

Integrating primary and secondary care for children and young people: sharing practice

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► Additional material is published online only. To view please visit the journal online (<http://dx.doi.org/10.1136/archdischild-2015-308558>).

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Received 9 March 2015

Revised 10 August 2015

Accepted 28 September 2015

Published Online First

20 October 2015

ABSTRACT

Objective To share innovative practice with enough detail to be useful for paediatricians involved in planning services.

Design A review of practice, adopting a realist approach.

Setting We collected detailed information about five initiatives which were presented at two meetings in July and October 2014 and telephone interviews between July and November 2014 with key informants, updating information again in February 2015.

Results The five case studies involved three clinical commissioning groups (CCGs): Islington CCG and Southwark and Lambeth CCG in London and Taunton CCG in the Southwest. All five initiatives involved acute paediatric units. We heard about four distinct types of services designed to bring paediatric expertise into primary care and/or improve joint working between paediatricians and primary care professionals: telephone multidisciplinary team, hospital at home, general practitioner (GP) outreach clinics, and advice and guidance. We defined four common ways that initiatives might work: promoting shared responsibility; upskilling GPs; establishing relationships between paediatricians and primary healthcare professionals; and by taking specialist care to the patient.

Conclusions We derived common aims and mechanisms and generated programme (mid-level) theory for each integrated care initiative about how they might work. These descriptions of what is being done can inform debate about which interventions should be prioritised for wider implementation. There is an urgent need for evaluation of these interventions and more in-depth research into how mechanisms and their effectiveness could be assessed.

INTRODUCTION

Integrated care for the elderly and adults with chronic conditions is informed by a growing body of research into models of care. The Department of Health is supporting continuous practice sharing and learning from innovation sites.¹ In contrast, there is a lack of research into effective models of integrated care for children and young people and a lack of case studies demonstrating how innovators are responding to the challenge of putting integrated care into practice. Services for children and young people still have a long way to go before they can offer the right care in the right place at the right time.²

Integrated care is an umbrella term to describe initiatives which aim to address fragmentation of care between and within public services.^{1 3 4} Integrated care can refer to care at the interface

What is already known on this topic

- Integrated care is an umbrella term used in this paper to describe initiatives which aim to address fragmentation of care between primary and secondary healthcare for children.
- Current NHS policies prioritise implementation of integrated care.
- There is a lack of research describing models of integrated care for children and young people or evaluating effectiveness.

What this study adds

- We identified four models of paediatric integrated care: telephone multidisciplinary team, hospital at home, general practitioner (GP) outreach clinics, and advice and guidance.
- Common mechanisms across initiatives included: promoting shared responsibility; upskilling GPs; establishing relationships between paediatricians and primary healthcare professionals; and taking specialist care to patients.
- These five case studies of what *is being done* inform debate about what *could be done* more widely.

between healthcare and social care services (horizontal integration),⁵ between primary, secondary and tertiary healthcare services (vertical integration), between different parts of a pathway within a single service, or between a child and family and each of the care providers that they rely on (integration around a patient).⁶ We define integrated care as the integration between primary and secondary healthcare for children and young people.

In this article, we review exemplars of integration between primary and secondary healthcare services for children and young people based on five case studies. These descriptions of innovation will improve understanding of what is feasible, for which children and with what possible impact. We use these descriptions of what is being done in order to inform debate about what could be implemented more widely and evaluated.

AIM

Our primary aim was to share innovative practice with enough detail to be useful for paediatricians



► <http://dx.doi.org/10.1136/archdischild-2015-309886>



To cite: Woodman J, Lewis H, Cheung R, *et al.* *Arch Dis Child* 2016;**101**:792–797.

involved in planning services. Paediatricians might consider whether any of the initiatives presented here could work in their own local environment, given their own population needs and the strengths and challenges in their own organisations. Commissioners and policy-makers may also find this article helpful when thinking about their role in helping paediatric units learn from each other and in building a robust evidence base.

METHODS

We collected detailed information about five initiatives using presentations given at two meetings in July and October 2014 and telephone interviews between July and November 2014 with key informants who had leading roles in the initiative: five paediatricians, one community matron and one GP. We contacted key informants by email again in February 2015 to make sure that we had the most up to date and correct information about the initiatives. We described the intended aims, target populations and key practices contained in each initiative as well as the facilitators and barriers to getting the initiatives up and running in each local context. We compared the five initiatives to identify common aims and ways of achieving these aims (mechanisms).

Our approach shares characteristics with a 'realist' approach to supporting quality improvement in healthcare.^{7 8} Our assumptions are that innovation and change in healthcare are achieved through dovetailing of change at multiple levels of the system and that local contextual factors determine effectiveness of intended mechanisms of change. In other words, the same intervention cannot get off the ground in every hospital/locality, nor should it be assumed to have the same impact if implemented in very different settings. A realist synthesis of evidence aims to generate theory about the interactions between contexts, mechanisms of change and outcomes so that learning can be meaningfully applied to other settings.^{7 8}

Generating such theory is beyond the scope of the descriptive case studies that we present here. However, articulating aims and presumed mechanisms can be thought of as a first step towards building a programme theory about these types of interventions—a mid-level theory that helps quality improvement by generating hypotheses about what is likely to work and how. This provides a framework for understanding how transferable these interventions might be to other local contexts and how evaluations could be planned.^{7 9}

We did not systematically collect data on impact of the five initiatives or cost/cost-savings, although we summarise informants'

thoughts on the impact of initiatives, where this was shared with us in the interviews. Questions of impact and cost are ones that need to be addressed in further research in order to convince commissioners to invest in these initiatives in the long term. As this study was part of an audit of practice, we did not require approval from an ethics committee. The study was registered as a clinical audit with the Great Ormond Street clinical audit team.

RESULTS

The five case studies involved three clinical commissioning groups (CCGs) in London and the Southwest of England: Islington CCG and Southwark and Lambeth CCG in London and Taunton CCG in the Southwest (see online supplementary table). All five initiatives involved paediatric units. We heard about four distinct types of services designed to bring paediatric expertise into primary care and/or improve joint working between paediatricians and primary care professionals:

1. *Telephone multidisciplinary team (MDT)*: an MDT telephone conference led by GPs for children and young people at risk of further hospital admission or visits to the Emergency Department (row A, see online supplementary table).
2. *Hospital at home*: joint management of acutely unwell children and young people in their own home by an enhanced community nursing team and paediatricians (row B, see online supplementary table).
3. *Two-GP outreach clinics*: two-GP outreach clinics (also called primary care paediatrics) where paediatricians either deliver clinics for children and young people jointly with GPs (row C, see online supplementary table), with GP trainees or health visitors (row E, see online supplementary table) or alone in general practice settings (row E, see online supplementary table).
4. *Advice and guidance*: An advice and guidance service for GPs to access specialist advice from paediatricians when they consider making a referral to a hospital paediatric outpatient clinic (row D, see online supplementary table).

See online supplementary table for a more detailed description of each initiative.

Who are the integrated care initiatives for?

The five initiatives targeted the whole spectrum of children and young people, from those who were acutely unwell, for example, with pneumonia or an exacerbation of asthma

Table 1 Common aims and mechanisms

Mechanisms and related initiatives	Aims			
	For patients			For services Reduce cost
	More convenience less disruption	Improve experience	Provide same or better care in the community as in hospital	
1. <i>Shared responsibility between paediatricians and primary care professionals</i> Telephone MDT, hospital at home			X	X
2. <i>Upskill GPs in paediatrics</i> Telephone MDT, GP outreach clinics, advice and guidance		X	X	X
3. <i>Establish professional relationships between paediatricians and primary healthcare professionals and share norms</i> Telephone MDTs, hospital at home, GP outreach clinics	X	X	X	X
4. <i>Take specialist care to the patient</i> Hospital at home, GP outreach clinics	X	X	X	X

GP, general practitioner; MDT, multidisciplinary team.

Table 2 Hypothesised relationship between activities, mechanisms and aims*

	Telephone MDT	Hospital at home
If....	GPs, paediatricians and a wider MDT discuss specific children and young people at high risk of ED attendances by phone each month	Specialist community nurses make daily visits to acutely unwell children and young people at home, followed by a telephone call between the community nurse and duty paediatric consultant
Then....	GPs will feel motivated and confident to manage these patients and will gain skills/have access to specialist support to do so (shared responsibility and upskilling GPs) MDT members will better understand their colleagues and their service thresholds (establish professional relationships and share norms)	Community nurses will have access to specialist paediatric support to manage these patients (shared responsibility) Community nursing and paediatric team will build relationships, trust and understanding (establish professional relationships and share norms)
So that....	Patients receive high quality care from their GP Families perceive a 'joined up' healthcare service and have a better patient experience GPs refer patients appropriately to ED	Paediatricians and community nurses jointly plan care (take specialist care to the patient) Community nurses can give parents extra skills and confidence to look after their unwell child
So that...	Patients trust the care they receive from the GP, feel motivated to seek help from primary care and become confident in managing their own chronic conditions Patients experience fewer exacerbations of chronic illness	Parents can look after their child overnight without professional support and can recognise when to seek urgent help Families experience a 'joined-up' healthcare service and a better patient experience
So that...	The need and motivation for ED visits is reduced Hospital costs are reduced and burden on overstretched ED services is eased Quality of healthcare is maintained There is less inconvenience and disruption for the patient and family	These children and young people can avoid emergency hospital admissions (along with hospital acquired infections) and if admitted, can be discharged earlier Hospital admission costs are reduced and beds are freed up Quality of healthcare is maintained There is less inconvenience and disruption for the patient and family
	GP outreach clinics (London)/paediatric primary care (Taunton)	Advice and guidance service
If....	If a consultant paediatrician runs a regular outpatient clinic in primary care, either jointly with a GP (London), GP trainee or health visitor (Taunton), or alone (Taunton)	If GPs have access to email advice and guidance from a consultant paediatrician when they are considering referring a child or young person to a hospital outpatient clinic
Then....	GPs will gain paediatric confidence and expertise, which they can disseminate to their colleagues (joint clinics; upskilling GPs) GPs, health visitors and paediatricians will better understand each other and the different service thresholds (joint clinics, establish professional relationships and share norms)	GPs will develop paediatric expertise (upskilling GPs)
So that....	Patients have access to paediatric examination and expertise closer to their home (Taking specialist care to the patient) Families perceive a 'joined up' healthcare service and have a better patient experience Families trust the care they receive in the community and are motivated to seek care outside of hospital	GPs can manage more children and young people without referring to hospital services Families have increased trust and confidence in primary care
So that...	These patients do not need to attend a hospital-located outpatient clinic These patients are less likely to go to ED for healthcare needs Healthcare costs are reduced and burden on overstretched outpatient and ED services are eased Quality of healthcare is maintained There is less inconvenience and disruption for the patient and family	Referrals from GP to hospital outpatient clinics are reduced These patients are less likely to go to ED for healthcare needs Healthcare costs are reduced and burden on overstretched outpatient and ED services are eased Quality of healthcare is maintained There is less inconvenience and disruption for the patient and family

*Formulated as a series of 'if-then' statements, following examples of articulating programme theory by Pawson *et al*⁷ Common mechanisms (see table 1) are in bold. ED, emergency department; GP, general practitioner; MDT, multidisciplinary team.

(hospital at home), to those with high levels of unplanned hospital use, including children with long-term conditions (telephone MDT, GP outreach clinics). Some initiatives included children and young people who could be managed entirely in primary care (advice and guidance and GP outreach clinics).

What were the aims?

The informants told us that the initiatives aimed to improved care for children, young people and their families and improve patient experience and quality of life (see online supplementary table). It was hoped that this could be achieved through avoiding the need for children and young people to go to hospital, either by avoiding the need for specialist care at all or by taking specialist care into the community. This is consistent with descriptions of approaches to integrated care for adults.¹

Informants reported that delivering care in patients' homes or in GP practices was more convenient and less disruptive for patients and their families, compared with expecting patients

and families to travel to and/or stay in the hospital. Informants argued that, for targeted groups of patients and with appropriate specialist support, care out of hospital could be of equal quality while offering a better experience for patients and saving money for services. Savings were anticipated through replacing expensive hospital activity for lower cost activity in the community. For example, in Taunton the tariff for a consultation in a GP outreach clinic was approximately 40% less than the tariff for a consultation in a paediatric outpatient department, because of increased administrative costs in hospital (GP outreach clinic in Taunton, see online supplementary table). Intended benefits to the service included reduction in costs and/or freeing up hospital capacity.

How were initiatives planning to achieve their aims (mechanisms of change)?

Based on reports from informants, we defined four ways that initiatives might work:

1. By promoting shared responsibility between paediatricians and primary healthcare professionals.
2. Upskilling GPs: increasing paediatric confidence and competence at the front end of care pathways
3. Establishing relationships between paediatricians and primary healthcare professionals: to promote shared norms, cultural understanding including of service thresholds and willingness to work together.
4. Taking specialist care to the patient: bringing paediatric expertise, treatment, specialist opinion and examination to the patient- 'care closer to home'.

As [table 1](#) shows, every one of these strategies was being used to try and maintain quality of healthcare provision while keeping children and families away from hospital, with a hoped for reduction in costs to services and increased capacity in hospitals. It was also hoped that some of the strategies would improve patients' experience of services and offer a more convenient way for child, young people and families to access high-quality healthcare ([table 1](#)).

Relationship between activities, mechanisms of change and aims

Unsurprisingly, the initiatives that involved MDT working had the most complex set of presumed mechanisms of change (telephone MDT, hospital at home and joint paediatric-GP outreach clinics; [table 2](#)). From the brief interviews, we could not explore in depth how hierarchies and leadership operated in practice in these MDTs. Organisations wishing to set up these kinds of initiatives will need to see if the presumed mechanisms of change set out in [table 2](#) are feasible and practical in their setting and use their programme theory (see Methods) to determine which outcomes to measure. For example, as well as measuring hospital use, it might be advisable to measure patient trust and confidence in primary care services which is a step on the presumed mechanisms of change in all of the initiatives (see [table 2](#)).

Barriers and levers

The most important context, acting as both level and barrier, across the five initiatives was related to funding (see online supplementary table). In many cases, the potential financial benefit to the CCG was clear: providing review in the community was cheaper than in hospital, especially where paediatric expertise was given electronically. In contrast, hospitals which were paid per patient (rather than paid a flat fee for a block of services) stood to lose income if the initiatives were successful in reducing hospital visits (see online supplementary table). Even where hospitals had negotiated a tariff from commissioners for each patient 'treated' away from hospital, there was a fall in hospital income (advice and guidance service, see online supplementary table).

Potential to free up both staff time and beds appeared to encourage hospital participation in the initiatives. For example, the advice and guidance initiative was reported to have created additional capacity in outpatient hospital clinics, which could help hospitals reach performance targets as well as generate additional income by hosting tertiary care clinics (detailed in see online supplementary table). In another example, clinicians spent less time transferring patients to other hospitals after hospital at home reduced admission and length of stay for other patients.

An additional lever was the existence of established and functional services. The hospital at home service extended a pre-existing expert community nursing service and good relations

between this team and acute paediatric services in the area. The GP outreach clinic in Taunton built on the success of the advice and guidance service and the telephone MDT (London) extended an existing scheme for adults (see online supplementary table). These services can be thought of as extended or enhanced services rather than completely new services.

Unsurprisingly, strong and committed leadership and organisational and stakeholder enthusiasm was a prerequisite to set up and sustain initiatives. Engagement and support was achieved through establishing a shared vision and agenda, which could be a difficult and lengthy process. In one case this involved external facilitators (hospital at home), codesigning services with organisational and front-line stakeholders and having committed and properly resourced leadership. This initiative required buy-in from wider team members, such as pharmacy and information technology services who needed to be responsive and flexible as services evolved quickly over time.

What was the perceived impact of these initiatives?

Key informants reported demonstrable benefits from initiatives, including meeting their aims of reduced hospital activity and in some cases reducing cost (advice and guidance and GP outreach clinic in Taunton). Unforeseen benefits were also reported. The hospital at home team noticed improved child safeguarding from the nurses making home visits and heightened awareness and paediatric referral to all community nursing services. In two cases, informants reported that commissioners and providers had raised potential harms and said that these would be explored in evaluations of the initiatives. Commissioners of the Taunton GP outreach clinics feared that thresholds for the joint clinic in primary care would be lower than for outpatient clinics and there would simply be an increase in service activity rather than a transfer of activity into primary care from hospitals (see online supplementary table). The informant for hospital at home raised the possibility that transferring hospital care into the community might threaten the existence of hospitals which were geographically near (see online supplementary table). No potential harms were mentioned for children, young people or their families.

DISCUSSION

Our primary aim was to share innovative practice at the interface of paediatric and primary care with enough detail to be useful for paediatricians involved in planning services. Informants cogently described their initiatives, each of which was reportedly feasible in their setting. We perceived common aims and mechanisms and generated programme (mid-level) theory for each about how they might work. These descriptions of what *is being done* can inform debate about what *could be implemented* more widely and evaluated.

Overwhelmingly, the initiatives aimed to reduce the need for children and their families to visit hospital for specialist paediatric care. It was thought this would improve or maintain quality of care for patients, improve their experience of healthcare services and/or quality of life and reduce costs for the health system. Hospital at home and the Telephone MDT were the most intensive and complex of the initiatives, working through a number of mechanisms and involving joint working within large MDTs. All of the initiatives, to varying degrees, intended to promote shared responsibility for patients between paediatricians and primary care professionals (specifically GPs or community nurses) and to establish relationships between these two groups as a mechanism for improving care and outcomes for children, young people and families.

What are the gaps in knowledge?

An obvious gap in this report is our restriction to five case studies in two areas in the South of England and only a handful of initiatives within these localities. We were also limited by the focus on paediatric informants. Widening the scope of enquiry geographically and in terms of informants would reveal additional types of interventions. For example, we know of education initiatives directed at children, young people and their parents to help them avoid unplanned hospital visits and to navigate the healthcare system. A survey of practice in paediatric units would provide breadth of coverage about initiatives currently in place in England. We found it difficult to collect information about exact costs of a service and throughput of patients and staff hours needed. This information might not have been available to informants although they were leaders/champions of the services. Alternatively, there may have been a reluctance to share this information and/or a lack of comprehensive costing where initiatives relied on 'slack resources' (availability of staff time) within organisations.

There is a lack of robust research evidence to tell us whether the initiatives we described achieved their stated aims for children, families or health services or mechanisms worked in the ways we imagined. Most of the initiatives are very new and some have planned evaluations. No results are available yet. As none of these evaluations involve comparisons with similar services without integrated care, the planned evaluations will provide learning on the design and implementation process rather than robust evidence about effectiveness.

The descriptions of the key practices, aims and mechanisms of the five initiatives presented here allows us to look for indirect evidence about their effectiveness, based on studies of similar interventions, including in different patient groups. Based on the common aims of the initiatives (table 2), we sought indirect evidence from literature reviews relevant to 'care closer to home', 'demand-management' (reducing burden on hospitals and increasing efficiency of services) and MDT working by telephone.

For example, Roland *et al* reviewed the evidence on specialist-led outpatient clinics located in primary care as part of a larger review on efficiency of outpatient services.^{10 11} Parab *et al* conducted a systematic review (2013) of specialist home-based nursing services for children evaluating a hospital at home alternative to admissions for acutely ill children.^{12–16} Blank and colleagues published a systematic review of 'gatekeeping services' for referral from primary to planned secondary care, relevant to the advice and guidance service in Taunton.¹⁷ Ke and colleagues conducted a systematic review on the cost-effectiveness of teleconferencing for MDTs in adult secondary care.¹⁸

Generally, the evidence included in the reviews is weak, with a high likelihood of bias even for the handful of randomised controlled trials evaluating hospital at home and gatekeeping services into secondary care.^{17 18} Most relevant evidence comes from before and after studies, not always with a control group.^{10 11 17 19}

There is some evidence that families prefer services, which bring specialist care out of hospital and into their home or the community,^{10 11 19} that health outcomes *might* be maintained when care is provided closer to home,^{10 11 13 19} but that they are not necessarily efficient for the NHS.^{10 11 17–19} Other reviews of integrated care initiatives in adults have also highlighted the potential for these initiatives to increase demand and/or cost despite ambitions to the contrary.¹ The lack of good quality evidence makes it difficult to draw firm conclusions about effectiveness.

High-quality comparative studies of the interventions that we have described will be challenging, but feasible—previous randomised controlled trials in this area have already been

undertaken. High-quality comparative studies are necessary to start untangling the effects of the intervention from other complex factors within and beyond the healthcare system.

Using a bottom-up approach to describe innovative services in terms of activities, aims, presumed mechanisms and the relationship between them is the first step to improving the evidence base in this area. However, more in-depth studies are needed in order to build theory around mechanisms when evaluating integrated care interventions.²⁰

Research also needs to evaluate how new commissioning reforms impact on the ability for local providers to innovate and push forward models promoting integrated care for children and young people.

Implications for services and policy

Paediatricians and other child health professionals can use the description of these five initiatives to consider whether any of them could work in their own local environment, given their own population needs and the strengths and challenges in their own organisations. Those running or planning similar services should also consider potential harms of the service and measure these as well as potential benefits in studies to evaluate the effectiveness of integrated care initiatives.

Services planners and leaders should share their innovative practice, including clear descriptions of the activities, aims, proposed mechanisms for achieving these aims and the service and population context.

Policy makers have a role in helping services learn from each other in order to innovate safely and efficiently. The NHS should consider commissioning a nationwide survey of integrated care projects with follow up to assess sustainability and unexpected effects. Commissioners could also be responsible for describing new initiatives in detail and making this information publically available. These are the first steps in working towards urgently needed comparative studies to determine which interventions work best and for whom.

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Acknowledgements We would like to thank the key informants for each initiative: Katie Coleman, Catherine Lad and Mando Watson (telephone MDT and the wider programme of Connecting Care for Children), Sara Hamilton and Jeanette Barnes (hospital at home), Claire Lemer and Janet Lailey (GP outreach clinics in Southwark and Lambeth), Sarah Bridges and Rebecca Mann (advice and guidance and paediatric primary care in Taunton). We are also grateful to Ingrid Wolfe who commented on a draft of this article. The authors would like to thank members of the Policy Research Unit for the health of children, young people and families: Terence Stephenson, Catherine Law, Amanda Edwards, Steve Morris, Helen Roberts, Cathy Street, Russell Viner and Miranda Wolpert. We are also grateful to Linda Haines.

Contributors RG, JW, RC and LPMMW conceived the paper and methods. HL and JW conducted the interviews with key informants and HL and LW gathered data from the meeting. JW and HL analysed the data and JW drafted the paper. RG, RC and LPMMW contributed to the interpretation of results, and revised the paper. All authors commented on the analyses and report, and read and approved the final manuscript.

Funding LPMMW and JW were supported by funding from the Department of Health Policy Research Programme through funding to the Policy Research Unit in the Health of Children, Young People and Families (grant reference number 109/0001).

Disclaimer The views expressed are not necessarily those of the Department of Health.

Competing interests None declared.

Provenance and peer review Not commissioned; externally peer reviewed.

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ARCHIVIST

Apple juice for rehydration

Oral rehydration therapy (ORT) has been the preferred treatment for mild gastroenteritis (GE) globally for decades. Solutions containing glucose and electrolytes are undoubtedly effective, but there's a problem: they taste awful (ever tried one?). Young children who are feeling unwell are even less likely to drink something unpleasant than they would when well, so many carers abandon attempts to force it down: the result, sometimes, is the eventual need for intravenous fluids. Could this be prevented by giving something more palatable?

Researchers from Toronto, Canada set out to see whether dilute apple juice was as good as standard electrolyte maintenance solution (EMS), here sweetened with sucralose (Freedman S, et al. *JAMA*. 2016; doi:10.1001/jama.2016.5352). In a non-inferiority trial, they randomised over 640 children aged 6 months to 5 years presenting to a single large children's emergency department (ED). To qualify they needed to have mild GE, ie, no or only minimal dehydration clinically, and no other complicating conditions. The study was single-blind, so the caregivers knew what they were giving after discharge from the ED, and they were given specific instructions: the apple juice group could drink what they wanted, while the EMS group were asked to stick with a rehydration schedule. They were followed up by telephone contact after 48–72 hours. No lab tests were done. Treatment failure was defined as the need for admission or IV fluids, re-attendance, or symptoms persisting >7 days.

They found that the apple juice group did better (17% were treatment failures vs 25% in the EMS group: $p < 0.001$ for inferiority, $p = 0.006$ for superiority). IV fluids were given to 2.5% of the apple juice group and 9% of the EMS group. The difference was greatest for older children, perhaps because they are more fussy about what they drink. The higher sugar content of apple juice, which in theory could cause a pro-diarrhoeal osmotic effect, did not seem to be a problem.

It is important not to extrapolate these findings to low-income countries, and where the nature and severity of GE is very different. But here in the West, we can now feel more reassured about what many of us are saying to parents already: if the child won't drink electrolyte solution, ask them to drink dilute juice instead.

Competing interests None.

Provenance and peer review Commissioned; internally peer reviewed.

Accepted 7 July 2016

Published Online First 19 July 2016

Arch Dis Child 2016;101:797. doi:10.1136/archdischild-2016-311566

