### **DIABETES UK**

# POSITION STATEMENT

Insulin pump therapy for adults and children with Type 1 diabetes

Last reviewed: August 2017

#### **KEY POINTS:**

- Both NICE and SIGN guidance recommend that insulin pumps be seen as a routine clinical option in the treatment of Type 1 diabetes in many adults and children.
- There is evidence to suggest that insulin pump therapy helps both adults and children with diabetes to improve HbA1c, reduce hypoglycaemia and manage their blood glucose levels in the long-term
- Although NICE and SIGN guidelines set out standards for both adults and children as to who could benefit from an insulin pump, variation exists as to the uptake of insulin pumps around the UK
- Insulin pump therapy should be offered to all adults and children with Type 1 diabetes who could benefit from it
- Awareness of insulin pump therapy should be raised among people with Type 1 diabetes, their families and healthcare professionals
- The variation in availability of pump use between specialst centers must be addressed
- Insulin pump centres should maintain comprehensive patient records and participate fully in national audits

### Introduction

Insulin pumps are small, portable batteryoperated devices that provide the body with regular doses of rapid acting insulin throughout the day. The pump is attached to the body, and the insulin it provides is delivered through a smallcannula inserted into the subcutaneous tissue located underneath the skin.

The insulin is delivered throughout the day and night, at variable rates that can be altered depending on the user's individual needs. These

are known as basal rates. The user of a pump can also release additional doses of insulin for example when eating or when blood glucose levels are high.

These are known as bolus doses. The nurse or dietitian can help the insulin pump user to work out how much insulin they will need.

Although insulin pump therapy was first reported in the UK in 1979, uptake in the UK has been well behind other European countries. In the US, Germany, France and Scandinavia, between 25-30% of people with Type 1 diabetes use insulin pumps, compared to under 10% in the UK.

Some insulin pumps can be linked to continuous glucose monitors and automatically stop insulin delivery in response to predicted or actual low sensor values, reducing or preventing episodes of hypoglycemia that are a key barrier to achieving optimal glucose control. This is particularly valuable for people with diabetes with problematic hypoglycaemia or those with hypoglycaemia unawareness.

#### ADVANTAGES OF USING INSULIN PUMPS

There are a number of advantages to using insulin pumps over insulin injections for both adults and children. These include:

- Better management of blood glucose levels as the absorption of insulin is more regular and predictable. The National Diabetes Insulin Pump Audit (2017) found that on average, those using an insulin pump had a lower HbA1c than non-pump users
- Less variability in blood glucose levels
- Fewer episodes of hypoglycaemia.
   Evidence suggests up to a 4-fold reduction in those who have problematic hypoglycaemia
- Higher patient satisfaction
- Easier to respond to changes in blood glucose levels due to, for example, food eaten, physical activity taken/planned, illness, growth spurts etc
- Fewer injections, as the cannula generally only needs replacing every 2-3 days
- More flexibility on timing and amount of

#### food eaten

### DISADVANTAGES OF USING INSULIN PUMPS

Equally there can be disadvantages of using insulin pumps which include:

- Frequent monitoring of blood glucose levels is vital. This is because the insulin is short-acting, which means that any interruption in supply could result in blood glucose rising very high very quickly
- The insulin pump has to be constantly attached to the body, and can usually only be disconnected for a maximum of around one hour
- There is a slight risk of infection at the cannula site
- The infusion tube of the insulin pump may become blocked, which can lead to high glucose levels and risk of diabetic ketoacidosis unless the cannula is changed as a matter of urgency, or the user switches to injections.
- There is a risk of "pump fatigue", where the intensive management of Type 1 diabetes becomes overwhelming and is abandoned, potentially leading to severe and/or regular hyper- or hypoglycaemia. This is a particular issue in adolescence.

People wishing to use insulin pumps need to spend quite a lot of time to learn about their insulin pump. This is particularly important in the beginning, but education should be ongoing through the duration of insulin pump therapy. On average in the UK it takes about 10 -12 hours of education time to manage a pump safely.

### Diabetes UK makes recommendations in the following areas:

- The right to insulin pump therapy
- Addressing variations in access to pump use
- Information management of local centres for insulin pump therapy
- Transitioning between services

- Budgets no longer allow staff to access the specialist training they need to support pump therapy
- Budget cuts in educational establishments have resulted in courses in insulin pump therapy no longer being available

### **Current situation**

Continuous subcutaneous insulin infusion, or "insulin pump", therapy has a key role to play in managing Type 1 diabetes in both adults and children. It is not only associated with an improved quality of life in general, but also with improved glycaemic control and reduction in severe hypoglycaemia.<sup>(1)</sup>

However, despite national guidelines that give clear indication of eligibility for insulin pump use (see below) Diabetes UK is becoming increasingly aware of problems in accessing pump therapy, especially for adults, such as:

- Individuals being refused access to pump therapy
- Having to wait an excessive amount of time for it
- Uncertainty about funding for the pump if an individual moves from one diabetes service to another. This is a particular concern for young people transitioning to adult services.

Healthcare professionals also report having difficulty obtaining the funding they need to provide pump therapy for all of their patients who fulfill national criteria and would benefit from it. This may be due to:

- Insufficient funds for the pumps and consumables themselves
- Diabetes teams are not sufficiently resourced to provide the support and education needed to support pump therapy

### **Clinical guidelines**

#### England, Wales and Northern Ireland

Insulin pump therapy has therefore been recommended by the National Institute for Health and Care Excellence (NICE) for the management of Type 1 diabetes since July 2008 <sup>(1)</sup>. NICE currently recommends:

### For adults and children over 12 with Type 1 diabetes:

Pump therapy recommended as a treatment option if either:

 Their attempts to reach target HbA1c levels with multiple daily injections are still resulting in them having hypoglycaemic episodes which are frequent or come without warning in such a way as to negatively impact on their life

Or

 Their HbA1c levels have remained high (over 69mmols/mol) even with multiple daily injections despite careful management of their diabetes.

### For children with Type 1 diabetes younger than 12 years:

Insulin pump therapy is recommended as a treatment option provided that:

- MDI therapy is considered to be impractical or inappropriate
- Children between the ages of 12 and 18 years have previously undergone a trial of MDI therapy.

For both adults and children, NICE recommends

that pump therapy be initiated only by a trained specialist team. This should normally consist of a physician with a specialist interest in insulin pump therapy, a diabetes specialist nurse and a dietitian. Specialist teams should provide structured education programmes and advice on diet, lifestyle and exercise appropriate for people using pumps.

#### Scotland

#### For adults and children:

Eligibility for pump therapy in Scotland is assessed against the Scottish Intercollegiate guidelines Network (SIGN)<sup>(2)</sup> guidance which states:

- Pump therapy is associated with modest improvements in glycaemic control and should be considered for patients unable to achieve their glycaemic targets.
- Pump therapy should be considered in patients who experience recurring episodes of severe hypoglycaemia.
- An insulin pump is recommended for those with very low basal insulin requirements (such as infants and very young children), for whom even small doses of basal insulin analogue may result in hypoglycaemia.
- Pump therapy should be available from a local multidisciplinary pump clinic for patients who have undertaken structured education.
- Targets for improvement in HbA1c and/or reduction in hypoglycaemia should be agreed by patients using CSII therapy and their multidisciplinary diabetes care team
- Progress against targets should be monitored and, if appropriate, alternative treatment strategies should be offered.

Both NICE and SIGN guidance therefore recommend that insulin pumps be seen as a routine clinical option in the treatment of Type 1 diabetes in many adults and children.

### **Clinical Impact**

### Impact of insulin pump therapy on clinical outcomes

The Insulin Pump Audit (part of the National Diabetes Audit (NDA) 2017)(3) collects information on the number and charactaristics of people with diabetes using an insulin pump, the reasons for starting pump therapy and the outcomes achieved since initiation. Improvements in participation and data quality mean that the findings are more comprehensive and clinically useful than previous audits. In addition, it includes the first data on insulin pump use submitted by Wales to the NDA. The audit found that in England 15.3% of people with Type 1 diabetes are using an insulin pump, and in Wales 5.8%. This apparent difference is likely to be due to data submission arrangements - in England submission is through specialist centres, in Wales through Local Health Boards. Blood glucose lowering was a more likely reason for starting insulin pump therapy than hypoglycaemia (in England 35%, in Wales 54%, comparent to 27% and 39% respectively starting for hypoglycaemia). However, it must be noted that there was poorer data completeness for England than there was for Wales. Between one third and two thirds of people on an insulin pump reached their target goal for blood glucose management. Between one third and three quarters reached their target goal for hypoglycaemia. However, these figures must be considered in the context of completeness of the data supplied.

Those on a pump were more likely to achieve NICE recommended treatment targets for HbA1c, cholesterol and blood pressure (in England 19.0% vs. 15.8%; in Wales 19.9% vs. 13.9%). Particularly, mean HbA1c is lowered for those using a pump. This is despite being of a younger age, and generally younger people are less likey to achieve treatment targets <sup>(4)</sup>.

## Prevalence and uptake of insulin pump therapy

#### Adults

The 2017 audit shows that in England and Wales, the percentage of people using an insulin pump varies from centre to centre, >50% to <5%<sup>(3)</sup>.

#### **England**

In England, the 2017 audit shows that 15.3% of people with Type 1 diabetes use an insulin pump. 35% started pump therapy for blood glucse management, 27% for hypoglycaemia and 6% for other reasons.

The rate at which people with Type 1 diabetes are starting insulin pump therapy has stabilized over the last 5 years<sup>(3)</sup>.

#### Wales

The 2017 audit shows that 5.8% of people with Type 1 diabetes in Wales use an insulin pump. 54% started pump therapy for blood glucse management, 39% for hypoglycaemia and 12% for other reasons<sup>(3)</sup>.

As in England, rates have stabilized over the last 5 years.

#### Scotland

The Scottish Diabetes Survey from December 2015<sup>(5)</sup> found that 7.1% of adults in Scotland were using insulin pump therapy. At the last election the Scottish National Party committed in their manifesto to triple the number of adults on pumps to 6000. However, anecdotal evidence suggests that funding for pump therapy is becoming more difficult to access.

#### Northern Ireland

There are approximately 8,500 adults and children in Northern Ireland with Type 1 diabetes. Of these, approximately 441 adults use a pump.

#### Children

#### **England and Wales**

The National Paediatric Diabetes Audit (NPDA) of 2016 found that 22.9% of children in England and Wales use an insulin pump, and their use is greater in younger children and less deprived areas<sup>(6)</sup>. Data is recorded by Paediatric Diabetes Network, and pump use ranges from 16.2% to 33.8%. However, there is no data on the reason for starting pump therapy, time from diagnosis to starting pump therapy or length of time on a pump.

#### Scotland

In Scotland 31.2% of children use a pump<sup>(5)</sup>.

#### Northern Ireland

Diabetes UK Northern Ireland estimate that there are approximately 8,500 adults and children in Northern Ireland with Type 1 diabetes. Of these, approximately 266 children use a pump. Additional funding for a further 119 will be made available by March 2017.

#### Recommendations

This section sets out Diabetes UK's recommendations in relation to insulin pump therapy. These recommendations apply to both adults and children.

#### THE RIGHT TO INSULIN PUMP THERAPY

Given the benefits of insulin pump therapy as identified in the 2017 audit, insulin pump therapy should be offered to all people with Type 1 who could benefit from it. All adults and children with Type 1 diabetes should be seen by a specialist clinician who is trained in pump therapy. They should assess their need and suitability for insulin pump therapy during annual care planning.

Clinicians should assess all adults and children with Type 1 diabetes in accordance with the NICE/SIGN guidelines and offer pump therapy to those who meet the criteria.

People with Type 1 diabetes who are interested in insulin pump therapy should discuss with their diabetes team whether it is likely to improve their diabetes management and what the advantages and disadvantages of the therapy are likely to be.

Gaining access to it should never be dependent on where the individual lives or on their ability to pay.

Clarification on funding for insulin pumps for children in England:

On 1st April 2017 funding for insulin pumps for children with diabetes was transferred from the NHS England specialist commissioning route back to CCG's. According to NHSE, the change is because children with Type 1 diabetes are generally managed by local hospitals, and so they have determined that there is no longer a

case to centralise commissioning for paediatric insulin pumps and continuous glucose monitoring. Diabetes UK is aware that some CCG's are grouping together to develop policies for insulin pump and CGM procurement. We would stress that funding for pumps should not be taken from the Paediatric Best Practice Tariff, which is paid for care and not devices.

### ADDRESSING VARIATION IN PUMP USE BY PEOPLE WITH TYPE 1 DIABETES

The reasons behind variation in pump use between specialist centres must be addressed. The 2017 audit showed that there is a 10-fold variation in pump use in people with Type 1 diabetes beween specialist centres.

All specialist services and commissioners should consider the potential barriers to pump use in their own locality. They should consider whether there is sufficient understanding, capacity and capability to explain and provide pump treatment.

#### 1. Understanding of pump therapy

Understanding and awareness of pump therapy as a treatment for Type 1 diabetes and its merits should be promoted. This should take place especially in areas which appear to be underperforming in terms of providing insulin pump therapy. All those working in health care should be aware of the NICE/SIGN guidance and clinical recommendations.

#### 2. Capacity to deliver pump therapy

Appropriately trained teams of healthcare professionals should be available nationally to initiate and supervise insulin pump therapy.

A lack of adequately and appropriately trained healthcare professionals who are in a position to provide insulin pump therapy on a consistent basis nationwide has been identified as a barrier to people with Type 1 diabetes accessing insulin pump therapy.

Insulin pumps are tools designed to facilitate the self-management of Type 1 diabetes. However, healthcare professionals must be involved to

make a clinical assessment in conjunction with the patient as to whether to initiate insulin pump therapy in the first instance, to provide the initial education, and thereafter offer ongoing support and education to the user.

### 3. Capability to provide a pump therapy service

The lack of healthcare professionals who are specifically trained to educate and support those using insulin pump therapy, such as DSNs, is a hindrance to consistent and effective uptake of this treatment.

CCGs should ensure that there are suitable numbers of specialist healthcare professionalsto support the development of local insulin pump centres.

Local pump centres should comprise a doctor who specializes in insulin pump therapy, a diabetes specialist nurse and a dietitian. This team should provide structured education programmes and advice on diet, lifestyle and exercise that is suitable for people using insulin pumps. In addition to this, however, there needs to be effective methods of education for new and potential users of insulin pump therapy so that they are fully aware of the advantages and disadvantages of using it and how they can use it effectively as a self-management tool. This requires commissioning bodies and local clinics to make judgments on how best to convey these messages.

There are currently different practices for obtaining funding for insulin pumps which depends on the area of the UK concerned. While some commissioning bodies will provide full funding for all requests that fit NICE/SIGN criteria, others place a cap on the number of pumps they will fund each year and still others provide clinical services with a fixed annual budget that they can use according to their clinical judgement. In both of these latter options, there is a risk that there will not be sufficient funds allocated to ensure that all people with Type 1 diabetes who fulfill relevant criteria for a pump will receive one.

There needs to be sufficient infrastructure in place at a local level to provide the framework within which insulin pump therapy can be provided. This means ensuring that there is a dedicated service within the healthcare settings

which will proactively suggest a pump to a person with Type 1 diabetes if they meet the criteria on the NICE/SIGN guidelines and if they believe that a pump would be beneficial to them. The service must also provide sufficient initial education so that they can manage all aspects of pump therapy as well as offering education and support when necessary thereafter.

Therefore there should be adequate funding and administrative arrangements in place at a local level to ensure that this form of service is made possible, and that all those eligible for a pump receive one.

There is evidence from international networks to suggest that centre size has an influence on outcomes. Units that are setting up and have less than 100 pump patients could benefit from a relationship with a larger local centre to allow development of expertise and delivery of a high quality service close to the patient.

### INFORMATION MANAGEMENT OF LOCAL CENTRES FOR INSULIN PUMP THERAPY

Insulin pump centres should maintain comprehensive patient records and participate fully in national audits

The 2017 audit identified a lack of data completeness and findings should be considered in the context of this. In order to accurately reflect how the country and local areas are performing in terms of access to insulin pump therapy, all pump services must participate in the pump audit as well as the wider National Diabetes Audit.

In order to participate fully in these audits, pump centres should consistently record:

- The number of people with Type 1 diabetes
- How many use insulin pumps and how many had pump therapy offered to them
- The indication for commencing pump therapy
- Baseline HbA1c and hypo risk
- Personal goals for pump therapy
- Whether the treatment goals are being achieved for those placed onto insulin pump therapy.

### TRANSITIONING FROM PAEDIATRIC TO ADULT SERVICES OR BETWEEN SEVICES

People with Type 1 diabetes who use insulin pumps should continue to receive funding for and support around pump therapy if they move from paediatric to adult services, from one paediatric service to another or from one adult service to another.

Healthcare professionals should provide a young person who is transitioning to adult care with the education and support they need to enable them to manage their pump independently in adult services. This process should start well in advance of the transition and education should gradually be tailored towards and directed to the young person, rather than the parent/carer.

Diabetes UK has heard of cases where pump users have experienced difficulty maintaining funding for their pump if they move to another service. A particular issue when transitioning from paediatric to adult services is that in addition to funding problems, there may be a lack of suitably qualified healthcare professionals in the adult service to continue to provide support and education.

When an insulin pump user needs to transfer to another diabetes team, there should be adequate funding and expertise within that team to allow them to continue to use their insulin pump.

#### **Further information**

For more information on access to insulin pump therapy please see:

- Type 1 technology guides for adults and for children:
- https://www.diabetes.org.uk/Upload/Type%201/JDRF-Type1Tech-Adults-8.pdfhttps://www.diabetes.org.uk/Upload/Type%201/Type-1-Tech-CYP.PDFINPUThttp://www.inputdiabetes.org.uk/altinsulin-pumps/

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