

1 **A TELEPHONE SURVEY TO DETERMINE THE EXPERIENCES OF CHILDREN, AND**  
2 **THEIR PARENTS/CARERS, FOLLOWING THE INITIATION OF A NEW MEDICINE**

3 **Corresponding author:**

4 Mr Jeff Aston  
5 Pharmacy Department  
6 Birmingham Children's Hospital NHS Foundation Trust  
7 Steelhouse Lane  
8 Birmingham  
9 B4 6NH  
10 UK  
11 Email [jeff.aston@bch.nhs.uk](mailto:jeff.aston@bch.nhs.uk) and [jeffaston36@gmail.com](mailto:jeffaston36@gmail.com)  
12 Telephone: 447774613311 and 44 121 333 9821

13 **Co-Authors:**

14 Professor Keith A Wilson  
15 School of Life and Health Sciences  
16 Aston University  
17 Aston Triangle  
18 Birmingham B4 7ET  
19 UK

20  
21 Professor Anthony Sinclair  
22 Pharmacy Department  
23 Birmingham Children's Hospital NHS Foundation Trust  
24 Steelhouse Lane  
25 Birmingham  
26 B4 6NH  
27 UK

28  
29 Dr David Terry  
30 School of Life and Health Sciences  
31 Aston University  
32 Aston Triangle  
33 Birmingham B4 7ET  
34 UK

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36 **Key Words**

37  
38 Medication Therapy Management, Medication Adherence, Paediatrics, United Kingdom

39  
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42 **ABSTRACT**

43 **Objective**

44 To determine what issues are experienced during the first few weeks of therapy by patients, and  
45 their parents/carers, when a child/young person has been prescribed a new medicine.

46 **Method**

47 One-hundred patients aged  $\leq 18$  years of age prescribed a new medicine for  $\geq 6$  weeks were  
48 recruited from a single United Kingdom National Health Service (NHS) specialist paediatric hospital  
49 out-patient pharmacy. Six weeks after the first dispensing of their new medicine the patient or their  
50 parent/carer received telephone follow-up by a researcher and verbally completed a questionnaire  
51 containing both open and closed questions. Patient or parent/carer experiences were identified and  
52 analysed using thematic analysis and descriptive statistics.

53 **Results**

54 Eighty-six participants were available for telephone follow-up. Six (7%) had not started their  
55 medicine. Paediatric patients and their parents/carers experienced a range of issues during the  
56 first few weeks after starting a new medicine. These included additional concerns/questions (24/80,  
57 30%), administration issues (21/80, 26.3%), adverse effects (29/80, 36.3%) and obtaining repeat  
58 supplies (12/80, 15%). The Morisky Medication Adherence Scale indicated that 34/78 (43.6%)  
59 participants had a high adherence rating, 35/78 (44.9%) medium and 9/78 (11.5%) a low rating.

60 **Conclusion**

61 Paediatric patients and their parents/carers experience a range of issues during the first few weeks  
62 after starting a new medicine. Further research is required to determine the type of interventions  
63 that may further support medicines use in this group of patients.

64

65 **Key Words**

66

67 Medication Therapy Management, Medication Adherence, Paediatrics, United Kingdom

68

69 **Key Messages**

70 **What is already known on this subject:**

- 71 • Little is known about the experiences of paediatric patients, and their parents/carers, during  
72 the first few weeks after child has started a new medicine.

73 **What this study adds:**

- 74 • This study has shown that children, and their parents/carers, experience a range of issues  
75 during the first 6 weeks after starting a new medicine.
- 76 • These issues include concerns/questions, information requirements, adverse effects,  
77 arranging further supplies and adherence.
- 78 • Interventions to support medicine taking during this period may optimise medicines use in  
79 this group of patients.

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87 **INTRODUCTION**

88

89 People prescribed self-administered medicines typically take about half their doses.[1] Efforts to  
90 assist patients with adherence might improve the benefits of prescribed medicines.

91

92 Medicines taking in children may be influenced by parents/carers beliefs about the condition,  
93 treatment regimen, child resistance, relationships within families, desire to preserve normal life and  
94 input from health professionals.[2]

95

96 A recent study of the experiences of medicine-related issues encountered by parents/carers of  
97 paediatric liver transplant patients found they reported problems obtaining their medicine,  
98 administering the medicines and side effects (including insufficient knowledge of side effect  
99 management).[3]

100

101 A review of the medical notes of 11 – 18 year old patients with juvenile arthritis found that despite  
102 the increasing complexity of drug regimens major gaps existed in the documentation of knowledge  
103 and skills relevant to the self-management of such regimens by patients.[4]

104

105 Barber *et al*, in a study of adult patients started on chronic medicines, found they quickly became  
106 non-adherent and identified a number of medicine related problems and information needs.[5]

107 These included side effects, concerns about taking a new medicine, swallowing difficulties and  
108 remembering the regimen. In response to these issues the National Health Service (NHS) funded

109 New Medicines Service (NMS) was established in England in 2011.[6] This is a medication review  
110 delivered through community pharmacists to support people with long-term conditions newly

111 prescribed a medicine. The NMS improves adherence by 10% and increases the number of

112 medicines problems identified and resolved.[7] Improved medication adherence has been shown to

113 improve disease outcomes in children with cystic fibrosis[8], asthma[9] and renal disease.[10]

114 However, the NMS may not be available to children and cannot be undertaken with a

115 parent/carer.[6]

116

117 The rationale of medication review could apply to children with chronic diseases.[11] Issues such as  
118 polypharmacy, wastage and medicine-related problems are likely to be similar to those in adults.  
119 However, a literature review, using AMED, British Nursing Index, CINAHL, EMBASE, HMIC, MEDLINE,  
120 PsycINFO and Health Business Elite, did not identify any studies of medication review specific to  
121 children. Recently, the UK National Institute for Health and Care Excellence (NICE) recommended  
122 further research concerning medication review in children, including minimising medicines related  
123 problems.[12] Other initiatives that may optimise medicines use include better partnerships with  
124 patients, telephone helplines, internet support websites and improving collaboration between  
125 healthcare professionals.[13]

126

127 The present study focused on the experiences of patients and their parents/carers during the first  
128 few weeks after a paediatric patient began taking a new medicine.

129

### 130 **Aim**

131

132 To determine what medicine-related issues are experienced during the first few weeks of therapy by  
133 patients, and their parents/carers, when a child/young person has been prescribed a new medicine.

134

### 135 **Ethical Approval**

136

137 The study was approved by Yorkshire and Humber –Sheffield, UK, National Research Ethics Service  
138 24/09/14 (REC reference 14/YH/1086, IRAS project ID 148123).

139

## 140 **METHOD**

141

### 142 **Setting**

143

144 The study was undertaken at a specialist UK paediatric hospital (34 specialties, 361 beds, over  
145 174,000 out-patient visits per year).[14]

146

### 147 **Participant Recruitment**

148

149 Potential participants were identified through presentation of a prescription to the out-patient  
150 pharmacy which met the study inclusion criteria. Consent and recruitment were undertaken by  
151 pharmacists based in the hospital's out-patient pharmacy whilst the participant waited for their  
152 prescription. Written consent was taken from the patient's parent/carer if the child was under 16  
153 years or the patient if 16 years or older. An assent form was used for patients aged 12 – 15 years  
154 and was signed by the patient alongside the parent/carer consent form. Age related participant  
155 information leaflets were provided. To minimise impact on service delivery a convenience sample of  
156 participants were recruited during the period February to July 2015. This study was exploratory and  
157 the authors considered a recruitment number of 100 participants would provide sufficient range of  
158 specialities and participants to identify important findings. There were no known published studies  
159 to guide recruitment numbers.

160

### 161 **Inclusion Criteria**

162

163 Participant inclusion criteria were: ages 0-18 years; prescribed a new medicine to be taken for 6  
164 weeks or longer; access to a telephone for follow-up; not receiving medication for a life-limiting

165 condition; could understand written and spoken English. The authors considered a period of 6  
166 weeks to have provided the patient, and their parent/carer, sufficient experience of taking the new  
167 medicine prior to follow-up.

168

#### 169 **Data Collection**

170

171 Demographic information was recorded from the patient's prescription: medical/surgical clinic  
172 attended, age/gender of the patient, medicine prescribed and therapeutic indication.

173

174 A questionnaire containing both open and closed questions was used as the research instrument.

175 This was completed by telephone with direct support from the lead study researcher. Cognisant

176 testing of the questionnaire was assessed with a parent of a child taking long-term medicines and

177 piloted with 5 participants. Six weeks following the dispensing of their new medicine participants

178 received telephone follow-up by the study lead researcher. Participants were asked: whether they

179 had researched further information about the new medicine themselves and why, any

180 concerns/questions occurring over the previous 6 weeks, if they had experienced any problems

181 taking/administering the medicine, whether they had experienced adverse effects from their new

182 medicine and any problems arranging repeat supplies. Participants' adherence was assessed using

183 the Morisky Medication Adherence Scale (MMAS-8).[15]

184

185 Responses were transcribed in real time by the researcher during the interview.

186

#### 187 **Data Analysis**

188

189 Responses were analysed using thematic analysis. The responses were listed, grouped by

190 similar/related theme and coded. Collated responses were analysed using NVivo version 10.

191 Quantitative results were analysed using descriptive statistics using The Statistical Package for Social  
192 Sciences (SPSS) version 22.

193

## 194 **RESULTS**

195

### 196 **Demographic Information**

197

198 One hundred participants were recruited to the study. Fifty-one patients were female and 49 male  
199 with a mean age of 8 years (range 0.33 years - 17 years). Patients were managed by one of 15  
200 specialities (Table 1).

201

202 **Table 1 Specialities**

<b>Speciality</b>	<b>N</b>
General Paediatrics	23
Ear, Nose and Throat	14
Neurology	13
Dermatology	10
Urology	9
Respiratory	7
Rheumatology	5
Emergency Department	3
Gastroenterology	3
Hepatology	3
Nephrology	3
Ophthalmology	3
Cardiology	2
Inherited Metabolic Diseases	1
Plastics	1

203

204 In total 145 medicines were prescribed which patients had not previously received (Table 2).

205

206 **Table 2 Medicines Prescribed for Study Participants**



<b>Therapeutic Use</b>	<b>Number of Medicines (%)</b>	<b>Medicine (n)</b>
Eczema	27 (18.6%)	Topical corticosteroid (13)
		Emollient (7)
		Dressings (3)
		Hydroxyzine (2)
		Potassium Permanganate (1)
		Topical tacrolimus (1)
Asthma	17(11.7%)	Beclometasone (6)
		Montelukast (4)
		Fluticasone (2)
		Fluticasone/Salmeterol (2)
		Salbutamol (2)
		Ipratropium (1)
Allergy	14(9.7%)	Fluticasone (8)
		Cetirizine (2)
		Adrenaline (1)
		Chlorphenamine (1)
		Desloratadine (1)
		Nutramigen (1)
Urinary Frequency/Enuresis	14 (9.7%)	Desmopressin (6)
		Oxybutynin (6)
		Tolterodine (2)
Migraine/Headache	11(7.6%)	Pizotifen (6)
		Propranolol (2)
		Sumatriptan (2)
		Migravele (1)
Gastro-Oesophageal Reflux	9 (6.2%)	Ranitidine (7)
		Lansoprazole (1)
		Omeprazole (1)
Epilepsy	8 (5.5%)	Levetiracetam(2)
		Acetazolamide (1)
		Carbamazepine (1)
		Lamotrigine (1)
		Sodium valproate (1)
		Stiripentol (1)
		Topiramate (1)

207

208

209

210

211

<b>Therapeutic Use</b>	<b>Number of Medicines (%)</b>	<b>Medicine (N)</b>
------------------------	--------------------------------	---------------------

Infection	8(5.5%)	Trimethoprim (3)
		Amoxicillin (1)
		Azithromycin (1)
		Co-trimoxazole (1)
		Erythromycin (1)
		Itraconazole (1)
Constipation	6 (4.1%)	Macrogols (5)
		Senna (1)
Vitamins	6 (4.1%)	Colecalciferol (2)
		Folic Acid (2)
		Alfacalcidol (1)
		Ergocalciferol (1)
Rheumatic diseases	5 (3.4%)	Nifedipine (2)
		Piroxicam (2)
		Hydroxychloroquine (1)
Immunosuppression	4 (2.8%)	Azathioprine (2)
		Ciclosporin (1)
		Methotrexate (1)
Cardiovascular	3 (2.1%)	Atorvastatin (1)
		Enalapril (1)
		Losartan (1)
Ophthalmic	3(2.1%)	Prednisolone (2)
		Fluorometholone (1)
Cholestasis	2 (1.4%)	Ursodeoxycholic acid (2)
Emesis	2 (1.4%)	Ondansetron (2)
Other	6 (4.1%)	Amitriptyline (1)
		Colestyramine (1)
		Dexamethasone/framycetin/gramicidin (1)
		Levomepromazine (1)
		Melatonin (1)
		Propranolol (1)

212

213 Eighty-six participants received telephone follow-up. Follow-up was undertaken with 83 (96.5%)

214 parents/carers and 3 (3.5%) young people (two aged 16 years and one 14 years following parental

215 consent). Fourteen participants were not contactable.

216

### 217 **Adherence to the Prescribed Regimen**

218

219 Telephone follow-up revealed that 6 (7%) patients had not taken their medicine. Two

220 parents/carers were concerned about side effects (macrogol and topical corticosteroid), 2 had not

221 required their medicine (chlorphenamine, pizotifen and sumatriptan), 1 patient refused to be

222 administered a macrogol suspension and 1 patient was concerned about how nifedipine would  
223 interact with her other medicines.

224

225 *"I read the leaflet that it came with then decided to try naturally. I haven't started her on it yet.*

226 *They said that she wasn't drinking enough. I pushed the fluids, she's been better than she was. It*

227 *can cause diarrhoea and I didn't want to send her the other way..."* Parent of Patient 18 (macrogol)

228

229 *"I haven't been taking it because I couldn't find out if it was compatible with my other medicines. I'm*

230 *doing my exams at the moment, I didn't think it would be very smart to take them."* Patient 46

231 (nifedipine)

232

233 The MMAS-8 was used to determine self-reported adherence. Thirty-four (43.6%) scored zero

234 indicating high adherence, 35 (44.9%) scored 1-2 indicating medium adherence and 9 (11.5%) had a

235 score >2 indicating low adherence. Two participants were receiving medicine that was used on a

236 'when required' basis and thus were excluded from the analysis.

237

238 Four (5%) participants had purchased medicine compliance aids.

239

240 *"We were advised to take it with or after food. If I'd forgotten I didn't know if I could then give it*

241 *and so I would miss the dose and give his next one."* Patient 61 (ursodeoxycholic acid)

242

243 *"I don't find it difficult to stick to the plan because I know we have to stick to it because it's for his*

244 *eyes. A bit inconvenienced...it blows his weekend out. We give it on a Saturday morning so we can*

245 *do something on a Friday night if we want to. I sometimes forget the folic acid as he has three days*

246 *off when he's on the methotrexate."* Parent of Patient 20 (methotrexate)

247

248 Eighteen (22.5%) participants intentionally omitted doses. These were due to adverse effects (5,  
249 27.8%), concurrent acute illness (3, 16.7%), timing of administration (3, 16.7%), the desire to look up  
250 more information before starting the medicines (2, 11.1%), incorrect use (2, 11.1%), child declining  
251 to take (1, 5.6%), a mother not wanting their child to have the medicine as, although not used for  
252 this indication, they were an antidepressant (1, 5.6%) and ran out of supplies (1, 5.6%).

253

254 *“He was poorly once and was taking Calpol, Nurofen and antibiotics. So I stopped giving it then as I*  
255 *thought it was a bit much.”* Parent of Patient 100 (ranitidine)

256

257 *“Only the first night because of reading the side effects. My husband looked on the internet. Then*  
258 *we read the information the doctor gave us and realised it was more related to children and my*  
259 *husband was much happier so we gave it.”* Parent of Patient 56 (desmopressin)

260

### 261 **Seeking Further Information**

262

263 Twenty-six (30.2%) participants sought further information about their medicine. Twenty-two  
264 participants (84.6%) searched the internet, 2 (7.7%) asked a friend/relative, 1 (3.8%) asked other  
265 parents and 1 (3.8%) had looked in the British National Formulary.

266

267 Participants sought further information to: find out about side effects (13, 50%), general interest (5,  
268 19.2%), reassurance about the appropriateness of treatment (4, 15.4%), research a specific query (3,  
269 11.5%) and check that there were no interactions with concomitant medicine(s) (3, 11.5%).

270

271 *"I'm giving something new. I want to know what side effects there are. [Patient 6] is on lots of*  
272 *medicines, she's having seizures and I want to see how it interacts with the others, I don't want to*  
273 *make these worse."* Parent of Patient 6 (levomepromazine)

274

275 *"Basically, is that the right drug? Is it common to use it at this stage?"* Parent of Patient 75  
276 (azathioprine)

277

## 278 **Concerns and Further Questions**

279

280 Twenty-four (30%) participants who had taken/administered their medicine had some concerns.  
281 These related to side effects (10, 41.7%), efficacy (6, 25%), administration (4, 16.7%) and other  
282 concerns (4, 16.7%). Other concerns were the: perceived stigma of taking an antidepressant, impact  
283 of a friend questioning the choice of therapy, anticipated repeat prescription problems through the  
284 General Practitioner (GP) and advice provided by a pharmacist.

285

286 *"There was one thing. My friend works in a hospital, I'm not sure what she does, but when she saw*  
287 *what [Patient 11] was on she said that they'd been told to stop using them. I don't know why that*  
288 *is."* Parent of Patient 11 (piroxicam)

289

## 290 **Administration Issues**

291

292 Issues regarding administration were experienced by 21 (26.3%) participants. These were issues  
293 concerning: dislike of the taste/smell (11, 52.4%), timing of administration (3, 14.3%) and the impact  
294 of autism/learning difficulties (2, 9.5%). Other (5, 23.8%) experiences included the: manipulation of

295 a tablet to obtain a part-dose, problems extracting a tablet from a blister pack, fear of an inhaled  
296 spacer device, absence of a bottle adapter and swallowing difficulties.

297

298 *“It was difficult to find a suitable time as needed to be taken on an empty stomach an hour before*  
299 *food. She took it at school as there’s no afternoon break. In the morning she has breakfast, then*  
300 *there’s lunchtime. When she comes home she has an evening meal and then she’s tired and it’s time*  
301 *for bed.”* Parent of Patient 23 (lansoprazole)

302

303 *“He’s got a new spacer now as he couldn’t cope with the big one. It scared him. He’s got a smaller*  
304 *one with bears on it now which is fine from the GP.”* Parent of Patient 33 (beclomethasone inhaler)

305

## 306 **Adverse Effects**

307

308 Whilst cause and effect was not established, adverse effects were reported by 29 (36.3%)  
309 participants (Table 3).

310

311 *“Upper abdominal pain under her rib cage for three weeks, periodic headache, exhausted, very, very*  
312 *tired, her menstrual cycle has gone haywire. She’s been off school for three weeks. I’m desperate to*  
313 *find out the cause to alleviate her symptoms. My head tells me it’s the side effects from the drug...”*

314 Parent of Patient 15 (ciclosporin)

315 *“I was told one of the side effects was increased appetite. But her appetite is much greater now. I*  
316 *didn’t realise just how much it would increase.”* Parent of Patient 30 (pizotifen)

317

## 318 **Table 3 Reported Adverse Effects**

Therapeutic Use	Medicine	Number of Patients Reporting Effect	Reported Adverse Effect(s)
Eczema	Topical corticosteroid	1	Staining of clothing.
	Hydroxyzine	1	Drowsiness
Allergy	Fluticasone	2	Nose bleed, sore throat
Urinary Frequency/Enuresis	Oxybutinin	2	Drowsiness, dry mouth.
	Tolterodine	2	Drowsiness, dry mouth, constipation, abdominal pain.
Migraine/Headache	Pizotifen	3	Behavioural changes, constipation, increased appetite.
	Propranolol	1	Fatigue
Gastro-Oesophageal Reflux	Ranitidine	1	Vomiting
Epilepsy	Levetiracetam	2	Behavioural changes
	Acetazolamide	1	Behavioural changes
	Lamotrigine	1	Suicidal ideation
Constipation	Marogol	1	Diarrhoea
Rheumatic diseases	Nifedipine	1	Nausea, dizziness.
	Hydroxychloroquine	1	Abdominal pain.
Immunosuppression	Azathioprine	2	Blacking out/fainting, hairloss.
	Ciclosporin	1	Abdominal pain, headache, fatigued, changes to menstrual cycle.
	Methotrexate	1	Abdominal pain.
Other	Amitriptyline	1	Drowsiness
	Atorvastatin	1	Jaundice
	Enalapril	1	Dry cough
	Itraconazole	1	Abdominal pain.
	Propranolol	1	Coldness of the extremities

319

### 320 Further Supply Issues

321 Twelve (15%) participants experienced difficulties obtaining further supplies. Forty-seven  
322 participants (58.8%) had sufficient supplies from the hospital and 21 (26.3%) obtained further  
323 supplies from their GP. The problems experienced by participants included: delays in posting out  
324 clinic letters to the GP (4, 33.3%), insufficient information on the letter for a repeat prescription (3,  
325 25%), insufficient quantities prescribed by the GP (2, 16.7%), misreading of a letter by the GP (1,

326 8.3%), cancellation of a follow-up out-patient appointment where a repeat prescription was to be  
327 provided (1, 8.3%) and confusion due to a therapy substitution by the hospital pharmacy which did  
328 not then match the information in the clinic letter (1, 8.3%).

329

330 *“Yes, there was some confusion between the doctors. The hospital hadn’t written to the GP, the*  
331 *letter hadn’t been sent so I had to phone the consultant who organised the letter. Missed a week of*  
332 *the antibiotic.”* Parent of Patient 26 (co-trimoxazole)

333

334 *“Ran out of tablets. The doctor said to take the course and we’ll see you back. Out-patient on 8<sup>th</sup>*  
335 *June cancelled by the hospital and arranged for much later in August. Had to phone up and get it*  
336 *brought forward. The doctor said to take it for 6 weeks. We only had a 4 week supply.”* Parent of  
337 Patient 45 (amitriptyline)

338

## 339 **DISCUSSION**

340

341 Patients have a right to decide not to take their medicine and may have different views about risks,  
342 benefits and side effects.[16] In this current study, 6/86 (7%) participants had not started their  
343 medicine and 18/80 (22.5%) participants had intentionally omitted some doses. Therefore some are  
344 reviewing the initial therapy decision and others are making treatment changes without consulting a  
345 healthcare professional. Shared decision making between clinicians and patients about treatment  
346 choice is important.[17] Poor communication may lead patients to obtain information outside of a  
347 consultation with a healthcare professional.[18]

348

349 Overall participant reported adherence in this study was comparable with that published in the  
350 paediatric literature.[19, 20] Thirty-four (43.6%) participants exhibiting high adherence and 35  
351 (44.9%) medium adherence. Four (5%) participants had purchased medicine compliance aids. Due



352 to a lack of beneficial outcomes with the use of compliance aids the UK Royal Pharmaceutical Society  
353 recommends original pack dispensing with appropriate pharmaceutical care including clinical  
354 medication review.[21]

355

356 A recent systematic review identified a number of findings that contribute to explaining treatment  
357 adherence in paediatrics.[2] Including beliefs about the condition or treatment, treatment regimen  
358 and child resistance. Findings from the present study were consistent with these. For example 3/86  
359 (3.5%) participants decided against treatment, 21/80 (26.3%) experienced issues with administration  
360 including the taste/smell of the medicine and timing of administration. Whilst the systematic  
361 review[2] focussed on long-term conditions it did not identify when during treatment these themes  
362 occurred. This current study found that they can occur within the first six weeks after starting a new  
363 medicine.

364

365 A study of adult patients prescribed a new long-term medicine found that once a patient has  
366 experienced their medicine, they gain some knowledge of what it does and new questions arise.[5]  
367 The current study has shown that children and their parents/carers have similar experiences after  
368 the first few weeks of therapy. This is illustrated by 26/86 (30.2%) participants researching further  
369 information about their new medicines, 24/80 (30%) having concerns or further questions and 29/80  
370 (36.3%) possibly experiencing an adverse effect to treatment.

371

372 Twenty-one (26.3%) parents/carers had difficulties administering the medicine to their child. In  
373 adults, oral solid dosage forms are mostly acceptable. However, potential paediatric patients may  
374 include neonates, toddlers, young children and adolescents, and hence will have widely varying  
375 needs.[22] A change in formulation is currently excluded from triggering a NMS consultation.[23] Any  
376 future paediatric medication review should include changes in formulation as a trigger for a  
377 medication review.

378

379 Current evidence suggests that when patients move between care providers the risk of  
380 miscommunication and unintended changes to medicines is a significant problem.[24] This current  
381 study suggests that this is an issue in paediatrics with 12 (15%) participants experiencing problems  
382 arranging a repeat supply with 7 (58.3%) due to a miscommunication.

383

384 A systematic review of interventions to improve the safe and effective use of medicines by  
385 consumers identified a scarcity of evidence in children/young people.[25] The benefits of a  
386 medication review through the NMS have been appraised.[7] The NMS appraisal identified a variety  
387 of factors impacting on adherence including forgetfulness, beliefs about treatment necessity, stigma,  
388 lack of peer/family support, lack of knowledge, side effects, fear of dependency, regimen  
389 complexity, inability to use the formulation and access to medicines. Each of these factors were  
390 identified in this current study. The NMS applies a structured approach to identifying and resolving  
391 these issues.[7, 23] However it may not be available to children and is not available to their  
392 parents/carers.[6]

393

394 The results of this current study suggest that paediatric patients and their caregivers may benefit  
395 from some support initiative after the first few weeks of treatment with one option being an NMS  
396 type intervention. In addition to medication review a number of other initiatives may further  
397 support patients realising the benefits of their medicines. These include fostering better  
398 partnerships with patients, the use of telephone helplines for information on medicines, developing  
399 specific internet support websites, and improvements to how different healthcare professionals  
400 collaborate together.[13]

401

402

403

404 The limitations of this study include sample size which was relatively small, specialist paediatric  
405 centre setting which may limit how generalisable the results are and the restriction to English  
406 language speakers.

407

408

409

## 410 **Conclusion**

411

412 Paediatric patients and their parents/carers experience a range of issues during the first six weeks  
413 after starting a new medicine. Intervention at this stage may provide useful support to both the  
414 patient and their parent/carer. Further research is required to determine the type of intervention  
415 and how it could be integrated in to practice to optimise paediatric medicine use.

416

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418

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423

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425

## 426 **Conflicts of Interest**

427

428 Nil.

429

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