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The Role of Pharmacists in Caring for Young People with Chronic Illness

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Declarations of Interests

Dr Gray, Professor Smith, Mr Burton and Dr Terry are all registered pharmacists in Great Britain.

Dr Roberts – employed by the sponsor, Pharmacy Research UK - is an author on this paper; she assisted the team in data analysis and interpretation in her capacity as a qualitative researcher, and helped to write the paper. Dr Gray wrote the first draft of the paper in her capacity as the principal investigator, supported by the study grant funding from Pharmacy Research UK.

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Abstract

Purpose

To explore the perceived and potential roles of pharmacists in the care of young people aged 10-24 years with chronic illness, through the exemplar of juvenile arthritis, from the perspectives of UK community and hospital pharmacists, health service commissioners, rheumatology health professionals and lay advocates.

Methods

A sequential mixed methods study design comprising: focus groups with community and hospital pharmacists; telephone interviews with pharmacy and rheumatology stakeholders and commissioners, and multidisciplinary group discussions to prioritize roles generated by the first two qualitative phases.

Results

The high priority roles for pharmacists, identified by pharmacists and rheumatology staff, were: developing generic healthcare skills among young people; transferring information effectively across care interfaces; building trusting relationships with young people; helping young people to find credible online health information, and the need to develop specialist expertise. Participants identified associated challenges for pharmacists in supporting young people with chronic illness. These challenges included parents collecting prescription refills alone, thus reducing opportunities to engage, and pharmacist isolation from the wider healthcare team.

Conclusions

This study has led to the identification of specific enhancements to pharmacy services for young people which have received the endorsement of a wide range of stakeholders. These suggestions

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could inform the next steps in developing the contribution of community and hospital pharmacy to support young people with chronic illness in the optimal use of their medication.

Keywords

Chronic disease; pharmacy; adolescent; young adult; transition to adult care; medication therapy management; juvenile arthritis; rheumatology; community pharmacy services; hospital pharmacy service.

Implications and Contribution

The role of community/retail and hospital pharmacists in the care of young people with chronic illness could be further developed to complement the role of other healthcare providers. Research in this area has been scarce. Priority roles, and associated challenges, are identified by stakeholders within and beyond pharmacy.

The role of the pharmacist as a member of the adolescent health team, particularly in the care of young people with chronic illness, has not been widely researched. The two main employment groups are community pharmacists (sometimes called ‘retail pharmacists’) and hospital pharmacists. In this paper, there will be reference to ‘pharmacists’ as a professional group across the two settings; in some places it will be necessary to differentiate between the two environments. There are good reasons to consider the engagement of pharmacists in adolescent medication use. In developed countries, transcending the way that health systems and medication supply are financed, the vast majority of prescriptions for medication for young people will have been reviewed, checked and/or dispensed by a pharmacist. Woods *et al.*¹ undertook secondary analysis of adolescent data from a large medical care dataset in Colorado and Utah. Medication-related events were the second most frequent source of safety problems, and the highest incidence of patient safety issues occurred in the pharmacy setting.

The role of the community pharmacist in reproductive and public health has attracted more research. Emergency contraception studies noted that young women have found the profession to compare well to other reproductive health providers - accessibility and non-judgmental attitude were positively cited², and 94% of adolescents said they would recommend the service to a friend³. Studies have also, however, highlighted the potential for community pharmacists to break confidentiality – when, for example, pharmacists might contact a parent before dispensing contraception to minors⁴. In relation to vaccination, there has been recognition of the potential of the community pharmacy setting as a ‘unique resource’ to increase adolescent immunization rates⁵ – but the need to increase pharmacists’ experience with young people was noted.

Pharmacists report a lack of training and confidence in engaging with young people⁴.

Community pharmacy staff are unsure whether their adult-focused services should be offered to young people, especially those aged under 16 years⁶. UK pharmacists may, however, be gaining confidence from providing public health services to young people. In a small study, almost two-thirds (62.2%) of the 143 community pharmacists surveyed felt 'reasonably confident' about engaging with young people, and almost another third (30.1%) felt 'very confident'⁷. Increasing numbers of community pharmacists internationally now provide commissioned services to discuss medication with patients. The most commonly used overarching term to describe these cognitive, patient-centered services that go beyond the supply function is 'pharmaceutical care'⁸, but other country-specific terms include 'medication therapy management' (US) and 'medicines optimization' (England). A study of UK community pharmacists reported significant self-reported engagement with young people⁷. Whilst approximately half of these pharmacists reported dispensing prescriptions 'often' and providing public health services 'often' for young people aged 13-19 years (53.8% and 45.4% respectively), only 5.2% reported chronic medication review activities 'often' with this age group.

The aim of this study was to explore the perceived and potential roles of pharmacists in the care of young people with chronic illness, through the exemplar of juvenile arthritis, from the perspectives of UK community and hospital pharmacists, rheumatology health professionals and health service commissioners (payers).

The WHO age range for young people of 10-24 years was adopted in this research in order to reflect the range of important biological, cognitive, psychosocial and vocational transitions that can impact on the use of medication⁹.

Methods

An overview of the project methods is provided in Table 1. A blog-based project called ‘Arthriting’ was undertaken by the authors in 2012/13 to elicit the views of young people attending a rheumatology service aged 11-19 years, and their parents/caregivers, about the links between identity, the arthritis condition and medication¹⁰⁻¹². This subsequent project would challenge pharmacists with the ‘Arthriting’ data to think how they could better engage with, and support, young people with chronic illness and their families.

The sequential mixed methods study design¹³ allowed stakeholders to identify, and then prioritize, current and future roles that would underpin the pharmacist’s contribution to the care of young people with chronic illness. The first two phases – pharmacist focus groups and stakeholder telephone interviews - were qualitative, reflecting the dearth of literature in this area and the need to capture and record ideas from pharmacists and stakeholders about current and future roles that would support young people and families. The final phase – multidisciplinary discussion groups - was quantitative, encouraging pharmacists and rheumatology professionals to discriminate between ideas and to prioritize roles to be developed or enhanced. Each phase had a particular objective within the aim of the overall study.

Institutional ethical approval for the study was given by Aston University Health and Life Sciences Research Ethics Committee.

Recruitment of Participants

A number of recruitment strategies were employed to recruit pharmacists to Phases 1 and 3, through gatekeepers in the Royal Pharmaceutical Society (RPS) - the national professional body for pharmacy, the national continuing education organizations in England and Wales, and the NHS regions surrounding the group venue in Scotland. The RPS does not represent all pharmacists – during the recruitment period 54% of all licensed pharmacists in Great Britain were members. It is, however, the national professional forum and that was deemed appropriate for recruiting pharmacists for this work. The continuing education organization and NHS mailing lists, however, do include most registered community and hospital pharmacists. We aimed for maximum diversity sampling to reflect different pharmacist characteristics in terms of length of time in practice, role in practice and practice setting. Administrators sent out an initial email asking for expressions of interest. Interested pharmacists were asked to reply direct to the project manager (NJG). An article was placed in the ‘Pharmaceutical Journal’, which was the weekly professional publication sent to all members of the Royal Pharmaceutical Society. The inclusion criterion was to be a practicing community or hospital pharmacist who could travel to the group venue on the advertised date – there were no exclusion criteria.

A list of stakeholders for telephone interviews in Phase 2 was generated by advisory group members and the project team. Inclusion criteria were participation at a senior level in a pharmacy or rheumatology organization. An email was sent to each suggested stakeholder,

including an outline of the interview study and an invitation to reply if they would like more information; one follow-up email was sent 7 days later. The study was also advertised by email to all members of the Barbara Ansell National Network for Adolescent Rheumatology (BANNAR) <http://bannar.org.uk/>. BANNAR includes the majority of adolescent/young adult focused rheumatologists in the UK, including both pediatric and adult multidisciplinary rheumatology professionals.

To recruit rheumatology staff in Phase 3 an email was sent to a facilitator in each of three hospital pediatric rheumatology centers for whom we had a contact among the project team and/or advisory group members. There are 15 similar training centers across the UK; the population served by these centers reflected their local communities well. The multidisciplinary rheumatology team members invited included doctors, clinical nurse specialists, occupational therapists, physiotherapists and transition coordinators. Again we aimed for maximum diversity within the targeted team to include different roles and length of experience.

All phases involved obtaining informed written consent from participants. All participants were offered a modest honorarium for their contribution. Travel expenses were offered in Phases 1 and 3. Locum backfill payments were offered to community pharmacists for Phase 3 as the groups were conducted during pharmacy opening hours.

Research Settings

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Phase 1 pharmacist focus groups were convened in the evening, scheduled for 90 minutes. The venues were also used for local pharmacy group meetings, thus familiar to participants. All four focus groups were facilitated by the project manager (NJG).

Phase 3 multidisciplinary discussion groups were convened at the targeted pediatric rheumatology centers across England and Scotland, and scheduled during a time dedicated to a regular weekly continuing medical education session for the multidisciplinary team. Hospital pharmacists, who would not normally have been included in those sessions, joined the rheumatology team from their base on-site. Community pharmacists travelled to the center to join the session.

Discussion and Interview guides

The Phase 1 topic guide included pharmacists' experience of engaging with young people about medication use and adherence; pharmacists' experience of engaging with specialist teams in hospital, including rheumatology, and their perception of current and future roles in the care of young people with chronic illnesses.

Phase 2 stakeholders were sent a briefing before the interview to give them background information and prompts which would guide the interview. It combined 'Arthriting' blog quotes, some innovative pharmacist case studies, and an interim analysis of the Phase 1 focus groups.

The telephone interview schedule was tailored to the role of the interviewee, including rheumatology team members' experience of engaging with hospital and/or community

pharmacists about young people (positive or negative), and commissioners’/payers’ views about pharmacists’ potential to support young people taking medication.

A quantitative approach was applied to the Phase 3 discussions, adopting techniques of prioritization and sorting deployed in nominal groups¹⁴. A consensus-building tool for a previous study¹⁵ was adapted to provide a structured format for paper-based prioritization exercises. Small multidisciplinary groups of 2-3 people undertook a paper-based exercise where they assigned a ranking (1-5, where 1 is low) to current or potential pharmacy roles.

Pharmacists and rheumatology staff attending the Phase 1 and 3 groups noted their demographic details on a structured pro-forma, before the session began, to help the team to monitor diversity.

Data Analysis

Data analysis in this project was dynamic, as each phase built upon the previous one to prioritize best practice development roles for pharmacists to better support young people and families.

Qualitative Data Analysis (Phases 1 and 2)

Phase 1 focus group discussions and Phase 2 telephone interviews were recorded on digital audio, which were transcribed verbatim, checked, and identifiers (names of people or places) were removed. A ‘middle-order’ thematic approach¹⁶ was used, which is consistent with ‘directed content analysis’¹⁷. The study objectives provided a source of categories with which to organize participants’ responses, whilst allowing other themes to emerge.

Issues of rigor and bias were anticipated and addressed within the qualitative work. In Phase 1, three clinicians on the team (JB, JMcD, DT) and the project manager (NJG) each listed all the current and future pharmacy roles contained in one focus group transcript. NJG then compiled a list of the most commonly cited roles to underpin the Phase 2 interview briefing; roles cited in 3-4 of the groups were included. A framework approach was employed for the analysis of Phase 2 interviews¹⁸. Each respondent had chosen their priority pharmacy roles. The responses were summarized by one of the interviewers (EP), and were independently reviewed by the project manager (NJG). Where Phase 2 stakeholders validated and supported pharmacy roles, this helped to confirm the list of roles to be scored in Phase 3. Consistency within and between phases was monitored to assess the trustworthiness of the findings.

Quantitative Data Analysis (Phase 3)

Phase 3 data were transcribed from paper data collection forms to an Excel™ spreadsheet. The analysis of data from the final discussion groups was basic descriptive statistical analysis of quantitative ranking (tables of frequencies). The mean rank for the score achieved for each pharmacy role was calculated.

Triangulation

Triangulation of data took place at two key milestones during the study. At the end of Phase 2, the data from both qualitative phases were compared to finalize the possible roles that would be incorporated into the Phase 3 prioritization materials. Following the analysis of the quantitative Phase 3 prioritization data, we returned to the qualitative data to provide context and illustration for the themes corresponding to the highest priority roles.

Results

Table 1 describes the participants in this study. There was diversity of setting, experience and role among pharmacists in the study. The focus groups took place in two large cities, one small city with rural outskirts and one small town. In Phase 1 focus groups, for example, the 9 community pharmacists reported their main settings as village (n=5), suburban high street (n=3) and local neighborhood shops (n=1). The 7 hospital pharmacists who provided data on their hospital type classified them as large (n=4), medium (n=1) and small (n=2). Three of the 9 participating hospital pharmacists were not based in pediatric institutions. Roles ranged from newly qualified pharmacists in their first managerial role through to chief pharmacists of large teaching hospitals.

[Table 1 goes about here]

In Phase 3 there was similar diversity of setting and experience among the pharmacy attendees. Rheumatology staff provided multidisciplinary input from physicians, nurses and a physiotherapist. Inevitably these specialist centers were based in three large cities, but community pharmacists travelled in from surrounding suburban and village settings to take part.

Table 2 reports the prioritization of pharmacy roles by Phase 3 participants, which represent the study priorities for community pharmacy service development.

[Table 2 goes about here]

In this section we present qualitative data from Phases 1 and 2 that complement the highest priority roles from Phase 3 results: developing generic healthcare skills among young people; transferring information across care interfaces to support clinical care; building trusting relationships with young people and their families; helping young people to find credible online information about health and medication, and the need to develop specialist expertise.

Pharmacist support of the development of generic healthcare skills among young people (such as getting a prescription refill and minimizing co-payments) received the highest prioritization. This was a strong theme across the study phases, reflected by pharmacists and rheumatology stakeholders alike:

It may be the first time that these young people are using healthcare and we need to make sure that they're using it effectively. And so it's a really key critical time and using a pharmacy and taking advice from pharmacists etc. is an important thing for them for the future. So it's trying to encourage that, I guess, as much as possible.

[SK30 – Rheumatologist, Phase 2]

The need for routine information transfer from the specialty hospital team to the community pharmacist was also a high priority. Hospital pharmacists reflected on the need for better routine communication with community pharmacy colleagues, and the challenge to incorporate that into their daily activities:

P14: But as community pharmacists, presumably you get all of your information via the GP [primary care doctor] and the patient, don't you? We as hospital pharmacists don't routinely communicate with community pharmacists, do we? In terms of discharge.

P15: And it's a pity, because we should be doing it, but there's just no time in the day.

[Hospital Pharmacists, Phase 1]

Building long-term relationships with young people was seen as a priority. Community pharmacists considered it difficult to engage young people with chronic illness as their parents tended to collect the prescriptions on their own:

We have a few [young people] with long-term conditions, but mainly their parents will come. We have got some that have got heart conditions, and they're not likely to come often. They may come once in a while, but mainly the parents will come instead of them.

[P05 – Community Pharmacist, Phase 1]

The collection of medication by unaccompanied minors was largely discouraged in both community and hospital settings; participants reflected that this approach could be changed to encourage empowerment and engagement:

I sometimes think we don't help ourselves... We have a notice up that says 'Children under 16 are not allowed to collect medicines', as opposed to putting it in a different way: 'If you are under 16, and you would like to collect your medicine, please talk to us'.

[P14 - Hospital Pharmacist, Phase 1]

Some participants identified the potential to build a relationship over a number of years and to see young people taking more responsibility for medication during adolescence:

We've got a few type 1 diabetics... When they're young - when they are ten or younger, their parents do everything for them... We are there all the time, we see them grow up... And then as they grew up through the teenage years, they take more responsibility and they come in and sometimes they want it, they don't want it, and they are very articulate about what they want. [P12 – Community Pharmacist, Phase 1]

In Phase 3, many participants supported pharmacists sharing websites and apps that could help young people to manage chronic illness. A number of community pharmacists in Phase 1 talked about technology underpinning their engagement with young people. One community pharmacist, for example, reported enquiries from young people inspired by information-seeking on the Internet:

Younger people... say 'We found something on the internet', or sometimes they show me something they found online... [They ask] 'What do you think from this?' or 'Is this true?' and different things like that... Just little bits that you wouldn't really get with any other age group, apart from the youngsters really. [P06 – Community Pharmacist, Phase 1]

The integration of the hospital pharmacist into the multidisciplinary specialty team was prioritized in Phase 3. Many young people with chronic illnesses like arthritis are seen in hospital outpatient clinics rather than inpatient wards. The pharmacist is not traditionally involved in these clinics beyond the dispensing task, but there was openness to include them:

We have a multidisciplinary team meeting every week, which everyone from social workers to our nurses, to the physio, OT, some of the nursing staff on the wards...And again pharmacy would be very welcome to attend if they wished to; in our hospital it would probably be a good place to start with interactions. [SK54 – Rheumatologist, Phase 2]

Other rheumatologists described innovation with pharmacists. One center had a pharmacist prescribing methotrexate in clinic. Another team had a dedicated pharmacist attached to their group, who answered the specialty team's queries but did not attend clinic.

Phase 3 participants prioritized the development of specialist expertise among pharmacists for chronic illnesses. Hospital pharmacists may do this; in recent years some have been employed directly by specialist teams. Whether it was reasonable for a generalist practitioner like a community pharmacist to embrace the specialty knowledge for all pediatric conditions was also discussed:

I do sympathize with a pharmacist who is working in the community and has a huge range of things that they need to be involved with and to be aware of...I think when you're talking about a very small population of people who are taking things like methotrexate in childhood, I think it's very hard for someone to keep abreast of all of that. [SK26 – Rheumatologist, Phase 2]

Discussion

This study identified a diverse range of potential opportunities, and clear priorities, to guide service developments to support pharmaceutical care for young people with chronic illness. The

high priority roles identified by pharmacists and rheumatology staff were: developing generic healthcare skills among young people; transferring information across care interfaces; building trusting relationships with young people; helping young people to find credible online health information, and the need to develop specialist expertise. The support offered must be sensitive to the multiple physical, emotional and social transitions experienced by young people aged 10-24, tailored to each individual.

It is relatively easy to develop pharmacy public health roles because the activities can be exercised independently of other professionals; a role in chronic illness management cannot be exercised in isolation. For juvenile arthritis, the rheumatology team may include doctors, nurses, physiotherapists, occupational therapists and transition-focused personnel. Primary care doctors will also play a role. A review of the case notes of 150 young people aged 11-18 attending the rheumatology service at a large UK paediatric hospital showed that pharmacy involvement was not being recorded¹⁹. The blog-based ‘Arthriting’ study revealed few references to pharmacists among the accounts from young people and parents¹⁰. Moreover, during the ‘Arthriting’ research, a scoping review of the literature was undertaken to determine the contribution of pharmacists to the care of young people with three exemplar chronic illnesses (juvenile arthritis, insulin-dependent diabetes mellitus IDDM and inflammatory bowel disease IBD)¹⁰. There was only one account of a pharmacist-directed peer support program for six young people with IDDM in the USA²⁰ – pharmacy initiatives are not widespread for this age group.

Juvenile arthritis has a prevalence similar to type I diabetes, affecting 1 in 1,000 children and young people in the UK²¹ with active disease that continues for a significant number into

adulthood, and is thus a useful exemplar for a range of chronic illnesses. Whilst each clinical condition will have its own features and challenges, chronic illnesses have common characteristics²². Community pharmacists are generalists, and many hospital pharmacists have to operate across a number of clinical specialties, so this ‘non-categorical’ approach²³ can enable the profession to engage with generic chronic illness issues during adolescence. All pharmacists must, however, possess enough specialist knowledge to ensure medication use is safe for all patients. There are a number of medication-related issues that particularly concern young people, such as interactions with alcohol and other drugs, and side-effects²⁴. Pharmacists will need to recognize these issues and be ready to offer relevant advice about medication dispensed for young people. We would expect the principles of young people friendly services²⁵ to apply across chronic illnesses, and that young people’s priorities regarding services - and the nature of their consultations with pharmacists - are also likely to be similar. It therefore seems reasonable to take insights from juvenile arthritis to inform the pharmacy contribution to the care of young people with a wide range of chronic illnesses.

Young people may be more open to using the pharmacist as a health information channel than adults. A 2014 survey of 4,182 consumers across France, Germany, Portugal and the UK reported that respondents aged 24 and younger were more likely than other age groups to consider pharmacists a trustworthy source of information²⁶. Many young people are very engaged in self-management in the home, but withdraw when they are in a medical setting²⁷; pharmacists based in a familiar retail setting may be able to recognize and foster the partnerships between young people and parents. They could also have a role in supporting young people through transition, as a constant and accessible source of advice when other services are

changing. Recent work in the UK has confirmed that the ‘You’re Welcome’ youth-friendly service criteria can be applied directly to the community pharmacy setting²⁸. To realize these aspirations, the training of pharmacists will have to include resources about providing developmentally appropriate care to young people, including physical and cognitive development.

This project was successful in engaging a broad range of participants across the UK. The present project was built on the findings from the previous ‘Arthriting’ study¹⁰, using ‘Arthriting’ data – direct blog quotes from young people and parents - as the stimulus. Both internal and external views of the pharmacy profession were considered to develop a vision of pharmacy care for young people with chronic illness. There was enthusiasm and interest in the topic from the pharmacy and rheumatology stakeholders. We acknowledge the limitations of the project, however. A relatively small number of participants were involved. Participants may have had a specific interest - and possible bias - for the topic of young people’s health and/or arthritis, but this underscores their frank admission of the challenges to better engagement. Not all multidisciplinary groups in Phase 3 completed the ranking for all roles in the time available.

Pharmacists have not hitherto been visible in the care of young people with chronic illnesses. If pharmacists wish to develop long-term therapeutic relationships with young people who have chronic illnesses, there may be untapped goodwill within the multidisciplinary care team. This study has led to the identification of specific enhancements to pharmacy services for young people which have received the endorsement of a wide range of stakeholders. Inevitably any change in practice will start with pharmacists who develop skills and interest in better care for

young people; hopefully a critical mass will then start a ‘ripple effect’ of normalization through to the wider pharmacist population. These prioritized roles could inform the next steps in developing the contribution of community and hospital pharmacy to support young people with chronic illness in the optimal use of their medication.

References

1. Woods DM, Holl JL, Klein JD, Thomas EJ. Patient safety problems in adolescent medical care. *J Adolesc Health* 2006; 38: 5-12.
2. Bissell P, Anderson C. Supplying emergency contraception via community pharmacies in the UK: reflections on the experiences of users and providers. *Soc Sci Med* 2010; 57(12): 2367-2378.
3. Sucato GS, Gardner JS, Koepsell TD. Adolescents’ use of emergency contraception provided by Washington State pharmacists. *J Pediatr Adolesc Gynecol* 2001; 14: 163-169.
4. Conard LAE, Fortenberry JD, Blythe MJ, Orr DP. Pharmacists’ attitudes towards and practices with adolescents. *Arch Pediatr Adolesc Med* 2003; 157: 361-365.
5. Schaffer SJ, Fontanesi J, Rickert D, Grabenstein JD, Rothholz MC, Wang SA, Fishbein D, for the Working Group on Complementary Settings. How effectively can health care settings beyond the traditional medical home provide vaccines to adolescents? *Pediatrics* 2008; 121(Suppl1): S35-S45.

6. Horsfield E, Kelly F, Sheridan J, Stewart J, Clark T. Could community pharmacies help to improve youth health? Service availability and views of pharmacy personnel in New Zealand. *Int J Public Health* 2014; 59(5): 789-798.
7. Gray NJ, Prescott J. Community pharmacists' engagement with young people aged 13-19 years. *Int J Pharm Pract* 2013; 21(Suppl 2): 128.
8. Hepler CD. Pharmaceutical care. *Pharm World Sci* 1996; 18(6): 233-235.
9. United Nations Youth. A definition of youth. UN online. Available at <http://www.un.org/esa/socdev/documents/youth/fact-sheets/youth-definition.pdf> Accessed 22/9/2016.
10. 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; December 2013.
11. Gray NJ, McDonagh JE, Prescott J, Smith FJ, Harvey K, Shaw KL, Terry D. Arthriting – Insights about the links between identity, arthritis and medication in the blogs of young people living with juvenile arthritis. *J Adolesc Health* 2014; 54: S18.

12. Prescott J, Gray NJ, Smith FJ, McDonagh JE. Blogging as a viable research methodology for young people with arthritis: A qualitative study. *J Med Internet Res* 2015; 17(3): e61.

13. Creswell JW, Plano Clark VL, Garrett AL. Methodological issues in conducting mixed methods research designs. In: Ed. Bergman MM. *Advances in Mixed Methods Research: Theories and Applications*. London: Sage Publications, 2008. pp66-83.

14. Tully MP, Cantrill JA. Exploring the domains of appropriateness of drug therapy, using the Nominal Group Technique. *Pharm World Sci* 2004; 24(4), 128-131.

15. Shaw KL, Southwood TR, McDonagh JE on behalf of the British Paediatric Rheumatology Group. Transitional care for adolescents with juvenile idiopathic arthritis: a Delphi study. *Rheumatol* 2004; 43(8): 1000-1006.

16. Becker H, Geer B. Participant observation: the analysis of qualitative field data. In: R. Burgess (Ed.), *Field research: a sourcebook and field manual*. London: Allen & Unwin, 1982.

17. Hsieh H-F, Shannon SE. Three approaches to content analysis. *Qual Health Res* 2005; 15(9): 1277-88.

18. Srivastava A, Thomson SB. Framework analysis: a qualitative methodology for applied policy research. *Journal of Administration and Governance* 2009; 4(2): 72-79.

19. McDonagh JE, Shaw KL, Stephenson R, Gray NJ. Are they ready and do we know they are ready? Documentation of medicine management tasks in an adolescent rheumatology clinic. *Rheumatol* 2014; 53 (suppl 3): iii10.
20. Sims LM, Haines SL. Challenges of a pharmacist-directed peer support program among adolescents with diabetes. *J Am Pharm Assoc* 2011; 51: 766-769.
21. Symmons DP, Jones M, Osborne J, Sills J, Southwood TR, Woo P. Pediatric rheumatology in the United Kingdom: Data from the British Pediatric Rheumatology Group National Diagnostic Register. *J Rheumatol* 1996; 23(11): 1975-1980.
22. Suris JC, Michaud P-A, Viner R. The adolescent with a chronic condition. Part I: Developmental issues. *Arch Dis Childhood* 2004; 89: 938-942.
23. Stein R, Jessop D. A non-categorical approach to chronic childhood illness. *Public Health Rep* 1982; 97: 354-362.
24. Gray N, Harvey K, McPherson A, Macfarlane A. Medicine dilemmas in adolescents' email messages. *Int J Pharm Pract* 2008; 16 (Suppl 1): A34-35.
25. Ambresin AE, Bennett K, Patton GC, Sanci LA, Sawyer SM. Assessment of youth-friendly health care: a systematic review of indicators drawn from young people's perspectives. *J Adolesc Health* 2013; 52(6): 670-681.

26. International Longevity Centre UK. *Next Generation Health Consumers: The Changing Face of Health Seeking Behaviour across Europe*. London: ILC-UK, 2015. Available at http://www.ilcuk.org.uk/index.php/publications/publication_details/next_generation_health_consumers Accessed 22/09/2016.
27. Newbould J, Smith F, Francis SA. "I'm fine doing it on my own": Partnerships between young people and their parents in the management of medication for asthma and diabetes. *J Child Health Care* 2008; 12(2): 116-128.
28. Alsaleh F, Smith FJ, Rigby E, Gray NJ. Applying the 'You're Welcome' youth-friendly service criteria to community pharmacy in the UK. *J Pharm Health Serv Res* 2016; 7(1): 71-79.

Table 1: Project Design

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	<ul style="list-style-type: none"> • 4 Focus groups • 9 community and 9 hospital pharmacists • Direct quotes from the Arthriting project¹⁰ used as stimulus points • Participants from England, Scotland and Wales • 90-minute duration 	<ul style="list-style-type: none"> • 15 Telephone interviews • 2 pharmacy policymakers, 3 service commissioners, 2 pharmacy staff members, 5 rheumatology professionals and 3 lay advocates • Direct quotes from the Arthriting project¹⁰ used as stimulus points • Participants from England, Scotland and Northern Ireland • 20-minute duration 	<ul style="list-style-type: none"> • 3 Discussion groups • 9 community pharmacists, 4 hospital pharmacists, 7 rheumatology physicians, 5 specialist nurses, and 1 physiotherapist • Direct quotes from the Arthriting project¹⁰ used as stimulus points • Participants from England and Scotland 90-minute duration
Data Collected	<ul style="list-style-type: none"> • Demographic participant data • Verbatim transcripts 	<ul style="list-style-type: none"> • Verbatim transcripts • Prioritisation of issues affecting adherence and affecting pharmacy engagement 	<ul style="list-style-type: none"> • Demographic participant data • Attitude statements • Prioritisation of pharmacy roles and skill developments
Priority-Setting 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

Table 2 – Results of the role prioritization activity in multidisciplinary discussion groups

Current / Future Role	Priority 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 GP.	4.71 ^b
Community pharmacists can build long-term relationships with young people and families.	4.71 ^b
Pharmacists share information with young people about apps and websites that support adherence and give information about JIA.	4.57 ^b
Hospital pharmacists are included in MDT sessions for rheumatology patients.	4.44
Pharmacists develop specialist expertise in pediatric/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 medicines optimization.	4.43 ^b
Community pharmacists can 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 ^b
Hospital pharmacists can build long-term relationships with young people and families.	4.14 ^b
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 ^b
Pharmacists develop better skills in communicating with young people and parents.	3.89
Rheumatology team members do continuing professional development sessions for community pharmacists about JIA medicines.	3.88 ^a
Pharmacists work with home delivery companies to optimize medication supply.	3.78
Pharmacists are advocates for young people with JIA and challenge prescribing decisions.	3.75 ^a
Pharmacists can be directly available to young people and parents/carers by email or telephone.	3.71 ^b
Hospital pharmacists can do clinics in the hospital for young people with JIA.	3.67
Young people with JIA carry a card to signal their condition and their ability to collect their own prescriptions.	3.63 ^a
Pharmacists do medication review for young people with JIA.	3.56
Pharmacists need to develop better skills in confidentiality and consent for young people.	3.22
Pharmacists need to develop better skills in safeguarding for young people.	3.11
Community pharmacists co-ordinate supply of JIA medication for young people.	2.89
Hospital pharmacists do clinics in the community for young people with JIA.	2.22

Priority mean scores are reported to 2 decimal places – data averaged from 9 multidisciplinary groups.

^a = 8 groups; ^b = 7 groups - some groups did not complete ranking for all roles.

1 was low priority for future development and 5 was high.