

# **Injecting Fresh Ideas Into the National Health Service**

Investing in Children 730+ Diabetic report

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## **Introduction**

In 2001 Dr Lamb, consultant paediatric diabetologist at Bishop Auckland hospital in County Durham was seeking ways to improve the diabetic clinic and services for young people and to find ways of motivating adolescents to look after their health. Instead of asking those who provide the service in the NHS their thoughts on improving the clinic, he chose to seek the opinion of the young people who attend the clinic – in his view the experts on their condition.

Dr Lamb asked Investing in Children to facilitate the group. Investing in Children is a County Durham initiative which seeks to create opportunities for young people to become genuine participants in decision-making processes about services that affect their lives.

James Davy, Ashley Des-Forges, Nina McGregor and Sarah Maughan assisted by Pippa Bell from Investing in Children worked for two years on the 730+ project (so named because 730 is the minimum number of insulin injections which is needed each year by young diabetics). They carried out their research using the following methods:

- Questionnaire  
The group devised a questionnaire to find out what other adolescent users of the clinic thought about the service.
- Group meetings and discussions
- Interviewing other diabetics
- Research visit to a Swedish paediatric diabetic clinic  
After meeting for 9 months the group wanted to compare how their clinic was run with another clinic. Dr Lamb suggested visiting a clinic in Uddevalla in Sweden run by world-renowned paediatric diabetologist Ragnar Hanas, because this clinic has one of the most successful rates for controlling young people's blood/sugar.

During the course of this research the group identified the issues that they felt most affect the lives of teenage diabetics. These issues fall into the following key categories and each one is considered in detail in the report.

1. Clinic waiting room
2. Treatment by medical staff
3. Awareness of the diabetic condition
4. Diabetic support programme
5. Motivation
6. Insulin pumps

**Issues raised by the 730+Diabetic group at Bishop Auckland Hospital, and possible solutions to the problems**

<p align="center"><b>Issues raised by 730+ group</b></p>	<p align="center"><b>The 730+ group' s ideas about how to solve these issues</b></p>	<p align="center"><b>The groups findings on how similar issues are tackled in Sweden</b></p>
<p><b>How to <u>build confidence</u> in newly diagnosed diabetics, and create a feeling of <u>security</u> for all young/adolescent diabetics</b></p>	<p><b>The group suggested that newly diagnosed diabetics (ndd) could learn a lot from other experienced diabetics. The diabetic medical team at the clinic could be instrumental in setting up a network, and putting young people with similar experiences in touch with each other.</b></p> <p><b>The group felt that parents also need support, and so they suggested that parents of ndd's should be introduced to parents with children who already have diabetes.</b></p> <p>The British Diabetic Association offers holidays where young diabetics can meet each other, and learn more about controlling diabetes. These holidays are not regional; diabetics attend them from around the country, so it is hard to sustain friendships from different ends of the country after they are over.</p> <p>At present, regular treat days out with the staff from the Bishop Auckland clinic, helps young diabetics get to know each other. These are also a reward for all the hard work it takes a young diabetic to continually control their b/s levels.</p>	<p>A newly diagnosed diabetic (ndd) is put in touch with a <b><u>sponsor family</u></b> (with a similar background) who has a long-term diabetic child of the same gender and a similar age.</p> <p>Young diabetics meet each other at the <b>Diabetic Camps</b>, which are held annually by Ragnar's clinic and other clinics in the area. There are 3 types of camps:</p> <ol style="list-style-type: none"> <li>1. For the youngest children a weekend camp (for one or two nights) is held which also includes the diabetics' families. As well as making friends, everyone learns how to cope with controlling diabetes.</li> <li>2. For adolescents, this is often a skiing camp the purpose of which is for making friends and for learning more about diabetes.</li> </ol>

**How to build confidence  
in newly diagnosed  
diabetics contd:**

**The group also had the  
idea of starting an  
adolescent diabetic social  
club**

which could be run every 3 months, at the hospital after the clinics have finished. This idea was suggested to fellow diabetics who attend the Bishop Auckland clinic via a questionnaire. Of those who responded to the questionnaire, the majority showed interest in the idea, but they were not sure if they would attend such a group!

**The group expressed a concern that on the rare occasions when their usual diabetic Dr did not see them, they would like to be seen by someone who knows something of their personal history. This would make them still feel secure when visiting the clinic while the usual Dr is away.**

3. For older adolescents, camp is a sailing week. In all camps, diabetics are in the majority, which is a unique experience for most of them.

As well as the camps Ragnar's clinic holds **regular diabetic youth groups for children and adolescents**, where they can socialise together. From experience Ragnar and his team have found that adolescents who have made friendships through the camps or social clubs in pre-pubescent days are more likely to continue these friendships through out adolescence. Whereas, they have found that it is harder to get adolescents to attend a group if they have had no previous experience of these events.

**If the Dr is not able to see a patient then the nurse, who knows the diabetic well is able to stand in.** If a Dr's opinion is needed she can call on one of the other paediatric Dr's to attend.

<p><b>How to <u>build confidence</u> in newly diagnosed diabetics <u>contd</u>:</b></p>	<p>If this isn't possible <b>then a comprehensive personal record (including personal interests or even dietary preferences) about each patient is needed so that the new Dr knows what to expect</b> when they meet, and consultation time isn't wasted going over old ground.</p> <p><b>The group suggested that a reward scheme for the diabetic with the best HbA1c that quarter, could be started at the clinic.</b> This would take the form of a congratulatory certificate, which could be displayed, on the notice board in the clinic. Each diabetic who has a good HbA1c that quarter could also be given a certificate of achievement. This could instigate competition amongst the diabetics and a desire to be the best at successfully controlling their blood/sugar (b/s) levels during the following months.</p> <p><b>Learning to administer your own injections as a nidd. creates a feeling of importance, and confidence,</b> that you are able to be trusted with managing your own b/s and controlling your diabetes</p>	<p>Ragnar's clinic compile <b>an HbA1C graph which plots every patients average HbA1c each quarter.</b> So, by looking at the chart a patient can easily see how well they are controlling their b/s compared to other diabetics who attend the clinic. If they are not doing well, a comparison of their position with others on the HbA1c chart encourages them to do better. If a diabetic sees that their position on the HbA1c chart is good, this acts as a pat-on-the-back and raises their self-esteem.</p> <p><b>Regular group teach-ins are held at the hospital or in the clinic</b> to show nidd's how to control their diabetes or use a pump. As well as having a practical purpose these sessions are useful for meeting other young diabetics</p>
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<p><b>Fear of the unknown – good communication is the solution</b></p>	<p>The greater the knowledge a young diabetic has about their condition the more confident they feel, and therefore they are less worried about coping with diabetes. <b>The group suggested that a CD-ROM for the computer could be made, which would be given to all ndds. This would be a reference source covering every aspect of diabetes,</b> and therefore it would also answer many frequently asked questions about diabetes.</p> <p>Therefore the CD-ROM could save the diabetic medical team time, by answering simple questions which they would usually have to deal with.</p> <p>Many of the issues that a new diabetic feels uncertain about can be dealt with by <b>talking them through with an experienced diabetic, preferably someone of a similar age.</b> These meetings can be arranged using some of the methods suggested above e.g. Social club, outings, camps and support network.</p>	<p>The new diabetic is given the <b>diabetic reference book that Ragnar has written.</b> This covers all aspects of diabetes. The book is also very useful for families and long-term diabetics who want to know all they can about their condition and how to cope with it.</p> <p>As well as being put in touch with a sponsor family a ndd is also given the opportunity to join an <b>emailing network where diabetics and their families are able to put questions and concerns via email</b> to other people in similar situations to themselves.</p>
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<p><b>Being treated as Equals</b></p>	<p>Adolescent diabetics would like to be treated as equals by the medical staff, and not patronised or talked at through their parents. <b>The group felt that medical staff should be able to communicate with a young person at their level and use medical terms that they can understand. By being treated as an equal the young diabetic will grow in confidence and will feel very able to successfully control their diabetes.</b></p> <p>They appreciate help from the dietician but would also like acknowledgement that they often know what is best for them.</p>	<p>As with the diabetic team in Bishop Auckland, Ragnar and his nurses recognise that the young people are the real experts on their own diabetic condition. They acknowledge that the young diabetic will often know better than the medical staff what works for them, how to handle their diet etc. It is very important to listen to and respect their views.</p>
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<p><b>Schools –being different from the crowd</b></p>	<p>After diabetes has been diagnosed the diabetic nurse visits the ndd's school and talks to the staff and pupils about diabetes, and how to cope if the ndd has a hypo. Often the school will initially fuss over a new ndd believing that they need special attention. Apart from the issues of diet and how to cope if a diabetic has a hypo this is not the case. Some members of the group remember being made to feel different when they were ndds, by staff at school. This is an extra burden to cope with when they are coming to terms with dealing with diabetes. To ease this situation <b>the group felt that the diabetic message from the pupil's point of view could be re-enforced with a good education leaflet written by young diabetics and given to schools when the nurse visits the school.</b> This could include quotes from diabetic pupils, as well as information about diet and how to deal with hypos. <b>The diabetic pupil could also talk to the teachers and fellow classmates with the diabetic nurse,</b> when she visits the school, and explain that they don't want to be treated any differently.</p>	<p>As in Britain the diabetic nurse goes to a ndd's school and talks to the teachers and fellow classmates about the diabetic's needs and how to deal with any emergencies.</p>
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<p><b>Motivating Adolescents</b></p>	<p>The young people are motivated to control their b/s because they know that if they don't they could die.</p> <p><b>The adolescents in this group also want to successfully control their diabetes as they have a lot of respect for their Dr and therefore want to please him.</b></p> <p>Some of the group has experienced chance meetings with peers who are now suffering problems (such as bad circulation and eyesight problems) through not controlling their b/s properly. This has had a very sobering effect on the diabetic and has made them more aware of the consequences of not controlling their b/s correctly.</p> <p><b>Perhaps meetings set up with diabetics who are now suffering long-term problems would emphasise the message (how important it is to correctly monitor your b/s) better than any Dr lecturing an adolescent on the subject.</b></p>	<p><b>The HbA1c chart,</b> (mentioned above) is a good motivational device amongst young people. They want to control their b/s and please their Dr.</p> <p>If the diabetic's b/s is on average higher than 8% (this is equal to 9% in Britain) in any 3 months, then the diabetic has to join <b>Ragnar's 8+ group</b>. This means that they have to visit the clinic monthly or even weekly to have their b/s monitored until it drops to a more healthy level.</p> <p>These regular visits to the clinic can be very motivating because the diabetic can then see that their b/s is good over a short period of time, although it may be harder to control and look higher over a period of 3 months. Ragnar has recently started a <b>9+ group</b> which includes seeing a psychologist as part of the routine. The hope is that seeing a psychologist regularly will deal with the diabetic's concern of "what's wrong with me?".</p> <p>Ragnar has employed extreme measures for adolescents who consistently have had high b/s results, and don't take looking after their health seriously. <b>He has organised meetings between such a diabetic and another diabetic (with a similar background)</b></p>
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<p><b>Motivating Adolescents</b> <b><u>Contd:</u></b></p>	<p>The group felt that some young diabetic's cavalier attitude to controlling their b/s is brought about through ignorance of their condition, or the fact that they don't want to be seen as different from their peers by not smoking or drinking. <b>Therefore the group suggested that a 'cool/groovy' leaflet could be designed, which spelt out the most important aspects of controlling your b/s levels. This would also show the bad effects of drugs, drink and smoking on a diabetic's health.</b> Using a famous trendy diabetic role model (e.g., footballer, popstar, actor) to spearhead such a campaign, would further re-enforce the message.</p> <p>It is important that a diabetic generally has a healthy lifestyle, diet and sport/fitness are part of this. <b>Therefore a leaflet encouraging young people to enjoy regular exercise and to explain that it has no detrimental effect on diabetics could prove persuasive for motivating adolescents.</b></p>	<p><b>who has neglected themselves in the past through drink or drugs and are now suffering the consequences eg.kidney failure. Meetings such as this have been successful</b> and have caused the diabetic to take more care of themselves and to comment that ; "I wish you had introduced me to them sooner"</p> <p>Ragnar and his nurses always encourage a young person to take up, or continue with, regular exercise and sporting activities.</p>
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<p><b>Clinic- Waiting Area</b></p>	<p>The old waiting area in Bishop Auckland hospital for paediatric outpatients and was situated in a corridor which was also a busy thoroughfare. The Décor was drab and there were no windows with natural light. There was nothing for adolescents to look at apart from a few biking magazines. There were a few toys and a table football table (which gave anyone above 4 foot back – ache if they tried to play it!) for the younger children but even this was limited.</p> <p><b>The group has suggested that to improve the area it should be a proper waiting room with a door, rather than a corridor, and it should be spacious and not cramped.</b></p> <p><b>Further ideas by the group for improving the area have included the following:</b></p> <ul style="list-style-type: none"> <li>- <b>Introduce plants</b></li> <li>- <b>Have windows to let the light in.</b></li> <li>- <b>Decorate the walls with child/adolescent friendly murals and designs.</b></li> <li>- <b>Have more books and magazines available for adolescents.</b></li> <li>- <b>Have a games console, preferably one that can't be stolen!</b></li> <li>- <b>More information leaflets about health issues relating to adolescent diabetics.</b></li> </ul>	<p>The waiting area for paediatric outpatients is large and airy and decorated in a bright yellow. It has a large number of toys available for young children including a big wooden ship to play on. There was a large bookcase with many magazines and books appealing to all ages. The video will give a small taste of the layout and atmosphere of the waiting area.</p>
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<p><b>Clinic – waiting area contd:</b></p>	<p><b>Retain the notice board as all the group find it useful as a source of diabetic news and what is happening to fellow diabetics.</b></p>	
<p><b>Waiting Time</b></p>	<p><b>To cut down the long wait for diabetics when they go to see the Dr and the various medical staff, the group suggested that ndd’s should be seen, if possible, on different clinic days to long term diabetics.</b> This is because ndd’s often have many more questions about their diabetes (as they are still learning how to control it) and therefore their appointments take much longer. Whereas long-term diabetics know more about their condition, and therefore should have a shorter consultation time.</p>	<p><b>Each patient is allocated 45mins consultation time</b> and this is often more than enough. However the <b>clinics run from 8.30 am every day, so there is more time for the diabetic team in Sweden to see everyone.</b> <b>The DCA 2000 machine speeds up the testing of b/s.</b> This can also be done while the diabetic is waiting for their appointment. <b>The Dr and nurse sit in the consultation together with the diabetic for about 1/3 of the consultation time.</b> This saves time for the diabetic, as they don’t have to repeat the same information twice to the Dr and nurse respectively. <b>There are 2 permanent full-time diabetic nurses who job share.</b> They therefore are able to relieve the Dr of some of the smaller diabetic matters.</p>

**Terms and abbreviations**

**Ndd** –Newly diagnosed diabetic

**Dr** -Doctor

**Hypo** – a hypoglycemic state when the body is lacking in glucose and the diabetic could, if not treated by an intake of sugar, go into a coma.

**B/S** – Blood sugar also known as **HbA1c**

**DCA2000**- A desktop machine to analyse blood and urine samples in the clinic.

**Comparisons between English adolescent diabetic care and Swedish adolescent diabetic care**

<b><u>England</u></b>	<b><u>Sweden</u></b>
<p><b>Clinic Statistics</b></p> <ul style="list-style-type: none"> <li>- Dr Lamb looks after 80 families in the Bishop Auckland clinic.</li> <li>- Dr Lamb works with Trisha a diabetic nurse who is part time.</li> <li>- The area of the clinic covers is .....miles</li> <li>- A diabetic can remain under Dr Lamb's care after they reach 20 years of age, but will have to move to an adult clinic by the time they are....</li> </ul> <ul style="list-style-type: none"> <li>- The clinic runs from 2 – 4pm, 2 days a week.</li> <li>- The clinic is held in a consulting room that is not only used by the diabetic medical team but used for other paediatric consultations as well.</li> <li>- There is no time limit on how long a patient can spend with the Dr. during a consultation.</li> </ul> <p><b>Pro</b> -If a person wants to discuss a big problem with the Dr then they won't feel they have to talk it over quickly because somebody is waiting.</p>	<ul style="list-style-type: none"> <li>- Ragnar Hanas looks after 110 families in an area of about 180 square miles.</li> <li>- Ragnar works with 2 permanent half-time diabetic nurses (one of whom is Catarina).</li> <li>- As they become adults diabetics have to leave Ragnar's care at the age of 20 or at 18 if they are leaving the area due to their further education. To make the transition to the adult clinic smoother the adult diabetic nurse will come and sit in on the diabetic's last appointment with Ragnar. After this they are then accompanied to the adult clinic by this nurse who shows them around, so that when they start their treatment there they are familiar with the clinic.</li> <li>- Diabetic clinics are held every day and run from 8.30am until 4.00pm</li> <li>- Each diabetic is allocated 45 mins consultation time with the Dr and nurse.</li> <li>- The diabetic consulting room is actually the office of the diabetic nurses, therefore it contains all the equipment (such as injection aids) used by diabetics. If the clinic is very busy then Ragnar will use another consulting room within the department.</li> <li><b>Pro</b>-Having a permanent diabetic nurse means that they are always available to deal with problems diabetics may have, (even when the Dr is away)</li> <li>- Having the diabetic equipment in the office means that it is easy to hand out the necessary supplies to the diabetic, resulting in little time wasting during the consultation appointment.</li> <li>- Having the paediatric Dr or nurse go to the new adult clinic with the diabetic for the first time, helps smooth the passage between the 2 clinics for the diabetic, and allows the medical staff to share their knowledge about the diabetic with each other.</li> </ul>

<p><b>Con</b> -As the clinic only runs for 2 days a week the medical staff are very busy trying to see all the diabetics. This also means that it may not be possible for a diabetic who is having trouble handling their b/s, and needs more attention to have frequent appointments.</p> <p>-As the diabetic consultant is not the only one who uses the consulting room; it is impossible to keep the diabetic equipment permanently in the room. This results in a further delay for everyone during the consultation, when the nurse has to go and retrieve the equipment the diabetic needs, as this is kept elsewhere in the hospital.</p>	<p><b>Con</b> -A 45 min slot for each patient is more inflexible than the English system. However, if a diabetic needs a longer discussion they are allowed to continue and are not shown the door!</p>
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**Clinic visits**

- A diabetic visits the clinic every 3 months
- Visits can be more frequent for a newly diagnosed diabetic who needs to learn about their glucose levels and how to manage their diabetes.
- After the consultation the Dr discusses with the diabetic when the next appointment should be. If the diabetic wishes they can be seen more frequently than every 3 months.
- Each diabetic is given the home phone number of the Dr and nurse(?) in case they have a query or a b/s problem out of consultation time.

**Pro-**It is reassuring for the diabetic that they can discuss with the Dr how frequently they should attend the clinic.

- As in England the visits are every 3 months.
- If a diabetic has problems regulating their HbA1c then the frequency of visits can be increased. The diabetic can then see the Dr. or nurse either monthly or even weekly.
- If a patient persistently fails to show up for their appointments, then the social services are called in to visit them and to explain how important it is for a diabetic to regularly attend the clinic.
- Each diabetic is given the home phone number of the Dr and nurses and e-mail addresses if requested.
- At present there are discussions about creating a 24 hour diabetes hot-line which would include Ragnar and his nurses and all Doctors and nurses in the larger geographical area (covering 1,000 diabetic patients), being on-call to patients by phone.

**Pro-** A diabetic who is able to visit the clinic more frequently has an opportunity to learn to regulate their b/s more efficiently. This also makes the diabetic feel more secure in their control of diabetes.

- A diabetic who can inspect their b/s results (which are regularly taken at the clinic) that they are successfully managing their diabetes, will have increased self-esteem.
- If a 24 hour diabetic hot-line was created then all diabetic patients in that area would have access to a good diabetic information service both day and night, which would engender peace of mind for diabetics and their families.

**Who sees the diabetic at the clinic?**

-The Dr and the nurse are seen separately by the diabetic during their consultation time at the clinic.

-The diabetic only sees the dietician or chiropodist if requested.

**Pro-** If you want to talk in confidence to either Dr or nurse this is possible.

**Con-** Seeing the Dr and nurse separately make the consultation times much longer, both for the diabetic and for the diabetics waiting to be seen.

-The nurse sees the patient alone for the first 10 mins, when she takes weight, height, HbA1c and urine tests. The Dr then starts the consultation while the nurse records the results in the same room. Then the nurse leaves the room and comes in towards the end of the consultation to hear if there are any specific health concerns that the diabetic may have.

-The diabetic asks if they wish to see a dietician or chiropodist.

**Pro-** Seeing both the Dr and nurse together for a third of the consultation time saves time for the diabetic. This is because the nurse has been in the room and heard how the diabetic is, and any concerns that they may have.

-This practice also saves time for the Dr and nurse as they both are in the room to hear what the diabetic has to say, and therefore they don't need a prolonged meeting after the diabetic has left to discuss their case.

**Con-** The diabetic may feel that they aren't having enough private consultation time with the Dr. However, private time is possible if specifically requested.

**Clinic waiting area**

- This is a small, shared area for all paediatric outpatients.
  - The waiting area in the old hospital was also a corridor, so people were always walking through it.
  - The seating was spread out around the area and this gave a disjointed look.
- There are games for younger children and a few toys, but there is little choice of amusements for adolescents apart from a few specialist magazines, and a table football table.

**Con-** The fact that the waiting area was small, and was for all paediatric outpatients made it very cramped. The siting of the waiting area, in a corridor, also made it an uninspiring place to sit! Therefore, the experience of waiting for a diabetic appointment is a negative one. The diabetic feels bored and uncomfortable, and dreads the thought of going to the clinic and having to wait.

-The waiting area is specifically for paediatric patients. It is at the entrance of the paediatric out – patient’s area and separated from the rest of the hospital by a door. It is a light and airy room, although it is an internal dept (light is let in via big windows onto a corridor).

-The waiting area and whole dept. is painted a warm yellow colour, which looks a lot less dreary than ‘hospital’ white!

-There are lots of low, comfortable chairs arranged casually around coffee tables.

-The waiting area is also a fun place for young children – there is a wooden boat to climb on and some sit and ride toys and some games. There is also a large bookcase full of books for adolescents to read and a drinks machine.

**Pro-**The waiting area is very welcoming and is a positive, fun experience for young people and children. Young children probably look forward to going to the clinic so that they can play with the toys!

**Waiting time at the clinic**

- The wait is usually about 20 mins before the diabetic sees the first medical person at the clinic.
  - The whole process of consultation can take around 2 hours (with extra waiting time in between) as the diabetic waits to see the Dr and nurse separately and then possibly other medical staff.
- Usually no one lets the diabetic know how long the wait will be.

**Con-** From past experience the diabetic always knows that they are in for a long wait when they visit the clinic. Therefore they often feel dispirited, and probably don't look forward to, attending the clinic.

-Seeing medical staff separately prolongs waiting time.

- The wait is usually 15 mins before the diabetic is called in to see the Dr. Waiting time is rarely more than 30mins.
- While the diabetic is waiting the nurse keeps them informed of how long the wait will be and if the wait is longer than 15mins she starts to do the b/s tests.

**Pro-**The diabetic is always informed and knows how long they will be waiting.

-Even if they are waiting longer than usual they feel that at least something is happening when the nurse starts the b/s tests. The diabetic therefore feels less frustrated than if they were just waiting around and doing nothing.

### Testing HbA1c

- A week before each appointment, the diabetic sends off samples of blood and urine to be analysed by the lab. These are either taken by their GP, or taken them, and sent to the clinic where they are sent off to the lab. The results are then discussed with the Dr when the diabetic attends the clinic.
- If the diabetic forgets to send off the samples then the tests can be done at the clinic.

**Cons-** If a patient can't get to a GP or they forget to go, or forget to send off their own samples:-

- It costs a lot to send a sample to the lab.
- The results of the tests done at the clinic are not as accurate as those sent beforehand.

-The test is done at the clinic (by the desk top DCA 2000+ machine) and the results are analysed while the diabetic is having their consultation with the Dr.

-Every month the Dr plots a graph of all his diabetics HbA1c results, so that he can show each patient attending the clinic where their HbA1c result falls on this graph.

**Pro-**As the blood and urine samples are always done at the clinic, the diabetic doesn't have the inconvenience of having to remember to send them in for analysis before the appointment.

-The blood and urine results are immediate.

-The cost of analysing the sample by the DCA 2000 machine is less, once the initial out lay of the machine has been covered.

-The DCA2000 is as accurate as a lab test (in Uddevalla they are part of a quality programme of control analysis of blood tests which regularly checks this).

-Showing each diabetic where they fall on the monthly HbA1c chart has a motivating effect on them. E.g.: if the diabetic has successfully managed their HbA1c that month and records a good result compared to others on the chart, then they will feel pleased with themselves. If a patient has had a bad month and their place on the chart is too high or too low, when looking at the chart, they can see which level they should be achieving next month.

**Con-**The DCA 2000 machine costs a lot of money to buy.

### Administration of Insulin

- With very few exceptions diabetics in Britain administer insulin through injections. The syringe injection is now usually in the form of a pen.

**Pro-** Diabetics learn to control their b/s very effectively and can administer the insulin exactly when it is needed.

**Con-** Diabetics are only human and mistakes can happen. If they forget or are unable to administer the correct dose of insulin then they are endangering their health.

-During adolescence hormones can cause insulin levels to vary a lot and often it is very difficult to administer insulin (as the doses have to keep changing) to properly regulate this.

-15-20% of diabetic adolescents in Sweden uses an insulin pump (40% of diabetics adolescents in Uddevalla) This pump constantly administers insulin into the blood stream and can be manually boosted at meal times.

- When the diabetic chooses to start using a pump they are given lessons with other diabetics who want to start using the pump. The 'pump school' is held over 3 days on the day care ward for 3-4 hours over lunch each day.

**Pro-**It is easier to regulate b/s levels with a pump, particularly when rates vary so much, due to hormones, during adolescence.

-Using a pump can create a feeling of security for the diabetic because residual insulin is always being pumped into the blood stream.

- The pump keeps a record of all the doses of insulin administered and at what time they are administered. When a diabetic visits the clinic they can get a print out of their insulin doses from the pump and can see where they have been having problems, and can then discuss with the Dr how to rectify this.
- The new pump user lessons at the hospital create a feeling of being part of an exclusive new gang of diabetic pump users!

**Con** – A pump costs c. £2,000 each so it is very expensive to give to each diabetic.

- The pump is always attached to the diabetic so they may at first feel very self-conscious about it. However, at certain times such as sports sessions it can be easily detached

- As the pump is permanently attached to the diabetic, this means that insulin is always being pumped into the subcutaneous tissue. Therefore a pump will continue to give insulin even if a diabetic's B/S level is low – however a pump can be removed to prevent a diabetic going into a hypo.

### **Newly Diagnosed Diabetics**

- The GP or the hospital where the diabetic has been diagnosed refers each newly diagnosed diabetic (ndd) to the diabetic clinic.

- Each ndd, who has been admitted to hospital and their family, are given the option of staying in the ward to learn how to control their diabetes.

-If the diabetic chooses not to stay in hospital then they return to the children's ward to spend the day learning how to control their b/s.

- During these hospital induction days the diabetic will meet the rest of diabetic team and will be given the equipment needed to monitor and control their diabetes.

- At a later date the nurse will visit their home and will talk to the diabetic and their family about their condition and will answer any questions they may have.

- The nurse will also visit the ndd's school and explain to the teachers and catering staff how diabetes is controlled. She will also talk to the ndd's class and explain about diabetes and that it is nothing to be feared.

- The British Diabetic Association (BDA) offers weekend courses for ndd's and their families to learn how to control diabetes.

- The BDA also offer diabetic holidays where children and adolescents can relax and enjoy each others company, as well as learning more about controlling their diabetes.

- The clinic regularly run days out and treats for the children and young people who attend their clinic.

**Pro-** The diabetic is very aware of the strong personal interest of the Dr and the nurse in their health, and teaching them how to cope with diabetes. This leads to a strong sense of security.

- Visiting the ndd's school teaches the Staff not to fear looking after a diabetic.

-The Dr and nurse visit each ndd in hospital. They speak to their family and teach them how to control their diabetes.

-These teach-ins at the hospital can either be just the ndd and their family or can be a group teach-in with other ndd's and their families.

-Each ndd is given a copy of the reference book Ragnar has written about diabetes: 'Insulin-Dependent Diabetes'.

- The Dr and nurse put the family in touch with a 'sponsor family' who have a diabetic child. The sponsor family will have a similar background (same gender child, similar age etc.) to the ndd's family.

- The ndd and family are also given Email contact via an email-mailing club with other diabetics and their families.

This service enables them to post questions onto email which are then sent to every subscriber of the service (similar to a internet chat room) and (hopefully!) answered by someone!

- The nurse will visit the ndd's school to see the staff and explain about diabetes, and will also talk to the ndd's classmates.

- The clinic with other clinics in the area takes young diabetics away on camp. The younger children attend with their family while the adolescents go on their own. Here as well as learning about their diabetes they can also meet friends who are in the same position as themselves.

**Pro-** Being diagnosed as a diabetic can be very daunting, therefore teaching ndd's and their families in groups at the hospital about how to control their diabetes creates a feeling of belonging to a special club, rather than a feeling of being 'different' to the rest of the world.

**Newly Diagnosed Diabetics:contd**

-Regular treat days for diabetics are an opportunity for them to enjoy each other's company and a reward for ably controlling their diabetes throughout the year.

**Con-** Through ignorance school staff may still worry about the diabetic condition, and therefore will single out the patient for special treatment (which is not what the diabetic will want!)

-Ragnar's book is a vital reference book for any diabetic, answering many questions new diabetics may have. This can also save

the Dr's consultation time as many queries may have simple answers found in the book and the diabetic may not feel the need to speak to him.

-The support of a sponsor family can lead to a sense of security for all members of the ndd's family! a feeling of 'they've been through this and survived' and 'we are not alone' are common thoughts. Also strong friendships lasting many years can be forged during this period.

-This support system can also relieve some of the pressure from the consultant as families can exchange information between each other. This is true also of the email network system.

- The diabetic camp is a very successful way of showing the diabetic that they are not alone. It increases their self-esteem as the diabetics are in the majority on camp, a situation that is very rare, and they often make long-lasting friendships. This is particularly important for the pre-pubescent diabetic; -as having supportive friends will help them negotiate the difficult years of adolescence and hormone changes!

**Con-**Some diabetics may prefer to learn how to handle their diabetes on a one-to-one basis with the Dr, and this is possible to arrange.

<p><b>Specific Adolescent Issues</b></p> <p>-The Dr or his nurse usually deals with specific teenage issues- Smoking, contraception (for girls), drinking and drugs when the young person reaches adolescence. Occasionally these issues may be discussed earlier if a diabetic asks specific questions.</p> <p>-Sometimes the medical staff may tell young people stories about other diabetics' experiences, usually bad, which may act as a warning to the diabetic of the consequences on their health of smoking or drinking.</p>	<p>-When a diabetic reaches adolescence the Dr and nurse talk through the particular issues that are raised during puberty such as, smoking, alcohol, drugs and contraception, and how these external stimuli can affect diabetes.</p> <p>-If necessary the Dr will bring in a specialist i.e. gynaecologist for the girls to fully discuss the issue with them.</p> <p>-If the Dr feels that the adolescent's health is being seriously affected by their lifestyle i.e.; bad dietary habits, irresponsible attitude to using insulin, smoking or taking drugs etc. Then he will arrange for the diabetic to meet a fellow diabetic alone, (who has a similar background and experience to the first) who is suffering the serious consequences (losing their sight, permanently attached to a kidney dialysis machine etc.)of bad health brought on by an irresponsible attitude to their diabetic control.</p> <ul style="list-style-type: none"> <li>- Adolescent diabetics like the nidd's and their families also have an email, mailing support system, where they can ask questions about specific issues in an email forum.</li> <li>- If the adolescent diabetic has been diagnosed from childhood, then it is quite likely that (through attending the diabetic camps and out-of-school diabetic social groups set up by the clinic) they will have a good network of adolescent diabetic friends. They can therefore share some of the problems of puberty with friends in the same position.</li> <li>- It is harder to regulate b/s during puberty because of the hormonal changes happening in the body, and an adolescent is more likely to have a hypo or very high sugar levels, particularly in the middle of the night.</li> </ul>
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**Specific Adolescent Issues: contd.**

**Pro-** The girls prefer having a female nurse to talk to about contraception.

**Con** –Sometimes the issues are tackled when the young person feels a bit too young and therefore the attitude is ‘They can’t be referring to me, I’m too young to start thinking about drugs or pregnancy’, and an opportunity may be missed to get the message across.

-Or the adolescent may have a real fear about one of the issues raised. In one instance an adolescent diabetic has a real fear about getting pregnant when she is older, because of how it may affect her diabetes.

**Pro-**It is better for adolescent diabetic to have a choice of who to talk to (either a male or female Dr or nurse ) about some of the more delicate issues that affect adolescents e.g. Contraception for girls.

- Although the medical staff can warn of the dangers of alcohol and drug taking and smoking, the young people are more likely to listen to a diabetic who has already experienced some of the pitfalls of adolescent life and is now suffering the consequences with bad health or disability.

- A social group and email are very good support systems for adolescents who are trying to be independent from their parents and who are more inclined to talk things through with their peers rather than someone in authority.

**Con-** if an adolescent has not been part of a prepubescent diabetic social club it is much harder to get the adolescent to join in with one during puberty. Adolescents are wary of sharing their concerns with people they consider to be strangers.

- The teenage email forum is also used much less than the family one because adolescents consider it to lack privacy, and many do not want to discuss very personal issues on a very open mailing system.

**Attitude of Dr’s-** Both consultants talk to the young people as equals and are not patronising. They encourage and recognise that the young diabetics are the true experts on their condition, as they have to live with it 24 hours a day and each Dr respects this.

## **An argument for Insulin Pumps**

During their trip to the Swedish clinic the group had learnt that at least 40% of the teenagers in the Uddevalla clinic were using a subcutaneous insulin pump to control their diabetes. On their return to the UK the group were very keen to find out whether this method of control was available to them. They discovered that insulin pumps are not freely available to diabetics on the NHS and the group determined to lobby their local Primary Care Trusts (PCT's) to change their minds about offering insulin pumps to diabetics through the NHS.

The following is the case for insulin pumps that the group put to the representatives of their local PCT's.

### **Q. Would you deny your partner a good night's sleep?**

Often a diabetic can experience very disturbed nights and be woken in the early hours of the morning experiencing nocturnal hypoglycaemia. Hypoglycaemia is when the blood/sugar level falls to a very low level and the patient experiences at the least weakness and dizziness and at the worst seizures and unconsciousness. This is particularly common in adolescent diabetics.

**Fact** – The use of a diabetic pump significantly reduces the incidence of hypoglycaemia by night and day as it pumps a variable basal rate of short-acting insulin directly into the individuals blood stream.

### **Q. Would you deny your child a good education or the ability to perform well in exams?**

It is difficult to control blood/sugar levels during periods of extreme stress. At school, particularly at exam time, diabetic students experience a roller coaster of blood/sugar levels of highs and lows. This makes it very hard to concentrate and occasionally certain physical tasks are performed more slowly.

**Fact** - an insulin pump controls these roller-coaster effects of highs and lows, because it is a more precise means of glycaemic control. Diabetic students who use pumps are known to have less time off school as they manage their diabetes more competently and therefore are less prone to diabetic related complications.

**Q. Would you willingly wish long-term illness on your friends?**

Diabetics who achieve improved blood/sugar control (an average HbA1c of 7.1% or less) have a great decrease in the risk of long-term complications of diabetes. Long-term complications include progressive damage to the eyes, kidney failure, damage to the nerves, and damage to the blood vessels and heart which gives an increased risk of coronary heart disease.

**Fact-** The use of the insulin pump is so effective at achieving an optimum level of blood /sugar control that the diabetic suffers less hypoglycaemic incidents. They therefore are more confident to aim for lower blood/sugars and reduce the risk of long-term complications.

Therefore the use of a pump also, in the long-term, reduces the cost to the NHS of treating diabetics with the complications previously mentioned, which far outweighs the initial cost of providing an insulin pump to those who it will benefit.

**Q. Would you deny any individual the chance of a better quality of life?**

The diabetic pump allows the user to control their own diabetes and not let the diabetes control them. The pump allows the individual to lead a life close to normal, a quality of life that most of you take for granted, due to better control of blood/sugar levels and therefore less risk of diabetic complications and consequently less time off school and work.

When we visited Sweden we met young diabetics who had been given the option of having a pump. Many had decided to take up the offer, but many others had decided that a pump was not the method of control best suited to them.

At Bishop Auckland Hospital we have previously not been given the option of using a pump. This is because some members of the medical staff are not allowed to train in pump management, as there are insufficient resources to provide safe 24 hour supervision. After hearing our discussion about pumps we are asking that you will reconsider your thoughts on the funding of diabetic pumps in this area.

**Following the presentation of this case by the group, and confronted by their compelling evidence, the Dales Primary Care Trust and the Sedgfield Primary Care Trust have agreed to fund subcutaneous insulin pumps for diabetics in their charge.**

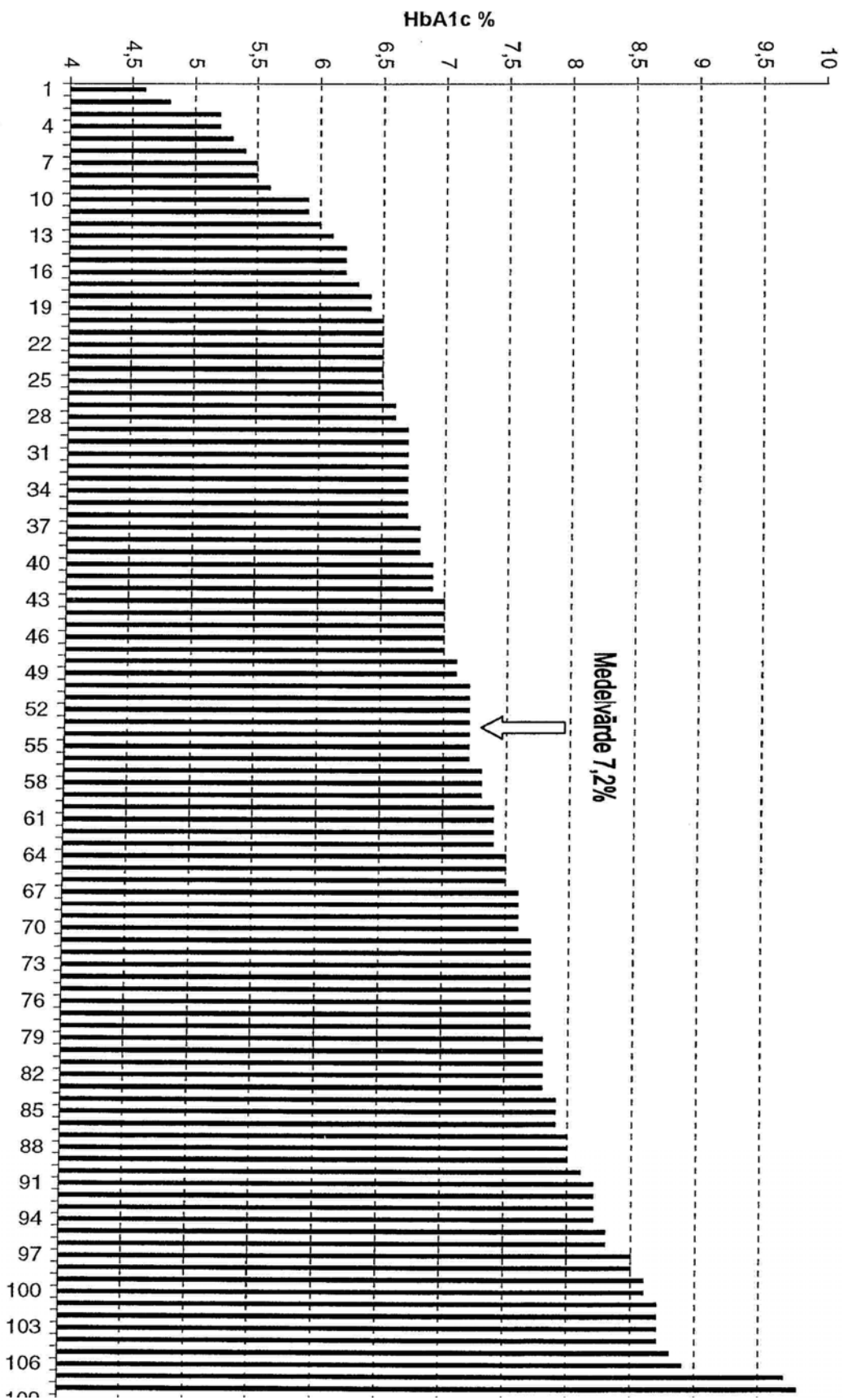
## Conclusion

On visiting Sweden, the group was surprised and delighted to find that many of the ideas they had considered about how to improve the clinic and services for diabetics at Bishop Auckland General Hospital, were already in practice in Sweden. In particular they noticed that a number of their ideas operating in Sweden were not expensive to instigate. They also found that many of the issues that had concerned them as adolescent diabetics were already being addressed in Sweden.

As a result of the 730+ diabetic group's research Bishop Auckland General Hospital's diabetic clinic have introduced many of the changes that the group suggested.

Without a doubt the group's biggest achievement has been that, as a result of their dialogue with the Primary Care Trusts, many diabetics in the Bishop Auckland area will now be given the option of using an insulin pump to control their diabetes.

HbA1c mars -02



Measurements - levels are +1% in England