

# Improving paediatric diabetes insulin pump access and service quality through an outreach team

*Sonja Allen, Jo Dalton*

**With increased pressures from children and young people (CYP) and their families to transition to insulin pump therapy, smaller paediatric diabetes services may require a significant number of their patients to be transferred to larger centres if they do not have the resources, skills or experience to confidently and competently start CYP on such therapy. The Outreach Pump Team is a solution for these services whereby staff are guided to increase their experience and competence in initiating and continuing insulin pump therapy, negating the need to transfer their patients. Consideration should be paid to administrative and financial support, and the time implications for initiating and maintaining CYP on insulin pump therapy, including use of continuous glucose monitoring systems and other emerging technologies.**

Insulin pump therapy is recognised to offer benefits to clinical outcomes and quality of life for children and young people (CYP) with type 1 diabetes compared to multiple daily injections (MDI; NICE, 2008). A 2008 NICE Technology Appraisal established a pathway to improve access to insulin pump therapy for CYP using certain criteria including that, for those over 12 years, HbA<sub>1c</sub> levels remain high with MDI and, for those under 12 years, MDI treatment is not practical or appropriate (NICE, 2014). Despite this, access to insulin pump therapy across the UK has been inconsistent for a number of reasons including lack of expertise among paediatric diabetes teams, poor staffing limiting time to provide the support required for CYP on insulin pump therapy and difficulties in attaining funding for the insulin pump and consumables.

## The Outreach Pump Team

The North East Thames Paediatric Diabetes Network incorporates North Middlesex University NHS Trust, Barts Health NHS Trust (including the

legacy sites of The Royal London Hospital [RLH], Newham University Hospital [NUH] and Whipps Cross University Hospital) and Barking, Havering and Redbridge (BHR) University Hospitals NHS Trust (Queen's Hospital and King George Hospital). In early 2011 there were approximately 850–900 CYP with type 1 diabetes in the Network; however, while it was felt by the paediatric diabetes teams as a whole that approximately 50% of these CYP would be suitable for pump therapy, only 73 (<8.5%) were actually using it. Of these, 54 (74%) attended RLH where there had been a move to engage with new technologies and pump therapy for a number of years. While ideally the majority of CYP should be supported to transition to pump therapy by their local paediatric diabetes team, it was calculated that the staff to patient ratio in most, if not all, local services would not support this level of pump initiation without external support. As such, in early 2011 an idea was conceived to establish an insulin pump outreach team to assist local paediatric diabetes teams to initiate insulin pump therapy within their own services.

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## Article points

1. A paediatric diabetes insulin pump outreach team has been designed and established to serve the North East Thames Paediatric Diabetes Network.
2. The Outreach Pump Team is a way to increase numbers of children and young people (CYP) on insulin pump therapy while improving the skills and experience of local hospitals so that CYP do not have to be transferred to larger centres.
3. The model established by the Outreach Pump Team, along with key learning points, can be used by other paediatric diabetes teams wishing to set up a similar service.

## Key words

- Insulin pump therapy
- Outreach

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### Page points

1. The aims of the Outreach Pump Team included improving access to insulin pump therapy, reducing waiting-list time, ensuring a high-quality service and structured education, sharing best practice and developing knowledge, skills and experience locally.
2. The role of the Outreach Pump Team was to support local teams in starting children and young people on insulin pump therapy.
3. An initiation pathway was finalised after liaison with a number of large paediatric diabetes teams that already ran successful insulin pump services.
4. The Outreach Pump Team initially runs group education sessions so children and young people and their families can evaluate if insulin pump therapy might be something they would consider.

The aims of the Outreach Pump Team were to:

- 1 Improve access to insulin pump therapy in the North East Thames Paediatric Diabetes Network.
- 2 Reduce waiting-list time for those wishing to access pump therapy.
- 3 Ensure that CYP and their families receive a high-quality service and structured education for initiation of pump therapy.
- 4 Share best practice, resources and up-to-date guidance for pump therapy among local teams.
- 5 Develop the knowledge, skills and experience of local teams to facilitate local pump starts without the need for the Outreach Pump Team.

### Funding for the Outreach Pump Team

To achieve these aims, £399 000 of funding was secured in early 2012 via a large project grant from Barts Charity. This enabled the establishment of an RLH-based Outreach Pump Team for 3 years, consisting of a full-time Paediatric Diabetes Specialist Nurse (PDSN), a 0.9 whole-time equivalent (wte) Paediatric Diabetes Dietitian (both starting in summer 2012) and a 0.4 wte Clinical Psychologist (starting in February 2013). The PDSN and Paediatric Diabetes Dietitian are certified pump trainers and have undertaken advanced insulin pump courses and training with insulin pump companies.

The role of the Outreach Pump Team was to support local teams in starting eligible CYP on insulin pump therapy. This was to include pre-assessment of CYP and/or their families' diabetes knowledge and skills, pump education and short-term follow-up, after which the CYP would continue their diabetes clinical care with their local service. To enable this, a hub-and-spoke service design was envisaged whereby while the Outreach Pump Team was funded by Barts Charity, the CYP does not become part of the RLH caseload but remains within their local service to assist in fulfilling local Best Practice Tariff. This was a groundbreaking initiative as we were not aware of a similar service in the UK for insulin pump therapy.

### Service set-up

The "insulin pump initiation package" provided by the Outreach Pump Team includes insulin pump therapy education sessions for CYP and their families; pre-pump assessment; "Pump

School" and follow-up.

As this was a new service, a structure for insulin pump initiation and resources was developed in the summer of 2012 by the Outreach Pump Team. An insulin pump initiation pathway was finalised following liaison with a number of large paediatric diabetes teams that already ran successful insulin pump services (University College Hospital, Leeds General Infirmary, Central Manchester University Hospitals NHS Foundation Trust and Addenbrooke's Hospital). This was agreed by the North East Thames Paediatric Diabetes Network. Written resources were also produced to support the insulin pump start, synthesised from information obtained from the above centres and from the insulin pump companies Roche, The Ypsomed Group and Medtronic, Inc.

### Initial insulin pump therapy education

The initial education session, which takes place at a local hospital, involves the Outreach Pump Team talking to families about how insulin pump therapy works, its benefits and challenges and what insulin pump initiation involves. If the CYP and their family are still interested in pump therapy, they then discuss this with their own service. If the local team are in agreement, and the child meets NICE criteria, the local team then send a referral to the Outreach Pump Team. There is no time limit on when the CYP and their family can decide if and when they wish to move forward to pump therapy or remain on MDI.

### Pre-pump assessment

One of the interesting and challenging aspects of the PDSN's role is to ensure that CYP and their families appreciate the amount of work and commitment required to move on to insulin pump therapy safely and that they get the most out of this treatment option. Insulin pump therapy is not suitable for everyone and patient selection is important for its safety and success. The pre-pump assessment helps ascertain the diabetes knowledge of the CYP and their family, along with their skills, motivation and expectations of pump therapy.

During assessment, the PDSN uses a Kaufman competency level score (Kaufman et al, 2001) simplified for CYP and families to understand and discuss together. This is used to help assess not only

knowledge of diabetes, but of the skills and ability to manage the practical aspects of insulin therapy, including sick day rules with blood ketone testing and insulin dose adjustment. CYP and their families must reach a competence level of 5 out of 8 to be considered for insulin pump therapy. There are also questions for the CYP and their family to ascertain whether they are able to follow basic insulin pump therapy rules and keep in close contact with both the Outreach Pump Team and their local diabetes team.

The CYP then wears a demonstration insulin pump (without a battery but with saline in the reservoir and tubing) for 3 days to see whether they can tolerate wearing the pump 24 hours a day. This is a practical assessment as CYPs can use this time to work out where and how to wear the pump to suit their clothing options. Families are given a booklet that includes links to a variety of websites, to useful places to purchase pump pouches and to information about the need to have pump insurance cover.

Also at this time, the Paediatric Diabetes Dietitian assesses the ability of the CYP and their family to carbohydrate count and adjust their insulin doses accordingly using a questionnaire – the PedCarbQuiz (Koontz et al, 2010) – adapted to better reflect the types of food eaten by the local population. The Paediatric Diabetes Dietitian also evaluates how well the CYP and/or family are able to carbohydrate count and dose adjust outside the family home. A discussion about managing diabetes while doing exercise/sport also takes place to ensure that the CYP and family are knowledgeable about the effects of such on blood glucose concentrations.

The outcomes of the pre-pump assessment can be:

- 1 Proceed with transition to insulin pump therapy.
- 2 Provide more education or support on a specific issue and re-assess following input.
- 3 Try a different demonstration pump device.
- 4 The CYP and/or their families decide that insulin pump therapy is not appropriate for them at this time and are discharged from the Outreach Pump Team. Patients can be re-referred in the future.

### Pump School

“Pump School,” the main educational component of the insulin pump initiation package, is held in an outpatient setting with 2 or 3 CYP and their

families. It includes 10 hours of teaching spread over two days roughly one week apart. The days are jointly led by a PDSN and Paediatric Diabetes Dietitian from both the Outreach Pump Team and local service (although due to staffing levels a local Paediatric Diabetes Dietitian is not always available).

Education on Day 1 of Pump School includes a review of knowledge of insulin pump therapy, teaching about basic button pressing and demonstration of pump set insertion. The CYP then wears a working insulin pump infusing with saline until Day 2 of Pump School.

During the week between Pump School days, the CYP and their family gain experience in button pressing and pump set changes, and complete a very detailed food, blood glucose and insulin diary, using their MDI routine, to determine the settings for their pump. The CYP and/or their families need to be able to complete four full days of a diary so that the Outreach Pump Team has enough details to calculate basal and bolus settings. Inability to complete four full days may highlight issues with commitment and motivation at this point and the decision has to be jointly made to re-arrange or cancel Day 2 of the Pump School for such participants.

Day 2 of Pump School focuses on determining insulin pump settings. At this point school/nursery staff also attend for 2 hours to learn how to give a bolus, how to treat hypoglycaemia and hyperglycaemia, and when to telephone the parents with concerns or call an ambulance. Using the food, insulin and blood glucose level (BGL) diaries, the Outreach Pump Team and local team calculate the total daily dose of insulin and decide on the basal:bolus split, taking into account variables such as the age of the individual. This calculation is based on advice from other pump services and experience of our own multidisciplinary team. The diaries are also used to work out what the carbohydrate ratios and sensitivity ratio should be (using the “100 rule” for calculation of the sensitivity ratio or the “300/500 rules” for calculating carbohydrate ratio as a comparison).

Extended features of the insulin pump are not taught at this stage as language barriers and differing educational levels can mean that the teaching of the basic functions of the insulin pump takes longer to convey than anticipated.

### Page points

1. Utilising several measures, the pre-pump assessment involves the Outreach Pump Team, the local paediatric diabetes team and the child and their family working together to ascertain whether the child is suitable for pump therapy.
2. The main educational component of the insulin pump initiation package is “Pump School”, which is held in an outpatient setting.
3. Pump School helps the young person and their family familiarise themselves with pump therapy through the use of a demonstration device and further education on what will be involved in this type of therapy.

**Page points**

1. Not until follow-up does the CYP actually get fitted with a fully functional insulin pump. During the first 48 hours of use they can access PDSN support round the clock, followed by shared support from the Outreach Pump Team and their local service during working hours.
2. One month after Pump School, an appointment with the Outreach Pump Team and the local team is made to review blood glucose levels and quality of life since the start of insulin pump therapy.
3. In the first 16 months of the Outreach Pump Team's remit, 49 children and young people were initiated on insulin pump therapy.

**Follow-up**

Over the first 48 hours of full insulin pump therapy, the CYP remains away from nursery, school or college. During this time, they are required to test their BGLs every 2 hours throughout the day and night to ensure the settings are optimised within a short time frame and in a safe manner. This also helps families gain confidence and competence in the functions of pump therapy in the very early stages. Many families take time to become sure in the knowledge that the insulin pump will deliver insulin requirements when they previously had to calculate those themselves. During this period they have 24-hour telephone access to a PDSN from either the Outreach Pump Team or, if available, their local service. After the first 48 hours, the CYP has shared care between their local team for regular follow-up but they can access the support of the Outreach Pump Team if they are unable to contact their local team.

One month after Pump School, the young person and their family return to their local outpatient clinic for an appointment with the Outreach Pump Team and their local team to review BGLs and quality of life since their insulin pump start. This appointment also includes education on interpreting the insulin pump download reports and on the extended features of the insulin pump including dual/multiwave and square/extended wave boluses. The team also reviews temporary basal rates for exercise and illness management. The Outreach Pump Team and local services, with the CYP and family, then agree any necessary pump setting changes.

**Outcomes**

Between September 2012 and December 2013 the Outreach Pump Team started 49 CYP on insulin pump therapy. The demographics of these CYP are shown in *Table 1* and *Figures 1* and *2*. The majority of CYP were female (55%,  $n=27$ ), between 6–12 years old (55%,  $n=27$ ; *Figure 1*) and from a white British background (47%,  $n=23$ ; *Figure 2*).

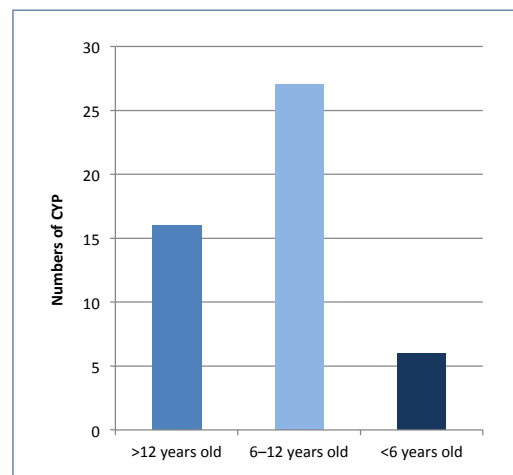
Of the 49 CYP who were started on insulin pump therapy, two of the RLH patients did not continue: one due to the level of commitment required and one due to a language barrier making it difficult to understand the information given about the insulin pump and its supporting documentation. An

**Table 1. Number of children and young people seen at each local service.**

Service	Number
The Royal London Hospital	47
BHR University Hospitals NHS Trust	14
Newham University Hospital	4
North Middlesex Hospital	2
Whipps Cross Hospital	2

additional three were taken off the pump (two from RLH, one from NGH) as they weren't following the safety rules and guidance, but subsequently restarted pump therapy following intensive input.

Overall, the HbA<sub>1c</sub> levels for the 47 individuals that remained on pump therapy decreased by an average 0.37% (4.0 mmol/mol) in the 3–6 months since initiation. Those with an initial HbA<sub>1c</sub> over 9% (>75 mmol/mol) ( $n=12$ ) had an average HbA<sub>1c</sub> decrease of 1.5% (16.4 mmol/mol). Those with an initial HbA<sub>1c</sub> of 7.5–9% (58–75 mmol/mol) also showed an average decrease, of 0.21% (2.3 mmol/mol). However, CYP with an initial HbA<sub>1c</sub> of <7.5% (<58 mmol/mol) ( $n=9$ ) showed an average HbA<sub>1c</sub> rise of 0.49% (5.4 mmol/mol) (*Table 2*). This may be due to experimentation with pump functions and increased diet and lifestyle flexibility; it is hoped this will improve once they gain more pump experience.



*Figure 1. Age distribution of children and young people (CYP) starting insulin pump therapy.*

Table 2. Examples of health related food taxes.

HbA <sub>1c</sub> prior to insulin pump therapy	Change in HbA <sub>1c</sub>	Spread of HbA <sub>1c</sub>
<7.5% (<58 mmol/mol)	0.49% (5.4 mmol/mol)	7.2% to 8.1% (55 to 65 mmol/mol)
7.5–9% (58–75 mmol/mol)	–0.21% (–2.3 mmol/mol)	7.0% to 9.0% (53 to 75 mmol/mol)
>9% (>75 mmol/mol)	–1.5% (–16.4 mmol/mol)	7.3% to 11.5% (56 to 102 mmol/mol)

The Outreach Pump Team PDSN and Dietitian assessed all the CYP commenced on pump therapy with a member from their local team. However, due to the lack of a Clinical Psychologist (0.4 wte position), not all CYP had a formal psychology assessment. As such, we did not formally evaluate quality of life pre- and post-insulin pump therapy initiation; however, all patients reported that they prefer this treatment option to MDI.

This model of working with partner Trusts to enable them to develop their own insulin pump services is unique to the Outreach Pump Team. One of our major aims was to provide enough knowledge, skills and experience to local paediatric diabetes services so they could then independently facilitate their own pump starts. In accordance

with this, after five group pump starts at Queen’s Hospital in Romford the local team is now running their own pump starts with pump company support.

### Challenges faced/learning points

#### Managing expectations

The initial hope to transition around 450 CYP to insulin pump therapy over the 3-year project would mean the Outreach Pump Team would have needed to complete 10 insulin pump starts per month. This was unachievable for the following reasons:

- Having a PDSN on call for 48 hours following insulin pump start was deemed essential. However, this required the Outreach Pump Team PDSN to take time off *in lieu*, which impacted on working days. While it was hoped that local PDSNs could fulfil this role, in some of the hospitals there was no management agreement to allow this. This limited pump start group sessions to 1–2 per month (4–6 participants).
- At the start of the project, the level of literacy and numeracy required was not fully anticipated meaning more time was needed for education prior to commencing insulin pump therapy.
- More time than anticipated was also needed to re-start those who came off their insulin pumps due to unsafe practices.

#### Logistical and organisational issues

- The original pump initiation pathway suggested pre-pump assessment was performed a month prior to insulin pump start. However, we found that if those families booked in for both were not ready to start following the assessment stage, it was too late to substitute them for another CYP, which impacted adversely on the numbers of CYP to be started within the time frame.
- Scheduling the insulin pump initiation package at a number of locations was logistically difficult as variables needing consideration included exam

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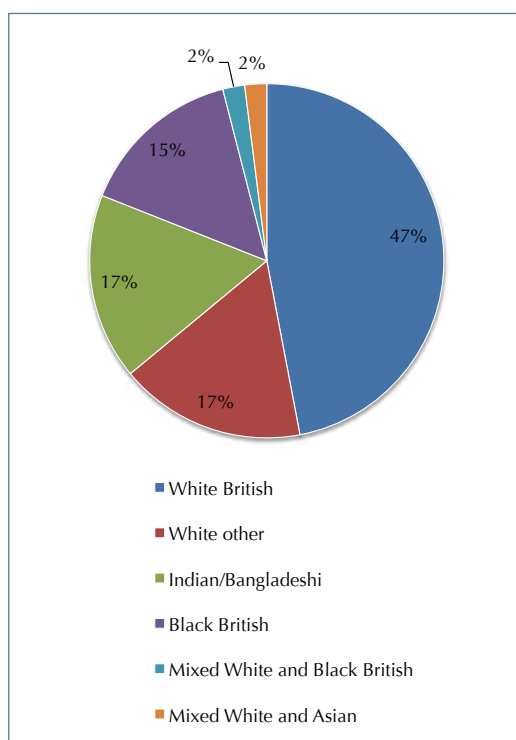


Figure 2. Ethnicities of children and young people starting insulin pump therapy.



**“The Outreach Pump Team has achieved all of its initial aims and this process is continuing despite changes in the paediatric diabetes landscape.”**

periods, religious festivals and availability of the Outreach Pump Team, the local paediatric diabetes team and their facilities.

- Pump starts at most partner hospitals required a significant amount of pump kit to be taken to the local hospital, often via public transport.
- Due to historical practice and amalgamation of Trusts, there was a need to use different types of pumps from different manufacturers, necessitating storage space for multiple stock items.
- The initial pump supply orders for CYP is the responsibility of the Outreach Pump Team members rather than hospital management staff, which takes up a considerable amount of time.

#### Changes in the paediatric diabetes world

- As word has spread about the Outreach Pump Team service, more CYP have become interested in initiating pump therapy. There have also been a number of technology improvements, such as continuous glucose monitoring systems and patch pumps. This has meant that instead of relieving local services, the work of the Outreach Pump Team has not only stretched what they themselves were initially going to provide, but also made local teams busier than first anticipated.
- During the time since the Outreach Pump Team has been established, not only have the NHS Trusts in the Network changed but also the Best Practice Tariff for Paediatric Diabetes has improved staffing levels in the hospitals in the Network.
- The movement from Primary Care Trusts (PCTs) to Clinical Commissioning Groups (CCGs) has led to considerable administration concerns as CCGs now require annual evidence for each CYP that insulin pump therapy has improved their diabetes control. In addition, *ad hoc* work was required for some CYPs on pump therapy whose details did not transfer completely from the previous PCT to their new CCG.

#### Future plans

For the remainder of the term of the Outreach Pump Team we have made several changes to improve the service:

- Assessment of readiness for insulin pump therapy is now carried out with groups of CYPs and their

families instead of individually.

- We provide a greater amount of time between assessment and the start of Pump School so CYPs and their families have a longer period to determine if pump therapy is right for them.
- We give CYP the option (if applicable) of starting on patch pumps or tethered pumps.
- Local services will hold their own pump stock items to avoid the Outreach Pump Team carrying large amounts of equipment between hospitals.
- As PDSNs from local services have now observed a number of insulin pump starts, and we have shared our resources with them, it is hoped that they will take over some of the 48 hour on-call service so the Outreach Pump Team is available for more pump starts.
- It is suggested that future funding provides administrative support to aid in scheduling.

#### Summary

Currently, we are not aware of any other Outreach Pump Teams in the UK. The establishment of the service has increased numbers of CYP on insulin pump therapy in the North East Thames Paediatric Diabetes Network and has improved confidence and competence in insulin pump therapy across the Network. The Outreach Pump Team has achieved all of its initial aims and this process is continuing despite changes in the paediatric diabetes landscape. The system we have put into practice, and adapted according to outcome findings and experience, can be used by other areas in the UK. It is suggested they work together as a local Paediatric Diabetes Network with each centre contributing money from the Best Practice Tariff for Paediatric Diabetes to the Network to fund posts and one contributing team hosting the Outreach Pump Team staff. ■

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