

## Pump Action

### A Review of Insulin Pump Uptake and NICE Guidance in English Primary Care Trusts (PCTs)

**Title of Report:** Pump Action – A Review of Insulin Pump Uptake and NICE Guidance in English PCTs

#### Summary of Report:

An FOI Survey of every English PCT shows significant inequity in the provision of insulin pumps across England and a lack of adherence to NICE guidance on pump provision, with low levels of insulin pump usage compared to the NICE benchmark. The MTG conducted the survey with backing from INPUT and Adrian Sanders MP, Chair of the All Party Group on Diabetes. A set of recommendations for the Government, healthcare professionals, NHS commissioners and patients has been developed in order to address the challenges that have been identified.

#### Note on the Report

This report was updated on 7 December 2010 to include a data correction for Blackburn with Darwen PCT further to the original data that was provided in response to the FOI.

#### Authors:

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- INPUT – a national advocacy group working to increase access to insulin pump therapy. INPUT is a member of the MTG. [www.input.me.uk](http://www.input.me.uk)
- Adrian Sanders MP – Chair of the All Party Group on Diabetes.

The research has been supported by the Juvenile Diabetes Research Foundation (JDRF), a member of the MTG.

#### Key words:

Diabetes; insulin pump therapy; Primary Care Trusts; local variation in service; NICE Commissioning Guides; insulin. **Introduction:**

Type 1 diabetes affects 250,000 people in the UK.<sup>1</sup> Rates of type 1 diabetes have been increasing over time, with the greatest increase in children younger than 5 years.<sup>2</sup> People with type 1 diabetes are unable to produce the natural hormone insulin which is needed to control and use glucose. Insulin is produced by the pancreas, and allows glucose to be moved out of the blood and used for energy<sup>3</sup>. In type 2 diabetes the body produces too little insulin or is unable to use it efficiently. In many cases type 2 diabetes can be managed through diet, weight control and exercise.

It is important for patients with type 1 diabetes to manage their blood glucose levels carefully to avoid complications, which both damage their health and are expensive to treat. Complications can include hypo- and hyper-glycaemia, diabetic ketoacidosis and in the longer term blindness. Blood glucose levels can vary dramatically and the reasons for this cannot always be controlled. This must be measured regularly and insulin doses adjusted accordingly.

Most patients control their insulin levels through multiple daily injections (MDI). This can lead to poor control of diabetes, as insulin is given in a few large doses, unlike a healthy pancreas which secretes and regulates insulin constantly. MDI can also affect patients' quality of life, as it can be difficult to manage anything outside the normal routine, such as a meal out, or spontaneous exercise. Once a dose of insulin is injected, it cannot be switched off or delayed. Long acting insulin is also subject to inconsistent absorption.

Insulin pumps are an alternative to MDI. Pumps are small devices worn continuously which provide a steady, adjustable stream of insulin. This is also known as continuous subcutaneous insulin infusion (CSII).

The principal benefits of insulin pump therapy for patients and the NHS are as follows:

- improved patient outcomes including management of blood glucose levels (HbA1c) which reduces the risk of severe hypoglycaemia (symptoms of severe hypoglycaemia include collapse and coma) and/or diabetic ketoacidosis (DKA);
- Reduced risk of complications (e.g. heart disease, stroke, blindness, kidney disease, nerve damage);
- General better health, improved treatment satisfaction, reduced anxiety and depression and improved quality of life;
- A reduction in emergency hospital admissions;
- A reduction in planned hospital admissions. Better diabetes self-management is linked to a reduction in inpatient supportive care and overall hospital stays and associated NHS costs<sup>4</sup>.

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<sup>1</sup> NICE Technology Appraisal Guidance 151: Continuous subcutaneous insulin infusion for the treatment of diabetes mellitus (<http://www.nice.org.uk/nicemedia/live/12014/41300/41300.pdf>)

<sup>2</sup> Ibid.

<sup>3</sup> NHS Choices (<http://www.nhs.uk/conditions/diabetes/Pages/Introduction.aspx>)

<sup>4</sup> NHS Technology Adoption Centre (<http://www.technologyadoptioncentre.nhs.uk/Continuous-Subcutaneous-Insulin-Infusion/benefits-v-barriers.html>)

Insulin pump therapy is a clinically and cost effective treatment option that is recommended by NICE for people with type 1 diabetes, whether adult or child, for whom multiple daily injections have failed, and for children under 12 if multiple daily injections are not deemed practical or appropriate.<sup>5</sup>

NICE has produced a Commissioning Guide to help commissioners plan and deliver services in line with NICE guidance<sup>6</sup>. NICE's commissioning guide on insulin pump therapy services states that the standard benchmark rate for the uptake of insulin pump therapy is 12% of people with type 1 diabetes, and 33% for children younger than 12 years old<sup>7</sup>. It is widely established that this benchmark has not been met.

### **Methodology:**

The Medical Technology Group, INPUT and Adrian Sanders MP (Chair of the All Party Group on Diabetes) undertook a survey of all 152 Primary Care Trusts (PCTs) in England to determine the true levels of insulin pump provision at the time of the survey (January-May 2010). The survey took the form of a Freedom of Information (FOI) request sent to PCT Chief Executives. Email reminders were sent to PCTs which did not respond.

The data was collected between January and May 2010. 133 PCTs responded, a response rate of 87.5%.

### **Questionnaire:**

- Q 1: What is the name of your PCT?
- Q 2: How many patients in your area have been diagnosed with type 1 diabetes?
- Q 3: How many patients in your area with type 1 diabetes are currently using insulin pump therapy?
- Q4: Do you give all eligible patients the choice of insulin pump therapy in line with NICE guidance on insulin pumps (TA151)?
- Q5: Have you used NICE's Commissioning Guide to help determine local service levels and deliver insulin pump therapy services?

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<sup>5</sup> NICE Technology Appraisal Guidance 151

<sup>6</sup> Commissioning Guide for Insulin Pump Therapy

(<http://www.nice.org.uk/usingguidance/commissioningguides/insulinpumps/insulinpumps.jsp>)

<sup>7</sup> NICE Benchmark

(<http://www.nice.org.uk/usingguidance/commissioningguides/insulinpumps/determininglocalservicelevelsinsulinpumps.jsp>)

- Q6: Are you commissioning in line with NICE’s benchmark of 12% (of the type 1 population) being eligible for pump therapy?
- Q 7: If yes, what made these factors possible?
  
- Q8: If not, why not? Please provide other reasons if appropriate.
  - Lack of specialist staff
  - Lack of appetite amongst clinicians in providing insulin pump therapy
  - Insufficient funding to implement NICE guidance
  - Lack of commissioning knowledge to implement NICE guidance
- Q9. Do you provide the following services for patients with type 1 diabetes?
  - a. Access to a multidisciplinary team including:
    - specialist diabetologist trained in provision of pumps
    - diabetology nurse trained in provision of insulin pumps
    - a dietician
  - b. Clear process of identifying patients that would benefit from pump therapy and offering them appropriate services
  - c. Specialist paediatric service
  - d. Management through transition
  - e. 24-hour emergency support
- Q 10: Is there a Diabetes Network in your area?
- Q11: Do you have a strategy in place to increase provision of insulin pump therapy in line with NICE guidance (TA151)? If yes, please could you include a copy in your response.

## Results

The survey results give the following headline findings:

- The average rate of insulin pump provision for people with type 1 diabetes is 3.7% compared to the 12% benchmark recommended by NICE;<sup>8</sup>
- Only one PCT gave information which suggests they are providing insulin pumps in line with the NICE benchmark.<sup>9</sup>

Other findings of note include:

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<sup>8</sup> Please note that prior to the corrected data being provided for Blackburn with Darwen PCT, the average rate was first reported at 3.9%

<sup>9</sup> Prior to the corrected data being provided for Blackburn with Darwen PCT, the study first reported that two PCTs gave information which suggests they are providing insulin pumps in line with the NICE benchmark.

- Only 5 out of 113 PCTs have a strategy in place to implement NICE guidance on insulin pumps in line with their statutory duty to adhere to NICE technology appraisals within 3 months of issue;
- Just over a third (35%) of PCTs do not use tools and guidance such as NICE's Commissioning Guide to help deliver adequate insulin pump therapy services;
- Current utilisation of insulin pumps for type 1 diabetes in the UK (3.7%) is extremely low in comparison to other countries, such as the US (estimated at 35%) and Sweden, France and Germany (estimated at 15-20%)<sup>10</sup>.
- Access varies across the country, with uptake ranging from 0.25% in Medway to 13 % in Halton & St Helens.
- 85.6% of PCTs say that eligible patients are given a choice of using insulin pumps – however this is not borne out by the low number of patients who use this popular technology
- PCTs which do not commission in line with the benchmark give reasons for this including:
  - Lack of specialist staff (66%)
  - Insufficient funding (49%)
- There is confusion and lack of understanding within PCTs about the applicability of NICE guidance, the infrastructure they must provide to allow eligible patients access to pumps, and the assistance (notably through Commissioning Guides) which NICE provides.

## **Conclusion**

### Uptake of insulin pumps

PCTs were asked to provide the number of people with type 1 diabetes in their area, and the number of insulin pumps they oversee. Based on the information provided, only one PCT exceeds the benchmark:

- Halton & St Helens: 76 out of 582 type 1 diabetics in the area have a pump - (13%)<sup>11</sup>

67 PCTs provided all the necessary information to calculate the pump uptake rate. Of these, the average rate of pump use is 3.7%, around a third of the suggested rate.

In some areas uptake is very low, with only a handful of patients using pumps. Notable examples include Medway, where 5 out of up to 1,991 patients have pumps – an uptake rate of 0.25%. The number of users in Croydon is even lower.

### Patient choice

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<sup>10</sup> Pickup J. Insulin pump therapy: then and now. In: Pickup J. Insulin Pump Therapy and Continuous Glucose Monitoring (ed), pp 1-10. Oxford University Press, Oxford, 2009  
([http://www.technologyadoptioncentre.nhs.uk/assets/files/documents/jun\\_10/nhs\\_1276849961\\_Other\\_parts\\_of\\_the\\_world.pdf](http://www.technologyadoptioncentre.nhs.uk/assets/files/documents/jun_10/nhs_1276849961_Other_parts_of_the_world.pdf))

<sup>11</sup> Prior to the corrected data being provided for Blackburn with Darwen PCT, the study first reported that two PCTs gave information which suggests they are providing insulin pumps in line with the NICE benchmark.

86% of PCTs claim that eligible patients are offered a choice of whether or not to use a pump. This relatively high figure is inconsistent with the first finding which demonstrates a low level of actual provision when calculated against the local prevalence figures (patient population). Insulin pump therapy is very popular among patients as it demonstrably improves their blood glucose control and quality of life<sup>12</sup>.

Several reasons behind this apparent disparity are suggested by PCTs' later responses to questions. These include:

- **[There is a] “Lack of appetite among clinicians in prescribing insulin pumps” (Luton).** This may imply that clinicians may steer potentially suitable patients away from pump therapy because it is not their preferred therapy option (this could be because of a lack of training or expertise in pump therapy).
- **“All pump patients are referred in to our accredited DAFNE training programme before initiation is considered” (Oldham).** In many areas there are long waiting lists for patients to find places on carbohydrate counting courses such as DAFNE. This may artificially restrict the number of patients considered eligible for pump therapy.

The NICE Technology Appraisal suggests that all eligible patients should be offered insulin pump therapy, and resources and infrastructure should be made available for this. Positive NICE guidance is based on an assessment of cost effectiveness- i.e. the therapy delivered in line with NICE guidance is deemed to be a cost effective use of NHS resources. Indeed, the therapy has been deemed by NICE to be cost effective and thus appropriate commissioning could be a long term cost saver for PCTs. Despite passing the cost effectiveness test, some PCTs said that the number of insulin pumps they commission is determined in part by the resources available:

- **“The number of patients/which patients are given pumps will not depend merely on NICE guidance but will also be determined partly by the capacity of the service, which in turn will be determined partly by costs/funding.” (Havering)**
- **[Choice is] “not currently [offered] due to capacity issues to undertake this time consuming intervention” (Salford)**

It is certain, therefore, that based on the results of this research, some PCTs are failing in their duty under the NHS Constitution to provide patients with *“the right to drugs and treatments that have been recommended by NICE for use in the NHS, if your doctor says they are clinically appropriate”*<sup>13</sup>.

#### NICE Commissioning Guide and Benchmarking

The NICE Commissioning Guide on Insulin Pump Therapy was published in 2009. This is a suite of documents and tools giving PCTs all the necessary information to appropriately commission the therapy. This includes the Benchmarking Tool<sup>14</sup>, which allows commissioners to determine a local

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<sup>12</sup> Hoogma RPLM, Hammond PJ, Gomist R et.al. Comparison of the effects of continuous subcutaneous insulin infusion (CSII) and NPH based multiple daily insulin injections (MDI) on glycaemic control and quality of life: results of the 5 nations trial. Diabetic Medicine. Original Article. 2005.

<sup>13</sup> The NHS Constitution

([http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/COI\\_NHSConstitutionWEB2010.pdf](http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/COI_NHSConstitutionWEB2010.pdf) )

<sup>14</sup> NICE Commissioning Tool (<http://www.nice.org.uk/usingguidance/commissioningguides/insulinpumps/commissioningtool.jsp>)

uptake benchmark depending on their demographic profile. The 12% benchmark is the average of all PCT's local benchmarks, and thus we would expect individual PCTs' figures to be clustered around this level.

65% of PCTs use the Commissioning Guide, several of those which do not say this is because their procedures were put in place before the Guide was available.

When asked whether they meet the 12% benchmark, 14% of PCTs said that they do. This is not consistent with the earlier findings. Indeed Barnsley PCT, for example, has answered "yes" despite only 2.2% of type 1 diabetics in their area being pump users.

Only 5 PCTs were able to confirm that they have a strategy in place to increase uptake in line with the benchmark. Halton & St. Helens has a strategy, and Blackburn with Darwen is developing one.

#### Good Practice and Barriers

PCTs were asked to explain how, if applicable, they meet the 12% benchmark. PCTs which both do and do not meet the benchmark answered this question. Key themes were rigorous adherence to NICE guidelines and having specialist staff.

Quantifiable answers were given in response to the question asking why the benchmark is not hit. Of the PCTs who answered this question, 66% said that they lack specialist staff, and 49% cited lack of funding (NB PCTs could give more than one reason). These themes were continued in the narrative responses given, with typical responses reading:

- **"There was a lack of specialist knowledge amongst staff with specific insulin pump training" (Eastern & Coastal Kent)**
- **"Lack of appetite among now retired clinicians in prescribing insulin pumps however this is now changing and newly appointed clinicians are embracing this". (Milton Keynes)**
- **"Lack of commissioning knowledge" (Luton)**
- **"Not all consultants are fully aware of the pump service" (Tower Hamlets)**

For patients to be given access to pumps, and for them to be a successful treatment option, it is vital that appropriate infrastructure and resources are in place. Of the 107 PCTs which gave information on the resources they provide:

- 101 (94%) provide access to multidisciplinary specialist teams
- 90 (84%) have a process for identifying patients
- 86 (80%) provide management through transition
- 75 (70%) provide 24 hour emergency support (often via pump manufacturers, or for diabetes care in general, rather than pump specific)
- 113 (out of 120, 94%) have a Diabetes Network or similar.

The apparently strong support and infrastructure provided by PCTs raises further questions about the reasons why provision is low. INPUT's contact with patients who are seeking a pump suggests that the problem is that both clinicians and patients need better information about the technology. Clinicians need to be kept up to date with pumps' efficacy and cost efficiency, and patients need to be fully informed about the blood glucose control and quality of life benefits they can bring.

#### **Recommendations**

Insulin pump uptake in England is unacceptably low, and there is an unfair postcode lottery of provision. This appears to be for three main reasons: a misunderstanding among commissioners about the nature of the NICE technology appraisal and the tools which can help them implement it; staffing issues, including clinicians' preferences and a lack of specialists; and poorly targeted resources. The report authors make the following recommendations to improve pump uptake:

PCTs and emerging GP consortia should make use of the 'How to Why to' Guide on Insulin Pumps produced by the NHS Technology Adoption Centre (NTAC).

The new guide has been specifically designed to save commissioners time, improve patient outcomes and enhance overall productivity. The guide helps to bridge many of the gaps identified by PCTs in the study by providing:

- Support for the development of a business case for the provision of insulin pump therapy in line with NICE guidance;
- A roadmap to implementation of a pump service including how to set up an implementation team;
- Guidance on how to effectively procure pump therapy technology and associated consumables.

In addition the MTG makes the following specific recommendations:

1. Diabetes patients should be given better information about their treatment options, including insulin pumps. Clinicians should routinely share high quality information with their patient, and information should also be available online and through printed materials. This will help patients to make appropriate choices about their care.
2. A comprehensive map of insulin pump services, such as specialist pump clinics, should be made available to GPs, and patients should be able to access specialist pump centres through the Choose and Book system. This will support GPs in their new commissioning role to ensure that patients can access the care they need in line with NICE guidance.
3. The new NICE quality standard on diabetes should support improved access to insulin pump therapy as one of the standard range of treatment options for people with type 1 diabetes.
4. Training and guidance on the use of insulin pumps should be readily available to both patients and clinicians to prevent unnecessary delays to provision:
  - Structured training modules should be made available to patients online to ensure safe and timely access to insulin pumps.
  - Insulin pump modules should be included within GP and secondary care training.
5. Patients' rights enshrined in the NHS Constitution to NICE-approved treatments such as insulin pumps should be made legally enforceable. Healthcare commissioners must take steps to ensure that patients in their local area have convenient access to high quality specialist insulin pump services that meet their clinical needs.

Acceptance of the above recommendations will go some way to ensuring that NICE guidance on insulin pump therapy is implemented. This will improve the care provided to type 1 diabetes patients. It will also go some way to correcting the health inequalities notable between areas which do and do not follow NICE guidance, and ensuring more cost effective use of NHS resources.

### A note on the report

This report was updated on 7 December 2010 to include a data correction for Blackburn with Darwen PCT further to the original data that was provided by the PCT in response to the FOI.

Please note that prior to the corrected data being provided for Blackburn with Darwen PCT, the average rate was first reported at 3.9%.

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### Appendix: Insulin Pump Uptake by PCT

