

# Pharmacy for young people with longterm conditions

through the case study of  
Juvenile Arthritis



# Pharmacy for young people with longterm conditions through the case study of Juvenile Arthritis

## Contents

### Key findings

**What is Juvenile Arthritis and why did we use it as an example?**

**Young people's views**

**Taking this work forward**

### The Authors:

Nicola J Gray PhD FFRPS MRPharmS  
Green Line Consulting Limited, Manchester

Janet E McDonagh MD FRCP  
Centre for Musculoskeletal Research, University of Manchester

Catrin Barker BSc (Hons) MSc MRPharmS  
Alder Hey Children's Hospital NHS Foundation Trust

Jonathan Burton BPharm (Hons) MFRPSII MRPharmS  
Right Medicine Pharmacy, University of Stirling

Roisin Campbell BSc (Hons) MPSNI  
Pharmacy Department, Musgrave Park Hospital

Julie Prescott PhD CPsychol  
School of Education and Psychology, University of Bolton

Karen L Shaw PhD  
School of Health and Population Sciences,  
University of Birmingham

Felicity J Smith PhD FFRPS FRPharmS  
UCL School of Pharmacy, London

David Terry PhD MRPharmS  
Aston Pharmacy School & Birmingham Children's  
Hospital NHS Foundation Trust

The authors would like to thank the professional participants and young advisers who took part in the study. We would like to thank Emma Pring (Birmingham Children's Hospital) for her assistance with the conduct and analysis of the stakeholder interviews. We appreciated the help of Catherine Duggan and the Membership Team (RPS) and Rachel Tattersall (BANNAR) during the recruitment of pharmacists and rheumatology staff. We would like to acknowledge Marie McGee (Birmingham



*"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... our pharmacists do repeat prescribing for stable patients on methotrexate for example."*

Rheumatologist

*"I think – if nothing else – the 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."*

Community Pharmacist

Children's Hospital), Alison Tennant and Catherine Wright (Arthritis Care Belfast) for their support with the young people's advisory groups. We would also like to thank the members of the PRUK Project Advisory Group – Alastair Buxton, Dick Churchill, Janet Gardner-Medwin, Manir Hussain, Lamis Mullgrave and Catherine Wright. Finally, we thank Rachel Roberts from PRUK for her ongoing support and wise counsel.

There is little research about the role of pharmacists in the care of young people with longterm conditions. However medicines are the most common intervention for a longterm condition. This document sets out the findings of a project which brought together young people, pharmacists and rheumatology staff to explore how to optimise the role of pharmacy for young people with longterm conditions using the case study of juvenile arthritis. It demonstrates the potential for pharmacists to support young people's management of their condition and move towards better self-management. It also highlights the different roles that hospital and community pharmacists can play and the importance of information sharing and integrated working with other professionals.

## Key findings

### **Developing communication skills with young people**

A strong theme throughout the work was the need for pharmacists to develop skills in talking to young people and their parents. These skills included assessing the level of engagement of a young person in conversations about medicines and managing the input of parents without excluding them.

---

### **Better information flow between community and hospital pharmacists**

Participants from all backgrounds agreed there is a need for better information sharing between pharmacists in the community and pharmacists in the multidisciplinary hospital team.

---

### **Development of specialist expertise among pharmacists**

Participants felt that developing the specialist role of the hospital pharmacist would be most feasible so that community colleagues could then call on them for advice.

---

### **Improving integrated working**

Despite service pressures, participants agreed that the hospital pharmacist should be better integrated within the rheumatology multidisciplinary team. Some stakeholders described innovative examples of working, including a move to pharmacist prescribing in a paediatric rheumatology clinic.

---

### **Coordinating young people's supplies of medicines**

Many young people access medicines for their condition from several places – hospital, home care, GP, community pharmacies etc. Good communication is needed to ensure that medicine supplies are coordinated. There were specific reports of the help that community pharmacists were giving to coordinate medicines supplies and clear potential to extend this role.

---

### **Developing young people's skills to access healthcare**

All the rheumatology teams prioritised the role of community pharmacy in developing young people's general healthcare 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, where applicable, as they move from full time education to work.

---

### **Supporting self-management**

There was significant discussion about the challenge of facilitating self-management among young people with regard to collection of prescriptions. Pharmacists spoke about the challenge of knowing when a young person was ready to take on that responsibility. There was consensus that pharmacists need to revisit their prescription collection policies to enable relationships to develop with young people.

---

## What is Juvenile Arthritis and why did we use it as an example?

Juvenile idiopathic arthritis (JIA) is a long term condition which causes pain and inflammation on one or more joints. It affects at least 12,000 young people who need multidisciplinary specialist care and complex medication, often continuing into adulthood.

Using a specific condition enabled us to engage with young people, clinicians and pharmacists in greater depth about the specific medicine and other issues they were facing. This work can inform how pharmacy supports young people with a wide range of longterm conditions.

Many of the challenges and opportunities we identified were about broad issues such as communication, organisational context and the culture of health care delivery rather than issues specific to the condition. It is also likely that there will be similarities in young people's priorities and the nature of their consultations with pharmacists across a range of conditions. This is something we would like to explore further in the future.

### **How: The work ran from May 2014 – July 2015 and involved:**

---

Four **focus groups** with 18 pharmacists

---

Development of a **briefing** from focus groups to inform interviews

---

15 stakeholders from pharmacy and rheumatology completed **semi structured telephone interviews**.

---

Three final **discussion groups** with 13 rheumatology professionals and 13 pharmacists to prioritise issues raised at focus groups and from interviews

---

20 **young people** involved in two advisory group meetings providing their **experience of engagement with pharmacists** and commenting on themes.

---

### **Why undertake this work?**

This work followed the 'Arthriting' study which looked at the experience of young people using medication to treat Juvenile Arthritis. In the 'Arthriting' study references to the pharmacist were rare. When young people and parents did refer to pharmacy they expressed frustration at the barriers to services e.g. getting prescription refills. There were some examples of innovative and excellent practice in the 'Arthriting' study but these professionals were isolated. For some young people and parents the profession was largely invisible. This project aimed to explore how pharmacy might develop a vision for the care of young people with longterm conditions and actively promote it.

*"I think that community pharmacists' confidence could be improved as in my community pharmacy the people who work there aren't very talkative. I would prefer it if they would engage in conversation as it would make the experience better for everyone."*

Young Person

*Of those who reported having a longterm condition, 59% of young people reported taking some kind of medication.*

2014 HBSC Study for England

## Young people's views

Once we had asked pharmacists and rheumatology staff for their views, two advisory groups of young people responded to the ideas they had proposed. This is what they said.

### **Young people don't think about going to the pharmacist themselves**

Young people with juvenile arthritis did not have much engagement with pharmacists. If they needed information about their medicines, they said they would generally ask a parent – who might then speak to a pharmacist or doctor on their behalf. Many said they would not have thought of going straight to a pharmacist themselves.

### **Pharmacists can find communication with young people difficult**

Young people agreed with themes that pharmacists did not know how to talk to young people, and tend to direct their conversation at parents.

### **Young people want access to specialist knowledge about their medicines**

Young people spoke about their frustration with dispensing mistakes. They said that sometimes community pharmacists did not have specialist

*“Found out about the chemist at the adult hospital when I went on my orientation visit. I wouldn't have known they were there. Didn't know they were in adult hospitals.”*

Young Person

knowledge about their condition, and that hospital pharmacists are too busy to talk. Some young people suggested that information be sent to community pharmacists about the young people in their care.

### **Young people want to build a relationship with their pharmacist**

If young people had a relationship with pharmacists they would feel more likely to use them all the time and ask questions when medication changed or when they weren't taking meds at all – all the young people felt it would be good to be able to be honest.

### **Young people want to understand when and how they can see a professional independently**

They felt it was important to have a clear policy for when you start to see a health professional by yourself but that there should be time for your parents to come in too.



# Taking this work forward

## Key questions for stakeholders

An improved offer from pharmacy for young people with longterm conditions is central to improving their care. For this to happen a range of professionals need to work together.

Below are some key questions for pharmacists; the wider healthcare team; health policymakers, and young people and families to help improve services in line with the findings from this work.

## Pharmacists

- How will you improve your communication skills and confidence to work with young people and their families?
- How can you better understand the day to day challenges for young people fitting health care into their lives?
- How will you ensure you can access information from specialist teams as part of the clinical check?
- How can you increase your confidence in taking consent from young people so that you can offer services like Medicines Use Review, and allow collection of prescription medicines?
- How can you adopt the principles of 'young people friendly services' as set out in standards like the 'You're Welcome' framework (DH England, 2011)?
- How can you support the involvement of the whole pharmacy team in this process?

## The wider healthcare team

- How do you ensure that pharmacists are integrated in your culture and processes?
- How can you link to a nominated community pharmacy where copies of information can be channelled, with the consent of the young person?

- How will you ensure that information flows to the nominated community pharmacist about specialist medicines?
- How will you ensure that community pharmacists have a point of contact in the multidisciplinary hospital team for medication queries?
- How will you raise awareness with young people and families in transition programmes that the pharmacist can help them with medicine and general health queries?

## Policy makers in both pharmacy and healthcare

- How can you work to improve education for pharmacists (undergraduate and post-qualification) about young people's health, and how adolescent development impacts upon medicine taking and decision making?
- How could you support the inclusion of young people's health in foundation and advanced practice frameworks?
- How can you ensure that further guidance about consent for medicine related activities is in place to facilitate more engagement?

## Young people, their families and advocates

- Can you start to think about pharmacy as a place to go for information about medicines?
- How could you start to build a relationship with a local pharmacist who can help you with your medicines?
- Can you agree a process for independent prescription ordering and collection with your pharmacy team?

For a copy of the full report, please visit

[www.pharmacyresearchuk.org/policy-and-practice/download-a-report](http://www.pharmacyresearchuk.org/policy-and-practice/download-a-report)

For more information, please contact Nicola Gray on 07951-017776 or [nicola@greenlineconsulting.co.uk](mailto:nicola@greenlineconsulting.co.uk)

Published June 2016

