

The ABCD Insulin Pump Network UK

Emma G Wilmot, Peter Hammond, Fiona Campbell

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Article points

1. Access to insulin pump therapy in the UK lags behind other countries, and there is marked geographical variation in pump provision throughout the country.
2. The Insulin Pump Network UK has been set up to provide a platform for teams working with insulin pumps to promote this therapy, overcome the barriers to its use, develop best practice and, ultimately, enhance access to insulin pump therapy for those who need it most.
3. The network also supports continuing professional development and conducts an annual meeting to discuss the issues and share best practice.

Key words

- Best practice
- Insulin pumps
- Insulin Pump Network UK
- Service delivery

Authors

Emma Wilmot is Consultant Diabetologist, Derby Teaching Hospitals NHS Foundation Trust; Peter Hammond is Consultant in General Medicine, Harrogate and District NHS Trust; Fiona Campbell is Consultant Paediatrician, Leeds Children's Hospital.

The UK lags behind other comparable countries in terms of the rate of insulin pump use in children and young people with diabetes despite the fact that, in the right patients, insulin pumps can significantly improve glycaemic control. A number of barriers have been identified, chief among which is a lack of appropriately trained staff and resources. The Association of British Clinical Diabetologists has therefore supported the development of the Insulin Pump Network UK (IPN-UK), a successor to the now defunct NHS Diabetes insulin pump network, to work to overcome some of the barriers to insulin pump therapy and the effective delivery of services. In this article, the authors describe the role of the IPN-UK and encourage all clinicians who work or wish to work with insulin pump therapy to join them.

Insulin pump therapy is now recognised as an integral component of type 1 diabetes care. Despite this, access to insulin pumps in the UK continues to lag behind other countries. For instance, only 6% of UK adults and 19% of children and young people (CYP) with type 1 diabetes use insulin pumps, a much lower rate than in Germany (>15%), Norway (>15%) and America (>40%; Pickup, 2011). There is a need for healthcare professionals working with insulin pump therapy to promote its benefits and ensure equitable access across the UK for those living with type 1 diabetes.

With this in mind, the Association of British Clinical Diabetologists (ABCD) has supported the development of the ABCD Insulin Pump Network UK (IPN-UK). Readers may recall the previous NHS Diabetes insulin pump network, which was one of the most successful networks, with over 500 members. Sadly, with the demise of NHS Diabetes in April 2013, the insulin pump network functions ceased. However, the number of people with diabetes who use insulin pumps has continued

to grow and there is an ongoing, unmet need for collaboration and support for insulin pump teams in this country. Thanks to unrelenting support from the ABCD, the authors and the IPN-UK Committee have successfully managed to reignite a UK-wide insulin pump network.

The benefits of insulin pump therapy

Insulin pump therapy provides a number of benefits for individuals living with diabetes. One of the greatest advantages is derived from the substantial reduction in variation in insulin delivery: <3% for insulin pump therapy compared with up to 55% for subcutaneous insulin injections (Lauritzen et al, 1983). This reduction in variation results in more consistent blood glucose patterns, which can have a positive impact on the individual's self-efficacy and quality of life (McMahon et al, 2005; Hammond et al, 2007; Nicolucci et al, 2008). Insulin pump therapy has been associated with improved glycaemic control, fewer admissions with diabetic ketoacidosis, lower frequency and severity of hypoglycaemia and, more recently, reduced

Table 1. Treatment regimens for children and young people with type 1 diabetes by UK country and region in 2013–2014.
Adapted from National Paediatric Diabetes Audit (2015).

	No insulin	1–2 insulin injections per day	3 insulin injections per day	≥4 insulin injections per day	Insulin pump therapy	Oral hypoglycaemic agents	Oral hypoglycaemic agents and insulin	Missing data
England and Wales	8.1%	7.1%	3.7%	54.8%	16.1%	0.1%	0.3%	9.8%
England	8.2%	7.2%	3.7%	54.3%	15.8%	0.1%	0.3%	8.2%
Wales	5.6%	5.9%	4.5%	63.6%	20.0%	0.1%	0.0%	5.6%
East of England	5.0%	9.8%	5.3%	54.6%	13.0%	0.0%	0.4%	11.9%
East Midlands	11.2%	1.9%	1.0%	52.1%	21.4%	0.1%	0.4%	12.0%
London and South East	6.5%	10.0%	3.4%	60.9%	16.4%	0.0%	0.4%	2.4%
North East	2.0%	10.9%	13.0%	51.7%	21.7%	0.0%	0.4%	0.2%
North West	13.4%	10.6%	3.8%	48.2%	9.9%	0.1%	0.4%	13.6%
South Central	3.6%	2.9%	3.1%	68.6%	20.7%	0.0%	0.1%	1.1%
South West	20.2%	4.6%	1.9%	42.4%	8.9%	0.1%	0.0%	21.8%
West Midlands	4.8%	5.2%	3.3%	56.8%	15.1%	0.0%	0.3%	14.5%
Yorkshire and The Humber	6.5%	3.8%	1.7%	47.7%	21.8%	0.2%	0.2%	18.0%

cardiovascular mortality (Pickup and Sutton, 2008; Johnson et al, 2013; Steineck et al, 2015).

Insulin pump therapy in CYP

Despite the potential benefits, insulin pump uptake in the UK remains low, and this is reflected in the level of glycaemic control achieved compared with other countries (McKnight et al, 2015; National Paediatric Diabetes Audit [NPDA], 2015; Sherr et al, 2016). In 2012, mean HbA_{1c} in CYP in the UK was 74 mmol/mol (8.9%), significantly higher than in Germany and Austria (64 mmol/mol [8.0%]) and the US (68 mmol/mol [8.3%]; Sherr et al, 2016). The rate of insulin pump use is substantially lower in the UK (14%) compared with Germany/Austria (41%) and the US (47%), and the worse metabolic control observed in the UK is, at least in part, a result of this low frequency of insulin pump use. Interestingly, HbA_{1c} was markedly higher for both injection- and pump-treated CYP in England and Wales compared to America and Germany/Austria. Whether this reflects differences in our

healthcare systems, such as delayed access to insulin pump therapy as a result of NICE guidance and/or suboptimal management, or whether it reflects wider social, demographic and cultural differences is uncertain. A key role for the IPN-UK will include promoting the potential benefits of insulin pump therapy and providing educational opportunities for healthcare providers to develop and maintain the skills needed to optimise patients on pump therapy.

The most recent 2013–2014 National Paediatric Diabetes Audit has demonstrated a modest improvement in glycaemic control in CYP with type 1 diabetes to a mean HbA_{1c} of 72 mmol/mol (8.7%); however, 24% still have an HbA_{1c} over 80 mmol/mol (9.5%; NPDA, 2015). Despite the fact that NICE has approved funding for insulin pumps in older children with an HbA_{1c} over 69 mmol/mol (8.5%) and in all children aged ≤11 years, uptake of insulin pump therapy remains low, with an average of only 15.8% of CYP with type 1 diabetes in England using this therapy in 2013–2014.

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1. Healthcare providers often have preconceptions that insulin pump therapy is more technically complex than multiple daily insulin injections; therefore, they are likely to restrict provision of the therapy to patients whom they think have the skills to use them.
2. However, the REPOSE trial demonstrated that more participants were able to make optimal use of the technology than the healthcare practitioners previously expected, and this preconception needs to be challenged.
3. Paediatric patients on average have access to more support from clinicians to assist with insulin pump therapy than adults; thus, young patients who want to continue using pumps into adulthood may face problems during and after transition.

Geographical variation in access to insulin pump therapy

There is wide variation in the use of insulin pump therapy in CYP across England and Wales, with rates varying from 8.9% to 21.8% depending on location (*Table 1*). The reasons for this variation are not clear. While some might assume it is a funding issue, the insulin pump audit conducted in 2013 did not demonstrate this and instead identified two main barriers: lack of diabetes specialist nurses with pump expertise and lack of capacity to train additional staff (ABCD, Diabetes UK and JDRE, 2013).

Staff attitudes: A potential barrier?

The REPOSE (Relative Effectiveness of Pumps Over Multiple Daily Injections and Structured Education) trial showed that healthcare providers perceive the benefits of insulin pumps to be the ability to “drip-feed” insulin, the ability to alter basal rates and other advanced features (Lawton et al, 2016). However, pumps are also viewed as more technically complex than multiple daily injections. For this reason, staff tend to select individuals for insulin pump therapy based on their perceptions about whether the individual has the necessary attributes to make optimal use of the technology.

However, working in the REPOSE trial, which randomised participants to insulin pumps or multiple daily injections, challenged the participating healthcare providers’ preconceived ideas about suitability for insulin pump therapy. Staff observed individuals whom they previously would not have recommended for this therapy making effective use of the pumps. Therefore, making presumptions about patient characteristics to predict clinical success may limit the opportunity for individuals to benefit from this therapy. Such preconceptions need to be challenged, and this is something we can all reflect on in our clinical practice.

The challenges of transition into adult services

As has already been highlighted, a lower proportion of adults with diabetes use insulin pump therapy compared to the paediatric population. In 2013, only 19% of adult diabetologists were involved in insulin pump training programmes, compared to 41% of paediatric diabetologists, which suggests

Table 2. Average WTEs of DSN time provided for all aspects of insulin pump care in adult and paediatric centres in the UK.

	Adult patients	Paediatric patients
WTE of DSN time per centre	0.64	0.74
Number of patients per centre	74	30
WTE of DSN time per patient	0.009	0.025

DSN=diabetes specialist nurse; WTE=whole time equivalent.

that paediatricians may have a more detailed working knowledge of insulin pump technology and its benefits. Furthermore, in the UK insulin pump audit (ABCD, Diabetes UK and JDRE, 2013), on average, paediatric patients had access to three times as much specialist nurse support as adults on insulin pump therapy (*Table 2*).

Three years on from the audit, it is entirely likely that this discrepancy in staffing support between services persists, and this will present a number of challenges, particularly when it comes to planning the transition for CYP on insulin pump therapy. Does the adult diabetologist leading the young adult clinic have a detailed knowledge of insulin pump therapy? Does the service download pump data to help optimise therapy? Does the nurse running the young adult service have the necessary time and expertise to adequately support these individuals? Does the transition team also work within the adult insulin pump team? If the answer to these questions is no, the paediatric team may have to consider alternative options to best support their patients’ transition, whether this is into the local pump service, which may not have a dedicated transition pathway, or to a nearby centre with pump expertise. Either way, these issues have the potential to negatively impact the transition experience of the individual.

NICE Technology Appraisal 151 recommends that CYP on insulin pumps undergo a trial of multiple daily injection therapy between the ages of 12 and 18 years (NICE, 2008). While some patients

do request a trial off insulin pump therapy during this transition period, anecdotal evidence would suggest that most clinicians are, unsurprisingly, not following the recommendation to provide this trial unless it is patient-driven. For CYP who wish to continue on insulin pump therapy throughout transition, there is the additional challenge of ensuring the individual is educated and capable of self-managing insulin pump therapy.

Impact of the Best Practice Tariff

The Best Practice Tariff has successfully facilitated intensive support for CYP with type 1 diabetes, and this has been reflected in the downward turn in the median population HbA_{1c} in England and Wales (Figure 1; NPDA, 2015). Unfortunately, the same cannot be said for young adult diabetes services, which report significantly less staffing and resources than their paediatric counterparts (ABCD, Diabetes UK and JDRF, 2013). Therefore, not only will young adults with an insulin pump potentially have less access to specialists with detailed knowledge of insulin pump therapy, they are also likely to experience less frequent follow-up and support to optimise their use of the technology.

Role of the IPN-UK

The ABCD IPN-UK is keen to work to overcome some of the barriers to insulin pump therapy and the effective delivery of services. Ongoing professional support and development is a prerequisite for the expansion of UK insulin pump services. There is currently no dedicated forum to support the approximately 160 teams in the UK who are delivering insulin pump therapy and the associated emerging technologies. We hope the IPN-UK will fill this gap, providing a platform for teams to communicate and work towards solutions to the issues highlighted, developing a shared vision of best practice and, ultimately, enhancing access to insulin pump therapy for those who need it most.

Working together to enhance patient access to technology

The IPN-UK aims to support insulin pump teams by providing opportunities for collaboration and education (Box 1). There are many clinical areas relevant to pump therapy that have no clear guidance or consensus. How do you arrange safe

and effective transition if the young adult team in your local adult centre does not have insulin pump expertise? How do you continue to expand your service to meet the needs of your patients within the financial constraints of the NHS? What are the optimal settings for predictive low glucose suspend? How do you manage patients on pumps who are not monitoring their glucose regularly? What do you do when a pump patient is lost to follow-up?

These are just some of the examples of the challenges presented to insulin pump teams in their day-to-day practice, and we thought it would be useful for teams to have the opportunity to come together to share ideas, leading to the development of protocols and best practice documents which will be hosted on the IPN-UK website (available at: www.ipn-uk.co.uk).

Previous issues identified by the NHS Diabetes insulin pump network

The previous, very successful, NHS Diabetes insulin pump network identified a number of themes, which are briefly outlined below. The IPN-UK hopes to build on these issues.

Service development

- Capacity planning, including flexible, virtual follow-up to increase capacity.
- Working towards effective transition for individuals on insulin pump therapy.

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1. The key role of the Insulin Pump Network UK is to overcome the barriers to effective delivery of insulin pump therapy and to provide ongoing professional support and development.
2. It encourages teams working with insulin pumps to come together to share ideas, leading to the development of protocols and best practice documents which will be hosted on the network's website: www.ipn-uk.co.uk.

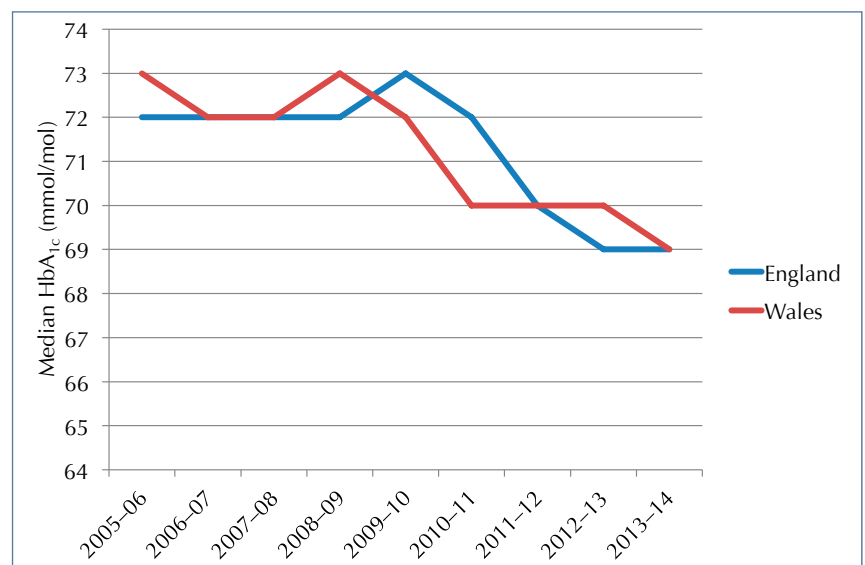


Figure 1. Change in median HbA_{1c} in children and young people with diabetes in England and Wales between 2005 and 2014. Adapted from National Paediatric Diabetes Audit (2015).

“Membership is open to all UK adult and paediatric multidisciplinary clinicians who work with services which deliver – or wish to deliver – continuous subcutaneous insulin infusion therapy. We look forward to working with you in the future.”

Box 1. Role of the Insulin Pump Network UK.

Collaborate:

- Communicate via website and e-newsletters
- Share protocols and best practice

Evolve:

- Promote patient access to the latest technology
- Professional development

Support:

- Education: online resources and annual meeting
- Facilitate annual national insulin pump audit

Professional development

- Ensuring staff have adequate access to continuous professional development.
- Adequate training opportunities for those interested in upskilling in insulin pump therapy.
- Adequate guidance for healthcare professionals working in settings where they might encounter pump users, such as the emergency department, labour ward and operating theatres.

Funding

- Ensuring funding is not a barrier to insulin pump therapy.
- Facilitating access to funding for continuous glucose monitoring for those who need it most.

Clinical pathways

- Standardising pathways to pump therapy: ensuring efficient delivery of services to maximise patient choice and deliver optimal support and education through pump initiation and follow-up.
- Developing and measuring relevant outcomes in this user group beyond HbA_{1c}: standardised measures of hypoglycaemia and quality of life.

Controversies in pump therapy

- Managing non-attenders at pump clinic.
- How do we define when insulin pump therapy is no longer suitable?
- Re-use of insulin pumps and trials of insulin pump therapy. In the previous insulin pump network, this drew an unprecedented sharing of practice, uncovering significant divergence in approach and prompting calls for definitive guidance.

IPN-UK meetings

The IPN-UK meetings will be held every year and will discuss the issues identified above. To register as a member of the IPN-UK for updates on upcoming events and relevant publications, please visit: www.ipn-uk.co.uk. Membership is open to all UK adult and paediatric multidisciplinary clinicians who work with services which deliver – or wish to deliver – continuous subcutaneous insulin infusion therapy. We look forward to working with you in the future. ■

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