Summary.

This chapter has reflected on the research process in terms of the challenges and subsequent decisions made to overcome these. It has acknowledged the development of the researcher throughout the professional doctorate process. Finally, it recognises the strengths and limitations of the study and makes them clear to the reader in order for them to evaluate the findings in relation to their own situation.

The final chapter will provide conclusions from the discussion, recommendations for changes in practice based on these conclusions and the plans for dissemination of the research findings. It will make clear the original contribution to knowledge that has been made.
Chapter 9: CONCLUSIONS AND SUMMARY.

Introduction.

Chapter 7 discussed the meaning of the findings from the interviews and their implications for extending existing knowledge and procedure in terms of their application to foot health care provision in rheumatoid arthritis.

From this discussion, conclusions will now be drawn which answer the research aims and present the contribution this study has made to theory, practice and policy. Also, recommendations for change in service provision and clinical approach have been suggested from these conclusions. All of these points will now be reported in chapter 9.

Fulfilling the research aim and objectives.

The overarching aim of this study was to increase our understanding of local footcare provision for patients with rheumatoid arthritis. The clinical observation prompting the investigation suggested that patients were not being referred to podiatry services in the timely and appropriate manner recommended in literature based on research evidence and best practice models. The preliminary fieldwork further highlighted that the recommendations were not being achieved and revealed that patients were relied upon to self report foot problems as they arose. No formal foot screening was in place to ensure potential foot problems were assessed in the opportune manner recommended but the effect of this on the uptake of podiatry services was not known.

As no education or self-management programmes were available to the patients, there was concern that the individuals were not adequately equipped to fulfil the responsibility placed upon them. The qualitative case study was designed to describe the patient’s understanding of, and attitude to, the effects of rheumatoid arthritis on the foot, and the services available to help limit these effects. The influence of the findings on the self-reporting of foot problems provided a greater understanding of this key role in accessing foot care services.
A summary of the findings as they relate to the individual objectives of the qualitative work (as set out in chapter 1) are listed below:

- *To explore patient understanding about the effects that rheumatoid arthritis can have on their feet.*

The participants recalled very little understanding of the potential effects that rheumatoid arthritis can have on their feet and consequently would be ill prepared to act appropriately on discovery of signs and symptoms relating to these effects. Patients have several opportunities to receive information from a variety of health professionals at one-to-one consultations throughout the year. The need for understanding may be related to the lack of formal education or self-management sessions but the extent to which this may occur is beyond the scope of this research.

- *To explore what patients understand about podiatry services and the help that is available for their rheumatoid foot problems.*

The participants reported limited knowledge of the nature and extent of podiatry services in terms of its ability to assist with the foot problems seen in RA. This was, in part, due to failings of communication during previous experience and “learned misunderstanding” from the experiences of others or from healthcare professionals. The general feeling is that podiatry is a service for those unable to cope with their own footcare and, as such, is considered last resort care.

- *To establish the views of the patient as to who is responsible for ensuring the health of their feet.*

There was confusion generally as to who should be considered responsible for the patient’s foot health. In the main, the rheumatology practitioner was the individual chosen for this task. This is a sensible choice as she tends to be the person coordinating care for the patient but there is concern that she may not be aware of the responsibility placed upon her. Confusion over the titles “chiropodist” and “podiatrist” were mentioned which should resolve over time following protection of
the titles and the gradual phasing out of the term “chiropody”.

- *To establish the existence of any barriers (real /perceived) to accessing this care.*

This was the area of questioning which revealed the majority of the issues relating to the research question. They have been presented in greater detail in chapter 7 (p.156) when describing the role of the patient in initiating rheumatoid foot care. The range of factors vary from practical appointment timing problems to fear of the effect of seeking help on employment or drug choice in disease management.

- *To offer an insight into the appropriateness of the current policy of patient responsibility for foot health in terms of foot screening.*

The conclusion here, in light of the above remarks, has to be that it is not appropriate to continue with the current policy as there is evidence to suggest that it is not effective in achieving its aim because of the multitude of factors individual to each patients which would influence their decision not to seek help in a timely way as recommended by the literature. Recommendation for changes in practice to help rectify this are discussed later in this chapter.

The audit therefore provided the numbers to support the clinical practice concern and identified the current referral pathway to podiatry services and the qualitative research investigated this pathway further to describe its appropriateness.

**Conclusions and impact.**

The recommendations for foot health provision described in the literature are not being addressed for the local RA patient population and the reliance on a podiatry referral pathway instigated by the patient seems to be a major reason for this.

From this study there are now known to be a variety of diverse factors that affect the decision to seek help for foot health concerns beyond a simple understanding of those
signs and symptoms that need further assessment. This being so, education programmes are unlikely to be sufficient to ensure patient sole responsibility for foot health is adequate to achieve recommendations in the literature. Whilst self management programs are reportedly more likely to change behaviour than simple foot education sessions, this alone can still not be relied upon to evoke the necessary level of change required due to the many and varied addition influences for the patient. Individuals have their own hierarchy of issues that have variable importance to them at any given time. This influences decision-making and has implications for podiatry if that the foot often fails to figure highly in this ranking.

Our understandings of podiatry service provision developed from both the preliminary fieldwork and the qualitative case study data led to the conclusion that the current practice of allowing the patient with rheumatoid arthritis sole responsibility for assessing and reporting foot health concerns is not safe in circumstances where additional support systems are not in place (i.e. regular foot screening and adequate self-management schemes to assist with the patient’s decision making process).

There are implications from the findings which impact on the patient, the podiatrist, the multi-disciplinary team, the NHS rheumatology service as a whole and government policy makers. Thus, these implications are relevant locally and nationally. Any delay in referral for podiatric assessment has consequences for the patient. These range in significance. Minimum impact is perceived as a lack of understanding as to the nature of the management plan instigated. This has been experienced when patients report that they choose to discontinue insole use once symptoms subside despite the fact that this action may be contra-indicated. When advice and follow-up with podiatry is in-situ, this outcome choice is less likely to occur. More seriously, the decision to impede podiatry involvement can lead to the lost chance to limit foot deformity when the window of opportunity to intervene is delayed. The majority of the literature emphasises the value of the podiatrist as a member of the rheumatology team. However, reports have been issued that support the view that podiatry as an important resource is still being underused (National Audit Office, 2009).

The implications for the podiatry profession have been acknowledged in the changes in practice which have already been implemented locally and are reported later in this
chapter. The need to engage fully with the patient to ensure improved communication is more important than originally appreciated. The consultation has been a missed opportunity to provide advice to the individual on a one-to-one basis. Also, this consultation should be an occasion to monitor for foot changes as well as provide treatment. The appropriateness of discharging patients with chronic illnesses, which may have variable effects on foot health over time, is brought into question due to the potential to lose patients to potential intervention.

Rheumatology practitioners need to be aware that failure to screen for foot involvement in RA may lead to the implications for patients listed above. The use of the DAS28 has allowed this to happen but this study has shown that patients will not necessarily self-report foot problems if their rheumatology team do not enquire specifically about these concerns. This being so, those bodies producing guidelines and standards of care documents need to be aware of this when publishing future recommendations and also of the limited impact of self-management programmes in achieving the aim of patient empowerment to seek help.

The original contribution to knowledge.

The original contribution of this research is the application of a diverse range of subject areas, each of which is well supported in the literature, to the context of foot health provision in rheumatoid arthritis such that the efficacy of self-management programmes as a tool to encourage patient self-reporting of potential problems is brought into question.

The qualitative case study described the variety of influences faced by the patient when making the decision to seek help for foot concerns. This information was not previously available to the podiatry profession. It has enabled a greater understanding of what is happening locally in terms of failure in uptake of podiatry services and how this is related to the role of the patient in the management of their own foot health.

This information is important as it helps to explain why patients are being referred to podiatry services at a stage in their disease when foot deformity has already occurred beyond the level which may have been prevented by podiatric intervention. This
undermines the long-term independence of the patient. From this enhanced understanding of the provision of foot health services, several recommendations for changes in practice can now be suggested.

**Recommendations for practice.**

This study has provided an understanding of the local position with regard to the provision of foot care services for patients with rheumatoid arthritis. The second part of the overarching research aim was to recommend changes, in response to the findings, which may improve this situation. The suggestions for this are as follows:

- Where self-management programmes are in place, and their goal is partly to encourage self reporting of RA related foot concerns, they should be evaluated in terms of their effect on behaviour instead of using simple satisfaction surveys. These surveys are often a reflection on the session itself and may not be repeated at a later date to check recall.

- Having established that self management programmes and education sessions may not fully address all the variables influencing the patient’s decision to self report foot health concerns, the responsibility for foot health should be returned to the health care professionals. A foot screening service ought to be available, as recommended in the literature, to ensure RA patients receive timely and appropriate foot care according to their needs and act on them. The findings from this study add weight to the argument in the literature for this. Locally, following involvement in the research, the rheumatology practitioner now tends to include questions on foot health in her routine patient review. Following dissemination of this research it is hoped that the importance of this change in practice will be acknowledged both locally and nationally.

- In addition to the above, it is suggested that annual foot reviews be offered by podiatry services to those patients who would normally have been discharged after failure to meet the eligibility criteria on the day of assessment. This change in practice has already taken place locally. This research questions the discharge of patients with a chronic disease of this nature where the gradual changes in
foot pathology need early intervention and may be missed is not screened for. This information will also be disseminated to the podiatry profession.

- As an alternative, or an adjunct to the above, a further recommendation would be to make podiatry the triage service for all foot problems regardless of their nature or symptoms. The podiatrist would then assess for suitability to be seen within the department or, if more appropriate, elsewhere. In order for this to happen, all parties concerned would have to meet and agree a robust referral pathway to ensure this service would not delay referrals to other departments if the matter proved not to be suitable for podiatric intervention. The problems of inter-professional communication could be a barrier for the implementation of this.

- The podiatry profession needs to make full use of each opportunity with the patient to educate them on a one to one basis regarding the potential effects of RA on the foot, what signs and symptoms to look for and which to report without delay. Written information for the patient to support this could be published by the Society of Chiropodists and Podiatrists in order that the information provided is standardised and evidence based. This regular and repetitive advice may help to improve the situation with regard to timely referral when used in conjunction with regular foot monitoring by a podiatrist.

If some of these changes could be implemented, the goal of equity in foot health services for patient with rheumatoid arthritis, in accordance with recommendations in the literature, could be nearer.

**The case for foot screening.**

The qualitative case study findings have further described the aspect of foot care provision in terms of the variety of influences faced by the patient when making the decision to seek help for foot concerns. Having commented on the questionable suitability of this patient role, it is necessary to understand more about the importance of foot screening as the findings would suggest that health care professionals would be more suited to resume the role of responsibility for foot health in RA in light of the questionable suitability of the patient to continue in this role.
The suggestion from the findings is that routine foot screening (conducted by an appropriately trained health care professional) is the safest way to ensure that appropriate treatment is effected in a timely manner. It would circumnavigate the problems of self reporting but the dilemma of who would have responsibility for this action must be solved. NICE guidelines imply that the person who is most qualified to conduct the recommended screening for RA patients is the podiatrist because he/she is the professional most qualified to provide foot health care for this patient group (NICE, 2009). However, NICE guidelines are not enforceable and rely on local interpretation of the recommendations. If a podiatrist were to be given the role of screening locally, communications between hospital and community services would have to be improved, by means of a clearly defined referral pathway agreed by all concerned, to facilitate this in view of the lack of a hospital based podiatrist.

Otter (2010) recently explored the nature and extent of foot complaints in rheumatoid arthritis. He found that a greater percentage of patients have foot pain than is reported by clinicians (rheumatologists and podiatrists) following examination suggesting that a number of patients with foot problems are not receiving foot care. This was discovered by asking direct questions to patients regarding specific foot symptoms. However, this questioning acted as a prompt. The findings of this study suggest that patients would not self-report these problems due to the variety of reasons discussed in chapter 7 and thus the foot would remain unmanaged unless specifically screened for at assessment. The types of foot problems reported in the Otter study could possibly be viewed by patients as attributed to other conditions and not necessarily associated with their RA. The author returns the responsibility to the health professionals in his recommendation that they develop a more patient-centred approach to the assessment and management of foot complaints. Additionally, this would further support the need for screening to identify these footcare needs.

Helliwell (2003), in his review of multidisciplinary rheumatoid foot clinics, highlights the lack of service provision in the area of foot screening and suggests that a consultant, podiatrist and orthotist should be the minimum personnel involved. He acknowledges that in diabetes regular foot screening is well established (Edmonds et al. 1986) but the case for dedicated podiatry care in rheumatology has yet to be made. One reason for this
is the well documented catastrophic effect of failing to provide good diabetes foot care in terms of potential lower limb amputation and the resulting personal implications for the patient and the economic effects on the health services and society in general. It is unlikely that the drivers needed for foot screening in RA will ever be viewed in the same way as those for diabetes because there is no one devastating consequence of failure to maintain good foot health. Although there are cost implications for hospital admissions of those with inflammatory arthritis resulting from foot complications, the figures have not been sufficiently publicised to prove useful in promoting a change in practice. It may be that they have not been measured. The failure to view the foot as separate to the disease as a whole further complicates this position as it would be necessary to ensure patients would be “on board” with this move.

Moreover, foot screening in diabetes is covered by the Quality and Outcomes Framework (QOF) introduced in 2004 as part of the General Medical Services Contract. The QOF is a voluntary incentive scheme for GP practices in the UK, rewarding them for quality care in certain pre-defined paradigms. This, however, does not guarantee the quality of the assessment as this is subject to the appropriateness of the individual carrying out the screening and their ability to translate the information into the appropriate action. It does however mean that a health professional is looking at the patients feet, giving the individual a prompted opportunity to report foot symptoms and is more likely to result in a referral to a specialist namely podiatry. Currently RA foot screening is not included in the QOF. This means that there is no incentive for GP’s to provide this service.

Local rheumatologists reported during the preliminary fieldwork that they did not routinely screen for foot problems. Practitioners may avoid examination of the RA foot during routine follow up appointments because the 28-joint count which is frequently used to assess disease activity excludes the foot and ankle. Kapral et al (2007) studied the validity of this exclusion and concluded that using the reduced joint count score was valid with respect to the assessment of disease activity but by-passes the important element of clinical evaluation of the foot and ankle with RA.
The importance of good patient education to achieve adherence to management strategies cannot be denied, but the majority of evidence still confirms that foot screening is fundamental to achieving good foot health in this patient group.

Future study.

This research has opened up several potential areas for future study.

- I plan to repeat the interviews in an NHS Trust where a well established and evaluated patient education programme was in place to discover the extent to which knowledge has an influence on potential for uptake of podiatry services. The attitude of this patient group to seeking help would be of particular interest. The extent to which the individual’s characteristics influenced self-reporting of symptoms, compared to the influence of good education, would then be exposed.

- Linked to the above, I would like to investigate further the timing and content of education sessions to establish the effect of this on maximising the influence of the information. Also, work to explore the implementation of an individually tailored package of health advice and behaviour counselling according to their personal needs and beliefs would be interesting but the assessment of these needs may be difficult to achieve because of its complex nature and the implementation of this practice would prove costly in terms of both time and money.

- I intend to explore the significance of individual themes raised in this study to establish an indication as to the extent of their individual influences affect the picture as a whole. The themes developed from the findings could be used to discover the importance of each to a wider audience. This could take the form of a questionnaire or a Delphi consensus exercise. From this, the themes could be ranked in order of importance to the rheumatoid arthritis population as a whole. The services of patient groups such as NRAS could be enlisted for this project.

- Having briefly mentioned in this thesis the role of the carer in the decision to seek health advice, I would like to research the significance of this role in greater depth. This may be in relation to the aims of this study or in terms of foot health in general.
In a change of direction, I would like to design a study to investigate further why foot screening for diabetes has become an integrated part of diabetes foot care but this has not been the case for rheumatoid arthritis. Findings would inform the process of attempting to achieve the goal of improving foot health in this “Cinderella Service” (Helliwell et al, 2007)

**Changes in practice achieved to date.**

Several positive outcomes from this research have already been implemented. The opportunity to expose and correct the reported problems within the podiatry department has been welcomed thus addressing the podiatric implementations from the research. The department has attended a rheumatology practice update study day and will have the opportunity to repeat this every two years. All current members of staff are now fully acquainted with current thinking in regard to rheumatoid arthritis and its management, including the clinical implications of the newer drugs being employed. The importance of good communication with the patient as to goals and expectations of foot management plans has been emphasised.

As well as practitioner updates, the main clinical implementation has been that of an annual foot screening tool for inflammatory arthritis patients. This is used to re-assess the foot for signs of potential problems in line with the changing nature of the underlying disease and as an alternative to discharging patients at the time of initial assessment and attempts to assure they are not lost to the system. Developing foot complications should now be discovered earlier and this action fulfils the recommendations of the literature. The decision was also made to treat RA patients as having automatic “at risk” status on initial assessment, thus ensuring eligibility for podiatry care, in order that their needs were met in a timely and appropriate fashion. The “Standards of Care for People with Musculoskeletal Foot Health Problems” (PRCA, 2008) was published at the time of these talks and this aided this alteration in practice as it provided a summary of the evidence base used to effect this change.

Another local outcome from the process of conducting the preliminary fieldwork and the qualitative research is that time spent at the hospital site has given the opportunity to improve communication with the local rheumatology team. Several potential areas of
misunderstanding have been rectified and the hospital team have subsequently sent more appropriate referrals to the community podiatry team following this informal “public relations” exercise.

**Dissemination of Findings.**

Conference presentations.

The following opportunities have been taken to disseminate information from the study to date:

- October 2006- Poole Hospital Study Day: “Standards of Care in Rheumatoid Arthritis”.
- November 2006- Society of Chiropodists and Podiatrists Annual Conference, Brighton- “Standards of Care in Rheumatoid Arthritis”.
- November 2006- Podiatry Rheumatic Care Association Annual General Meeting (at the above meeting): “An Audit to Assess and Quantify the Need for Podiatry Services for Local Patients with RA”.
- October 2007- Society of Chiropodists and Podiatrists Annual Conference, Harrogate: “An Audit to Assess and Quantify the Need for Podiatry Services for Local Patients with RA” (poster presentation).
- September 2008- Qualitative Research Conference, Bournemouth University: “Potential Barriers to Provision of Podiatry for Patients with Rheumatoid Arthritis” (poster presentation).
- October 2008- Society of Chiropodists and Podiatrists Conference, Bournemouth: “Potential Barriers to Provision of Podiatry for Patients with Rheumatoid Arthritis”.

This final presentation was timed to coincide with the launch of the “Standards of Care for People with Musculoskeletal Foot Health Problems” (PRCA, 2008) to highlight some of the potential pitfalls in service provision impacting on the implementation of the document’s recommendations.
The full findings of the qualitative case study will be submitted for oral presentation at the Society of Chiropodists and Podiatrists Annual Conference and the British Society for Rheumatology/ British Health Professionals in Rheumatology AGM in 2011.

Potential publications.

The following potential publications will be considered following feedback at the Conferences mentioned above.

- “An Audit to Assess and Quantify the Need for Podiatry Services for Local Patients with RA”. Potential Journal: Musculoskeletal Care.

With this dissemination plan, it is hoped that the proposed changes in practice to ensure equity in provision of foot care services for patients with RA, in accordance with published recommendations, will be considered by a wider audience.

Summary.

This study has described the particular role the patient plays in recognising foot health in rheumatoid arthritis. In this way it has achieved its aims of providing further understanding of foot health provision and describing how patient understanding and attitude to the effects of rheumatoid arthritis on the foot, and the services available to help limit this, influences self reporting of foot problems The effectiveness of the responsibility of the individual in achieving timely and appropriate podiatry referral, as recommended in the literature, has been brought into question and alternative practices have been suggested.
The findings from this research have indicated that the responsibility for foot health should rest with a suitably qualified health professional in order to achieve the early foot interventions required to ensure the patient remains mobile and independent. This is, after all, the goal for all involved in rheumatoid arthritis.
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APPENDICES
Appendix 1: The Audit tools and scoring forms.

**PODIATRIC LOWER LIMB SCREENING (RHEUMATOLOGY)**

<table>
<thead>
<tr>
<th>Mr/Mrs/Ms</th>
<th>Surname</th>
<th>Hospital No</th>
<th>Forename</th>
<th>Clinic (tick)</th>
<th>DATE:</th>
<th>Clinician: (tick)</th>
<th>□ A.Blake</th>
<th>□ Primary</th>
<th>□ Follow-up</th>
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<tbody>
<tr>
<td>Address</td>
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</table>

**Rheumatology Condition**

- □ RF +ve / -ve
- □ Enosine Y /N
- □ Duration
- □ Prognosis

**Medication** (Rheumatology related)

- □ Pain relief / NSAIDs
- □ DMARDs
- □ Steroids: oral, IM, IA
- □ Biologic:
  - □ Adalimumab (Humira)
  - □ Etanercept (Enbrel)
  - □ Infliximab (Remicade)

**Health Status / Co-morbidities**

- □ CVD / PVD
- □ BP
- □ Diabetes
- □ Smoking
- □ Eumones
- □ Operations
- □ Falls

**Other Medication**

**Vascular**

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<th>R DIP</th>
<th>PT</th>
<th>Temp. Gradient</th>
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</table>

<table>
<thead>
<tr>
<th>L DIP</th>
<th>PT</th>
<th>Temp. Gradient</th>
</tr>
</thead>
<tbody>
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</tbody>
</table>

**Symptoms of claudication**

<table>
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<tr>
<th>Y / N</th>
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</table>

**Sensory Neurology**

<table>
<thead>
<tr>
<th>B: 10mg monofilament</th>
<th>/10</th>
<th>/10</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>L: Vibration 1st MPTJ</th>
<th>Y / N</th>
<th>Y / N</th>
</tr>
</thead>
</table>

**Comments:**

**Tissue viability** (if "yes", note site)

- □ Ulcer history Y / N
- □ Current Ulcer Y / N
- □ Previous vascular surgery Y / N
- □ Amputation Y / N

**Current Foot Problem(s)?**

**A. VAS (foot):**

**B: Descriptor:**

1. No Pain
2. Mild
3. Discomforting
4. Distressing
5. Horrible

**Current footwear adequate Y / N**

**Comments:**

**Current or previous foot orthoses Y / N. If ‘Yes’, state source & status………..**

**Plan**

**Outcome:**

- □ Discharge
- □ SOS
- □ Annual Screening / SOS
- □ Podiatrist Appointment
  - □ Urgent / Soon / Routine

**Podiatrist Appointment**

- □ Community
- □ Lower Limb

**Intervention/s (if indicated)**

- □ Education
- □ Leaflets provided?
- □ Orthoses / Footwear
- □ General Foot care
- □ Tissue viability
- □ Other

**Actions (initial / date )**

- □ Assessment verified (PA only)
- □ Data entry
- □ Podiatrist Appointment

**Signed: ______________________ Date: ______________________

Podiatrist / Podiatry Assistant (Idries)
Figure 1: Self administered footwear checklist.

FOOTWEAR CHECKLIST

1. IS THE HEEL OF YOUR SHOE LESS THAN 2.5CM (1 INCH)?
   As the height of your heel increases, the pressure under the ball of your foot becomes greater. Increased pressure can lead to callus and ulceration.

2. DOES YOUR SHOE HAVE LACES, BUCKLES OR ELASTIC TO HOLD IT ONTO YOUR FOOT?
   If you wear slip-on shoes with no restraining mechanism, your toes must curl up to hold the shoes on. This can cause the tops of your toes to rub on your shoes leading to corns and calluses. Secondly, the muscles in your feet do not function as they should to help you walk; instead, they are being used less efficiently to hold your shoes on.

3. DO YOU HAVE 1CM (APPROXIMATELY THUMB-NUIT LENGTH) OF SPACE BETWEEN YOUR LONGEST TOE AND THE END OF YOUR SHOE WHEN STANDING?
   This is the best guide for the length of the shoe, as different manufacturers create shoes which are different sizes. Your toes should not touch the end of the shoe as this is likely to cause injury to the toes and place pressure upon the toe-nails.

4. DO YOUR SHOES HAVE A WELL-PADDED SOLE?
   Shoes should have a supportive, but cushioned sole to absorb shock and reduce pressure under the feet. Padded footwear, socks and some innersoles can significantly reduce the pressure under your feet.

5. ARE YOUR SHOES MADE FROM A MATERIAL WHICH BREATHES?
   A warm, moist environment can harbour organisms such as those which cause tinea. Moist skin is softer and more prone to injury. Try to wear hosiery which will remove moisture from you skin and allow your skin to breathe.

6. DO YOUR SHOES PROTECT YOUR FEET FROM INJURY?
   The main function of footwear is protection from the environment. Ensure your shoes are able to prevent entry of foreign objects which can injure the foot. If you have diabetes, a closed toe is essential to prevent injury to the foot. Make sure your shoes to not cause injury to your feet.

7. ARE YOUR SHOES THE SAME SHAPE AS YOUR FEET?
   Many shoes have pointed toes and cause friction over the tops of the toes which can lead to corns, callus and ulceration. If you can see the outline of your toes imprinted in your shoes, then the shoe is probably the wrong shape for your foot.

8. IS THE HEEL COUNTER OF YOUR SHOE FIRM?
   Hold the sides of the heel of your shoe between your thumb and forefinger and try to push them together. If the heel compresses, it is too soft to give your foot support. The heel counter provides much of the support of the shoe and must be firm to press.

If you have not put a ✓ in every box, your footwear is probably not protecting and supporting your foot as much as it should be.
# Modified Foot Structure Index

## Patient ID

### Forefoot Score

<table>
<thead>
<tr>
<th>Deformity</th>
<th>Right</th>
<th>Left</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hallux Valgus</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A - no deformity</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>B - mild deformity</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>C - moderate deformity</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>D - severe deformity</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>5th MPJ Exostosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Y=1, N=0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hammer/Claw Toes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-5 Present</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MTP Subluxed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-5 Present</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1st MTP Jr ROM</td>
<td></td>
<td></td>
</tr>
<tr>
<td>* Full</td>
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<td></td>
</tr>
<tr>
<td>* Limited</td>
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<tr>
<td>* Rigid</td>
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<tr>
<td>Total Forefoot</td>
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<td>16</td>
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</tbody>
</table>

### Hindfoot Score

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<tr>
<th>Deformity</th>
<th>Right</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Calc Valg/Var</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-5</td>
<td>0</td>
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<tr>
<td>6-10</td>
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<td>11-16</td>
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<tr>
<td>&gt;15</td>
<td>3</td>
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<tr>
<td>Ankle Total ROM</td>
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<td>48-60</td>
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<td>31-45</td>
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<td>15-30</td>
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<tr>
<td>&lt;15</td>
<td>3</td>
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<tr>
<td>Pes Planus/Cavus</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Y = 1, N=0</td>
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<td></td>
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<tr>
<td>Total Hindfoot</td>
<td>7</td>
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</tr>
</tbody>
</table>

## Total Forefoot

## Total Hindfoot

## Foot Structure Index Score

/46
## MANCHESTER FOOT PAIN AND DISABILITY QUESTIONNAIRE

**PLEASE TICK A BOX FOR EACH STATEMENT**

<table>
<thead>
<tr>
<th><strong>Because of pain in my feet:</strong></th>
<th>None of the time</th>
<th>On some days</th>
<th>On most/ every day(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I avoid walking outside at all</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I avoid walking long distances</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I walk slowly</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have to stop and rest my feet</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I avoid hard or rough surfaces where possible</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| **Because of pain in my feet:** | |
|---------------------------------|-----------------|-------------|----------------------|
| I avoid standing for a long time |                 |             |                      |
| I catch the bus or use the car more often |             |             |                      |
| I need help with housework/shopping |             |             |                      |
| I still do everything but with more pain and discomfort |             |             |                      |
| I get irritable when my feet hurt |             |             |                      |
| I feel self conscious about my feet |             |             |                      |
| I get self conscious about the shoes I have to wear |             |             |                      |

| **Because of pain in my feet:** | |
|---------------------------------|-----------------|-------------|----------------------|
| I have constant pain in my feet |             |             |                      |
| My feet are worse in the morning |             |             |                      |
| My feet are more painful in the evening |             |             |                      |
| I get shooting pains in my feet |             |             |                      |

| **Because of pain in my feet:** | |
|---------------------------------|-----------------|-------------|----------------------|
| I am unable to carry out my previous work |             |             |                      |
| I can no longer do all my previous activities (sport, dancing, hill walking etc) |             |             |                      |

**TICK HERE WHEN YOU HAVE READ ALL THE STATEMENTS ON THIS PAGE.**

---

E:MANCHESTER FPDQ[1]- adapted to Ilmouth PCP,[1].3-05.doc

221
Treatment Indicators - based on Assessed Lower Limb Risk Factors

<table>
<thead>
<tr>
<th>PRESENTING CONDITION</th>
<th>DISEASE OF FOOT</th>
<th>SOCIAL</th>
<th>SELF-TREATMENT</th>
<th>PAIN</th>
<th>Maximum - 32</th>
<th>Maximum - 32</th>
<th>Maximum - 16</th>
<th>Maximum - 16</th>
<th>Maximum - 24</th>
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<tbody>
<tr>
<td>Ulceration</td>
<td>32 Amputation</td>
<td>32 No Carers</td>
<td>16 Ineffective (Mobility)</td>
<td>16 VAS 90-100</td>
<td>24</td>
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<tr>
<td>Infection</td>
<td>32 Ischaemia</td>
<td>32 Neglect</td>
<td>14 Ineffective (Lesion)</td>
<td>16 VAS 70-89</td>
<td>18</td>
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<tr>
<td>O/C</td>
<td>32 Neuropathy</td>
<td>28 Can not Take Resp’ility</td>
<td>10 Partially Effective (Mobility)</td>
<td>8 VAS 30-69</td>
<td>10</td>
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<tr>
<td>Breakdown</td>
<td>26 Immuno-Suppressed</td>
<td>20</td>
<td>Partially Effective (Lesion)</td>
<td>8 VAS 10-29</td>
<td>6</td>
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<tr>
<td>Inflammation</td>
<td>20 Impaired Arterial Circulation</td>
<td>20</td>
<td>Self Help Not Advisable or not indicated for presenting condition</td>
<td>16 VAS 0-9</td>
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<td></td>
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<tr>
<td>Extravasation</td>
<td>20 Impaired Venous or lymphatic drainage</td>
<td>15</td>
<td></td>
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<tr>
<td>Previous Ulceration</td>
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<tr>
<td>Involution</td>
<td>16 Hyperkeratosis</td>
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<td>HD’s/HM’s</td>
<td>14 Deformity</td>
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<tr>
<td>Heavy Callous</td>
<td>14 Reduced Clotting</td>
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<td>H. Millies/Fissures</td>
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<td>Thick Nails</td>
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<td>Fungal Skin/Nail Condition</td>
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<td>Normal Nails</td>
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</table>

NOTES:
1. Although the patient may present with more than 1 item from each category – e.g. (Ulceration and Heavy Callus) you may only choose one of these. Choose the one with the highest score.
2. Scores must be repeated at Annual Reviews or if patient lower limb status changes (whichever occurs sooner)

<table>
<thead>
<tr>
<th>DATE</th>
<th>PRES. COND</th>
<th>FOOT DIS</th>
<th>SOCIAL</th>
<th>SELF-TR’T</th>
<th>PAIN</th>
<th>TOTAL</th>
<th>PODIATRIST</th>
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<tbody>
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</tbody>
</table>
Appendix 2: Letter of Ethical Research Committee approval

Salisbury and South Wiltshire Research Ethics Committee
Room 11
John Apley Building
Royal United Hospital
Combe Down
Bath
BA1 3NG
Telephone: 01225 825725
Facsimile: 01225 825725

08 November 2006

Dr Philip J. Mandy
Director of Quality
University of Brighton
Faculty of Health
Mayfield House
Falmer, Brighton
BN1 9PH

Dear Dr Mandy

Full title of study: The patient's perspective of the use of podiatry services to manage their rheumatoid footcare needs.

REC reference number: 06/Q2008/45

The Research Ethics Committee reviewed the above application at the meeting held on 25 October 2006.

Documents reviewed

The documents reviewed at the meeting were:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
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</thead>
<tbody>
<tr>
<td>Application</td>
<td>5.1</td>
<td>06 October 2006</td>
</tr>
<tr>
<td>Investigator CV</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Protocol</td>
<td>2.1</td>
<td>02 October 2006</td>
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<tr>
<td>Letter from Sponsor</td>
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<td>05 October 2006</td>
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<tr>
<td>Interview Schedules/Topic Guides</td>
<td>2.1</td>
<td>02 October 2006</td>
</tr>
<tr>
<td>Letter of invitation to participant</td>
<td>1.2</td>
<td>26 September 2006</td>
</tr>
<tr>
<td>Participant Information Sheet</td>
<td>1.2</td>
<td>26 September 2006</td>
</tr>
<tr>
<td>Participant Consent Form</td>
<td>1.2</td>
<td>26 September 2006</td>
</tr>
<tr>
<td>Letter from Dr Phil Mandy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CV</td>
<td>Alison Blake</td>
<td>24 November 2005</td>
</tr>
<tr>
<td>Letter to Dr R Smith</td>
<td>1.2</td>
<td>06 October 2006</td>
</tr>
</tbody>
</table>

Provisional opinion

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to The Chair.

Further information or clarification required

(a) Please ensure that the study title is consistent throughout.

An advisory committee to South West Strategic Health Authority
(b) Hospital headed paper must be used for correspondence.

(c) The Committee felt that the wording on the invitation letter should be changed from 'you have rheumatoid arthritis and may need the services of podiatry' to 'you have rheumatoid arthritis and some people may need the services of podiatry'.

(d) Please confirm that Dr Smith has agreed to refer patients.

(e) Can the applicant please clarify whether Alison Blake will need an honorary contract with the hospital.

When submitting your response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 08 March 2007.

Ethical review of research sites

The Committee agreed that all sites in this study should be exempt from site-specific assessment (SSA). There is no need to complete Part C of the application form or to inform Local Research Ethics Committees (LRECs) about the research. However, all researchers and local research collaborators who intend to participate in this study at NHS sites should notify the R&D Department for the relevant care organisation and seek research governance approval.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

REC reference number 06/Q2008/45 please quote this number on all correspondence

Yours sincerely

Kirsten Peck
Chair
Salisbury and South Wiltshire Research Ethics Committee

Email: kirsten.peck@ruh-bath.swest.nhs.uk

Ents: List of names and professions of members who were present at the meeting and those who submitted written comments.

Copy to: University of Brighton - Registry
Mithras House, Lewes Road,
Brighton
Appendix 3: Consent forms and participant information.

Study Number:

Participant Information Number for this trial:

CONSENT FORM

Title of Project: The patient’s perspective on the use of podiatry services to manage their rheumatoid footcare needs.

Name of Researcher: Miss Alison Blake. Lead Podiatrist.

Please initial box

1. I confirm that I have read and understand the information sheet dated ................. for the above study
   (version ............... ) for the above study

2. I understand that my participation is voluntary and that I am free to withdraw at any time without
   my medical care or legal rights being affected.

3. I am willing to allow any interviews to be tape recorded.

4. I agree to take part in the above study.

Name of participant ___________________________ Date __________ Signature ______________

Name of person taking consent
(if different from researcher) ___________________________ Date __________ Signature ______________

Researcher ___________________________ Date __________ Signature ______________

1 for participant; 1 for researcher; 1 to be kept with the recorded data
INFORMATION FOR PARTICIPANTS ABOUT THE STUDY

Study Title: The patient’s perspective on the use of podiatry services to manage their rheumatoid footcare needs.

What is the purpose of the study?
To explore the views of patients on the use of podiatry services to manage their rheumatoid foot problems.

Why have I been chosen?
You are a patient with rheumatoid arthritis attending the Salisbury District Hospital Rheumatology outpatient department. You may or may not have problems with your feet at the time of the study.

Who is organising the study?
The study is being organised by Alison Blake who is a Lead Podiatrist in the Podiatry Department of South Wiltshire PCT. She is based at Central Health Clinic, Avon Approach, Salisbury. The research is being carried out as part of a professional doctorate programme at University of Brighton.

The study will be supervised by two members of the University Staff (Dr P.J. Mandy and Dr A. Hammond) who will ensure it is carried out in an appropriate manner.

What will happen to me if I take part?
If you consent to take part in this study you will be invited to attend an interview at a time and location agreeable to you.

During the interview you will be asked questions about any previous experience you have had of Podiatry (Chiropody) services and your views on that experience. You will also be asked for your opinions of what Podiatry Services can do to help people with rheumatoid arthritis. It will last approximately 30 minutes and may be tape recorded subject to your permission. Within two weeks of the interview you will have the opportunity to read the transcript and confirm that it is an accurate representation of what was said before the information is used in the study.

Are there any disadvantages in taking part in this study?
It will involve your time for the duration of the interview.

What are the possible benefits of taking part?
There are no personal rewards for being involved in the study but the findings will inform the process of delivery of patient care. Potentially the information could be used to improve access to podiatry services.

What happens when the study stops?
You will continue exactly as before. However, if it is discovered that you would benefit from a referral to podiatry, this service will be offered to you.
Confidentiality – who will know I am taking part in the study?
Only the researcher, their university adviser and the consultant rheumatologist will know that
you are taking part. All information which is collected about you during the course of the
research will be kept strictly confidential. Any information about you that leaves the clinic will
be anonymised so that you cannot be recognised or identified from it.

Local Research Ethics Committee Approval
The Salisbury Local Research Ethics Committee has given its approval for this study to take
place.

What will happen to the results of the study?
They will be written up and published in professional journals. Also, the results will be
presented at conferences. A copy of the results will be available at the Podiatry Clinic, Avon
Approach, Salisbury.

Contact for further information
For further information contact Alison Blake (Lead Podiatrist) on 01722 422257.

If you would like to be included in the study please complete the slip below and send it
to.................................................................in the envelope provided.

Thank you for your time.
Dear Patient,

Study Title: The patient's perspective on the use of podiatry services to manage their rheumatoid footcare needs.

A study is being carried out that looks at the opinions of patients regarding podiatry services and how it is believed that this service can help patients with rheumatoid arthritis.

Please read the enclosed information. If you would like to take part, please complete the slip at the end of this letter and return it to.........................in the envelope provided. You will later be asked to sign a consent form. It is up to you to decide whether to take part or not. If you do not wish to take part your decision will not affect your current or future position and you are free to withdraw at any time.

All the information collected about you during the study will be kept strictly confidential. Any published report will not identify you.

Consumers for Ethics in Research (CERES) publish a leaflet entitled 'Medical Research and You'. This leaflet gives more information about medical research and looks at some questions you may want to ask. A copy may be obtained from CERES, PO Box 1365, London N16 0BW.

If you have any questions, please feel free to contact me on 01722 422257.

Thank you for your time.

Yours sincerely,

Alison Blake. Lead Podiatrist.

_________________________________________________________________________________________________________

I am willing to take part in the study entitled: The patient's perspective on the use of podiatry services to manage their rheumatoid footcare needs.

Signed: Please Print Name:

Date:
Appendix 4. Example of Framework Analysis Technique.

Interview data indexed (coded) according to:

- Patient’s attitude to foot problems in RA.

The text is highlighted in relation to this main theme from the research question:

Interview 001.

AB  So they’ve just sort of talked about the problems that you’ve reported.

001  Yes, I mean they’ve just taken that as part of everything else.  ATTITUDE
     (Part of General RA)

AB  ..in general..

001  .. as opposed to separately, which is why, I think, when she saw all the hard skin and the toes.. ‘cos my son cut my toe nails the last time and he cut them like that..

AB  Oh yes

AB  No.  That’s good from my point of view. Having the hard skin and everything, how does that make you feel?

001  Well, I mean, its not very nice, because you know, its always there, in the summertime.  I like my bare.. I hate shoes & socks..

AB  um

001  I like my bare feet.  I don’t go out very much so its only in my house but, you know, if I go out and wear sandals in the summer its not really very nice.  ATTITUDE
     (Appearance)

Interview 002.

002  But it’s my feet really, I get a corn under my feet...

AB  Yes

002  Which is why I’m seeing you ‘cos I complained to the hospital about the appointment

AB  Oh, I see.
I used to see the chiropodist once a month, then it was changed to two months then three months then four months and the last time I saw them was a couple of weeks ago. Before that it was early January.

Oh that is a long time.

You see that I was housebound because of my feet (Deformity/pain)

Interview 004.

Well, yes I suppose. I’ve never really thought about them much. ATTITUDE

Um I did have my feet x-rayed and they told me that I had osteoarthritis in my feet. (Part of RA)

Yes

Um, and sometimes they hurt a bit but when you’ve got big pain, ATTITUDE

Like the one in my back at the moment, it really takes over, (Part of RA) and um you don’t notice…. If I didn’t have other pain then….
<table>
<thead>
<tr>
<th>Main Themes</th>
<th>Atitudes to Feet</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Appearance</strong></td>
<td><strong>Part of general RA</strong></td>
</tr>
<tr>
<td>T/001-3,4 -2,3</td>
<td>&quot;With regard to hard skin etc &quot;Well, I mean, it’s not very nice, because you know, it’s always there, in the summertime...I like my bare...I hate socks and shoes&quot; &quot;...I like my bare feet.....if I go out in the summer it’s not really nice.&quot; &quot;it’s a bit awkward when it’s hot&quot;</td>
</tr>
<tr>
<td>T/002-5 -1,1</td>
<td>&quot;If they take the appointments over a long period my health will deteriorate&quot;</td>
</tr>
<tr>
<td>T/003-4 -4,5</td>
<td>Comparing foot problems to hand problems &quot;I do have problems with my hands so I assume they would give me some type of shoe or something.&quot;</td>
</tr>
<tr>
<td>Time</td>
<td>Statement</td>
</tr>
<tr>
<td>------</td>
<td>---------------------------------------------------------------------------</td>
</tr>
<tr>
<td>0:004-6,7</td>
<td>“I’ve gone past how they look now. Everything’s dropped or drooped. So now I go for comfort.”</td>
</tr>
<tr>
<td>-3,3</td>
<td>“At that time I went for looks not comfort.”</td>
</tr>
<tr>
<td>-2</td>
<td>“Sometimes they (feet) hurt a bit but when you’ve got big pain, like the one in my back at the moment, it really takes over, and um, you don’t notice. If you have other pain then...”</td>
</tr>
<tr>
<td>3,2,9,</td>
<td>“I’ve never really thought about them much.”</td>
</tr>
<tr>
<td></td>
<td>“It’s a bit difficult to move farther away”</td>
</tr>
<tr>
<td></td>
<td>“It makes my feet ache and, because big feet run in the family, they’ve always been difficult”</td>
</tr>
<tr>
<td></td>
<td>“The toes are so long and so it’s alright in shoes like this but, if it’s any shoes that’s...you know, coming round, then it squashes them up a bit and that’s why they’re bad of course. When I was younger I always wore 3” heels”</td>
</tr>
<tr>
<td></td>
<td>“The only problem I have is on this foot, the ball of the foot, it gets hard. But it doesn’t on this one.....I wondered if it was because that side has to have the lift.”</td>
</tr>
</tbody>
</table>
| **T:005-8,11, -7, -5,** | “I have nasty bumps on each side of my big toe, which, um, to be quite honest, I think I had rheumatoid arthritis a long time ago. ....I used to hide it”

When asked whether looks or comfort was more important:

“Oh crumbs. How they feel!”

With reference to a toe injury whilst on holiday:

“...when I got back it still hadn’t healed and I couldn’t stay on the Infliximab if you’ve got an unhealed wound.....so I said to Dr X (rheumatologist) “this is ridiculous, I need, I mean I’m ill now” and I said “can’t you cut it off” and she said “yes if you like”. So I said “Yes, let’s get rid of it”.

| **T:006-3,4, -4, -3, -1,2,** | “...they are ugly feet and they, you know, I always think “God, I’ve got to cut my toe nails” but the fact is a week later, I might get round to doing it!”

“It would be quite nice to wear opened toed sandals”

“Because I was “I’d deal with it if my toes went crooked. I’d just think, well that’s just part of it (RA) but I don’t really want them to get that unsightly.

“with all my false bits (joint replacements) it’s very hard to get down there (feet)”

| **005 “Well I can’t walk properly”**

**AB “Is that because of pain or swelling?”**

**005 “Pain yes, yeh. Sometimes they’re (feet) swollen, sometimes they’re not.”**

| **Um, my feet are quite bad. I could do with new ankles but just don’t go down that road at the moment”**

“I get a lot of pain in the sides of my feet......I constantly get nail infections because of the steroids and embril and if I have a problem then it pulls so I pick it out...” |
on Inflixiab and they didn’t want to give (lamisil) to me..........he thought it (fungal toe nails) was purely cosmetic and I said “well it’s alright for you, you wear socks and shoes but I don’t wear socks and shoes all the time- in the summer I want to wear some sort of sandal.”
“T’ve got an infection (fungal) in my big toe nail now and it looks terrible.”
“Your toes aren’t the nicest things.”

<table>
<thead>
<tr>
<th>T/007-4, -2, -3, -2</th>
<th>When asked how he would feel if the RA started to alter the look of his feet: “...as long as they don’t hurt, no.....not at my age”</th>
<th>“I think it’s (foot swelling) symptomatic of whatever it is”</th>
</tr>
</thead>
<tbody>
<tr>
<td>“...because it’s not easy to cut your toe nails. You can get down there but its staying down there long enough to do “They (feet) burn and swell up a little bit around the ankles and that makes you feel a bit, you know, they’re uncomfortable to walk on.””</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

234
| T/008-4, -2 | When asked if he was concerned regarding how the foot looks: "I've got passed it." | The job." | With regard to a rheumatoid nodule, "...the ball of my foot swelled up. It didn’t hurt so they say "if it’s not broke don’t fix it!” So I left it for about 10 years and eventually it began to give me a bit of a problem putting my shoe on. So I went to the surgery (podiatry)."

| T/009-3,4, -2 | "I mean, is it the rheumatoid that’s doing that (foot shape) or is it the way I’m walking? Is it just me?"

  "... it’s your joints again, the same as your fingers and hands." | "at the same time that I got rheumatoid arthritis I noticed that I was walking really badly over on the left, outwards." |
Appendix 5: Example of transcript.

Interview 003.

*Right so how long have you had rheumatoid arthritis?*
About seven years.

*What took you to the doctor in the first place?*
Er, Fibromyalgia.

*And you went to the doctor*
Yes I went to see Dr R.

*Oh Yes*
And he was treating me for Fibromyalgia then he did some more tests and it turned out that I’d got some non-specific rheumatoid arthritis.

*And how does it affect you generally?*
Hands, feet, generally, neck shoulders…

*Bit of everything.*
Yes a bit of everything.

*Right, and what medication are you currently taking?*
At the moment I’m just on prednisolone 15mg daily but I’ll explain why later.

*OK.*
Ametrazole because I’ve got an ulcer, one quinine tablet because I suffer from cramps and I’m on a tablet for an enlarged prostate.

*OK.*
It’s not a cancerous prostate, just an enlarged prostate.

*Just enlarged, right OK.*
And I used to be on methotrexate…But, um, I developed um well, I generally had a bit of a cold which I couldn’t shift and I developed pins and needles in my hands, feet, legs, face and neck. And I went to my own doctor and he advised me to go and see [Rheumatology practitioner] and he put it down as peripheral neuropathy.

*Oh right, yes.*
Unspecified as to why. I then went to see professor someone or another from neurology dept and he diagnosed Guillain – Barré syndrome.

*Oh. And this happen this year?*
Yes. And thankfully it went off rather quickly

*It’s settled down.*

I’ve still got pins and needles in my hands and my legs and that’s it.

*So was that the reason you came off the methotrexate?*

Yes I thought it was the methotrexate that was causing the problem.

*Right.*

Because I had one or two odd symptoms you know um… er… persistent constipation basically know that type of thing.

*Yes.*

And even though generally my blood pressure was fluctuating up and down like a yo-yo you know… well then he took it three times in one day.

*Yes.*

The doctor did it was 85 over 70 to start with then it went up to 92 over 80 then it went up to 105 over 80.

*Oh right.*

And I suffered from light-headedness and everything so he said stop the methotrexate and see what happens.

*And did it all settle after that?*

Yes, it all settled.

*So it’s quite possible it was the methotrexate.*

Yes, it’s quite possible although I had been taking it for seven years.

*Oh right, so you went on it pretty much as soon as you were diagnosed.*

Yes, it was about then.

*So you’re now on prednisolone?*

Yes I’ve been on prednisolone for a long time because I… in 1992 I was involved in a road traffic accident and I had a crushed chest which left me with COPD. I’ve got everything!

*So you take the prednisolone for that?*

Yes

*So from the arthritis point of view are you able to cope without the methotrexate for that?*

Yes. Joints are sore, it’s playing up but I manage.

*Right. How often are you going up to see [Rheumatology Practitioner]?*
Every six weeks at the moment.

*Right so quite frequently.*

Yes quite frequently. I saw her two weeks ago when she gave me the letter.

*Yes.*

I see [Rheumatologist] in July.

*So, in all the time you’ve been going up there then and you’ve been diagnosed with RA how has that affected your feet? Or hasn’t it?*

Well I was having trouble because I couldn’t do my toe nails properly and my feet were sorry, so was I.

*Yes.*

And, um, we have a friend who used to work for [Podiatric Surgeon] and she was one of his clinical nurses… clinical podiatry nurses.

*Yes.*

Yes I’m seeing her on Wednesday. She looks after us.

…..*cuts your nail and keeps you up together but you don’t see anybody else about your feet that’s the lot?* 

Yes, we don’t see anybody else.

*Apart from nails and keeping things comfortable from that point of view, have you had any other problems with your feet?*

No, I’ve got numbness in my feet.

*Right.*

They said that was all to do with the G-B syndrome. But at the moment it’s like walking on gravel.

*So it’s a very odd sensation.*

Yes.

*Right. Do you get a pain sensation with that as well or is it just numbness?*

I am basically numb from here [knees] down, right the way down and Dr. K. when I saw him, last time, he just got a pin and stuck it in me. He said “can you feel that”? and I said “no” and he said “you’ve got a needle sticking out of your leg!”

*Right.*

He said this should try and sort it out.

*So, all the time you’ve been going to the rheumatology department, have they*
given you any advice about footcare or how RA might affect your feet?
No

No, so you’ve not had any specific education on footcare?
No

Have you picked up any information on footcare from anywhere else?
[Podiatry Assistant] is very good, she does sometimes say “what you need is this, this and this”. She really does look after our feet so I’m really happy.

Yes, but do you know the ways in which RA could affect your feet?
Yes, you get distortion of the bones and that sort of thing and you can grow nodules which some people grow on their fingers but I don’t. I’ve got distorted fingers. But I think this is why he said it was non-specific.

Right so you know about the deformities you could get.
Yes

So, who do you feel, out of the people who look after you generally, who do you think is responsible for your foot problems if you were developing something?
Somebody at the hospital I think? I do have problems with my hands so I assume they would give me some type of shoes or something. What the hell is her name, I’ve got the card here I can tell you exactly. There we are [OT]

Oh yes, I saw her recently at a conference so it’s nice to put a face to the name. She would look after your feet as well as your hands would she?
Yes she would do. Yes.

So if you saw something change with your foot structure you would see [OT] would you?
I would see Jane and she would recommend that I see [OT] or I would see my doctor and he would sort of chase it up for me.

Do you think if you were given information early on about exactly what to look for on your feet and what problems RA could cause, do you think that would be useful to flag up problems you have?
Yes I do.

Yes?
Yes definitely.
You would be quite happy to flag up your own problems if you had the information.
Most definitely

*So if your feet were to be deformed because of arthritis, specific structural problems, how would that make you feel, would it bother you at all?*

Yes it would rather as I depend upon my feet a lot.

Yes?

I would have to drive an automatic not a manual car because of changing gears and all the rest of it. So would certainly restrict me and I also go to work part time 15 hours a week so I would have to pack that up and I am dependant on walking in my job.

*What do you do?*

I work at Homebase.

*Oh so you clock up a few miles then. So you obviously have a vested interest in keeping your feet comfortable so do you think it’s more the pain or the deformity, how they look or how they feel that’s important to you?*

It’s pain and how they feel rather than the look, I’m not bothered how they look as long as they work. Mine aren’t bad compared to some people’s feet that I’ve seen.

*So it’s not how they look it’s how they function for you.*

How they function to me, that’s the most important thing.

Yes.

Keeping your job, independence and your mobility and your car and everything.

*Yes. So, coming back to podiatry then, I know you’re with [Podiatry Assistant] and that suits you but do you know what a podiatrist can do?*

Oh yes, yes, my wife’s recently had 2 bunions removed by [Podiatric Surgeon]. It was [Podiatry Assistant] who told her and kind of recommended it. It’s been absolutely fantastic. They used to be badly deformed before but now they’re perfectly straight. Lovely she’s pleased. I wouldn’t like my feet to get in that position - this is the second time she’s had this operation on her bunions – and the first time they deformed tremendously, but now they’re in alignment it looks like a foot.

*So you know what we can do with regards to your nails, corns and that kind of thing and you know about the other end of things with surgery, but do you know*
what else we can do in between?
No.
So you haven’t really come into contact with anybody with regards to insoles or that kind of thing?
Yes, talking about it, I do have um… when I was first diagnosed with Fibromyalgia I had an x-ray.. not an x-ray.. some tests on my spine which shows a curvature.

Oh like Moire Fringe?
Yes and the consultant said that I needed a 5mm heel in my shoes and this was issued to me and then from there it progressed to my gel heels now which are absolutely fantastic. They make you feel really comfortable when you walk. With this at the moment I can’t feel anything.

And where did you get your gel heels from, was it the same place?
[OT] I’ve got to admit that I’ve been very well looked after at the hospital. They’ve been fantastic, they really are.

So if you needed more specific podiatry care than [Podiatry Assistant] would provide for you, what do you think would happen to your feet?
I would have asked [Rheumatology Practitioner] or [Podiatry Assistant] to help. [Podiatry Assistant] does it for us as a favour more than anything else, she’s a kind friend.

But if you needed more you would see your doctor or somebody?
Yes I wouldn’t like to impose on [Podiatry Assistant].She likes doing it, she’d do anything for us.

But of course she’s worked with us, she knows how far she can go.
Oh yes. Oh I’m quite sure she would recommend what action we should take

Is there anything that would stop you coming along to us? I know for you it would be the [North] clinic wouldn’t it?
I’d sooner come here.

Well the service generally. Is there anything that would stop you coming in?
No.
Anything that would be a barrier? Not the journey or…
No I’m quite happy. It’s just the timetable, obviously with working I’d like to fit in. I work Monday morning, Tuesday and Friday p.m. and Saturday
morning. So it leaves me Wednesday and Thursday and the half days in between.

So you've got some flexibility we could work any appointment around you. We find that with a lot of people, you have so many health problems and that means a lot of appointments so it can take over your life can't it?
Yes no problems at all.

So as long as we could fit in with that you'd be ok
Yep.

Is there anything you'd like to add about your feet or anything generally
No that’s it accept that the service I’ve personally had from the hospital has been absolutely stupendous. From the time of the accident 92 ’93 and right up to the present day.

Oh right.

There’s so much that they can do you know, and as I say, the staff have been wonderful so when I walk in the hospital now they say “Hi J, how are you?”
It’s a nice family feel.
Yes, my wife said I don’t know why you don’t take your bed there.

Yes but it’s nice when people say good things as well as the bad things.
I do have a lot of appointments which does get a bit overbearing at times.
Yes.

Like, I’ve got one…I’m supposed to see Dr K. next week at 9.30 but now I’ve got a letter to say I’ve got to see him at 1.45. I start work at 1 pm, so I can’t do it. I don’t want to mess them up at work with only 16 hours a week.

Yes, I suppose they feel that if you have appointments you could arrange them in the other times.
Yes, which I do try to do.

….. as much as possible.

One day, next Friday 6th, I’ve got to go to the injection clinic for my thumb.
That’s at 1 o’clock but I know there’s no other time I can do then. I told them at work and they said “well work another day”.
That’s OK. They’re quite good as long as you do your hours.
Yes but I can’t do it too often. You’re taking the mickey then.

Thank you very much.
Appendix 6: Excerpts from research diary.

Reflection on the First Interview.


I have completed my first patient interview, which seemed to go well. A few practical points were raised on the back of this (parking, room-booking etc) which I have now been able to address. Having nearly finished the transcript, initial thoughts indicate that the information gained falls into several categories.

1. The experience of the patient in terms of:
   - duration/extent of disease
   - exposure to health professionals
   For the patient I had interviewed, she was diagnosed with RA 3 years ago and has been attending the hospital every 6-8 weeks since then. Her RA is not controlled and she suffers constant pain.
   She has had exposure to 2 consultants and the nurse practitioner.
   The medication she is currently taking suggests that she is high risk in terms of tissue viability and would be eligible to attend for NHS podiatry. Indeed, she is at risk of developing major problems (according to the literature) if she does not see a podiatrist for assessment.

2. The experience/knowledge of podiatry services:
   - what they determine to be their foot problems
   - exposure to foot health advice
   She feels that the pain she experiences in her ankles and ball of feet is solely due to the general arthritic condition and will settle when her RA is controlled. She has never seen a podiatrist previously and admits that she has no idea of what we do beyond cutting nails and removing callus.
   Despite frequent exposure to hospital services she has never been given any foot health advice or received any formal education sessions.
   She relies on the nurse practitioner to take care of any referrals needed and would expect her to arrange any foot care required.
2. The barriers to accessing podiatry services:
   - practical problems with attending clinic.

The patient lived on the border of our catchment area and she is aware that this sometimes means that she cannot access services in Salisbury. At the same time, she feels that the journey into the city is a long one and she would have to have plenty of notice for an appointment if she were to consider attending so that she could make the arrangements she needs. She was unaware that we have a clinic in a small town much nearer to her.

She is comfortable driving and has a disabled parking badge but her main concern regarding appointments is her dog. Dogs are her life and she has a puppy, which cannot be left.

She also mentioned that she may feel unwell on the day of the appointment (as she often has bad days) and she would have to cancel and short notice. She was concerned about inconveniencing people.

Her stated specific foot problems (for which she feels a podiatrist could help) are callus and ingrowing toe-nails. From this point of view she was more concerned about what her feet looked like (and would not wear sandals because of this) than any pain.

She also mentioned that, because she didn’t know what to expect from podiatry, she would feel a little anxious attending for treatment.

I know (from the audit) that the health professions in the team rely on the patient to flag up foot problems before they will consider making a referral. However, I can see several occasions here when it would have been an appropriate time/prompt for the professional to ask/assess foot issues based on evidence available to them (i.e. when the patient reported ankle/ball of foot pain, when the patient first commenced anti-TNF therapy).

The patients says that she has had no experience or education on foot health problems specific to RA or the role of podiatry services so she does not have the necessary skills to be able to report problems for referral. Also, she reported that she feels the nurse practitioner would take on the responsibility. Makes me wonder if the nurse practitioner is aware of this?

The barriers to access were interesting. I feel that our podiatry department is unaware of the importance to patients with a chronic illness of the practicalities of a visit to
clinic (i.e. distance, dog-sitting etc) and how they are feeling on the day. After all, these patients have to attend a lot of appointments and it can rather take over their lives.

18th May 2007.

Having emailed these initial thoughts to my supervisor for comments, he suggested that I review them together with the transcripts of additional interviews to ensure that the questions I am asking are eliciting the right response and to identify any new areas cropping up that had not been on the interview schedule.

He points out that the themes are quite specific. Rather than the patient experience of podiatry services, I should look for their understandings they have of RA and its effects on the foot and where they got this information from. There is particular interest in the comment of being more concerned about appearance than pain. This needs pursuing.

I think I have been over excited at the information received and will need to remain focused on the research question. I will have to find a way to pursue the body image issue without prompting the patients too much as the whole idea is to see what the individual can remember without prompting.

Reflections following interview 008.

27th October 2007

I have just interviewed an elderly gentleman. As well as having been diagnosed with RA over 30 years ago, he has had three strokes and other co-morbidities which means he now relies on his wife for assistance with most activities. He was a man of few words and I found it difficult to get much information from him. The nature of the RA out-patient group locally means that I am likely to interview similar elderly patients.

Do age and the co-morbidities impact on the research questions? I decided not to exclude patients with co-morbidities from the study because the ability to self-report foot problems is as important for them as it is for those who just have RA. However, what if age and the co-morbidities affected the ability to recognise foot concerns? I need to reassure myself that I have made to correct decision.
Bugeja et al (1997) reported on a number of studies which could have included older adults but had excluded them with no justification. Jacelon (2007) reports that older adults are excluded from research because they are not perceived as being competent. She goes on to say that the older the subject, the more diverse and varied the person’s resources and functional ability are likely to be and they have been more affected by life events. Their contribution is therefore extremely complex but valuable. The individual feels that participating in research allows them to leave a legacy in the form of expressing their viewpoint (Resnick et al, 2003). In general, the literature supports the inclusion of older adults in research as it has benefits for both parties.

There are several reasons why it would be wrong for me to exclude older adults from this study just because they may have co-morbidities which affect their ability to fully articulate their opinions. Firstly, they form a significant proportion of the group under investigation. Their need to recognise foot concerns is the same and, even if influenced by their co-morbidities, recording their attitudes and understandings will expose the extent to which this is an issue. Participant 008 may rely on his wife to recognise his foot problems for him but this surely adds to our understanding of the ability of patients to self report foot problems and thus is important to the study. I will continue as before.

Reflections on the process of analysis.


Initial attempts to develop themes from the data have proved frustrating. They were not jumping out at me as the literature had led me to believe. Having revisited my literature files I discover a presentation handout from the Society of Chiropodists and Podiatrist Annual Conference which outlines the Framework Approach described by Ritchie and Spencer (1994). The idea of charting the data appeals to me as a way to start organising the themes.

Having checked that this approach is congruent with my philosophical position and methodology, I use the research aims and interview schedule to provide headings and
sub-headings for the charts. It is early days, but organising the data in this way seems to be making more sense of it. Maybe it’s my positive background requiring the security of structure. Emerging themes will need to be developed and refined as the analysis progresses.