

# Exploring the Perceived and Potential Medicines Optimisation Role of Pharmacy for Young People with Long-Term Conditions, Through the Case Study of Juvenile Arthritis



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FINAL REPORT

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## Glossary

Term / Abbreviation	Meaning
A1C	HbA1C – indicator of diabetic control
Arthriter	Young person who took part in the 'Arthriting' blog project - a name coined by the young people themselves.
Arthriting	The name of the previous project undertaken by this team to explore the links between identity, arthritis and medication use for young people with Juvenile Arthritis – this was a blog project involving young people and parents. This name was chosen by the young people's advisory group for that project.
BANNAR	Barbara Ansell National Network for Adolescent Rheumatology
CMS	Chronic medication service – A national pharmacy service in Scotland, where a person 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
CYPHOF	Children and Young People's Health Outcomes Forum
DH England	Department of Health (England)
DMARD	Disease-modifying anti-rheumatic drug e.g. methotrexate
Competence	Test to determine whether a young person can consent to their own treatment
GP	General practitioner / primary care doctor
IDDM	Insulin-dependent diabetes mellitus - Type 1 diabetes
Juvenile arthritis	A range of inflammatory conditions diagnosed in young people aged less than 16 years. These include juvenile idiopathic arthritis and lupus.
JIA	Juvenile idiopathic arthritis
LPF	Local Practice Forum – local meeting network within RPS
LTC	Long-term condition
MDT	Multidisciplinary team
Medicines Optimisation	A person-centred approach to safe and effective medicines use, enabling people to obtain the best possible outcomes from their medicines (NICE, 2015)
MEP	Medicines, Ethics and Practice guide - published annually by RPS
MO	Medicines Optimisation
MUR	Medicines use review – an advanced pharmacy service, specified and commissioned nationally (England & Wales) where a pharmacist can consult with an individual in a confidential area about all their medicines. Also in operation in Northern Ireland to targeted groups <a href="http://www.psn.org.uk/pages/mur.html">http://www.psn.org.uk/pages/mur.html</a>
NHS	National Health Service
NICE	National Institute for Health and Care Excellence – officially linked to England only, but provides guidance and services to all the other UK home countries
NIHR	National Institute for Health Research – research funding body
NMS	New medicine service – a new advanced pharmacy service, specified and commissioned nationally (England & Wales) where a pharmacist can consult with an individual 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.psn.org.uk/pages/nms.html">http://www.psn.org.uk/pages/nms.html</a>
NRES	National Research Ethics Service
NSAID	Non-steroidal anti-inflammatory drug e.g. ibuprofen
OT	Occupational therapist
PRUK	Pharmacy Research UK
RCPC	Royal College of Paediatrics and Child Health
REC	Research Ethics Committee
RPS	Royal Pharmaceutical Society – professional body for pharmacists in Great Britain
SOP	Standard operating procedure – used in pharmacy practice to standardise procedures like handing out prescriptions
YP	Young people (defined as people aged 10-24 for this project)

# 1. Introduction and Context

## 1.1 Medicines Optimisation – Getting it Right for Young People

The recent NICE guidance on medicines optimisation (NICE, 2015) defines the term as ‘a person-centred approach to safe and effective medicines use, enabling people to obtain the best possible outcomes from their medicines’. The Royal Pharmaceutical Society (RPS) differentiates medicines optimisation from medicines management by virtue of its emphasis on “outcomes and patients rather than process and systems” (RPS, 2013: p3). The first Guiding Principle of medicines optimisation in the RPS guide is “Aim to understand the patient’s experience”. Existing literature about young people’s use of health services, from general practice and specialty care (e.g. Churchill *et al.*, 2000; Klosterman *et al.*, 2005; Hambly *et al.* 2009), indicates that health professionals find it difficult to communicate with, and relate to, young people. GP consultations have been shown to be shorter with young people than adults: in the past, GPs reported them as an opportunity to ‘catch up’ (Jacobson *et al.*, 1994). We know little about pharmacists’ everyday engagement with young people.

Pharmacists have found a greater focus on young people since the Millennium, with the establishment of the first emergency hormonal contraception NHS patient group direction services. There are now several services that help pharmacists to address adolescent public health priorities. A survey by members of our team (Gray & Prescott, 2013), however, showed that pharmacists are failing to take opportunities to provide medicines optimisation services like medicines use reviews (MURs), despite dispensing significant numbers of prescriptions for this age group (Table 1).

Pharmacy service provided	% of pharmacists reporting specified frequency of provision of service to young people aged 13-19 years			
	Never	Rarely	Sometimes	Often
Dispensing prescriptions (n=143)	1.4	4.9	39.9	53.8
Medicines Use Review (MUR) (n=135)	23.7	60.7	10.4	5.2
Enhanced services (n=130)	3.1	22.3	29.2	45.4

**Table 1 – Pharmacists’ perception of service provision to young people aged 13-19 years (Gray & Prescott, 2013)**

In the aforementioned study, the majority of pharmacists (62.2%) felt ‘reasonably confident’ about engaging with young people, and a significant minority (30.1%) felt ‘very confident’. Pharmacies are accessible settings for young people, and pharmacists should consider widening their scope of engagement to include discussions about medicines adherence and optimisation. There are likely to be structural and individual factors limiting these opportunities: we need to understand these factors to create a vision for better care of this population that minimises barriers to care.

## 1.2 Findings from the Arthriting Study of the Blogs of Young People

In 2012-13, a group of 21 young people with juvenile arthritis aged 11-15 years, and 6 parents, took part in a blogging study at a UK paediatric hospital conducted by our team. A young person from our advisory group coined the name ‘Arthriting’. The blogs showed that different health services, and their providers, were important to young people and families in assisting decision-making and supplies of therapies (Gray *et al.*, 2013). Rheumatology doctors, nurses and other hospital staff were 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 rarely mentioned, and even then they were not described as particularly autonomous or empathic. There was an isolated suggestion in an online survey of participants that they could be an information resource. Data from the blogs suggested that patients and parents viewed their pharmacist as a technical dispensing role. Moreover, they were sometimes unable to do that role without making errors that frustrated parents and young people alike. The errors cited involved simple matters like a difference between tablets and capsules: things that could be noted, and thus avoided, from an engagement like an MUR.

The following (unedited) blog quote reflects a perception from a young person that the pharmacist would not give the prescription directly to them, so their mother had to be involved:

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

It is indeed possible that a pharmacist – presented with a prescription for certain medicines commonly prescribed in Juvenile Idiopathic Arthritis (JIA), like methotrexate or a high-dose NSAID – might prefer to give it to an adult for reasons of risk management. If, however, a young person has taken on responsibility for the medicine in the home, and the pharmacist denies them the right to collect their own medicine, how will that foster the development of their independence? Each case is different: the process of medicines optimisation should support and record that transition as and when it is appropriate for each young person / parent pairing. Guidance from the Royal Pharmaceutical Society about collection of medicines by children and young people provides questions that can help pharmacists to make decisions on a case-by-case basis (RPS MEP July 2014, p64): we wished to explore pharmacists’ confidence in these situations.

In the Arthriting report we cited two case studies; a hospital paediatric rheumatology pharmacist in Northern Ireland and a community pharmacist working on a University campus in Scotland. Both pharmacists worked with young people as their main client group; both had developed their communication skills with young people and parents to a high level, and were focused on providing medicines-related services to this age group. But they are unusual in their own respective fields, and thus isolated in the pharmacy network.

### **1.3 Building a multi-disciplinary team to support young people with long-term conditions**

The Arthriting study showed that pharmacy could co-lead a young-person-centred research project with rheumatology professionals. It challenged the multi-disciplinary rheumatology team to think about medication issues, and the interface between pharmacy and the medical and nursing team.

The NICE (2015) medicines optimisation guidance cited ‘professional collaboration’ as one of its key issues: “Medicines optimisation focuses on actions taken by all health and social care practitioners and requires greater patient engagement and professional collaboration across health and social care settings”. (p8) This proposal enabled us to examine these issues for young people’s health - both between pharmacists across the interface, and beyond into the adolescent rheumatology team.

### **1.4 The Policy Context – Why Pharmacists need to Consider this Now**

The recent NICE guidance on medicines optimisation (2015) emphasised that children, adolescents and adults using medicines were eligible to receive medicines optimisation services. The 2013 scoping

document for this guidance also emphasised that anywhere which received public funding, including independent contractor settings, will be venues for these services.

Our scoping review showed that there were some examples of innovative and excellent practice, but that those professionals are isolated. Our Arthritising young person and parent blogs revealed that the profession more generally is largely invisible to them. Pharmacy needs to develop a cross-sector vision for the care of young people with long-term conditions such as juvenile arthritis in its communities, and actively promote it. Pharmacists may be unclear whether key services to support medicines optimisation for young people can currently be employed. Some may believe that it is not possible to conduct MUR or NMS for an unaccompanied young person under 16, but the regulations do not prevent this if competency is established (Personal Communication, Alastair Buxton – PSNC, November 2013).

Russell Viner, in the Chief Medical Officer's Annual Report for 2012, said that "Caring for adolescents is everyone's business" (Viner, 2013: p10). The Lancet has recently established a global commission on adolescent health and wellbeing, and has published two separate high-visibility series of papers devoted to adolescent health in the last 6 years (2007 & 2012). Voices are joining together to advocate for better outcomes regarding the health of young people: pharmacists must not be absent from this activity. Juvenile arthritis is an excellent case study upon which to base a pharmacy strategy for a range of long-term conditions:

- The drug therapy is changing rapidly (with the advent of biologics) (Kahn, 2012)
- Some medicines used to treat juvenile arthritis (such as non-steroidal anti-inflammatory drugs, NSAIDs) are available over-the-counter while others are only available on prescription
- The progression and symptoms of the condition are unpredictable and positive future health outcomes depend on good adherence
- Medicines used in juvenile arthritis (including methotrexate, NSAIDs, and biologics) are associated with a number of safety risks if taken without good explanations and ongoing support
- The condition is characterised by periods of remission and relapse, requiring young people to take medication regularly for prolonged periods even when they feel well with no functional impairment

We can take insights from the JIA condition to inform the pharmacy contribution to the care of young people with a wide range of long-term conditions. For example, we would expect the principles of young people friendly services to apply to the wider population, and young people's priorities regarding services and the nature of their consultations with pharmacists are likely to be similar across a range of conditions.

## **2. Guiding Question, Aim and Objectives**

**Guiding Question:** What is the perceived and potential medicines optimisation role of pharmacy for young people with long-term conditions, explored through the case study of juvenile arthritis?

**Aim:** To explore the current role, the potential role, and the needs of pharmacists to deliver services to young people with arthritis.

### **Objectives:**

1. To scope current knowledge and practice of pharmacists regarding young people, including those with juvenile arthritis;

2. To explore the perceived and potential roles of pharmacists in the care of young people with juvenile arthritis, from the perspectives of community and hospital pharmacists, rheumatology health professionals and commissioners;
3. To inform the development of models of care, integrating pharmacy within the multidisciplinary team, in order to help young people with juvenile arthritis to optimise their use of medicines.

### 3. Methods

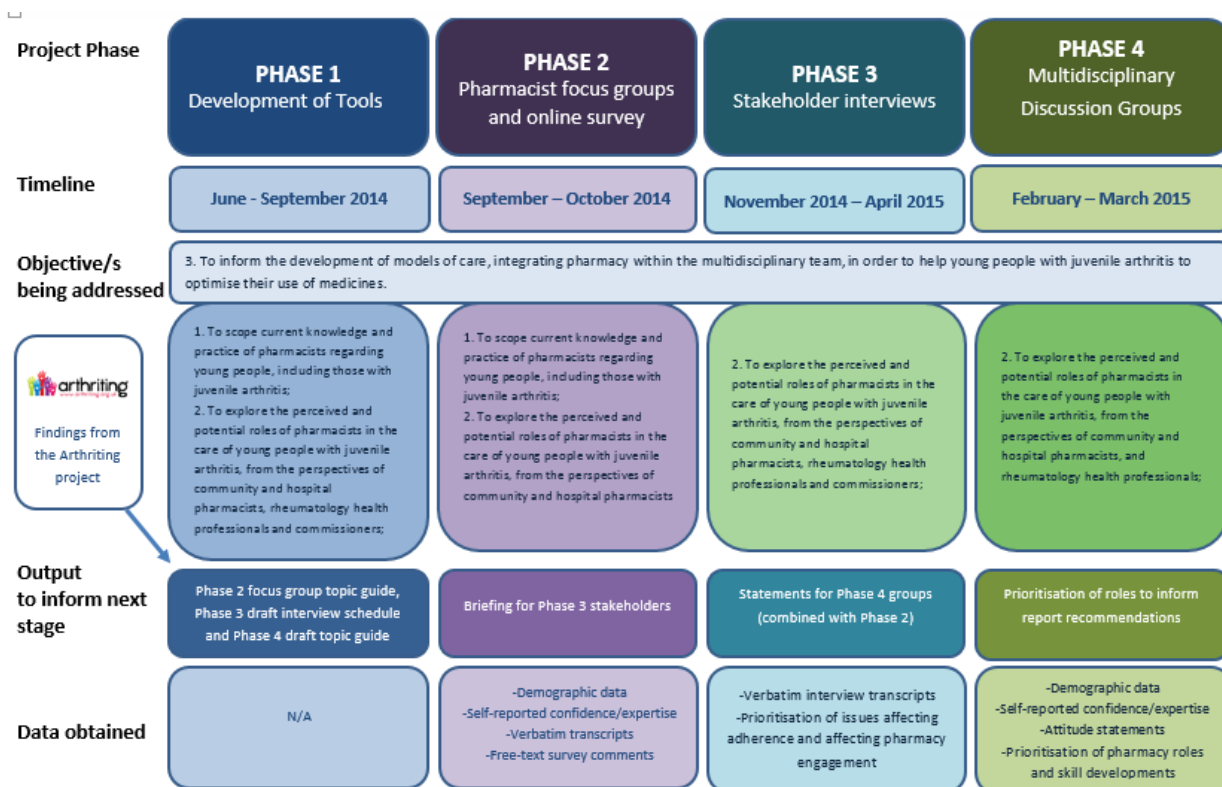
#### 3.1 Project Overview

This multi-phase project was planned to build on the findings from the previous Arthriting project, and each phase to then build on the last (Figure 1 overleaf). Using Arthriting data as stimulus points for focus groups of pharmacists, it was then possible to share ideas from those pharmacists with stakeholders and – finally – multidisciplinary groups of pharmacy and rheumatology staff. There was an imperative to build consensus around key issues, and to test the validity of the emerging results with young people themselves.

#### 3.2 Ethical Approval

NRES classified this current project as research that did not require NHS REC Approval, as it was solely undertaken with healthcare staff (Appendix 1). Institutional ethical approval was given by Aston University Health and Life Sciences Research Ethics Committee (Ref: #674) on 4<sup>th</sup> July 2014 (Appendix 2). A minor amendment was sought in August 2014 to add further recruitment methods and materials for the focus groups, which was approved on 18<sup>th</sup> August 2014 (Appendix 3). A second and final minor amendment was submitted to undertake an online survey, and approved on 29<sup>th</sup> September 2014 (Appendix 4). We also successfully submitted the project to the research approval process for Boots Pharmacy, which is required if any Boots Pharmacy staff are to take part.

**Figure 1 – Overview of the project**





### **3.3 Phase 1 – Development of the Study Instruments**

In this phase, the Project Team and Advisory Group developed the draft focus group topic guide and the stakeholder telephone interview guide. The telephone interview guide, however, was further informed and validated by the emerging results of the focus groups. Project team and advisory group members met for a one-day workshop in Birmingham on 16<sup>th</sup> June 2014 to consolidate their ideas and orientate themselves to the aim and objectives of this new project. Quotes from the Arthriting study were shared at this meeting and members chose a number of quotes that best illustrated different issues for them. These were then circulated to members who could not attend for comment. The young adviser from the Advisory Group, who had also been an Arthritiser, attended on that day.

This work took place across the four countries of the United Kingdom. We were advised by team members beyond England that the term ‘medicines optimisation’ was an England-specific term. We used ‘pharmaceutical care’, on their advice, in materials (information sheets etc.) sent to the other home countries.

### **3.4 Phase 2 – Focus groups with Hospital and Community Pharmacists (September 2014)**

Four focus groups of community and hospital pharmacists (mixed in each group) were convened across Great Britain (1 in Wales, 1 in Scotland, and 2 in England). We aimed for maximum diversity sampling to reflect different pharmacist characteristics in terms of:

- length of time in practice;
- role in practice (community locum, pharmacist manager, pharmacy owner – different hospital grades and seniority);
- practice setting (different types of community pharmacies [such as independent, multiple, health centre, out-of-town retail park] and hospitals [e.g. teaching or other, Foundation Trust or not, specialist rheumatology team on-site or not]);
- perceived confidence and experience in engaging with young people about public health services and medicines use services.

A number of recruitment strategies were employed to convene the focus groups:

- The Local Practice Forums (LPFs) of the Royal Pharmaceutical Society that were close to the focus group locations were asked by the RPS team to circulate a message to their members
- The ‘Research Ready’ community pharmacy network convened by the RPS (Gray *et al.*, 2013c) sent an email alert to members
- Pharmacists in the project team sent an email to their local networks
- A request was posted in the Pharmaceutical Journal (28<sup>th</sup> August 2014)
- An email was sent from local pharmacy postgraduate education facilitators in the group areas
- An email was sent within Boots Pharmacy to pharmacists in the areas for the groups

An initial email asked for expressions of interest (Appendix 5). A flyer was also developed, approved by the ethics committee through the first minor amendment (Appendix 6). Most of these emails were sent out by gatekeepers; indeed, NJG stressed to the gatekeepers not to cc: her into any circulation email so that people did not feel obliged to respond and she would not know anyone’s identifying details until they responded. Some of the original emails had the information sheet (Appendix 7) and consent form (Appendix 8) attached – these sheets were customised with the date and venue of the specific focus group,

and either 'medicines optimisation' (England) or 'pharmaceutical care' (Wales and Scotland). Other emails just had the flyer, as we recognised that it might be better to send the study information only to those who expressed interest. Interested pharmacists were asked to reply direct to NJG, who supplied the information sheet and consent form if they had not already seen them. A NHS permission form was also supplied for pharmacists in the managed sector (Appendix 9). Written informed consent was obtained for each participant.

Focus groups were convened at a place and time suitable for the attendees, with local information from project team contacts. They were scheduled to last for 90 minutes. Discussions were recorded on digital audio. NJG moderated each group. NJG took field notes to supplement the audio recordings and administered the payment of participation fees (£30 per participant) and travel expenses. Pharmacists attending the focus group noted their demographic details and self-assessment of confidence on a structured pro-forma, before the session began, to help the team to monitor diversity (Appendix 10).

The topic guide (Appendix 11) included the following issues:

- Pharmacists' experience of engaging with young people in general
- Pharmacists' experience of engaging with young people about medicines use and adherence
- Pharmacists' experience of engaging with specialist teams in secondary and tertiary care e.g. rheumatology
- Perceived barriers to more engagement with young people about medicines (confidence, training, workload, confidentiality and consent, high risk medicines, isolation from the rest of the team)
- Reflection upon the issues raised by young people in the Arthriting study and scoping review (collecting prescriptions, technical role of the pharmacist)
- Potential for pharmacists to engage with young people and parents through MO services (using our case studies from Belfast and Stirling as stimuli)
- Potential models of care and how these might complement existing service provision, both in terms of meeting young people's needs and operational aspects (liaison, communication referral with other providers)
- Support needed to realise this potential
  - What could they do now?
  - What could they do with a little support?
  - What more beyond that?

A PowerPoint presentation was created, primarily to display the Arthriting quotes for the participants but also to provide some background about the study (Appendix 12). NJG used the topic guide and the presentation to fulfil the objectives of each group. Each recording was transcribed verbatim, checked and identifiers (names of local people or places) were removed.

### ***Phase 2 Online survey (October 2014)***

There was a small but significant number of pharmacists who wished to take part in the project but who could not attend the focus groups due to distance or unavailability at the date/time. Following a second successful minor amendment to the ethics committee, an online survey was created in SurveyMonkey™ software (a pdf copy generated by SurveyMonkey™ software is Appendix 13) and the link circulated to these pharmacists. A completion fee of £20 was offered. The survey was circulated after the focus groups had finished, and some preliminary analysis had taken place.

The survey included the same quotes from the Arthriting data that were used in the focus group. For each comment the survey asked:

- What does this comment make you think about?
- How could pharmacists in community and hospital practice support young people and families with this issue?

As we were formulating the briefing for stakeholders in Phase 3 with the focus group results at this time, we also asked survey pharmacists to comment on what the focus groups had said about:

- Why young people might find it difficult to take medicines
- Challenges for community pharmacists engaging with young people
- Challenges for hospital pharmacists engaging with young people
- Ideas for moving forward together

The SurveyMonkey™ program collated the results of the free-text comments from participating pharmacists, and the statistical demographic details.

### **3.5 Phase 3 – Telephone Interviews with Adolescent Rheumatology Professionals and Other Stakeholders (November 2014 – April 2015)**

We proposed a series of up to 30 telephone interviews with adolescent rheumatology professionals (principally medicine and nursing), pharmacy policy stakeholders, and commissioners. We aimed for a maximum diversity sample of professionals in terms of location across the UK, gender, seniority, and their engagement with primary and secondary care. Ms Emma Pring (EP), the Research Assistant based with Dr David Terry at Birmingham Children’s Hospital / Aston University, worked with NJG in Phase 3.

A sample frame of pharmacy policy stakeholders and commissioners was obtained from steering group members and project team. We asked for the name, role and email address of each identified stakeholder. We also advertised the study by email to rheumatology health professional members of the Barbara Ansell National Network for Adolescent Rheumatology (BANNAR).

An email was sent to each suggested stakeholder to recruit participants (Appendix 14). One final follow-up email was sent 7 days later. Stakeholders who responded were sent an information sheet (Appendix 15) and consent form (Appendix 16) to obtain written informed consent. An NHS permission form was also available for stakeholders in the managed service (Appendix 17). Once consent had been confirmed, a briefing was sent to the stakeholder to give them background information about the interview and to provide structured prompts which would guide the interview (Appendix 18). The briefing combined the Arthriting results, the pharmacist case studies from the scoping review, and the pharmacist focus group themes. The latter came from a preliminary top-level thematic analysis of the focus group transcripts.

EP and NJG each undertook telephone interviews, which were recorded on digital audio with the participant’s consent. The researchers also took field notes as necessary – the briefing pro-forma was useful for this purpose. Telephone interviews were scheduled at a time convenient for the participant, and scheduled to last for 30 minutes. A participation fee was available of £30 per participant for each completed interview. Each recording was transcribed verbatim, checked, and identifiers (names of local people or places) were removed. EP and NJG had regular telephone conversations about the interviews. EP had to finish work on the project in February 2015, and NJG took over at that point to complete Phase 3.

The telephone interview schedule (Appendix 19) included issues dependent on the role of the interviewee (rheumatology team member RT, pharmacist policymaker PP, pharmacy staff PS or commissioner C):

- Their current practice about medicines use and adherence – who in the team is involved, in terms of policy and practice? (RT, PS)
- Reflection upon the issues raised by young people in the Arthriting study and scoping review (collecting prescriptions, technical role of the pharmacist) (RT, PP, PS, C)
- Their experience of engaging with hospital and/or community pharmacists about young people (positive or negative) (RT, PS)
- Whether they could see a role for hospital and/or community pharmacy to help with their work (RT, C)
- Potential models of pharmacy involvement (RT, PP, PS, C)
- Perceived barriers to more engagement with pharmacists (confidence in pharmacists' training and skills, workload, confidentiality and consent, high risk medicines, physical isolation of pharmacy from the rest of the team) (RT, PP, PS, C)
- Ways to work together to overcome barriers (RT, PP, PS, C)

The aim was to continue to recruit participants until data saturation was achieved (i.e. no new themes were emerging).

### **3.6 Phase 4 – Consensus-building discussion groups combining pharmacists and rheumatology stakeholders (February 2015 – March 2015)**

We convened three multidisciplinary discussion groups of hospital and community pharmacists, each group joined by rheumatology stakeholders (to provide context and field queries). There were two groups in England and one group in Scotland. These groups considered the combined ideas from the Phase 2 pharmacist focus groups and the Phase 3 stakeholder interviews to try and build consensus around pharmacy roles that would add value to their clinical practice for their patients.

Three members of the project team/advisory group advised NJG, and acted as gatekeepers to prospective participants in their local area. Discussion with these contacts concluded that the best way to bring the professionals together was to work with the rheumatology staff to find a time that they might use for educational meetings where we could convene a discussion group at a convenient location. Pharmacists were then invited to these meetings. An attendance fee of £30 was offered to each participant. As these meetings took place during working hours, community pharmacists who wished to attend but would have to leave their pharmacy were offered locum backfill fees to make this possible. Travel expenses were also paid. Different recruitment strategies were employed for rheumatology staff and pharmacists.

Pharmacists – As for Phase 2, a number of strategies were used to recruit community and hospital pharmacists to Phase 4:

- The 'Research Ready' community pharmacy network convened by the RPS (Gray *et al.*, 2013c) sent an email alert to members
- Pharmacists in the project team sent an email to their local networks
- An email was sent from local pharmacy postgraduate education facilitators in the group areas
- An email was sent within Boots Pharmacy to pharmacists in the areas for the groups

Some pharmacists from the Phase 4 study areas had registered their interest in the project with NJG from the wide distribution of information for Phase 2, and their contact details had been kept on file.

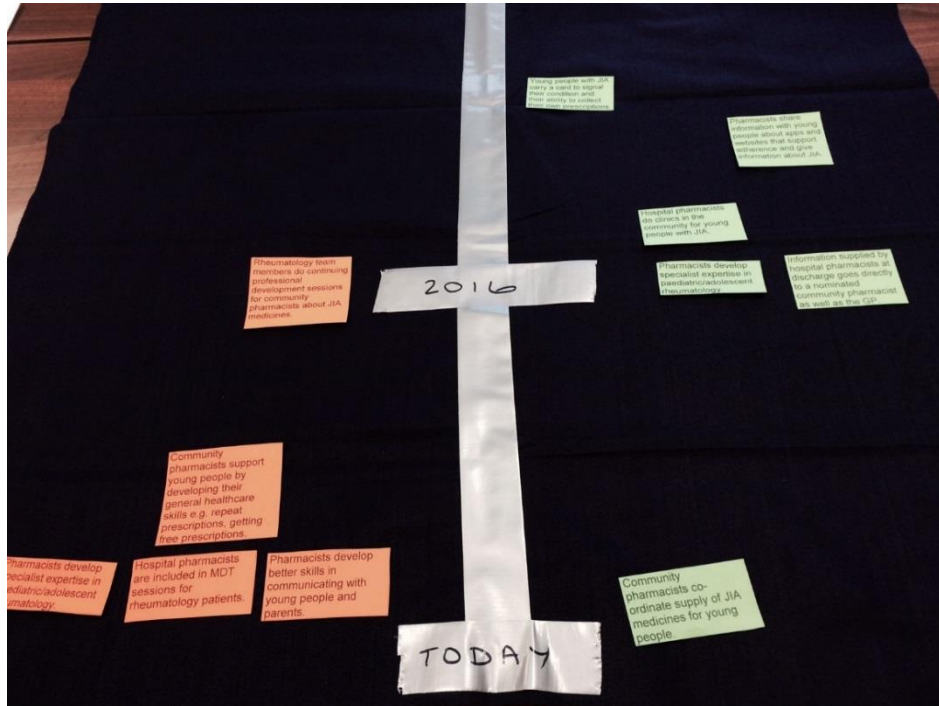
An email was sent to each gatekeeper for circulation to prospective participants (Appendix 20), with a flyer attached that had been adapted from Phase 2 (Appendix 21). As for Phase 2, expressions of interest were directed to NJG, who then sent an information sheet (Appendix 22) and consent form (Appendix 23) to obtain written informed consent. Each information sheet was customised with the venue, date and time of the specific discussion group.

Rheumatology Staff - An email was sent to each team facilitator for circulation to prospective rheumatology team participants in each of the three centres (Appendix 20), including an information sheet (Appendix 22) and consent form (Appendix 23) to obtain written informed consent. The multidisciplinary rheumatology team members invited included doctors, clinical nurse specialists, occupational therapists, physiotherapists and transition coordinators.

A more structured approach was applied to these discussions, adopting some techniques of prioritisation and sorting deployed in nominal groups (Tully & Cantrill, 1997) but still allowing more free-flowing discussion if needed. Small group working was employed. The groups were not recorded. Project team members Janet McDonagh and Karen Shaw had developed a consensus-building tool for a previous piece of work (Shaw *et al.*, 2004); the format of this tool lent itself well to our objective for a consensus-building session so the format was adopted for some paper-based exercises during the group work.

The plan for running the groups was as follows (Appendix 24):

- Each participant individually completed a background and context survey (Appendix 25) which noted some demographic details about them (including discipline, time in practice, self-reported confidence talking about adherence) and had some statements about pharmacy and medicines
- Small group work (mixed of pharmacists and rheumatology team) looking at some of the Arthriting quotes to start a conversation – ice breaker
- Small group work (mixed of pharmacists and rheumatology team) to assess the best practice prioritisation and feasibility of a number of pharmacy roles suggested primarily during the focus groups, but also discussed during stakeholder interviews (Appendix 26)
- Small group work (pharmacists and rheumatology team separately) to choose a ‘top 5’ group of pharmacy activities / roles (statements from exercises 2 and 3, transcribed on to cards, and to place them on a timeline (Figure 2) to indicate by when they should be implemented
- Each participant individually revising any responses they wish from the context survey (Appendix 25)



**Figure 2 – Example of a timeline used in one of the multidisciplinary group discussion sessions**

The resulting data were thus quantitative in nature, and transferred from paper data collection forms to an Excel™ spreadsheet database.

### 3.7 Data Analysis

Data analysis in this project was dynamic as each phase built upon the previous one. Although the last few Phase 3 stakeholder interviews were undertaken in parallel with the Phase 4 multidisciplinary groups, strong broad consensus themes Phase 2 and Phase 3 were already emerging and persisted.

Analysis of Phase 2 focus groups: Focus group digital audio recordings were transcribed verbatim. Qualitative analytical procedures were used. A ‘middle-order’ approach (Becker and Geer, 1982) was used, which is consistent with ‘directed content analysis’ (Hsieh & Shannon, 2005). The study objectives provided a clear source of categories with which to organise participants’ responses, whilst allowing other themes to emerge. We were interested in differences across the home countries, and the perspectives of hospital and community pharmacists therein. Alongside the traditional qualitative analysis undertaken by the academic researchers on the team (JP, RR, KS, FS), we also engaged clinicians on the team (JB, NG, JMcD and DT) to take one focus group transcript each and to list all the current and future pharmacy service developments that were contained therein. A summary briefing of preliminary key themes was generated shortly after the focus groups to inform the stakeholder interviews in Phase 3.

Analysis of Phase 3 stakeholder interviews: Interview digital audio recordings were transcribed verbatim. As for the focus groups, qualitative analytical procedures were used. We were interested to explore differences across home countries, and different stakeholder groups. Detailed analysis of data for each theme were undertaken, to identify situational factors, experience of beliefs that potentially highlight the extent to, or ways in which, findings are context specific or likely to be relevant more widely. We identified any specific perspectives and experiences of different stakeholders interviewed, and then examined

common themes bringing together all perspectives. At the end of Phase 3 we generated a list of statements linked to the emerging analysis of Phases 2 and 3 in order to underpin the prioritisation and ranking exercises planned for Phase 4.

We undertook thematic analysis of the pharmacist focus groups, and the stakeholder interviews, and described any new - or modified current - aspects of care that have emerged as ideas therein. We will undertake further analysis - as part of underpinning feasibility work for a further NIHR grant application - to describe them in terms of their input/resource, activities/process and outputs/impact.

Analysis of Phase 4 multidisciplinary discussion groups: These structured groups followed accepted procedures which involve a process of prioritisation. This drew primarily on quantitative ranking methods. Further qualitative analysis to identify potential barriers and opportunities regarding different aspects of care will form part of the underpinning work for the next grant. This will enable the project team and steering group to select some novel care strategies to pursue in terms of providing educational support for pharmacists and designing an intervention.

### **3.8 Patient and Public Involvement**

Two meetings took place towards the end of the project to engage our young advisers from the previous Arthriting project, and young advisers working with Arthritis Care, to comment upon the themes coming from the pharmacists and other stakeholders in the project. One group took place in England; the other in Northern Ireland.

No assumptions were made about the baseline knowledge of pharmacists held by the young people in the session. We assumed that they would have low awareness and expectations of community and hospital pharmacists as reported by the participants in the previous Arthriting Project. The session plan (Appendix 27) was as follows:

- Explore any previous contact with pharmacists in community or hospital settings;
- Ask young people for comments about:
  - Pharmacists' perceptions of their challenges when taking long-term medication
  - Challenges for community pharmacy in engaging with young people
  - Challenges for hospital pharmacy in engaging with young people
  - Ideas for better engagement with young people

## **4. Results**

As the project was conducted so that each layer of data collection and analysis was informed by the previous phase, preliminary results reported here will focus on the final consensus-building timeline activity within the Phase 4 multidisciplinary discussion groups will illustrate of the associated underpinning qualitative data from the preceding phases.

Further in-depth analysis of each of the Phases will be reported - following peer review - in academic papers from this project.

## 4.1 Project Participants

Our methodological imperative was to include a diverse group of pharmacists and other stakeholders in the project (Table 2). We believe that we achieved this.

Phase 2 Focus Groups	18 Pharmacists (4:4:4:6) 7 hospital: 10 community: 1 public health/community 4 Wales: 4 Scotland: 10 England
Phase 2 Survey	5 Pharmacists 4 community: 1 hospital 1 Wales: 4 England
Phase 3 Stakeholder Interviews	15 Stakeholders 3 pharmacist commissioners 2 pharmacist policymakers 2 pharmacy staff members (1 community and 1 hospital) 4 rheumatologists 1 specialist nurse 3 lay advocates 1 Northern Ireland: 1 Scotland: 13 England
Phase 4 Stakeholder Discussion Groups	26 Participants (11: 8: 7) 13 pharmacists; 13 rheumatology staff 9 community pharmacists 4 hospital pharmacists 6 rheumatologists 5 specialist nurses 1 physiotherapist 8 Scotland: 18 England
PPI work with young people	20 participants (13: 7) 7 Northern Ireland: 13 England

**Table 2 – Participants in each phase of the project**

The pharmacists in Phases 2 and 4 showed diversity in terms of:

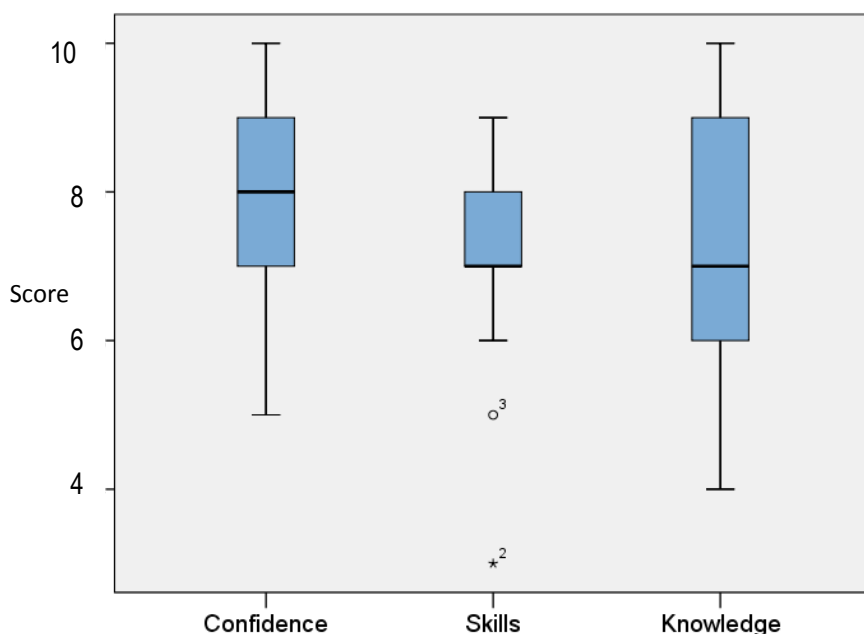
- Gender and age
- the community pharmacist role (e.g. strategic head office work, pharmacist/owner or employee/locum, working for)
- the hospital pharmacist role (e.g. chief pharmacist, specialist rheumatology pharmacist,)
- practice setting
  - different hospital types - teaching and non-teaching, paediatric and adult
  - large multiples, regional multiples and small independent community companies
  - urban, suburban and rural communities
- length of practice experience, including pre-registration pharmacists and senior pharmacists
- self-reported knowledge, confidence and skills in rheumatology and young people's health

## 4.2 Self-reported confidence and expertise

Pharmacists in Phase 2 were asked to gauge their confidence and skills in working with young people (Figure 3 overleaf). There was some diversity in the sample; only one pharmacist rated themselves 10 for any of these attributes, and one pharmacist rated their communication skills as low as 3.



The median value and range for each aspect of personal practice was 8 (5-10) for confidence; 7 (3-9) for skills and 7 (4-10) for knowledge.



**Figure 3 – Box plot showing self-reported confidence, skills and knowledge when engaging with young people in consultations among Phase 2 focus group pharmacists (1 is low; 10 is high) (17 pharmacists – 1 response missing)**

Pharmacists and rheumatology staff in Phase 4 were asked to gauge their own knowledge about rheumatology medicines and MO/adherence; general medicines and MO/adherence; and generic young people’s health issues, such as sexual health (Table 3). Community pharmacists reported a lower median knowledge score regarding rheumatology-specific MO than the other professional groups, while community and hospital pharmacists reported the highest median score for general MO and generic young people’s health issues. Community pharmacists showed the widest range of rating for their knowledge of generic young people’s health issues, from 1-5 among the group.

Knowledge Topic	Professional Group (n=)			
	Median (Range) : 1 is low; 5 is high			
	Clinical Nurse Specialists (5)	Paediatric Rheumatologists (6)	Community Pharmacists (9)	Hospital Pharmacists (4)
Medicines optimisation and medication adherence in rheumatology	3 (3-4)	4 (2-4)	2 (1-3)	3 (all 3)
General medicines optimisation and medication adherence	3 (2-4)	3.5 (1-4)	4 (2-4)	4 (3-5)
Generic young people’s healthcare issues, such as sexual health	3 (3-4)	3.5 (3-4)	4 (1-5)	4 (1-4)

**Table 3 – Self-reported knowledge score (median and range) among discussion group participants about MO and young people’s health (1 is low; 5 is high)**

### 4.3 Issues prioritised during consensus-building

Table 4 on the following page shows the support among rheumatology (Rh) and pharmacy (Ph) members, in each of the three multidisciplinary discussion groups, for different services.

#### ***The development of communication skills with young people and parents among pharmacists***

A strong theme throughout the groups was the need for pharmacists to develop skills in talking to young people and parents. Rheumatology staff emphasised that these extend beyond understanding confidentiality and consent – which pharmacists are becoming familiar with through provision of public health services such as emergency contraception.

*I think there are a specific set of skills, communication skills - which were over and above sort of understanding confidentiality - which are often the barrier to why people don't engage with young people well. [SK33, Rheumatologist, England]*

These skills included: gauging the level of engagement of the young person with conversations about medicines; managing the input of parents without excluding them, and tailoring information in a developmentally-appropriate way. Most pharmacists were not trained to do this, and many learned by experience. A major barrier identified to developing these skills in community was the lack of opportunities to engage with young people directly, as their parents tended to collect their prescriptions.

#### ***Information flow between sectors***

Participants throughout the work, from all backgrounds, showed strong consensus about the need for better information flow between pharmacists in the community and pharmacists in the multidisciplinary hospital team. One area often cited was the sourcing of 'specials' by community pharmacy:

*I think communication from our part is really important - from the hospital going back into community as well. So, with us, anything unusual which comes in tablet or capsule form, which is very difficult to obtain in the community, we send out the patient with a letter which gives them all the information where we've ordered the preparation from, so that you guys in the community don't have an issue obtaining it. [P03, Hospital Pharmacist, England]*

It was apparent, however, that community pharmacists recognised their lack of knowledge about specialist areas like JIA and really wanted a pharmacy contact within the hospital to whom they could turn with other specialist clinical queries. Community pharmacists suggested that educational sessions run by local hospital pharmacists on such topics might then result in an ongoing relationship, with the hospital pharmacist as a known point of contact for future queries.

#### ***Pharmacists developing specialist expertise***

Development of specialist expertise among pharmacists was a major discussion topic across all phases of the project. It was recognised that community pharmacists were unlikely to develop specialist knowledge about a range of areas. Although some might become a pharmacist with a special interest in one area, participants felt that it was more workable to develop the specialist role of the hospital pharmacist and then for community colleagues to be able to call on them for advice. It was recognised, however, that hospital pharmacists were often expected to cover a number of different paediatric specialties and this limited their integration into any multidisciplinary team (MDT).

*if a pharmacist is dealing with patients with such rare conditions - such unusual conditions - how many of these kind of conditions does a pharmacist need to be involved with in order to maintain those skills?...Maybe there need to be designated people, within a group of community pharmacists, who perhaps specialise in these sorts of treatments and conditions. [SK26, Rheumatologist, England]*

Statement of Current / Future Service	Group (Rheumatology Rh & Pharmacy Ph)						
	Rh1	Rh2	Rh3		Ph1	Ph2	Ph3
Pharmacists develop better skills in communicating with young people and parents.	Today						By 2016
Hospital pharmacists do medication review for young people with JIA.		Today	Before 2016				
Hospital pharmacists do clinics in the community for young people with JIA.		By 2016			By 2017		
Hospital pharmacists do continuing professional development sessions for community pharmacists about JIA medicines.						By 2016	
Hospital pharmacists are included in MDT sessions for rheumatology patients.	Today		By 2016				By 2016
Rheumatology team members do continuing professional development sessions for community pharmacists about JIA medicines.	2016						
Community pharmacists co-ordinate supply of JIA medicines for young people.					Today		
Community pharmacists support young people by developing their general healthcare skills e.g. repeat prescriptions, getting free prescriptions.	By 2016	By 2016	By 2016				
Pharmacists work with Healthcare at Home to optimise medicines supply.		H only - Today	Today				
Pharmacists are advocates for young people with JIA and challenge prescribing decisions.		Today					
Pharmacists develop specialist expertise in paediatric/adolescent rheumatology.	Today	H only - today	H only - Before 2016		2016		
Pharmacists develop specialist expertise in young people's medication use for other long-term conditions (asthma, diabetes).							By 2016
Young people with JIA carry a card to signal their condition and their ability to collect their own prescriptions.					By 2018	2016	Today
Pharmacists share information with young people about apps and websites that support adherence and give information about JIA.		By 2017			By 2018	By 2016	
Pharmacists facilitate young people's self-advocacy skills (e.g. decision-making, effective communication, disclosure).						By 2018	
Information supplied by hospital pharmacists at discharge goes directly to a nominated community pharmacist as well as the GP.		Before 2016			2016	Outpts by 2018	Today
Pharmacists support transition services for young people going into adult rheumatology care.		2016				2017	
Pharmacists provide educational sessions for the multidisciplinary rheumatology team about medicines optimisation.		H only before 2016					

**Table 4 – Results of the timeline prioritisation activity in Phase 4 discussion groups**

### ***Integration of hospital pharmacists within the rheumatology MDT***

Despite the service pressures noted in the previous section, the specialisation discussions reached a broad consensus point that the hospital pharmacist should be better integrated within the rheumatology MDT. Some rheumatology stakeholders described innovative examples of working that were hitherto unknown to the project team, including a move to pharmacist prescribing in a paediatric rheumatology clinic:

*I've moved in my experience as a doctor...from the frustration of the junior doctor with the green writing on the medicines card...To viewing pharmacists as being a fantastic resource...The other thing I should just say is that actually we "use" our pharmacists as well to do repeat prescribing for patients, so our pharmacist does repeat prescribing for stable patients on methotrexate for example. [SK33 Rheumatologist, England]*

The project team stressed to rheumatology colleagues that we were not trying to 'sell' pharmacy when we discussed possible value from pharmacy input. Their reflections following this declaration, however, still resulted in their feeling that pharmacy input would be appreciated as a complementary role to clinical nurse specialists.

### ***Pharmacists co-ordinating supplies of medicines***

Despite the relatively low prevalence of juvenile arthritis in the average community pharmacy practice, there were specific reports of help that community pharmacists were giving in co-ordinating supplies of medicines:

*I have come across one young person with arthritis, and did speak to that patient, but I would say he was an adolescent and he was having certain problems with medication...I can say there were issues of specific formulations and allergies...It took 7 months actually to resolve, in the end, but we did find a particular make that the patient found suitable and acceptable and did, as far as I'm aware, carry on taking his medicine, to the best of my knowledge. [P09 Community Pharmacist, Wales]*

There was also a significant amount of discussion about the advantages and disadvantages of home care delivery services, nurse-led initiatives which were used widely for subcutaneous injection products. Many young people might be accessing medicines for their JIA through several channels; hospital / home care for the biologics or methotrexate injections, and their GP / community pharmacist for non-steroidal analgesia. Good communication was needed.

### ***Empowerment of Young People***

One of the most interesting findings in the final discussion groups was that all the rheumatology teams prioritised the role of community pharmacy in developing 'general healthcare system' skills, whilst none of the pharmacy groups did so. These skills might include helping young people to understand and navigate the repeat prescription service in general practice, and helping them to minimise prescription charges as they move out of full-time education to work. It is unclear whether the pharmacists either assumed it was part of their core activity, or whether it did not seem aspirational enough as a role:

*I think - if nothing else – it (consultation)'s just an opportunity to spend a small portion of protected time with a patient, and almost just impress on them what way you can help. So it's part medication review and it's part education about the service - that's sort of the way that I approach it. [P17 Community Pharmacist, Scotland]*

There was also significant discussion across all phases of the project about the challenge in facilitating self-management among young people with regard to collection of prescriptions. Pharmacists in the focus groups – in both hospital and community settings - spoke at length about the challenge of knowing when a young person was ready to take on that responsibility, and their own responsibility/liability:

*It is in the SOPs that it is over 16s; it is in the procedure, so I think that is where the fear factor comes from. So once you break procedure, then even indemnity insurance and things have implications, so that like could be an issue. [P11 Community Pharmacist, England]*

There was consensus that pharmacists had to revisit their prescription collection policies (enacted through Standard Operating Procedures, SOPs) to enable relationships to develop where an empowered young person could collect their medication themselves.

#### **4.4 Reflections of Young People in the Advisory Groups**

As anticipated by the project team, young people with juvenile arthritis in England did not have much engagement with pharmacists. If they needed information about their medicines, they reported that they would primarily ask a parent – who they recognised might then speak to a pharmacist or doctor on their behalf. Frustration about dispensing mistakes was reported. Young people agreed with themes that pharmacists did not know how to talk to young people, and tend to direct their conversation at parents; that community pharmacists did not have specialist knowledge about JIA, and that hospital pharmacists are too busy to talk.

In Northern Ireland, however - where there is a dedicated paediatric rheumatology pharmacist – there were more reports of useful advice and engagement with hospital pharmacy. Awareness of, and confidence in, community pharmacy remained low.

### **5. Discussion**

In February 2013, the DH England system-wide response to the report of the Children and Young People's Health Outcomes Forum (CYPHOF) created a board, jointly chaired by the Chief Pharmaceutical Officer and the President of the RCPCH, to develop a programme to optimise the use of medicines in children. This included an objective to improve workforce capacity and capability (DH England, 2013: p36). This project has helped to elicit how to increase the capacity, capability and confidence of pharmacy staff.

It is an excellent time for pharmacists to reflect on the current and potential roles that they have in the care of young people with long-term conditions: this project has offered the opportunity for the profession to do that, and then to identify the support that they will need to make changes to their practice with confidence.

#### **5.1 Strengths and Limitations of the Project**

This project was successful in engaging a broad range of participants across the UK. There was enthusiasm and interest in the topic from the pharmacists, rheumatology stakeholders and young advisers. It has provided a wealth of information and ideas to inform pharmacy practice development. We acknowledge the limitations of the project, however. Inevitably the participants in the group discussions and interviews will be among those most positive about these issues. It was very difficult to engage stakeholders beyond England in our interviews, which was frustrating as we tried hard to dispel an 'England-only' perspective. We believe, however, that there was sufficient diversity of participation in each of the home countries to be able to say something insightful about the impact – and, indeed, opportunities – of devolution.

## 5.2 Future Work

This project team started by exploring young people's perspectives of medicines and pharmacy services. This project has added the perspective of the pharmacist and rheumatology team and commissioners. Now completed, these two studies underpin the robust development and testing of one or more enhanced models of care - for a wider range of long-term conditions - that will go forward for NIHR intervention funding in 2015/16. We believe that there are certain components of pharmacy practice, such as communication skills and risk management, where great improvements are possible to enhance medicines optimisation for this important – yet often overlooked - patient group.

At the end of the project, we believe we have fully addressed the study aim and objectives. We had also hoped to address each of the following issues for current and future proposed roles.

1. Describe each current and potential role in terms of the necessary resources, processes and desired outcomes.
2. Map the support needs of each proposed role.
3. Explore the acceptability and feasibility of the proposed roles with other professionals in the clinical rheumatology team.
4. Explore the acceptability of the proposed roles with the young advisers on the previous Arthritising advisory group, and young advisers associated with Arthritis Care.
5. Reflect upon the wider applicability of arthritis-focused services for young people with other long-term conditions.

We believe that we have addressed issues 3-5 in some detail, and that we have started to explore issues 1 and 2. The latter will be further developed as we move towards the intervention study proposal.

## 6. Conclusion and Recommendations

As a multidisciplinary project team, we seek better clinical outcomes for young people taking medicines for a long-term condition. We support the principles of the NICE Guidance for Medicines Optimisation, and specifically that young people should be supported to make their own decisions about their medicines. Juvenile arthritis is a very good exemplar of the challenges and opportunities associated with pharmacy and its potential to add value to existing practice for young people with a range of long-term conditions. Many of the existing challenges are rooted in communication and interfaces. Other challenges come from the organisational context and culture of health care delivery.

We believe that pharmacists and other members of the pharmacy team can help young people to achieve optimal use of medicines as an integrated part of the multidisciplinary team. Young people may not be aware of the possible contribution of the pharmacist to their care. They should be better-informed about the pharmacist's skills and training. The point of dispensing, especially of a new medicine on prescription, provides an excellent opportunity to develop a relationship between a pharmacist and a young person. Parents should be encouraged to visit with their son/daughter to maximise that opportunity. The concerns and involvement of young people with their medicines will change over time as they navigate the physical and psychosocial developmental changes of adolescence. The medicines optimisation process has to recognise this, and build in more points for revisiting information and facilitating independent medicine-taking.

## 7. Recommendations for Stakeholders

The project team recognises that a number of stakeholders have to play complementary roles for young people to be able to derive value from the expertise of the pharmacist. Our recommendations are grouped for four stakeholder groups: pharmacists; the wider healthcare team; health policymakers, and young people and families.

<b>For Pharmacists</b>
<ul style="list-style-type: none"><li>• Build communication skills and confidence with young people and their families</li><li>• Understand the specific demands for a young person in the context of their health and health care and ongoing everyday life</li><li>• Recognise that information from specialist teams may be needed as part of the clinical check</li><li>• Build confidence in taking consent from young people in order to properly offer services like Medicines Use Review, and revise policies to allow collection of prescription medicines by ‘expert’ young people</li><li>• Adopt the principles of ‘young people friendly services’ like the ‘You’re Welcome’ framework (DH England, 2011) and Walk the Talk (NHS Health Scotland: <a href="http://www.walk-the-talk.org.uk">www.walk-the-talk.org.uk</a> )</li><li>• Involve the whole pharmacy team in this process</li></ul>
<b>For the Wider Healthcare Team</b>
<ul style="list-style-type: none"><li>• Meaningfully integrate the pharmacist within your culture and processes</li><li>• Routinely document a nominated community pharmacy where copies of information can be channelled, with the consent of the young person</li><li>• Ensure that information flows to the nominated community pharmacist about specialist medicines</li><li>• Ensure that community pharmacists have a point of contact in the hospital MDT for medication queries</li><li>• Raise awareness with young people and families in transition programmes that the pharmacist is available to them, and can help them with general health system skills and their medicine queries</li></ul>
<b>For Pharmacy / Healthcare Policymakers</b>
<ul style="list-style-type: none"><li>• Improve education for pharmacists (at undergraduate and post-qualification stages) about young people’s health, and how adolescent development impacts upon medicine-taking and decision-making</li><li>• Include young people’s health in foundation and advanced practice frameworks</li><li>• Give further guidance about consent for medicine-related activities to facilitate more engagement</li></ul>
<b>For Young People and Families, and their Advocates</b>
<ul style="list-style-type: none"><li>• Think about pharmacy as a medicines information resource</li><li>• Build a relationship with a local community pharmacist who can help you with your medicines</li><li>• Agree a process for independent prescription ordering and collection with your pharmacy team</li></ul>

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

<b>Appendix Number and Title</b>
1. NRES decision about study approvals
2. Aston University ethical approval 4 <sup>th</sup> July 2014
3. Aston University minor amendment 1 ethical approval 18 <sup>th</sup> August 2014
4. Aston University minor amendment 2 ethical approval 29 <sup>th</sup> September 2014
5. Phase 2 Focus group expression of interest email text
6. Phase 2 Focus group flyer
7. Phase 2 Focus group information sheet
8. Phase 2 Focus group consent form
9. Phase 2 Focus group NHS permission form
10. Phase 2 Focus group pharmacist characteristics / confidence structured pro-forma
11. Phase 2 Focus group topic guide
12. Phase 2 Focus group PowerPoint presentation
13. Pdf copy of Phase 2 Online Survey
14. Phase 3 Stakeholder Interview invitation email
15. Phase 3 Stakeholder Interview information sheet
16. Phase 3 Stakeholder Interview consent form
17. Phase 3 Stakeholder Interview NHS permission form
18. Phase 3 Stakeholder Interview briefing
19. Phase 3 Stakeholder Interview schedule
20. Phase 4 Discussion group expression of interest email text
21. Phase 4 Discussion group flyer
22. Phase 4 Discussion group information sheet
23. Phase 4 Discussion group consent form
24. Phase 4 Discussion group plan
25. Phase 4 Discussion group background and context survey
26. Phase 4 Discussion group best practice prioritisation pro-forma
27. YP advisory group session plan