

Why is the UK lagging behind in the pump usage stakes?

Debbie Hicks

While attending the European Association for the Study of Diabetes (EASD) meeting in Amsterdam this September, I attended a symposium on insulin pump use in the Netherlands. The symposium was a very practical 'this is how we do it' programme presented by a group of very enthusiastic clinicians including Dr Henk-Jan Aanstoot, Dr Evert van Ballegoie, Dr Roel Hoogma, Hilda van der Heyde and Professor Johann Wiechers. During the individual presentations from clinicians and a person with diabetes who is an insulin pump user, I realised that there are many similarities in insulin pump use in the Netherlands with our own experience in the UK, but I was also aware of some distinct differences relating to availability and reimbursement. This article will compare and contrast the experience of insulin pump use in the two countries and offer some possible reasons for the major differences.

Evidence made available by the International Diabetes Federation (IDF) suggests that the incidence of type 1 diabetes is increasing worldwide by about 3% per year and this pattern is shared across high- and low-incidence countries (IDF, 2007). The number of people with type 1 diabetes managed by continuous subcutaneous insulin infusion (CSII) can be estimated from a variety of sources, including national registers, manufacturer's records and published reports of insulin pump practice in various countries. CSII therapy use is approximately 15% in Germany, 17% in Israel and over 25% in the US. In most of the UK's European neighbours (for example, France, Sweden and the Netherlands), a substantial proportion (about 10%) of people with type 1 diabetes use insulin pump therapy for routine management. In contrast, the overall UK insulin pump usage is probably no more

than 1% of people with type 1 diabetes and, in some areas of the country and in children, it is much less (perhaps 0.1% of children with diabetes). Thus, the present uptake of CSII in the UK is dramatically lower than in most other countries of comparable economic standing and level of healthcare provision (Selam, 2005).

The Netherlands

The Netherlands has a general population of over 16 million, and an estimated population of 670 000 people with diabetes: approximately 70 000 with type 1 diabetes, 600 000 with type 2 diabetes and a possible further 100 000 as yet undiagnosed.

The Dutch healthcare system is built on the notion of 'three pillars', these being equality, accessibility and solidarity, all underpinned by collaboration. The healthcare system is funded by compulsory health insurance. This

Article points

1. The present uptake of continuous subcutaneous insulin infusion (CSII) in the UK is dramatically lower than in most other countries with comparable economic standing and level of healthcare provision.
2. There are many similarities in pump use in the Netherlands with our own experience in the UK, but also some distinct differences relating to availability and reimbursement.
3. The overwhelming factor that is contributing to the difference in numbers between the UK, USA and the rest of Europe seems to be the way in which the pumps and consumables are funded.

Key words

- Continuous subcutaneous insulin infusion
- The Netherlands
- Pump initiation
- Training

Debbie Hicks is a Diabetes Nurse Consultant at Enfield Primary Care Trust.

Page points

1. There are approximately 8000 GPs, 90 general hospitals and seven academic teaching hospitals in the Netherlands. There is a strong primary care diabetes service provided by the GP teams who look after 75% of all people with type 2 diabetes.
2. There are over 36000 GPs in the UK and 94 hospitals and teaching hospitals. Since 1948, healthcare has been free for all living in the UK and is funded by the national insurance scheme that we all pay for via our taxes.
3. Clinicians in the Netherlands are very proud of their diabetes service and rightly so, as they have evidence to prove that care and outcomes are improving.

is calculated for the individual person at a partially fixed rate and a partially income-dependent contribution.

There are approximately 8000 GPs, 90 general hospitals and seven academic teaching hospitals in the Netherlands. There is a strong primary care diabetes service provided by the GP teams who look after 75% of all people with type 2 diabetes and this service is underpinned by national guidelines for the treatment of type 2 diabetes. The target HbA_{1c} within these guidelines is 6.8–7.3%.

People with type 1 diabetes, those wishing to become pregnant or who are pregnant, people on pump therapy or people with complex type 2 diabetes are seen by specialist hospital teams. As yet, there are no 'intermediate services' in the Netherlands.

There is full reimbursement for GPs and hospitals for diabetes medication and equipment such as OHAs, insulin, injection devices, blood glucose strips and meters, and insulin pumps and infusion sets.

Key factors in the Dutch diabetes care system are as follows.

- Full reimbursement of all diabetes medication and equipment – no restrictions on strip accessibility.
- 100% use of injection-delivery systems (pen devices).
- Task delegation to DSNs and practice nurses.
- Rapid implementation of national guidelines.
- Major collaboration between the Dutch government and the Netherlands Diabetes Federation (represented by doctors, nurses, people with diabetes, dietitians, podiatrists and researchers) from 1995.

The UK

The UK has a population of over 60 million (National Statistics, 2007). The UK has an estimated population of 2.2 million people with diabetes, of which 20% have type 1 diabetes and 80% have type 2 diabetes. It has been estimated that there may be up to a further 750 000 people with type 2 diabetes as yet undiagnosed (Diabetes UK, 2007).

There are over 36 000 GPs in the UK (DoH, 2004) and 94 hospitals and teaching hospitals. Since 1948, healthcare has been free for all living in the UK and is funded by the national insurance scheme that we all pay for via our taxes. Anyone with diabetes who requires treatment is exempt from prescription charges. This does not, however, include insulin pumps.

Historically, diabetes services have been delivered by hospital-based diabetes teams until the White paper *Our health, our care, our say: a new direction for community services* was published by the DoH in 2006, which directed the care delivery for long-term conditions including diabetes to be shifted towards primary care. Recently, more care is transferring back to GP teams or 'intermediate diabetes teams' established by PCTs to support the GP teams (Hicks and McAuley, 2006; Avery et al, 2008).

Diabetes care in the Netherlands

Clinicians in the Netherlands are very proud of their diabetes service and rightly so, as they have evidence to prove that care and outcomes are improving. In the last few years, they report very few hospital admissions for diabetic ketoacidosis, and hospital admissions for severe hypoglycaemia have reduced. As far as diabetic nephropathy is concerned, it is present in only 55 people with diabetes per 1 000 000 of the general population, whereas Germany reports diabetic nephropathy in 237 people with diabetes per 1 000 000 of the general population, and the US reports 501 people with diabetes out of 1 000 000 of the general population with diabetic nephropathy. They have seen a recent 34% reduction in the number of foot amputations and attribute most of these reductions in long-term complications to the increase in insulin pump use throughout the Netherlands.

CSII use in the Netherlands

In 1979, there were two individuals on the Mill Hill infuser. This first pump was the size of a large rucksack and owing to its novel use, both individuals were hospitalised. Today, there are over 13 000 people using insulin pumps in

the Netherlands, all managed as outpatients with access to a 24-hour telephone helpline. Approximately 10% of insulin pump users have type 2 diabetes while the majority have type 1 diabetes. Each hospital that wishes to initiate CSII therapy has to fulfil national requirements for a pump service. These criteria are to:

- identify a CSII team including a doctor, nurses and dietitian,
- provide a 24-hour helpline,
- have a recognised pump training programme of 2 days duration).

There are no national criteria for patient selection; it is up to the individual hospital to assess the individual's suitability; however, they do follow good practice guidelines and assess areas including the following.

- Medical indications such as sub-optimal glycaemic control, severe hypoglycaemic episodes, hypoglycaemia unawareness, complications and pregnancy.
- Technical and physical capability.
- Intellectual capability.
- Motivation of the person with diabetes and the team.

Clinicians in the Netherlands believe their success with CSII therapy is attributed to decision making jointly with the individual and the diabetes team, motivated patients, optimal training of the diabetes teams, reimbursement and research.

CSII therapy initiation and training

A DSN presented the process behind an individual commencing CSII therapy in the Netherlands. This process did not differ from that of many sites in the UK. She stressed the importance of building a good rapport with the user to enable exchange of information and confidence in the equipment. She also explained how much education was necessary to ensure safety. The main difference between the process in the Netherlands and the UK is the numbers that both of the teams are looking after.

An insulin pump user's perspective

I always find it immensely useful to understand the therapy from a user's perspective 'warts and all'. The user was a pharmacist by training

who had had diabetes since the age of 11 years. Professionally, he has had an interest in skin penetration enhancement since 1989. He had previously tried MDI regimens but never quite got to target. His major frustrations were trying to adjust his two different insulins when passing through various time zones during frequent trips abroad. He explained how his life has been improved by the use of CSII therapy and, although he still struggles to reach the target HbA_{1c}, he provides education and support, and facilitates the use of CSII therapy in the UK. This network provides training courses for those teams wishing to commence insulin pump therapy as well as regular study days throughout the year. There is a very supportive network for healthcare teams specialising in CSII therapy in the UK called Pump Management for Professionals (PUMP). PUMP's objectives are as follows.

- To arrange bi-annual forum meetings.
- To provide education about all aspects of CSII therapy for multidisciplinary team members.
- To support forum members and others embarking on insulin pump therapy.
- To establish and maintain a national register of insulin pump users in the UK.
- To promote research and audit of insulin pump therapy in the UK.

This highly enthusiastic organisation is helping to raise knowledge and awareness of pump therapy in the UK. The group promotes the benefits of CSII therapy by example and demonstrates that there is a real opportunity for people with diabetes struggling to manage their diabetes on conventional MDI therapy to gain better glycaemic control using insulin pump therapy. Clinicians in the Netherlands have challenged their Government continuously to ensure that those individuals who would benefit from CSII therapy have access to it. Perhaps clinicians in the UK should do the same.

It seems that the biggest difference between the two countries is the reimbursement pathway. In the Netherlands, there are no restrictions as to who is eligible to have an insulin pump; however, in the UK, anyone wishing to use one has to fulfil the NICE criteria (NICE, 2003).

NICE has recommended insulin pump therapy

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3. PUMP is an organisation helping to raise knowledge and awareness of CSII therapy in the UK. The group promotes the benefits of insulin pump therapy by example and demonstrates that there is a real opportunity for people with diabetes struggling to manage their diabetes on conventional injections to gain better glycaemic control using CSII therapy.

Page points

1. Even when the individual fulfils the NICE criteria, it is still up to the PCT responsible for the funding of the equipment to have the final decision.
2. Each PCT within England and Wales only provides funding for a limited number of insulin pumps per annum. This usually falls far short of demand.
3. The overwhelming factor that is contributing to the difference in numbers between the UK, and the US and the rest of Europe seems to be the way in which the insulin pumps and consumables are funded.

as one option for people with type 1 diabetes provided that MDI therapy (including using insulin glargine when appropriate) has failed, and they are willing and able to use insulin pump therapy effectively. NICE considers that MDI therapy has failed when someone has been carefully trying to manage their diabetes but has not been able to keep their blood glucose levels within recommended target levels without having 'disabling hypoglycaemia.' This means that they have repeated and unpredictable hypoglycaemic episodes for which they need help from other people, and which make them anxious about the episodes occurring again and significantly affecting their way of life. These recommendations about insulin pump therapy for type 1 diabetes are also valid for children, adolescents, pregnant women and women who are intending to become pregnant. However, pregnant women and women who are intending to become pregnant should only change to insulin pump therapy when under the care of the specialist team. NICE does not recommend insulin pump therapy for people who have type 2 diabetes and need to take insulin.

At the moment, here in the UK as I understand it, we're not fully utilising the NICE guidelines as they stand. In other words, more people could go on pump therapy just with the current limited guidelines. Of course, these guidelines are currently being reviewed and will hopefully broaden eligibility.

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Conclusion

It is clear from the presentations given at the symposium that Dutch clinicians firmly believe that the use of CSII therapy has significantly contributed to their improved clinical outcomes, which they can now report. The use of insulin pump therapy never faltered in the early-to-mid-eighties in the Netherlands as it did in the UK. It is really only over the last 10 years that clinicians in the UK have

begun to feel more confident using insulin pump therapy. There are now regular CSII courses available in the UK for healthcare professionals. There is also a pump association that supports the use of CSII therapy throughout the UK; however, we still seem to be lagging far behind the US and the rest of Europe in respect to individuals using insulin pump therapy. Why is this?

The overwhelming factor that is contributing to the difference in numbers between the UK, and the US and the rest of Europe seems to be the way in which the insulin pumps and consumables are funded. In the US and the Netherlands, there are no restrictions as the insulin pumps and consumables are fully reimbursed through the individuals' medical insurance. This is not the case in the UK. Unfortunately, the use of CSII therapy has been seen by NICE as a last resort when every other method of insulin administration has failed. Perhaps if it was more readily available in the UK, we could report better clinical outcomes. ■

Avery L, Butler J (2008) An evaluation of the role of diabetes nurse consultants in the UK. *Journal of Diabetes Nursing* 10: 58–63

Diabetes UK (2007) *Defuse the timebomb*. Available at www.diabetes.org.uk (accessed 20.01.2008)

DoH (2004) *NHS Hospital and Community Health Service. Non-Medical Workforce Census*, DoH, England

DoH (2006) *Our health, our care, our say: A new direction for community services*. DoH, London

Hicks D, McAuley K (2006) Redesigning diabetes services and its benefits. *Journal of Diabetes Nursing* 10: 304–5

IDF (2007) *Diabetes Atlas*. 3rd ed. IDF, Brussels

National Statistics (2007) *Population estimates. UK population grows to 60.6 million*. Available at: <http://www.statistics.gov.uk/CCI/nugget.asp?ID=6> (accessed 25.02.08)

National Statistics (2002) *D7662. 3.3 Population density, 2002*. Available at: <http://www.statistics.gov.uk/STATBASE/ssdataset.asp?vlnk=7662> (Accessed: 25.02.2008)

NICE (2003) *TA57 Diabetes (type 1) – insulin pump therapy: Guidance*. NICE, London

Selam JL (2005) Insulin pumps in Europe. *Infusystems International* 4: 19