**Title**

The experience of obtaining repeat complex paediatric prescriptions in the UK

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**Improving the experience of obtaining repeat paediatric prescriptions in the UK**

In the UK, medicines for chronic conditions in children and young people (CYP) are typically initiated within secondary or tertiary care, with responsibility for ongoing supply often then passed to the child’s general practitioner (GP) and community pharmacist. The patient should then be reviewed in regular specialist clinics, with two-way communication for any changes in medications or clinical status undertaken between primary and secondary/tertiary care. This arrangement allows long term medications to be obtained close to home.

Although this is what parents expect, the reality is often messy, with families regularly needing to source some medicines from the GPs and others via hospitals or homecare services. In addition these arrangements are not uniform, they vary across different areas of the United Kingdom (UK) and depend on individual GP or hospital prescriber acceptance.(1) When neither primary, secondary or tertiary care accepts it is their responsibility to prescribe, or patients are under multiple specialists, families often feel left to navigate this complex and variable supply system themselves.(1) Obtaining a prescription is only the start of the process for families as, dispensing from a community pharmacy can also be challenging.

In this article we set out the barriers and potential solutions to this complex issue. We use the term specialist prescribers to include not only paediatricians but all other specialists looking after CYP including child and adolescent psychiatrists, ophthalmologists, dermatologists, surgeons etc as well as non-medical prescribers.

**Extent of the problem**

Globally using primary care records a scoping review found around 40% of CYP were on more than one medicine.(2) Polypharmacy is common in many conditions, for example: nine years after surviving childhood cancer 5% were on ≥5 chronic medications(3), children with medical complexity (CMC) averaged five chronic medications(4), in CYP with autism incidence varies with 7% - 87% being on one or more medication(5), and CYP with chronic kidney disease (CKD) on >3 medication increases from 42% at stage II to 87% at stage IV CKD.(6)

Although barriers to supply can affect many medicines used in CYP they are magnified for unlicensed and off-label medicines which often have to be used.(7) In a survey from 2006, a third of families encountered difficulties obtaining repeat prescriptions from primary care after discharge from a specialist children’s hospital. The main barriers identified were community pharmacies being unable to source the medication and GPs not prescribing.(8) In a separate study, families commonly experienced ‘panic’ and ‘frustration’ and feeling ‘afraid’ when unable to obtain further supplies.(1) Families reported frequent barriers in the community healthcare system: from receptionists refusing to engage as the prescription has not been put on repeat in the computer system, distrust that refusal is due to cost considerations, limited quantities dispensed, fearful of different preparations and strengths being dispensed, prolonged and variable delays between request and delivery, and being left to roam community pharmacies to source the medicine themselves. Families living in remote and rural communities are at further disadvantage as the choice of community pharmacies is limited.

The care burden for CMC is already onerous, but made worse by difficulties sourcing medicines or managing deliveries.(9) In one US study families were spending an average of 11 – 48 hours per week providing direct hands-on care, with an additional 1 – 7 hours per week care coordination which includes obtaining supplies and medications.(10, 11).

**Whose responsibility is it to prescribe?**

The General Medical Council (GMC) guidance ‘Good practice in prescribing and managing medicines’ is steadfast that the accountability for patient safety rests entirely on whoever signs the prescription.(12) Recommending medicines for primary care to prescribe, shared care arrangements and unlicensed medicines are covered in the guidance but ultimately acceptance is voluntary.

*“Good organisation of care across the interface between primary and secondary/tertiary care is crucial in ensuring that patients receive high quality care – and in making the best use of clinical time and NHS resources in all care”* was the noble vision of the NHS England guidance document produced in partnership with Royal College of General Practitioners, NHS Clinical commissioners, British Medical Association and the Royal College of Nursing and last updated in 2018.(13) CYP are not specifically mentioned with the exception that the British National Formula for Children (BNFC) is a suitable evidence base to base dosage on for unlicensed medicines. The guidance advocates a traffic light system to be constructed by area prescribing committees to indicate who would be best to prescribe each type of medication:

Green – Suitable for routine prescribing in primary care

Amber – For share care agreements – subject to voluntary acceptance by individual GPs for individual patients

Red – For specialist prescribers only

Each of the 8,000 GP practices in England is part of a clinical commissioning group (CCG). There are more than 200 CCGs each commissioning care for an average of 226,000 people.(14) The prescribing traffic light system implementation and delivery is determined by about 50 local Area Prescribing Committees (APC), each a collaborations of several CCGs, hospital and mental health trusts in a locality. Unfortunately, the voluntary nature of accepting prescribing means in one UK children’s hospital 1 in 8 declined requests from primary care was for medications on the local area prescribing policies formulary’s ‘green list’.(15)

Shared care agreements are a formalised transfer of clinical responsibility from a specialist service to general practice to facilitate prescribing by the GP. These shared care agreements are condition and medication specific, and each can run to several pages. Writing these guidelines is time consuming and acceptance is entirely voluntary at the individual patient level. Anecdotally few specialist prescribers know about the traffic light system or its content in their locality. For tertiary care prescribers the situation is further complicated by working over several APCs each with their own different traffic light list, and each requiring separate shared care agreement negotiations and documentations. Currently five APCs serve the single children’s hospital in the North East and North Cumbria; London is also served by five APCs. Few shared care agreements have been written across the UK for CYP and no national standardised templates exist.

**Difficulties facing primary care colleagues**

Primary care prescribers are right to question if they have the information and skillset to safely prescribe high risk medications for CYP with complex conditions.(16) In the initial phase of the KidzMed project in the North East and North Cumbria, a focus group comprising GPs, pharmacists and commissioners at a regional prescribing forum was consulted and several themes were generated (table 1). Even if shared care agreement devolves safe monitoring to secondary/tertiary care, without easy access to hospital notes and blood results GP’s have little assurance monitoring is being followed. Reading a patient’s electronic medical records held in different organisations across a region may soon become a reality as several UK regions are investing in Health Information Exchanges (HIE) although these projects are still in the embryonic stages. No UK HIE system can currently display clinical correspondence and medication lists bidirectionally across both primary and hospital care.(17, 18)

For CMC, there are nuances that GPs may not be aware of or are inadequately resourced to accommodate. For example, where medications are administered in multiple settings (e.g. home, school, and respite hospice), the responsibilities and practicalities for prescribing and requesting multiple supplies can become onerous.

Something we can all help with is, where appropriate, to convert children from liquid to tablet/capsule medication at the earliest opportunity. It is easier to select on primary care IT prescribing systems, and repeat prescriptions are minimised as expiry durations are much longer.

**Direct prescribing from secondary/tertiary care**

Hospitals typically have onsite dispensing pharmacy for out-patient dispensing. By their nature they will stock or have networks to source the widest range of medications, including specials and unlicensed medications. They can reduce costs by bulk buying or specially negotiating prices direct from manufacturers. However, for families living far away especially those reliant on public transportation, travelling to their secondary/tertiary care pharmacy can be a huge burden.

During COVID-19 to support remote consultations, social distancing inside pharmacies and to protect clinically extremely vulnerable patients, the NHS temporarily funded home delivery services.(19) Many specialist hospital pharmacies have utilized this resource to deliver a wide range of medicines directly to patients’ homes, which can be highly beneficial to families. Unfortunately, in the post-pandemic era the continuing funding for these services is uncertain. The increased environmental carbon footprint of having medicines individually delivered or collected from the tertiary hospitals far away rather than through well-established community pharmacy supply chains is substantial

Like GPs, hospital specialists can directly issue paper prescriptions (FP10(HNC), WP10H, or HBP forms in England, Wales and Scotland respectively) in clinic or send to patient’s homes by post, to take to community pharmacies for dispensing. There are clear concerns regarding confidentiality and fraud if posted prescriptions go astray.(20) Unlike in primary care where electronic transfer of prescriptions to pharmacies and patient apps for repeat prescriptions are well established, we know of no hospitals who have set up routine electronic transfer of prescriptions to community pharmacies although some pilots have taken place. Repeatedly writing out FP10 prescriptions by hand is time consuming and difficult for all parties. The cost to the hospital for common medications are usually similar, but differences can be considerable and can be oblivious to the specialist prescriber (e.g. adalimumab for juvenile idiopathic arthritis cost ≈£80 hospital procurement vs ≈£600 FP10 dispensing in one hospital, personal communication). Due to these constraints hospital prescribing dispensed in the community using FP10 (HNC) are rare, accounting for <1% of NHS hospital medicine budgets.(21)

Homecare services are private companies that provide specialist medicines and their associated services to patients in their homes ranging from just delivery (e.g. growth hormone), through to nurse administered intravenous infusions (e.g. eculizumab for atypical haemolytic uremic syndrome). Homecare is becoming increasingly ubiquitous and in 2014 served over 200,000 patients representing £1.5 billion of the £4 billion spent on hospital medicines in the UK.(22) Although home delivery are welcomed, each company are usually responsible for just one medication resulting in a fragmented set up for CYP receiving polypharmacy. Waiting at home all day for an untimed or late delivery can be challenging for parents/carers needing to go to work.

**Where in the NHS budget does medication cost come out of?**

Funding arrangements for medication is complex, ever-changing and varies between the UK nations. Primary care is funded mainly by capitation where a sum is given depending on the practice size. For hospitals the block contract is the main payment system in Scotland, Wales, and Northern Ireland e.g., a set amount to provide a service to a region (e.g., paediatric cardiology care). Pre-COVID in England, the national tariff (payment by results) dominated payments made to hospitals; income was based on the number of patients seen in clinic, number of procedures performed or the number of admissions to hospital. The cost for outpatient hospital prescribing is borne by the hospital unless it is for a listed high-cost medication commissioned by NHS England (e.g. everolimus for refractory focal onset seizures associated with tuberous sclerosis complex) or sporadically by local block contracts negotiated with CCGs.

The requirement for each prescribing organisation to pay for the medication they prescribe therefore generates a disincentive on all sides to prescribe especially when items are perceived to be high cost. The biggest challenge to families is navigating the complex system of where to obtain repeat medications. The traffic light system forces families to obtain some medication from their local pharmacy and others from the hospital pharmacy, or homecare. A child on multiple medications can end up obtaining repeat medications from four different providers – tertiary hospital, secondary care (local) hospital, community pharmacy and homecare.

**Challenges facing community pharmacies**

Once a prescription reaches a pharmacy, there are still be complexities to be overcome such as avoiding formulations that expose young children to excessive or unsuitable excipients (e.g. Propylene glycol in amiloride, ethanol in phenobarbitone), or arranging supplies for children who refuse any change in flavour or texture of their medicine.(23) Community pharmacies may be contracted to limited suppliers, particularly for unlicensed medicines, preventing them from procuring certain makes or strengths of medicines after discharge from hospital. Parents are familiar with the volume of liquid medication their child has first been dispensed with and will not expect the concentration to change when repeats are obtained which can inadvertently result in under- or overdosing.(1, 24) For this reason, the Neonatal and Paediatric Pharmacists Group (NPPG) and the Royal College of Paediatrics and Child Health (RCPCH) have produced joint consensus recommended concentrations for common unlicenced medicines.(25)

Rarely used medicines pose additional challenges. In one survey only 40% of community pharmacists had dispensed an off-label prescription in the previous month.(26) Drug supply chains are global, long, and complex. Supply can be precarious, and prices can fluctuate. Specialist paediatric pharmacist knowledge and networks can ameliorate these challenges, but many community pharmacies do not have easy access to such specialists. In Autumn 2021 levamisole, used to prevent frequently relapsing nephrotic syndrome, suddenly became unavailable to the main UK importer; pharmacists from children’s hospitals rapidly communicated and shared limited stocks until new imports arrived in the UK. Rather than a seamless national health service where problems are tackled behind the scenes, often families are left desperate without supplies and left to contact specialist hospital teams to resolve themselves.(1)

In 2018 the Transfers of care Around Medicine (TCAM) project was set up with an explicit aim to reduce avoidable harm caused by medicines when patients transfer between different care settings.(27) The improvements consisted of 1) patient shared decision making with a community or GP pharmacist within a week of discharge and 2) the IT infrastructure to enable medication lists to be updated in the GP system. In 2021, this service was contractually rolled out nationally as the NHS Discharge Medicines Service available to all discharged patients, including children.(28) This could be an excellent opportunity to link community pharmacy, primary and hospital care. The infrastructure has not been developed yet but it will be essential to create networks with specialist paediatric pharmacists to upskill and support community pharmacists to develop experience and knowledge to counsel complex paediatric patients.

**Can integrated care systems help?**

In 2019 the NHS Long-Term Plan set the ambition for all parts of the country to become integrated care systems (ICS). The central aim of England’s 42 ICSs will be to integrate care across different organisations and settings, join up hospital and community-based services, physical and mental health, and health and social care. Similar infrastructure changes are being established in Wales, Scotland, and Northern Ireland. There is no set model on what it will look like, and it may end up varying between ICSs. A collaborative financial system where primary, secondary, and tertiary care share the cost of treating complex patients, including medication costs, rather than the current system where the cost is carried by the prescribing institution may incentivise cooperation.

**The challenge for our NHS**

The NHS was designed to bring care close to home and provide seamless healthcare. Families of with CYP with the most complex conditions face a complex ever-changing system they are required to navigate in order to obtain life enhancing medicines, adding to their already onerous care burden. The lack of clear boundaries and responsibilities challenges health professionals from prescribers, pharmacists, administrators and specialist nurses in primary and specialist care. Multiple parallel medication distribution networks are wasteful and environmentally damaging. Collaborating regionally and nationally may improve the situation in the short term and we have listed some suggestions in table 2. Structural transformations with the emerging ICSs are required – we need to co-produce with families the medication system they deserve.

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| --- |
| ‘Wicked problem’ spanning healthcare system  Main concern was safety - patients and medications are rare, complex, resulting in a knowledge gap  GP IT systems often not easy for liquids or weight-based dosing  Written information from secondary/tertiary often incomplete or delayed |

Table 1. Prescribing of paediatric medicines. Feedback from a focus group of GPs, pharmacists, and commissioners

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| --- | --- |
| **Short term quality improvement** | **Long term system transformation** |
| * Attempt deprescribing medications that are likely to have no or limited benefit * Paediatric pharmacists integral to the multi-disciplinary care from admission to discharge * Medication reconciliation at each clinic visit * Clear rapid communication between care providers * Converting children to tablets at the earliest opportunity where appropriate (29) * Follow standardised concentration for unlicenced specials as per RCPCH/NPPG guidelines (25) | * Community pharmacy medicine reconciliation using the new NHS Discharge Medicines Service for CYP after discharge from hospital * Standardising national traffic light system for prescribing paediatric medicines with clear boundaries of who prescribe which medicines * National templates of shared care guidelines co-produced with families and national subspecialty groups * Shared care guidelines to be created across new larger Integrated care systems footprints * Digital transformation to widen hospital use of electronic FP10 (HNC) system allowing prescriptions (with instructions for formulation and strengths) to be transmitted directly from secondary/tertiary care to community pharmacies and electronic ordering by parents/carers of repeat prescribing with set review periods |

Table 2. Example of possible medication system improvements for wider testing.

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