Initiating Self-Administration of Medicines for inpatients with cystic fibrosis

Ian M Balfour-Lynn ,[1] Khola Khan,[2] Nimla Pentayya,[3] Clare Pheasant,[3] Sian Bentley,[2] Sukeshi Makhecha[2]

► Additional material is published online only. To view please visit the journal online (http://dx.doi.org/10.1136/archdischild-2019-318368).

[1]Department of Paediatric Respiratory Medicine, Royal Brompton Hospital, London, UK
[2]Pharmacy, Royal Brompton Hospital, London, UK
[3]Nursing, Royal Brompton Hospital, London, UK

Correspondence to
Dr Ian M Balfour-Lynn, Department of Paediatric Respiratory Medicine, Royal Brompton Hospital, London, SW3 6NP, UK;
i.balfourlynn@ic.ac.uk

SB and SM are joint last authors.

Received 8 October 2019
Revised 28 January 2020
Accepted 12 March 2020
Published Online First 7 April 2020

ABSTRACT

Introduction Children with cystic fibrosis (CF) take a multitude of therapies at home. Self-Administration of Medicines (SAM) is a scheme whereby the parent/carer and/or older child keep control of their own medicines in hospital. We initiated a scheme and assessed drug errors, cost implications, and parent and nurse satisfaction.

Methods Following a pilot stage, the SAM protocol was initiated and amended as necessary. Drug errors were analysed from the Datix hospital electronic reporting system. Cost analysis of use of the patents own drugs was carried out. Questionnaires were given to parents and nursing staff.

Results In the initial 10 months, 97 children had 159 admissions, and 60% were deemed suitable for SAM. Drug errors still occurred—33 in 5 years. Cost savings for the hospital over 1 year were £20 022 for 123 admissions. Patient/parent satisfaction was high, and all wished to partake in SAM for further admissions.

Conclusions The scheme was a success although it took 3 years to bring to fruition. Drug errors still occurred but we were able to amend the protocol appropriately to react to these. Cost savings are an incidental benefit from use of patient's own medication. The SAM scheme is applicable to all children with chronic disease on long term medications when they are in hospital.

What is already known on this topic?

- Self-administration of medicine for hospital inpatients has been recommended by the Department of Health.
- It is thought to improve patients' knowledge and be acceptable, but systematic reviews of evidence on adherence and medication errors are inconclusive.
- There is minimal published information on its use in children.

What this study adds?

- We presented our experience setting up a Self-Administration of Medicines scheme for children with cystic fibrosis to inform other paediatric units who are considering implementing this.
- Drug errors still occurred, mostly due to documentation issues and problems of communication when drug regimens were altered.

INTRODUCTION

Children with cystic fibrosis (CF), especially those with a level of disease requiring hospitalisation, usually take a large number of oral and inhaled medications several times a day. At home this polypharmacy is managed by their parents/carers, and as they get older by the patient themselves. When they are admitted to hospital the responsibility for the medications is traditionally taken over by the ward nurses. While some families find this a respite, others feel disempowered, and are concerned about late timing of medications and drug errors. This is not surprising considering medication has become part of everyday life, and parents perceive themselves as experts in supervising their child's therapy.[1] Self-Administration of Medicines (SAM) schemes are an option whereby patients bring in and take their own medication when in hospital.

SAM is not a new concept in adult hospital wards and systematic reviews have been published[2–4]; there is also published experience from a large CF unit with teenagers in the USA[5] and our own adult CF unit.[6] There is scant paediatric literature, although there is a publication from a paediatric oncology and surgical unit in Nottingham.[7] Our online survey of the UK CF Pharmacists' Group showed that of the nine specialist paediatric CF units that responded, five centres did not have a SAM scheme, and of the four that did, two had started recently.

As part of our ongoing Quality Improvement initiative in CF, we developed a SAM Policy in our paediatric specialist CF Unit. The aim of this paper is to present our scheme with an assessment of drug errors, cost implications and patient/parent/carer and nursing satisfaction.

METHODS

The SAM scheme was developed by a group comprising specialist pharmacists, respiratory paediatricians and senior nurses. A risk assessment was carried with the Clinical Governance team. The policy was ratified by the Hospital's Medicines Management Board after a 1-year pilot study. Training of ward nurses and hospital pharmacists was carried out. Doctors are informed of the scheme at induction to the unit. Parents were informed at a parents' evening and by newsletter. All CF children and their parents/carers admitted to the ward in our large Specialist CF Centre were assessed for the SAM scheme, and data were collected for the first 10 months.

To cite: Balfour-Lynn IM, Khan K, Pentayya N, *et al*. *Arch Dis Child* 2020;**105**:986–990.

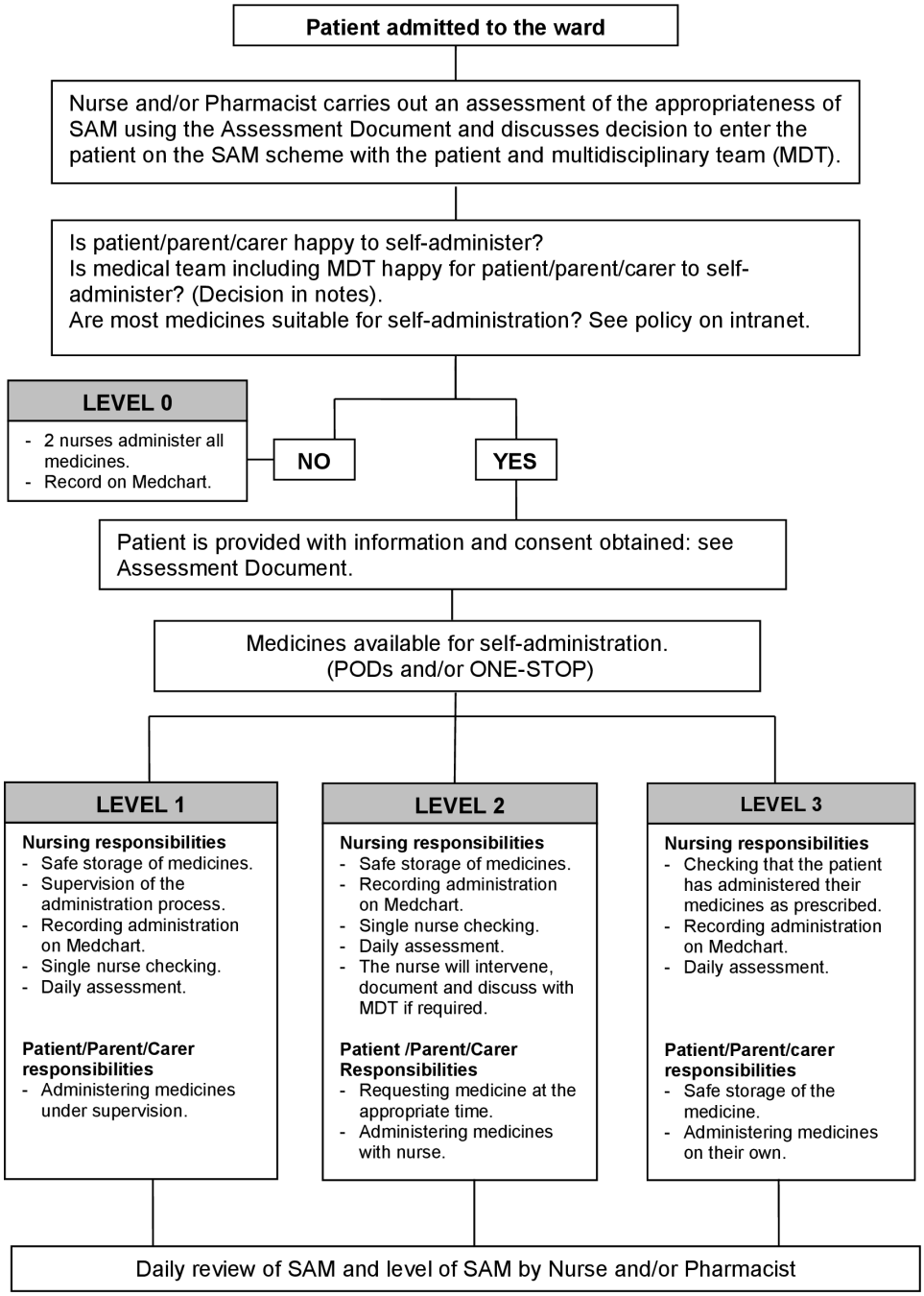

Figure 1 Algorithm for SAM scheme. SAM, Self-Administration of Medicines; PODs, Patients' Own Drugs.

The SAM policy

All CF patients/parents/carers responsible for administering their own medicines at home are considered in a shared decision process (figure 1). The decision is discussed with the CF multi-disciplinary team (MDT) on the daily ward round. The patient and parent/carer are given a written information sheet (online supplementary (OLS)) and signed consent is obtained. Medicines suitable for the SAM scheme are those the child was

Table 1 Categories of drug administration responsibilities in the SAM scheme

Level	Medicine administration	Medicine storage	Documenting on Medchart
0	Two nurses	Nurse	Two nurses sign they have administered drug
1	Supervising nurse comes to patient and gives with patient/parent/carer	Nurse	Nurse signs patient on Level 1
2	Patient/parent/carer prompts nurse and give together	Nurse	Nurse signs patient on Level 2
3	Patient/parent/carer	Patient/parent/carer has access to drug locker	Nurse checks given by patient/parent/carer and signs patient on Level 3

SAM, Self-Administration of Medicines.

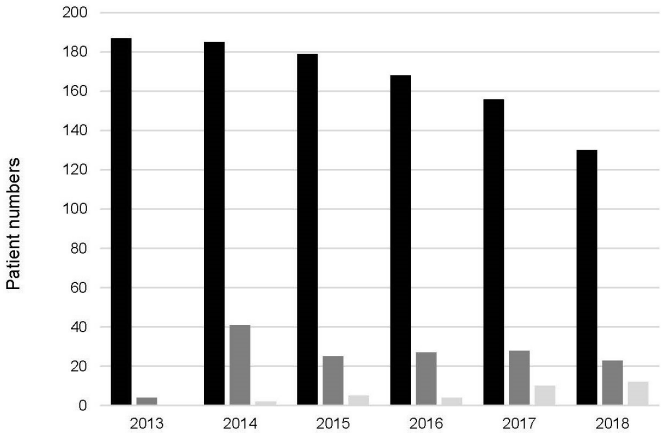

Figure 2 Number of CF admissions each year (black bars), with total reported in-patient medication errors for children with CF (dark grey bars) and those on the SAM scheme (pale grey bars). The pilot scheme ran actively from June 2014 to June 2015, and the full scheme was introduced in October 2015. CF, cystic fibrosis; SAM, Self-Administration of Medicines.

taking prior to admission, and those that will be continued on discharge (generally 5–12 drugs for each patient). We do not include controlled drugs nor postoperative pain infusions. Patient exclusion criteria are detailed in OLS.

Assessment

The suitability assessment is carried out on admission by the child's nurse using the self-administration tool (OLS). The patient is assigned to a SAM level (table 1). The decision can also be made later in their stay, or at an MDT pre-admission meeting which will be confirmed on admission.

Throughout the admission, the SAM level is reassessed by the nurse at the start of each shift, as the patient's condition and level of supervision required may change. The ward pharmacy team also checks the SAM level when checking the drug chart on their daily round. If a parent/carer administering medicines is to be absent, then the level of SAM is revised for that period. Other rules are in the OLS.

Drug errors

The hospital's Datix Online Reporting System (Datix, London UK) was analysed for 1 year prior to, and 5 years post initiation of the SAM scheme. We excluded errors related to controlled drugs as they were not included in the scheme.

Cost analysis

This was carried out for a 12-month period after initiation of the SAM scheme to assess the financial impact of using the patient's own medications. All drugs brought in that are supplied by the GP (General Practitioner) were recorded, and then costed for what it would have cost the hospital had we supplied that drug, based on the contract prices our pharmacy pays. These are for the CF drugs included in the Payment by Results (PbR) tariff which are not reimbursed to the hospital. For the high cost drugs (eg, nebulised antibiotics, dornase alfa) that are excluded from the PbR tariff, and which are reimbursed to the hospital by National Health Service England (NHSE), we calculated the 20% Value Added Tax savings to NHSE, as the tax is payable if the hospital supplies the drug, whereas there is no tax if they are delivered to the patient's home and then bought into hospital.

Table 2 Categories of 33 reported medication errors

Error type	No.
Poor documentation—uncertainty if drug given*	13
Poor communication to parents when prescription changed*	10
Parental confusion over drugs	5
Nursing errors	4
Out of date drugs brought from home	3
Miscellaneous	3

Miscellaneous included—one child drank the nebulised Promixin; one parent gave an intravenous flush when learning home intravenous antibiotics as uncertain what she was allowed to do on the ward; one grandparent gave the sibling's CF medication to the patient as they shared drugs at home.
*n=5 errors in both categories

No costings were done for nursing and pharmacy time spent on the SAM scheme.

Feedback from patient/parents/carers and nursing staff

Questionnaires were given out for the first 10 months to families in the SAM scheme and ward nurses to assess their satisfaction.

RESULTS

Assignment of administration levels

In the 10-month assessment period, there were 159 admissions for 97 children with CF, with a mean age of 12 years (range 4 months to 16.9 years). In 64/159 (40%) they were assigned Level 0 that is, all medicines given by the nurses as per standard practice. Reasons for this were too short an admission (n=32); refusal by parents (n=13); patient acutely unwell (n=5); known poor adherence (n=5); parent/carer not present throughout admission (n=5); reason not recorded (n=3); and first ever admission (n=1). The proportion of admissions assigned other levels were Level 1—36/159 (23%); Level 2—30/159 (19%); and Level 3—29/159 (18%). Note that during the pilot stage, patients were allowed to start at Level 3. For the 95 admissions that started at Level 1 or above, in 15 (16%) the level was increased while in 3 (3%) it was decreased; the rest 77 (81%) stayed the same throughout their stay.

Drug errors

In the 6 years, there were 148 errors in 1005 CF admissions (14.7%) compared with 117 errors in 5818 respiratory (non-CF) admissions (2.0%). Classification by severity (see OLS for grading) were CF—0 red, 1 amber, 7 yellow, 140 green; and for non-CF—0 red, 0 amber, 8 yellow, 109 green. There were two that related to intravenous antibiotics for children with CF. Reported medication errors on the ward in children with CF, and those related to the SAM scheme are outlined in figure 2 (as well as total number of CF admissions). There were 33 errors related to the SAM scheme in its 5 years, categorised in table 2.

Amendments to the original policy

- The drug chart was initially a standard paper chart but later became part of electronic prescribing using Medchart. This was a Hospital policy change.
- Parents of patients on Level 3 document drug administration on their own paper chart (as they are not allowed access to Medchart), which is also checked by the nurse. Nurse then records on Medchart.
- Children cannot start an admission on Level 3 but have to be on Level 2 for 24–48 hours; so they cannot come in and start

Box 1 Advantages and disadvantages of the Self-Administration of Medicines scheme

Advantages
- Patient and parent empowerment.
- Home routine maintained.
- Parents no longer concerned that drugs not given at exact time stated on drug chart.
- Error identification, for example, out of date medicines, wrong techniques of inhalation of drugs or insulin injections, wrong timing for pancreatic enzyme replacement around mealtimes.
- May highlight poor adherence, for example, we can see patient forgets to take on time or totally.
- Opportunity for education, for example, what drugs are for, how to take correctly, especially during pretransition phase.
- Cost savings to the hospital from use of Patient's Own Drugs.

Disadvantages
- Inpatient stay can relieve parents of some of the daily burden of care and give them some rest time, and this is diminished.
- Drug errors not significantly reduced.
- Stigmatisation of some parents when the multi-disciplinary team feel they need to be on Level 0.
- Initial staff engagement and time taken for training.
- Burden on parents bringing in all the drugs.
- Cannot be safely started on weekends.

Level 3 on a weekend. This was a safety net brought in due to errors caused by having no ward pharmacist on weekends.
- No PODs can be used until checked by pharmacy for condition and expiry date. Parents quite often brought in out of date medication.

Cost savings

In a 12-month period, for 123 patient admissions, the hospital saved £20 022 from using the patients' own drugs, compared with if our pharmacy had supplied them. NHSE saved £4819 which was for the tax on the reimbursable high cost drugs that is paid if the hospital supplies the drugs.

Feedback from patient/parents/carers and nursing staff

See OLS.

DISCUSSION

We decided to introduce the SAM scheme after feedback from a parent who gave all the treatments at home to her two children but was unhappy handing over responsibility to the ward nurses. It took 3 years to develop the policy, have it ratified by the Trust, run a pilot, amend the scheme, have the final policy ratified, and train the nursing staff. Importantly, once it was running, we made several amendments as issues arose and in response to medication errors. We hope this paper will help other CF units (and indeed any paediatric unit) considering a SAM scheme to learn from our experience, and thus enable them to initiate their scheme quicker and more effectively.

We have outlined the various advantages and disadvantages of SAM schemes in box 1. Many are obvious, but some are difficult to prove. The most recent 2014 systematic review assessed 43 publications but excluded studies where the drug was administered by relatives or carers, so is less relevant for paediatrics.[4] Nevertheless, they found that schemes increased patient knowledge, but evidence on adherence and medication errors was inconclusive. The SAM scheme certainly helps us identify suboptimal adherence, for example bringing in out of date drugs; signing for a drug that could not have been given as in one case it was not available on the ward, and in another the nebuliser was not working; and one patient drank the antibiotic meant for inhalation. We hope that our scheme helps improve adherence once home, following the extra nursing and pharmacist education, and by maintaining or starting medication routines, but we are unable to prove this.

Drug errors still occur which is inevitable given human factors; the error rate is significantly higher in children with CF (15%) compared with other respiratory admissions (2%), likely relating to the large number of drugs (mostly ranging from five to 12). We did not find a consistent change in the overall number of errors once the SAM scheme was introduced. The increase in SAM-related errors over time is probably due to more patients being enrolled, but unfortunately, we do not have patient numbers for each year. In the SAM scheme, the most common cause for an error was poor documentation, so it was not always certain whether a drug had been given. The other main reason was poor communication from the medical staff to the parents when a drug regimen had been amended. It does not help that the medical staff use an electronic prescribing system that parents cannot access. It is important that the nurse checks with the parents/carers each drug individually and does not simply ask if all the drugs have been given. We hope that the SAM scheme reduces drug errors that we presume happen at home, but that is impossible to prove. Our error rate may be an underestimate, as we cannot be certain that errors did not occur that were not reported on the Datix system, although we encourage error reporting in a non-judgmental way to improve patient safety. Of course, some errors will also go undetected, and some parents may choose not to report them. Surprisingly, one Australian study of 220 adults on a nursing convalescent unit using a SAM scheme, did not have a single patient-initiated drug error reported in 6 months.[8]

There are cost savings to the hospital due to parents bringing in their own drugs. However, this is not exclusive to a SAM scheme, and a stand-alone Patient's Own Drugs scheme will also save a hospital money. We have not assessed the cost implications from nursing time. This would be difficult as there is an initial increase in time spent, but then there is considerable time saved for Level 3 patients; and for those on Levels 1 or 2, the nurse checks the drugs with the parent rather than a second nurse. One Danish study on adults in an acute surgical unit found staff time to dispense and administer medication was significantly reduced but there were no significant differences in medication costs, despite using patient's own medicines; they commented that the literature provided contradicting results on cost savings.[9]

The Department of Health recommended self-administration programmes for suitable patients with long term conditions back in 2004.[10] We have presented our SAM scheme for children with CF and feel it has been a success. We have now adopted it for all respiratory and cardiac admissions for children on long term medications. We hope other specialist and general paediatric units can benefit from our experiences, as it is applicable to all children with chronic disease who are on long term medication.

Acknowledgements We wish to thank other members of the team who helped initiate the policy—Elizabeth Maynard, Elizabeth Biggart, Rupinder Pannu and Michele Puckey as well as all members of the CF team. We also want to thank Mary West (Deputy Sister and Medicine Management Champion Rose Ward). Thanks to Dr Elizabeth Haxby for help with governance issues. Thanks also to Penny Mortimer who provided the Datix information. We also wish to thank Mrs Lyster who first suggested we allow parents to give the children their medicines. We also wish to

acknowledge all those parents, family members, carers and friends who continue to look after their children with CF so diligently.

Contributors All authors contributed to data gathering and writing the paper. Please note that SB and SM are joint last authors.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient consent for publication Not required.

Ethics approval Data were collected as part of a service evaluation so ethics approval was deemed not to be required.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data sharing not applicable as no datasets generated and/or analysed for this study. All data relevant to the study are included in the article or uploaded as supplementary information.

ORCID iD

Ian M Balfour-Lynn http://orcid.org/0000-0002-0754-3863

REFERENCES

1 Slatter A, Francis S-A, Smith F, *et al*. Supporting parents in managing drugs for children with cystic fibrosis. *Br J Nurs* 2004;13:1135–9.
2 Lummis H, Sketris I, Veldhuyzen van Zanten S. Systematic review of the use of patients' own medications in acute care institutions. *J Clin Pharm Ther* 2006;31:541–63.
3 Wright J, Emerson A, Stephens M, *et al*. Hospital inpatient self-administration of medicine programmes: a critical literature review. *Pharm World Sci* 2006;28:140–51.
4 Richardson SJ, Brooks HL, Bramley G, *et al*. Evaluating the effectiveness of self-administration of medication (SAM) schemes in the hospital setting: a systematic review of the literature. *PLoS One* 2014;9:e113912.
5 Sterner-Allison JL. Management of adolescent and adult inpatients with cystic fibrosis. *Am J Health Syst Pharm* 1999;56:158–60.
6 Trapp M, Barton S, Morgan H, *et al*. Self-Administration of drugs for cystic fibrosis. *Prof Nurse* 1998;14:199–203.
7 Wright A, Falconer J, Newman C. Self-Administration and reuse of medicines. *Paediatr Nurs* 2002;14:14–17.
8 Grantham G, McMillan V, Dunn SV, *et al*. Patient self-medication--a change in hospital practice. *J Clin Nurs* 2006;15:962–70.
9 Houlind MB, McNulty Helle Bach Ølgaard, Treldal C, *et al*. One-Stop dispensing: hospital costs and patient perspectives on self-management of medication. *Pharmacy* 2018;6. doi:10.3390/pharmacy6020046. [Epub ahead of print: 28 May 2018].
10 Department of Health (UK). Management of medicines. A resource to support implementation of the wider aspects of medicines management for the National service frameworks for diabetes, renal services and long-term conditions, 2004. Available: https://webarchive.nationalarchives.gov.uk/20120504025905/http://www.dh.gov.uk/dr_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4088755.pdf [Accessed 13 Aug 2018].