



ISPAD
International Society for Pediatric and Adolescent Diabetes



Improving data quality in a growing pediatric diabetes registry from 2010 to 2015: The SWEET – Initiative with 48 centers from five continents

Michael Witsch (Luxembourg), Anke Schwandt (Germany), Henk Veeze (Netherlands), Stephane Besançon (Mali),
Banshi Saboo (India), Mario Scharf (Brazil), Danièle Pacaud (Canada) and the SWEET-Group

Background

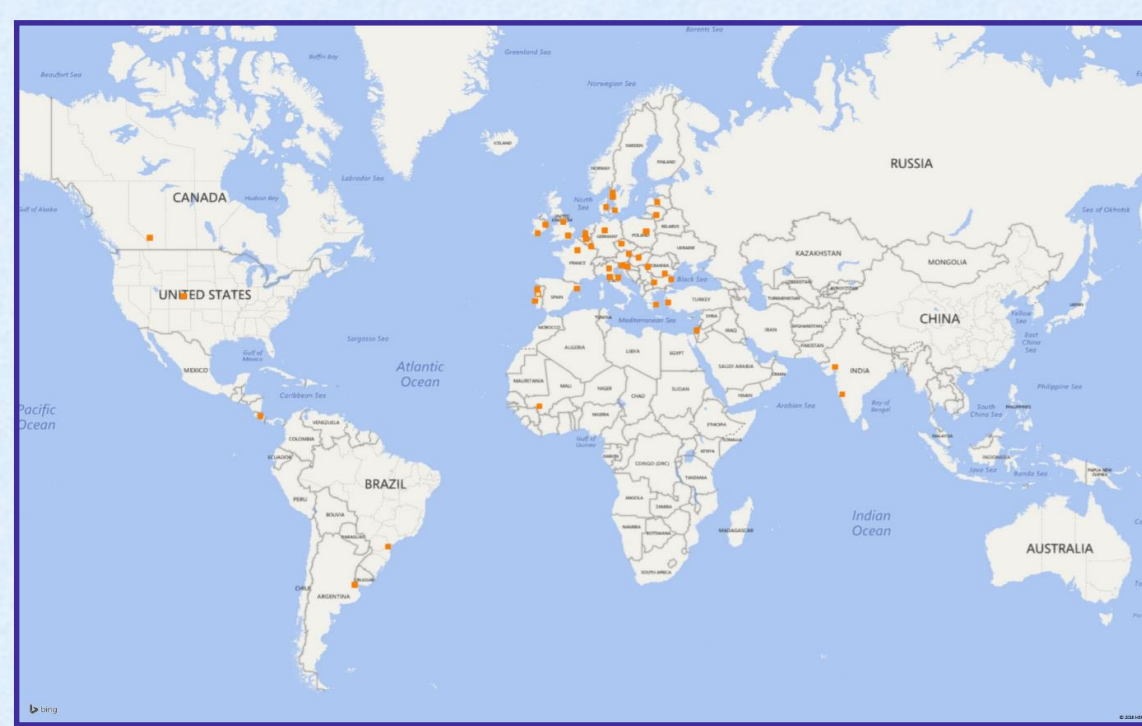
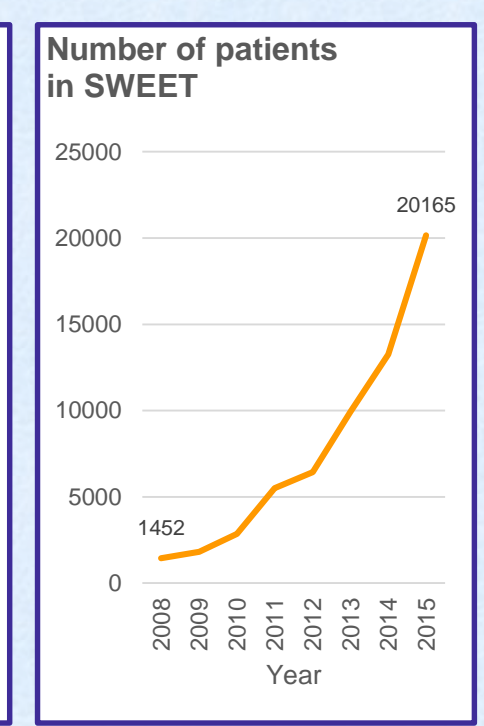
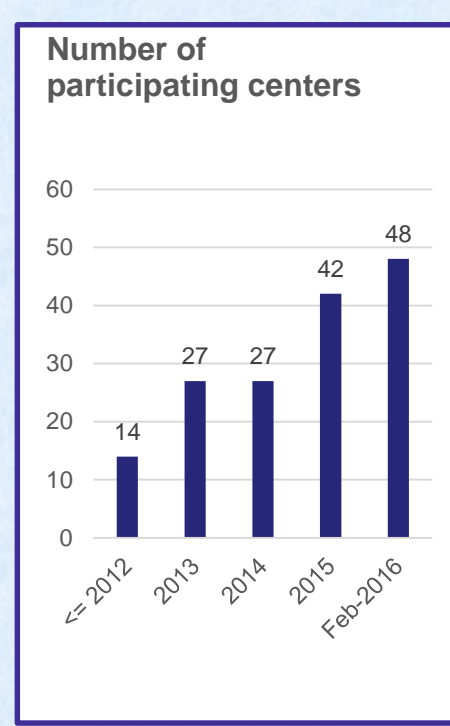
- "SWEET (“Better control in pediatric and adolescent diabetes: Working to crEate cENterS of reference (CoR)”) is a registered charity with close ties to the ISPAD.
- Since 2006 it aims to create and certify CoR for childhood diabetes in each country or region.
- One of the requirements is a continuous electronic documentation of at least 150 pediatric diabetes patients treated by a multidisciplinary team based on the ISPAD Clinical Practice recommendations.
- Smaller centers and centers that cannot comply with all requirements as yet, can participate as collaborative centers.
- Currently, SWEET centers are present in 25 European countries, Argentina, Brazil, Canada, Costa Rica, India, Israel, Mali and the US.

Methods

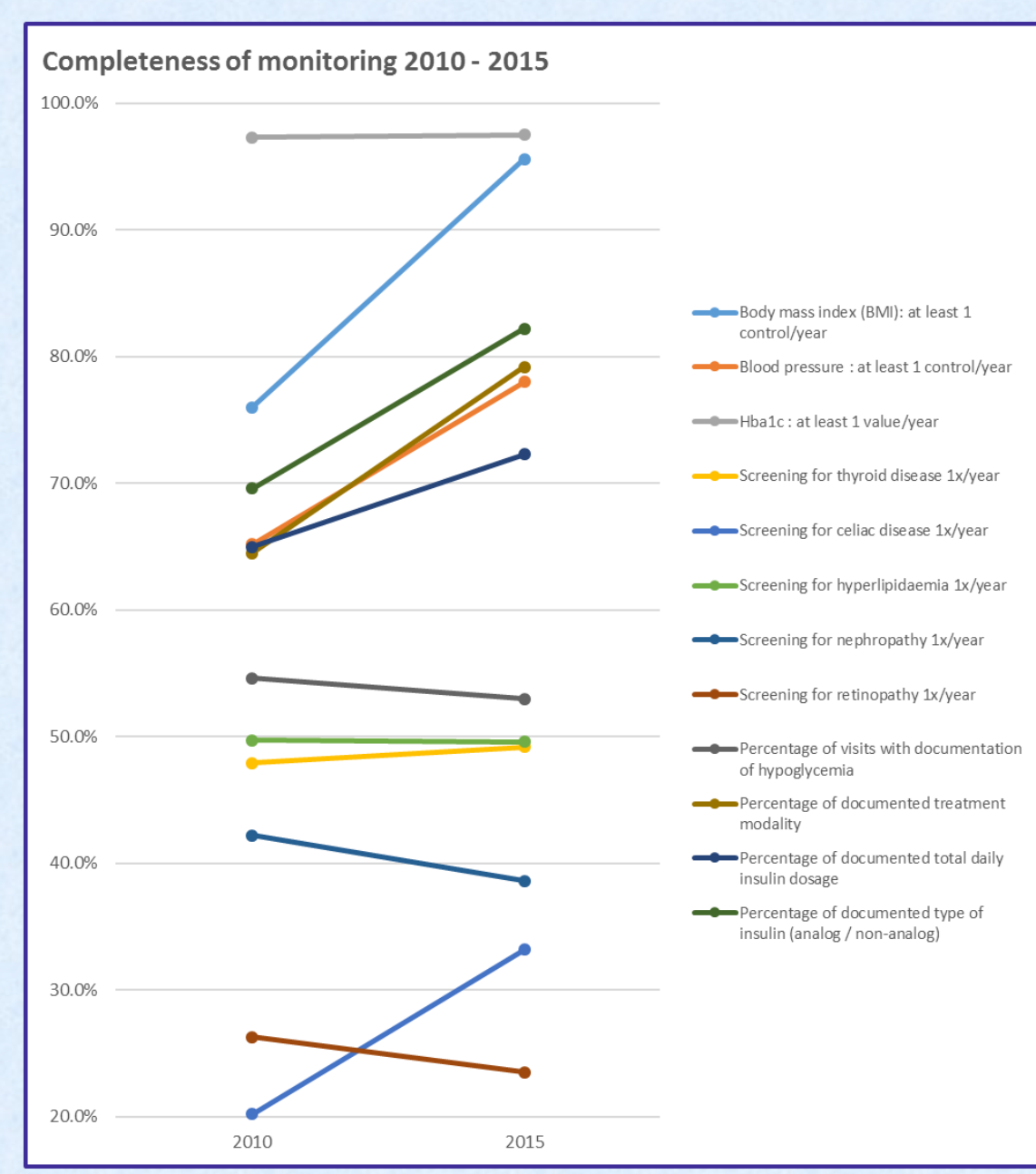
- The SWEET dataset consists of a list of quality indicators collected through routine pediatric care. It includes information on process and structural aspects, as well as outcome of diabetes care.
- Anonymized data can be submitted by Excel files compliant with a standardized format or by use of a dedicated electronic health record (DPV software), currently available in English, French and German.
- These data are used for biannual benchmarking and for scientific analyses.

Results

- 48 participating centers
- 28,667 patients (overall: 2006-2015)
- 20,165 patients 2015, all ages
- 95.4% T1 DM
1.3% T2 DM
3.3% other types 2015, all ages
- 14.2 years Median age 2015, T1 DM
- 7.8% (61.7 mmol/mol) A1C median 2015, T1 DM
- 14 centers with median A1C<7.5% 2015, T1 DM
- 40% pump-user 2015, T1 DM
- 4% CGM-user 2015, T1 DM



	2010	2015
Number of patients	2,836	19,131
Percentage of male patients	50.3%	51.6%
Median age (years)	13.5	14.2
Median diabetes duration (years)	4.4	4.8
Percentage of type 1 diabetes	96.0%	95.4%
Percentage of type 2 diabetes	1.2%	1.3%
Percentage of other types of diabetes	2.8%	3.3%
Body mass index (BMI): at least 1 control/year	76.0%	95.6%
Blood pressure : at least 1 control/year	65.2%	78.0%
HbA1c : at least 1 value/year	97.3%	97.5%
Screening for thyroid disease 1x/year	47.9%	49.2%
Screening for celiac disease 1x/year	20.2%	33.2%
Screening for hyperlipidaemia 1x/year	49.7%	49.6%
Screening for nephropathy 1x/year	42.2%	38.6%
Screening for retinopathy 1x/year	26.3%	23.5%
Percentage of visits with documentation of hypoglycemia	54.6%	53.0%
Percentage of documented treatment modality	64.5%	79.2%
Percentage of documented total daily insulin dosage	65.0%	72.3%
Percentage of documented type of insulin (analog / non-analog)	69.6%	82.2%
HbA1c median (%)	7.7	7.8
HbA1c median (mmol/mol)	60.7	61.7
Severe hypoglycemia per 100 patient-years	6.0	2.6
Diabetic ketoacidosis per 100 patient-years	1.2	2.5
Percentage of pump-users	26.6%	40.2%
Percentage of CGM-users	0.7%	4.0%



Conclusion

- Ensuring good data quality in a rapidly growing international network with centers from different backgrounds is challenging.
- The SWEET group is continuously discussing measurements to improve data completeness and quality.
- The biannual benchmarking reports, face-to-face meetings of the whole group and a rising interest for scientific publication seem to have a positive impact on data completeness and quality.
- The results of 2015 are showing improvement in completeness of data compared to previous years, despite the number of patients and participating centers is rapidly rising.
- SWEET enables ...
 - continuous evaluation of diabetes treatment and outcome variables
 - benchmarking data to exchange best practices and to reduce inequalities
- the SWEET network wishes ...
 - to harmonize and improve care of children and youth with diabetes
 - to facilitate dissemination of new approaches and techniques
- the SWEET group hopes ...
 - to further extend to reflect a worldwide picture of the pediatric diabetology

You are very welcome to join us!

The SWEET group: R. Hall, A. Schwandt, M. Witsch, C. de Beauvoir, T. Dornel, O. Kobzarova, B. Aschermann, C. Mazza, D. B. Ram-Mohan, K. Chhabra, M. Konstantinova, V. Istovoi, M. Schmitt, D. Pacaud, E. Richmond-Padilla, J. Vancoren, J. J. Vozzani, Z. Szirmai, T. O. Cheng, M. Brakeman, L. Cabral, B. Corradi, P. L. Battersby, C. D'Amico, G. Santoro, G. Serrano, L. M. Serrano, L. O'Connell, D. Coppi, M. Phipps, M. Fish-Shaw, M. Saboo, D. Hoareau, S. Jahn, V. Cheung, B. Pignatelli, C. Muller, R. Verhaak, K. M. L. Ooster, L. D. S. Santos, M. J. H. Vreech, P. Parkash, A. Zygo, P. P. Rousso, C. Casati, F. Russo, C. Lindner, A. Mitsuhashi, M. V. Vitellio, S. S. Sanjay, R. K. Kulkarni, N. Bhatnagar, D. Gnanapavan, F. Camargo, C. M. Heffernan, D. M. Mann, J. A. E. Marshall, J. S. Franca, J. S. Franca.

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