

24 September 2007-09-24

To the Esteemed Members of the HTA Group:

I have been asked by JDRF UK to respond to your report on *Clinical and Cost-effectiveness of Continuous Subcutaneous Infusion for Diabetes* as the mother of a young child who has been using the Medtronic's pump for almost two years. I read with great interest the thorough review and was most impressed by the high level of analysis performed with very sketchy data. In this next review I would urge you to consider the following:

**Total absolute cost of higher pump penetration is low:**

If the UK achieved the 25% penetration achieved in the US amongst the target under 16 age group, the total cost would be but £7.5 million per annum. This comprises .15% of the total budget for diabetes in the UK in 2007 (*The Economist Intelligence Unit 2007: The Silent Epidemic: An Economist study of diabetes in developed and developing countries.*)

**Current pump usage statistics do not adequately enumerate benefits or costs:**

Because the critical mass of pump usage has not been achieved in the UK (and the studies that were analysed and incorporated into the econometric models in your report rely on such small numbers) best practice methods for pump usage have not been incorporated into reduced hba1c, morbidity and mortality figures. Until there is a large group of professionals familiar with optimising the pump and a large group of diabetics using it, the optimal results will not be achieved. As a small example, if every child were able to use a pump from diagnosis, hba1c improvements on both a 'metabolic memory' and on an on going basis will have longer term cumulative impact.

Additionally, the indirect costs of lost productivity currently not incorporated adequately in your model will be realised. The costs to which I refer are the lost productivity of carers of young type 1's who have to give up work in order to keep their child alive. Initially I did not return to work when my child was diagnosed two years ago as I needed to go to her school to test blood at lunch, make adjustments to insulin boluses, etc. However, now because she is on the pump, she is much more independent at age 8 than her peers who are on a multiple injection regime as she can program the pump handily with little supervision. I have begun working part-time and expect to rejoin the work force full-time within the next year. In my experience this will not be the case for equivalent aged children using multiple injections. The time spent on my daughter by members of her school staff is less than that spent on the child using injections. This obviously has an opportunity cost associated with it that has flow through impact on the economy as a whole.

Finally, until a substantial sub group of the population has migrated to the pump, economies of scale and experience cannot be utilised. These will range from reductions in pump prices seen in all consumer electronics as well as consumables manufacture, increases in the size of training sessions, reducing the training costs per capita, etc.

With the addition of the continuous blood glucose monitoring technology to the pumps, the benefits enumerated above will be even greater.

The above points all have tangible costs and benefits associated with them, although they are hard to determine and have clearly not yet been captured, despite your best attempts. But, there are further reasons that the pump is the most efficacious method of treating type 1 in children at this time. First and foremost the reduced fear of hypos mean that parents and patients alike live with a lower level of anxiety. We still awaken every night to test her blood at 2 am. But we would be doing this even more were she not 'on the pump'.

Also, the pump, by allowing a more normal lifestyle should reduce the burn out associated with diabetics when after years of jabbing themselves in the finger and in the stomach, a child will suddenly hit a wall and say: 'I don't want to be diabetic anymore. I am on strike. I will not test my blood; give myself those extra three shots a day.' Dangerously this is often when children reach adolescence which is a particularly difficult period to control because of increased hormone-related insulin resistance. If even some of this burn out can be prevented, the pump is an improvement.

I thank you for the opportunity to express my views and I am grateful if there is any insight that will result in increased pump penetration. The pump has literally saved my daughter, who has a terrible fear of injections, from a tortured life while maintaining an hba1c of between 5.5 and 6.9.

Thank you for your consideration.

Yours sincerely,

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