



# ***Arthrititing: Exploring the relationship between identity and medicines use, and to identify the contribution of medicines and pharmacy services, for the care of young people with arthritis***

## **FINAL REPORT**

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**Any data presented here must be treated as preliminary until they have been subjected to external peer review and therefore not published elsewhere by anyone other than the authors.**  
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## Table of Contents

Section	Page
Cover pages – Project team names and affiliations, and acknowledgements	1
Table of contents	3
Glossary and abbreviations	4
<b>1. Background to the Project</b>	<b>4</b>
1.1 Identity, arthritis and medication	4
1.2 The role of pharmacy	6
1.3 Background to the service at BCH, and to medication issues in juvenile arthritis	8
1.4 Participation of young people from Birmingham Children's Hospital and Arthritis Care	9
<b>2. Aim and Objectives</b>	<b>9</b>
<b>3. Methods</b>	<b>10</b>
3.1 Project overview	10
3.2 Recruitment of young people and parents to the project	11
3.3 The Arthrititing blog and survey website	11
3.4 Exploring discussion forum postings on the Arthritis Care website	12
3.5 Case note review	13
3.6 Data preparation and analysis	13
3.7 Scoping review	16
3.8 Validation of results with young advisers from BCH and Arthritis Care	17
3.9 Ethical and R&D approvals	17
<b>4. Results and Discussion</b>	<b>18</b>
4.1 Recruitment of young people at BCH	18
4.2 Recruitment of parents at BCH	19
4.3 Blog and survey activity on the Arthrititing website	20
4.4 Case note review at BCH	23
4.5 Discussion forum postings on the Arthritis Care website	24
<b>5. Discussion, incorporating Insights from the Scoping Review</b>	<b>24</b>
5.1 Overview of results from the scoping review	24
5.2 Case studies of relevant innovative practice in Northern Ireland and Scotland	27
5.3 How did the data address the Arthrititing Project aims and objectives?	29
<b>6. Future Implications for Practice, Education and Research</b>	<b>30</b>
6.1 Innovation and limitations in the Arthrititing Project	30
6.2 Implications for future practice and education	30
6.3 Implications for future research	31
7. Dissemination – Making things happen	32
8. Conclusions	33
References	34
List of Appendices	37

## **Glossary and Abbreviations**

<b>Term / Abbreviation</b>	<b>Meaning</b>
A1C	Haemoglobin A1C (US abbreviated term)
BCH	Birmingham Children's Hospital NHS Foundation Trust
CAM	Complementary and alternative medicine
CI	Confidence interval
CMS	Chronic medication service – A national pharmacy service in Scotland, where a patient can register with a pharmacy of their choice to receive pharmaceutical care. <a href="http://www.communitypharmacy.scot.nhs.uk/core_services/cms.html">http://www.communitypharmacy.scot.nhs.uk/core_services/cms.html</a>
CPD	Continuing professional development
DERC	Diabetes Education and Research Center (in Florida, USA)
DH England	Department of Health (England)
DMARD	Disease-modifying anti-rheumatic drug e.g. methotrexate
GP	General practitioner / primary care doctor
HaH	Healthcare at Home
IBD	Inflammatory bowel disease
IDDM	Insulin-dependent diabetes mellitus (Type 1 diabetes)
JIA	Juvenile idiopathic arthritis
LTC	Long-term condition
MUR	Medicines use review – an advanced pharmacy service, specified and commissioned nationally (England & Wales) where a pharmacist can consult with an individual patient in a confidential area about all their medicines. <a href="http://www.psnc.org.uk/pages/mur.html">http://www.psnc.org.uk/pages/mur.html</a>
NELM	National Electronic Library of Medicine – Research article database hosted by the NHS <a href="http://www.nelm.nhs.uk">www.nelm.nhs.uk</a>
NMS	New medicine service – a new advanced pharmacy service, specified and commissioned nationally (England & Wales) where a pharmacist can consult with an individual patient in a confidential area about a new medicine received on prescription (there is a specified list). This new medicine can be discussed in the context of their other medicines as well. <a href="http://www.psnc.org.uk/pages/nms.html">http://www.psnc.org.uk/pages/nms.html</a>
NSAID	Non-steroidal anti-inflammatory drug e.g. ibuprofen
Off-label	The use of a medicine that is not included in its marketing authorisation (licence). Many medicines are used 'off-label' in children and young people, as clinical trials in these age groups have, until recently, been uncommon.
OT	Occupational therapist
PIL	Patient information leaflet – more specifically, the regulatory information leaflet that is found in the box of a dispensed or purchased medicine.
PRUK	Pharmacy Research UK
RMG	Research management group – the authors
YP	Young people

## **1. Background to the Project**

### ***1.1 Identity, Arthritis and Medication***

An adolescent's search for self-meaning is set against a backdrop of rapid physiological and cognitive change, and occurs within a context of family, peer and societal demands. Adolescents have to adjust to their changing body image, develop increased abilities to contemplate the future and free-choice, deal with emotional changes that may manifest in volatile emotions and mood swings, and make decisions about their values, sexual behaviour, friendships, and vocation. Developments in neuroscience are revealing that adolescent brain development extends into the twenties with the

changes being primarily related to aspects of executive functioning such as forward planning, evaluation of risk and reward, and regulation of behaviour and emotion (Steinberg, 2010).

A range of adult ‘health identities’, ranging from ‘expert patient’ to ‘resisting consumer’ have been proposed (Fox and Ward, 2006). Traditionally, identity has been viewed as something that is fixed and immutable. However, research, particularly in the social sciences, has recently come to challenge such an essentialist view of identity construction, where one’s identity is conceived in terms of being stable and unitary. Identity has come to be seen as ‘something shifting and multiple, something people are continuously constructing and reconstructing in their encounters with each other and the world’ (Cameron, 2001: 170). Adolescents are building their own identity through their teenage years: the onset of a long-term condition during this time is likely to disrupt and challenge the already turbulent process.

Significantly, identities are enacted in, and through, language. It follows then that if accounts of health and identity are to be adequately dissected, research needs to take into account the linguistic choices through which individuals construct identities for themselves. This is particularly acute in relation to the theme of health and medication. Health has been described as a matter of identity: realising health, and the state of being ‘healthy’, are features that define the self (Crawford *et al.*, 2006: 402). The personal meanings attached to medication are complex and can have a profound influence over one’s sense of identity - and sense of self.

Medication was a key area (amongst many) identified by young people to be addressed by health professionals during adolescence (Shaw *et al.*, 2004). Managing treatment was identified as a major theme of living with Juvenile Idiopathic Arthritis (JIA) reported by young people in a systematic review of the qualitative literature (Tong *et al.*, 2012). Although it is difficult to consider such issues about medication in isolation from other considerations about a young person’s condition and broader life, studies in other illness groups have shown that taking medication can have an identifiable impact. For example, work by Garfield *et al.* (2003) with adults with depression showed that being prescribed a medicine confirmed their diagnosis: thus, whilst it might have enabled them to lead a normal life, at the same time it conferred a sense of stigma, or labels of non-normality or stigma.

‘Normality’ is a powerful aspiration for any young person, not least those living with juvenile arthritis (including JIA), manifest as the ability to participate in activities with their peers and families.

“Striving for normality” was another major theme identified by young people in the aforementioned systematic review of the qualitative literature (Tong *et al.*, 2012). The use of the word ‘normal’ in emails to an online teenage health doctor was associated with a statement that they felt was ‘wrong’ (Harvey *et al.*, 2007). A ‘trade-off’ of adherence, and thus the success of therapy, against ‘normal’ adolescent activities (such as drinking alcohol) might occur. A major issue for young people with arthritis is the need to continue to take medication, even when well: recommended practice in JIA is to continue disease-modifying anti-rheumatic drugs [DMARDs] and/or biologic therapy for at least 2 years of remission. The variation in individuals’ development of abstract thought during adolescence (Suris *et al.*, 2004), and reversion to concrete thought during times of distress (Hamburg *et al.*, 1998), might make the consideration of long-term consequences of non-adherence during remission very difficult.

Adherence of young people to medication is lower than that of adults, and of younger children under the care of parents, ranging from 10% to 96% (Staples & Bravender, 2002; Costello *et al.*, 2004). In a recent study of fifty-two 13-20 year olds with JIA, 46% reported non-adherence (Lawson *et al.*, 2011) In a study of children with a mean age of 10, perceived adherence to medications was consistently high, with average adherence at baseline, 3, 6, 9, and 12 months being 86%, 92%, 90%, 92%, and 89%, respectively (Feldman *et al.*, 2007a). However, in another study, using an 80% adherence cut point, 25 (52%) patients were classified as adherent and 23 (48%) as non-adherent (Rapoff *et al.*, 2005). Non-adherence to appropriately prescribed medicines can lead to poor health outcomes. In children with JIA, moderate adherence to medication was associated with lower active joint count (Feldman *et al.*, 2007b). The side-effects of medicines like methotrexate, which can result in pain upon administration, and anticipatory and post-administration nausea, pose a considerable challenge to sustained adherence. Increasing age during adolescence is strongly associated with increasing non-adherence across a range of clinical areas.

Family dynamics and the nature of medication partnerships between parent and the young person are likely to indicate a young person's readiness for transition to adult rheumatology services. For example, 20% of 17 year-olds were not self-medicating at the time of transfer to adult services (Shaw *et al.*, 2005). Medication adherence was considered the third most essential component of transition by rheumatology practitioners (Hilderson *et al.*, 2012). Self-medication was a predictor of improvement in HRQoL at 12 months following the implementation of a transitional care programme which included skills and knowledge training in this area (McDonagh *et al.*, 2007). However, other authors have reported that discussion regarding self-management does not always take place - with no such discussions being reported by 25% of parents of 12-17 year olds with arthritis, significantly less than parents of similar aged young people with diabetes (Scal *et al.*, 2009). Pharmacy support for self-medication and repeat prescription services could further encourage the development of such skills required for the transfer of health management responsibilities.

## **1.2 The Role of Pharmacy**

The medicines for young people with arthritis may be supplied by a combination of hospital and community pharmacy services, and home health care companies. This is a challenge in terms of service integration and co-ordination. Whilst we assume that care close to home will be preferred by patients, a study of young people's and their parents' views on the use of infliximab asked for their opinions about switching to adalimumab, which would not require travelling to specialist centres. Most wanted to stick to the status quo, because they valued the specialist care (Hazen *et al.*, 2008). In a study of adolescent satisfaction in rheumatology, knowledgeable (and honest) staff were considered essential aspects of best practice (Shaw *et al.*, 2007).

There is often confusion among health professionals about the nature of the rheumatic condition experienced by young people. JIA is often confused with adult rheumatoid arthritis, or simply dismissed as 'growing pains'. Screening of the musculoskeletal system in children and young people has been reported to be suboptimal in general paediatrics (Myers *et al.*, 2004), and yet is the second or third most common presentation of young people in primary care (Churchill *et al.*, 2000; Haller *et al.*, 2007). Many young people are not diagnosed early, even when specialist services are available (Foster *et al.*, 2007): awareness by pharmacists of JIA as a possible cause of repeat prescriptions for,

and/or purchases of, analgesics could improve referral. Community pharmacists are concerned by prescriptions for high-dose NSAIDs. Further education is needed about these issues to improve referral processes and medicines management for young people with arthritis.

The changes to the community pharmacy contractual framework for England in 2005 created opportunities for extending cognitive services for patients (Blenkinsopp *et al.*, 2007). All three tiers of the framework offer possibilities for enhancing the care of young people with arthritis: 'essential service' developments such as signposting to care and monitoring sales of OTC medicines; locally-commissioned 'enhanced services'; and the nationally-commissioned 'advanced service' of medicines use review. Hospital pharmacy services are developing closer alignments with clinical directorates: these circumstances might facilitate integrated services tailored to young people with arthritis.

It is recognised that, in general, there are barriers to accessing health services for adolescents (e.g. Churchill *et al.*, 2000). The potential to access information and advice online fits with adolescents' more general information-seeking activities (Gray *et al.*, 2005a), and young people have reported feeling empowered by email communication with health providers (Valaitis, 2005), but young people feel overwhelmed by the volume of information available, and sometimes unsure whom to trust (Gray *et al.*, 2005b). Research with young people with JIA has shown that a desire for knowledge is a key theme (Tong *et al.*, 2012), and - in particular – that they would like more online information resources (Shaw *et al.*, 2004 and Stinson *et al.*, 2008). Moreover, other JIA-specific work has highlighted the dearth of age-appropriate online resources (Stinson *et al.*, 2009). The level of detail seen in young people's emails about medicines and health is surprisingly extensive (Harvey *et al.*, 2008): emails about medicines having an average length of 85 words, as opposed to emails about other health issues with an average of 16 words (Gray *et al.*, 2008). It seems reasonable to explore a combination of online and face-to-face information and advice services for young people, especially when they live at a distance from a specialist centre.

Just as unmet training needs have been identified in rheumatology professionals in the UK (McDonagh *et al.*, 2004), as with other paediatric professionals (McDonagh 2006a, Dieppe *et al.*, 2008), it will also be necessary to consider pharmacists' lack of training in providing services to young people, and to build a foundation that incorporates the principles of the 'You're Welcome' framework regarding issues such as access, consent and confidentiality, environment, and staff training and values (Department of Health, 2011). This framework provides a basis for accreditation for all providers, across health service boundaries, and this project offers an opportunity to explore the opportunities and challenges for pharmacists in meeting these requirements. The recent report of the Children and Young People's Health Outcomes Forum (CYPHOF) has recognised pharmacists as one of the front-line professionals working with young people (CYPHOF, 2012). In its system-wide response to the forum's report, DH England has asked the Chief Pharmaceutical Officer to co-chair a sub-committee of the new Forum to oversee the development of a programme to optimise the use of medicines in children and young people (DH England, 2013). The profession is thus included within that group's calls for better training, better integration of services, and putting young people and their families at the heart of health care.

### **1.3 Background to the Service at BCH, and to medication issues in juvenile arthritis**

#### *The Service:*

The weekly adolescent clinic at BCH was established 12 years ago. Over half (58%) of patients seen in the rheumatology service as a whole are in the adolescent age group. The adolescent rheumatology team includes a part-time charity-funded transition co-ordinator to support young people (YP) with all types of long-term rheumatic conditions and an evidence-based transitional care programme (McDonagh *et al.*, 2006b) starting at age 11 years for all YP, irrespective of their long-term condition. The service refers YP on to 30 adult rheumatologists in the region, and there are 2 clinics specifically set up for young adults (16-25 year-olds). YP undergo transfer when they are ready, not necessarily linked to their age. Janet McDonagh and the team encourage YP to have at least part of their consultation alone, and then bring in their parent at the end so YP can explain the action plan, thereby both assessing understanding and demonstrating competency.

#### *The Medication:*

The main medicines used in clinic at BCH are:

- NSAIDs – Piroxicam, ibuprofen and naproxen being the most frequently used;
- Paracetamol;
- Methotrexate (MTX);
- Anti-emetics for MTX nausea;
- Folic acid for prevention of MTX-related side effects, such as mouth ulcers;
- Biologics – etanercept (sc once or twice weekly), adalimumab (sc once fortnightly), infliximab, (day case infusion every 4-8 weeks) anakinra (sc daily), abatacept (fortnightly day case infusion) , rituximab (2 infusions 2 weeks apart – may be repeated after 6 months);
- Calcium and/or vitamin D supplements;
- Eye drops if there is eye disease;
- Mycophenolate – for eye disease, SLE-related arthritis;
- Prednisolone – for severe arthritis, SLE-related disease.

A few patients also receive growth hormone injections.

Young people often do not count injections as ‘medicines’ – ‘medication’ is thus seen as a more inclusive term. Medication supply pathways are complex, and any one family may have to navigate several at once. BCH does not supply medicines on hospital or FP10 prescriptions beyond 2 weeks. BCH sends a letter to the GP to request that they prescribe longer-term medication. GPs are sometimes resistant, for reasons given previously, and probably also on grounds of cost - as well as concerns about safety if they are unfamiliar with the use of such drugs in childhood. BCH supplies prescription instructions to Healthcare at Home (HaH) for biologics and methotrexate. Healthcare at Home is well regarded by YP and families, and by BCH staff – they have good relationships with nurses at BCH.

YP are likely to be getting different medicines in different ways e.g. biologics and methotrexate as above, but folic acid and NSAIDs through community pharmacies. Most monitoring is done at BCH as primary care does not take it on – primary care providers sign a shared care agreement to confirm this one way or another. YP do not always like coming into BCH for day case treatment as there is no adolescent unit nor dedicated adolescent outpatients or day case area. Subcutaneous injections may

be administered by YP themselves, parents or community nurses, although the community nurse service stops at age 16. Some YP thus find themselves going back to adult services to have injections, after 5 years of injecting at home. Complementary and alternative medicines (CAM) use among these patients is not well understood: their cultural background may influence choices. . In a US-based on-line survey of 134 young people with arthritis aged 14-19, 72% reported the use of complementary medicine (Seburg *et al.*, 2012). In summary, YP and parents are navigating a complex multifaceted system to get their medication, potentially interacting with a number of different agencies.

#### ***1.4 Participation of Young People from Birmingham Children's Hospital and Arthritis Care***

This project has benefited from the sustained and insightful participation of young people from Birmingham Children's Hospital NHS Foundation Trust and Arthritis Care. The project title 'Arthrititing' was the idea of a young person with inflammatory arthritis in Birmingham, the look-and-feel of the website was developed through a meeting with young people from Birmingham, and ongoing feedback and advice from both users and non-users of the blog site at a later meeting during the project. The blog categories and questions were also simplified and refined with their help.

During our analysis phase, we convened another participation meeting in Birmingham in February 2013 to start to develop artefacts from the project, informed by preliminary analysis of the themes from the blogs. In parallel, an Arthritis Care young people's residential weekend in Belfast in mid-February gave us another opportunity to show our preliminary analysis of the blog themes and survey to another group of young people, and to invite comments and challenges. A further small group of young advisers from Arthritis Care in Belfast spoke with Nicola Gray towards the end of the project and described at length, with great enthusiasm, their pharmacy care. This led to the engagement of a key informant who could help us to design a new case for pharmacy involvement.

We are indebted to the young people in Birmingham and Belfast who contributed to the project, and to Marie McGee at Birmingham Children's Hospital, Catherine Wright at Arthritis Care (Belfast office), and to Lindsay Starbuck from the Association for Young People's Health for their participation work on our behalf. This project could not have been done without these partnerships.

## **2. Aim and Objectives**

**2.1 Aim:** To investigate the relationship between identity and medication use amongst adolescents with arthritis, and to explore the role of pharmacy in delivering services to this group.

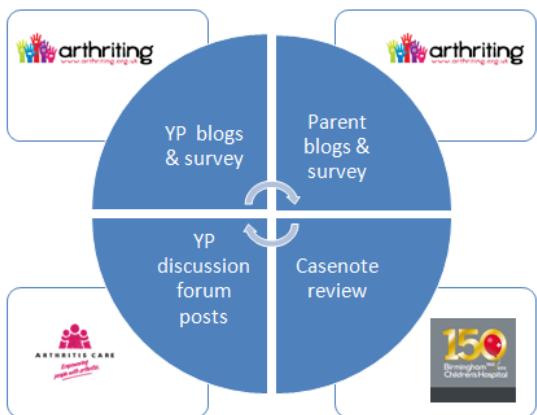
### **2.2 Objectives:**

1. To investigate the relationship between identity and medication use amongst adolescents with juvenile arthritis.
2. To scope current patterns of care among young people with juvenile arthritis, and to map the current contribution of pharmacy and medicines to their treatment.
3. To scope current knowledge and practice of pharmacists regarding young people and juvenile arthritis.

### **3. Methods**

#### **3.1 Project Overview**

This project had four interlinked strands of primary and secondary data collection, depicted schematically in Figure 1. During the project, young people (aged 11-15) with arthritis – and some parents – from the clinics at Birmingham Children’s Hospital NHS Foundation Trust (BCH) wrote blogs on our ‘Arthrititing’ website, specially created for the project under the guidance of young people at BCH. These private blogs included thoughts about identity, the arthritis condition, medication and the use of health services. Young people and parents also had the chance to complete a survey about medication tasks and information-seeking. A case note review of 150 rheumatology clinic patients at BCH, and observation of the Young People’s Discussion Forum on the Arthritis Care website [www.arthritiscare.org.uk](http://www.arthritiscare.org.uk), added complementary data.



**Figure 1 – Data collection workstreams within the Arthrititing Project**

Data from each workstream contributed to meeting the study aims and objectives as in Table 1.

<b>Aims:</b> To investigate the relationship between identity and medication use amongst adolescents with arthritis, and to explore the role of pharmacy in delivering services to this group.	<b>Objective</b>	<b>Relevant data from:</b>
1. To investigate the relationship between identity and medication use amongst adolescents with juvenile arthritis.		<ul style="list-style-type: none"><li>• Blog entries</li><li>• Discussion forum postings</li></ul>
2. To scope current patterns of care among young people with juvenile arthritis, and to map the current contribution of pharmacy and medicines to their treatment.		<ul style="list-style-type: none"><li>• Blog entries</li><li>• Discussion forum postings</li><li>• Online Survey</li><li>• Case note review</li><li>• Scoping review</li></ul>
3. To scope current knowledge and practice of pharmacists regarding young people and juvenile arthritis.		<ul style="list-style-type: none"><li>• Scoping review (including conversations with key informants)</li></ul>

**Table 1 – Contribution of each workstream to the project aims and objectives**

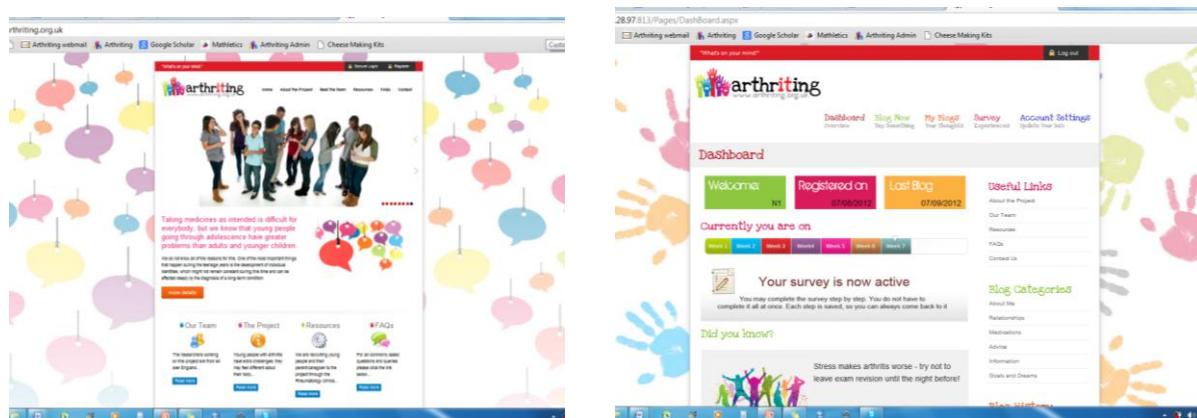
### **3.2 Recruitment of Young People and Parents to the Project**

In August 2012, Rachel Stephenson was confirmed in post as the Clinical Research Assistant for the project. Rachel is a Senior Occupational Therapist at BCH and worked 2 days per week on the Arthriring project through to the end of February 2013. Pre-visit invitation letters were sent to eligible young people (Appendix 1). JMcD and RS were then present within the young people's rheumatology clinics to recruit eligible patients. The information sheet for 11-15 year-olds is Appendix 2: we also developed separate materials for 16-19 year-olds and young people with mild learning disabilities. We invited a parent/carer to take part in the study at the same time as the young person, although parent participation was not obligatory for young people to take part. Their information sheet is Appendix 3.

Upon consent, young people and parents were given an information pack about the website, and a personal login ID that they should use to register with the site. At that point, they would be asked to choose a nickname and password for future logins. They were aware from the information materials that the nickname was the way that they would be identified with their blog, and would appear in reports, and should thus not be linked to their real name. The user then determined whether/when they would register with the site, and then whether/when/how often they would actually write a blog. They could visit the site for 2 months. The young people were given a £50 Amazon online shopping voucher if they contributed at least one blog, as noted in the information sheet. This was sent to them with a thank you letter after their two-month period of engagement had ended.

### **3.3 The 'Arthriring' Blog and Survey website**

During the Easter holiday in April 2012, a group of young people met at BCH to generate ideas to inform the development of the project website. The web designers, Ambinet, had developed a series of questions to focus the discussion at this meeting, and many excellent ideas surfaced. One of the issues under discussion was the branding of the project, and young people were invited to generate ideas for the project name and the logo that would go with it. One of the young people at the meeting suggested the name 'Arthriring', and they also suggested the features of the logo i.e. an emphasis on hands, and bubbles that convey ideas and blogs. The young people had very strong ideas about the look and feel of the project website. The partnership in development of the website worked extremely well. The website had a public face and function, storing resources for interested visitors like the consent materials and the background to the project (Figure 2).



**Figure 2 – Arthriring website public homepage and logged-in dashboard (dummy demo testing user)**

[Reproduced here with the permission of Ambinet Limited – website designers]

The website also had a secure login function for young people and parents who were using its facilities for blogging and the online survey. Once logged in, participants had a project ‘Dashboard’, which showed them where they were in the project and gave them a launching-off point to the blog space and survey (Demo test dashboard screen grab is shown in Figure 2). The website was tested so that it worked on a computer or Smartphone, as many young people access the Internet in this way. Our desire to have tight security on the site, however, made it difficult to access it in environments where firewalls existed, so young people and parents had to use it in a non-work environment.

When using the blogs, participants were able to choose their own font style and colour, and to choose an emoticon to express how they were feeling that day. They were invited to choose a blog category (which were developed by the project team but finalised by the young project advisers) (Appendix 4), and to write their own title for the blog. They could edit or delete blogs at any time during their 2-month engagement with the project. There were no minimum or maximum blog lengths or number of blog entries for participants: we hoped that they would visit and revisit during their 2-month stay.

The online survey became live 4 weeks after registration – the half-way stage - and the dashboard gave a countdown facility to that point and advised the blogger when the survey was active – but only if they were logged in. The themes explored in the survey were: information-seeking about medicines; use of complementary and alternative therapies (CAM); and medicines partnership activities with parents/carers (which activities are done by young people themselves, and which are shared or done by adults). The majority of the questions in the survey had been developed from previous work by Felicity Smith and Nicola Gray and others on medicines management partnership activities among older people and caregivers (Francis *et al.*, 2002). The project team had edited the first draft, and the young advisory group reviewed the survey questions. The final list is included as Appendix 5.

### **3.4 Exploring discussion forum postings on the Arthritis Care website**

This workstream involved the identification and analysis of relevant postings from the Young People’s Discussion forum on the Arthritis Care website [www.arthriticcare.org.uk](http://www.arthriticcare.org.uk). The young people taking part in this forum represented a more diverse group than our BCH cohort in terms of geography, age and circumstances. They identified themselves as young people living with arthritis and might not – at the time of posting - have a formal diagnosis.

The participants in the young people’s discussion forum within the Arthritis Care website were already engaging in communication and creating narratives about themselves and their condition. This would be different from the Birmingham blogs as they are communicating with each other – asking questions and receiving responses, upon which they may reflect. This is a public forum, with non-identifiable participants, and debate among researchers continues as to whether such postings are indeed ‘public’ or ‘private’. Some feel that they are available without limitation to use for research, and others do not. An excellent paper by Gunther Eysenbach - editor of the Journal for Medical Internet Research and a key thinker in this research field - described a framework which we used to shape this section in our ethics application (Eysenbach & Till, 2001). The issues that they

identified for reflection were intrusiveness; perceived privacy; vulnerability; potential harm; informed consent; confidentiality, and intellectual property rights.

We put an announcement of the study on the home page of the Young People's discussion forum <http://www.arthriticcare.org.uk/forums/young-people-s-forum-f10/> prior to beginning observation of postings that explained the study and had been approved by the ethics committee. The announcement went live on 1<sup>st</sup> October 2012 and our observation period began with postings submitted on or after that date. We collected postings from a 4-month period of observation, which ended on 31<sup>st</sup> January 2013.

### **3.5 Case note review**

Case notes (including transitional care planning documentation developed as part of an evidence based transitional care programme (McDonagh 2006b, 2007) of 150 patients with inflammatory arthritis aged 11-18 years attending the adolescent rheumatology service were reviewed using a structured pro-forma (Appendix 6). Anonymised data were collected, including patient and disease demographics, the most recent functional ability score as measured by the Childhood Health Assessment Questionnaire CHAQ (Nugent *et al.*, 2001) or Health Assessment Questionnaire (Fries *et al.*, 1980), the most recent patient global well being score as measured by a visual analogue scale VAS (0-100mm), the most recent pain score as measured by a visual analogue scale VAS (0-100mm), documentation of transition planning to date with particular reference to relevant transition readiness markers, current medication use, allocation of responsibility of medicines management, adherence issues and pharmacy involvement.

### **3.6 Data preparation and analysis**

#### ***Qualitative Data – blog entries and forum postings***

A sub-group of RMG members with the appropriate experience to undertake qualitative analysis of the blog data was convened: the group members were NJG, JP, RR, KLS, FJS and DT.

#### **Data Preparation**

*Blog entries:* For each blog participant, all of their blogs were extracted from the website into one file each, and tagged with their nickname, date of posting for each, and 'smiley status' for each. Basic demographic and relevant clinical data (which we asked permission to extract during the consent process) were added to each blog, but participants were not identified. These data were: age; sex; ethnic group; age at diagnosis, and number of medications.

*Forum postings:* All of the forum postings that were from individuals who identified themselves as being up to 25 years of age were extracted into one composite file, with postings grouped under forum 'threads'. Thus an individual could appear in more than one thread.

## Data Analysis

*Thematic analysis (Lead – NG):* Rigorous procedures were used to enable themes and categories to be generated from the data through processes of induction (i.e. moving from the data towards generalizations, hypotheses, or theory). A ‘middle-order’ approach (Becker and Geer, 1982) was used, which was consistent with ‘directed content analysis’ (Hsieh & Shannon, 2005). Primary attention was directed at identifying broad categories of data, followed by specific line-by-line categorisation. This approach was possible because the data were not entirely lacking in structure. Indeed, the blog activity was designed to generate data in relation to specific research objectives. The study objectives provided a clear source of categories with which to organise participants’ responses, whilst allowing other themes to emerge.

Each participant’s blog file was uploaded into QSR NVivo version 10 (2012) data management software as a separate file. Both inductive and deductive analytical methods were applied. A codebook was constructed from a preliminary reading of all the blogs by NJG, and grouped according to the framework that would address the objectives of the project: identity; arthritis; medicines, and use of health services. This codebook was then considered by the rest of the qualitative analysis group and revised. The index of the final version is included as Appendix 7, annotated with the numbers of young people and parents who contributed comments for each theme. The qualitative group split into pairs (NG with JP, RR with DT and KS with FS). Each pair was assigned nine of the 27 blog transcripts to code with the codebook. Each person coded the blogs independently, and then each pair discussed their coding practice for the same blogs together. The whole qualitative analysis group spoke at intervals during the analysis phase by teleconference.

At the RMG meeting on 6<sup>th</sup> February 2013 at Birmingham Children’s Hospital, the subgroup members agreed to participate in the next stage of analysis. NG assigned a number of themes to each member, about which they prepared a section of the writing for this report. NG received all completed sections, and then ensured consistency of presentation and to cross-link threads between the results sections.

*Corpus linguistics (Lead - KH):* Given that this project aimed to explore health identity through the use of language, a corpus linguistics approach was applied to the corpus of text generated by extracting all the blog entries into one file. Corpus linguistics, which employs computational and statistical tools for the analysis of transcribed conversation, can identify significant patterns of conversational behaviour or written language and extract these for further analysis by means of sophisticated concordance programmes. It is different from, but often complementary to, discourse analysis. It is increasingly being used in health care settings (Adolphs *et al.*, 2004).

The word content from the YP blogs was organised into one Word document to form the complete corpus. The text-only corpus was uploaded into Wordsmith Tools version 5 (Scott, 2008). In order to identify the salient themes across all the blogs (a total of 69,568 words), KH generated a list of keywords relating to this collection of postings. Keywords are words that appear in one corpus with a significantly higher frequency when compared to another corpus. Keywords are words that can be said to characterise a language or reveal the ‘aboutness’ of a text. They are words that occur prominently in a particular corpus and are constitutive of salient themes and topics, and thus worthy of further contextual investigation. In order to generate a list of keywords, KH compared the blog data with a 2 million word collection of help-seeking emails posted to the Teenage Health Freak

website (an online service which allows young people to email their questions about health to a GP) [www.teenagehealthfreak.org](http://www.teenagehealthfreak.org). It represented another collection of web-based adolescent language.

These keywords in themselves did not tell us anything about the actual context in which they originally appeared. Another staple corpus tool, concordancing, allowed us to look at a chosen keyword in all of its original contexts of use. Given that the term ‘arthritis’ was the most key of all the keywords, KH reproduced a set of concordances in which the word features (Figure 3).

7 When your told at an early age that your **child** has **arthritis** its something that you do not want to hear  
8 . However because in Ireland young **children** with **arthritis** can meet up with others and discuss how  
9 to pick sixth forms now need to **consider** my **arthritis** in the planning to make sure they'll  
10 catch up tv. 26/10/12 – Happy – **Coping** with **Arthritis** - When your told at an early age that your  
11 mel! With the pressure of exams and **course** work **arthritis** really doesn't help. I think that even  
12 a section about illnesses, had to **describe** my **arthritis**, sometimes school does not understand,  
13 a whole lot as a result of being **diagnosed** with **arthritis**. I say I have changed, simply because I  
14 – How do others see you? - I was **diagnosed** with **arthritis** at a young age, back then everyone was  
15 any different in her life as she was **diagnosed** with **arthritis** at such an early age, I suppose that has  
16 i am different since i have been **diagnosed** with **arthritis** as i was diagnosed when i was tiny so i  
17 . At the moment, I am feeling quite **down**. My **arthritis** has really been playing up on me within

**Figure 3 – Concordance lines from the analysis of the node word ‘arthritis’ (extract)**

As for the thematic analysis, independent oversight by NG; an interim teleconference between KH, NG and FS; and discussion among the RMG members provided quality assurance for this analysis phase. Relevant aspects of the corpus linguistic analysis have been included in each results chapter.

### **Quantitative data – online survey and case note review**

#### Data preparation and analysis

*Online survey (Lead – JP):* Quantitative survey data were extracted from the website into an Excel spreadsheet by Ambinet, which was then used by JP to enter data into SPSS for Windows version 20 (IBM Corp, 2011). As the online survey dataset was small, descriptive statistics were used to illustrate the patterns of medicines-related activities, problems with medicines, engagement with the NHS, and information known and sought about the arthritis condition and medicines.

*Case note review (Lead – JMcD):* JMcD transferred the data from the paper forms to a Microsoft Excel 2002 spreadsheet. With reference to objective 2, we explored the extent to which relevant data were already routinely documented in the case notes: these included current medication use, allocation of responsibility of medicines management, adherence issues and pharmacy involvement. Any gaps in documentation were explored, as such gaps are of interest to us in order to improve the quality of care provided to adolescents with arthritis and their families particularly with respect to medicine management and development of self-management knowledge and skill set.

### **3.7 Scoping review**

A scoping review was performed to review available data about patterns of care, and to map the contribution of pharmacy and medicines therein. We already know much about the facilitators and barriers to providing pharmacy services (e.g. evaluation of new community pharmacy contract work – Blenkinsopp *et al.*, 2007). We sought to extend this knowledge into services for young people with arthritis and integration with other health services.

Scoping reviews follow similar methodological steps as systematic reviews, including the use of rigorous and transparent methods for data collection, analysis and interpretation (Arksey and O’Malley, 2005). However, while systematic reviews seek answers to specific research questions within a narrow range of quality appraised studies, scoping reviews aim for ‘comprehensive coverage’ and include findings from a range of different study designs. No attempt is made to synthesise or weight data to determine whether findings are generalisable. Instead, scoping studies aim to facilitate visualisation of the research area by revealing key issues and the main sources and types of available evidence. This approach suits areas that are complex, multi-faceted or lack comprehensive review and is typically used to (i) examine the extent, range and nature of research and practice activity; to summarise and disseminate research findings; and to identify gaps in the existing literature.

The search strategy was performed by accessing relevant published articles using specific electronic databases: Cinahl; National Electronic Library of Medicine (NELM); International Pharmaceutical Abstracts; Medline; and Sociological Abstracts. In October 2012 the RMG agreed a list of key terms that formed the basis of our interrogation of both peer-reviewed and ‘grey’ literature (the latter including policy documents, editorial, commentary, practice reports). These terms are listed in Table 2. As we did not anticipate finding a significant amount of literature specifically relating to pharmacists and young people with arthritis, we cast a wide net – primarily looking at the engagement of pharmacists with children and young people, but also looking at the engagement of young people with arthritis with health services and medicines. We chose two comparator conditions – type 1 diabetes mellitus and inflammatory bowel disease – as they share some similar issues regarding medication use and formulations as juvenile arthritis.

Search terms relating to:				
<b>1 Young People</b>	<b>2 Pharmacy/cist &amp; Pharmacy Services</b>	<b>3 Medicines</b>	<b>4 Conditions - Juvenile Arthriti(de)s and diabetes / IBD (comparators)</b>	<b>5 LTCs in general</b>
Young people	Pharmac*	Medicine*	Arthriti*	Long-term condition
Adolesc*	Enhanced service*	Medication	JIA	Chronic illness
Youth	New medicines service	NSAID	Juvenile arthriti*	Transition
Teen*	Medicines Use Review	Methotrexate	Inflammatory Bowel Disease	Adherence
	Pharmacy	Biologic*	IBD	Compliance
	Pharmacy service		Diabetes	

**Table 2 – Search terms used in combination for the scoping review**

These database-derived papers were supplemented by using a snowballing approach (i.e. the references of each article were examined for further papers of interest). Grey literature was sought from internet resources and contact with the project team and subject area specialists. The main inclusion criterion for document selection was that it provided young people's and/or pharmacists' perspectives or experience on providing medicines and services to young people with arthritis. Further inclusion criteria included the documents being published after 1<sup>st</sup> January 2000, being written in English, and providing sufficient information for assessment. The titles and abstracts of identified citations were pre-screened according to the selection criteria. The resultant articles were read in full.

### **3.8 Validation of Results with Young Advisers from BCH and Arthritis Care**

The concept of 'participant checking' is one of the quality markers of qualitative research (Tong *et al.*, 2007). The project team were keen to engage young people during the analysis process in order to confirm or challenge our themes and groupings. During thematic analysis of the blog data, we generated sheets containing the theme name and some examples of the issues that we had grouped with that theme: some examples of these themes and examples are shown in Box 1. We did not circulate original blogs as the young people at BCH had not expressly agreed to this use of their data within their consent for the Arthriring project. This information was presented to four young people who had blogged in the project at a project meeting in Birmingham, to three young advisers to Arthritis Care through a closed discussion forum on their website, and to two groups of other young advisers at a residential weekend. All young advisers were aged 11-16 years.

#### **Self-image**

- Not being defined by arthritis
- Still able to do everything we want
- Have become a better/stronger person because of arthritis

#### **Medication supply issues**

- Getting prescriptions from GPs and pharmacies/chemists
- Parents being frustrated at short length of supply
- Young people not being able to collect their own prescription

*Box 1– Two sets of themes and examples from the analysis summaries circulated to young advisers at BCH and Arthritis Care*

### **3.9 Ethical and R&D Approvals**

**Ethical approval** for the project was granted unconditionally by Coventry & Warwickshire REC on 4<sup>th</sup> July 2012 (Letter included as Appendix 8).

We received **R&D approval** for the project from Birmingham Children's Hospital on 30<sup>th</sup> July 2012 (email included as Appendix 9).

## **4. Results and Discussion**

### **4.1 Recruitment of Young People at BCH**

We aimed to engage a group of young people who reflected the diversity of young people with juvenile arthritis. When recruitment closed on 30<sup>th</sup> November 2012, we had sent letters to 107 young people, approached 70 face-to-face, and consented 36 young people. Table 3 shows key demographic features of the 21 young people who registered and contributed at least one blog.

Age at recruitment:	11-15	16-19			
Number of YP:	18	3			
Gender:	Male	Female			
Number of YP:	4	17			
Age at diagnosis:	YP diagnosed before age 11 (not inc 11yr)	YP diagnosed in adolescence (11+)			
Number of YP:	13	8			
Ethnic group:	Non-white	White			
Number of YP:	4	17			
Type of juvenile arthritis:	JIA	Other			
Number of YP:	19	2			
Number of arthritis medicines being used:	1	2	3	4+	
Number of YP:	9	2	4	6	
Type of arthritis medicines being used*:	Injectable biologics	Injectable methotrexate	Oral methotrexate	Oral NSAIDs	Other
Number of YP:	9 Etanercept Infliximab	3	1	13 Ibuprofen Feldene™/ (Piroxicam)** Naproxen	11 Paracetamol Co-codamol Prednisolone Hydroxychloroquine Mycophenolate Omeprazole / Losec™ Lansoprazole Ranitidine Ondansetron Folic acid Remixilone eye drops Vitamins Hydrocortisone Pyridostigmine Implanon™

**Table 3 – Demographic features of the blog cohort of young people (n=21)**

\*Total is more than total (n) as more than one may be used

\*\*Specific Feldene Melt™ once-daily formulation of piroxicam is used

We looked at the sample of 21 young bloggers in terms of diversity, and whether it was broadly representative of the BCH rheumatology clinic population. It seemed that the sample broadly reflected the wider clinic population in terms of age and type of arthritis diagnosis, but that white young people and young women were over-represented in our blog sample. The RMG reflected that this was consistent with literature showing that young women are more likely to use online health information sources.

#### **4.2 Recruitment of Parents at BCH**

We invited parents/carers to take part in the study at the same time as the young people, although parent participation was not obligatory for young people to take part. When recruitment closed on 30<sup>th</sup> November 2012, we had approached 70 parents/ carers, and consented 14 parents/ carers to the study. All but one were mothers. Six parents (all mothers) went on to register with the site and contributed at least one blog. All six blogging mothers had a son/daughter who blogged as well.

Table 4 summarises the number of possible participants at each stage of the process. It can be seen that face-to-face follow-up in clinic resulted in a 50% recruitment rate. Only one young person replied directly from receiving the invitation letter. Once consented, there was significant drop-off in registering with the site. Once registered, most young people - and all parents - contributed at least one blog. There was more significant attrition for the survey: in retrospect, leaving survey activation until 4 weeks after registration will have impacted upon this if the young person or parent decided to complete their blogging involvement before that time.

Recruitment and Activity Stage	Group	
	Young People	Parents
Number of letters sent	107	107
Number approached in clinic	70	70
Number consented	36	14
Number registered with site	25	6
Number doing at least 1 blog	21	6
Number doing survey	10	4

**Table 4 – Stages in the recruitment and participation of young people and parents as of 31<sup>st</sup> January 2013**

Young participants that declined to participate in the study gave reasons to the researchers when they were approached. These included not having enough time, and not using the Internet very much. Some reasons that were given by parents (for not participating themselves) verbally during the process were that they did not have time, thought it was more about their child than them, felt they had all the information they needed.

Reasonable telephone and email reminders to register (once consented), to blog (once registered), and to do the survey were given by RS. Care was taken not to burden young people and parents.

#### **4.3 Blog and survey activity on the Arthrititing website**

Twenty-one young people and six parents posted blog entries on the site during the project. Among the young people, the average number of blogs posted was 8, and the range 1-36. Among the parents, the average number of blogs posted was 4, and the range 1-12.

Ten young people and four parents completed the survey on the site. Most of the young people and parents who completed the survey (8 and 3, respectively) entered blogs over more than 4 weeks. This was notable as the survey did not go live until the beginning of the fifth week after registration.

A summary of the results of the blog and survey activities has been organised here according to the three main areas of interest: identity, the arthritis condition, and the use of medication and associated health care services. Links across the areas will be identified.

#### ***Identity***

The young people in the group give a strong sense of identity development that was intertwined with their arthritis condition. Although many felt that they were a stronger and better person because of their experience with the condition, there were other strong expressions of frustration. The impact of other people round them on their identity was profound. Relationships with others were often affected by the condition: friends showed their 'true colours', one way or the other. The concept of arthritis as a 'hidden condition' meant that the young person could often choose whether to disclose or not, and they had to weigh up the consequences of that decision.

*It doesn't really affect me because i don't really tell people about my illness because i don't want them to treat me differently. I think that people do treat you differently when they find out because they don't no about the illness.*

Close friends might be brought into a 'circle of trust', with others left uninformed. Siblings and family members brought support and frustration in equal measure. Visible side-effects, like weight gain, could have social consequences such as bullying, as could poor symptom management that limited what they could do with family and friends. Feelings of limitations in life and impacts upon goals and dreams were mixed among the group. Many young people denied any impact on their present and future life, and in some cases they had a greater desire to achieve goals because of the condition. Others expressed regret for goals that they now felt they could never achieve. Some described their private frustration with their symptoms. There was already a link expressed between identity as a young person with arthritis, and the act of taking medication.

*My illness doesn't really affect me apart from when i have to take my medication other than that i can't feel it.*

Corpus linguistic analysis found that expressions such as 'getting on with it' and 'putting up with it' were not uncommon in the blogs examined here. These are metaphorical expressions. The most common metaphor which undergirds human experience is the conceptual metaphor 'life is a journey'. The expression 'getting on with it' reflects this underlying metaphor: living with arthritis is part of a journey which one has to undertake.

### ***The Arthritis Condition***

The main physical symptom of the arthritis condition was pain, with some other major effects being tiredness and stiffness. The 'off and on' nature of the pain and other physical symptoms of arthritis was problematic because it could affect their need for medication and other therapies. Getting new pain, or having changes in pain, could bring on anxiety and a flurry of activity to confirm whether it was linked to arthritis or not. Pain management seemed 'hit and miss', aggravated by side-effects and uncomfortable procedures. We saw evidence of active decision-making by young people about their symptoms and medication.

*When it comes to painkillers such as 'Paracetamol,' or 'Ibuprofen,' I have made decisions. I used to have to take these on a regular basis, however after a while I found that it had an effect on my stomach, and made me feel great discomfort. As a result of this, I decided it was best to stop taking the painkillers on such a regular basis and take them whenever the pain of my arthritis or other symptoms became unbearable.*

These physical symptoms were intertwined with psychological effects of arthritis such as anger and frustration. Again, the 'hidden' nature of the condition was highlighted. The social effects of limited activities were described. Ignoring the condition to go ahead and take part in social activities could result in physical punishment later, but gave psychological lift. A range of coping strategies were employed, but medication or other therapy use for any mental health problems was not described. Parents and friends had their own emotional concerns when seeing loved ones in pain.

Some young people and parents hoped that the condition would one day resolve, but some realised that it might not. The blogs of both young people and parents suggested that use, and acceptance, of medication might mirror their level of acceptance of their condition. Most young people diagnosed as infants and toddlers recognised the condition from their earliest memory: those diagnosed recently, during adolescence, seemed to struggle more with it.

*I'm glad i take medication because without it i wouldn't be well. However sometimes when i am angry i don't feel like taking it because i can't be bothered and think why should i have to take it. WHY ME????*

Survey information added some insights about getting information about the arthritis condition: rheumatology doctors and family members were most often consulted, and some used the Internet. Two young people out of ten mentioned pharmacists for information, but none of the four parents.

The journey with arthritis was complex: the timeline since diagnosis including changing relationships and expectations. There was reference to important changes in life, past and future: parents seemed to dwell on these more than young people.

Corpus linguistic analysis of the blogs further explored the attitudes behind the use of terms such as 'my arthritis'. Possession of the condition was seen arguably more often in this group than with adults diagnosed with a long-term condition (Cassell, 1976). The recurring metaphorical ideas of 'endurance' and 'struggle', in the journey of a young life with arthritis, were common. It confirmed the importance of the act of diagnosis in young people making sense of their own story.

## **Using Medication and Health Services**

Taking medication is a key feature of living with arthritis. Medicines have positive and negative effects, and the secret of successful medicine-taking is balancing these effects. The goal of medicine-taking differs among young people, as does their tolerance to side-effects. Some will put up with serious physical side-effects, and others will not. Active decision-making by young people, and thoughtful explanations of the decisions taken, are described in the blogs. Those taking the arthritis medicine methotrexate wrote about a range of side-effects, including nausea at the thought of taking it: etanercept seemed to have fewer side-effects, and was described positively by those who took it – especially when they had been changed over to it from methotrexate.

*I've just been for my 3 month check after starting my embrel medication (injections). Everything is well and all my joints are good.*

The formulation of a medication also seemed to have its own effect on the use of that medicine. Tablet formulations were linked with nausea, and other unpleasant effects. They were remembered most successfully if associated with another daily task, like a particular meal. Injections led to some strong physical and psychological reactions, and their routine was having an 'injection night'. Young people wrote positively about newer injecting apparatus with 'invisible' needles, and every injection that did not, in itself, cause pain was seen as an everyday triumph against the condition.

Young people had help with many aspects of medication use: mothers often helped with getting supplies, setting routines, and in giving medication. Some young people, however, had already taken on the responsibility for their medicines.

*I feel really pleased that my daughter has taken full responsibility for taking her medication, there have only been a few times when she has forgotten to take it in the last two & a half years! She takes it once a day at tea time & is in the routine of before sitting down for her meal she has her tablet. [parent]*

Family relationships sometimes affected decisions about medicines: for example, one young person did not want to change their medication, but their parent wanted the change. These partnerships were viewed positively, but no doubt brought their own tensions. Young people and parents reported that they felt knowledgeable about the medicines that they used. Their knowledge was not complete, however, when different aspects of information were explored in more depth, and the blogs demonstrated varying ability to spell the names of medicines.

Different health services, and their providers, are important to young people and families in assisting decision-making and supplies of therapies. Rheumatology doctors, nurses and other hospital staff are viewed very positively in terms of their credibility, expertise and empathy: the role of the GP, however, was overshadowed by doubts about their expertise in prescribing for this condition. Pharmacists were not mentioned often, and they were not described as particularly autonomous or empathic. They seemed relegated to a technical role, and unable to do that role without making errors that frustrated parents and young people alike. There was an isolated suggestion in the survey, however, that they could be an information resource.

*My mother helps by getting my prescription and collecting the medication from the chemist as i am not aloud because i am to young.*

Young participants were asked an initial question in the survey as to whether they thought they had enough information about their arthritis medication overall, recognising that they may feel they had differing amounts of information about different medications used. Six young people said “Yes, all of it”, 3 said “Yes, some of it” and 1 said “No”. This was explored further in another series of questions where we asked whether they thought they had enough information about different issues related to medicines use. Whilst the majority of young people felt that they knew the answers to the questions, there were significant numbers of young people wanting more information about most issues, and particularly about future effects on fertility, what to do about missed doses and the way that a dose might change in the future. Seven young people (out of 10) reported that they had had problems with their medication, which included ‘I had a side-effect from my medication’ (n=5), ‘I ran out of my medication’ (n=4) and ‘I kept forgetting to take my medication’ n=4).

Corpus linguistic keyword analysis showed that a number of words related to use of medication and health services occur in the keyword list, such as ‘injection’, ‘tablet’ and ‘prescription’. These keywords occur with statistically greater frequency in our Arthritis blogs than in the comparator Adolescent Health Corpus. These results must be balanced against the context of the blogs, that young people and parents knew that Arthritis was a project about medicines and pharmacy.

#### **4.4 Case note review at BCH**

Of the 150 cases, 128 young people were taking at least one medication. Those used most commonly were NSAIDs, followed by oral or subcutaneous methotrexate, and a similar number receiving etanercept. In none of their case notes was a local pharmacist identified, and half of them were registered with Healthcare at Home. No specific pharmacy issues were identified in the case notes, other than routine funding requests for subcutaneous and/or biologic therapies.

Self-management skills training are integral to transitional care planning. Unfortunately, in almost half of the case notes of young people on regular medication, it was unclear as to who was currently responsible for medication management. As for the Arthritis Blog study, the mother was the parent documented to be most involved in medication management. Self-management related topics were identified by a quarter of young people, with some young people in the late transition stage wanting further support regarding ordering and collecting prescriptions and booking appointments as well as calling the hospital themselves with their queries. Only a minority of young people wanted to know more about what their medications were for and their side effects which could reflect adequate knowledge already, a reluctance of young people to disclose their ignorance, or ambivalence towards the topic.

In view of the challenges anti-rheumatic medications present, it was surprising that adherence difficulties were only documented in one-quarter of the case notes. In those case notes where adherence difficulties were documented, the most common reason was related to side effects, reflecting the results of the Arthritis Blogs.

#### **4.5 Discussion forum postings on the Arthritis Care website**

All postings on the Young People's forum of the Arthritis Care website, from people self-identified up to 25 years of age, were included from October 2012 to January 2013. There were 45 postings noted from 28 young people, aged 16-25 years, in 14 different discussion threads. Only 6 of the 28 young people declared an age of 18 years or less. The mean number of postings was 1.6 (range 1-5). This dataset was quite different from the blogs, as it reflected an older age group, of whom some still did not have a formal diagnosis. There were a number of young adults with rheumatoid arthritis and psoriatic arthritis. Although not included in the dataset, we noted during observation of the forum that there were also contributions from mothers of YP with arthritis, and self-confessed 'not young people' with arthritis.

Previous research has highlighted the differences between adolescents and young adults in reporting their main concerns about living with arthritis (Table 5).

<b>Children /Young People growing up with JIA</b>	<b>18-30 year-olds living with JIA</b>
<ul style="list-style-type: none"><li>• Aversion to being different</li><li>• Striving for normality</li><li>• Stigma and misunderstanding</li><li>• Suspension in uncertainty</li><li>• Managing treatment</li><li>• Desire for knowledge</li></ul>	<ul style="list-style-type: none"><li>• Physical impact – inc pain and fatigue</li><li>• Medication</li><li>• Relationships and family</li><li>• Friends</li><li>• Perception of their future</li></ul>

*Table 5 – Published differences between main themes of concern among CYP and young adults with JIA (Eyckmans et al., 2011)*

Although the data in the blogs and discussion postings could not be compared directly, we might be able to develop anticipatory guidance for clinicians that is useful during transition from adolescence to young adulthood. The young adults exchanged a lot of information about University life, jobs and vocational training. The different social aspects of life, such as being able to wear adult high heeled shoes and to drink significant amounts of alcohol, were also highlighted. Twenty-one young people wrote about medicines, and there were specific discussion threads about methotrexate.

### **5. Discussion, incorporating Insights from the Scoping Review**

The results chapter summaries have provided a foundation for discussion. In this chapter, the implications of the results will be considered more fully in the light of existing literature and practice, before moving on to our ideas about future practice and research in Section 6.

#### **5.1 Overview of results from the Scoping Review**

As we did not anticipate finding a significant amount of literature specifically relating to pharmacists and young people with arthritis, we had to cast a wide net – primarily looking at the engagement of pharmacists with children and young people, and also looking at the engagement of young people with arthritis with health services and medicines. The database searches yielded 60 papers as

potentially useful for the review (and 23 of particular interest), on the strength of their title and abstract. Upon full reading, 15 of these provided relevant insights and are described below.

### ***Engagement between pharmacists and young people with arthritis***

As anticipated, references to pharmacists' very specific practical engagement with young people with arthritis were not found in the scoping review. The only relevant artefacts, of which the RMG was already aware as it involved RMG members as authors, were a continuing professional development (CPD) article in the Pharmaceutical Journal (NG and JMCD in Gray *et al.*, 2010) and a pharmacy-led research project exploring young people and families' preferences for the venue of their infliximab injection (FS in Hazen *et al.*, 2008).

The article by Gray *et al.* (2010) presents the context of JIA, and its difference from adult arthritis; challenges of diagnosis. It describes the goals of treatment, which are to: control inflammation; relieve pain; maintain range of movement and function in the joint; and to promote normal growth and development (physical, psychological and cognitive). It describes the main therapies, and offers roles for pharmacy staff. The article notes that the BSPAR/ARMA guidelines (2010, available at [www.arma.uk.net](http://www.arma.uk.net)) highlight the need for pharmacists and technicians in all sectors, as part of the multidisciplinary team, to support children, young people and families living with JIA. Roles include:

- Referring when JIA is suspected (e.g. repeated purchases of non-prescription painkillers);
- Providing treatment information to support shared decision-making, and
- Supporting adherence to therapy, including compliance aids, such as monitored dosage systems.

The article concludes with an illustrative case study, and a list of resources.

Hazen *et al.* (2008) reported that young people and their families preferred to have their infliximab injections in the hospital setting, where they could access their clinical staff, rather than in isolation at home. They were prepared to trade off the extra burden of travelling to hospital, with some even making an event of the trip. This seemed at odds with policy imperatives to deliver care closer to home, but seems consistent with a focus on putting young people and families at the heart of care if given a choice. There were no references to pharmacy staff in the paper.

### ***Engagement between pharmacists and young people with other long-term conditions***

We employed two comparator conditions in the review – insulin-dependent (Type I) diabetes mellitus (IDDM) and inflammatory bowel disease (IBD). These two conditions were chosen as they necessitate the use of some similar therapeutic approaches and formulations. IBD is also a remitting/relapsing symptomatic condition like JIA, and both conditions – like juvenile arthritis – require consistent use of therapies throughout childhood and adolescence in order to secure the best future health outcomes for young people.

Newbould *et al.* (2008) explored medicines partnerships between young people with IDDM and their parents. There was an example of a 15 year-old young woman with IDDM who undertook all

medicine activities apart from collecting prescriptions from the pharmacy, when her mother sometimes helped. The paper covers important issues, like changing patterns of partnership and responsibilities for medicines over time. It concludes with a reflection on the contrast between the passive role that young people tend to assume with health professionals in the medical consultation and in obtaining supplies of medicines from the pharmacy, with the “extensive roles of medication management” that they undertook at home.

Sims and Haines (2011) published an interesting account of a pharmacist-directed peer support program for six young people with IDDM in the US. The first of 4 peer support sessions was held at a tenpin bowling alley as an icebreaker, the next two in a conference room at their School of Pharmacy, with a final luncheon for young participants and families at DERC. The clinical pharmacists aimed to improve clinical indicators (glycosylated haemoglobin A1C), self-management skills and diabetes-related quality of life. They trained young people as peer educators. The educational intervention uses a 3-by-5 foot table-top display from the US Diabetes Conversation Map program called ‘On the Road to Managing your Diabetes’. The map content includes foundation knowledge of medications as one component in IDDM self-management. A1C values actually increased, but people in the groups enjoyed the opportunity to spend time with peers who shared similar experiences. Session location and being “forced to participate” by parents were negative aspects. Pharmacists were seen as a resource for young people and parents.

### ***Medication issues for young people with arthritis***

Young people aged 14-21 with arthritis, in a focus group with Secor-Turner *et al.* (2011), identified everyday medication management as their primary challenge. They found it difficult to remember to take them, and to find therapies that worked for them. This US study reported cost of medication as a significant challenge: whilst the UK health system does not entail co-payments and other personal costs at least until young people leave secondary education, there was still an advocacy challenge to secure biologic therapies, and young people have to be proven intolerant to methotrexate in order to be considered for it. The authors commented on the finding in a 2007 paper by members of our RMG (KS, JMcD) that 20% of young people were not managing their own medication by age 17 (Shaw *et al.*, 2005). A paper by Guell (2007) reported children of a range of ages (7-16) talking easily about medication, using abbreviated names and discussing dosages. They aimed for discipline and strict timekeeping for taking medication. Uncertainty of the illness was balanced by asserting such control and discipline. The author concluded that “Treatment can be successful only if children, indeed, are taken seriously and can act autonomously in decision-making and therapy processes”.

### ***Medication issues for young people with IDDM and IBD***

The literature for IDDM care yielded a number of relevant articles, but few publications involved pharmacists in any capacity. Haugbolle and colleagues from the Royal Danish School of Pharmacy (2002), however, published an interesting and very relevant paper including the role of pharmacy from the perspective of young people with IDDM. All users found ‘confirmation’ of their activities by doctors important. Most users had never had information from their pharmacies. Users never asked

for information from pharmacy staff. Their doctors met their needs. Most users struggled to imagine a role for the pharmacy, and felt insecure about the knowledge and competence of pharmacy staff in advice-giving for IDDM. A minority of participants, however, held the pharmacy "in high regard" and offered ideas for developing their role:

- Referring patients on to other appropriate practitioners when necessary;
- Handing out leaflets about new treatments, and having a IDDM noticeboard;
- Co-operation with diabetes charities to inform patients about self-care issues such as nutrition and weight loss;
- Demonstration of blood glucose devices with advice about advantages and disadvantages.

Newbould *et al.* (2007) explored young people's experiences of managing IDDM at school. They found that all the young people with IDDM took condition-related items to school, including glucose monitoring equipment, insulin injections, blood testing strips and fast-release glucose food items. Most young people used their equipment without seeking permission, as needed. Insulin users found it difficult to locate a private place to inject. It was also difficult to eat when they needed to, as the school schedule was not flexible on this point. 'Informed friends' were their main support, rather than staff. The authors made a plea for more work by schools to develop protocols that support young people in condition management. Alsaleh *et al.* (2011) did a qualitative literature review about the experiences of young people and parents with insulin pumps, and they particularly noted the perceived advantage of greater flexibility in lifestyles and not having to carry syringes. This was balanced, however, for some young people by the visibility of the pump itself.

Scoping review literature about IBD made the observation that young people with IBD had higher rates of depressive disorders than either healthy peers or those with other long-term conditions like IDDM (Kim & Ferry, 2004). Papers emerging in the review were associated with adherence to medication among young people with IBD (Hommel *et al.*, 2008; Greenley *et al.*, 2010; Reed-Knight *et al.*, 2010). Fishman *et al.* (2011) tested medication knowledge among young people with IBD. Most participants could list their IBD medications, but some patients forgot to include their biologic therapy. Dosage recall was lower than name recall, and this was again worse for biologic therapies. Knowledge of possible adverse effects was relatively low. The authors felt that medication knowledge was an early marker of a move to self-management, and thus knowledge deficiency that persisted into late adolescence would hinder transfer of responsibility. These papers are relevant to pharmacy practice - but not led or informed by it.

Authors of the adherence papers made a case for routine discussion to potential barriers to adherence during routine consultations: the opportunity exists for pharmacy to play a role through the medium of medicines use review (MUR) and the new medicines service (NMS). This opportunity might be limited, however, by the dislocation of the pharmacist from where clinical services are offered.

## 5.2 Case Studies of Relevant Innovative Practice in Northern Ireland and Scotland

During conversations with young advisers to Arthritis Care in Northern Ireland, it was discovered that a Belfast pharmacist had become integrated with the Paediatric Rheumatology team in the city. It seems likely that this is the only centre in the United Kingdom where such integration has

occurred, but the narrative of its development and operation provide a roadmap for other centres to innovate in this field (Box 2):

### **A vision for Pharmacy Involvement in the Paediatric Rheumatology Service**

Roisin Campbell is the Paediatric Rheumatology Pharmacist at Belfast Health and Social Care Trust in Northern Ireland. She has developed her role over the past 3 years as the pharmacist within the paediatric rheumatology unit, working with children as young as 7 months old, and their parents, through to young adults up to 22 years of age. She attends the weekly inpatient day ward, where she is able to establish a good foundation of honest communication with children, young people and parents: "Our only rule is 'Tell the truth'".

Before the patients see the doctor, Roisin takes a medication history and identifies medication-related problems. With older patients, they are encouraged to spend time alone with the pharmacist to have privacy to explain any concerns or problems. Many patients are in email contact with Roisin, as it is recognised that they feel more comfortable with email communication and open communication can be fostered. Roisin also reviews the needs of attendees at the weekly outpatient clinic, and targets patients and families there who might need medicines support.

If a new drug is started, Roisin provides tailored counselling to patients and parents, to provide a good foundation. She has also implemented training for young patients in subcutaneous methotrexate injection. Roisin communicates with community pharmacies, and using standard letters to explain the hospital's use of high-dose NSAIDs in order to avoid confusion and inconvenience for patients when getting repeat supplies. As NSAIDs and anti-emetic drugs used in this field are off-label, there is concern about how community practitioners cope: Roisin can provide information and support.

The hospital does its own dispensing for biologics and DMARDs, and this means that Roisin knows if changes to doses and labelling have occurred and can contact patients and parents to support their knowledge of the changes. Biologics are delivered by a home care service, but with the backup of the pharmacy service. Roisin works closely with the specialist nurse on the team, providing comprehensive "wraparound" care for patients and families by pooling their expertise. Queries can be channelled to the appropriate professional, and this in turn takes pressure off the medical team – with the only paediatric rheumatologist in Northern Ireland.

The driver for the development of this model of care was the introduction of biologic therapy: at this point, there was no nurse specialist on the team. A risk assessment was done. A critical incident, in the form of an administration error, also added to the case for developing this model of care. Roisin started visiting the ward purely to see the patients using biologics, but it quickly became apparent that there were other medicines management issues – like ingrained non-adherence and resistance to the use of drugs like steroids - where the support of a pharmacist would prove invaluable.

Roisin reflects that the first year of implementing the model was frustrating, and her mindset to "sell the value of the pharmacist" - coupled with perseverance in the face of "knock-backs" – got her through. Now three years into the service, she has achieved recognition as an invaluable resource for patients, parents and other professionals in the team. She has recently completed her independent prescribing accreditation, and this will allow further development of her support of established patients.

The only downside to the role is the "pharmacy isolation" that Roisin feels. She has had to develop service documentation from scratch, and has no sounding board within the pharmacy profession for her service developments. She has appreciated her collaboration with Arthritis Care: their seminars and activity weekends have provided opportunities to engage with young patients and parents who might have otherwise been 'lost' in the busy clinics. Her ability to innovate - in a part-time role with split responsibilities - is testament to her commitment to the patients and families she sees.

#### ***Box 2 – Case study from Northern Ireland showing pharmacy involvement in young people's arthritis care***

The likelihood of any specialist services in community pharmacy practice was almost negligible, but there are opportunities for engaging with young people with long-term conditions through medicines use reviews. A contact in Scotland, known to NG as a community pharmacist located in a University campus setting, was contacted. This pharmacist contributed knowledge about the Scottish Chronic Medication Service (CMS) for another case study (Box 3).

### **The Scottish Chronic Medication Service and High Risk Review – Opportunities to Engage?**

The Chronic Medication Service (CMS) in Scotland can be used to register and review/care plan for patients of any age with a chronic condition. Jonathan Burton and colleagues at the Right Medicine Pharmacy Campus Pharmacy at the University of Stirling have approximately 120 patients registered and reviewed there, and estimate that 75% of these are between the ages of 17 and 25. Common chronic conditions for which campus pharmacists have done pharmaceutical care records (PCRs) and, where necessary, associated pharmaceutical care plans for students are depression, asthma, acne, eczema/dermatological conditions, irritable bowel syndrome (IBS) and hypothyroidism. One notable aspect of the CMS (PCR) is a high risk review for patients taking methotrexate. Pharmacists at the university site have done one or two of these, but not necessarily for its use in JIA.

#### ***Box 3 – Case study from Scotland showing potential pharmacy involvement in young people's arthritis care***

These papers had findings consistent with our data, in that young people with JIA and other long-term conditions were interested in medication, could talk about it and report active decision-making, and described medicine-taking that offered them some control over an unpredictable condition.

### **5.3 How did the data address the Arthrititing Project aims and objectives?**

There was a significant amount of qualitative data supporting a strong link between identity, arthritis and medication use (Aim 1 and Objective 1). There was a limited amount of survey data to complement the blogs regarding patterns of care. The case note review noted the gaps in data collection about medicines activities, as well as contextual trends in condition management skills.

The act of taking medication differentiated young people from peers without a long-term condition, and might be the only outward feature of a 'hidden' condition. The taking of medication, and the development of routine, might thus offer a marker of acceptance and developing control of the condition. Many young people expressed a need to communicate with other young people with arthritis about the condition and medication, perhaps reflecting an adaptation to a new normality among those who have the condition, rather than 'healthy' peers.

Current patterns of care for this group (Objective 2) centred on hospital practitioners and home care services. Many young people were being treated by a range of providers. The pharmacist was not seen as an authoritative medicines information source, and not visible as part of their provider team. Parents played a key role in the supply and administration of medicines.

Current knowledge and practice of pharmacists of young people with JIA (Objective 3) was not a topic addressed in papers found in the scoping review, although the key informant interviews offered case studies of innovations in care. With regard to the role of pharmacy in delivering services to this group (Aim 2), the few references to current pharmacist involvement were in the context of a technical role, which in itself was not always well executed. The future may offer more promise.

## **6. Future Implications for Practice, Education and Research**

### **6.1 Innovation and Limitations in the Arthriring Project**

This project offered a novel way of engaging with young people and parents, by creating a secure individual blog-space. Young people took different approaches to the blog opportunity, with some concentrating 'on task' and describing many detailed aspects of medication use. Other young people provided more detail about the context of their lives, treating the blog more like a diary than a project. There are many analytical opportunities for exploring this dataset.

The limitations to the Arthriring study, however, are that the sample was self-selected and lively to reflect those who feel competent with online activities and who have reasonable literacy skills. We saw substantial attrition at each recruitment stage of the study, and the expectation of a 2-month engagement might have been too ambitious. The online survey had a very low response rate, and perhaps should have been activated earlier in the study with more consideration given to its length, structure and priority questions. We are still unaware exactly how many young people and parents tried to register or login, but could not due to technical difficulties. In our quest for security, we may not have achieved the right balance with access. The fact that these blogs were for private to each individual, and not associated with a community where issues could be discussed, might also have been off-putting to those who wished to communicate with others.

Online research with young people is not easy: this project shows that it might not be the best way to engage a large, diverse group of young people. This project has shown, however, the potential to give young people and parents space and empowerment to express their own ideas and concerns.

### **6.2 Implications for Future Practice and Education**

Our findings need to be considered against a background of adolescent brain development: we now understand that this continues well into young adulthood. The brain areas where consideration of risk-benefit and long-term consequences are not fully formed until the mid-twenties, in contrast with the limbic system that dominates adolescence. This will have an impact upon decision-making. Despite this turbulent physiological background, young people of all ages reported active decision-making and involvement in taking responsibility. There is thus a need for a developmentally appropriate approach to involving young people in decision-making during consultations.

Revisiting medicines information at intervals across this period of rapid development is advantageous, and pharmacists may have a complementary role to play to, or within, the arthritis provider team by providing regular, age- and developmentally-appropriate information in the consultation opportunities afforded by Medicines Use Review and the New Medicines Service in England, the Chronic Medication Service in Scotland, and the Medicine Review Service / Discharge Medicines Review Service in Wales.

Consultations with young people must take account of the psychosocial context in which young people take medicines. The influence of families, school life, and relationships with peers all merit

detailed exploration. Understanding a young person's beliefs about their medicines, and their experiences of different formulations, will help to provide relevant and credible advice. Keeping a channel open for young people to ask questions would also be advantageous. Similarly, a closed online forum where young people (particularly those aged 11-15) could share and compare experiences would enable this younger group of 'digital natives' to shape their identity within a community of young people with arthritis.

Young people should have the same access to cognitive pharmacy services as other age groups. Currently, it seems they may not be well served. The potential to create long-term trusting relationships during adolescence, and to give young people an opportunity to disclose concerns and adherence issues, should be an important consideration for the pharmacy profession, if it is to serve the needs of diverse populations of medicines users. It was disappointing to see evidence that young people did not feel that they were allowed to collect their own prescription: the pharmacy was portrayed as a place for adults only to visit. The impetus of the CYPHOF mandate to the chief Pharmaceutical Officer and others to seek medicines optimisation strategies for children and young people may stimulate further innovation for interventions. Pharmacists must, however, consider how they will achieve effective inter-agency working across the primary-secondary care interface.

All of these aspirations must be underpinned by a robust training and education strategy that equips pharmacists with the confidence and competence to engage with young people and families.

### **6.3 Implications for Future Research**

Our data and published literature support a move towards an intervention for young people who are taking medication for JIA and conditions like IDDM and IBD with similar medication profiles. This intervention would be multidisciplinary, would have to navigate the primary-secondary care interface, and be cognisant of the multiple contexts in which medication is prescribed, dispensed and administered.

This intervention would address the gaps in reporting factors of interest in the case note review, such as when young people started to take responsibility for medicine-taking, and whether they can identify a community pharmacy from which to obtain supplies of medication.

The engagement of pharmacists with young people about medication for long-term conditions, and their perceptions of the challenges therein, merits further work to underpin any intervention.

## 7. Dissemination – Making Things Happen

Acting upon the recommendations of this research project will involve a number of advocates and stakeholder groups. In Table 6, we have proposed action points relevant to the recommendations for different advocate / stakeholder groups. ‘Pharmacy leaders’ include professional groups (such as the Royal Pharmaceutical Society and the Neonatal and Paediatric Pharmacists’ Group), education providers (Schools of Pharmacy [undergraduate] and the Centres for Pharmacy Postgraduate Education across the UK), and policymakers (such as the Pharmaceutical Services Negotiating Committee and Pharmacy Voice).

Possible next steps (dependent on resource)	Stakeholder Group					
	Young People & Parents	Rheumatology Teams	Pharmacy Providers	Pharmacy Leaders	Service Commissioners	Arthritis Organisations
To promote existing pharmacy services to young people with JIA and other long-term conditions, such as the New Medicines Service and Medicines Use Review.		●	●	●		●
To develop new medicines optimisation services that are developmentally appropriate for young people with JIA*.	●	●	●	●	●	●
To provide and promote training sessions for pharmacists about the support of young people and families with JIA*.		●		●		●
To participate in training sessions for pharmacists about the support of young people and families with JIA*, including developmental and psychosocial aspects of medicines use.	●	●	●			●
To provide CPD opportunities for pharmacists to explore the impact of our better understanding of brain development in adherence to medicines among young people.				●		
To fund and support research to explore pharmacists' engagement, confidence and competence in supporting young people with JIA*.				●		●
To create an online forum for young people aged 11-15 where they can share experiences and information about living with arthritis.	●					●
To share case studies of good pharmacy practice in this area.			●	●		
To promote ongoing communication between local pharmacists and the rest of the multidisciplinary rheumatology team about prescribing and adherence.		●	●	●	●	●

\*Where possible, this could be extended to the needs of young people living with JIA may be transferable to other young people living with long-term conditions.

**Table 6 – Action points for different stakeholder groups in order to address the recommendations of the Arthriring project**

## **8. Conclusions**

Context is everything: in order to engage with young people and their families, and to have meaningful conversations about medication, the context of that young person's life – both in the way that they see themselves (and their condition) and relate to others – must be explored and acknowledged. This project provided evidence to support significant links between identity, arthritis and medication. The level of use of medication seemed to mirror general acceptance of the condition. Weighing the benefits and harms of medication was important, and young people described their thoughts, decisions and actions with great clarity. Parents and friends provided a strong support to young people, but the 'hidden' nature of the condition for some young people meant that they thought carefully about telling people about their illness. This could lead to challenges at school. If pharmacists wish to develop their role in the care of young people with long-term conditions like juvenile arthritis, they must think carefully about effective working in a multidisciplinary team, and where their skills might complement those already offered to young people and families - particularly in the context of transitional care provision. They must also ensure that their technical role is discharged to the best possible standard.

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### **List of Appendices (Available from the authors upon request)**

<b>Appendix Number and Title</b>
1. Invitation letter to BCH participants
2. Information sheet for 11-15 year-olds
3. Information sheet for parents
4. Blog categories table
5. List of online survey questions – young person's version
6. Case note review data collection form
7. Codebook index annotated with numbers of YP and parents blogging for each theme
8. Ethical approval letter
9. R&D approval email