A plan to improve global type 1 diabetes epidemiology data

A roadmap for type 1 diabetes epidemiology

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The discovery and subsequent introduction of insulin therapy in 1922 led to fundamental changes in type 1 diabetes. In Boston, life-expectancy for people with type 1 diabetes diagnosed at 10 years of age increased from 2.6 years between 1914-1922 to 45 years between 1939-1945.[1] Therefore, type 1 diabetes is no longer only a condition of the young.[3,4] Lower life-expectancy in people with type 1 diabetes compared with the general population still persists at a global level,[2] but survival continues to improve, especially in high income countries. In many of these settings, diabetes registries have contributed to a better understanding of diabetes epidemiology as well as enabling improvements in care.[5]

The article by Ward et al.[6] recently published in *The Lancet Diabetes & Endocrinology* provides novel estimates of incidence of type 1 diabetes in 0–19-year-olds that account for health system performance. It suggests 355,900 incident cases of type 1 globally in 0-19 year olds,[6] which is 1.8 times higher than the estimates from Gregory et al.[4] and 2.4 times higher than those of the International Diabetes Federation[7]. (Table 1) Validation of these estimates are difficult since fatal hyperglycemia might be missed with current autopsy practices.[8] Both Gregory et al.[4] and Ward et al.[6] also include estimates of missing and undiagnosed cases as well as future projections of numbers of cases based on existing, incomplete, data, therefore requiring substantial assumptions which are acknowledged in both articles as limitations[4,6].

Although the methods used and the resulting data differ between the studies by Gregory et al.[4] and Ward et al.[6] and other global estimates[3,7,9] (Table 1) they all highlight the scarcity of data on incidence and mortality for type 1 diabetes, especially in older people.

We therefore propose a roadmap to increase our knowledge of type 1 diabetes epidemiology to improve services and outcomes for people with this condition. This roadmap would include actions both at global and national level.
At a global level, it is recommended to map data gaps found in existing estimates and propose targeted studies to address these; Re-launch global studies such as the WHO Diabetes Mondiale (DIAMOND) study and the EURODIAB register and broaden their scope beyond just incidence studies in childhood and adolescence; to develop guidelines and tools to assist countries in data collection.
At a national level it is proposed to develop targeted studies in specific countries on incidence, prevalence, mortality (including causes) and proportion of undiagnosed cases to fill existing gaps in knowledge; document the existing information on type 1 diabetes in countries from published and unpublished data; use any information on complications and deaths when available and accessible in patient file reviews, routine registrations and monitoring of quality of care or from research projects; develop sustainable ongoing data collection versus snapshots; develop registers and links with existing global initiatives such as SWEET, with expansion to all ages.

Khunti et al.[5] suggest guidance on the development of registries in the European context for type 2 diabetes. Many of these recommendations are relevant also for type 1 diabetes and for the proposed roadmap. Improved data collection will be essential to monitor the WHO's first global coverage targets for diabetes[10] adopted at the 75th World Health Assembly. These targets include the aim of "100% of people with type 1 diabetes having access to affordable insulin and blood glucose self-monitoring". Clearly, a better understanding of type 1 diabetes epidemiology is essential in achieving this goal.

Table 1 – Comparison of estimated numbers of incident and prevalent cases for type 1 diabetes for the world, Denmark, and Tanzania from different studies (Denmark and Tanzania are used as examples in this table; most of these studies include estimates for all countries)

Study (year of estimate)	Global		Denmark		United Republic of Tanzania	
	Incident cases	Prevalent cases	Incident cases	Prevalent cases	Incident cases	Prevalent cases
Green et al.[3] (2017)	234,710 (all ages); 97,580 (0-14 years)	9,004,610 (all ages); 541,180 (0-14 years)	720 (all ages); 260 (0-14 years)	28,700 (all ages); 1,510 (0-14 years)	360 (all ages); 230 (0-14 years)	10,970 (all ages); 1,100 (0-14 years)
Gregory et al.[4] (2021)	510,000 (all ages); 193,516 (0-19 years)	8,420,000 (all ages); 1,476,030 (0-19 years)	1,154 (all ages); 355 (0-19 years)	32,229 (all ages); 3,197 (0-19 years)	2,960 (all ages); 1,422 (0-19 years)	20,664 (all ages); 6,517 (0-19 years)
Ward et al.[6] (2021)	355,900 (0-19 years)	N/A	403 (0-19 years)	N/A	6,886 (0-19 years)	N/A
International Diabetes Federation[7] (2021)	149,500 (0-19 years)	1,211,900 (0-19 years)	325 (0-19 years)	3,103 (0-19 years)	1,189 (0-19 years)	5,655 (0-19 years)
Institute for Health Metrics and Evaluation[9] (2019)	569,451 (all ages); 288,263 (0-19 years)	21,968,799 (all ages); 2,693,826 (0-19 years)	822 (all ages); 335 (0-19 years)	42,899 (all ages); 3,307 (0-19 years)	4,318 (all ages); 2,723 (0-19 years)	97,148 (all ages); 22,619 (0-19 years)

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