The National Rheumatoid Arthritis Society Mapping Project

Mapping the Patient’s Journey in Rheumatoid Arthritis
The National Rheumatoid Arthritis Society Mapping Project

Susan Oliver, Ailsa Bosworth, Ivan Lax, Mara Airoldi
and the Mapping Project Advisory Board

Mapping the patient's journey with Rheumatoid Arthritis

Acknowledgement and thanks:

The inspiration from this study came from the excellent work undertaken by the James Parkinson's Centre in Cornwall, although this work differs in that they had not considered attributing costs¹

Thanks to:
Sue Thomas: RCN Nurse Advisor for chronic conditions and representative of Parkinson’s disease Pathway Project.

Dr Sarah Ryan: Provided independent qualitative researcher support in this project.

Declaration of Interest: The research and development of this project was funded by an unrestricted educational grant from Roche Products Ltd. And its publication by an unrestricted educational grant from Wyeth Laboratories
TABLE OF CONTENTS
Multi-professional and Patient Advisory Board.............................................................. 4
Executive Summary........................................................................................................... 5
Chapter 1: Introduction.................................................................................................. 7
Chapter 2: Methods........................................................................................................ 11
Chapter 3: Results ......................................................................................................... 17
  Figure 1: Flow chart of Research Flow Methodology.................................................. 19
  Figure 2: Demographics of participants ...................................................................... 20
  Figure 3: Time from symptom onset to seeing General Practitioner ......................... 21
  Table 1 Number of visits participants made to General Practitioner –....................... 22
  Figure 4: Time taken from GP appointment to being seen by Specialist (n= 22)........ 24
  Figure 5 Time from first presenting symptoms to first DMARD ............................. 26
  Table 2 Number of Consultant Rheumatologist Follow-up appointments from first episode to end of study ................................................................. 26
  Table 3 Private patients with access to multi-professional teams.............................. 30
    Figure 6: Participants who received either one-to-one or group education on ........ 32
    Table 4: Number of nurse consultations .................................................................. 33
    Figure 7: Illustrating the ratio of personal to healthcare provider costs................... 35
    Figure 8: Illustrating the ratio of personal to healthcare provider costs................... 36
    Figure 9: Illustrating the ratio of personal to healthcare provider costs for patients diagnosed between 2 years and <3 years 6 months  (n=7) .............................. 37
    Figure 10: Costs incurred to healthcare and participants eligible for biologics n=6 39
    Figure 11: Breakdown of primary healthcare costs for each participant broken down into categories from time of diagnosis. Diagnoses <one year ....................... 41
    Figure 12: Breakdown of primary healthcare costs for each participant broken down into categories from time of diagnosis. Diagnoses 1 – 2 years  ....................... 42
    Figure 13: Breakdown of primary healthcare costs for each participant broken down into categories from time of diagnosis. Diagnoses >2 years and <3.6 years 43
  Table 5 Illustrating some personal costs examples (n=4) ........................................... 45
  Table 6 Participants receiving biologics – cost analysis for the period of this study compared with a sample of DMARD patients.............................................................. 45
    Figure 14: Total Cost analysis for each participant ................................................. 46
Chapter 4: Discussion .................................................................................................... 48
  Figure 15: Option one. Example of patient pathway reflecting standards of care in management – traditional DMARD ................................................................. 52
  Table 7: Cost analysis of each step in the gold standard pathway (Figure 10). Based upon aggressive pro-active management in the first year of RA: Treatment with DMARD ......................................................................................................................... 53
  Figure 16: Option 2: gold standard pathway - example of pathway for those failing two DMARDS and treated with biologic therapy ..................................................... 54
  Table 8: Cost analysis of each step in the gold standard pathway (Figure 11)
    Option 2 Patient pathway with aggressive therapy and pathway to biologics – first year of treatment ................................................................................................................. 55
Chapter 5: Conclusions .................................................................................................. 57
| Appendix 1 | References ............................................................................................................... | 64 |
| Appendix 2 | Potential spectrum of needs for RA patients ..................................................... | 69 |
| Appendix 3 | Advisory Panel-Patient Pathway Process Mapping .............................................. | 70 |
| Appendix 4 | Purposive Sampling of Potential Interviewees .................................................... | 71 |
| Appendix 5 | Patient Letter on the mapping project and consent form .................................... | 73 |
| Appendix 6 | Outline of costing points .................................................................................. | 75 |
| Appendix 7 | Questions for Establishing Process Followed .................................................... | 78 |
| Appendix 8 | Demographics of participants ........................................................................... | 82 |
| Appendix 9 | Copies of Each Participants Map ....................................................................... | 83 |
| Appendix 10 | Telephone Follow up record of patient views post telephone interview ............... | 108 |
| Appendix 11 | DMARDs and biologics prescribed to participants .............................................. | 111 |
| Appendix 12 | Cost Sheets ....................................................................................................... | 112 |
| Appendix 13 | Breakdown of costs per individual ..................................................................... | 124 |
| Appendix 14 | Analysis of Access to Healthcare Professional Support ....................................... | 130 |
| Appendix 15 | Details of Edits Made Following Patient Review of Maps ................................... | 132 |
Multi-professional and Patient Advisory Board:

<table>
<thead>
<tr>
<th>Name</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anne O’Brien</td>
<td>Physiotherapy Lecturer, Keele University</td>
</tr>
<tr>
<td>Dr Anthony Redmond</td>
<td>arc Lecturer in Podiatry, Chapel Allerton Hospital, Leeds</td>
</tr>
<tr>
<td>Claire McAleer</td>
<td>Specialist Practitioner in Rheumatology, Westminster Rehabilitation Services</td>
</tr>
<tr>
<td>Prof David Scott</td>
<td>Professor of Rheumatology, Norfolk &amp; Norwich University Hospital</td>
</tr>
<tr>
<td>Diane Home</td>
<td>Nurse Consultant Rheumatology, West Middlesex University Hospital (QR)</td>
</tr>
<tr>
<td>Dr John Dixon</td>
<td>GP with Special Interest in Rheumatology, Primary Care Rheumatology Society</td>
</tr>
<tr>
<td>Dr Alan Steuer</td>
<td>Consultant Rheumatologist, Wexham Park Hospital</td>
</tr>
<tr>
<td>Susan Oliver</td>
<td>Nurse Consultant Rheumatology, Chair of the RCN Rheumatology Forum (QR)</td>
</tr>
<tr>
<td>Ailsa Bosworth</td>
<td>Chief Executive</td>
</tr>
<tr>
<td>Penny Cavanna</td>
<td>NRAS volunteer</td>
</tr>
<tr>
<td>Audrey Callum</td>
<td>NRAS volunteer</td>
</tr>
<tr>
<td>Ivan Lax</td>
<td>Project Worker</td>
</tr>
<tr>
<td>Catalyze</td>
<td>Ivan Lax ◊ Catalyze Ltd - 'enabling effective decisions' ◊ <a href="http://www.catalyze.co.uk">www.catalyze.co.uk</a> Address: 20 Appletree Road, Chipping Warden, Banbury OX17 1LW United Kingdom</td>
</tr>
<tr>
<td>Qualitative Research Support</td>
<td>Dr Sarah Ryan, Nurse Consultant, Musculoskeletal Primary Care, Hayward Hospital. Stoke-on Trent, Staffordshire (QR)</td>
</tr>
<tr>
<td>Mara Airoldi</td>
<td>Research Officer, London School of Economics. London (QR)</td>
</tr>
<tr>
<td>Lorraine Tanner &amp; Helen Bunyan</td>
<td>NRAS Telephone Helpline Team</td>
</tr>
</tbody>
</table>

(QR = Qualitative Researcher)
Executive Summary

This report provides the results of this project exploring the experiences of 22 patients’ pathways of care from first symptoms and seeking advice from their general practitioner, to the first three years of their care. Individuals were recruited from the National Rheumatoid Arthritis Society (NRAS) Membership and represent a UK-wide geographic spread.

A multi-professional advisory board was created to oversee this project and guide the planning phase. An additional independent qualitative researcher added rigour by reviewing draft documents and data collected.

The data was collected using two forms of enquiry: Qualitative research interviews and process mapping. In addition a researcher for the London School of Economics carried out an economic analysis based upon data collected using recognised economic principles.

The data collected included:

- Key points in patient management that can be measured against guidelines and standards set out for Rheumatoid Arthritis
- Details of pharmacological and non-pharmacological management with time frames in relation to changes in treatment or management
- The costs of healthcare were calculated. These costs included costs of generalist and specialist support, costs of drugs over the times prescribed and inpatient or surgical costs
- The costs to the individual – these included work related losses and costs related to support and additional needs that resulted from their inability to manage activities of daily living or costs related to frequent hospital visits and additional support required
- There were specific issues related to the use of private healthcare and this was calculated as a healthcare cost

The results demonstrate that:

- Delays in accessing early treatment tend to exacerbate the lay belief that there is ‘nothing that can be done for arthritis’.
- Current standards and guidelines need to be more rigorously implemented.
- People presenting with joint pain remain unaware of the standards they should be able to expect, leaving them vulnerable to sub-optimal care.
- 7 of 11 participants seen within 12 weeks of symptoms in this study were seen as a result of a private referral.
- 16/22 participants received treatment with a disease modifying drug (e.g. methotrexate) within 6 months of first presentation.
- Delays in referral or receiving a definitive diagnosis/treatment can result in significant costs. Personal costs for 3 individuals in this study averaged £1,990.27.
• The indirect costs are high and borne silently by the individual with RA (and their family) (e.g. job losses). 7 participants had to take early retirement or job losses directly attributed to the RA within the time of this study.

• Individuals who have aggressive disease are heavy users of healthcare.

• For those calculating the direct costs of RA, the assumptions of healthcare costs fail to adequately capture the wide use of healthcare resources – patients are admitted and often managed through a range of medical specialities.

• Early, more proactive management will reduce healthcare use and enable individuals to remain in work.

• Some individuals could be identified as heavy consumers of healthcare resources early on in their disease, regardless of costs of drug therapies.

• Half of the participants eligible for biologic therapies (anti-TNFα inhibitors – adalimumab, etanercept or infliximab) experienced delays before accessing treatment (delays ranged from 2-10 months).

This project has revealed some important insights that may help to inform Primary Care Trusts and enable commissioners to identify key issues in their local services. This process of exploring patient journeys in the local community could be repeated to identify specific issues in healthcare provision.

The limitations of this study are that these results could be seen as representing a broadly proactive and able population of individuals who were members of NRAS and therefore had the ability to seek support themselves. This study did not represent areas of deprivation or those who have specific learning needs, cultural or ethnic minority needs. However, it is likely in these areas the needs and the results outlined will demonstrate a much greater need than reflected in this study.
Chapter 1: Introduction

Introduction:

Rheumatoid Arthritis (RA) is a long-term painful and disabling condition that can result in joint deformities and disability and ultimately a reduced life expectancy. Pain is the most longstanding and debilitating of symptoms associated with Rheumatoid Arthritis. Generalised systemic effects are also common with anaemia of chronic disease, as well as effects on other organs such as the heart and lungs.

For the individual with RA the diagnosis starts the process of negotiating the healthcare system and trying to make sense of this often complex journey. In routine clinical work it can sometimes be overlooked how confusing, stressful and sometimes convoluted the experience can be to the patient. Although the individual is usually respected and recognised as a person with unique needs and expectations, sometimes the process can still be intimidating and demoralising for those negotiating their health needs. Some individuals may have a simple journey with limited needs and straightforward access to vital resources. Others might require access to a range of healthcare professionals and specified interventions and it can be a confusing experience that doesn’t always leave the individual more informed or able to negotiate their healthcare needs.

The introduction of protocols and guidelines over recent years has resulted in a process of continual change with the aim of improving the management of patients. More recently there has been a renewed focus on Integrated Care Pathways (ICP) which may improve the patient’s experience of healthcare.

Variable access to high quality care does have important implications for patient outcomes. The rapid changes in functional ability over a 3 year period are important factors to consider as once damage is sustained the loss is irreparable and results in a loss to society, costly adaptations, splints and walking aids. A study in 1995 showed that out of 119 patients employed prior to their diagnosis of RA 62% reported some form of work disability\(^2\) and 42% had to leave their employment. For those 38% who stated they were working without any restrictions, 10% of the total group had not encountered any changes within their jobs. The rates of work disability at 1, 2, 5 and 10 years after symptom onset were identified in one UK community based study undertaken in 2000, were 14, 26, 33 and 39% respectively\(^2\). This compares to 42% registered as work disabled after 3 years in a 1999 study in the Netherlands\(^3\).

In 2000 a UK research study followed individuals with early RA for 5 years\(^4\). 9.4% of those assessed had marked functional loss at presentation, 10% of patients had home adaptations and wheelchairs at 5 years. Work disability was seen in 27% of those in paid employment at onset\(^5\). Similar studies showed a consistent theme of increased functional disability (as measured by the Health Assessment Questionnaire (HAQ)). This disability correlated with worst outcomes and greater loss of work productivity\(^6,7,8,9\).

---

\(^1\) Scheduled for 3rd year.

\(^2\) Rates at 1, 2, 5 and 10 years after symptom onset.

\(^3\) Reported as work disabled after 3 years in a 1999 study in the Netherlands.

\(^4\) In 2000 a UK research study followed individuals with early RA for 5 years.

\(^5\) Work disability was seen in 27% of those in paid employment at onset.

\(^6\) Similar studies showed a consistent theme of increased functional disability.

\(^7\) This disability correlated with worst outcomes.

\(^8\) Greater loss of work productivity.

\(^9\) Measured by the Health Assessment Questionnaire (HAQ).
Research of early RA patients in Sweden studied for over a 3 year period demonstrated that the patients who eventually received biologic therapies incurred higher healthcare costs before they were treated with biologics\textsuperscript{10}.

As the National Health Service (NHS) strives to improve care, the focus has, in recent years, been on the patient experience and the individual's perspective of the care received. A number of health policies emphasise improvements in service delivery, often applying a new, more patient centred approach, to the provision of care. The recent White Paper, ‘Your Health, Your Care, Your Say’\textsuperscript{11}, was the result of wide national consultations to explore what changes patients wished to see in the provision of healthcare as well as improving services within the local community\textsuperscript{12,13}. There is no doubt that as a result of these initiatives, the individual patient experience is now 'on the map' and has provided valuable insights for all healthcare professionals.

Patient led charitable organisations routinely support and advise individuals receiving care from the NHS. The National Rheumatoid Arthritis Society (NRAS) was launched in 2001 and is a registered charity and patient voluntary organisation that provides support, information, advocacy and training for individuals with RA. NRAS has initiated and been involved in many projects with the aim of raising awareness and striving towards improvements in service provision and ultimately, care for individuals with RA.

The NRAS experience of listening to people with RA, is that patient stories are diverse and do not always recall positive experiences through their healthcare journey, particularly in the early phases of their condition when anxieties and needs are high. Significant changes are often required to lifestyle, environment and behaviours, and personal costs can be significant. Exploring these views, it appeared that chance often plays too great a part and that in many cases people have eventually stumbled across the right pathway to care rather than taking a pre-planned path. This may be based upon poor patient knowledge of the clinical decision-making processes. However, this raises some interesting issues in relation to understanding the process and knowing how to make the important and strongly advocated ‘patient choice’\textsuperscript{13} decisions. It is not entirely clear how vulnerable groups can become empowered in the ‘choice’ agendas when there are additional barriers such as numeracy, literacy or cultural issues that may mean they are already receiving sub-optimal care as they travel through their healthcare journey\textsuperscript{14}.

For healthcare professionals the individuality of patients' needs has to be combined with the development of standards and guidelines that support consistent healthcare decisions, whilst enhancing transparency of process and equity of care.

This study set out to explore the real experience of individuals with RA and attribute empiric costs incurred by the individual and the NHS as a result of the various pathways taken. The mapping process cannot be considered a definitive research process in either quantitative or qualitative terms\textsuperscript{15}. However, aspects of qualitative research principles have been applied to the process of mapping the patient journeys, and as far as possible qualitative factors are outlined in detail and quantitative factors explored rigorously and appropriately.
It has been advocated that process mapping can reveal key system failures\textsuperscript{16}. A process such as detailed in this report can reveal the limitations of the current healthcare systems. Mapping was initially used in industry to explore bottlenecks in production and aid decision making to match capacity with demand\textsuperscript{17}. More recently these principles have been advocated and generally applied in healthcare to follow or discuss the limitations to the patient’s journey for specific treatments or episodes of care\textsuperscript{18}. Similar papers outlining patient journeys through healthcare have identified the difficulties individuals experience as a result of their healthcare experiences and lack of knowledge about how to negotiate their healthcare\textsuperscript{19,20,18}. These journeys also revealed some powerful insights into the patient experience and disparities between perceived and actual standards of care provided\textsuperscript{21,1}.

The Parkinson’s Centre in Cornwall undertook a patient mapping project although the process of data collection and the analysis differed\textsuperscript{1}. This RA mapping project is unique as costs have been attributed to the individual patient journeys. Extensive literature searches covering the period of 1999 – 2006 using the usual professional healthcare databases did not identify similar mapping projects to this study.

In order to explore the patient journey in RA a mapping project was designed to explore the NRAS members’ experience during the first 3 years of their journey through the healthcare system. This was not a clinical trial, nor an audit but a mapping of the patient’s processes from the time of onset of symptoms that caused them to seek medical advice, to the end of their first 3 years of living with their condition.

To define a discreet group that should have an identified route of care, NRAS members with a clearly documented diagnosis of Rheumatoid Factor (sero-positive) RA for 3 years or less were selected and invited to participate.

A multi-professional advisory panel was invited to guide the project and review methodology and any potential ethical issues that might arise. The lead author (SO) and 2 members (MA, DH) of the advisory panel were experienced qualitative researchers. Other members of the multi-professional and lay panel were experienced in research methodology and analysis.

The two main issues that the project set out to explore were:

a) to identify the costs related to RA in the first 3 years of diagnosis, and
b) to review the standards of care that individuals received and how this journey made sense to them in negotiating their healthcare needs.

The maps were analysed to explore:

1. The patient’s story of their experience comparing their healthcare experience with professionally endorsed standards and guidelines for individuals with inflammatory arthritis (for example RA).

2. The similarities and differences between what might be considered a theoretical gold standard map of care and the patient journeys undertaken in this mapping process. A particular focus will be on the use of healthcare resources.
3. The costs attributed to the individual and healthcare as a result of their disease.

4. Key themes from the qualitative nature of the mapping.
Chapter 2: Methods

Methods

The initial concept of mapping the patient’s journey was informed by a project undertaken in Parkinson’s disease. The preliminary proposal and methodology for the project were prepared by SO, AB and IL. To guide the project and ensure rigour in the development of the mapping project, a group of healthcare professionals were invited to form an advisory panel. The advisory panel represented the range of healthcare professionals routinely involved in the care of individuals with Rheumatoid Arthritis (RA).

National Health Service research ethics procedures did not apply to this membership study although a rigorous approach was applied to ensure that, not only was confidentiality protected but also participants were actively supported throughout the process. This support included the option of additional advice and information about the project as well as post interview telephone support from the NRAS telephone helpline team.

Methodological robustness, quality assurance and openness to the data collection were ensured through peer review by an experienced independent qualitative researcher.

The full advisory board and the independent qualitative research reviewed the proposed project outline. Database search criteria for recruitment were refined following guidance from the advisory panel. The interviews were undertaken by one interviewer, IL, who was experienced in the use of open ended interview techniques. IL was also the lead on the transcribing of interview data into a process map with additional support and secondary review of transcribing by MA. IL had extensive experience in process mapping and had previously undertaken a healthcare process mapping project.

As a registered charity supporting individuals with RA, the NRAS has an established database of members throughout the 4 nations (England, Scotland, Wales and Northern Ireland). The database was investigated by the NRAS Help Line Manager, LT, to identify members who were eligible to participate in the project. NRAS members were advised of the study and invited to participate by email, letter or telephone. The advisory board supported the principle of having a basic purposive sample of potential participants to reflect the breadth and scope of experiences across the 4 countries of the United Kingdom (Appendix 4). In addition it was hoped that the responses would be broadly representative for gender, age, culture, social needs and geographic areas. These principles guided the collating of members’ interest in participating against their demographic data and enabled the data collection to be driven by sufficient recruits to match these criteria.
The inclusion criteria:

- Diagnosis of RA (individuals were asked to check with their healthcare team that they could confirm a definite diagnosis of sero-positive Rheumatoid Arthritis).
- At the initial recruitment phase individuals were included if they had a diagnosis of sero-positive RA for 3 years or less.

The exclusion criteria:

- Unable to participate in a telephone interview

Those that expressed an interest in participating were sent a letter outlining the project, and a copy of the questions that might be asked together with a consent form (Appendix 5). The letter invited those who wished to participate to sign a consent form and return it to the NRAS office. Once this was received, the NRAS team contacted the interviewer, IL, with the participant details and the telephone interview was arranged. Patient confidentiality was maintained and apart from a telephone interview patients were not subjected to any other intervention. All maps were anonymised.

Each potential participant was advised that they could withdraw from the project at any time without prejudice and for any reason. A trained NRAS telephone helpline member of staff was available for support should the participants wish to discuss any aspects of the project subsequently.

**Data Collection Methods**

Telephone interviews were conducted by one researcher (IL). The interviews were undertaken to explore patient journeys from first presenting symptoms up to the first three years of their healthcare journey. Participants were asked to collate details of drug therapies and records of appointments and other supporting evidence about their healthcare experiences and any costs related to care.

An interview schedule outline was prepared by IL, SO and AB to aid the interviewee in recall of their experiences of their RA journey (Appendix 7). Questions were based upon qualitative research principles (for example, non-directional, open-ended questions/prompts). The questions were peer reviewed and agreed by the advisory board and the independent qualitative reviewer (SR).

Two pilot interviews were undertaken prior to the first meeting of the advisory board by 2 patient representatives who had been appointed to the advisory board. This was to explore the value of the approach and enable the interviewer to refine the telephone interview style. Following the advisory board meeting it was agreed that in order to ensure robustness of data collection, telephone interview transcripts would be verified by a qualitative researcher (MA). The data when mapped would then be returned to participants to ensure that interpretations made were correct.

All maps were coded to maintain anonymity. IL, SO and AB, being the only members who could track the data from coded maps back to demographic information provided
by NRAS telephone help line team. The rest of the NRAS team did not have access to codes attributed to each patient’s map.

IL contacted each participant to arrange a convenient time for the telephone interview and general information was given to participants about the interview and information to have to hand for that telephone call. If participants were uncertain about their RA sero-positive status they were asked to confirm this with their own doctor before the interview. The interviewer was flexible to the individuals’ needs and, if requested, interviews might be conducted over one or 2 shorter periods rather than one longer interview. The interviewees consented to the interview being recorded to aid analysis. Telephone interviews were recorded verbatim electronically using a computer software system (Copy call).

All telephone interviews were undertaken by IL using a semi-structured interview schedule and open, non-directive questioning. Examples of the prompts used included:

- Can you describe it to me?
- In what way?
- How did that feel?
- What did that mean to you?
- What type of?
- What happened next?

The participants who consented to participating in this study were asked to recount their healthcare journey from their first point of contact with their doctor, when presenting with joint symptoms, through to their referral to a specialist and on-going management following the diagnosis, for a period of up to 3 years. Demographic data, including details of participants’ general health status and social issues, is held on the NRAS database together with relevant medical history spreadsheet, and provided useful information to identify the range of social and medical characteristics.

All information collected from the telephone interviews was electronically recorded and transcribed.

Upon completion of the interviews IL contacted the NRAS helpline team to inform them that an interview had been completed. The NRAS helpline support team telephoned every participant within 24 - 48 hours after the interviews were completed and were available to provide support. The participants were asked if they were content with the process and if they had any additional questions or concerns they wished to discuss. This also provided an opportunity for the participants to discuss any thoughts or issues that presented as result of recall, allowing for an opportunity for ‘debriefing’ or ‘cool down’. The team were also supported by an experienced nurse consultant in rheumatology with qualitative researcher experience (SO) if any further support were required.
The first 5 maps were disseminated to the advisory board after initial verification by the participants to review the process and data retrieved. The corrected maps were returned to the participants for final verification. Following the advisory board’s review and satisfaction with the rigour of the process of the first 5 maps, the mapping project then continued with interviews and mapping for the remaining participants.

Recorded interview data was stored by IL in a password protected computer system. At the end of the study the recorded data was stored in a locked cabinet at NRAS offices and will be destroyed a year following publication of the project.

A brief outline of the participants’ comments on completion of the interview was noted on a spreadsheet by the NRAS telephone helpline team (Appendix 10).

**Data analysis**

All interviews were transcribed verbatim by IL from the electronic data recording system (copycall). Transcribing was undertaken from the electronic recordings to form a unique map documenting each point of the participant’s healthcare journey.(appendix 9). All recorded telephone interviews were independently reviewed by (MA) a researcher experienced in qualitative interview techniques to agree that transcribing was accurate and then mapped by IL. Additional supervision was provided by SO.

The individual’s completed maps were then sent to the participant to review, edit and verify/correct errors. All maps were returned for minor refinements (spelling or typographical errors), most maps had refinements that were related to additional costs related to care (information that came to light when the participant reviewed their map aiding recall of key events) (See appendix 17). The returned maps were then refined and returned to the participant for final verification or refinement. Corrected maps were then returned for review and refinement by participants a second time. All maps were returned as accurate on second submission for review and verification. SO and AB reviewed each map to ensure that there were no discrepancies in relation to information required on clinical issues or missing data (for example spelling mistakes related to drugs). All maps were revised and verified as correct by the participants before final dissemination to the advisory board.

The data generated from each individual participant’s maps were continually reviewed with themes being generated throughout data collection. The themes were clustered around key points in the participant’s journey as identified by clinical standards and guidelines and events in patient care (for example when participants were seen by consultant rheumatologist). At the end of the mapping process and review of data collected six key themes were identified (see results).

The themes were identified, documented, discussed and agreed by AB, SO and IL. All maps and the initial analysis of the data were sent for critical appraisal to the advisory board members and independent qualitative researcher. Two members of the advisory board sought clarification of the data generation for health economic analysis and availability of additional data to support themes identified. Two advisory board members with qualitative expertise supported final review of maps and
refinement of quotes used in the presentation of data. In all responses from advisory board were positive and related to editing, rewriting issues related to the report.

In addition to these themes, sub themes were identified that helped to guide the project in relation to the use of healthcare resources and the social consequences of the individual participant’s journey. Themes and sub-themes also added context to the economic analysis. The economic researcher (MA) was included in all reviews of themes to guide and support presentation of economic data.

However, in demonstrating robustness and rigour of the qualitative principles applied in this project it is important to recognise that the data although applying qualitative principles the main focus of this project was to identify the patient journey based upon what currently constitutes good practice as set out by standards and guidelines. Data collection was driven by mapping the process of care as recalled by the patient. Maps and economic analysis did then reveal key time points along the patient journey for example, time from presenting symptoms to seek medical advice, referral to specialist teams and time before starting a disease modifying drug. As far as the authors are aware this is the first time process mapping and qualitative research principles have been combined, particularly with a focus on economic consequences of RA.

**Standards and guidelines**

The process of exploring the participant’s journey was formed from published standards and guidelines in the management of Rheumatoid Arthritis. These documents included:

- The Arthritis and Musculoskeletal Standards of Care for Inflammatory Arthritis (2004)\(^{22}\)
- The British Society for Rheumatology Guidelines for the standards of care for people with Rheumatoid Arthritis (2005)\(^{23}\)
- The British Society for Rheumatology Guidelines for the management of Rheumatoid Arthritis (The first 2 years) (2006)\(^{24}\)
- The British Society for Rheumatology Guidelines for prescribing anti-Tumour Necrosis Factor alpha therapies (2001) superseded by the update/revision (2004)\(^{25,26}\)
- The National Institute of Health and Clinical Excellence – in the treatment of RA with infliximab and etanercept\(^{27}\)

The Arthritis and Musculoskeletal Alliance (ARMA) Standards were used as the main indicator as these standards encompassed consensus by all patient and professional organisations involved and reflected standards identified in the BSR guidelines.

Consideration was also given to health policy initiatives including:

- Self care and choice\(^{28}\)
- Creating a patient led NHS\(^{29}\)
- The Musculoskeletal Strategy Framework\(^{30}\)
- Our Health, Our Care, Our Say; a new direction for community services\(^{11}\)
Economic analysis

Once the journey was mapped the information was used to form the basis of the economic analysis of the participants' healthcare journeys. Individuals were asked to provide their own information on personal costs attributed to their journey and this was combined with the formal health economics data.

The economic analysis of the completed maps identified the range of costs related to each individual participant’s journey. These included:

1. Costs to the NHS and healthcare providers (costs associated with primary, secondary care attendances, pharmacological and other health technologies’ costs as detailed above). The healthcare costs were calculated using NHS costs and these have been used to reflect healthcare interventions for both the NHS and private providers.
2. Costs to the patient (financial and personal).
3. Hidden costs – related to inappropriate referral, waiting times, other health seeking options that the patient may explore.

The cost of private health insurance premiums has not been included as a personal cost to the patient. This is because the premium may not necessarily be attributed purely to RA and other members of the family may be covered by the policy. In addition company health care schemes may attribute the cost and level of the premium to private business rather than the patient.

Sources used to explore healthcare costs can be seen in the Economic Analysis and Results Chapter (page 37) on economic analysis.

Categorisation of disease duration was undertaken because those who had had their disease for a shorter time frame may have incurred lower costs. Therefore participants were broken down into 3 groups depending upon their length of diagnosis:

1. less than a year
2. one to 2 years
3. more than 2 years and less than 3 years 6 months.

The costing exercise assumes:

- The cost of private insurance premiums is not attributed directly to the RA or the individual with RA.
- The cost of private consultation is priced as in the NHS (Health Resource Groups HRG prices). The costs of all private care were calculated using these principles.
- The home care provided by family members is not costed directly.
- Costs of medication not directly attributable to RA are excluded (conservative assumptions on the exclusion of other medications).
- Costs to the government (e.g., tax income, statutory sick pay, disability allowance) are reported only when the patient volunteered to speak about these issues.
- Costs are calculated up to the end of the year 2005 (31.12.05).
Chapter 3: Results

Presentation of the data

The results section is presented with a description of the participant demographics followed by a summary of the results as they relate to six key themes derived from the qualitative component of the mapping process.

Each of the key themes is developed in detail and is presented relative to the recognised professional guidelines and standards. Guidance and standards have been published by national patient and professional groups. The Arthritis and Musculoskeletal Alliance (ARMA) have published Standards of Care for Inflammatory Arthritis,\textsuperscript{31} and the British Society for Rheumatology recommend evidence based pathways of care \textsuperscript{24,23,32} These guidelines and standards cover primary and secondary care, assessment needs, diagnostics, pharmacology and non-pharmacological treatments as well as access to multi-professional teams. Initial interventions and follow up care are discussed.

The results are presented with supporting evidence to guide the reader on the significance of the evidence and how variances have an impact or fall outside recognised good practice guidelines.

Key themes generated from the qualitative study of the mapping process.
1. Primary care access and initial treatment
2. The impact/ significance of the time to seeing a consultant rheumatologist & receiving treatment with a disease modifying anti-rheumatic drug and/or biologic therapy
3. Disease Management and individualised care plans.
4. Access to multi-professional teams including routine and basic nursing care and extended roles
5. Access to patient education
6. Costs attributed to the individual and to the healthcare services

Participant demographics

Potential participants who fulfilled the search criteria (diagnosis of sero-positive RA for less than 3 years) were initially identified from the NRAS database by LT and HB members of the helpline team. Members were invited to participate in the study. Initially 33 expressed an interest in the project. In total 27 participants responded and requested the additional information. A letter and consent form were sent to all those interested. Out of the initial 27, 3 individuals did not return a signed consent form and therefore were perceived as declining to participate. For the mapping project the advisory board agreed that a purposeful sample of 24 was considered reasonable, based upon qualitative principles of exploring common themes.
At the end of the data collection 2 participants were withdrawn from the analysis. Both participants were having their diagnoses reviewed; one following transfer to another specialist unit (map 021) and the other was under review due to uncertainty about their definitive diagnosis (map 015). At the time of collating the data these 2 patients’ diagnoses of sero-positive RA was under review and therefore these 2 maps were withdrawn from the analysis.

In total 22 maps were therefore included in the final analysis.

The interviews took place from 8 December 2005 to 20 February 2006. Length of interviews ranged from 40-90 minutes. Patient confidentiality was maintained throughout and apart from a telephone interview patients were not subjected to any other intervention (such as blood tests or contact from other healthcare professionals).
Figure 1: Flow chart of Research Flow Methodology

NRAS & SO prepared outline and funding proposal. Email consultation, scope of project and framework outlined Advisory Panel membership agreed

Proposal scoped and outline prepared by NRAS and SO
Advisory Board Convened & project planned
Review of pilot interviews
Additional qualitative supervision recruited

NRAS Membership Invited to Participate
Purposeful sampling
Telephone helpline team and support provided (SO) for queries

Letter outlining project and consent form sent

24 Participants returned consent forms
5 Male 19 Female

Interviews carried out between 8th December 2005 to 20th February 2006

Interview schedule and interview processes refined

Advisory Board review/consultation

33 Responded
11 Males & 22 Females

Data released to interviewer (IL) telephone interview date planned

Interviews recorded and transcribed into a visual map. First 5 maps reviewed by Ad Board

Comments post interview collated and recorded.

22 Maps reviewed by 2 Qualitative researcher & Economist/Advisory Board
Analysis of costs
Analysis of maps & Key points identified according to Standards of Care (ARMA & BSR)

Final review of data and results by:
Qualitative Supervisors
Additional independent researcher/Advisory Panel
Advisory Panel

Non responders Excluded from study
6 Male 3 Female

Maps sent to participants to verify or adjust draft map/returned to researcher and edited. Cycle repeated for verification.

Review of maps revealed 2 participants being considered for alternative or additional diagnosis
Withdrawn from analysis

Final version of maps sent to participants
Post interview telephone contacts were documented and are detailed in Appendix 10. All participants stated they were pleased to have taken part and found the process of value in itself. None of the participants required a further follow-up call although they were encouraged to contact the helpline if they changed their minds.

Most maps had some minor modifications by the patient (such as spelling of drug or dosage). One or 2 had significant changes that were as a result of patient recall following the interview and required major modifications. The corrected maps were always returned to the participant for final verification. All participants verified that the final map represented a satisfactory and accurate representation of their own pathway.

**A key component of this project was that of exploring variance between individual maps and national standards of care. This key theme underpins all six key themes and is considered at all points in the analysis.**
Theme 1. Primary care access and initial treatment

1a) Time from symptom onset to seeing General Practitioner

There are no specific standards set for individuals seeking medical advice on their joint pain, although it is acknowledged that public health messages should stress the importance of seeing a healthcare professional promptly to make a diagnosis and provide symptom control. However, it is recognised that there is a poor understanding of RA and many individuals experiencing joint pain attribute their symptoms to the lay term of arthritis, usually referring to osteoarthritis or to non-specific musculoskeletal pain. The most frequently cited statement from individuals surveyed about their joint pain is that they believed ‘nothing can be done’.

It is important to note that while responsibilities for delays in the healthcare journey can lie with any of the healthcare professionals or systems than an individual meets along their journey there is a significant and common source of delay in the patient seeking a first appointment with their own general practitioners. The delay from first contact with a GP practice to appointment would rarely exceed seven days yet it is this delay in first contact that accounts for the majority of the large variance in the figures three. This means that in many circumstances the participant themselves frequently delay seeking a first appointment with their own general practitioner.

Figure 3: Time from symptom onset to seeing General Practitioner

* One participant advised by practice nurse not to see GP as symptoms were related to an allergy.
** One participant had 2 years of relapsing and remitting symptoms.
1b) Initial treatment in primary care

There appeared to be a significant variability between the levels of knowledge and support that individuals perceived they had had from the general practitioner. One GP was so concerned about the participant because of the lag between specialist referral that they themselves eventually instigated treatment with a Disease Modifying Anti-Rheumatic Drug (DMARD).

Another participant had access to a General Practitioner with a Special Interest in Rheumatology (GPwSI).

005: First GP very helpful but not diagnosed at this time
Current GP has a specialist interest in RA which is wonderful

Three GPs were reported as providing excellent support and determination in gaining their patients access to specialist services. There were also some reported cases of what the participants perceived as poor understanding of inflammatory conditions. Examples of initial diagnosis included one patient being refused a referral as they were told ‘they were going through the menopause’, and another that they had ‘an episode of gout’. When the diagnosis of gout was revised to possible RA the participant was still advised that they did not need a specialist referral. A further participant delayed seeking a face to face appointment following telephone advice from a practice nurse who suggested the inflamed joints were related to an allergy.

Table 1 illustrates how frequently participants visited their General Practitioner

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Number of Visits to GP (range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis &lt;1 year N=6</td>
<td>(Range) 3 – 7</td>
</tr>
<tr>
<td>Diagnosis of 1-2 years N=9</td>
<td>(Range) 3 – 24</td>
</tr>
<tr>
<td>Diagnosis &gt;2 years and &lt;3.6 years N=7</td>
<td>(Range) 3 - 54</td>
</tr>
</tbody>
</table>
Theme 2. Access to secondary care

2a) Time to seeing a consultant rheumatologist & receiving treatment with a disease modifying anti-rheumatic drug and/or biologic therapy

Once a patient has made contact with the health care system then a strong case can be made for the system taking responsibility for expediting the most appropriate and timely path towards definitive diagnosis and best management. Clear standards of care have been defined to deal with maximum periods of appropriate delay between when a person with probable inflammatory arthritis presents in primary care and when appropriate secondary care is initiated.

**ARMA Standard of Care (2004) – Standard 4** All people with suspected inflammatory arthritis should be seen by a specialist in rheumatology within 12 weeks of referral from their GP, to confirm diagnosis and enable prompt and effective treatment. A developmental standard of 6 weeks is proposed.

**ARMA Standard of Care (2004) – Standard 6** People with inflammatory arthritis should have access to safe, effective, evidence based care and management strategies with appropriate monitoring arrangements. People should have access to personalised education programmes to enable them to make informed choices about treatment options, including recognised self management programmes.

**British Society for Rheumatology (BSR) (2006) Management of Rheumatoid Arthritis (the first 2 years)**

1) Diagnosis should be made as early as possible.
2) Patients with suspected early synovitis [should] have rapid access to a multidisciplinary team that includes specialists in rheumatology (6-12 weeks).
It is of note that a number of participants sought a faster route to a specialist by seeking out private referrals. This was sometimes recommended by the GP because of long waits locally. Out of the 9 participants using the private referral route, 6 had private health insurance at the onset of their symptoms and 3 paid themselves to be seen privately.

Of the 22 participant maps, half the participants fell outside the current ARMA (2004) standards of care for referral to a specialist within 12 weeks. Two of these participants were private referrals. Of the 11 participants who met the current ARMA standards of care for referral times, 6 of these were as a result of private referrals. There were 7 participants who met the aspirational standard set of referral within 6 weeks, however 6 of these were private referrals. Two patients had to wait between 11 and 13 months before being seen by a consultant rheumatologist. (Figure 4)

The time that elapsed between being seen by the GP and the consultation with a rheumatologist varied significantly as can be seen in Figure 4. The reasons can be chiefly attributed to long waiting times for a new referral into secondary care, poor referral pathways and occasionally reticence by the GP to refer.

018: GP felt inadequately equipped to deal with RA as it was beyond his expertise. However the patient felt that his support had been incredible.

For some patients, the time waiting to be seen by a specialist added an additional burden to their journey. For this group of participants the wait added to the personal costs related to employment or social issues that impacted upon the individual’s life. (005, 006, 007, 009, 010, 011, 012, 016, 018, 019, 022, 023).
On long term sick leave since July 2004 (when she should have returned after maternity leave). After 13 weeks the basic salary was reduced by 25%. This resulted in a loss of earnings as well as the loss of company car allowance of £7000. Has been reviewed by company doctor in the last 12 months.

2b) Time from initial presenting symptoms to first Disease Modifying Anti-Rheumatic Drug (DMARD)

<table>
<thead>
<tr>
<th>ARMA Standard of Care (2004) – Standard 4</th>
<th>All people with suspected inflammatory arthritis should be seen by a specialist in rheumatology within 12 weeks of referral from their GP, to confirm diagnosis and enable prompt and effective treatment.</th>
</tr>
</thead>
<tbody>
<tr>
<td>ARMA Standard of Care (2004) – Standard 6</td>
<td>People with inflammatory arthritis should have access to safe, effective, evidence based care and management strategies with appropriate monitoring arrangements. “Current evidence supports early aggressive treatment with single or combination DMARDS.”</td>
</tr>
<tr>
<td>BSR (2006) Guidelines point 8</td>
<td>Management of Rheumatoid Arthritis (the first 2 years). Patients with RA should be established on disease modifying therapy as soon as possible after a diagnosis of RA is established (6-12 weeks). DMARD therapy should be part of an aggressive package of care, incorporating escalating doses, intra-articular steroid injections, parenteral methotrexate and combination therapy, rather than sequential monotherapy, with the aim of those eligible progressing to a biologic (for example treatments such as anti-tumour necrosis factor alpha (anti-TNFα) therapy).</td>
</tr>
</tbody>
</table>

While there remain important debates in relation to the use of systemic steroids as a bridging therapy in early disease there is a strong body of evidence that identifies the need for prompt treatment with DMARDs. Systemic steroids may provide reasonable symptom control and potentially some control of the inflammatory processes but this should not delay the prompt prescribing of disease modifying drugs. Nor should treatment simply be confined to Non Steroidal Anti-Inflammatory therapies (NSAIDs) which may relieve symptoms but not halt joint erosions.
Figure 5 Time from first presenting symptoms to first DMARD
NHS and private referrals

Table 2 Number of Consultant Rheumatologist Follow-up appointments from
first episode to end of study

<table>
<thead>
<tr>
<th>Diagnosed &lt;1 year</th>
<th>Diagnosed 1-2 years</th>
<th>Diagnosed &gt;2 years and &lt;3.6 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Consultant Visits</td>
<td>Number of Consultant Visits</td>
<td>Number of Consultant Visits</td>
</tr>
<tr>
<td>Range: 1 – 4 Follow Up</td>
<td>Range: 1 – 34 Follow Up</td>
<td>Range: 6 – 20 Follow Up</td>
</tr>
</tbody>
</table>

1c) Time taken to initiate NICE guidance

National Institute of Clinical Excellence Guidance for Etanercept and Infliximab\(^{27}\) In spite of NICE guidance (published in March 2002) access to these drugs for those who meet the eligibility criteria, remains for many with RA, a postcode lottery\(^{35}\). Recently financial constraints have been identified as a common barrier to implementation of NICE guidance\(^{36}\).

Five participants in this study were taking biologic therapies (002, 005, 010, 016, 023). None of these patients was receiving biologic therapies from a private healthcare provider. One additional participant fulfilled the eligibility criteria in September 2005 but was advised this would have to be deferred until February 2006 (and after the data collection for this study) due to funding issues (007). Three of the participants had experienced similar delays before commencing treatment despite fulfilling eligibility
criteria (002, 010, 016). The delays ranged from 2 months to 10 months before receiving treatment. One participant whilst waiting for access to treatment was forced to accept early retirement while conversely one participant improved so dramatically 10 months after starting biologic therapy that he was no longer eligible for incapacity benefit.

002: Patient experienced “big improvement after only 2 injections of Enbrel”. However they reported that “a lot of damage has already been done to hands fingers, toes and ankles”.

023: January 2005 started Etanercept – until February 2006 this participant has only had 5 days’ absence from work in 2005.

Theme 3) Disease management and individual care plans

ARMA standards – Standard 5 Assessment should involve the full rheumatology multidisciplinary team and any other relevant specialities.

The ARMA Standards of Care (2004) – Standard 6 People with inflammatory arthritis should have access to safe, effective evidence based care and management strategies with appropriate monitoring arrangements.


The plan should include:
- Clear pathways for ongoing care and treatment
- Information about treatments, care providers and services
- Access to self-management advice if required
- Details of national and/or local support groups and helplines
- Details of social services and employment services
- Information about what to do in the event of worsening symptoms, including contact details for urgent advice
- Information for schools and employers on how to support people with inflammatory arthritis in education and work.

BSR guideline (2006) Patients with RA should be provided with a plan of care from diagnosis which outlines the principles of management including a commitment to training patients to self-manage some aspects of their disease.

It was not entirely clear how many participants had an insight into their disease management or a framework for regular disease assessment and review. This may not reflect the level of care but simply reflect the lack of detailed information that enables the participants to understand some of the management decisions and review processes as well as the rationale behind them. Eight participants who received care
from the National Health Service (NHS) were aware of regular review and assessment of their disease but an additional 5 were unsure.

Eleven participants had regular and active disease assessment with, a further 9 participants having such care although the participants had not been informed (or did not recall) that this was the approach being applied. However, 2 participants were clear that they received no such approach.

The ARMA Standards of Care for Inflammatory Arthritis (IA) advocate individualised care plans as do the Department of Health and other healthcare organisations. In this study none of those interviewed were aware of a care plan that had been discussed with them.

According to the participants’ recall and data collected from the interviews none of the participants had any form of care plan. It is however, important to outline that care plans are, in effect, still at the early stages of implementation and for many of these patients their treatment would have started their health care journey at a time prior to the inception of the care plan.

It appears from comments recorded that participants would welcome such an approach and may be able to better manage their condition, and perhaps be more active participants in their care once they are aware of the rationale behind some of the current healthcare interventions.
Theme 4) Access to the multi-professional team including routine and basic nursing care and extended role practitioners.

<table>
<thead>
<tr>
<th><strong>ARMA (2004) – Standard 5</strong></th>
<th>Access to psychosocial and pain management needs. Assessment should involve the full rheumatology multi-disciplinary team and other relevant specialties</th>
</tr>
</thead>
<tbody>
<tr>
<td>Timing and format (group/individual/written) of educational support to meet individual needs must be considered. Patients should be offered a cognitive behavioural approach to patient education, delivered at the appropriate time in order to promote long-term adherence to management strategies.</td>
<td></td>
</tr>
</tbody>
</table>

**BSR (2006) Guidelines for the management of RA (first 2 years). Guidelines point 2.** Rapid access to a multi-disciplinary team includes specialists in rheumatology, and includes members from both primary and secondary care in order to provide seamless services for patients.

Participants who were recipients of private consultations were associated with reduced access to full multi-professional teams compared to NHS participants. For those who transferred to NHS care this situation improved. For those that received private care initially, out of all the disciplines, they were most likely to be referred for a private physiotherapy appointment.

The standards for those receiving NHS care varied with some participants receiving a standard of care conforming closely to the Arthritis and Musculoskeletal Alliance (ARMA) Standards of Care for Inflammatory Arthritis.

| 024: Patient has nothing but praise for the way he has been looked after by all the health professionals and the health service. |
Table 3. Private patients with access to multi-professional teams

<table>
<thead>
<tr>
<th>Participant Number</th>
<th>Access to multi-professional teams</th>
</tr>
</thead>
<tbody>
<tr>
<td>001</td>
<td>Only consultant</td>
</tr>
<tr>
<td>002 (Part NHS Part PP)</td>
<td>&gt; 3 members of team</td>
</tr>
<tr>
<td>004</td>
<td>Only consultant</td>
</tr>
<tr>
<td>005</td>
<td>Only consultant</td>
</tr>
<tr>
<td>006</td>
<td>Only consultant</td>
</tr>
<tr>
<td>008</td>
<td>Consultant + physiotherapist</td>
</tr>
<tr>
<td>016</td>
<td>Consultant + occupational therapist</td>
</tr>
<tr>
<td>018 (part NHS Part PP)</td>
<td>Only Consultant</td>
</tr>
<tr>
<td>023</td>
<td>&gt; 3 members</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Participant Number</th>
<th>Access to multi-professional teams</th>
</tr>
</thead>
<tbody>
<tr>
<td>003</td>
<td>&gt; 3 members</td>
</tr>
<tr>
<td>007</td>
<td>Consultant + nurse</td>
</tr>
<tr>
<td>009</td>
<td>&gt; 3 members</td>
</tr>
<tr>
<td>010</td>
<td>&gt; 3 members</td>
</tr>
<tr>
<td>011</td>
<td>&gt; 3 members</td>
</tr>
<tr>
<td>012</td>
<td>Consultant + physiotherapist</td>
</tr>
<tr>
<td>013</td>
<td>&gt; 3 members</td>
</tr>
<tr>
<td>014</td>
<td>&gt; 3 members</td>
</tr>
<tr>
<td>017</td>
<td>&gt; 3 members</td>
</tr>
<tr>
<td>019</td>
<td>&gt; 3 members</td>
</tr>
<tr>
<td>022</td>
<td>&gt; 3 members</td>
</tr>
<tr>
<td>024</td>
<td>&gt; 3 members</td>
</tr>
</tbody>
</table>

Theme 5) Access to educational support

Patient education is a cornerstone for building self management principles, improving concordance and risk management. Education should be considered an integral aspect of care. The limited access to formal education programs (only 6 participants had received a disease specific, hospital education program) was disappointing, although this does reflect anecdotal reports in recent years, that pressure on the services has resulted in cuts to specialist patient educational programs. In some areas the only option for individuals is that of participating in the Expert Patient Programme (EPP). This however, does not deal with specific issues related to the disease itself and increasing knowledge about the disease and its consequences nor does it manage key issues about safety and true informed consent on drug therapies and treatment options.

Access to education and other disease related information and support were also limited in the private sector with only 2 patients receiving private care stating they had received written information. One participant had been lent a book on arthritis by the
consultant and another was provided with an Arthritis Research Campaign (ARC) leaflet. One participant receiving private care actively sought out, at their own instigation, an Expert Patient Program (EPP) to attend which would provide a generic chronic disease level of support without covering specific guidance on RA.

The majority of participants had limited access to structured educational programmes. Eight NHS participants received only basic information about their condition and an additional participant (017) was probably provided with the information but stated that she was ‘bombarded’ with information at a time she was in total denial about her condition.

For those participants (n=8) who received limited educational input, researchers noted that they spontaneously volunteered that they would have liked more information and had actively sought out information themselves via websites or from patient networks (such as NRAS Volunteer Network or Expert Patient Program). Three participants (004, 007, 008) expressed concerns about the quality of some information they accessed as some websites appeared to have more of a promotional angle and did not seem to be affiliated to any professional organisation or registered charity.

---

007: Lack of advice and information… “you needed to ask, nothing offered”

This patient later added

“Registrar was very abrupt – yes, I think you have RA; of all the things you can get this is what you did not want… You won’t get better.”
Figure 6: Participants who received either one-to-one or group education on their condition and treatment options

Individuals (n=9) who received disease educational input plotted against time from diagnosis

Note: Educational input defined as: Educational Programme either group or one-to-one sessions consisting of: information on disease, symptom control, self management and treatment advice on side effects and monitoring.

004: No advice offered other than a leaflet on Methotrexate. Left to do own research, mostly via the internet

003: Experienced good information programme at the hospital. Basic information leaflet supplied for drugs i.e. Methotrexate

009: No additional education support apart from original arc leaflets provided by Consultant. Patient sourced other material directly from ARC and NRAS.

Demonstrating the benefits of patient education is complex and needs vary significantly, as participant (017) highlights; timing and regular opportunities to build on initial information is key, particularly as individuals may not be ready to take on information provided at one specific time point. In contrast, participant (021) had significant unmet needs.
3c) Access to ‘gold standard nursing care’ included education and extended scope nursing support

For the terms of this mapping exercise, the term ‘gold standard nursing care’ is defined as “support from a nurse who works in an extended role providing nurse led follow-up services that offered education on a one-to-one basis, rapid access services and telephone advice line support”. These principles reflect care expected in professional standards and guidelines. The educational support would be ongoing based upon individual needs, and incorporated areas such as treatment, monitoring, advice on drug therapies and reviews of blood monitoring.

It appears that 10 participants received this level of support (participant maps: 002, 006, 007, 008, 016, 017, 018, 020, 023, 022). However, 3 additional participants stated they had been provided with some educational input about their condition from a specific nursing intervention although it was not clear that other aspects of nursing support were available (003, 013, 019). It is also possible that some educational support was provided by the Occupational Therapist or Physiotherapist although this information was not possible to identify from the data.

Table 4: Number of nurse consultations

<table>
<thead>
<tr>
<th>Diagnosed &lt; one year</th>
<th>Diagnosed 1-2 years</th>
<th>Diagnosed &gt; 2 years and &lt; 3.6 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>0, 3, 1, 1, 0, 5</td>
<td>0,0,1,0,3,0,3,0,0</td>
<td>0,21,0,0,1,5,4</td>
</tr>
<tr>
<td>Range 0 – 5 visits</td>
<td>Range 0 – 3 visits</td>
<td>Range 0 -21 visits</td>
</tr>
<tr>
<td>Median = 1</td>
<td>Median = 0</td>
<td>Median = 1</td>
</tr>
</tbody>
</table>

017: As an introduction to the trial the patient was bombarded with information about the condition (the drugs, physiotherapy etc) but very little of this contained advice on what she would experience and how to manage the pain on a day to day basis other than painkillers.

021: Very poor initial education offered on RA. Most came from self study on the internet.

021: Patient not told by original consultant that she had RA. He took her to the RA nurse and as he handed the file to the nurse he told the nurse that the patient had RA. This was the first time this was mentioned.
Theme 6) Costs attributed to the individual and to the healthcare services

The economic analysis was prepared based on a framework that attributed costs to a set of identified options to care delivery (Appendix 6). The economic analysis was prepared with the support of a research officer at the London School of Economics seconded to Catalyze and undertook the process mapping. Reference documents and data used are key documents used for National Health Service cost analyses. If uncertainty existed, data were excluded or an under-estimate of costs were applied based upon available data.

Private insurance policy premium were not accounted for in the personal costs to the individual as they may not have been RA specific, other members of the family may be All data attributed to healthcare provided (either NHS or private) were calculated based on NHS costs as outlined below.

However, in some cases the economic analysis data failed to truly represent the actual costs of RA. This is because total health and individual costs are not accounted for in either NHS or private insurance costs.

Sources used to direct healthcare costs included:


The Personal Social Services Research Unit, Unit Costs of Health and Social Care 2005 Compiled by Lesley Curtis and Ann Netten of the University of Kent. [http://www.pssru.ac.uk/uc/uc2005contents.htm](http://www.pssru.ac.uk/uc/uc2005contents.htm)

The NHS Health Technology Assessment Programme [http://www.hta.ac.uk/index.htm](http://www.hta.ac.uk/index.htm)


D Symmons, K Tricker, C Roberts, L Davies, P Dawes and D L Scott (2005). The British Rheumatoid Outcome Study Group (BROSG) randomized controlled trial to compare the effectiveness and cost-effectiveness of aggressive versus symptomatic therapy in established rheumatoid arthritis, Health Technology assessment, 9 (34).

6a) Participants diagnosed for less than year

![Graph illustrating the ratio of personal to healthcare provider costs for participants diagnosed < 1 year (n=6)](image)

| Age/Sex: | 37F | 46F | 73M | 65M | 36F | 32F |

Figure 7: Illustrating the ratio of personal to healthcare provider costs for participants diagnosed < 1 year (n=6)

There was a range of costs incurred by the group with a disease duration of <1 year. Most of the year one costs related to hospital and specialist care with a relatively low proportion of costs borne by patients themselves. Participant 007 had significant and rapid changes that resulted in several problems related to their work, travel to work and costs related to staying in work. This was despite support from the employers.

An additional burden may have been placed on this participant as a result of the delay in referring (6 months). Sadly, this patient did not get access to specialist nursing or probably multi-professional team support until 6 months after the diagnosis.

Access to further support or education did not follow for a number of months resulting in a time of feeling very depressed and time off work (Map 007).

This participant (007) had been waiting 6 months to start a biologic due to funding constraints. On completion of the interviews this permission had been granted.
b) Participants diagnosed between 1-2 years

Figure 8: Illustrating the ratio of personal to healthcare provider costs for participants diagnosed between 1-2 years (n=9)

6c) Participants with a diagnosis between >2 years and <3 years

By the second year after diagnosis, data suggests that total costs are accumulating and a larger proportion of the total cost is being borne by the patients. Two patients in this group had spent significant sums on alternative therapies, and attendance for hospital and specialist care also presented a personal burden. Alterations to home and home carer support were first required by some patients in this group. Costs to the NHS can be seen to be rising but with most patients on conventional DMARDs the NHS costs are largely limited to hospital attendances for review. The average age of this group was 51 years (range 31 – 71 years). Cumulative costs to this group are significantly larger than for those of shorter disease duration. NHS costs vary strikingly, largely because 4 patients in this group were taking expensive biologic drugs which contributed to significant increases in the NHS cost. The majority of participants receiving biologic therapies (4 of 5) were in the group of disease duration >2 years and up to 3 years (participant maps, 002, 010, 016, 023). Personal costs also varied however, with home carer support again impacting significantly. However, those identified as eligible for biologics had rapidly increasing healthcare costs before the prescribing of a biologic therapy.
Figure 9: Illustrating the ratio of personal to healthcare provider costs for patients diagnosed between 2 years and <3 years 6 months (n=7)

![Bar chart showing the ratio of personal to healthcare provider costs for patients diagnosed between 2 years and <3 years 6 months.]

<table>
<thead>
<tr>
<th>Age/Sex</th>
<th>Patient IDs</th>
</tr>
</thead>
<tbody>
<tr>
<td>71F</td>
<td>002</td>
</tr>
<tr>
<td>59F</td>
<td>003</td>
</tr>
<tr>
<td>51F</td>
<td>009</td>
</tr>
<tr>
<td>31F</td>
<td>010</td>
</tr>
<tr>
<td>65M</td>
<td>016</td>
</tr>
<tr>
<td>36F</td>
<td>018</td>
</tr>
<tr>
<td>50M</td>
<td>023</td>
</tr>
</tbody>
</table>

Figure 9: Diagnosed >2 years and <3 years 6 months

For participant 010 (aged 31 years) the symptoms resulted in a loss of employment and for a period of time the condition was so disabling that it resulted in a time of clinical depression; a period of being bed-bound followed by an emergency admission to hospital, followed by a period of intensive multi-professional support and a total of 21 hospital inpatient bed days over the time period mapped. Although identified as eligible and requiring a biologic, it took 7 months before the patient could receive this therapy due to funding issues. During this period the participant’s marriage ended. Social support and the inability to live alone due to disability forced the need for this participant to return to live in the parental home for support.

For participant 016 (aged 65 years) the journey has had a significant impact and they had carefully documented costs and losses related to this journey. The need to take early retirement, the death of their partner and, ultimately, the need to move closer to family to ensure they had a level of social support during difficult times of their condition were some of those losses. This participant unfortunately had to take early retirement and accept incapacity benefit before receiving a biologic. They improved so much following 9 months of treatment with a biologic (to the participant’s delight) that they were no longer eligible for incapacity benefit. In the period that this participant
was mapped (13 months) they had been to their GP more than 40 times and had been seen by their consultant rheumatologist 10 times.

Similar costs related to employment issues can be seen in the journey of participant 009 (age 51 years) who felt forced to resign after a protracted period of sick leave. The participant now relies heavily on support from partner who is self employed with a resulting impact upon the family’s income. At a time when significant losses and changes as a result of the disease were impacting, this participant felt that the level of support available from the specialist team was sub optimal and particularly the inability to be assessed by a physiotherapist. In a relatively short time frame this participant has experienced significant limitations in functional ability judging from the amounts of assistive devices that have been acquired, including a wheelchair.

6d) Optimising management and costs related to sub-optimal management

The consequences of sub optimal management could sometimes have significant effects on the individuals’ personal perspective of a treatment and their understanding of future therapies opportunities.

One participant pointed out that they were not going to be able to be considered for newer therapies. This participant, on discussing further treatment options, was found to be eligible for a biologic (018). However, they were advised that because ‘she had tuberculosis (TB) as a teenager’ this was not pursued. It is possible that treatment might have been postponed for further consideration (for instance after more detailed medical assessment and possible treatment for the underlying TB risk). To the participant this statement implied that future treatment options were closed to them because of the past history.

The time taken from being identified as eligible for a biologic and receiving treatment ranged from one month to 10 months. The reasons cited related to delays in gaining permission to start the treatment due to financial constraints.

This presents some important financial issues that need to be considered particularly as job losses and early retirement (n=10), work adaptations (n=6), or more than 2 weeks of sick leave (n=13), emergency and inpatient admissions (N=10) were high in this group of participants. Six participants were registered disabled (Incacity Benefit).

When considering the costs and implications for poorly controlled disease it can be seen that some participants were high users of healthcare resources. In total the 5 participants who ultimately received biologics accounted for 2 emergency admissions and 47 hospital inpatient admissions during the first 3 years of their diagnosis. In total 7 out of the 22 participants accounted for 7 emergency admissions and 86 inpatient days in this mapping study. Four additional participants not receiving biologic therapies made up the rest of the emergency and inpatient admissions (participant map 012, 019, 022, 024).

Participant 012 (age 27 years) was working at the time of the mapping process but had to reduce working hours and, as result, stated they faced a significant financial impact as a result of this reduction. Map 019 (age 36 years) was facing a number of issues related to the loss of income and reduced working hours and had to request a
significant input from the occupational therapy department to support aids and adaptations to the home, despite significant support from her family. This participant is in the category of participants diagnosed between one to two years had already had 21 inpatient admissions since being diagnosed.

Participant Map 022 also faced a potential job loss with numerous absences from work and loss of income. This participant had also had emergency admissions (2) and inpatient admissions (2). As this mapping study was completed participant 024 was advised that they were being made redundant (at the age of 39 years). One participant (014) had significant support from her employers who actively sought advice from the GP about the consequences of the disease and received prompt Occupational Therapy support in the home.

Although clearly biologics are an expensive treatment and need to be considered in the context of eligibility criteria, it has to be considered in the context of a wider range of factors. Clinicians are aware of patients who have poor outcomes, who are young and may be able, with proactive management, to continue their work, contribute to society and rely less heavily on specialist inpatient and emergency services.

![Participants receiving biologics](image)

**Figure 10: Costs incurred to healthcare and participants eligible for biologics (n=6)**

All participants were diagnosed for >2 years except participant 007 (diagnosis <1 year). Participant 007 went onto biologic therapy at the close of the mapping project.
7) Economic Analysis

The methods detailing the establishment of costs are detailed previously in Chapter 4.

The activity, drug prescriptions and other healthcare costs can be tracked for each participant in Appendix 13.

7a) Costs to primary care

Section 7a describes primary healthcare teams’ management costs attributed to seeing participants specifically in primary care setting. The 3 figures (figures 7, 8 and 9) outline the costs attributed according to the year of diagnosis and do not include drug costs.

- Less than one year (figure 11).
- One to 2 years (figure 12).
- Greater than 2 years and less than 3 and a half years (figure 13).

From these figures it can be seen that basic GP costs vary widely as does the level of support provided to the patient. It can be seen in Figure 9 (disease for >2 years and <3.5 years) that for some participants with disease duration of between two and three years the use of primary healthcare resources rise significantly in the third year. This is despite the fact that all participants were also being seen by a rheumatologist in secondary care.

There are limitations to the data as they do not include costs related to district nurse visits, occupational therapy visits or consultations, or out of hours doctor services
Figure 11: Breakdown of primary healthcare costs for each participant broken down into categories from time of diagnosis. Diagnoses <one year

It can be seen that participant 007 was the most costly in primary care provision. This participant had 4 GP visits and 24 blood tests. This was in contrast to participant 011 who had one GP visit and 4 blood tests. The time from diagnosis ranged 5 months to 10 months in this group.
Diagnosis 1 to 2 years: costs to primary care

Figure 12: Breakdown of primary healthcare costs for each participant broken down into categories from time of diagnosis. Diagnoses 1 – 2 years

Participant 013 costs less in primary care than participants with a similar time span for diagnosis. However for this participant secondary care support was high with 29 consultant appointments and 3 secondary care nurse appointments. Participant 005 was a heavy user of both primary and secondary care resources with 5 GP visits and 13 consultant appointments and 43 blood tests. Reference range from time of diagnosis in this was 1 – 2 years (with an average length from diagnosis of 21 months).
Diagnosis 2 years to 3 years and 6 months: costs to primary care

Figure 13: Breakdown of primary healthcare costs for each participant broken down into categories from time of diagnosis. Diagnoses >2 years and <3.6 years

Participant 002 had 3 GP visits and 20 consultant appointments (with 6 inpatient admissions), and 28 blood tests. In contrast, participant 009 had 54 GP visits and 10 consultant visits with one nurse specialist visit and 4 blood tests. Range from 30–39 months (average time from diagnosis 35 months).

7b) Personal costs related to managing the condition and time frames (including loss of employment and private treatments, referrals)

The cost of private health insurance has not been included as a personal cost to the patient.

In total 9 of the patients received private care at any time (see Figure 5).
Loss of employment was a significant issue in this mapping project. The loss of employment or productivity is reflected in other European studies from Germany, Netherlands, and Sweden. A systematic review in the United Kingdom in 2000 was undertaken on the burden of rheumatoid arthritis. Medication constituted between 8% and 21% of costs and inpatient stays between 17% and 88%. A study in France in 2004 calculated drugs costs as 13%.

The average number of days absent from work due to the condition ranged from 2.7 to 30 days per year. Evidence suggests that the last 6 years have seen a reduction in rheumatology inpatient admissions. Some of these reductions in use of healthcare resources may be transferred to the additional costs for a more aggressive approach to drug management and newer therapies that have improved patient outcomes.

- Total average medical costs in the present study ranged from £3,575 to £3,638 depending on length of time from diagnosis and using core economic data from 1996. Direct costs in this study included medical costs such as treatment costs, hospital costs and indirect personal costs such as transport and specialist aids, and came to an average for all participants, regardless of time from diagnosis, of £8,471.21 up to and including the first 3 years of diagnosis. However there were methodological issues that need to be borne in mind that related to discrepancies in the average (per person) annual costs of RA.

A number of participants reported experiencing a range of challenges to their social support structures as a result of their condition. These included difficulties in maintaining work, gaining appropriate benefits and costs related to adaptations (particularly when access to multi-professional teams is lacking). These costs also impact on partners with an increasing burden on carers providing support. Also for those who are self-employed, loss of earnings must be acknowledged. The costs of moving home, home adaptations, travelling to hospital appointments and costs related to parking all add to the social impact on the individual.

Examples of calculated costs related to home care and support can be seen in Table 5. Four participants were selected to show the different aspect of personal costs. A participant was selected according to length of time since diagnosis, representation of gender, a broad range of ages and one patient who was receiving incapacity benefit at a young age. It can be seen that although participant 024 was relatively young they were already registered disabled a year from diagnosis. However, the costs attributed at this point to personal costs can be seen as relatively small. Total healthcare and personal costs for this participant (024) amounted to £4,748.17 without considering the societal costs of loss of work capacity.
Table 5: Illustrating some personal costs examples (n=4)

<table>
<thead>
<tr>
<th>Home care support</th>
<th>Costs</th>
<th>Reasons given for costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>002</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female Aged 71</td>
<td></td>
<td></td>
</tr>
<tr>
<td>years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnosed &gt;2 yrs</td>
<td>£2,7685.00</td>
<td>Purchase of aids and adaptations, tap turners, arch supports,</td>
</tr>
<tr>
<td>&lt;3.6 yrs</td>
<td></td>
<td>splints and car changes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>007</td>
<td>£650.10</td>
<td>Complementary therapies, parking, prescription charges</td>
</tr>
<tr>
<td>Female Aged 46</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnosed &lt;1 year</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>024</td>
<td>£2,824.00</td>
<td>Loss of employment earnings, costs for parking, travel</td>
</tr>
<tr>
<td>Male Aged 39</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnosed 1 – 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Incapacity benefit</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 6  Participants receiving biologics – cost analysis for the period of this study compared with a sample of DMARD patients

<table>
<thead>
<tr>
<th>Biologic participants</th>
<th>Total Cost to Health provider</th>
<th>Total Cost to Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>002</td>
<td>£30,836.21</td>
<td>£3,675.47</td>
</tr>
<tr>
<td>005</td>
<td>£1,941.03</td>
<td>£2,150.70</td>
</tr>
<tr>
<td>007</td>
<td>£2,071.78</td>
<td>£3,135.42</td>
</tr>
<tr>
<td>010</td>
<td>£21,738.55</td>
<td>£11,097.00</td>
</tr>
<tr>
<td>016</td>
<td>£24,084.21</td>
<td>£8,382.33</td>
</tr>
<tr>
<td>023</td>
<td>£10,975.30</td>
<td>£413.00</td>
</tr>
<tr>
<td>Grand Total</td>
<td>£91,647.08</td>
<td>£28,853.92</td>
</tr>
<tr>
<td>DMARD participants</td>
<td>Total Cost to Health provider</td>
<td>Total Cost to Patient</td>
</tr>
<tr>
<td>--------------------</td>
<td>------------------------------</td>
<td>----------------------</td>
</tr>
<tr>
<td>004</td>
<td>£304.10</td>
<td>£514.00</td>
</tr>
<tr>
<td>007</td>
<td>£2,071.78</td>
<td>£3,1135.42</td>
</tr>
<tr>
<td>009</td>
<td>£3,346.32</td>
<td>£444.94</td>
</tr>
<tr>
<td>011</td>
<td>£1,218.56</td>
<td>£11.00</td>
</tr>
<tr>
<td>018</td>
<td>£727.60</td>
<td>£348.50</td>
</tr>
<tr>
<td>019</td>
<td>£10,034.56</td>
<td>£2,937.60</td>
</tr>
<tr>
<td>Grand Total</td>
<td>£17,702.92</td>
<td>£7391.46</td>
</tr>
</tbody>
</table>

Figure 14: Total Cost analysis for each participant over the mapping time frame (Sept 2005 – Feb 2006)

This graph demonstrates clearly, as previous studies have demonstrated that some individuals with aggressive disease rapidly become high consumers of healthcare resources, irrespective of treatment regime and drug costs.

A detailed breakdown of healthcare support can be seen in Appendix 14.

This mapping process has provided some insights into 22 patient journeys. The key points identified include:
• Participants experience varying journeys before and after their initial diagnosis. The cost implications of these varying journeys warrant further study.
• This study group did not represent all societal and cultural groups, and people with access to private health care may be over-represented.
• The ability to negotiate healthcare needs in the early stages of a disease such as RA are difficult and leave the patient vulnerable to poor long term outcomes, threats to their employment status and significantly impact on the individual’s quality of life with poorly controlled symptoms.
• Within the first 3 years of diagnosis it can be seen that some participants have aggressive disease that results in much higher use of resources and ultimately healthcare costs.
• The expensive biologic therapies have changed the outcomes for RA. Further research is required to demonstrate the changes in quality of life, work related activities and reductions in healthcare resources as a result of improvements in health following treatment.
• The indirect costs are heavy and borne by the patient but also ‘silently’ by society with an increasing number of participants relying on social support and incapacity benefit.
• Participants’ reflections of their journeys show varying degrees of satisfaction and different levels of satisfaction in negotiating their needs.
• Education about RA and the need to seek prompt advice remains a significant need for the public and all members of primary care teams.
Chapter 4: Discussion

Patient perspective

The participants invited to take part in this mapping project were recruited from the NRAS database. About 60% of the members of NRAS are those who have access to IT. They are more likely to be able to negotiate their healthcare needs more effectively and have English as their first language. Many were employed prior to diagnosis. They are also actively involved in positive approaches to manage their condition, as reflected in their membership of NRAS.

The participants’ maps demonstrate that care for individuals with RA remains variable and some patients gained appropriate care after a long and circuitous route, sometimes more by luck than judgement. Equally it was clear that many struggled with gaining appropriate information to guide them about what they should expect in care, and it was only in retrospect that they understood the complex journey they had made to receive the treatment required. The research team believe that participants in this study were unusual in that a number of participants worked and were in reasonably well remunerated employment; they had good recollection and in some cases had excellent records of their care. In some cases meticulous records were held of care received; blood monitoring time frames, results and treatments started and stopped, others had less information available. They were also able to negotiate their needs and, if necessary, some paid for additional private healthcare. Although individuals participated from throughout the United Kingdom, ethnic minorities or socially deprived groups were not represented. A similar mapping project to evaluate the experiences of those who are less able to negotiate their healthcare needs should be considered and compared with the results from this study.

It is important to consider that in this study all information relies upon the participants’ experiences and recall. Recall can be flawed and this has been demonstrated in studies showing level of information retained following outpatient care or interventions\(^\text{42,43}\). However, all participants were advised to collate information about the treatments, appointments and time frames before the telephone interview.

Despite these limitations this study begins to explore the patient experiences of healthcare and makes some rudimentary analyses of the cost implications related to variations in care. There are potential limitations but also benefits to undertaking such an approach. There were valuable reflections of the journeys these individuals experienced, that are not fully captured in quantitative trials and identified more of the ‘real’ indirect costs as a result of these varying journeys.

In this study there were a number of patients who elected to be seen privately. This may reflect the more pro-active members who seek patient support groups and have positive coping styles as well as the financial resources to elect for private care. Four participants elected to be seen privately had no health insurance and sought this route because of the long waiting times advised by their general practitioner. This revealed some hidden costs whilst seeking out alternative options to achieving early symptom relief and ultimately a diagnosis. The use of private referral pathways are not routinely discussed in guidelines and standards. In addition it appears that access to multi-professional teams and support infrastructure are not readily available for those receiving private care.
Standards and Guidelines

The British Society for Rheumatology (BSR) Guidelines\textsuperscript{32,24}, supported by current research evidence, advocates that those with RA should receive prompt treatment with DMARDs in order to reduce the potential long term damage to joints. In addition, evidence supports aggressive proactive management to ensure optimum disease control with rapid dose escalation and either step up or step down combination therapies. This means that if optimum treatment is to be achieved regular disease assessments and review processes should be in place. It is still a matter of concern that many patients in this study received sub optimal access to specialist advice and support as advocated by the BSR and ARMA\textsuperscript{24}.

In this small sample of participants it can be seen that there is a range of reasons why access to prompt specialist advice is lacking. These include a poor understanding by the general public of symptoms that should alert them to seek medical advice, varying knowledge and expertise in primary care of the indicators for considering a diagnosis of RA, as well as long waiting times to access a rheumatologist.

Adherence to the National Institute of Health and Clinical Excellence Guidance for anti-tumour Necrosis Factor alpha treatments (otherwise known as biologics) has not been actively implemented, with a number of patients having to wait due to funding constraints, despite being eligible for treatment \textsuperscript{27}.

The mapping reveals that despite limitations it is clear that the pathway to referral and goals of management were variable and reflect a greater need for implementation of standards and guidelines for RA.

Multi-professional Teams, Information and Care Plans

Participants in this study expressed concerns about the quality of some information they accessed. The limited access to formal education programmes (only 5 participants had received a disease specific hospital education programme) reveals a lack of consistency in adhering to guidelines and standards of care. The perceived limitations in educational support programmes does reflect anecdotal views in recent years, that as a result of pressures on the service many specialist patient educational programmes have been withdrawn. It is also disappointing to see that access to expert nurse/practitioner support was variable and access to a full multi-professional team equally limited, yet again falling short of ARMA standards of Care for Inflammatory Arthritis\textsuperscript{22}.

It is possible that individual care plans may have aided these participants’ experience in those early years of their condition. It may be that implementation remains sub optimal in the use of care plans. However, some consideration should be given as to whether individuals failed to understand the significance of care plans discussed with them by members of the team, or had been provided information of their planned care but may have mislaid it. This study suggests that participants would welcome involvement in their care plans and may be able to manage their condition and be more active participants in their care once they are aware of the rationale behind some of the current healthcare interventions. If individuals with RA are to successfully self manage their condition, primary care teams must work more pro-actively with specialist teams and other healthcare providers to ensure transparency of care and aid the patients in understanding their healthcare options.
Economic Issues

Equally economic analysis is outlined but cannot be definitive. The principle of under-estimating costs rather than over-estimating was applied throughout this mapping analysis.

Total health and individual costs are not accounted for in either NHS or private insurance costs. The costs related to healthcare were calculated at the same rate for NHS and private healthcare. The data attributed to healthcare provided (either NHS or private) were calculated based on NHS costs as outlined below.

An important caveat in this study relates to private health insurance and must be considered when interpreting the total costs of RA to the individual and society. Individuals who had a private health policy were identified but the costs related to their private health insurance policy were not attributed to the individual because:

a) The policy may have covered other underlying conditions and therefore affected the premium the individual had to pay.
b) The policy may include other family members.
c) The policy may be partly or wholly paid for by the employer.

The economic analysis presented focuses solely on disease duration and does not differentiate according to other factors that might affect the care pathway such as: an aggressive disease, participant’s age or presence of co-morbidities. It must also be acknowledged that historical patterns of delivering services may drive costs rather than the care being based on patient need (for example some units routinely admit patients when newly diagnosed). Although it is of some interest comparing results from economic studies, in doing this, it must be considered with caution as there is a range of issues in comparing differences in the sense of:

Medical and drugs costs may vary at different time points and also within different countries

However, this mapping project reiterates results in quantitative research trials exploring economic analysis of individuals with RA\textsuperscript{44,45}. In particular there are individuals with aggressive RA who have a disproportionately high use of healthcare resources. Studies have reported that one quarter of patient populations studied accounted for 43% to 75% of annual medical costs\textsuperscript{4,44}. Some participants in this study reflected this phenomenon and ultimately were treated on biologic therapies; however the costs of their care were already high without the inclusion of the more expensive drug therapies, chiefly related to inpatient and emergency admissions.

Direct Costs of variance from gold, standard pathways

It is difficult to compare the costs attributed in this small project against larger prospective quantitative studies with differing methodological issues. Yet it is important to raise the issue of the costs related to RA. A UK study in 2002 showed mean annual direct costs of RA in their community group to be £3,980\textsuperscript{44}. However costs are higher in the younger mean age of the patient group, with differing disease duration and severity of disease. Those are more likely to be in full time employment may have additional costs related to loss of work, extended periods of sick leave and reduction in work hours.\textsuperscript{2,4,44,39}
In this mapping project the average medical costs ranged from £3,575 to £3,638 depending on length of time from diagnosis and using core economic data available from 1996. A study published in 2005 calculated costs of hospital resources (including drug monitoring but excluding drugs costs) which were shown to be £1,824.17 in controls and £5,856.63 for cases in a group who were ultimately eligible for anti-TNF\(\alpha\) therapy\(^{46}\). This result is supported by other studies exploring costs of RA\(^{10,45}\). Participants receiving biologics were already requiring higher costs to maintain/improve their health status as they were high consumers of healthcare services, possibly reflecting the issue of higher use of healthcare resources in individuals with aggressive disease. This supports results in this mapping process that demonstrate individuals with aggressive disease area high users of healthcare resources before receiving treatment with biologic therapies. One of the challenges currently facing healthcare providers is that once patients have their disease more effectively controlled with biologies treatment criteria set by the National Institute of Health and Clinical Excellence \(^{27}\) dictate regular assessments and review which adds to the overall cost of treatment. Some studies have demonstrated the additional early benefits seen in biologic therapies particularly in relation to the reduction in joint replacement surgery and use of healthcare resources.\(^{47}\). However it is clear that use of telephone helpline services, inpatient admissions and frequent requests for emergency outpatient appointments decline in this group\(^{46,45,47}\).

Two hypothetical maps have been prepared to provide a simple care pathway that reflects a ‘gold’ standard level of care based upon the first year of diagnosis. The hypothetical maps have also had costs attributed in line with analysis undertaken on the participants’ pathways in this study, however it has to be recognised that for the purposes of these maps they are only a ‘thumb nail sketch’ and personal costs have not been attributed. The numbers attributed to each box within the figures (Figure 15 & Table 7) provide models to demonstrate the hypothetical costs attributed to a participant’s journey with each primary care activity tracked from the left hand box of the tables (Figure 16 Tables 9). The costs calculated represent the same reference costs that have been used throughout the mapping process.

The first map (Figure 15) sets out standard care pathway for immunotherapy not escalating to biologic therapies. This map considers a patient who has disease adequately controlled with Disease Modifying Anti-Rheumatic Drugs (DMARDS). The second map (Figure 11) shows a rapid escalation to gold standard treatment for those requiring a biologic therapy.
Gold Standard: Year 1:
Patient Journey - Standard of Care

1. Initial Symptoms
2. 1st GP Visit symptom control Instigate tests & referral
3. Initial Test Results
4. First Referral

5. Confirmed Diagnosis
6. Medication Established

7. Team Review & monitoring
7a Education

8. Medication Adjustment

9. Exacerbation of disease
10. Access to prompt Team support
11. Team review
12. Education
13. Medication review Symptom control

Commen DMARD

DMARD use:-
- MTX accepted as gold standard 1st line DMARD
- Single 
- Combination
- Step up or step down

+ Aggressive early treatment is gold standard. Adjustment & dose/route dependent upon risk factors, weight / renal function/co-morbidities

1,2,3 = cost activity points

Treatment if disease poorly controlled/flare

Referral within 6 weeks of presenting symptoms
Table 7: Cost analysis of each step in the gold standard pathway (Figure 10). Based upon aggressive pro-active management in the first year of RA: Treatment with DMARD

| 1,2,3. | GP Consultation: Initiate investigations (£23.83)  Non Steroidal anti-inflammatory (4 months script for the year) + co-dydramol (8mg/500mg) (£160.34) Referral to secondary care specialist | **Total £164.17** |
| 4, 5, 6 | New Outpatient consultation (£212)  Commence DMARD Mtx – 10-20mg/weekly + folic acid 5mg once/wkly (£245.32)  Nursing appointment (£38.00 ). Continue drugs from (1,2,3) Monitoring (£2.17) | **Total £497.49** |
| 7,7a, | Team Review (£38.00 nurse + £59 physio + £67 OT).  Care Plan.  Education session £46.67. x 2 = £93.34  3 Disease Activity Scores in one year = £38 x 3 = £114.00  Add in Sulfasalazine 1G bd. (£136.00 pa) | **Total £507.34** |
| 6a, 8 | Podiatry outpatient appointment x follow up £72.00  Follow up appointment (£124.00 x 2 = £248.00)  Shared care monitoring (£2.17 x 17 = £36.89) | **Total £356.89** |
| 9 | £100.00 options symptoms control: IV/IM/ IA steroid. (x 2)  Treatment change. Nurse Follow up £38.00 +/- Consultant follow review £124.00 +/- additional DMARD (Leflunomide) change £255.00 | **Total £617.00** |
| 10, 11 | Team Review £59 Physio +/- £67 OT x 2 + £134.00 | **Total £134.00** |
| 12 | Costs to Patient | Additional Education support – Expert Patient Programme (cost variable)  Prescription charges. £93.20. Parking: 28.00. Kitchen aids/splints etc approx £40.00 | **Total cost to patients £161.20** |
| Cost Savings: | Patient maintains work/social activities. No emergency admissions to hospital/casualty episodes/No request for GP urgent appointments | **Total Healthcare Provider Costs: £2,276.89**  **Total Patient Costs: £161.20** |

The participants who had been diagnosed less than a year were mapped against this hypothetical standard and costs compared. The 6 participants’ (004, 007, 008, 011, 014, 017) healthcare costs were calculated (personal costs were excluded). The costs ranged from £304.10 to £2,071.78. The average health cost for these participants totaled £722.47 significantly lower than those outlined in the hypothesized model (Figure 15 and Table 7) reflecting poorer quality care according to guidelines and standards.

However, one participant (007) who at the time of entering the study had received their diagnosis for a year or less was assessed as eligible to receive a biologic at the end of the study period but had to wait to start treatment due to funding issues. Health care cost for 007 were £3,135.42. This participant’s total costs were calculated at £5,207.20 (Personal costs £2,071.78 and Health care £3135.42) before starting a biologic.

Consideration should be taken to the year on year costs of individuals receiving sub-optimal care.
Figure 16: Option 2: gold standard pathway - example of pathway for those failing two DMARDs and treated with biologic therapy

Gold Standard: Year 1: Biologic
Patient Journey - Standard of Care

1. Initial Symptoms
2. 1st GP Visit symptom control Instigate tests & referral
3. Initial Test Results
4. First Referral
5. Confirmed Diagnosis
6. Medication Established
   Commence DMARD
7. Team Review & monitoring
   7a Education
8. Medication Adjustment
9. Exacerbation of disease
10. Access to prompt Team support
11. Team review
12. Education
13. Medication review Symptom control

DMARD use:
- MTX accepted as gold standard 1st line DMARD
- Single Sulfasalazine or Leflunomide alternatives
- Combination Biologic when failed 2 DMARDs and fulfills criteria
- Step up or step down Exacerbation of disease cycle x 2 with no inpatient admission

Referral within 6 weeks of presenting symptoms

+ Aggressive early treatment is gold standard. Adjustment & dose/route dependent upon risk factors, weight / renal function/co-morbidities

Cycles repeated until criteria achieved & failure of 2 DMARDs

Nos: 1, 2, 3 = cost activity points
### Table 8: Cost analysis of each step in the gold standard pathway (Figure 11) Option 2 Patient pathway with aggressive therapy and pathway to biologics – first year of treatment

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
<th>Cost Components</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>1,2,3.</td>
<td>GP Consultation: Initiate investigations (£23.83) Non Steroidal anti-inflammatory (4 months script for the year) + co-dydramol (8mg/500mg) (£160.34)</td>
<td></td>
<td>£184.17</td>
</tr>
<tr>
<td>4, 5, 6</td>
<td>New Outpatient consultation (£212) Commence DMARD Mtx – 10-20mg/weekly + folic acid 5mg once/wkly (£245.32) Nursing appointment (£38.00) ) Continue drugs from (1,2,3) Monitoring £2.17</td>
<td></td>
<td>£497.49</td>
</tr>
<tr>
<td>7,7a,</td>
<td>Team review (£38.00 nurse + £59 physio + £67 OT). Care Plan. Education session £46.67. x 2 = £93.34 3 Disease Activity Scores in one year = £38 x 3 = £114.00 Add in Sulfasalazine 1G bd. (£136.00 pa)</td>
<td></td>
<td>£507.34</td>
</tr>
<tr>
<td>6a, 8</td>
<td>Podiatry outpatient appointment x follow up £72.00 Follow up appointment (£124.00 x 2 = £248.00)</td>
<td></td>
<td>£320.00</td>
</tr>
<tr>
<td>9</td>
<td>£100.00 options symptoms control: IV/IM/IA steroid. (x 2) Treatment change. Nurse Follow up £38.00 +/- Consultant follow review £124.00 +/- additional DMARD (Lefluonamide) change £255.00</td>
<td></td>
<td>£617.00</td>
</tr>
<tr>
<td>10, 11</td>
<td>Team Review £59 Physio +/- £67 OT x 2 + £134.00 Nurse follow up assessment &amp; training for administration of subcutaneous therapy x 3 £38.00 = £114.00. Blood test additional £3.36 + x-rays £19.00. Potential to start biologic after 9 months of DMARD treatment</td>
<td></td>
<td>£717.12</td>
</tr>
<tr>
<td>12</td>
<td>Costs to Patient</td>
<td>Additional Education support – Expert Patient Programme (cost variable) Prescription charges. £93.20. Parking: 28.00. Kitchen aids/splints etc approx £40.00</td>
<td>£161.20</td>
</tr>
<tr>
<td></td>
<td>Cost Savings:</td>
<td>Patient maintains work/social activities. No emergency admissions to hospital/casualty episodes/No request for GP urgent appointments</td>
<td></td>
</tr>
</tbody>
</table>

**Total Healthcare Provider Costs: £3254.37**

**Total Patient Costs: £161.20**

Direct comparisons with the participants mapped in this project against the theoretical gold standard for biologic therapy is difficult because only one participant (007) who had a diagnosis for less than a year was considered eligible for biologics at the end of the mapping project. Due to funding constraints, they had not been prescribed a biologic and therefore biologics were not included in their cost analysis. However, if an assumption could be made that all participants in this study who were at any time point in this study treated with a biologic were considered in this analysis the healthcare costs ranged from £10,975.30 to £30,836.21 (average £17,915.06) over the total study time frame (maximum of <3 years 6 months from diagnosis). Personal costs ranged from £413 to £3,675.47 (average £5,143.70). However, this analysis is not comparable with the data outlined as the total doses of biologic agents these participants received ranged from 4 to 288 doses administered. The number of doses administered varied according to length of time prescribed a biologic agent, licensed indications and frequency of dosing. Three participants were treated with Etanercept and 2 with Adalimumab.
Indirect Costs of variance from gold standard pathways

Work disability, including early retirement, incapacity benefit and statutory sick pay and/or loss of employment were issues for many of the participants. Work disability has been shown to be between 4 and 15 times greater in people with RA than the general population in a Netherlands study\(^3\). A German study of 338 patients with RA had 98 patients retired prematurely due to their RA with a cost per patient year attributed to this of £5,192 (2003 data) and a further 96 patients remained employed but incurred sick leave costs\(^9\).

Limitations of the study

In this mapping project, did not differentiate between those with more aggressive disease, more severe disease consequences and costs attributable to the differing age groups and needs of the individuals, nor other co-morbidities.

Presentation of inflammatory arthritis can be difficult and medical information was not available to show the clinical decision making in these cases. We also recognise that there are potential limitations when exploring the patient’s perspective of care and recall over a three year period. There are also many reasons for differing memories and perceptions about the care process from the time of initial symptoms to ultimately coming to terms with the diagnosis and various illness crises. The individual’s perspective on their condition and their recall may be altered at a time when they are coming to terms with a stressful life changing diagnosis particularly with a long term condition where the number of treatment interventions increase and may involve a wide range of services. More formal, prospective study of patient pathways in future would provide a more robust body of evidence but in the meantime this study provides a valuable insight.

The economic analysis for this work used a robust, but simplistic analysis of healthcare costs. In particular private healthcare was calculated at the same cost as the NHS and no specific differentiations between these two providers were made for these costs, potentially resulting in an under estimate of healthcare provision and personal costs related to private health insurance. The aim of this project was to show a basic overview of healthcare costs that could be attributed to each participant’s healthcare journey. However it is hoped that this first step in the process of mapping patient journeys can provide a guide for future mapping projects that explore healthcare costs. The comparisons of published research trials exploring economic consequences of RA broadly reflect the results in this study, although it has to be recognised differing methodological issues, time frames and patient populations.
Chapter 5: Conclusions

The authors were unable to find similar mapping studies that have explored the patient journey using an economic perspective. The authors believe therefore that this is the first such study that explores the personal reflections of patients’ healthcare journeys using a mapping process that examines the costs both to the individual and the healthcare system.

This small study provides a snapshot of the experiences of 22 individuals with sero positive RA and their journeys through their first three years following diagnosis of their condition. It is important to reiterate that there are potential limitations when exploring the patient’s perspective of care and recall over a three year period. In some cases the deviation from the outlined Standards of Care may relate to specific patient exceptions based upon sound clinical judgment. The mapping project is unable to explore this reliably as it is based on the patient’s experience and recall. Despite these limitations variations were observed in patient satisfaction and costs incurred

The study cannot be considered broadly representative of the experiences of all individuals with RA. However, it is possible that the experiences reflected in this mapping project are also relevant to other patient populations with chronic conditions revealing valuable insights into the current limitations of service delivery and access to care. Although it could be debated that the outcomes for this set of patients may be superior to individuals who are less able to negotiate their healthcare needs, particularly for those who may have limited financial support, live in deprived areas or are illiterate or do not have English as their first language. This ‘snapshot’ of 22 patient journeys may be a useful resource to guide healthcare professionals in new service design.

The project has revealed some fascinating insights into the patient’s journey with Rheumatoid Arthritis in the first three years of diagnosis. Some key points that warrant emphasis include:

**General aspects of care - access**

- Half of all participants saw their GP within three weeks of symptom onset
- 7/11 participants seen by a Consultant Rheumatologist within 12 weeks were private referrals
- 16/22 participants received a DMARD within 6 months of first presenting symptoms
- Half of the participants eligible for biologic therapies experienced delays before access to treatment (delays ranged from 2 – 10 months).
- 12/22 participants had access to multi-professional teams (2 or less multi-professional team members )
- 8/22 participants received structured educational support.
- 10/22 patients receive ‘gold standard’ nurse/practitioner support (4 of these were those eligible for biologics).

**Work related issues:**

- The average age of all participants in this project was 49 years of age.
- 7 participants had to take early retirement/job losses directly attributed to their RA
- 6 participants had to make significant reductions in their work hours directly attributed to their RA
• 13 participants during the study time period had taken > 2 weeks sick leave
• 10 participants had inpatient or emergency admissions
• 6 participants were registered disabled (incapacity benefit)

Economic Issues:

• Delay in referral or receiving a definitive diagnosis/treatment can result in significant costs to the individual, particularly for those who are employed
  o Personal costs for three working averaged £1,990.27 (005,007, 012)
• Some participants could be identified as being heavy consumers of healthcare resources early on in the disease, regardless of costs of drug therapies.

Research evidence has demonstrated the need to aggressively treat early disease, the so called ‘window of opportunity’. Only six of the twenty two participants received their first disease modifying drug (DMARD) within three months from first presenting symptoms. This demonstrates the importance of raising public awareness of the need to seek early medical advice for symptoms that suggest RA, but also to encourage primary care teams to ensure prompt referrals are made to a specialist. The development of referral routes via Clinical Assessment Teams (CATs) together with the additional pressure to manage more patients in the community stresses the need for early signs of RA to be identified by healthcare professionals at all points of the individuals’ journey.

• The costs to the individual are high and often fail to be considered in economic analyses and this data is supported by other studies. These include
  o Private referral or private insurance
  o Work related issues (outlined separately)
  o Loss of independence and reliance on partners or family for social support
  o Use of additional aids and devices, use of more expensive options to transportation (for example car adaptations)

The costs implications of failing to effectively manage individuals with RA can be seen clearly particularly for individuals with aggressive disease who rapidly become heavy users of healthcare resources. The long term implications of this sub optimal management may result in a greater functional disability and possible increasing co-morbidities such as cardiac disease. Studies have effectively demonstrated that total costs for those treated with a rapidly escalating and aggressive treatment regime were significantly lower although the use of healthcare resources did not differ significantly from routine patient groups. Additional outpatient and prescribing costs for the intensive group were balanced by the higher inpatient costs for the routine patient. There are also potential long term gains as a result of better long term outcomes including reduction in co-morbidities (such as cardiovascular disease) and reduction in surgical interventions particularly joint replacements. However, collecting comprehensive data that details the true costs incurred as a result of RA are compromised by poor coding of medical or surgical admissions (for example rheumatoid lung is coded as a respiratory event often without documentation of the contributing diagnosis of RA). In addition there still remains limited data on the use primary care resources that can be directly attributed to the condition.
This study demonstrates that patients still experience a complex and sometimes circuitous route to receiving specialist multi-professional care despite the wealth of guidelines and standards. In some cases participants attempts to negotiate their healthcare journey still resulted in challenges to receiving the optimum in care.

People with musculoskeletal conditions are the second largest group receiving incapacity benefit after mental health. In this small study the number of patients (n=7) whose careers were significantly compromised or prematurely ended as a result of their condition is worrying.

Many have had significant periods of sick leave (n=13), job losses or early retirement, often accompanied by cost implications related to loss of income. In the future there will be an increasing focus on work capacity and reducing the need for long term incapacity benefits. It is possible that this initiative will focus on supporting those who wish to continue employment whilst awaiting a diagnosis and effective treatment regimes. This may benefit individuals with RA who wish to continue their employment and retain their independence and ability to contribute in a wider sense to society. However, this means that health and social initiatives need to have more joined-up thinking to ensure focus on providing appropriate assessment and support for these patients when they need it.

The indirect costs experienced by these participants are significant and reflect a real burden from the disease that is not fully recognised in healthcare policies, particularly as social and health care costs fail to be calculated from a global perspective. The participants have been given a small ‘voice’ as a result of participating in this study. However there remain many unvoiced agendas that have been revealed in this project and it is hoped that future research will explore the changing direct and indirect costs to individuals in light of future changes in the provision of care for individuals with long term conditions such as RA.

These questions are particularly pertinent when we are considering RA where it transpires there is limited data due to poor healthcare coding of activities related to the disease. In general terms there is minimal, if any, activity coding undertaken in primary care services to enable accurate tracking of what really happens to the individuals with RA negotiating their journey.

It would be helpful to explore a similar study in an area that reflected some areas of social deprivation or areas with cultural diversity. There are also unique challenges which this mapping project has been unable to demonstrate where there are language and literacy problems or when English is not the first language.

Although this study is small and based upon patient reported experiences, evidence in this study reflects earlier research demonstrating that participants who were high consumers of healthcare resources and who were subsequently prescribed an anti-Tumour Necrosis Factor alpha therapy (anti-TNFα) were the highest consumers of healthcare resources regardless of the cost of the anti-TNFα. Some participants in this study lost their jobs whilst waiting to be assessed or prescribed a biologic therapy.
The implementation of standards and guidelines in the management of RA continues to present challenges that ultimately have an impact on the use of healthcare resources and opportunities to improve patient outcomes. Future research should focus on reducing National Health Service (NHS) costs by addressing the optimum in patient management at the same time as ensuring transparency and equity of access to prompt specialist expertise and treatment.

Choice’ has yet to really hit the healthcare agenda and in order to manage this additional complexity in healthcare, a clearer understanding of current processes and options must be considered. Current health initiatives stress the need to improve care by encouraging patient choice. Although this may seem an admirable concept it can be seen from these participants’ journeys that in the early phase of new diagnosis patients have inadequate knowledge to make choices and limited opportunity to negotiate their healthcare needs. Important questions need to be asked about what really happens in the patient journey. Are standards and guidelines working? If they aren't, where and how do we address improvements in care? Should the focus be on improving the public knowledge and awareness about these conditions or is it a matter of educating professionals along the continuum of the journey, or both? How will these issues be addressed when numerous providers are involved in the patient journey?

Participants in this study had variable access to multi-professional teams and patient education programmes. It is hoped that organisational initiatives such as the development of Integrated Care Pathways (ICPs) ultimately result in a structured approach that can be measured and evaluated.

The Patient perspective of the mapping project

From NRAS’s earliest inception, it has been clear that people's access to best standards of care was extremely variable around the UK and this is something which we, as the national patient organisation representing those with Rheumatoid Arthritis, have campaigned strenuously to improve. It has also become clear over time and experience that guidelines are not universally followed, nor do patients automatically know what they should be entitled to receive in terms of care, services and treatment. It was therefore with great enthusiasm that we played a major role in the development of the ARMA Standards of Care for Inflammatory Arthritis. Though these Standards were published in late 2004, we still have a long way to go to see them implemented throughout the UK.

We knew anecdotally how much the actual patient journey varies from the ‘clinical’ pathways drawn up by rheumatology health professionals. So, when the potential for this project was first discussed between Sue Oliver and Ailsa Bosworth, NRAS were excited by the prospect of being able, even with a relatively small sample group, to explore the real patient experiences.

Pain is the major symptom that individuals have to cope with when living with RA. It can significantly impact on the individual’s quality of life and contribute to fatigue, feelings of isolation and ultimately depression. Some key needs identified in this project were prompt access to expert support and advice to help relieve symptoms, receiving a clear diagnosis and getting started on treatment as early as possible.
We, as a community, are all very well aware of the benefits of early detection and treatment, but this knowledge is not readily available to those who present in the initial stages of the disease with the early signs of RA. It is clear that we need to improve GPs’ knowledge of the need for rapid referral, which is variable.

To support these patients, early patient education and information is vital to give people the confidence and reassurance they need to self-manage effectively and seek rapid access to expert help when they need it. Again, even in this group, we see identification of problems in being able to access the right information. Education and information has to be tailored to the individual and has to be on-going, not a one-off action. Giving newly diagnosed people access to NRAS and any other organisation that might be helpful is very important as our Helplines are available and manned on a daily basis and whilst we do not give medical advice, people value the support they get and the access to the Volunteer Network. We can sign-post and provide the much needed emotional support which people need at certain times, particularly at time of diagnosis when they are particularly vulnerable.

The impact of disease on the ability of some of the participants to continue to work is a major factor that has costs to the individual and society and an area that NRAS will be exploring in more detail. Much is said about the need to treat early and aggressively so that people can remain in work, looking after their families and in control of their lives. However, it is only on close inspection of these patient journeys that one realises the true impact of loss of employment on their financial status, their self-esteem, their position in the family and the wider society. The emotional and financial impact of these losses fails to be fully recognised. It was interesting therefore that the participants who might be considered more expensive to the NHS because they were on biologics, were still the most expensive to healthcare resources excluding the costs of the biologics. This is not an unexpected result for specialists in the field of rheumatology as those with the most aggressive, erosive disease are, in the long term, more likely to be disabled, and be subject to surgical procedures such as joint replacements.

Participant 016 is a typical example of how ‘expensive’ treatment can deliver financial benefit as well as quality of life benefits. This participant’s map states, ‘improved’ so much following 9 months of treatment with a biologic (to the participant’s delight) that they were no longer eligible for incapacity benefit.’

The financial costs to the individual and their close family is not generally discussed or recognised by the NHS. Yet, it can be seen in this mapping project that these personal costs are not without implications to the healthcare system but importantly have a greater societal cost through loss of employment and consequences to the close family members’ ability to work and participate in society.

One of the ‘hidden’ costs, not attributed in this study, is that of the care provided by partner or other family member/s.

This study recruited NRAS members who might be considered to be more informed and better able to self-manage; despite this point the project highlighted many areas for concern. This raises the question – if this group are having problems, how much greater must be the issues for people without a family or social network, who may be on benefit and/or have language/literacy problems?
There are important issues that this study has highlighted and supports a wealth of literature outlining the costs related to poorly controlled disease. Tight control of the disease, together with pro-active multi-professional team management, has the potential to enhance self management and reduce emergency and inpatient admissions. This work has also demonstrated that some patients can be rapidly identified as potential high users of healthcare resources based upon the aggressive nature of their disease. Studies have also demonstrated that functional ability (as measured by the Health Assessment Questionnaire) is an important indicator of poor outcome and heavy users of specialist services.

In this study, however, many participants experienced numerous financial and social losses as a result of their condition. Twenty of the 22 participants at the time of the study were eligible for some form of employment. Yet several of these participants had to reduce their work significantly, were made redundant shortly after diagnosis or had to retire due to ill health. Some of these participants (n=3) were employed at the time of being eligible to start biologic therapies yet all 3 had lost their jobs by the time they actually received treatment.

The range of economic studies undertaken in RA has varying populations, for example: time from diagnosis, severity of disease, health economies, eligibility criteria, data collection and time frame of analyses. It has, therefore, not been possible to make direct comparisons although the results in this small project appear broadly within the expected range of similar studies.

There is evidence that those individuals who continue employment are less depressed and have less of a financial burden as result of their disease. These losses must be addressed in the future, particularly as the retirement age is set to rise and those contributing to society and taxes will become more important to the economy with the growing elderly and chronic disease population set to double by 2020. There should be greater recognition of the individual's workplace needs and occupational therapy support for appropriate advice, to ensure employees learn to accommodate the functional needs required to maintain work activities using appropriate adaptations and new ways of working.

Future work could explore the long term consequences of the various pathways that these participants have experienced in the first 3 years of their RA and to attribute costs to the wider economic issues as well as the costs to healthcare, and explore how commissioners can more proactively identify the best models of care based upon new ways of delivering healthcare in the future. The implementation of Integrated Care Pathways (ICPs) should ensure that the evidence base and national guidelines are incorporated into new ways of delivering care. It would be valuable to repeat this mapping project for newly diagnosed RA patients, who have a proactive approach to management using an ICP.

There are certainly significant challenges in ensuring that patients are adequately informed and able to make decisions about their healthcare choices. We can see from this study that many had minimal information initially to request access to a full multi-professional team and adequate information. In many circumstances symptom control, particularly pain management was poorly provided and these shortcomings had consequences upon the individual's life. A randomised control trial exploring effectiveness and cost effectiveness of individuals with established RA, demonstrated
that the most cost effective approach was that of targeting symptom control\textsuperscript{63}. Ultimately, if the disease is adequately controlled symptoms are usually well controlled too.

The individuals who participated in this study, upon their own reflection, highlighted the need to have a more transparent and efficient route to receiving a diagnosis. A number of these participants were able to arrange additional advice and support for their healthcare needs by using the private referrals route, with varying results.

This is a unique study exploring an economic model within the context of mapping 22 individuals' experiences of their first 3 years through healthcare. Although this sample is small it may be possible to generalise in respect of other groups of patients but certainly highlights some key areas that warrant further research. In particular identifying:

- The outcomes and costs related to the first 3 years of RA using an ICP approach to care compared to a control group.
- Opportunities to reduce changes to functional ability based upon informed decision making and patient self management approaches based upon new models of care.
- Exploring the cost savings attributed to reduction in healthcare utilisation, employment and productivity as a result of tight disease control and biologic therapies.
- The impact such changes would have on quality of life and symptom control.
- Studies in areas where social and cultural needs differ from this patient population.

Given these caveats it has to be recognised that the individual's recall of care is an important factor that affects their perception of their disease, their ability to be an active participant in decision making and ultimately their will to self manage their condition over time.
Appendix: 1  References

Reference List


Department of Health London


44. Cooper NJ, Mugford M, Symmons DPM, Barrett EM, and Scott DGI. (2002). Total costs and predictors of costs in individuals with early...


Appendix 2: Potential spectrum of needs for RA patients.
### Appendix 3 - Advisory Panel - Patient Pathway Process Mapping

<table>
<thead>
<tr>
<th>Name</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anne O’Brien</td>
<td>Physiotherapy Lecturer, Keele University</td>
</tr>
<tr>
<td>Dr. Anthony Redmond</td>
<td>Lecturer in Podiatry, Chapelle Allerton Hospital, Leeds</td>
</tr>
<tr>
<td>Claire McAleer</td>
<td>Specialist Practitioner in Rheumatology, Westminster Rehabilitation Services</td>
</tr>
<tr>
<td>Prof. David Scott</td>
<td>Professor of Rheumatology, Norfolk &amp; Norwich University Hospital</td>
</tr>
<tr>
<td>Diane Home</td>
<td>Nurse Consultant Rheumatology, West Middlesex. Hospital QR</td>
</tr>
<tr>
<td>Dr. John Dixon</td>
<td>GP with Special Interest in Rheumatology, Primary Care Rheumatology Society</td>
</tr>
<tr>
<td>Dr. Alan Steuer</td>
<td>Consultant Rheumatologist, Wexham Park Hospital</td>
</tr>
<tr>
<td>Susan Oliver</td>
<td>Nurse Consultant Rheumatology, Chair of the RCN Rheumatology Forum QR</td>
</tr>
<tr>
<td>Ailsa Bosworth</td>
<td>Chief Executive NRAS</td>
</tr>
<tr>
<td>Penny Cavanna</td>
<td>NRAS volunteer</td>
</tr>
<tr>
<td>Audrey Callum</td>
<td>NRAS volunteer</td>
</tr>
<tr>
<td>Ivan Lax</td>
<td>Project Worker Catalyze Ivan Lax Catalyze Ltd - 'enabling effective decisions' <a href="http://www.catalyze.co.uk">www.catalyze.co.uk</a> Address: 20 Appletree Road, Chipping Warden, Banbury OX17 1LW United Kingdom</td>
</tr>
<tr>
<td>Qualitative Research Support</td>
<td>Dr. Sarah Ryan, Nurse Consultant, Musculoskeletal Primary Care, Hayward Hospital. Stoke-on Trent, Staffordshire. QR</td>
</tr>
<tr>
<td>Mara Airoldi</td>
<td>Research Officer, London School of Economics. London. QR</td>
</tr>
<tr>
<td>Lorraine Tanner &amp; Helen Bunyan</td>
<td>NRAS Telephone Helpline Team</td>
</tr>
</tbody>
</table>

**Note:** QR = Qualitative Research Experience
<table>
<thead>
<tr>
<th>M/F</th>
<th>REGION</th>
<th>RELIGION</th>
<th>LANGUAGE</th>
<th>18-25</th>
<th>26-45</th>
<th>46-60</th>
<th>61-75</th>
<th>F/T WORK</th>
<th>PROFESSION</th>
<th>REG</th>
<th>DISABLED</th>
<th>CHILDREN UNDER 15</th>
<th>ALONE</th>
<th>JOINT REPLAT</th>
<th>HOSPITAL ADMISSION</th>
<th>DMARD'S</th>
<th>BIOLOGICS</th>
<th>CO-MORBIDITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>F</td>
<td>N East</td>
<td>C of E</td>
<td>ENGLISH</td>
<td>X</td>
<td>N</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>N</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>Y</td>
<td>MTX</td>
<td></td>
<td>N</td>
</tr>
<tr>
<td>M</td>
<td>N Ireland</td>
<td>protestant</td>
<td>ENGLISH</td>
<td>X</td>
<td>N</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>N</td>
<td>Y</td>
<td>N</td>
<td>Y</td>
<td>N</td>
<td>MTX</td>
<td></td>
<td>N</td>
</tr>
<tr>
<td>F</td>
<td>Middlesex</td>
<td>JEWISH</td>
<td>ENGLISH</td>
<td>X</td>
<td>N</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>MTX</td>
<td></td>
<td>N</td>
</tr>
<tr>
<td>F</td>
<td>Scotland</td>
<td>N/A</td>
<td>ENGLISH</td>
<td>X</td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>N</td>
<td>Y</td>
<td>N</td>
<td>Y</td>
<td>N</td>
<td>MTX</td>
<td></td>
<td>N</td>
</tr>
<tr>
<td>F</td>
<td>WEST SUSSEX</td>
<td>COFE</td>
<td>ENGLISH</td>
<td>X</td>
<td>N</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Y</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>SUCYCLS</td>
<td>PRORIN</td>
<td>Enbrel</td>
</tr>
<tr>
<td>F</td>
<td>Scotland</td>
<td>N/A</td>
<td>ENGLISH</td>
<td>X</td>
<td></td>
<td>Part time</td>
<td>Y</td>
<td>Loss Adjustor</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>SSZ</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>F</td>
<td>Bristol</td>
<td>N/A</td>
<td>ENGLISH</td>
<td>X</td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>MTX</td>
<td></td>
<td>N</td>
</tr>
<tr>
<td>F</td>
<td>KENT</td>
<td>CATHOLIC</td>
<td>ENGLISH</td>
<td>X</td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>MTX, just off SSZ</td>
<td></td>
<td>N</td>
</tr>
<tr>
<td>F</td>
<td>East Midlands</td>
<td>N/A</td>
<td>ENGLISH</td>
<td>X</td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>MTX SSZ</td>
<td></td>
<td>High BP</td>
</tr>
<tr>
<td>F</td>
<td>West Midlands</td>
<td>C of E</td>
<td>ENGLISH</td>
<td>X</td>
<td>N (part time vol)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>MTX</td>
<td></td>
<td>N</td>
</tr>
<tr>
<td>F</td>
<td>N East</td>
<td>Catholic</td>
<td>ENGLISH</td>
<td>X</td>
<td>N</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>N</td>
<td>N</td>
<td>Y</td>
<td>N</td>
<td>Y</td>
<td>MTX</td>
<td></td>
<td>N</td>
</tr>
<tr>
<td>F</td>
<td>Newcastle upon</td>
<td>N/A</td>
<td>ENGLISH</td>
<td>X</td>
<td></td>
<td>Part time</td>
<td>Y</td>
<td>Education Consultant</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>MTX</td>
<td>N</td>
<td></td>
<td>N</td>
</tr>
<tr>
<td>M</td>
<td>South West</td>
<td>C of E</td>
<td>ENGLISH</td>
<td>X</td>
<td>N</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>N</td>
<td>Y</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
<td>MTX</td>
<td></td>
<td>N</td>
</tr>
<tr>
<td>M</td>
<td>LANCASHIRE</td>
<td>N/A</td>
<td>ENGLISH</td>
<td>X</td>
<td>P/T</td>
<td>Learning</td>
<td>N</td>
<td>DISA IN PROCESS</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>SSZ</td>
<td>N</td>
<td>Asthma</td>
<td></td>
</tr>
<tr>
<td>F</td>
<td>Rutland</td>
<td>N/A</td>
<td>ENGLISH</td>
<td>X</td>
<td>N</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>was on SSZ</td>
<td></td>
<td>N</td>
</tr>
<tr>
<td>M</td>
<td>South Wales</td>
<td>C of E</td>
<td>ENGLISH</td>
<td>X</td>
<td>N</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>MTX</td>
<td></td>
<td>N</td>
</tr>
<tr>
<td>F</td>
<td>Cheshire</td>
<td>C of E</td>
<td>ENGLISH</td>
<td>X</td>
<td>N</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>N</td>
<td>Y</td>
<td>N</td>
<td>Y</td>
<td>Y anaemia</td>
<td>MTX</td>
<td></td>
<td>Enbrell Inj</td>
</tr>
</tbody>
</table>

Appendix 4: Purposive Sampling of potential interviewees
<table>
<thead>
<tr>
<th>Gender</th>
<th>Age</th>
<th>Name</th>
<th>Occupation</th>
<th>Diagnosis</th>
<th>Treatment</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>F</td>
<td>5</td>
<td>twins</td>
<td>Student</td>
<td>Endometriosis</td>
<td>Leflunomide</td>
<td>Humira</td>
</tr>
<tr>
<td>F</td>
<td>Y</td>
<td></td>
<td>P/T Garden Centre</td>
<td>Sjogrens syndrome</td>
<td>Prednisolone</td>
<td>High B/P</td>
</tr>
<tr>
<td>F</td>
<td></td>
<td></td>
<td>F/T Student</td>
<td>Septicaemia, Cellulitis</td>
<td>LFLN</td>
<td>Prednisolone</td>
</tr>
<tr>
<td>M</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 5: Patient Letter on the mapping project and consent form.

Headed NRAS Patient:

Address and contact details:

Dear

Many thanks for agreeing to take part in this survey.

This survey will provide very useful information on what happens to individuals' daily lives when they have Rheumatoid Arthritis. The survey will look at people's experiences from when they were first seen by their own doctor with joint problems, through to being seen in the hospital, and treatments given. We also hope to learn more about how your condition has an effect on your daily lives - things that are sometimes not considered when talking about RA.

We are working with Sue Oliver (our chief nurse advisor) and a company called Catalyze who are experienced in this type of work. We will also have an advisory panel who will review the work we are doing and guide the project.

All the information you provide will be treated with absolute confidence and your name will not be traceable to the results in the survey.

Once we have all the information we will prepare a report that can be used to show a picture of how RA affects people’s lives. We would like to include costs that you have had to consider when coping with RA.

We would appreciate it if you could fill in the form enclosed. The form provides lots of information that will be useful before the telephone interview.

If you would like to ask anything about the questions or the survey before you decide whether you want to take part, please telephone [NRAS team member] as soon as possible and they can provide any extra information you might want.

We have enclosed a picture that shows you an example of a 'patient journey' from some people who have Parkinson's disease. As you can see the picture shows lots of different coloured lines - each one of these coloured lines shows one person's experiences and contacts they made when receiving care for their condition. They show that many people with the same disease have different experiences and problems.

This information could be very useful because what we would like to find out is whether your experiences match what we believe you should be getting in the way of healthcare support. We would also like to see whether you get the best treatment available at the right time. We also are hoping to understand more about the additional things that may be needed when you have RA (for example - whether you managed to stay in work or needed extra child care whilst you were ill).

If you are happy to take part, the next step will be to fill in the enclosed forms and post them in the prepaid envelope. You will then be contacted by Ivan Lax from a company called Catalyze.
to arrange a time that is convenient to you for the telephone interview. This interview usually takes about 1 hour.

We really appreciate your help with this important study.

Sincerely

Signed Ailsa

Consent Form:

Name:

Address:

Full telephone number:

I have read the letter from NRAS explaining about the work you wish to carry out on mapping the patient's journey with Rheumatoid Arthritis. Please tick

I am happy for the Catalyze team to have the above contact details for the purpose of contacting me to carry out a telephone interview. Please tick

I understand that all the information I provide will remain confidential to NRAS and Catalyze and that if I wish to change my mind and not participate in the study I am free to do so at any time. Please tick

Please return this form to: Mr Ivan Lax, Catalyze, 20 Appletree Road, Chipping Warden, Banbury OX17 1LW
Appendix: 6 Outline of costing points

1. New Patient Episode: outpatient costs

Seen by consultant rheumatologist

Referred to nurse specialist for education/information about drugs and disease

Includes: x-ray of hands and feet/chest/respiratory function tests -

Blood tests: include FBC LFTs, urea and electrolytes.
Prescribing of DMARDS (set mid point of all traditional DMARD costs)
Prescribing of NSAID
Prescribing of basic pain relief (co-dydramol)

Include on costs at 20% for hospital overhead costs: facilities etc.

2. Multi-professional referral - outpatient

Assessment by physiotherapist

or

Assessment by occupational therapists

Assessment by nurse (including standard cost for blood monitoring as part of this)

Assessment by podiatry/chiropody

Preparation of slips or hydrotherapy sessions

3. Surgical referral – outpatient

Medical referral to surgeon (GP or consultant rheumatologist time in preparing referrals)

Orthopaedic surgeon clinical time

X-ray investigations/blood tests/multi-professional team referral

Need to include costs for other medical specialty referrals – eg respiratory consultant referrals, neurologist referrals etc
4. Nurse/Practitioner/Team Educational Session

Either individual one-to-one sessions x 2 sessions by nurse or physiotherapist

or

Educational programme x 6 sessions with approx 6 patients. Running for 6 weeks supported by multi-professional team

5. Urgent access

Urgent patient referral via GP referral or telephone advice line request

Specialist team for management of flare

Include: average cost based on 2 joint injections (by either nurse or consultant)

or

intravenous methylprednisolone infusion (requires day case for 4 hours in hospital) specialist unit

6. Inpatient admission (specialist rheumatology)

Nursing time 4 hours (set an amount of nursing time from ward nurse) x number of days

Healthcare assistant time – 3 hours healthcare assistant time

Inpatient bed cost per day

Treatment costs per day

Investigation costs (average amount based upon x-ray hands and feet/chest/blood test and investigations)

Radiologist time in x-ray time which includes reading and reporting on x-rays

Filing time includes medical records costs

Consultant time + junior doctor time + pharmacist time reviewing medications + physiotherapist time (include hydrotherapy) + occupational therapist + nurse

Medical time includes: clinical decisions, ward rounds, daily reviews by junior doctor, preparation of discharge summary

Additional option cost: social services/podiatry/chiropody costs
7. Inpatient admission (orthopaedic)

Nursing ward based time x number of days as inpatient

Inpatient bed costs per day

Treatment costs per day

Investigation costs (based upon some investigations – xray, bloods)
Consultant time + junior doctor time, pharmacist time reviewing medications + physiotherapist time

Additional optional extra: social services or occupational therapy time

8. Patients commencing anti-TNFα therapy

Include: nurse review clinic x 2

Include: completing data entry include 20 minutes.

Include: small amount of time nurse telephone advice line support

Include: bloods and monitoring review

Subcutaneous: Adalimumab/Etanercept – include 2 nurse training sessions with nurses to teach patient to self administer – (see RCN biologics guidance document)

Dispensing time of drugs – pharmacy cost

Consultant review time costs: - include 30 minute sessions x 2

9. Routine follow-up care – rheumatology nurse:

30 minutes nurse clinic time

15 minutes dictation or documentation time

Blood tests and investigations (x-rays of hands and feet)

DMARD costs (average drug cost)
Dispensing cost
NSAID drugs (average drug cost)

1 joint or depo-medrone (average cost based upon syringe, needle, and 5 minutes nurse administration time)

Liaison time – 5 minutes

For consultant follow-up as per nurse follow-up by costs for rheumatology consultant

Equally for physiotherapist/occupational therapist/podiatry apply same principles: check re basic cost and time and equipment costs – with AD board members
Appendix 7- Questions for Establishing Process Followed

RA Project

Introduction: This note focuses on the telephone interview. We will begin a short refresh on the intention of the project; to look at ways we can suggest improvements to the RA patient process. We will do this by looking for increased efficiency and effectiveness by understanding each patient’s personal experiences of the RA processes. Essentially we will be asking you about: What happened?

1.1 When it happened?

1.2 Who did you see?

1.3 Were there any delays?

1.4 What was the impact of those delays?

1.5 What went well?

1.6 We will also look to collect information about your medication regime and costs outside of the NHS such as employment, care needs, etc, and we have left some spaces so that you may want to make some notes before the call.

2 Pre-diagnosis

2.1 When did you first experience health problems that caused you concern?

2.2 How long did you wait before you decided to consult your doctor?

2.3 How easy was it for you to get an appointment?

2.4 Did you get to see your doctor of choice?

2.5 Did you have to wait for an appointment to see your doctor?

2.6 If there was a delay did this impact you in any way?

2.7 Were you offered any alternatives, such as an appointment with a nurse?
3 Diagnosis

3.1 What happened when you met with the doctor?
3.2 Were you referred to anyone else at the Health Centre? If so, who?
3.3 What happened next?
3.4 Did you see them immediately or was another appointment needed?
3.5 What happened after your initial consultation?
3.6 Were you referred to anyone else elsewhere in the NHS? If so, who?
3.7 How was this referral made?
3.8 Was any time expectation set? If so, how long? Was this met?
3.9 Was any medication prescribed when you first met the doctor?
3.10 If yes, what was this? Was any process put in place to monitor this?
3.11 If yes, what?
3.12 Were you sent for any tests?
3.13 Consultant referral

3.13.1 Can you describe this process?
3.13.2 Were you referred to anyone else?
3.13.2.1 We are looking to establish understand more about the reason you were referred and what was planned during this referral. Can you talk about this? Would it help if I go through a list of possible people/services? (We can use a checklist to help refresh patient's memory if needed.)

3.14 In each case what was your experience of the process?
3.14.1 Did it work smoothly?
3.14.2 What if any expectations were set? Were these met? If they were not, was any explanation given?
3.14.4 Were you offered any additional information such as leaflets to read or sources of further information?
3.14.4 Were you informed of any voluntary support groups or organisations that might be useful?
3.15 Were there any delays?
3.15.1 What did these delays mean to you?
3.15.2 Did they have an effect on your home or work life?
3.15.3 Can you say in what way?
3.15.4 Maintenance: I want you now to think about what has happened since your diagnosis was confirmed.
3.15.5 What has been the frequency of your visits to your doctor?
3.15.6 What has been the frequency of your visits to hospital? Can we think about who you have seen? (Here we will look to draw out each contact that has been made with any hospital based service.)
3.15.7 What other services have you drawn upon?
3.15.8 Has your work been affected in any way by your illness? For instance have you had to take any time off work or needed support with particular equipment to help you stay at work?
3.15.9 Medication: do you have any additional thoughts about your medications and how you manage your medications.
3.15.10 We asked earlier about what medication you were originally prescribed; are you still on this medication?
3.15.11 If not, when did you change? Who prescribed this and when?
3.15.12 Have you experienced any problems with medication?
3.15.13 If yes, with whom and how did you address this?
3.15.14 Has your illness affected your work at all? Have you been required to change your work?
3.15.15 Have you lost any days through illness directly attributed to RA? If yes, how many?
3.16 Access to and Use of Appliances
3.16.1 At any point in the process were you offered access to any aids or appliances?
3.16.2 If so when and by whom?
3.16.3 If yes, how useful were these? Would you identify any particular items more than others?
3.16.4 Was the offer timely?
3.16.5 Did you receive these at the right time for your needs?
3.17 Impact at Home

3.17.1 Has your illness affected your home life? Can you tell me about this – in what way has it affected you?

3.17.2 How have your family understood and coped with your condition?

3.17.3 Has this required any one else to seek medical help?

3.18 Impact on work

3.18.1 Has RA affected your work?

3.18.2 In what way?

3.18.3 Has your employer commented on your illness or your work in relation to your RA?

3.18.4 Has your employer incurred any costs that relate specifically to your RA such as sick leave, temporary staff, and special furniture?

3.19 Have you required any surgery as a result of RA?

3.20 Other areas of support. (We are looking to establish what other support services you may have drawn on inside and outside of the NHS.)

3.20.1 Have you used any other services such as Social Services, privately funded care, voluntary services, employer support or complementary health therapy?

3.20.2 complex

3.21 Have you had any other problems caused by other illnesses or diseases and RA?
### Appendix: 8 Demographics of participants

<table>
<thead>
<tr>
<th>M/F</th>
<th>F/T WORK</th>
<th>Age</th>
<th>Hospital Admis</th>
<th>PROFESSION</th>
<th>REG DISABLED</th>
<th>Participation</th>
</tr>
</thead>
<tbody>
<tr>
<td>F</td>
<td>N</td>
<td>62</td>
<td>No</td>
<td>N</td>
<td></td>
<td></td>
</tr>
<tr>
<td>F</td>
<td>N</td>
<td>71</td>
<td>Yes</td>
<td>N</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>F</td>
<td>N</td>
<td>59</td>
<td>N</td>
<td>N</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>F</td>
<td>Y</td>
<td>37</td>
<td>N</td>
<td>Computer admin</td>
<td>N</td>
<td>4</td>
</tr>
<tr>
<td>F</td>
<td>N</td>
<td>59</td>
<td>Yes</td>
<td>Y</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>F</td>
<td>Y</td>
<td>55</td>
<td>N</td>
<td>Development manager</td>
<td>N?</td>
<td>6</td>
</tr>
<tr>
<td>F</td>
<td>Y</td>
<td>65</td>
<td>N</td>
<td>Project Manager</td>
<td>N</td>
<td>7</td>
</tr>
<tr>
<td>M</td>
<td>N</td>
<td>73</td>
<td>N</td>
<td></td>
<td></td>
<td>8</td>
</tr>
<tr>
<td>F</td>
<td>PT</td>
<td>51</td>
<td>N</td>
<td></td>
<td></td>
<td>9</td>
</tr>
<tr>
<td>F</td>
<td>N</td>
<td>31</td>
<td>N</td>
<td></td>
<td></td>
<td>10</td>
</tr>
<tr>
<td>M</td>
<td>P/T</td>
<td>65</td>
<td>Y</td>
<td>LEARNING DISA</td>
<td>IN PROCESS</td>
<td>11</td>
</tr>
<tr>
<td>F</td>
<td>PT</td>
<td>27</td>
<td>Y - Twice</td>
<td>Nanny</td>
<td>N</td>
<td>12</td>
</tr>
<tr>
<td>F</td>
<td>PT</td>
<td>58</td>
<td>N</td>
<td>Education Consultant</td>
<td></td>
<td>13</td>
</tr>
<tr>
<td>F</td>
<td>PT</td>
<td>36</td>
<td>N</td>
<td>Loss Adjustor</td>
<td>N</td>
<td>14</td>
</tr>
<tr>
<td>M</td>
<td>N</td>
<td>65</td>
<td>N</td>
<td>Y</td>
<td></td>
<td>16</td>
</tr>
<tr>
<td>F</td>
<td>Y</td>
<td>32</td>
<td>Y</td>
<td>writer</td>
<td>N</td>
<td>17</td>
</tr>
<tr>
<td>F</td>
<td>N</td>
<td>36</td>
<td>N</td>
<td>Y</td>
<td></td>
<td>18</td>
</tr>
<tr>
<td>F</td>
<td></td>
<td>36</td>
<td>N</td>
<td></td>
<td></td>
<td>19</td>
</tr>
<tr>
<td>F</td>
<td>P/T</td>
<td>63</td>
<td>N</td>
<td>Lecturer</td>
<td>N</td>
<td>20</td>
</tr>
<tr>
<td>F</td>
<td>P/T</td>
<td>44</td>
<td>Y</td>
<td>Garden Centre</td>
<td>N</td>
<td>22</td>
</tr>
<tr>
<td>M</td>
<td>Y</td>
<td>50</td>
<td>N</td>
<td>Sales</td>
<td>N</td>
<td>23</td>
</tr>
<tr>
<td>M</td>
<td>N</td>
<td>39</td>
<td>Y</td>
<td></td>
<td></td>
<td>24</td>
</tr>
</tbody>
</table>

![Participants place of residence](image)
APPENDIX 9 – COPIES OF EACH PARTICIPANT’S MAP
25 March 2004
Patient's GP is now at the hospital, which he has not been in for a while.

2 weeks later, patient is discharged with a prescription for anti-inflammatory medication.

April 2004
Situation worsens and patient is discharged. GP is now at hospital, which he has not been in for a while.

Mid-April 2004
34 days after patient was discharged, patient presents at hospital with a history of a rash on the left hand.

May 2004
Patient is discharged with a prescription for anti-inflammatory medication.

October 2005
Patient is discharged with a prescription for anti-inflammatory medication.

December 2005
Patient is discharged with a prescription for anti-inflammatory medication.

Patient Comments:
1. Happy with information given by GP and RC as this suits patient style. Able to gather a lot of other data from the internet.
2. No other help offered. Unaware of other services such as RA Nurse, etc. until made aware through voluntary sector (NRAS and ARC) reading.
3. Patient has used NRAS helpline.

Costs summary:
1. Patient does not pay prescription charges.
2. Patient indicates that she has spent £83 on complimentary and alternative treatments including:
   a. Acupuncture £30
   b. Chinese medicines
   c. Food testing
   d. Holistic medical advice (£40)
To this is added the cost of supplements such as Glucosamine (which is not included on prescription) and the use of Aloe Vera. However, as she indicates, "when in so much pain and discomfort one will try anything in the hope of some relief."
May 2002
Patient’s husband died suddenly & unexpectedly. A great shock & very stressful time for the patient.

December 27th 2002
Met with GP (own GP not available) who believed problem was osteoarthritis. It was not Rheumatoid Arthritis. Prescribed Celebrex.

December 28th 2002
Weekend: calls the following morning and could not move apart from hips.

December 30th 2002
Appointment with own GP. Took blood tests and X-rays & was to come back in a few days.

January 7th 2003
Surgery telephone man came to see patient urgently.

January 8th 2003
Methotrexate started.

January 9th 2003
Met with Rheumatologist Consultant. Very concerned. Diagnosed:
1. active aggressive Rheumatoid Arthritis
2. Chronic atrial fibrillation
3. Osteoarthritis

Rheumatologist Consultant
Telephoned patient the following day and the day after that. Patient feeling better by second day. Arranged to see Consultant again the following week.

February 6th 2003
Prescribed:
1. prednisolone 12 tablets 5 mg daily to be taken immediately.
2. Laronopozole
3. Cooxenfor for pain relief

Patient also saw opthamologic specialist the same day.

January to June 2003
Patient initially saw Rheumatologist & Ophthalmologist Consultants weekly for 3 weeks (private). This was reduced to fortnightly then monthly visits under NHS. During the period:
1. Blood tests were taken (weekly for 1 month then fortnightly and eventually monthly)
2. Weight dropped from 10 stone to 8 stone
3. All swelling, pain & stiffness was reduced.
4. Eye OK after 1 month
5. Prednisolone gradually reduced to 10 tablets (after 2 weeks) then 5 tablets, then 3 tablets (Jivine).
6. February 2003 Methotrexate introduced beginning at 1 x 2.5 mg/m2 increasing to 20 mg/m2 over the 9 months.

June 2003
Patient went on holiday to Italy (2 weeks) but quite unwell, symptoms had returned.

July 2003
Patient telephone to RA Nurse; blood count very low, ambulance sent to admit to hospital, remained there for 6 days. Further tests given and patient required four blood transfusions.

July 2005
Patient telephone to RA Nurse; blood count very low, ambulance sent to hospital, remained there for 6 days. Further tests given and patient required four blood transfusions.

August 2003
Rheumatologist Consultant discusses prescribing stanozolol (Primobolan) but patient declines. Patient later telephoned to say he was approved and District Nurse would contact him to begin weekly injections.

Next steps:
1. Entosporin 25 mg twice weekly injections
2. Methotrexate 20 mg every week
3. Prednisolone 1 x 2.5 mg daily
4. Folic Acid 5 mg daily

Also took 1 aspirin per day.

Between June and September 2003 the NHS Podiatrist visited the patient on 4 occasions at home.

September 2003
Patient attended in place of Monthly blood tests at hospital.

October 2005
Patient sees Rheumatologist Consultant. Suggests now is the time to consider surgery for foot. Patient is on NCS waiting list which is 6 months. Patient discussed value of having only 1 foot done and feels this is not logical but instead wishes to have both done.

Cost Items:
1. Patient estimated that more than £1000 was spent on private consultations.
2. Patient attends a gym at a cost of £20/month = £240 per year. (Half price because of referral from RA Unit.)
3. Home help costs (approximately):
   - Gardening £370 per year
   - Cleaning £364 per year
4. Travel to hospital 1½ hours by bus at £17 per journey. However a taxi is sometimes used at £12 per journey (one way) for early morning appointments.
NRAS Client 003 – Female: DoB 25.07.1946

Wednesday, April 19, 2006

Patient Comments:
1. Experienced good education programme at the hospital.
2. Partner able to provide support at home.
3. Enjoys active exercising such as walking, bicycling.
4. Basic information leaflet supplied for drugs, i.e. methotrexate.

Patient Costs:
1. Patient has a pre-paid prescription certificate for medication at £93.20 per year.
2. Return journey to hospital is 10.2 miles (based on IR figures of 40p/mile = £4.08 per visit), Parking is £1.00 per hour.
3. Special Knife and fork cost £16.00
4. Vitamin supplements cost approximately £5.00 per annum.

Early 2003
Patient (2nd parcel from car & when they returned, they experienced difficulty putting hands on steering wheel.

Feb/Mar 2003
Patient put up with swelling in hands. Took non-prescribed & un-proven tablets for pain relief.

22 April 2003
Patient made appointment to see her GP. Unable to see own GP but saw practice GP.

Dec 2003
GP wrote patient to continue with Painkillers and return in 2 weeks.

GP makes referral to Consultant Rheumatologist.

13 May 2003
Second visit to GP who requested patient to have blood tests. (Taken at surgery – 18 May).

20 May 2003
Patient sees GP and is advised to be kept blood tests. She returns. Patient very relieved based on earlier information from rheumatologist.

Physiotherapist demonstrated relaxation techniques that we will receive in a single session.

22 July 2003
First appointment with Consultant Rheumatologist. Blood tests & advice taken. Carpal tunnel syndrome identified & injection given in each wrist. Consultant Rheumatologist recommends Methotrexate beginning at 5mg and increasing over next weeks to 15mg. Referral made to RA Unit.

End July 2003
Met with RA Nurse Specialist at hospital. RA Unit, agreed to take part in 12 month research project agreed.

11 November 2003
First Assessment

Management & Monitoring Programme was put in place: attend to every 6 weeks, see GP every 6 months.

December 2003
Condition stable. Medication regimen unchanged. Indication that 6 weekly monitoring will be maintained at hospital RA Unit.

6 monthly reviews with Consultant Rheumatologist to be continued by alternately 6 monthly reviews with RA Nursing Staff & Consultant Rheumatologist.


This series of meetings provided an opportunity for patients with a good indication of the effects of RA & resources available.

Next visit to RA discussed: a review of the RA issues. Requested further blood test that confirmed thyroid OK.

Thyroid tests undertaken on: 1. 12th November 2004
2. 13th September 2005

During 2004:
Regular 6 weekly blood tests performed at hospital.

This series of meetings provided an opportunity for patients with a good indication of the effects of RA & resources available.

Patient Costs:
1. Patient has a pre-paid prescription certificate for medication at £93.20 per year.
2. Return journey to hospital is 10.2 miles (based on IR figures of 40p/mile = £4.08 per visit), Parking is £1.00 per hour.
3. Special Knife and fork cost £16.00
4. Vitamin supplements cost approximately £5.00 per annum.

Page 1
Patient Comment:
1. No advice offered other than a leaflet on Methotrexate.
2. Would have liked some advice on diet, life style.
3. Left to do own research mostly via the Internet.
4. Concerned about reliability of some Internet resources.
5. Not warned about fatigue as part of symptoms. Patient has discussed this issue with her employer who has agreed that if this becomes particularly fatigued she can work from home. This has happened on one occasion to date which avoids the patient taking time off work.
6. No adjustment have been required at the patients workspace.

Patient Costs:
1. The patient pays for prescriptions which averages out at approximately £18.00 per quarter.
2. Patient has been required to pay a further £50.00 annual health insurance excess.
NRAS Client 005 – Female: age 41

Patient Comments:
1. First GP very helpful but not diagnosed at this time. Second GP good but not particularly ‘clued-up’ on RA and saw this as a ‘old-age’ disease, (only 12 patients with RA in practice). GP had no knowledge of disease being prescribed. Current GP has a specialist interest in RA which is wonderful.
2. Patient was well informed about RA because of father’s experience and therefore she was able to be mostly self-sufficient in areas such as home aids, etc.
3. Patient was made to have hydrotherapy but this has not happened.
4. Since being prescribed etanercept the patient has experienced a marked improvement.

Patient's personal perspective of costs:
1. Cost of private health care provided by employer.
2. Patient has been on long-term sick leave since July 2004 when she should have returned to work after maternity leave. After 13 weeks from 27/09/04 basic salary of £33,334 was reduced by 25% under the terms of long-term illness insurance cover provided by employer. This resulted in a loss of earnings of £13,334.00. Patient examined by the insurance company doctor (who provide this cover to her employers) about 12 months ago.
3. Patient did benefit from a company car allowance of £7000 but this stopped when she still has the expense of running her car for personal use.
4. OT was able to supply splints for the patient that the patient paid for.
5. Travel costs:
   a. Hampshire – negligible
   b. Cambridge – £10.00 per visit to Consultant
   c. Suffolk – 3 months’ bus pass £10.40

6. Prescription costs: up to August 2004 the patient did not pay prescription charges under maternity rules. Thereafter she purchased an annual pre-paid certificate at £90.00 per annum.
7. Patient saw a podiatrist in May 2004 for 8 sessions and financed this herself at £280.00 per session.

<table>
<thead>
<tr>
<th>Item Description</th>
<th>Total MHSCost</th>
<th>Total Patient Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community based care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Days</td>
<td>23</td>
<td>23</td>
</tr>
<tr>
<td>Care of relatives</td>
<td>£25.80</td>
<td>£25.80</td>
</tr>
<tr>
<td>Transport and parking</td>
<td>£1.90</td>
<td>£1.90</td>
</tr>
<tr>
<td>Hospital and specialist</td>
<td>£34.70</td>
<td>£34.70</td>
</tr>
<tr>
<td>Other expenses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Travel and sundries</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>£23.00</td>
<td>£23.00</td>
</tr>
<tr>
<td>Total</td>
<td>£65.70</td>
<td>£65.70</td>
</tr>
</tbody>
</table>
NRAS Client 006 – Female: DoB 13.04.1951

Cholesterol 2002

Patient complained of rash over chest, back and neck, including sensitive ears and skin irritation. Patient had been prescribed shingles vaccine 3 months ago.

23 June 2004

Second visit with Consultant Rheumatologist – Prednisolone

1. Continue with prednisolone 30 mg 3 times daily for 1 week. Gradually reduce dose to 20 mg and then 15 mg.
2. IF needed, add a second medication.
3. Follow-up with Consultant Rheumatologist.

9 July 2004

Blood test at GP with nurse.

4 August 2004

Further appointment with Consultant Rheumatologist – Blood tests taken at hospital. Patient set up for 4 weekly visits with monthly blood tests at GP.

15 September 2004

Consultant Rheumatologist gave steroid injections in shoulder and provided a splint to support one wrist.

21 September 2004

Blood test taken by GP nurse.

December 2004

Consultant hands over to a GP nurse for continuing monitoring and management in place.

January 2005

Referral to ENT for head shape.

February 2005

Telephoned to book mini appointment.

A further appointment with Consultant Rheumatologist – Blood tests taken at hospital.

15 May 2005

Consultant Rheumatologist referred for treatment of mild to moderate susceptibility.

20 May 2005

Blood test taken by GP nurse.

May 2005

Consultant Rheumatologist referred for treatment of mild to moderate susceptibility.

23 May 2005

Blood test taken by GP nurse.

12 March 2006

Bone density scan to be performed at a cost of £800.

18 December 2006

Letter received from GP surgery confirming her referral back to the hospital in January 2007. Next appointment with Consultant Rheumatologist decided by NHS system. (See Patient Comments)

July 2007

17 July 2007

17 October 2005

Hospital contacted patient and advised her to return for further treatment.

30 September 2005

Meeting with Consultant Rheumatologist who is to see the patient.

10 November 2005

Consultant Rheumatologist referred patient for treatment of mild to moderate susceptibility.

Patient Comments:

1. No other services have been offered.
2. During the period the patient has had 2 weeks paid sick leave; no other.
3. Because of their work the patient became aware of the ‘expert patient’ scheme and has volunteered for this and has now tutored 2 courses.
4. Husband redundancy has meant that he is unable to support in the home, shopping, etc.
5. Phlebotomist only takes blood and cannot comment on condition.

Casting Information:

1. Patient has had 40 swimming lessons at a cost of £840.
2. Until September 2004 patient paid normal prescriptions charges totalling £494/month. Since then they have used a quarterly session ticket for prescriptions at a cost of £48 per quarter.
3. Journey to hospital 40 miles = £160.00 per return (based on Ireland Revenue mileage costs) = £1.50 parking.
4. Other costs:
   - Telephone £120.00
   - Parking £90.00
   - Refreshments £20.00
   - Meals £50.00
June 2005
Patient experienced pain in both feet. Visited GP and diagnosed as osteoarthritis & referred to Orthopaedic Consultant.

Beginning September 2005
Patient is examined by Rheumatologist Consultant. 
Consultant refers patient to RA Unit at hospital, hospital physiotherapist and back to GP for treatment.

Consultant feels continued private consultation necessary as hospital has excellent RA unit.

Patient is already taking medication: 
Methotrexate 15 mg & Prednisolone 2.5 mg

Physiotherapy gives patient an exercise regime and enrols him as a RA programme for new patients comprising 6 x 1 weekly sessions of two hours:
1 hour exercise
1 hour talk by a range of professionals.

September 2005
Patient sees GP for treatment as per Consultant's recommendation. 
Patient given steroid injection and prescribed Methotrexate 7.5 mg & Folic Acid 5 mg

Patient is very satisfied with RA Unit

Further steroid injections planned at 1 month intervals.

Patient travel costs:
1. Nine (9) hospital visits at 37 miles each way @ 40p/mile = £266.40
2. Eleven (11) GP visits at 7 miles each way @ 40p/mile = £51.60

Patient has BUPA medical insurance therefore private referral is made.

July 2005
(2 weeks later)
Orthopaedic Consultant suggests foot supports & return patient to necessary clinic. 
However, Consultant also notes swelling to right foot. Patient also suffers from vertigo and as such the swelling was due to this but felt it was not. No further action taken.

BUPA cover costs £330 per month for patient & wife.

July 2005
(2 weeks later)
Foot swelling gets worse and swelling in wrists and hands now evident. Pain intensity increasing. Patient visits GP but is seen by another GP rather than his own. 
GP prescribes painkillers and refers for blood tests. 
Patient instructed to see own GP in 2 weeks when test results known and own GP returns from holiday.

3 weeks wait to see Rheumatologist Consultant.

Patient arranges appointment to see own GP in 2 weeks.

Patient uses own GP who confirms that results from blood test show RA. 
GP makes referral to private Rheumatologist Consultant as patient has private medical insurance.

August 2005
Patient seen by RA Practitioner nurse at hospital. 
Experiencing slight pain in wrists but able to answer 'yes' to all questions on patient questionnaire.

Raised problem: 60% of the time he experiences a lumpy feeling in the ball of his feet. Will be referred to physiotherapist for possible supports. Not serious enough to inhibit walking.

Late October 2005
Patient delays second steroid injection till 17th week as he does not feel the need.

Patient suffers no prescription charges due to age.

Patient comments:
1. Patient highly complimentary about his experiences with hospital, both education programme & RA Unit.
2. Expressed some concerns on lack of information available at his GP surgery (no literature on display).
3. Because of his private referral, the patient is now seen by this hospital RA Unit. However, this would not be the normal hospital used by his GP. Enquiries with other local patients have shown that programmes such as the one he has experienced are not available there. He expressed concerns over lack of consistency.
NRAS Client 009 - Female: DoB 25.06.1955

Background: Summer 2002
Patient describes a very sudden onset and referred to death of father. First noticed some swelling of the ankles, then started walking with a limp and feeling of strain. She was prescribed HRT treatment.

February 2003
Patient returned from a holiday in China where she had lost weight and was started on a diet plan. Immediately after she noted swelling and feeling tired. She went to their GP and was referred to a consultant. She was prescribed HRT treatment.

April 2003
Patient was referred to the consultant rheumatologist for a follow-up appointment.

May 2003
Patient started to feel better and returned to GP for reassurance. GP American asked if there was any history of rheumatoid arthritis in the family. Patient replied that she had none.

July 2003
Patient was referred to the consultant rheumatologist for a follow-up appointment.

July 2003 - November 2003
Patient was referred to the consultant rheumatologist for a follow-up appointment.

November 2003
Patient was referred to the consultant rheumatologist for a follow-up appointment.

December 2003
Patient visits GP but does not feel well.

Patient Comments:
1. Patient resigned her job at Sainsbury’s after a period of absence on sick leave. She now works for her husband on a casual basis but is unable to return to work as she cannot lift enough.
2. Patient referred to a Consultant Rheumatologist for further assessment.
3. Patient was referred to a specialist rheumatologist for further assessment.
4. Patient was referred to a specialist rheumatologist for further assessment.
5. Patient was referred to a specialist rheumatologist for further assessment.
6. Patient was referred to a specialist rheumatologist for further assessment.
7. Patient was referred to a specialist rheumatologist for further assessment.

Preliminary early costs incurred by Patient:
1. Employment: Patient received basic statutory sick pay from Sainsbury’s from 25th June 2003. It was later increased to 100% of her normal earnings. This resulted in a total loss of earnings of £500 per month.
2. Consulting: Patient relies on her husband who is self-employed and works from home. However, this does impact his own time and earnings particularly regarding hospital visits etc. but they regard benefit outweighs cost.
3. Patient: Patient also received benefits such as:
   - [Details provided in the image]
4. Private health consultation costing approximately £100.00
5. Patient has made claims for:
   - Care Allowance and receives mid-band payment but only after appeal.
   - Mobility Allowance but this currently applies at appeal stage.

Page 1
NRAS Client 011 – Male: age 65

2003
Patient noticed general stiffness and swelling to knees but put this down to age.

2004
Patient decided to go to chirodetck as big loss become painful. The chirodetck made built-up shoes to take pressure of big toe.

Spring 2005
Knees get worse and fingers begin swelling along with increased stiffness. Patient decides to go to GP. GP decide to refer to Consultant Rheumatologist. GP prescribed meloxicam 7.5 mg daily.

Appointment arranged in 6 weeks.

May/June 2005
Consultant Rheumatologist takes blood tests, x-rays and x-rays of fingers, wrists, elbows & feet.

July 2005
Second visit to Consultant Rheumatologist confirms Rheumatoid Arthritis and Prescribed sulphasalazine 500 mg/day. Patient to also continue with meloxicam. Weekly blood tests taken at hospital for the following 6 weeks. Referral made to physiotherapist who provided patient with advice on exercise.

August 2005
Third visit to Consultant Rheumatologist who decides sulphasalazine could be increased and that he needs to take meloxicam 7.5 mg to be taken once a week and once a daily. He declines to take for 1 month and then review to see if progress is made. Also con hydrocor for pain relief.

September 2006
Monthly review with Consultant Rheumatologist. On this occasion patient is seen by deputy and plan to supplement sulphamethoxazole with methotrexate is implemented. Plans made to admit patient for fluid on knees.

October 2006
Patient admitted to hospital for 24 hours (overnights) to have fluid drained from knees. Also given a steroid injection. Seen by Consultant Rheumatologist before discharge and follow-up appointment made for January 2007.

Patient visited by Occupational Therapist within hospital who reviewed needs. Agreed not to use that might help and these were sent to patient, i.e. single hon, with improved handle, vegetable cutter, paper cutter, etc.

11th January 2007
Patient saw consultant and Methotrexate was increased to 10 mg/week.

Patient comments:
1. RA has impacted work as a Health Care Worker looking after Learning Disability Clients in own homes where activities need to be carefully managed.
2. Patient also has asthma and takes Solbutamol and Seritide as needed.
3. Patient happy with treatment and advice given to date.

Patient’s personal perspective of costs:
1. Patient does not pay prescription charges due to age exemption.
2. Patient employed by NHS and does not incur travel costs as he is able to make appointments to suit his work schedule.

<table>
<thead>
<tr>
<th>Patient</th>
<th>Total NHS Cost</th>
<th>Total Patient Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>011</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community-based care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drugs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Minerals</td>
<td>£3.80</td>
<td></td>
</tr>
<tr>
<td>DMAPS</td>
<td>£4.09</td>
<td></td>
</tr>
<tr>
<td>NSAIDS</td>
<td>£7.80</td>
<td></td>
</tr>
<tr>
<td>Analgesic</td>
<td>£5.00</td>
<td></td>
</tr>
<tr>
<td>Other expenses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home care and support</td>
<td>£30.00</td>
<td></td>
</tr>
<tr>
<td>Hospital and specialist care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital and specialist care</td>
<td>£1048.11</td>
<td>£11.09</td>
</tr>
<tr>
<td>011 Total</td>
<td>£2,178.96</td>
<td>£11.09</td>
</tr>
</tbody>
</table>

Page 1
NRAS Client 014 – Female: DoB 04.12.1970

Wednesday, April 19, 2006

Patient Comments:
1. The patient was offered a place on a clinical trial but decided to decline because of her age and desire to possibly have more children (she currently has one child).
2. The patient has been happy with her treatment and the responsiveness of the medical profession.
3. The introduction via the OT to another patient nearby was very useful as this gave the patient someone to compare herself to and share experiences.
4. Patients employer has contacted her GP to ask for guidance and advice on what can be done at work to support her.
5. Blood test taken at GP surgery every 2 weeks by nurse since medication prescribed. This will change to 4-weekly tests form 2006 with a planned reduction to 3-monthly from March 2006 unless the patient is unwell.

Patient Costing:
1. Patient has lost no income due to her illness as she has been paid her full salary during the short period of sick leave.
2. Patient benefits from Working Tax Credits and therefore she has medical exemption and no prescription charges are made.
3. OT advised patient of ability to claim VAT exemption which was available due to RA diagnosis, and she has purchased a number of aids.
4. Hospital visits: patient took a day’s paid leave for both visits made to date (Sept 2005 & Jan 2006). Return journey was 70 miles @ 40p/mile = £28.00 plus £3.00 for car parking per visit.
5. No costs for GP visits.

Prescription for Sulphasalazine:
1. Week 1: beginning at 1 x 500 mg tablets daily.
2. Week 2: increased to 1 x 500 mg tablets a.m. + 1 x tablet bedtime.
3. Week 3: increased to 1 x tablet spread across the day. Patient felt very sick and advised to be reduced back to 3 tablet daily.
4. Week 4: increased back to 3 tablets daily.

By this time the patient had developed swelling in the neck and shoulders, and hands had got worse. She was finding it difficult to deal with many household tasks and care of her daughter. I.e. changing nappies.

During the period from diagnosis by her Consultant the patient has also been referred to:
1. Occupational Therapist: visited patient at home giving advice on adaptations etc. OT also put patient in touch with another patient nearby, to share experience and generally support one another.
2. Physiotherapist: has had 3 physiotherapy sessions.
3. Dietitian: patient has an appointment to meet patient for advice on weight.

Conclusion: Patient commends the consultant and the care she has received. She now has an improvement in her symptoms and is able to return to work and manage her daily life better.
NRAS Client 015 – Female: DoB 27.09.1971

August 2002
Patient had a hysterectomy due to endometriosis. As a result she was prescribed HRT treatment.

16th January 2004
Patient noticed swelling in feet and legs. Went to GP who carried out immediate blood tests. Result was that patient had Rheumatoid Arthritis and referred back to Rheumatologist. Advice at that time would be about 13 weeks.

During this period patient experiences problems due to swelling and is advised to see HRT treatment. (18th May 2004)

A further scan is scheduled to investigate abdominal pain. (This results in delay in referral to Consultant Rheumatologist.)

11th May 2004
Patient attends for a scan related to scheduled operation in relation to earlier hysterectomy. (Due to swelling)

Patient visits relatives in Turkey for 3 weeks post-surgery. Swelling had subsided and GP agreed not to start HRT treatment.

July 2004
Patientbooked to see Consultant Rheumatologist. Scans were performed and patient was referred to Consultant Rheumatologist. (Due to swelling)

Patient booked to see Consultant Rheumatologist. (Due to swelling)

July 2005
Patient went to Turkey (where parents now live). Saw Consultant at hospital, given results of MRI scan that confirmed no more issues. Operated on later that same week. (Due to swelling)

Patient Comment: Consultant tells patient that he keeps letting doctors blood tests are not conclusive & they should not diagnose RA.

31st August 2005
Patient saw Consultant for check up. She was advised that due to the operation on her knee that she had done in Turkey there was no reason to see physiotherapist again. She provided the patient with exercises and advised that if she would leave this case open for 2 months in the event that she needed to return.

Patient Cost Summary:
1. Turkish costs incurred by patient:
   - MRI scan £116.00
   - Operation & aftercare £750.00
   - Medication £20.00

2. Prescription Charges: patient purchased a private certificate at a cost of £33.99 per 4 months since February 2004 and continues to renew.

3. Patient has a disabled badge but has paid for parking on at least 4 occasions when spaces were not available. Cost £2.50 each time. Travel cost: return journey 2 miles @ 40p/mile = £0.80.

Patient Comments:
1. Patient remains unsure as to whether they have RA or not.
2. Lack of any education from professionals: patient bought book on RA to find answers to questions.
3. Patient required to have hysterectomy at 31 years and is equally frustrated with lack of information for someone of her age undergoing this treatment. All literature on HRT refers to later age group.
4. Little faith in hospital system, particularly with regard to RA.
5. No support offered other than physiotherapist.

January 2006
Patient still undergoing HRT treatment but unsure as to RA diagnosis. Seen by different Rheumatologist. Consultant was rude and not happy that she had chosen to have the operation in Turkey. Advised the patient that she doesn’t believe another operation but could not give her answer between 2 weeks and 2 months. Consultant then asked if the patient had had answers from the hospital in Turkey but continually asked questions about what had been done. Patient kept referring to the letter as a course of answers. Consultant asked the patient if they (Turkey) had done this operation why was it still in pain. Generally very dismissive and patient left angry and frustrated.
Patient Comments:
1. The patient trial the patient is part of looking at the effectiveness of DMTARD's in the early stages of diagnosis, and single versus combination medication.
2. The patient was able to refer to an Occupational Therapist and Physiotherapist but there may be some time before she was seen.
3. As an introduction to the trial the patient was 'bombed' with information about the drugs (the drugs, physiotherapy, etc.) but the patient was not the only person with this experience. The patient sought out her own information on nutrition and diet advice.
4. The patient networked with other patients and did a lot of her own research about how she could help herself through techniques and aids.
5. When the OT visited the patient at home she confirmed that the patient was doing a lot to help herself. OT helped with a number of items such as a special key-ring, taps and techniques for using other muscles. The OT put the patient in touch with a patient education group which can last 6 weeks. This was very useful but the patient commented that she was the youngest member of the group by some 20 years. (October/November 2005)
6. The patient tries to get out for a walk each day and does pilates.
7. As well as the thyroid condition the patient was diagnosed with Hashimoto's disease in 2001.
8. The patient commented that it was not helpful to her, but the patient was told by the consultant that it was not needed as it would not work with the patient's medication.
9. The patient commented on the issue of age. At 32 years the reaction from many people is a sense of disbelief that she has this condition.

Patient Costs:
1. Prescription costs: drugs prescribed as part of the clinical trial are free of prescription charge.
2. Price estimates that medication has cost about £10 per month for bioprophylaxis.
3. Travel costs: the patient uses public transport to make the trip to the clinic at a cost of £6.50 per return journey. However, she also spends £10:05.00 per month on tax.
4. Price estimates that she has spent approximately £20.00 on aids at home ranging from lighter utensils to grips.
5. The patient is self-employed and while this has allowed her to be flexible on work times and workload she estimates that she has lost approximately 30% of her income.
6. The patient does not qualify for any help; financial or otherwise because she is not regarded as disabled. This is despite the fact that she lives alone and finds many general household tasks impossible. She has applied for help with cleaning at £7.50 per hour but this was denied as she was judged insufficiently mobile. She has also applied to her local council social support for assistance in the purchase of voice activated software (Dragon Naturally Speaking) at £398.00.
7. Subscriptions to charity & support organisations (all annual): NRAS £17:50; Arthritis Today £15.00; Pain Concern £14:50.
**Patient Comments:**
1. No one advised patient about items such as Disability Living Allowance. She was only aware of this because of part-time voluntary work at the Citizens Advice Bureau.
2. Patient needed to change car to automatic gear change.
3. Patient mentioned discussion with Consultant Rheumatologist on Parvovirus that was found some years earlier.
4. Very little education given. Patient found out most information via the internet.
5. GP provided most support while patient was in the private system. GP felt inadequately equipped to deal with the RA as it was beyond her expertise. However, the patient felt that her support has been incredible. Since moving into the NHS system the patient has access to an RA Nurse who helps. However the distance involved in travelling to the hospital is prohibitive.
6. Patient diagnosed at 35 with a thyroid illness that requires thyrinix.

**Patient Costs:**
1. Patient has lost considerable income because of her diagnosis and retired within one year of diagnosis.
2. Patient has claimed Disability Living Allowance.
3. Patient was told that she may be entitled to Incapacity Benefit but this required her to attend an interview and she simply did not feel well enough to attend and therefore she has not done this.
4. Travel costs: trips to the hospital involve a journey of 36 miles each way; one hour by car. Cost: 72 miles @ 40p/mile = £28.80 per visit.
5. Patient funded private consultations, MRI and ultrasound. Cost £300 for each scan = £600.00 plus £80.00 per consultation.
6. Prescription costs; because of a pre-existing condition the patient qualifies for a pre-exemption medical certificate and pays no prescription charges.
7. A private referral was made to an Occupational Therapist and the patient purchased resting splints. (Spring 2004) Cost £80.00.
8. Patient had invested heavily (£3000) in training for her new role. Eventually this was refunded because of health position. (December 2002)
9. Patient has purchased a number of domestic appliances to ease her situation.
10. Patient’s travel insurance has been cancelled because of RA and lung complications.
Patient Comments:
1. She found it very hard to come to terms with the RA diagnosis and in her own words was “in strong denial” asking why this was happening to her. This continued even when admitted to hospital where the patient found it hard to accept her inability to walk. Counselling was offered while in hospital but the patient felt she was not ready for this. Patient felt very angry about her condition.
2. The patient lives in a major city but had moved from her parents home (approximately 5 miles) some time before the diagnosis while retaining her family GP. An issue arose with the need for a fortnightly visit by the phlebotomist. This was initially agreed by one of the practice GP’s but later rescinded. The issue was eventually resolved but required intervention by the Patient Advice & Liaison Service (PALS) and the Practice Manager. The patient later moved GP and blood testing was undertaken by the hospital.
3. New GP had no experience of RA medication believing that this too was specialist for a GP practice. This has remained with the hospital.
4. Patient has educated herself on her condition rather than rely on others.
5. Various items of equipment have been provided via the Occupational Therapist on NHS Icn; this has included a bath lift, bath grab rails, bath step, commode, folding a banister, cutlery, mesh cooking baskets, ergonomic knife, jar opener, perch stool, foot stool, trolley, walking sticks and a walking frame.

Patient Costs:
1. Loss of patient income due to sick leave and reduced working hours. Allowing for statutory sick pay this still amounted to £4,000.00 lost income.
2. Travel Costs: Hospital journey was 6 miles each way = 12 miles @ 40p/mile = £4.80. Visits to GP were 2 miles e/w = £1.60.
3. Prescription costs: Patient initially paid prescriptions as issued but since February 2006 she has purchased an annual pre-paid certifictate at a cost of £93.20.
4. Patients mother has supported her with daily visits that required loss of work and travel costs. This has been estimated at £200.00 in loss of mothers earnings and travel costs (based on a return journey of 10 miles daily for almost 7 months) of £784.00.
5. Employer Costs: The patients employer had to provide cover during her absence and they have estimated this at £5500.00.
NRAS Client 020 – Female: DoB 29.07.1942

December 2003
Patient became aware of tenderness to sides of feet and sore mouth and tongue. Visited GP with this and was referred for a vitamin B12, GP carried out blood tests.

January 2004
Both blood tests for B12 and SLE proved negative but because of swellings, GP decided to have further blood tests for Rheumatoid Factor. GP prescribed Voss but patient took this for only 4 days before stopping due to severe headaches and neck stiffness.

February 2004
Tests for RA factor came back very high. As result, GP referred patient to Consultant Rheumatologist. There was an estimated waiting time of 17 weeks.

May 2004
Patient given canceled appointment, seen by Consultant Rheumatologist. Not sure if diagnosis was correct as more tests were taken. In the meantime, patient continued to have intermittent swelling and pain.

May 2004
Test results confirmed RA and patient prescribed celecoxib.

Monitoring programme set up with alternating 3-monthly appointments with the Consultant Rheumatologist and the specialist RA nurse.

October 2004
Patient prescribed sulphasalazine. However, after only 8 days the patient was forced to stop this drug due to a severe reaction.

November 2004
Patient saw Consultant Rheumatologist who prescribed:
1. Methotrexate 7.5 mg weekly
2. Celecoxib
In addition to the existing celecoxib.

During the period the patient was referred to:
1. Occupational Therapist, who supplied walking sticks
2. Podiatrist, for in-soles supports.

This was maintained until April 2005 and it was at this time that the patient seemed to feel the benefit of the drug.

April 2005
Blood tests and CRP became more normal.

May 2005
Patient experienced a return of swelling and noticed change in her joints. Abnormalities began showing once again in CRP and blood tests.

June 2005
Patient was referred to Consultant Rheumatologist and it was agreed that medication would be reviewed.

Patient stopped taking Celecoxib in October 2005 due to headaches and nausea which the patient attributed to the methotrexate but which reduced with the cessation of the celecoxib.

October 2005
Patient was prescribed methotrexate with the cessation of celecoxib but found that she developed tenderness and a skin irritation. She stopped the medication after one week upon referral to her GP.

Early December 2005
Patient’s prescription increased to 10 mg of methotrexate.

Patient Comments:
1. Discovering the relatively small things you cannot do comes quite hard and rather frustrating.
2. With regard to the alternating hospital visits, the Consultant was always available should the RA nurse need an immediate consultation.
3. Another OT who was visiting a relative of the patient suggested other changes that might be made in the patients home; taps, etc.

Patient Costs:
1. Patient does not incur prescription costs.
2. Travel costs:
   - Hospital is 45 miles each way; at 40p/mile this costs £36.00 for each return journey plus parking at £1.80.
   - GP surgery is within walking distance.
   - OT and Podiatrist 40 miles return journey; at 40p/mile this costs £16.00 per visit and the patient has made 2 visits to each. Parking is £1.00 each visit.
3. Appliances: kitchen taps £25.00; aid for bathroom taps £8.00.
NRAS Client 021 – Female: DoB 26.08.1987

Patient noticed they were getting a feeling of stiffness overall and particularly in the hands. They put down a period of study preparing for the final exams. Patient went to GP who referred to hospital.

December 2003

Took this time to get an appointment at the hospital. Patient met with Consultant Rheumatologist who examined the patient but decided nothing would be done. No tests taken and patient not showing any signs of swelling at this time.

September 2004

Patient was referred for a second appointment and met with Consultant Rheumatologist. On this occasion Consultant prescribed:
1. Captopril
2. Prednisolone

Patient lived with the problem during 2004 but felt she must return to the Consultant.

November 2004

Patient saw Consultant Rheumatologist and on this occasion they prescribed sulphasalazine beginning with 500mg daily for the first week and increasing over the coming weeks by the addition of an additional 500mg tablet until 24th January 2005 when dose was 500mg three times daily.

Patient referred to RA Clinical Nurse who explained the use of sulphasalazine. Nurse referred patient to physiotherapist.

July 2005

Patient asked about physiotherapy and began a programme of physiotherapy, monthly for the following three months.

Patient began therapy but college schedule meant patient only had 3 sessions of hydrotherapy.

December 2004

Attended RA Clinic but saw second consultant who offered to increase sulphasalazine.

9th May 2005

Saw consultant Rheumatologist. Meds increased to 10mg weekly dose.

9th June 2005

Saw Consultant Rheumatologist, given further test injection to both shoulders by him. Patient in attendance but at the event that patient fainted period one was not. Patient did not return to perform injections.

10th May 2006

First appointment with new Consultant Rheumatologist. Given blood tests, x-rays, etc. during the morning. A nurse again in the afternoon. Consultant explained everything, reasons for headaches, sickness etc. Stopped methotrexate.

Keep going with the pain killers (tramadol). Consultant advised on other things the patient could do to help herself including breathing techniques for doing with the pain. Consultant thinks patient may have upper respiratory. Consult patient's experience to other consultant.

1st February 2006

Patient is continuing to Victoza RA with pain killers. GP increased DHC Continus to 120mg per day.

Patient Comments:
1. Patient not told by original consultant that she had RA. He took her to the RA Nurse and as he handed the file to the nurse he told the nurse that the patient had RA. This was the first time this was mentioned.
2. Always felt rushed and unimportant with this consultant – she had a 10-minute slot and that was it.
3. Patient frustrated by the frequency of cancelled appointments.
4. Very poor initial education offered on RA. Most came from self study via the internet.
5. Situation since transferring to new location/hospital completely different. Consultant taking time to explain things and show interest/concern over patients illness.

Patient Costs:
1. No prescription charges as yet because of age and full time student status.
2. Travel costs: Local costs – taxi £3.00 each way or taken by mother which incurred a £2.00 parking fee. Consultant visits: Train journey £10.60 plus £5.00 each way taxi from station to hospital.
3. Patient has spent various amounts on vitamins, etc. but has not received full cost.
NRAS Client 023 – Male: DoB 29.05.1956

**Thursday, April 20, 2006**

**Patient Comments:**
1. Patient believes that the RA unit he visits is very diligent and has provided excellent support.
2. RA Nurse has started an informal patient group with informative talks from various specialists that is very good.
3. Comment made about ‘cross-border’ services and the challenges this brings for the patient such as travel, etc. but also issues concerning duplication of paperwork.
4. Patient feels that he is probably living a healthier lifestyle as a result of the advice he has been given.
5. Patient raised the point that while he understands his treatment is very costly, without it he would now be unable to work and require even greater financial support from the state.
6. Patient also commented on the advantage of bringing service into the community. The Consultant and RA Nurse attend a weekly clinic at a local medical centre about equidistant from the patient’s GP surgery (15 minutes walk) which is very helpful and means that means a more troublesome journey to the hospital is rare.

**Patient Costs:**
1. Absence from work in 2004 meant that the patient was reduced to statutory sick pay for some weeks.
2. Travel costs: because of the structure of the local health provision the patient must visit a health centre other than his GP surgery for blood tests, etc and the hospital for other services.
3. Prescription charges: the patient has purchased an annual pre-paid certificate at a cost of £59.20.
4. Private consultation (April 2003) cost £180.00 and patient saw this as money well spent.
16th February 2005
Patient met Consultant Rheumatologist. Further blood tests taken. Consultant asked to have knee X-rays taken and to be seen in hospital later that day. RA confirmed.

Patient was in hospital for 6 nights. Various blood tests and X-rays were taken. Friday 18th he was seen in hospital with right foot and right shoulder. Further injection to the patient's right knee was planned for the Monday but proved unnecessary.

22nd February 2005
Patient was discharged from hospital and the following drugs were prescribed:
1. Pulsar 400 mg (2 tablets) twice daily, morning & evening.
2. Salagen (500 mg) (2 tablets) twice daily, morning & evening.
3. Methotrexate 10 mg weekly.
4. Folic acid.
5. Aminosorb 120 mg daily.
6. Phenergan 25 mg as required.
7. Panserin 25 mg twice daily.
8. Erythromycin 500 mg 6 hourly.

Patient was discharged and was reviewed in the Rheumatology Clinic on 8th March 2005. He was to be seen by the Rheumatologist on the 9th March 2005.

27th January 2005
Patient saw GP. Blood tests were taken. The patient returned a few days later for the results and was advised that it indicated a positive RA factor. His GP advised him that he was feeling better and referred him to a Consultant Rheumatologist.

Patient comments:
1. The patient has nothing but praise for the way he has been looked after by all the health professionals and the health system.
2. Regarding the initial hydrotherapy he does report feeling a little sore after each session and believes that the treatment may have come a little too soon after his discharge from hospital. A further programme of treatment has started in April 2005.
3. The patient has been advised this past week that he has been made redundant and is now unemployed. He is investigating this as no reason has been given to him for the redundancy and whether this is due to his absence or a general reduction in employees.

26th July 2005
Patient again met with Physiotherapist & Podiatrist for monitoring and further advice.

Patient costs:
1. The patient had taken out private critical illness insurance some time ago at a cost of £832.00 per week and is now benefiting from payments made by this policy.
2. The patient has qualified for Disability Living Allowance.
3. The patient has been receiving statutory sick pay (E85 per week).
4. Travel costs: return journeys to hospital are 28 miles which at 40p/mile = £11.20 and parking is £3.00. For the hydrotherapy treatment the patient must attend a hospital 46 mile distant; at 40p/mile this amounts to £10.00 per visit plus parking at £3.00.
5. Prescription costs: the patient has purchased 6 monthly pre-paid certificates at a cost of £33.96 per certificate.

Patient comments:
1. The patient has nothing but praise for the way he has been looked after by all the health professionals and the health system.
2. Regarding the initial hydrotherapy he does report feeling a little sore after each session and believes that the treatment may have come a little too soon after his discharge from hospital. A further programme of treatment has started in April 2005.
3. The patient has been advised this past week that he has been made redundant and is now unemployed. He is investigating this as no reason has been given to him for the redundancy and whether this is due to his absence or a general reduction in employees.
## Appendix 10  Telephone Follow up record of patient views post telephone interview

<table>
<thead>
<tr>
<th>Patient Map No</th>
<th>Date interview completed</th>
<th>Date of follow up call</th>
<th>Result of phone call</th>
<th>Any additional needs/problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>08/12/2005</td>
<td>21-Dec</td>
<td>interview fine although she didn't really understand what it was about. Did however wish to talk to helpline and SN re other problem. HAS been followed up</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>08/12/2005</td>
<td>20/12/2005</td>
<td>no problems - Ivan had promised copy of interview - reminded him</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>16/12/2005</td>
<td>21/12/2005</td>
<td>fine- went very well</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>16/12/2005</td>
<td>21/12/2005</td>
<td>fine - no problems at all</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>14/12/2005</td>
<td>21/12/2005</td>
<td>fine, he explained everything well and she is looking forward to seeing the results - wanted info of ring splints- done</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>14/12/2005</td>
<td>21/12/2005</td>
<td>fine - hopes it was helpful</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>20/12/2005</td>
<td>21/12/2005</td>
<td>went well, no problems</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>20/12/2005</td>
<td>23/12/2005</td>
<td>fine, no problem</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>20/12/2005</td>
<td>22/12/2005</td>
<td>excellent - already has flow chart and is making a couple of amendments and will email to Ivan</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Date 1</td>
<td>Date 2</td>
<td>Comment</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>----------------</td>
<td>-----------------</td>
<td>----------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>21/12/2005</td>
<td>22/12/2005</td>
<td>fine, &quot;what a lovely man&quot;</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>23/12/2005</td>
<td>04/01/2006</td>
<td>brilliant, friendly man, very good</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>28/12/2005</td>
<td>04/01/2006</td>
<td>very nice man, very easy to talk to, fine</td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>10/01/2006</td>
<td>13/01/2006</td>
<td>no problems - just felt a bit guilty that she had rabbitted on! Commented that in remembering what happened it struck her that it is often more painful for the person caring for you than the individual with the disease</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>10/01/2006</td>
<td>13/01/2006</td>
<td>no problem, very helpful and good</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>11/01/2006</td>
<td>no reply 13/1/06</td>
<td>fine - still waiting for map - has found financial info talked about</td>
<td></td>
</tr>
<tr>
<td></td>
<td>31/01/-6</td>
<td>22/2/06</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>12/01/2006</td>
<td>31/01/2006</td>
<td>really good, very worthwhile thing to do, Ivan a very nice man</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>12/01/2006</td>
<td>13/01/2006</td>
<td>very nice man, very good telephone manner</td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>18/01/06</td>
<td>18/01/2006</td>
<td>absolutely fine, no worries as she is currently preoccupied with revision</td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>31/01/2006</td>
<td>31/01/2006</td>
<td>quite enjoyed it and very happy to do it - able to choose a good time to call</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Date</td>
<td>Date</td>
<td>Feedback</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>-----------</td>
<td>-----------</td>
<td>--------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>23/01/06</td>
<td>31/01/2006</td>
<td>very good, he did find it difficult to come to terms with the disease but everything is fine now</td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>30/01/06</td>
<td>31/01/2006</td>
<td>excellent - very nice man who fully explained about the project and was very understanding</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>26/01/06</td>
<td>31/01/2006</td>
<td>pleased to help - had no queries or issues to raise</td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>6/02/2006</td>
<td>07/02/2006</td>
<td>13/2/06 - fine - went well awaiting map</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>20/02/2006</td>
<td>21/01/2006</td>
<td>fine very interesting - interested in whole project like to be a volunteer</td>
<td></td>
</tr>
</tbody>
</table>
**Appendix: 11- DMARDs and biologics prescribed to participants:**

<table>
<thead>
<tr>
<th>Drug</th>
<th>1&lt;sup&gt;st&lt;/sup&gt; Prescription number</th>
<th>As a second/third prescription</th>
</tr>
</thead>
<tbody>
<tr>
<td>Azathioprine</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ciclosporin</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gold (Myocrisin)</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Hydroxychloroquine</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Leflunomide</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Methotrexate</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>Penicillamine</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sulfasalazine</td>
<td>12</td>
<td>1</td>
</tr>
<tr>
<td>Biologics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adalimumab</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Etanercept</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Infliximab</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Note: Some participants would be prescribed 2 or 3 therapies. Sequentially or in addition to previous DMARD prescribed.
<table>
<thead>
<tr>
<th>Patient</th>
<th>Community-based care</th>
<th>Drugs</th>
<th>Other expenses</th>
<th>Hospital and specialist care</th>
<th>Total NHS</th>
<th>Total Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>001</td>
<td>Diagnosed 2 years, age 62</td>
<td>Community-based care</td>
<td>DMARDs, Gastroprotector, NSAID, Steroids</td>
<td>Alternative medicine and non prescribed treatments</td>
<td>£121.34</td>
<td>£571.03</td>
</tr>
<tr>
<td></td>
<td></td>
<td>DMARDs</td>
<td>£83.16</td>
<td></td>
<td></td>
<td>£5,979.00</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Gastroprotector</td>
<td>£75.04</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>NSAID</td>
<td>£286.80</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Steroids</td>
<td>£4.69</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>DMARDs</td>
<td>£83.16</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Gastroprotector</td>
<td>£75.04</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>NSAID</td>
<td>£286.80</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Steroids</td>
<td>£4.69</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>002</td>
<td>Diagnosed 3 years, Age 71</td>
<td>Community-based care</td>
<td>Biologics, Minerals, DMARDs, Gastroprotector, NSAID, Analgesics, Steroids</td>
<td>Alternative medicine and non prescribed treatments, Home care and support, Travelling and parking</td>
<td>£153.67</td>
<td>£30,836.21</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Biologics</td>
<td>£25,816.32</td>
<td></td>
<td></td>
<td>£4,304.00</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Minerals</td>
<td>£30.24</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>DMARDs</td>
<td>£166.30</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Gastroprotector</td>
<td>£83.72</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>NSAID</td>
<td>£25.35</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Analgesics</td>
<td>£0.98</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Steroids</td>
<td>£20.55</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>DMARDs</td>
<td>£83.16</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Gastroprotector</td>
<td>£75.04</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>NSAID</td>
<td>£286.80</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Steroids</td>
<td>£4.69</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>002 Total</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>£30,836.21</td>
<td>£3,675.47</td>
</tr>
</tbody>
</table>


### 003
**Diagnosed 3 years**  
**Age 59**  
**Community-based care**  
- Community-based care: £73.67  
**Drugs**  
- Minerals: £3.60  
- DMARDS: £90.72  
- Analgesics: £13.93  
**Other expenses**  
- Alternative medicine and non prescribed treatments: £50.00  
- Home care and support: £16.00  
- Travelling and parking: £142.24  
- Prescription charges: £217.16  
**Hospital and specialist care**  
- Hospital and specialist care: £1,477.17  
**003 Total**  
- £1,584.17  
  - £283.16

### 004
**Diagnosed < 1 year**  
**Age 37**  
**Community-based care**  
- Community-based care: £80.18  
**Drugs**  
- DMARDS: £7.20  
- NSAID: £270.72  
**Other expenses**  
- Prescription charges: £54.00  
**Hospital and specialist care**  
- Hospital and specialist care: £460.00  
**004 Total**  
- £304.10  
  - £514.00

### 005
**Diagnosed 2 yrs**  
**Age 59**  
**Community-based care**  
- Community-based care: £214.65  
**Drugs**  
- Biologics: £358.56  
- Minerals: £2.58  
**Hospital and specialist care**  
- Hospital and specialist care: £540.00  
**005 Total**  
- £569.21  
  - £869.00
<table>
<thead>
<tr>
<th>Other expenses</th>
<th>DMARDS</th>
<th>Gastroprotector</th>
<th>DIMMUN</th>
<th>NSAID</th>
<th>Steroids</th>
<th>Travelling and parking</th>
<th>Prescription charges</th>
<th>Tot Cost Patient</th>
<th>Tot Cost NHS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>£691.44</td>
<td>£106.50</td>
<td>£240.00</td>
<td>£434.70</td>
<td>£12.30</td>
<td>£202.00</td>
<td>£119.70</td>
<td>£1,829.00</td>
<td>£1,941.03</td>
</tr>
<tr>
<td>Hospital and specialist care</td>
<td>Hospital and specialist care</td>
<td>Hospital and specialist care</td>
<td>Hospital and specialist care</td>
<td>Hospital and specialist care</td>
<td>Hospital and specialist care</td>
<td>Hospital and specialist care</td>
<td>Hospital and specialist care</td>
<td>Hospital and specialist care</td>
<td>Hospital and specialist care</td>
</tr>
<tr>
<td></td>
<td>£364.50</td>
<td>£1,304.00</td>
<td>£846.30</td>
<td>£60.00</td>
<td>£110.00</td>
<td>£210.00</td>
<td>£432.00</td>
<td>£2,641.93</td>
<td>£2,766.00</td>
</tr>
<tr>
<td>Diagnosed &lt; 2 yrs</td>
<td>Community-based care</td>
<td>Community-based care</td>
<td>Community-based care</td>
<td>Community-based care</td>
<td>Community-based care</td>
<td>Community-based care</td>
<td>Community-based care</td>
<td>Community-based care</td>
<td>Community-based care</td>
</tr>
<tr>
<td>Age 55</td>
<td>Minerals</td>
<td>DMARDS</td>
<td>NSAID</td>
<td>Analgesics</td>
<td>Steroids</td>
<td>Alternative medicine and non prescribed treatments</td>
<td>Home care and support</td>
<td>£120.00</td>
<td>£140.90</td>
</tr>
<tr>
<td></td>
<td>£1.59</td>
<td>£59.81</td>
<td>£216.60</td>
<td>£13.93</td>
<td>£24.60</td>
<td>£572.00</td>
<td>£110.00</td>
<td>£543.87</td>
<td>£567.50</td>
</tr>
<tr>
<td>Drugs</td>
<td>Minerals</td>
<td>DMARDS</td>
<td>NSAID</td>
<td>Analgesics</td>
<td>Steroids</td>
<td>Alternative medicine and non prescribed treatments</td>
<td>Home care and support</td>
<td>£120.00</td>
<td>£140.90</td>
</tr>
<tr>
<td></td>
<td>£1.59</td>
<td>£59.81</td>
<td>£216.60</td>
<td>£13.93</td>
<td>£24.60</td>
<td>£572.00</td>
<td>£110.00</td>
<td>£543.87</td>
<td>£567.50</td>
</tr>
<tr>
<td></td>
<td>Minerals</td>
<td>DMARDS</td>
<td>NSAID</td>
<td>Analgesics</td>
<td>Steroids</td>
<td>Alternative medicine and non prescribed treatments</td>
<td>Home care and support</td>
<td>£120.00</td>
<td>£140.90</td>
</tr>
<tr>
<td></td>
<td>£1.59</td>
<td>£59.81</td>
<td>£216.60</td>
<td>£13.93</td>
<td>£24.60</td>
<td>£572.00</td>
<td>£110.00</td>
<td>£543.87</td>
<td>£567.50</td>
</tr>
<tr>
<td></td>
<td>Minerals</td>
<td>DMARDS</td>
<td>NSAID</td>
<td>Analgesics</td>
<td>Steroids</td>
<td>Alternative medicine and non prescribed treatments</td>
<td>Home care and support</td>
<td>£120.00</td>
<td>£140.90</td>
</tr>
<tr>
<td></td>
<td>£1.59</td>
<td>£59.81</td>
<td>£216.60</td>
<td>£13.93</td>
<td>£24.60</td>
<td>£572.00</td>
<td>£110.00</td>
<td>£543.87</td>
<td>£567.50</td>
</tr>
<tr>
<td></td>
<td>Minerals</td>
<td>DMARDS</td>
<td>NSAID</td>
<td>Analgesics</td>
<td>Steroids</td>
<td>Alternative medicine and non prescribed treatments</td>
<td>Home care and support</td>
<td>£120.00</td>
<td>£140.90</td>
</tr>
<tr>
<td></td>
<td>£1.59</td>
<td>£59.81</td>
<td>£216.60</td>
<td>£13.93</td>
<td>£24.60</td>
<td>£572.00</td>
<td>£110.00</td>
<td>£543.87</td>
<td>£567.50</td>
</tr>
<tr>
<td>Patient</td>
<td>Age</td>
<td>Diagnosed</td>
<td>Community-based care</td>
<td>Hospital and specialist care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------</td>
<td>-----</td>
<td>-----------</td>
<td>----------------------</td>
<td>-----------------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>007</td>
<td></td>
<td>&lt; 1 year</td>
<td>£2,071.78 £3,135.42</td>
<td>£1,475.26</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>008</td>
<td>73</td>
<td>&lt; 1 year</td>
<td>£169.00</td>
<td>£346.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>009</td>
<td>51</td>
<td>&lt; 3 yrs</td>
<td>£1,437.93</td>
<td>£102.87</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Other expenses

<table>
<thead>
<tr>
<th>Item</th>
<th>NHS cost</th>
<th>Patient cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minerals</td>
<td>£28.40</td>
<td>£28.40</td>
</tr>
<tr>
<td>DMARDs</td>
<td>£39.31</td>
<td>£39.31</td>
</tr>
<tr>
<td>Gastroprotecter</td>
<td>£131.40</td>
<td>£131.40</td>
</tr>
<tr>
<td>NSAID</td>
<td>£260.03</td>
<td>£260.03</td>
</tr>
<tr>
<td>Analgesics</td>
<td>£3.48</td>
<td>£3.48</td>
</tr>
<tr>
<td>Steroids</td>
<td>£8.85</td>
<td>£8.85</td>
</tr>
<tr>
<td>Home care and support</td>
<td>£2,685.00</td>
<td>£2,685.00</td>
</tr>
<tr>
<td>Travelling and parking</td>
<td>£41.60</td>
<td>£41.60</td>
</tr>
<tr>
<td>Prescription charges</td>
<td>-£155.33</td>
<td>£155.33</td>
</tr>
<tr>
<td>Other</td>
<td>£250.00</td>
<td>£250.00</td>
</tr>
</tbody>
</table>

### Hospital and specialist care

<table>
<thead>
<tr>
<th>Item</th>
<th>NHS cost</th>
<th>Patient cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community-based care</td>
<td>£169.00</td>
<td>£169.00</td>
</tr>
<tr>
<td>Minerals</td>
<td>£0.45</td>
<td>£0.45</td>
</tr>
<tr>
<td>DMARDs</td>
<td>£5.40</td>
<td>£5.40</td>
</tr>
<tr>
<td>Analgesics</td>
<td>£8.40</td>
<td>£8.40</td>
</tr>
<tr>
<td>Travelling and parking</td>
<td>-£76.17</td>
<td>£76.17</td>
</tr>
<tr>
<td>Prescription charges</td>
<td>-£328.00</td>
<td>£328.00</td>
</tr>
<tr>
<td>Other</td>
<td>£250.00</td>
<td>£250.00</td>
</tr>
</tbody>
</table>

### Other expenses

<table>
<thead>
<tr>
<th>Item</th>
<th>NHS cost</th>
<th>Patient cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>DMARDs</td>
<td>£102.87</td>
<td>£102.87</td>
</tr>
<tr>
<td>NSAID</td>
<td>£260.03</td>
<td>£260.03</td>
</tr>
<tr>
<td>Analgesics</td>
<td>£3.48</td>
<td>£3.48</td>
</tr>
<tr>
<td>Steroids</td>
<td>£8.85</td>
<td>£8.85</td>
</tr>
<tr>
<td>Home care and support</td>
<td>£2,685.00</td>
<td>£2,685.00</td>
</tr>
<tr>
<td>Travelling and parking</td>
<td>£41.60</td>
<td>£41.60</td>
</tr>
<tr>
<td>Prescription charges</td>
<td>-£155.33</td>
<td>£155.33</td>
</tr>
<tr>
<td>Other</td>
<td>£250.00</td>
<td>£250.00</td>
</tr>
<tr>
<td>Patient</td>
<td>Diagnosed 3yrs</td>
<td>Age 31</td>
</tr>
<tr>
<td>---------</td>
<td>----------------</td>
<td>--------</td>
</tr>
<tr>
<td>009</td>
<td></td>
<td></td>
</tr>
<tr>
<td>010</td>
<td>Diagnosed 3yrs</td>
<td>Age 31</td>
</tr>
<tr>
<td>011</td>
<td>Diagnosed &lt; 1 year</td>
<td>Age 65</td>
</tr>
<tr>
<td>Patient</td>
<td>Age</td>
<td>Hospital and specialist care</td>
</tr>
<tr>
<td>---------</td>
<td>-----</td>
<td>------------------------------</td>
</tr>
<tr>
<td>011</td>
<td></td>
<td>£1,218.56</td>
</tr>
<tr>
<td>012</td>
<td>27</td>
<td>£6,020.79</td>
</tr>
<tr>
<td>013</td>
<td>58</td>
<td>£4,837.70</td>
</tr>
<tr>
<td>012</td>
<td></td>
<td></td>
</tr>
<tr>
<td>013</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>Diagnosis</td>
<td>Community-based care</td>
</tr>
<tr>
<td>-----</td>
<td>-----------</td>
<td>----------------------</td>
</tr>
<tr>
<td>36</td>
<td>&lt;6 months</td>
<td>£216.35</td>
</tr>
<tr>
<td></td>
<td>DMARDS</td>
<td>£222.05</td>
</tr>
<tr>
<td></td>
<td>Analgesics</td>
<td>£7.46</td>
</tr>
<tr>
<td></td>
<td>Travelling and parking</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hospital and specialist care</td>
<td></td>
</tr>
<tr>
<td>65</td>
<td>3 yrs</td>
<td>£1,430.28</td>
</tr>
<tr>
<td></td>
<td>DMARDS</td>
<td>£13,782.73</td>
</tr>
<tr>
<td></td>
<td>Minerals</td>
<td>£21.21</td>
</tr>
<tr>
<td></td>
<td>Gastroprotectors</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Steroids</td>
<td>£44.60</td>
</tr>
<tr>
<td></td>
<td>Homecare and support</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hospital and specialist care</td>
<td></td>
</tr>
<tr>
<td>32</td>
<td>&lt;1 year</td>
<td>£302.68</td>
</tr>
<tr>
<td></td>
<td>DMARDS</td>
<td>£30.42</td>
</tr>
<tr>
<td></td>
<td>Analgesics</td>
<td></td>
</tr>
<tr>
<td>Other expenses</td>
<td>Hospital and specialist care</td>
<td></td>
</tr>
<tr>
<td>------------------------------------</td>
<td>-----------------------------</td>
<td></td>
</tr>
<tr>
<td>Home care and support</td>
<td>£354.50</td>
<td></td>
</tr>
<tr>
<td>Travelling and parking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Hospital and specialist care</strong></td>
<td>£354.50</td>
<td></td>
</tr>
<tr>
<td><strong>017 Total</strong></td>
<td>£727.60 £348.50</td>
<td></td>
</tr>
<tr>
<td><strong>patient tot cost</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>NHS tot cost to patient</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>018</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Community-based care</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community-based care</td>
<td>£151.79 £20.00</td>
<td></td>
</tr>
<tr>
<td>Minerals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DMARDS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gastroprotector</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other drugs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NSAID</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Analgesics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Steroids</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Other expenses</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home care and support</td>
<td>£126.00 £27.00</td>
<td></td>
</tr>
<tr>
<td>Travelling and parking</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Hospital and specialist care</strong></td>
<td>£142.50 £920.00</td>
<td></td>
</tr>
<tr>
<td><strong>019 Total</strong></td>
<td>£9,414.73 £1,259.20</td>
<td></td>
</tr>
<tr>
<td><strong>patient tot cost</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>NHS tot cost to patient</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Drugs</td>
<td>Other expenses</td>
</tr>
<tr>
<td>------------------------</td>
<td>--------------------------------</td>
<td>---------------------------------------------------</td>
</tr>
<tr>
<td></td>
<td>DMARDs</td>
<td>Home care and support</td>
</tr>
<tr>
<td></td>
<td>NSAID</td>
<td>Travelling and parking</td>
</tr>
<tr>
<td></td>
<td>Analgesics</td>
<td>Prescription charges</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>019 Total</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>020</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnosed 2 years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age 63</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>020 Total</td>
<td></td>
<td></td>
</tr>
<tr>
<td>patient</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Drugs</th>
<th>Other expenses</th>
<th>Hospital and specialist care</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>DMARDs</td>
<td>Home care and support</td>
<td></td>
</tr>
<tr>
<td></td>
<td>NSAID</td>
<td>Travelling and parking</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Analgesics</td>
<td>Prescription charges</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>020</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnosed 2 yrs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age 44</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>022</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Hospital and specialist care

<table>
<thead>
<tr>
<th>Description</th>
<th>Patient Tot.</th>
<th>NHS Tot.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital and specialist care</td>
<td>£2,537.71</td>
<td></td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drugs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Biologics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Minerals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DMARDs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NSAID</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Analgesics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Steroids</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prescription charges</td>
<td>-£186.40</td>
<td>£186.40</td>
</tr>
<tr>
<td>Total</td>
<td>£3,598.59</td>
<td>£504.19</td>
</tr>
</tbody>
</table>

## Community-based care

<table>
<thead>
<tr>
<th>Description</th>
<th>Patient Tot.</th>
<th>NHS Tot.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community-based care</td>
<td>£208.14</td>
<td></td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drugs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Minerals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DMARDs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NSAID</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Analgesics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Steroids</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prescription charges</td>
<td>-£233.00</td>
<td>£233.00</td>
</tr>
<tr>
<td>Total</td>
<td>£10,975.30</td>
<td>£413.00</td>
</tr>
</tbody>
</table>

## Other expenses

<table>
<thead>
<tr>
<th>Description</th>
<th>Patient Tot.</th>
<th>NHS Tot.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alternative medicine and non prescribed treatments</td>
<td></td>
<td>£9.99</td>
</tr>
<tr>
<td>Travelling and parking</td>
<td></td>
<td>£307.80</td>
</tr>
<tr>
<td>Prescription charges</td>
<td>-£186.40</td>
<td>£186.40</td>
</tr>
<tr>
<td>Hospital and specialist care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other expenses</td>
<td>£170.00</td>
<td>£398.40</td>
</tr>
<tr>
<td>----------------------------------------------------</td>
<td>---------</td>
<td>---------</td>
</tr>
<tr>
<td>Alternative medicine and non prescribed treatments</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Travelling and parking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prescription charges</td>
<td>£101.70</td>
<td>£101.70</td>
</tr>
<tr>
<td>Hospital and specialist care</td>
<td>£3,495.28</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>£4,098.07</strong></td>
<td><strong>£650.10</strong></td>
</tr>
</tbody>
</table>

**Grand Total**

<table>
<thead>
<tr>
<th></th>
<th>£</th>
<th>£</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>139,748.25</td>
<td>46,618.43</td>
</tr>
</tbody>
</table>
Appendix 13  Breakdown of costs per individual

This table shows:

1. The number of episodes (e.g. number of GP visits or days of inpatient admission to hospital or number of blood tests).

2) A list of different drug treatments each single patient went through from the onset of the condition (all items starting with a capital ‘D’).

The numbers in the column for the drugs represents the number of pills. When a 0 is reported, the patients started the treatment and immediately interrupted it (eg. because of adverse reaction).

These figures are intended to supplement and not substitute the map. Information available on the map such as the duration of the condition is essential to interpret this data.
<table>
<thead>
<tr>
<th>patient</th>
<th>item</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>001</td>
<td>GP visits</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>RA consultant visits</td>
<td>34</td>
</tr>
<tr>
<td></td>
<td>DDMARDS1</td>
<td>924</td>
</tr>
<tr>
<td></td>
<td>DGAstro1</td>
<td>938</td>
</tr>
<tr>
<td></td>
<td>DNSAID1</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>DNSAID2</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>DNSAID3</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>DNSAID4</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>DNSAID5A</td>
<td>196</td>
</tr>
<tr>
<td></td>
<td>DNSAID5B</td>
<td>273</td>
</tr>
<tr>
<td></td>
<td>DSTER1A</td>
<td>189</td>
</tr>
<tr>
<td></td>
<td>DSTER1B</td>
<td>280</td>
</tr>
<tr>
<td>002</td>
<td>GP visits</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>RA consultant visits</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>Blood tests</td>
<td>28</td>
</tr>
<tr>
<td></td>
<td>Inpatient admission</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Emergency access</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Other community based specialist visits</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>DBIO1</td>
<td>288</td>
</tr>
<tr>
<td></td>
<td>DDMARDS1</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>DDMARDS2</td>
<td>1284</td>
</tr>
<tr>
<td></td>
<td>Dfolicac</td>
<td>1008</td>
</tr>
<tr>
<td></td>
<td>DGAstro2</td>
<td>182</td>
</tr>
<tr>
<td></td>
<td>DNSAID2</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>DPain2</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>DSTER1A</td>
<td>2055</td>
</tr>
<tr>
<td>003</td>
<td>GP visits</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>RA consultant visits</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>RA nurse</td>
<td>21</td>
</tr>
<tr>
<td></td>
<td>Educational course</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>DDMARDS2</td>
<td>756</td>
</tr>
<tr>
<td></td>
<td>Dfolicac</td>
<td>120</td>
</tr>
<tr>
<td></td>
<td>DPain3</td>
<td>112</td>
</tr>
<tr>
<td>004</td>
<td>GP visits</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>RA consultant visits</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Blood tests</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>DDMARDS2</td>
<td>60</td>
</tr>
<tr>
<td></td>
<td>DNSAID</td>
<td>480</td>
</tr>
<tr>
<td>005</td>
<td>GP visits</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>RA consultant visits</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>Blood tests</td>
<td>43</td>
</tr>
<tr>
<td></td>
<td>Visits with other specialists</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>DBIO1</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>DDMARDS1</td>
<td>48</td>
</tr>
<tr>
<td></td>
<td>DDMARDS2A</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>DDMARDS2B</td>
<td>27</td>
</tr>
<tr>
<td></td>
<td>DDMARDS3</td>
<td>150</td>
</tr>
<tr>
<td></td>
<td>DDMARDS3A</td>
<td>120</td>
</tr>
<tr>
<td></td>
<td>DDMARDS3B</td>
<td>120</td>
</tr>
<tr>
<td></td>
<td>DDMARDS4</td>
<td>30</td>
</tr>
<tr>
<td></td>
<td>Dfolicac</td>
<td>86</td>
</tr>
<tr>
<td></td>
<td>DGAstro3</td>
<td>150</td>
</tr>
<tr>
<td>Code</td>
<td>Value</td>
<td></td>
</tr>
<tr>
<td>----------</td>
<td>---------</td>
<td></td>
</tr>
<tr>
<td>DGASTRO4</td>
<td>150</td>
<td></td>
</tr>
<tr>
<td>DIMMUN</td>
<td>150</td>
<td></td>
</tr>
<tr>
<td>DNSAID2B</td>
<td>300</td>
<td></td>
</tr>
<tr>
<td>DNSAID5B</td>
<td>410</td>
<td></td>
</tr>
<tr>
<td>DNSAID6</td>
<td>180</td>
<td></td>
</tr>
<tr>
<td>DSTER1A</td>
<td>1080</td>
<td></td>
</tr>
<tr>
<td>DSTER1B</td>
<td>150</td>
<td></td>
</tr>
</tbody>
</table>

**006**
- GP visits: 4
- RA consultant visits: 11
- Blood tests: 21
- RA nurse: 1
- DDMARDS1: 141
- DDMARDS2A: 53
- DDMARDS2B: 51.42857143
- DFOLICAC: 53
- DNSAID6: 1140
- DPAIN3: 112
- DSTER1A: 2340
- DSTER1B: 120

**007**
- GP visits: 11
- RA consultant visits: 4
- Blood tests: 24
- RA nurse: 3
- DDMARDS1: 216
- DDMARDS2A: 165.5714286
- DFOLICAC: 34.28571429
- DGASTRO5: 547.5
- DIRON: 547.5
- DNSAID2: 225
- DNSAID5: 345
- DNSAID6: 30
- DPAIN3: 28
- DSTER1A: 705
- DSTER1B: 180

**008**
- GP visits: 7
- RA consultant visits: 1
- Blood tests: 4
- Visits with other specialists: 1
- RA nurse: 1
- Educational course: 1
- DDMARDS2A: 45
- DFOLICAC: 15
- DPAIN2: 120

**009**
- GP visits: 54
- RA consultant visits: 10
- Blood tests: 29
- Visits with other specialists: 1
- Other community based specialist visits: 8
- DDMARDS2A: 786.4285714
- DDMARDS3: 5
- DFOLICAC: 124.2857143
- DGASTRO2: 60
- DGASTRO5: 870
- DNSAID6A: 105
- DPAIN1: 120
<table>
<thead>
<tr>
<th>Code</th>
<th>GP visits</th>
<th>RA consultant visits</th>
<th>Blood tests</th>
<th>Visits with other specialists</th>
<th>Inpatient admission</th>
<th>Emergency access</th>
<th>DBIO2</th>
<th>DDMARDS1</th>
<th>DDMARDS2A</th>
<th>DDMARDS3</th>
<th>DNSAID</th>
<th>DPAIN1</th>
<th>DDMARDS2</th>
<th>DDMARDS2A</th>
<th>DDMARDS3</th>
<th>DNSAID2</th>
<th>DPAIN3</th>
<th>DDMARDS2</th>
<th>DDMARDS2A</th>
<th>DDMARDS3</th>
<th>DNSAID2</th>
</tr>
</thead>
<tbody>
<tr>
<td>010</td>
<td>4</td>
<td>20</td>
<td>68</td>
<td>1</td>
<td>21</td>
<td>1</td>
<td>870</td>
<td>90</td>
<td>102.8571429</td>
<td>104</td>
<td>60</td>
<td>011</td>
<td>165</td>
<td>51.42857143</td>
<td>360</td>
<td>240</td>
<td>300</td>
<td>012</td>
<td>1</td>
<td>12</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>016</strong></td>
<td><strong>GP visits</strong></td>
<td>60</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>RA consultant visits</strong></td>
<td>40</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Blood tests</strong></td>
<td>10</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Visits with other specialists</strong></td>
<td>33</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Inpatient admission</strong></td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>RA nurse</strong></td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>DBIO2</strong></td>
<td>60</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>DDMARDS1</strong></td>
<td>40</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>DDMARDS2B</strong></td>
<td>141.4285714</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>DFOLICAC</strong></td>
<td>707.1428571</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>DGASTRO2</strong></td>
<td>1980</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>DSTER1A</strong></td>
<td>4460</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>CCSPEC6</strong></td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| **017** | **GP visits** | 6 |
|   | **RA consultant visits** | 1 |
|   | **Other community based specialist visits** | 2 |
|   | **RA nurse** | 5 |
|   | **DDMARDS1** | 338 |
|   | **DPAIN3** | 1 |

| **018** | **GP visits** | 3 |
|   | **RA consultant visits** | 6 |
|   | **Blood tests** | 35 |
|   | **Other community based specialist visits** | 1 |
|   | **RA nurse** | 5 |
|   | **DDMARDS1** | 4290 |
|   | **DDMARDS2B** | 68.57142857 |
|   | **DFOLICAC** | 154.2857143 |
|   | **DNSAID6** | 2300 |
|   | **DPAIN6** | 160 |
|   | **DSTER1** | 1020 |
|   | **DDMARDS2C** | 120 |
|   | **DDMARDS4** | 120 |
|   | **DGASTRO6** | 900 |
|   | **DSTER2A** | 900 |
|   | **DVISCO** | 300 |
|   | **DTHYRO** | 300 |

| **019** | **GP visits** | 4 |
|   | **RA consultant visits** | 1 |
|   | **Blood tests** | 26 |
|   | **Visits with other specialists** | 16 |
|   | **Inpatient admission** | 21 |
|   | **Emergency access** | 1 |
|   | **Other community based specialist visits** | 2 |
|   | **Educational course** | 1 |
|   | **DDMARDS4** | 150 |
|   | **DNSAID5** | 150 |
|   | **DPAIN3** | 240 |
|   | **DPAIN5** | 300 |
|   | **DPAIN6** | 240 |
|   | **DPAIN7** | 240 |

| **020** | **GP visits** | 5 |
|   | **RA consultant visits** | 4 |
|   | **Blood tests** | 11 |
|   | **Other community based specialist visits** | 11 |
| Date  | GP visits | RA consultant visits | Blood tests | Visits with other specialists | Inpatient admission | Emergency access | Other community based specialist visits | DDMARDS1 | DDMARDS2A | DDMARDS2B | DDMARDS5 | DFOLICAC | DGASTRO3 | DNSAID6 | DPAIN2 | DPAIN3 | DSTER1A | DSTER1B | DBIO1 | DCALCIUM | DDMARDS1 | DDMARDS2B | DDMARDS4 | DFOLICAC | DNSAID4B | DNSAID7 | DPAIN3 |
|-------|-----------|----------------------|-------------|-------------------------------|--------------------|-------------------|-------------------|----------|----------|----------|---------|----------|---------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|        |
| 022   | 24        | 9                    | 57          | 1                             | 2                  | 2                 | 8                 | 1519     | 24       | 4        | 29.5    | 98       | 441     | 1386   | 1386   | 240    | 1010   | 495    |         |         |        |        |        |
| 023   | 5         | 10                   | 40          | 1                             |                    |                   |                   | 153      | 10       | 4        | 900     | 104      | 900     | 840    | 49     | 49     |        |        |        |        |        |        |        |        |        |
| 024   | 2         | 2                    | 44.57142857 | 4                             | 6                  |                   |                   | 624      | 89.14285714 | 1248 | 44.57142857 | 312 | 210 | 280 |        |        |        |        |        |        |        |        |        |        |
Appendix 14 Analysis of access to healthcare professional support

Code for Appendix 14

MDT = Multi-professional team> More 3 disciplines make up the team (excluding doctors) e.g. physiotherapist, occupational therapist and nurse.
MDT <2 = as above but only 2 disciplines.
EDU PROG = Full educational programme. Usually run over a few weeks with formal educational content and presented by a number of members of the team.
NURSE GOLD = Access to extended role nurse specialist carrying out regular outpatient follow up, rapid access services, one-to-one educational support and telephone advice line.
NURSE BLOODS = Nurse clinics for predominantly blood monitoring clinic activities.
EMERG ADM = Emergency Admissions
IP ADM = Inpatient admissions. No. GP Visits = GP appointments
No. Con App = Number of consultant rheumatologist appointments.
No. Nurse Consultants = Number of nurse led consultations
Physio = Physiotherapist access
OT = Occupational Therapist access.
Podiatry = Podiatry access
<table>
<thead>
<tr>
<th>Map</th>
<th>Age</th>
<th>MDT&gt;3</th>
<th>MDT&lt;2</th>
<th>EDU prog</th>
<th>Nurse Gold</th>
<th>Nurse Bloods</th>
<th>Emerg adm</th>
<th>IP adm</th>
<th>No GP Visits</th>
<th>No Con App</th>
<th>No Nurse Con</th>
<th>Physio</th>
<th>OT</th>
<th>Podiatry</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>62</td>
<td>✔</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>5</td>
<td>34</td>
<td>0</td>
<td>✔</td>
<td>✔</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>71</td>
<td>✔</td>
<td>✔</td>
<td></td>
<td>✔</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>6</td>
<td>3</td>
<td>20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>59</td>
<td>✔</td>
<td>✔</td>
<td></td>
<td>✔</td>
<td></td>
<td></td>
<td></td>
<td>3</td>
<td>6</td>
<td>21</td>
<td></td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>4</td>
<td>37</td>
<td>✔</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3</td>
<td>3</td>
<td>0</td>
<td></td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>5</td>
<td>59</td>
<td>✔</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>5</td>
<td></td>
<td>13</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>55</td>
<td>✔</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>4</td>
<td>11</td>
<td>1</td>
<td></td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>7</td>
<td>65</td>
<td>✔</td>
<td>✔</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>4</td>
<td>4</td>
<td>3</td>
<td>✔</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>8</td>
<td>73</td>
<td>✔</td>
<td>✔</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>7</td>
<td>1</td>
<td>1</td>
<td>✔</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>9</td>
<td>51</td>
<td>✔</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>54</td>
<td>10</td>
<td>0</td>
<td>✔</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>10</td>
<td>31</td>
<td>✔</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>21</td>
<td>4</td>
<td>20</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>11</td>
<td>65</td>
<td>✔</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>1</td>
<td>4</td>
<td>✔</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>12</td>
<td>27</td>
<td>✔</td>
<td>✔</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2</td>
<td>8</td>
<td>5</td>
<td>12</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>13</td>
<td>58</td>
<td>✔</td>
<td>✔</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3</td>
<td>29</td>
<td>3</td>
<td>✔</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>14</td>
<td>36</td>
<td>✔</td>
<td>✔</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3</td>
<td>1</td>
<td>0</td>
<td>✔</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>15</td>
<td>65</td>
<td>✔</td>
<td>✔</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>21</td>
<td>40</td>
<td>10</td>
<td>1</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>16</td>
<td>32</td>
<td>✔</td>
<td>✔</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>6</td>
<td>1</td>
<td>5</td>
<td>✔</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>17</td>
<td>36</td>
<td>✔</td>
<td>✔</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3</td>
<td>6</td>
<td>5</td>
<td></td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>18</td>
<td>63</td>
<td>✔</td>
<td>✔</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>21</td>
<td>3</td>
<td>1</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>19</td>
<td>36</td>
<td>✔</td>
<td>✔</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>✔</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>20</td>
<td>44</td>
<td>✔</td>
<td>✔</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2</td>
<td>2</td>
<td>24</td>
<td>9</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>21</td>
<td>50</td>
<td>✔</td>
<td>✔</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>5</td>
<td>10</td>
<td>4</td>
<td></td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>22</td>
<td>39</td>
<td>✔</td>
<td>✔</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>6</td>
<td>2</td>
<td>2</td>
<td></td>
<td></td>
<td>✔</td>
</tr>
</tbody>
</table>

**Total number by age group:**

- <40: 8
- 41 - 65: 12
- 66 - 73: 2

**Diagnosis by Age:**

- < 1 YEAR DIAGNOSIS
- 1-2 YEAR DIAGNOSIS
- > 2 < 3.6 YEARS

**Total:**

- 86 EPIS
- 13 PEOPLE
- 17 PEOPLE
- 10 PEOPLE
Appendix 15: Detail of edits made following patient review of maps:

- Map 1 – minor amendments, typo, etc.
- Map 2 – some additions and additional details regarding visits to Consultant and medication amounts
- Map 3 – recalled one additional injection associated with an existing hospital visit
- Map 4 – amended some typo’s and provide some specific dates rather than simply the month and year
- Map 5 – additional personal costs provided
- Map 6 – refined dates and added some additional appointments
- Map 7 – minor additional details on dates and medication
- Map 8 – added additional traveling costs and 1 further issue raised with Consultant as part of already captured appointment.
- Map 9 – provided some additional patient comments as background
- Map 10 – some additional ancillary costing and transfer information between Bath and local specialist
- Map 11 – noted recent increase in medication between interview and return of map
- Map 12 – changed one date after checking medication record
- Map 13 – only spelling changes
- Map 14 – more detail provided on increasing medication routine early in diagnosis from medical record booklet
- Map 15 - withdrawn
- Map 16 – additional GP and home visits (District Nurse, etc) identified
- Map 17 – minor typo amendments
- Map 18 – some additional patient comments and costs
- Map 19 – additional appointments recalled, patient costs and medication details
- Map 20 – some additional patient costs
- Map 22 – recalled additional appointments and further cost details
- Map 23 – some additional cost details and patient comments (withdrawn)
- Map 24 – one additional cost item