Pharmacy Academic Practice Unit
ASTON UNIVERSITY
IN PARTNERSHIP WITH BIRMINGHAM CHILDREN'S HOSPITAL

# The Role of the Pharmacist in the Support of Young People with Chronic Illness, through the Exemplar of Juvenile Arthritis

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# A Multidisciplinary Project Team

- Janet McDonagh (Rheumatology – Manchester)
- Catrin Barker (Pharmacy – Liverpool)
- Jonathan Burton (Pharmacy – Stirling)
- Roisin Campbell (Pharmacy – Belfast)
- Nicola Gray (Pharmacy – Manchester)
- Julie Prescott (Psychology – Bolton)
- Karen Shaw (Psychology – Birmingham)
- Felicity Smith (Pharmacy – London)
- David Terry (Pharmacy – Aston)
- Rachel Roberts (Pharmacy Research UK)

# Background – The Role of the Pharmacist

- ‘Clinical pharmacy’ movement of the 1980s in hospitals
- Pharmacy ‘came out of the dispensary’
- Pharmaceutical care’ (Hepler & Strand, 1990)
  - … Medicines Management
  - …. Medicines Optimisation
- Skill mix revolution with support staff
- Community pharmacy (sometimes called retail pharmacy) took longer to change, but change has come
- Millennium – first EHC service without prescription
- Since 2005 in the UK, the scope for community pharmacy services beyond dispensing prescriptions has expanded dramatically – contract-led enhanced services
- Independent prescribers - 2006

# Snapshot of UK YP pharmacy services, 2014

| Pharmacy Service (n=46 unless otherwise stated) | For YP aged 13-19 |
|---|---|
| Selling condoms | 38 (83%) |
| Selling pregnancy test kits (n=45) | 35 (78%) |
| Dispensing EHC on prescription | 35 (76%) |
| Supplying EHC via Patient Group Direction | 24 (52%) |
| Medicines Use Review (MUR) (n=45) | 23 (51%) |
| Selling Nicotine Replacement Therapy | 23 (50%) |
| New Medicines Service (NMS) (n=45) | 22 (49%) |
| Chlamydia infection screening | 21 (46%) |
| Quit smoking consultation service | 20 (43%) |
| 'C-Card' Service (condom service) | 17 (37%) |
| Selling non-prescription EHC products | 16 (35%) |
| Methadone dispensing | 13 (28%) |
| Flu Vaccination (n=45) | 11 (24%) |
| Chlamydia infection treatment | 10 (22%) |
| Selling weight management products | 8 (17%) |
| Alcohol advice service | 8 (17%) |
| Needle exchange service | 6 (13%) |
| Weight management consultation service | 3 (7%) |
| HPV Vaccination (n=45) | 2 (4%) |

[Alsaleh et al, 2016]

# Why Juvenile Arthritis?

- Drug therapy is diverse and changing rapidly
- Some medicines (e.g. NSAIDs) are available over-the-counter while others are only available on prescription
- Progression and symptoms are unpredictable, and positive future health outcomes depend on good adherence
- Medicines used (e.g. methotrexate, NSAIDs) are associated with a number of safety risks without ongoing support
- Young people need to take medication regularly for prolonged periods, even during remission when they feel well

the past few times i have picked up my precrisptions from the chemist they have given me capsules instead of tablets. this annoys me as the percrisptions are for tablets and could easily be avoided. [YP]

As soon as i recovered after i got diagnosed i took full responsibility over my medication as i knew i would be taking them all my life and i would get into a routine. I kind of enjoy being in charge of my medication because sometimes i feel like a pharmacist??? (Weird, i know!!!!!!!)

Gray NJ, McDonagh JE, Harvey K, Prescott J, Shaw KL, Smith FJ, Stephenson R, Terry D, Fleck K, Roberts R. *Arthriting: 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. Pharmacy Research UK, London; 2013

# Aim of the Project

- **Guiding Question:** What is the perceived and potential pharmaceutical care 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, using the exemplar of juvenile arthritis

    - Scope – current role
    - Explore – potential
    - Identify - development

# Methods


| Study Phase | Phase 1 - Pharmacist Focus Groups |
|---|---|
| Fieldwork Period | September - October 2014 |
| Fieldwork Objective | To elicit the experiences and opinions of a diverse group of practising hospital and community pharmacists about their engagement with young people who take medication for chronic illness |
| Fieldwork Features | • Focus groups<br>• Community and Hospital pharmacists<br>• Direct quotes from the Arthriting project used as stimulus points<br>• Participants from England, Scotland and Wales<br>• Anticipated 90-minute duration |
| Data Collected | • Demographic participant data<br>• Verbatim transcripts |
| Consensus-building Output | Briefing for Phase 2 stakeholder interviews |

# Methods


| Study Phase | Phase 1 - Pharmacist Focus Groups | Phase 2 - Stakeholder Interviews |
|---|---|---|
| Fieldwork Period | September - October 2014 | November 2014 - April 2015 |
| Fieldwork Objective | To elicit the experiences and opinions of a diverse group of practising hospital and community pharmacists about their engagement with young people who take medication for chronic illness | To share the ideas of practising pharmacists about their current and future roles in the support of young people who take medication for chronic illness with stakeholders in order to devise a list of roles for prioritization |
| Fieldwork Features | • Focus groups<br>• Community and Hospital pharmacists<br>• Direct quotes from the Arthriting project used as stimulus points<br>• Participants from England, Scotland and Wales<br>• Anticipated 90-minute duration | • Telephone interviews<br>• Pharmacy policymakers, service commissioners, rheumatology professionals and lay advocates<br>• Direct quotes from the Arthriting project used as stimulus points<br>• Participants from England, Scotland and Northern Ireland<br>• Anticipated 20-minute duration |
| Data Collected | • Demographic participant data<br>• Verbatim transcripts | • Verbatim transcripts<br>• Prioritisation of issues affecting adherence and affecting pharmacy engagement |
| Consensus-building Output | Briefing for Phase 2 stakeholder interviews | Statements for Phase 3 group participants to prioritize (consolidated with Phase 1 data) |

# Methods


| Study Phase | Phase 1 - Pharmacist Focus Groups | Phase 2 - Stakeholder Interviews | Phase 3 - Multidisciplinary Discussion Groups |
|---|---|---|---|
| Fieldwork Period | September – October 2014 | November 2014 – April 2015 | February – March 2015 |
| Fieldwork Objective | To elicit the experiences and opinions of a diverse group of practising hospital and community pharmacists about their engagement with young people who take medication for chronic illness | To share the ideas of practising pharmacists about their current and future roles in the support of young people who take medication for chronic illness with stakeholders in order to devise a list of roles for prioritization | To submit a list of possible best practice roles for community and hospital pharmacists to the critical reflection and prioritization of multidisciplinary groups of pharmacists and rheumatology professionals |
| Fieldwork Features | • Focus groups<br>• Community and Hospital pharmacists<br>• Direct quotes from the Arthriting project used as stimulus points<br>• Participants from England, Scotland and Wales<br>• Anticipated 90-minute duration | • Telephone interviews<br>• Pharmacy policymakers, service commissioners, rheumatology professionals and lay advocates<br>• Direct quotes from the Arthriting project used as stimulus points<br>• Participants from England, Scotland and Northern Ireland<br>• Anticipated 20-minute duration | • Discussion groups<br>• Community pharmacists, hospital pharmacists and rheumatology professionals<br>• Direct quotes from the Arthriting project used as stimulus points<br>• Participants from England and Scotland<br>• Anticipated 90-minute duration |
| Data Collected | • Demographic participant data<br>• Verbatim transcripts | • Verbatim transcripts<br>• Prioritisation of issues affecting adherence and affecting pharmacy engagement | • Demographic participant data<br>• Attitude statements<br>• Prioritisation of pharmacy roles and skill developments |
| Consensus-building Output | Briefing for Phase 2 stakeholder interviews | Statements for Phase 3 group participants to prioritize (consolidated with Phase 1 data) | Consensual prioritization of roles to inform study recommendations |

# Results - Participants

| | |
|---|---|
| **Phase 1 Focus Groups (4 groups)** | 18 Pharmacists (4:4:4:6) 8 women: 10 men<br>7 hospital: 10 community: 1 public health |
| **Phase 2 Stakeholder Telephone Interviews (15 interviews)** | 15 Stakeholders 11 women: 4 men<br>3 pharmacist commissioners; 2 pharmacist policymakers<br>2 pharmacy staff members (1 community and 1 hospital)<br>4 rheumatologists; 1 specialist rheumatology nurse; 3 lay advocates |
| **Phase 3 Consensus Groups (3 groups)** | 26 Participants (11: 8: 7) 18 women: 8 men<br>13 Pharmacists; 13 Rheumatology staff<br>9 community pharmacists; 4 hospital pharmacists<br>6 rheumatologists; 5 specialist rheumatology nurses; 1 physiotherapist |

# Cross-cutting Themes

- Enhance communication skills with young people and families
- Better information flow across hospital ⇔ community sectors
- Missed opportunities if parents collect prescriptions alone
  - System challenges e.g. unaccompanied minors collecting prescriptions
- Development of specialist expertise among pharmacists
- Better integration of pharmacists within the wider specialist team
- Empowering young people with general healthcare skills

# Developing Better Communication Skills

*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]*

Enhance communication skills with young people and families

# Communication between Pharmacists

*I think communication from our part is really important - from the hospital going back into community as well. So…anything unusual…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]*

Better information flow across hospital ⇔ community sectors

# System-related Challenges – Collecting Prescriptions

*It is in the* [Standard Operating Procedures] *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]*

Missed opportunities if parents collect prescriptions alone

# Integration of Hospital Pharmacists within the Rheumatology MDT

*Once we had a named pharmacist who had responsibility for the paediatric rheumatology patients it became a lot easier…there's now one person who I can call and say "There's a problem" or who our nurses can call and say "There's an issue". Or they can call us. That makes life a lot easier because I get to deal with the same person all the time.*

*[SK26 Rheumatologist, England]*

Development of specialist expertise among pharmacists

# Empowerment of Young People

*I think well parents just do it a lot, do the prescription filling…for a lot of young people, and continue to - even you know into their late teens and twenties… And so I suppose if it was a bit more, if it was a bit easier…Then it's something that young people would perhaps would be better at taking on, and that parents would feel better about letting go as well.*

*[SK58, Clinical Nurse Specialist, England]*

# Building a Relationship

*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]*

# Multidisciplinary Scoring of Roles

| Current / Future Role | Best Practice Score |
|---|---|
| Community pharmacists help young people to develop their general healthcare skills e.g. prescription refills, getting free prescriptions. | 4.78 |
| Information supplied by hospital pharmacists at discharge goes directly to a nominated community pharmacist as well as the primary care doctor. | 4.71** |
| Community pharmacists build long-term relationships with young people and families. | 4.71** |
| Pharmacists share information with young people about apps and websites that support adherence and give information about JIA. | 4.57** |
| Hospital pharmacists are included in multidisciplinary team sessions for rheumatology patients. | 4.44 |
| Pharmacists develop specialist expertise in paediatric/adolescent rheumatology. | 4.44 |
| Pharmacists develop specialist expertise in young people's medication use for other long-term conditions (asthma, diabetes). | 4.44 |
| Pharmacists provide educational sessions for the multidisciplinary rheumatology team about medication. | 4.43** |
| Community pharmacists support young people and families in medication-taking. | 4.33 |
| Pharmacists facilitate young people's self-advocacy skills (e.g. decision-making, effective communication, disclosure). | 4.29** |
| Hospital pharmacists build long-term relationships with young people and families. | 4.14** |
| Hospital pharmacists do continuing professional development sessions for community pharmacists about JIA medicines. | 4.11 |
| Pharmacists support transition services for young people going into adult rheumatology care. | 4.00** |

Best practice (BP) mean scores reported to 2 decimal places – data averaged from 9 multidisciplinary groups (* = 8 groups; ** = 7 groups) - some groups did not reach the end of the list. Scored from 1 (low) to 5 (high).

# Strengths and Limitations

**Strengths**

- Multi-stage consensus building exercise
- Use of data from previous YP-centred project and ability to see themes emerge across phases
- Input from a diverse range of pharmacy and rheumatology stakeholders across the UK

**Limitations**

- Small numbers of participants in each phase
- Likely bias to those who had some interest in the project, through young people or through arthritis

# Discussion

- Consensus within and beyond the pharmacy profession that pharmacists could add value to the care of young people with chronic illnesses like juvenile arthritis
- The roles of hospital and community pharmacists were seen as different but complementary
  - Better information flow and networking across sectors required for the benefit of the young person
- Community pharmacists may underestimate the value of their core role of helping people to manage prescription refills and copayments

## For Pharmacists

- Build communication skills and confidence with young people and their families
- Understand the specific demands for a young person in the context of their health and health care and ongoing everyday life
- Recognise that information from specialist teams may be needed as part of the clinical check
- 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
- Adopt the principles of ‘young people friendly services’ like the ‘You’re Welcome’ framework (DH England, 2011) and Walk the Talk (NHS Health Scotland: www.walk-the-talk.org.uk )
- Involve the whole pharmacy team in this process

## For the Wider Healthcare Team

- Meaningfully integrate the pharmacist within your culture and processes
- Routinely document a nominated community pharmacy where copies of information can be channelled, with the consent of the young person
- Ensure that information flows to the nominated community pharmacist about specialist medicines
- Ensure that community pharmacists have a point of contact in the hospital MDT for medication queries
- 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

## For Pharmacy / Healthcare Policymakers

- 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
- Include young people's health in foundation and advanced practice frameworks
- Give further guidance about consent for medicine-related activities to facilitate more engagement

## For Young People and Families, and their Advocates

- Think about pharmacy as a medicines information resource
- Build a relationship with a local community pharmacist who can help you with your medicines
- Agree a process for independent prescription ordering and collection with your pharmacy team