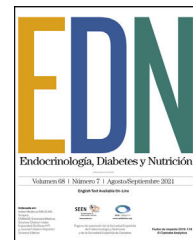




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EDITORIAL

The ABC of diabetes registries

El ABC de los registros de diabetes

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Childhood diabetes is a relatively common chronic disease in Europe, though its prevalence varies around the globe.¹ Since worldwide variation in the incidence of childhood diabetes was first reported by the Diabetes Epidemiology Group in 1988², several international collaborations have been established, confirming very low yearly incidences in some countries in Africa and Asia (<5 cases/100.000) and very high levels (>30 cases/100.000) in some Scandinavian countries.¹ While these incidence registries are widespread, those focusing on quality of care are less common, though a few have emerged since the early 1990's, leading to international benchmarking.^{3–6} Since glycated haemoglobin (HbA1c) is the best known predictor of long-term outcome and has been associated to the risk of psychiatric comorbidity, it is also the most studied benchmarking factor.^{7–9} Indeed, benchmarking and registries have, by themselves, a positive influence on HbA1c trajectories. The first sign of the ability of **Awareness** to create changes was seen in the Hvidovre study group, where HB Mortensen found his own clinic to have much higher HbA1c than many other centres in the group³. This led to several changes in the clinic and a substantial improvement in HbA1c from 1998 to 2005. Similarly, the power of awareness has also been demonstrated in Denmark and Sweden, where significant drops in HbA1c were

seen after open benchmarking and a quality improvement program were initiated in 2005 and 2012, respectively.^{10,11}

However, awareness alone does not always seem to work. In the Hvidovre study group, for example, only two centres improved their HbA1c from 1998 to 2005 and one reason for this could be **Beliefs** about comparability. The Hvidovre study Group comprised 14 centres from around the world, with different resources and economies. If the best performing centres also had better educated population and better access to technology and health care providers, then the results may have seemed unobtainable for other clinics. This belief was challenged in Denmark by comparing all 16 diabetes clinics: the best performing centre had the lowest proportion of pump users and adjusting for socio-economic status did not substantially change the HbA1c ranking. Furthermore, no correlation was found between the number of visits in the clinic and HbA1c, nor when including phone contacts. The only parameter that contributed to explain the variation between centres was the number of daily blood glucose tests per patient. This suggests that training, target setting and education may be much more relevant than clinic resources.¹² It also indicates that it is important to believe that we all can improve. This is most clearly shown by SweDiabKids, where all centres have moved the national mean in HbA1c from 67 mmol/mol (8.2%) to 55 mmol/mol (7.3%) over a 20 year period, while the variation between clinics has diminished and is now the lowest in the world.¹³ This achievement is remarkable and serves as a lighthouse for all working with clinical diabetes and diabetes registries.

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Since the first publication of centre comparisons, there has been a worldwide search for factors explaining the differences and attempts to find the key to optimal glycaemic regulation. Structure and treatment have been in focus but the one factor that has been robustly associated with HbA1c is target setting.¹⁴ Indeed, awareness and belief in change should be combined with **Collaboration** and **Commitment** from the health care providers. Furthermore, the individual centres need to look at their own performance with an open mind; they need to allocate time and resources to discuss goals and exchange ideas to create the basis for commitment within the teams. Small clinics may have an advantage where fewer health care providers need to agree on new targets or new ways to approach patients, whereas larger centres may have advantages in having more possibilities to be inspired through participation in conferences or international meetings. There is in fact some indication that new staff and new eyes may be beneficial.¹⁵ Engagement and an optimistic view have been repeatedly mentioned as drivers of improvement in Sweden, England, Norway and Iceland, whenever I have been attending meetings where quality improvement has been on the agenda. In all these meetings the possibility to receive regular feedback, where you can follow your own results has been highlighted as extremely important.

The study by Florentino Carral in recent issue of *Endocrinología, Diabetes y Nutrición* covering both adults and children confirms the positive effect of registries by showing, not just a substantial improvement in HbA1c but also a relatively low risk of microvascular complications in those with 10-19 years of diabetes. To what extent the results are due to awareness, changes in educational strategies, targets or treatment in the clinic remain to be documented. Nevertheless, building the registries is the first step in creating awareness and the positive results may increase the beliefs in the clinic that further improvement is possible. The creation of an optimistic and open-minded team may pave the way for collaboration and commitment.

With the hope of continuous improvement for the benefit of patients in Cadiz and worldwide I hope more registries will emerge and more committed health care providers will believe in the power of educating our patients in self-care and in the use of the available treatment. I hope benchmarking within countries and between countries will lead to exchange of good ideas for improvement. Finally, I hope for the use of lower targets and more focus on psychological well-being by including person reported outcomes in registries will benefit patients worldwide.

References

1. Patterson CC, Karuranga S, Salpea P, Saeedi P, Dahlquist G, Soltesz G, et al. Worldwide estimates of incidence, prevalence and mortality of type 1 diabetes in children and adolescents: Results from the International Diabetes Federation Diabetes Atlas 9th edition. *Diabetes Research and Clinical Practice*. 2019 Nov;157:107842.
2. Group DERI. Geographic Patterns of Childhood Insulin-Dependent Diabetes Mellitus. *Diabetes*. 1988 Aug 1;37(8):1113-9.
3. Beaufort de CE, Swift PGF, Skinner CT, Aanstoot HJ, Åman J, Cameron F, et al., Continuing Stability of Center Differences in Pediatric Diabetes Care: Do Advances in Diabetes Treatment Improve Outcome? The Hvidoere Study Group on Childhood Diabetes. *Dia Care*. 2007 Jan 9;30(9):2245-50.
4. Gerhardsson P, Schwandt A, Witsch M, Kordonouri O, Svensson J, Forsander G, et al. The SWEET Project 10-Year Benchmarking in 19 Countries Worldwide Is Associated with Improved HbA1c and Increased Use of Diabetes Technology in Youth with Type 1 Diabetes. *Diabetes Technology & Therapeutics [Internet]*. 2021 Feb 10 [cited 2021 Mar 7]; Available from: <http://www.liebertpub.com/doi/10.1089/dia.2020.0618>.
5. Fredheim S, Delli A, Rida H, Drivvoll A-K, Skriverhaug T, Bjarnason R, et al. Equal access to health care may diminish the differences in outcome between native and immigrant patients with type 1 diabetes. *Pediatr Diabetes*. 2014 Nov 1;15(7):519-27.
6. Foster NC, Beck RW, Miller KM, Clements MA, Rickels MR, DiMeglio LA, et al. State of Type 1 Diabetes Management and Outcomes from the T1D Exchange in 2016-2018. *Diabetes Technology & Therapeutics*. 2019 Feb;21(2):66-72.
7. McKnight JA, Wild SH, Lamb MJE, Cooper MN, Jones TW, Davis EA, et al. Glycaemic control of Type 1 diabetes in clinical practice early in the 21st century: an international comparison. *Diabet Med*. 2014 Dec;15.
8. Beneficial effects of intensive therapy of diabetes during adolescence: Outcomes after the conclusion of the Diabetes Control and Complications Trial (DCCT). *The Journal of Pediatrics*. 2001 Dec;139(6):804-12.
9. Sildorf SM, Breinegaard N, Lindkvist EB, Tolstrup JS, Boisen KA, Teilmann GK, et al. Poor Metabolic Control in Children and Adolescents With Type 1 Diabetes and Psychiatric Comorbidity. *Diabetes Care*. 2018 Nov 1;41(11):2289-96.
10. Svensson J, Johannesen J, Mortensen HB, Nordly S, on behalf of The Danish Childhood Diabetes Registry. Improved metabolic outcome in a Danish diabetic paediatric population aged 0-18 yr: results from a nationwide continuous Registration. *Pediatric Diabetes*. 2009 Nov;10(7):461-7.
11. Samuelsson U, Åkesson K, Peterson A, Hanas R, Hanberger L. Continued improvement of metabolic control in Swedish pediatric diabetes care: S AMUELSSON, et al. *Pediatric Diabetes [Internet]*. 2016 Nov 3 [cited 2016 Nov 7]; Available from: <http://doi.wiley.com/10.1111/pedi.12467>.
12. Skipper N, Thingholm PR, Borch L, Gaulke A, Eriksen TM, Svensson J. Center differences in diabetes treatment outcomes among children with type 1 diabetes: a nationwide study of 3,866 Danish children. *Abstract ATTD [Internet]*. 2021; Available from: <https://attd.kenes.com/scientific-program/>.
13. Charalampopoulos D, Hermann JM, Svensson J, Skriverhaug T, Maahs DM, Akesson K, et al. Exploring Variation in Glycemic Control Across and Within Eight High-Income Countries: A Cross-sectional Analysis of 64,666 Children and Adolescents With Type 1 Diabetes. *Diabetes Care*. 2018 Jun;41(6):1180-7.
14. Swift P, Skinner T, De Beaufort C, Cameron F, Åman J, Aanstoot H-J, et al., Target setting in intensive insulin management is associated with metabolic control: the Hvidoere Childhood Diabetes Study Group Centre Differences Study 2005. *Pediatric Diabetes*. 2009 Nov 6;11(4):271-8.
15. Hanberger L, Samuelsson U, Berterö C, Ludvigsson J. The influence of structure, process, and policy on HbA1c levels in treatment of children and adolescents with type 1 diabetes. *Diabetes Research and Clinical Practice*. 2012 Jun;96(3):331-8.