



# Health professionals' perspectives on delivering home and hospital management at diagnosis for children with type 1 diabetes: A qualitative study from the Delivering Early Care in Diabetes Evaluation trial

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## Funding information

Diabetes UK, Grant/Award Number: RD06/0003353; National Institute for Social Care and Health Research Clinical Research Centre

## Peer Review

The peer review history for this article is available at <https://publons.com/publon/10.1111/pedi.13023>.

## Abstract

**Objective:** To explore the delivery of home and hospital management at diagnosis of type 1 diabetes in childhood and any impact this had on health professionals delivering care.

**Methods:** This qualitative study was undertaken as part of the Delivering Early Care in Diabetes Evaluation randomized controlled trial where participants were individually randomized to receive initiation of management at diagnosis, to home or hospital. Semi-structured telephone interviews were planned with a purposive sample of health professionals involved with the delivery of home and hospital management, to include consultants, diabetes and research nurses, and dieticians from the eight UK centres taking part. The interview schedule focused on their experiences of delivering the two models of care; preferences, impact, and future plans. Data were subject to thematic analysis.

**Results:** Twenty-two health professionals participated, represented by consultants, diabetes and research nurses, and dieticians. Overall, nurses preferred home management and perceived it to be beneficial in terms of facilitating a unique opportunity to understand family life and provide education to extended family members. Nurses described a special bond and lasting relationship that they developed with the home managed children and families. Consultants expressed concern that it jeopardized their relationship with families. Dieticians reported being unable to deliver short bursts of education to families in the home managed arm. All health professionals were equally divided over which was logically easier to deliver.

**Conclusions:** A hybrid approach, of a brief stay in hospital and early home management, offers a pragmatic solution to the advantages and challenges presented by both systems.

## KEY WORDS

care delivery, childhood, diagnosis, healthcare professionals, type 1 diabetes

The research was conducted at Cardiff University.

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## 1 | INTRODUCTION

When a child is diagnosed with type 1 diabetes (T1D), patients and their families need to acquire a vast amount of information regarding the condition and its management, of which they may have little prior knowledge. Education is recognized as crucial to the successful self-management of T1D.<sup>1</sup> The education required differs from other common chronic childhood diseases due to the constant and complex management and the necessity for continuous awareness of the symptoms of acute hypoglycaemia and diabetic ketoacidosis. Whether to deliver this education and take care of newly diagnosed clinically well children at home or in hospital has been debated for a number of years.<sup>2</sup> Worldwide a number of different practices have been adopted ranging from a 2-week stay in hospital<sup>3</sup> to discharge home immediately after diagnosis.<sup>4</sup> The Swedish approach of 14 days in hospital is designed to allow one or both parents to learn how to manage the condition, whereas the advantages of immediate discharge are described as reducing the use of hospital resources, while improving families' ability to manage the condition. However, there are limited published data from high quality clinical trials, and only one in a UK context, to inform whether initiation of care at home or in hospital is best in terms of successful long-term management of the condition.<sup>5-7</sup>

Our recently reported study, the Delivering Early Care in Diabetes Evaluation (DECIDE) randomized controlled trial was designed to evaluate the effects in terms of physical, psychological, social and economic outcomes of either initial management at home or 3 days of hospital management of children under 16 years of age at onset of T1D in eight UK centres. Results from this trial show that there was no difference in physical, psychological and serious adverse event outcomes between those whose management was initiated in home and those managed in hospital,<sup>7</sup> suggesting both models are safe.

In order to participate as a site in the DECIDE trial, some centres had to change their current practice of hospital management only from diagnosis to accommodate the intervention and study design, that is, to enable randomization to home or hospital when a child was newly diagnosed with T1D.<sup>8</sup> Introducing a new service in any setting raises a number of challenges. For the paediatric diabetes services taking part in the DECIDE trial, establishing a novel method of management raised potential issues, for example, a shift in responsibility among staff, a change in working environments and effective communication. To help facilitate these changes, a DECIDE paediatric diabetes research nurse was employed at each centre for 18 months through the research funding. Their intended role was to support the provision of clinical care for home and hospital managed patients, as well as supporting the research activity, for example, collecting and recording of data. The logistical issues and any impact the two models of care had on those working within paediatric diabetes services were important to consider. Therefore, this article reports on a qualitative study undertaken to gain insight and understanding on the effect of delivering the two models of care from the perspective and experiences of health professionals participating in the trial, with the aim of informing future implementation.

Our study sought to provide generalizable messages about how this complex organizational intervention may interact with its context and how that may support or hinder implementation. This places this work largely in the "Context" function of the MRC guidelines for process evaluations but also would shed light on other functions such as "Mechanisms of Impact."<sup>9</sup>

## 2 | METHODS

The structure of hospital and home management in the DECIDE trial has been described in detail elsewhere<sup>7,8</sup> but in brief, hospital management comprised three overnight stays in hospital and home management comprised six supervised injections delivered over 3 days in the participant's own home. As this was a pragmatic individually randomized controlled trial, some centres with a large geographical case-load spread offered elements of home management in their outpatient clinics to some participants. All education and dietary advice were given as per local procedures and as such should have been consistent across the two arms, the only difference being the location in which it was delivered. All centres offered 24 hours on call out of hours cover, but some ensured this was delivered by the specialist paediatric diabetes team.

In this qualitative sub-study, a purposive sampling framework was developed to ensure representation of each discipline from each of the eight UK centres taking part in the DECIDE trial. This included at least one consultant, one diabetes specialist nurse and one research nurse from each of the centres. In addition, a smaller sample of dieticians were randomly selected from two sites. All interviews were conducted by telephone and digitally audio recorded.

The interview schedule was semi-structured, which, while ensuring generation of relevant data, allowed exploration of ideas and topics raised by participants. The interview schedule was developed with clinicians, a psychologist and methodologists from the trial management group. Two general topics were included, namely clinical practice and conducting the trial, which were split further to explore potential differences between home and hospital management. The interview schedule regarding the two models of care included topics on health professional roles, experience of delivery, preference, impact on teams and future practice.

J. T., who was the Trial Manager, and experienced in qualitative research methods, undertook the semi-structured interviews, by telephone. Data were transcribed verbatim by the study administrator, although any identifiable data were anonymized. Familiarization with the data were gained through a combination of re-reading and re-listening to transcripts by the researcher (J. T.). The data were organized using the MS Word "spike" facility,<sup>10</sup> which enabled development of an initial coding framework. Ensuring the consistency of coding within the initial coding framework was performed by the CI, an experienced qualitative researcher (L. L.). This framework was refined using a thematic analysis approach.<sup>11</sup> All authors were involved in discussions regarding the emerging themes and provided consensus over the interpretation of results.

Ethical approval for the DECIDE trial from MREC for Wales (07/MRE09/59) included the qualitative study of health professionals. Written informed consent was provided by all participants.

### 3 | RESULTS

In total, 22 interviews were undertaken by the researcher (J. T.). Interviews were conducted between 3 and 9 months after centres had completed recruitment.

All centres were represented in the final sample, which comprised eight consultant paediatric endocrinologists, seven DECIDE research nurses, three paediatric diabetes specialist nurses (PDSNs), two dieticians, and two Comprehensive Local Research Network nurses undertaking the role of a DECIDE research nurse. Within all disciplines, some had a more active role in the conduct of the study than others, for example, attending monthly study management meetings. The DECIDE research nurses were employed by each centre specifically for the study, and were provided with training where needed, although all were required to have at least 5 years paediatric nursing experience. The average length of each interview was 20 minutes. The quality of one recording from a consultant paediatric endocrinologist was too poor to be transcribed, and therefore, the final data analyses were performed on 21 recordings.

Four main themes, with several sub themes, were identified from the data: Changing Practice (motivation and managing change), Models of Care (the differences, impact and ease of delivery of home and hospital management), Relationships (reliance), and Future Practice.

### 4 | CHANGING PRACTICE

Only two of the eight participating centres were delivering home management before the DECIDE trial commenced, so it was a new experience for many centres and initial negotiations within teams about introducing home management raised issues around logistics, hours to be covered and anticipation of a heavy workload. Two centres adopted a model of working where the DECIDE research nurse carried out all the home management care, with the PDSNs caring for participants randomized to the hospital arm. The other six centres divided the workload equally between the DECIDE research nurse and the PDSNs, and therefore experienced providing care for both home and hospital managed participants.

#### 4.1 | Motivation

Some consultants stated that they had expressed interest in taking part in the study explicitly to introduce home management as part of the service in their centre.

I had other motives as well to take (part)... that was to get our nurses... to the idea of managing children at home ... at the time of diagnosis [Consultant 1]

#### 4.2 | Managing change

The importance of involving all the team in discussions about initiating home management was emphasized and those teams that did include all members in initial discussions seemed to work more effectively. In some cases, the decision to take part was taken from the top down and this led to difficulty in terms of how teams worked together and how the nurses engaged with the study.

There...are up times and down times. There were times I felt I wasn't supported... the nurses initially were quite hostile 'cause they didn't actually want to take part in the study, it was sort of thrust on them [DECIDE nurse 1]

Teams that considered that they worked well together, shared the workload equally and some nursing teams provided full on call cover for all newly diagnosed children out of hours. Those teams that were reluctant to take part designated the specifically recruited DECIDE research nurse to undertake all of the home management. These DECIDE nurses undertook this work but all felt that it would not have been sustainable outside of the study as it resulted in many additional unsocial hours which were difficult to take back in lieu.

When I was doing it I thought this is OK but when I stopped doing it and looked back, that's when I realised gosh you know that was a bit unsocial for me coming in at nine o'clock at night and you know I couldn't have kept that going long term... [DECIDE nurse 3]

### 5 | MODELS OF CARE

#### 5.1 | Differences

##### 5.1.1 | Increased nurse responsibility

All health professionals stated that the diabetes service was already nurse led but thought that home management increased nurse responsibility. Nurses made decisions about prescription regimens when children were seen at home, whereas in the hospital setting a doctor would be called to determine their medication. Most nurses enjoyed the increased responsibility but some felt this was too much responsibility for their grade.

...in the home setting we can ...titrate doses of insulin ...right from ...day one, whereas if they'd been in

hospital for two or three days we wouldn't have done that, that would have been left to the consultant [PDSN 1]

## 5.2 | Impact

### 5.2.1 | Impact on consultants

Some centres recognized early on in the study that there was the potential for participants in the home managed arm to miss out on contact with a consultant at diagnosis. Primarily, this was due to the time of day that participants presented at hospital and were subsequently sent home with subsequent lack of opportunity for the consultant to have contact during an in-patient stay. It was felt that this adversely affected the rapport consultants had with the child and family when they saw them in clinic a couple of weeks later. Some consultants also felt they were taken less seriously because other health professionals had already had to make important decisions about a child's care. To rectify the potential for this situation, some centres made the decision that all participants randomized to the home managed arm would see a consultant before going home.

...and you know, maybe it becomes more difficult to build up a rapport with them because I haven't seen them at that critical time, it's harder when you've never met the patient and they've just been managed by nurses to then stand in and say, ok, well we're going to do this and we're going to do that... [Consultant 2]

## 5.3 | Preferences

Overall, nurses expressed preference for home management but all health professionals were equally divided concerning which was logistically easier to deliver. Consultants and dieticians were equally split over which they preferred but all health professionals felt more confident with discharging clinically well children earlier rather than keeping them hospital for 3 days.

...it feels uncomfortable now keeping them in for three days...when you know you can manage them right from the word go at home [DECIDE nurse 2]

## 5.4 | Ease of delivery

### 5.4.1 | Benefits of home management

One of the positive aspects of home management from the nurses' perspective was that education was better received and it was easier to deliver because the families were more relaxed in their own home. They felt that families got back into their own routine and adjusted to

diabetes management more quickly at home whereas families with a child in hospital would almost have to "start again" once they were discharged. They recounted how, in the hospital environment, education was more likely to be interrupted due to other health professionals needing to see the child and said it was more difficult to have privacy on a hospital ward. They felt that they spent longer with home managed families and could identify gaps in their education more easily.

I like home management because I felt you got to know their home life more quickly and how diabetes was going to fit into their life [DECIDE nurse 5]

Another advantage of home management was that it gave the nurses a greater opportunity to extend the education to wider family members, for example, grandparents and siblings, which may not have happened in hospital. They recalled they had more time to spend with families and could quickly evaluate how families would cope with diabetes management by seeing them in their own home, as they got a sense of family life and how families functioned and related to each other.

It was quite good in that it allowed you to teach some of the extended family a bit more about diabetes...siblings and grandparents...you would not get that extended family for when they were in hospital [DECIDE nurse 4]

### 5.4.2 | Negative aspects of home management

Dieticians felt that they had less opportunity to deliver short bursts of education to the home managed arm as they would to those hospitalized because lack of resources would often only allow them to make one home visit. This led to some nurses feeling a responsibility to deliver more of the dietary education. Dieticians also felt that communication and feedback within the clinical team, on how families were doing, suffered as a result of home management. This was due to fewer opportunities to quickly catch up with other team members who were out on home visits rather than opportunistic meetings that occur in the hospital.

If they're in hospital obviously you're bumping into people...into other team members and maybe have a chat about how things are going with the new patients [Dietitian 1]

One aspect of home management that some consultants, nurses, and dieticians expressed concern over, was that by sending clinically well children home, the severity of the condition was minimized. It was felt that hospitalization emphasized the serious nature of the diagnosis and some families who were randomized to the home management arm, would not perceive it as significant. They worried how

this would be interpreted in the individual's wider community and extended family and how this could affect future management.

I think some families will take it seriously no matter who they are but I think some families will think oh well this can't be that bad if they've allowed me to go home [DECIDE nurse 2]

## 5.5 | Relationships

All nurses, except one, described a stronger relationship with the home-managed participants, especially over the first few days. In part, this was due to the amount of time they were spending with the families but there was also the unique experience of seeing someone in their own home which changed the relationship. Nurses described it as a special bond where they would become the focus of the family's world, someone who came to their house and helped them, who was more approachable. It was felt that the families trusted them and they were the ones that they were most likely to contact if they needed advice.

I think it probably improved your relationship with the family...if they were able to go home straight away then you become...the only person who's name they get to know [PDSN 2]

The special bond and trust which was built up with the nurses and the home managed families meant that families, in particular fathers, were more likely to open up and visits could become longer and more emotional as they felt more relaxed in their own home to express their feelings.

I had a couple of parents who really broke down and that was quite difficult to deal with and calm them down again...I suppose being in the house because it was their own environment he could relax and kind of felt comfortable to break down, rather than the hospital setting [DECIDE nurse 4]

## 5.6 | Reliance

Sometimes the special bond had a negative effect and there was recognition from the other health professionals that it could lead to over-reliance and dependence on one individual and some nurses also felt that families perhaps relied on them too much.

I sometimes feel perhaps they rely on you too much... get a bit freaked out when you're not in the house with them...between visits they can sort of get a bit worried...and overnight [DECIDE nurse 4]

This special relationship and reliance would sometimes encroach on the nurses' private lives and nurses themselves would worry about families and feel a responsibility for them. Nurses stated that they would be more likely to phone a home managed family in the evening just to check they were all right, whereas in the hospital they felt more confident that the medical staff would take care of them if necessary.

... a lot of the time ... you go on holiday and they're still texting and ringing me which I don't mind really cos ... I wouldn't like somebody to be at home worrying but they know that they're meant to ring the specialist nurse ... if they can't get hold of them they just ring me straight away... [DECIDE nurse 6]

A dietitian also mentioned the importance of building a relationship with the home managed families and felt they were more empowered than those hospitalized.

I've always felt that patients who are managed at home are far more empowered to feel that actually they manage the diabetes, whereas patients who are managed in hospital, I always have the sense that they look to us a lot more [Dietitian 2]

## 6 | FUTURE PRACTICE—AT THE END OF THE STUDY

Interestingly, only two centres continued offering home management after the DECIDE trial had finished and these were not the original two centres that had offered home management before the trial started. The main reasons for discontinuing home management were a lack of resources and a change to the out-of-hours policy at a number of centres, which meant that nurses were no longer paid for or allowed to work weekends. In addition, funding ceased for the research nurses who had been provided to each centre for the duration of the trial, leading to a reduction in staff in some centres.

After the trial finished, some DECIDE centres reported adopting a hybrid model of home and hospital management in which newly diagnosed children would be kept in for one overnight stay only before discharge home, allowing for a more flexible approach to resource use. Consultants described feeling more at ease with this model.

My own personal opinion is that taking the heat out of the situation by admitting people for twenty four hours is no bad thing, and you've got flexibility so that families that adapt really quickly can go home quickly [Consultant 3]

Individual choice and geographical considerations also affected the health professionals' consideration as to whether to practice

hospital or home management in the future. Health professionals reported that for those families who lived a long distance from the hospital, it was less practical to do home visits two or three times a day. In these situations, they suggested a more pragmatic approach might be adopted in which children are admitted to hospital or seen in an outpatient clinic for a few days after diagnosis.

## 7 | DISCUSSION

The main finding from this study, from the perspective of the PDSNs who led delivery of the service for initial management of children at diagnosis, is that home management is preferable and the perceived benefits outweigh the negative aspects of the logistical issues of delivery, although the provision of adequate resources is essential. Results from the other health professionals suggest a more ambivalent conclusion on the benefits of "pure" home management, specifically with respect to how this approach may influence families' perception of the seriousness of the condition. Interestingly, in a qualitative study conducted with parents and children participating in DECIDE, participants also initially perceived home management as preferable but reflected equally the benefits and challenges of both, finding either acceptable in hindsight.<sup>12</sup> Parents had initially preferred home management because they felt it was less disruptive to family life, particularly if they had to arrange childcare for siblings. Whereas most children initially wanted to go home because they disliked the hospital environment, stating that it made them feel "down" and "sad."

All health professionals recognized the importance of establishing effective relationships with families. Nurses felt that they developed a special bond with the home managed children and their families, whereas consultants felt having not met families at diagnosis compromised their future relationship and how the education they delivered was interpreted. The establishment of effective relationships is reflected in results from a Swedish study, where families managed in the hospital-based home care arm had significantly higher satisfaction with healthcare services, reflecting the value families placed on the time and availability of health care professionals.<sup>5</sup> The importance of establishing and maintaining relationship-based care with health professionals and the desire for an individualized approach to provision and management of care is also reported in a synthesis of qualitative findings of paediatric diabetes services conducted by Curtis-Tyler 2015.<sup>13</sup>

In our study, the relationship nurses described as a "special bond" facilitated by home management was not reflected in the DECIDE qualitative study conducted with parents and children.<sup>12</sup> However, it is acknowledged that there is an acute phase of intense grief at initial diagnosis, similar to a bereavement.<sup>14</sup> Therefore, parents, while appreciative of the support provided may not have attributed the same significance to the special bond described by the nurses. However, the importance of continuity of care, ensuring procedures are in place to provide consistency with the same health professional, building trust and establishing a relationship, were some of the conclusions from a study of parent's experiences of paediatric diabetes consultations.<sup>15</sup>

Large clinics which lacked these personal connections were felt to deliver a more generalized education not taking account of individual differences.

Understanding individual family circumstances, having the opportunity to educate extended family members and fitting the management of T1D into family life were recounted as beneficial in our study. This was also reflected in a study of children's and parents' lived experiences of T1D, in which parents expressed frustration that care suggested by health care professionals in paediatric diabetes clinic was not easy to implement in the individuals' family setting.<sup>16</sup> It is perhaps, therefore essential that an element of home management is delivered initially to ensure that health professionals truly understand individual family situations and can adapt education and management to individual's own circumstances. In addition, this may also be essential when ensuring that care is personalized, focusing on the individual needs and goals of families, while also promoting empowerment and allowing families the space to express their feelings and emotions as necessary. However, we recognize that the resources and change in working practice required to deliver home management may not be feasible for some teams. The results of the DECIDE health economics analyses will provide further evidence to support or dismiss our recommendation of at least some home management for newly diagnosed children.

## 8 | STRENGTHS AND WEAKNESSES

One of the strengths of this study is that all disciplines of health professionals involved in the initial management of children with onset T1D were represented in the analyses. This provided rich and in-depth data, with sometimes opposing views from different staff disciplines. For example, although the majority of PDSNs were in favour of home management, disadvantages were articulated by other staff who experienced less immediate contact with families. However, given the demands on centres of participating in this trial, it is likely that those involved in this qualitative study, were biased in favour of the option of home treatment, as for several centres, the resources provided to take part allowed them to introduce this option for the first time.

A further weakness of the study was not seeking the perspectives of those involved with decision making and the commissioning of services. However, at the time of the study, most centres had no experience of delivering home management and were awaiting the results of the DECIDE trial to make inference of any benefit or cost efficiency.

## 9 | IMPLICATIONS FOR PLANNING SERVICES

Given that the results from the DECIDE randomized controlled trial showed no difference in glycaemic control, psychological outcomes, or serious adverse events,<sup>7</sup> this qualitative study provides important

findings and considerations for health professionals and commissioners planning the delivery of management to children and their families at the time of diagnosis of T1D. Ensuring that all team members are involved and engaged with any planned changes to the delivery of services is essential.<sup>17</sup> Without this co-ordinated approach, the provision of high-quality services will be compromised. In our study, teams in which members worked together and took an equal share in the workload appeared to provide a more effective service. Although not part of the intervention, members of DECIDE research team, namely the Chief Investigator and Trial Manager provided support and guidance to centres as required. They also facilitated a weekly teleconference session, whereby nurses could seek advice and support regarding any aspect of the study or delivery of the intervention.

Some nurses felt the relationships they formed with families produced a situation of "over reliance" and that the model of out of hours care was not sustainable over time. Therefore, it is important that workload is shared equally among team members to ensure effective, efficient, and sustainable delivery. It is also essential to maintain communication between all members of the team so that all health professionals are fully informed of how families are progressing with learning to manage and adapt to living with T1D. This would also allow education and number of visits to be adapted to what was required, and or requested, rather than a one size fits all approach.

Currently, NICE guidelines state that the decision of where initial management takes place, of children diagnosed with T1D, should be based on "clinical need, family circumstances and wishes."<sup>1</sup> Results from our randomized controlled trial<sup>7</sup> and this study show that health professionals providing initial and ongoing clinical care support these guidelines and highlight some of the considerations needed to make it work in practice.

## 10 | CONCLUSION

The initial advantage that home management provides is an early understanding of individual lives, education of extended family members and the ability to adapt management appropriately. However, this approach introduced significant challenges for paediatric diabetes team members. Given that the DECIDE trial showed no differences in any clinical or psychological outcomes, the findings from this qualitative study suggest that even when local logistical practicalities prevent the provision of a "home management service" from diagnosis of T1D, consideration should be given to discharging these patients from hospital as soon as is practically possible. Therefore, the hybrid approach adopted by some centres at the end of the DECIDE trial would seem an effective and pragmatic compromise between home and hospital whereby children are discharged early to home management, giving both health professionals and families the advantages of both models of care.

## ACKNOWLEDGEMENTS

Many thanks to all the DECIDE centres (Cardiff, Southampton, Belfast, Cambridge, Hull, Liverpool, Newcastle, Nottingham), Principal

Investigators and staff that took part and contributed to the DECIDE trial. We would also like to thank our funders Diabetes UK, and the support provided by National Institute for Social Care and Health Research Clinical Research Centre (NISCHR CRC).

## CONFLICT OF INTEREST

The authors declare that there is no conflict of interest associated with this manuscript.

## AUTHOR CONTRIBUTIONS

Julia Townson was responsible for the data collection, analyses, and drafting the manuscript. John W. Gregory and Lesley Lowes are the joint chief investigators and guarantors of the study in its entirety. Julia Townson, Lesley Lowes, John W. Gregory, Kerry Hood, and Michael Robling were responsible for the study design, methodology, and interpretation of the results. All those listed as authors contributed to the study delivery and were responsible for reading, commenting upon, and approving the final manuscript. Julia Townson is the guarantor of this work, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the analysis.

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**How to cite this article:** Townson J, Lowes L, Robling M, Hood K, Gregory JW. Health professionals' perspectives on delivering home and hospital management at diagnosis for children with type 1 diabetes: A qualitative study from the Delivering Early Care in Diabetes Evaluation trial. *Pediatr Diabetes.* 2020;21:824-831. <https://doi.org/10.1111/pedi.13023>