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to challenges



FIGHTING DIABETES
PRESERVING A LEGACY

Surveillance Data Availability

Diabetes In Youth

This Tutorial is based on the SFBLF Research Report,
Youth Living with Diabetes and Comorbidities
Available Surveillance Data – A Status Assessment, (September 2017)
You can access the full report at www.bantinglegacy.ca/count-the-children

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David Sadleir, Ph.D. P.Eng.

President, SFBLF
info@bantinglegacy.ca

The mission of SFBLF is to Fight Diabetes and Preserve a Legacy

Our focus is on disease prevention and disease self-management through education, clinical innovation and sustained support with an emphasis on youth.

Minimizing the transition challenges faced by youth living with diabetes as they navigate from the paediatric to the adult healthcare system is a key priority.

The SFBLF Diabetes Management and Education Centre (DMEC) is located in Alliston, Ontario, Canada at the Banting Homestead Heritage Park, birthplace of Sir Frederick Banting, co-discoverer of insulin and Canada's first Nobel Laureate.

P.O. Box 137, Alliston, Ontario Canada L9R 1T9 www.bantinglegacy.ca

Surveillance Data Availability - Diabetes In Youth

Learning Objectives

This tutorial provides an overview of the status of availability of surveillance data for youth living with diabetes (as at the end of 2017).

On completion of this tutorial, you should understand:

1. What is surveillance and why it matters.
2. Why surveillance is difficult
3. Current surveillance capability in Canada, Australia United Kingdom and USA
4. Needs and opportunities for improvement
 - a. Prospects for improvement are 'mixed'
 - b. Integrated studies are required
 - c. Inherent potential should be exploited
 - d. Collaborative leadership is required
 - e. Value requires action
 - f. Qualitative initiatives are in progress

You will also find the following information:

Highlighted studies from around the world

References cited in this Tutorial

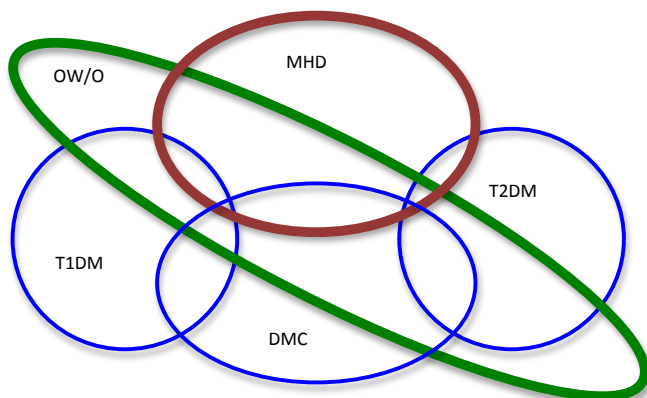
[Note: As organizations update their websites, 'links' may change. If you encounter difficulties with any of the links included on the reference list, please advise us at info@bantinglegacy.ca.

Thank You]

What is surveillance?

In this tutorial, ‘surveillance’ means the task of collecting, assembling, analyzing and making available the data necessary to calculate the prevalence (number of cases) and incidence (number of new cases in a stated timeframe) of the diseases and conditions under study; for example,

Diabetes, Obesity/Overweight, Mental Health ... A perfect storm for youth



Surveillance is required to answer, “What are the relative sizes [prevalence numbers and %] of these ‘overlapping domains?’”

Why surveillance matters

Surveillance of the prevalence and incidence of any chronic disease matters for many reasons. Perhaps, the most pragmatic reason is that failure to do so and the resulting absence of insights make it very easy for the ‘problem’ to be ignored.

Global and National Views

“Type 2 diabetes in childhood has the potential to become a global public health issue leading to serious health outcomes. More information is needed urgently”

IDF World Diabetes Atlas, 8th edition, Nov 2017 (p 60)

“By arming ourselves with greater knowledge, we will be able to develop the tools and programmes required to bring the rise of diabetes under control.” [GL1]

- Professor Nam Han Cho, Chair, IDF Diabetes Atlas Committee, Seventh Edition, 2015 (p.9)

“Diabetes is on the rise. No longer a disease of predominantly rich nations, the prevalence of diabetes is steadily increasing everywhere, most markedly in the world’s middle-income countries. When diabetes is uncontrolled, it has dire consequences for health and well-being.” [GL 2]

- Dr. Margaret Chan, Director-General, World Health Organization Global Report on Diabetes 2016 (p. 6)

“Effective national surveillance is vital in order to gain a better understanding of the magnitude, characteristics and public health consequences of type 1 and type 2 diabetes in Canadian children and youth.” [C1]

- Public Health Agency of Canada, 2011

..... the ability to monitor type 2 diabetes will contribute to understanding the epidemiology of the disease. Thus, monitoring can help in guiding preventive measures, determining clinical service provision and informing health policy and planning. As well, studies in adults have shown

that diabetes complications may be prevented with appropriate and timely treatment and management; therefore early detection of any growth trends is paramount. [A1]

- Australian Institute of Health and Welfare 2014

“Surveillance will underpin the protection and improvement of health and service delivery, through outputs that are timely, accurate, accessible and meaningful to users of this information at the local, national and international level.” [UK19]

- Public Health England, 2012

“The prevalence of infant, childhood and adolescent obesity is rising around the world. Although rates may be plateauing in some settings, in absolute numbers there are more children who are overweight and obese in low- and middle-income countries.” [GL5]

- ECHO, Report of the Commission on Ending Childhood Obesity, 2014 WHO

“More comprehensive surveillance is needed to develop a public health approach that will both help prevent mental disorders and promote mental health among children” [US5]

- Centre for Disease Control and Prevention, United States, 2013

Diabetes trends and relationships with other conditions

There are widely held opinions on the related trends applicable to youth age 19 years and under but the documented evidence base is sparse and inconsistent.

Specific trends and relationships frequently noted include, for example:

- * Type 1 diabetes and Type 2 diabetes in youth are both increasing worldwide
- * There is a strong correlation between overweight/obesity in youth and the increase in Type 2 diabetes in youth
- * Over 42 million children under age 5 worldwide were overweight in 2013
- * Over 12% of children age 4 to 17 years have experienced at least one diagnosable mental disorder
- * The occurrence of mental health difficulties in combination with diabetes in youth is increasing
- * There are bi-directional relationships between diabetes and mental disorders and one condition can ‘mask’ the other.
- * The age of onset for each of overweight/obesity, diabetes and mental disorders is decreasing
- * The earlier the onset, the greater is the risk for developing condition-related complications.
- * Indigenous communities comprise over 370 million people in 70 countries. Diabetes prevalence rates vary greatly between indigenous communities. In many cases, the prevalence is greater than the surrounding population. [GL1]
- * Relative deprivation arising from circumstances of history, geography, climate, limited access to healthy food and routine medical care contributes to risk of disease.

These trends have implications for diagnosis, treatment, continuity of care and for determination of related guidelines, the agenda for evidence-based research and the educational curricula adjustments necessary to ensure availability of health care professionals with the requisite education and training.

They increase the complexity of planning and prioritizing the allocation of resources necessary to take required action and provide essential services.

Inherent pressures

* **Existing and emerging challenges = need for better decision support information**

Health care policy planning and evaluation, optimal allocation of resources, evolving the educational curricula for health care providers, designing health care delivery systems and support processes, ensuring access to, and continuity of, health care and determining health research priorities are essential and generally difficult requirements faced by all nations.

Finding ways to reduce the demand for such requirements through effective awareness and prevention approaches is equally necessary and challenging. Defining and confirming what responses are ‘effective’ takes time, resources and requires surveillance support.

All of the above require access to a very wide array of information to define the nature, scale, scope and priority of the needs to be met. Disease and health condition surveillance data are fundamental insights for support of these decision-making processes.

* **Escalating demand and changing nature of demand = the need for more cross-discipline training and awareness**

In very broad terms, all national health care systems face long-standing existing problems and never ‘enough resources’ to meet the current demands. Those realities are exacerbated when existing demand types increase and new demand types are added.

The diabetes pandemic is not only the source of increasing demand for established services and processes, e.g., youth with Type 1, adults with Type 1 or Type 2 but is also the source of ‘new’ demands of both ‘volume’ and ‘nature’. Type 2 in ever-younger youth, associated diabetes-related complications and increasing comorbid diabetes and mental health difficulties in youth with either Type 1 or Type 2 add to the challenge. In many jurisdictions there is already an unmet demand for mental health support services for youth.

* **Disease severity = the need to anticipate longer-term impact**

Type 1 diabetes cannot be prevented, has no cure and requires immediate treatment and persistent, on-going use of insulin and careful management to sustain life. 70% of Type 2 cases can be prevented or at least delayed. There is no cure for Type 2 diabetes. In some cases, Type 2 can be managed for a time without medication through exercise and diet but because the disease is progressive, eventually medication, possibly augmented with insulin will be required. That same progressive nature is the basis for delayed diagnosis. Type 2 can be invisible for a very long time so that at the time of diagnosis, cell damage may be in progress. That is one reason why Type 2 diabetes in youth is potentially more severe than is Type 1 in youth.

* **Systemic disconnects = the need for improved planning for continuity of care**

Eventually, all youth are required to move from paediatric to adult health care. That ‘transition’ can be daunting and despite decades of awareness, essential support processes range from excellent to non-existent. That is the case for a youth living with either diabetes or a mental disorder. How much more daunting and risky is such a transition for a youth living with comorbid diabetes and a mental disorder ?

Why surveillance is difficult

Surveillance is a difficult and costly undertaking and to be effective requires repetition on a consistent basis and frequency.

General challenges

Chronic, non-communicable diseases are not considered ‘reportable’ diseases. Hence, there is no inherent, compelling public safety motivation for healthcare practitioners, public health agencies or related reporting systems to assemble NCD disease-specific surveillance data routinely. In some countries, the ‘billing codes’ used by physicians and hospitals do create a basis for surveillance data but often do not support sufficient detail or can apply to more than one condition.

At the global level, a full picture is not possible because no country has diagnosed every person living with a chronic disease. At the national level, there is a wide disparity in the resources available to undertake such tasks. The cost of population-wide ‘screening’ would be prohibitive in any case.

The skills and processes required to make reliable distinctions in diagnosis are also widely variable. Symptoms common to more than one disease or condition can compound the diagnostic difficulty.

So, the challenge ‘starts’ with practical issues of basic data collection and is amplified by the analytical intent, that is, what one wishes to achieve with the data if the facts can be collected.

Some analytical objectives are thwarted due to ineffective design of data repositories and inadequate ‘coding’ structures used for data identification and to facilitate electronic data collection, storage and manipulation.

Some countries have national ‘registries’ for one or more diseases but generally, are based on voluntary participation or accumulated from medical records. Likewise, some registries can be found at the next level of government, for example, province, state or region but different data criteria can impede accumulation for broader totals.

Comparative studies are impeded by the lack of consistency and standardization in the design of data collection processes, study methodologies and scope of studies; for example, use of different age ranges, inclusion of different medical conditions, absence of age stratification and gender identification.

In the face of these realities, researchers, scientists and epidemiologists invoke a wide array of techniques and mathematical tools to create at least order of magnitude prevalence estimates and incidence trend lines. Many use national census data as the ‘denominator’ in ratio calculations and that data can be seriously out of date.

Most results from such studies have inherent ‘ranges of uncertainty’ that may not be identified and the studies may not apply to like populations beyond the particular study focus. All need to be used and interpreted with caution and in context, especially extrapolation to other populations.

Surveillance capability – Global, Canada, Australia, UK, USA

Global capability

Both the International Diabetes Federation (IDF) and the World Health Organization (WHO) produce ‘global’ diabetes surveillance reports that include many countries; over 200 for IDF and over 177 for WHO. IDF produce their Diabetes Atlas every 2 years in November. The WHO report on diabetes published in 2016 was a first.

Each provides varying degrees of underlying detail by country and/or by their defined ‘Regions’ (7 for IDF and 6 for WHO) but do not provide surveillance data for diabetes in youth. The IDF Diabetes Atlas 2015 did include estimates for Type 1 diabetes in children 14 years and under for the first time. The Diabetes Atlas 2017 upgraded the Type 1 in children estimate to include ages 19 and under. WHO also reports on obesity and mental illness but data for youth are sparse.

Availability vs Capability

[A detailed list of key national systems or processes for the 4 countries cited can be found in the full report on this website.]

- * There are significant data gaps and no consistency across countries or between disease/conditions within countries for age ranges, age stratification and/or gender distinctions and/or disease type as encompassed in national surveillance studies.
- * There is a wide variation within all 4 countries and across countries with respect to the frequency with which national surveillance studies are undertaken and reports produced. Globally, IDF produce their Diabetes Atlas every 2 years. WHO reports of interest are either ‘first time’ and/or absent an indication of planned repetition.
- * More data may be held in national repositories than are included in published reports generally available. ‘Accredited’ researchers generally have more timely access to broader data bases.
- * All 4 countries have demonstrated capability to undertake effective national surveillance relative to youth. What is significantly different across countries is the apparent priority and ‘will’ to bring that capability to bear on each of diabetes, diabetes-related complications, overweight/obesity and mental illness as well as the emerging comorbidities especially, diabetes and mental illness in youth. A few diabetes surveillance studies include some consideration of diabetes-related complications and in some cases, also consideration of obesity and the ‘psychosocial’ implications of diabetes. The latter may or may not include a more detailed identification of specific mental illness difficulties or at least selected ‘groups’ of mental illness.

Availability vs ‘Readability’

- * In general, national surveillance studies are reported with a professional audience in mind, e.g., epidemiologists, other researchers and health system professional analysts. Many are intended for peer review and publication in medical or related journals.
- * The translation of these technical and usually complicated reports into summaries suitable for general consumption and easy comprehension is done in some cases by the originating organization. Most of the abstracted, summarized reports easily accessible by the general public are produced by national disease-specific advocacy groups such as those focused on one of diabetes, obesity or mental illness.
- * Surveillance summaries assembled for general consumption tend to be susceptible to lack of precision in the use of related terminology. For example, a summary report on overweight and obesity may not include a clear description of the difference between “overweight” and “obesity” and may use one or the other as a generic term. Identification of age ranges may be overlooked with the result that the reported prevalence numbers can lead to confusion. On one web site, for example, in separate sections, 3 different numbers were used as the current prevalence for the disease being reported. All were correct in context but that ‘age range’ detail was omitted in every case. For general public reports on diabetes prevalence, a frequent confusion arises from lack of clarity regarding the inclusion or otherwise of estimated ‘undiagnosed’ cases.

* Even for highly technical reports published in professional journals, there can be, for example, lack of clarity regarding the study methodology and time frames involved.

Overview of available surveillance data - Global

For youth age 19 and under

1. A cohesive, complete, global surveillance data set (prevalence or incidence) for youth age 19 and under for each of the following base cases does not exist:
 - a. Diabetes by type, gender and age stratification
 - b. Overweight/obesity by gender and age stratification
 - c. Mental Illness by type (or main group), gender and age stratification
2. Related studies at the same level of detail for ‘combinations’, i.e., diabetes and overweight, diabetes and mental disorders, diabetes-related complications, and with distinctions such as ethnicity and the impact of relative deprivation are also non-existent at the global level.
3. Multi-national surveillance studies exist, for example, comparisons of member countries in the Organization for Economic Cooperation and Development (OECD) which includes Australia, Canada, United Kingdom and United States [GL3], and several exist for the European Union [GL17].
4. As described above, both the International Diabetes Federation (IDF) and the World Health Organization (WHO) produce global surveillance reports that include many countries. These reports provide varying degrees of underlying detail by country and/or by their defined ‘Regions’ but either do not report on youth or do so with inconsistent and/or incomplete age ranges and detail.

Overview of available surveillance data - Country

For youth age 19 and under (for the 4 countries reviewed):

5. In general,
 - * more surveillance data can be found for prevalence than for incidence.
 - * age of onset, a critical variable, is often overlooked or at least not reported.
 - * the age range (0-19) selected for this study was motivated by the fact the IDF Diabetes Atlas reports on adults (20-79). The definition of ‘adult’ can vary from country to country and this has some impact on the applicability of the summary statements included in this report regarding ‘availability’ of data in selected studies. For example, in Canada, ‘adults’ are defined as persons 18 years of age and older.
 - * it is likely that in all countries, people with a formal mandate to conduct disease surveillance have earlier access to a wider variety of data. In Canada, again for example, researchers can also apply to the Research Data Centre network to access more complete and timely data.
6. None has cohesive, complete, national surveillance data sets (prevalence or incidence) for youth age 19 and under for all of the following base cases:
 - a. Diabetes by type, gender and age stratification
 - b. Overweight/obesity by gender and age stratification
 - c. Mental Illness by type, gender and age stratification

7. All have partial data sets for the above but with inconsistent age range inclusions and varying “data age”, i.e., ranging from ‘current’ to a decade or older. Those inconsistencies impede comparative analyses both within a country and between countries.
8. All have studies that provide partial data sets at various levels of detail for some but not all ‘combinations’, e.g., diabetes-related complications, diabetes and overweight, diabetes and mental disorders, and distinctions such as ethnicity and the impact of relative deprivation.
9. Fundamental surveillance strategies:
 - * Universal screening is not seen as a practical nor cost-effective approach given the numbers of youth involved. There is wide agreement that identifying risk factors and of those, which are susceptible to modification, along with identification of the populations at greater risk is a more pragmatic approach.
 - * In highly over-simplified terms, there are 3 fundamental approaches to surveillance beyond using predictive mathematical models; ‘sample the youth’ directly (or by parental proxy for younger children), ‘sample the caregivers’ or analyze the growing capability inherent in electronic medical records. In both direct sampling options, the results are achieved by face-to-face interview or through completion of a questionnaire or by telephone or combinations of these techniques. In some cases, both of the fundamental direct options are invoked.
 - * ‘Sampling the caregivers’ or accessing electronic medical records generally means one is seeking data for conditions already diagnosed. ‘Sampling the youth’ requires varying degrees of screening to produce meaningful results.
10. The most comprehensive, continuing diabetes surveillance system among the 4 countries is the National Paediatric Diabetes Audit (NPDA) produced annually for England and Wales. [UK7]
11. The most ‘timely’ continuing diabetes surveillance system among the 4 countries is the Australian National Diabetes Services Scheme (NDSS), a voluntary diabetes registry for all ages that is updated daily with ‘snapshot’ summaries produced quarterly. [A11]
12. The United States faces the largest surveillance challenge in terms of scale but have addressed that for diabetes through the SEARCH project, a multi-centre, continuing study begun in 2000 and involving 20,000 study participants. [US10]
13. Canada has among the largest number of national surveillance systems with a youth component. However, the public data available for youth are produced with widely varying frequency. The number of systems and inherent ‘overlap’ of focus make it challenging to achieve an ‘integrated’, consistent understanding.
14. There are many ‘non-national’ systems or processes in each country that provide prevalence and/or incidence estimates for each disease/condition and a growing evidence-base for the bi-directional relationships and emerging trends between and among diabetes, obesity and mental illness.
15. These ‘non-national’ studies are also highly variable with respect to level of detail reported, e.g., gender and age range distinctions, ‘types’ of disease/conditions included (aggregate diabetes, one or both of T1DM and T2DM, some or no mental disorders; underweight, overweight, obese).

16. Surveillance systems and processes for indigenous populations tend to reflect the geographic ‘concentration’ of the population and hence, may be addressed by the regional or territorial agencies and/or related band or tribal councils and organizations. Treaties and other historic relationship agreements can affect the participation of national government agencies in the surveillance task

More details for both the global context and for each country reviewed can be found in Section 5.0 Surveillance Landscape of the 2017 SFBLF Report

Needs and Opportunities for Improvement

Summary

1. Prospects for improvement are ‘mixed’
2. Integrated studies are required
3. Inherent potential should be exploited
4. Collaborative leadership is required
5. Value requires action
6. Qualitative initiatives are in progress

1. Prospects for improvement for surveillance of youth in the short to medium term are ‘mixed’:

- * At the global level, neither IDF nor WHO have identified plans to improve surveillance of youth 19 years and under. As part of the ongoing monitoring of non-communicable diseases, WHO have established a number of targets to be addressed by member countries. Included in that list, Target #7 is focused on reduction of obesity and diabetes but the expectation set is for monitoring of adults 18 years and older.
 - * The 2016 *ECHO, Ending Childhood Obesity* report [GL12] from WHO notes that prevalence data for older children and adolescents, “... are currently being verified and are due to be released by WHO in 2016”. As of August 2017, these data had not been released.
- * Continuing and/or repetitive surveillance actions such as encompassed by the annual National Paediatric Diabetes Audit (UK), the voluntary, daily updated National Diabetes Services Scheme registry (AUS) and the SEARCH project (US) each hold strong prospects for continuous improvement in completeness and/or quality of diabetes surveillance data for youth.
 - * Because the NPD Audit [UK7] also includes benchmarking of surveillance results against standards of care specified by NICE [UK9] and recommendations to improve both quality of care delivery and quality and completeness of surveillance data, the combination represents a ‘virtuous circle’ that can only lead to constant improvement.
 - * The Australian NDSS has an inherent incentive that will foster continuous improvement. Specifically, registrants in the NDSS data base receive access to essential diabetes supplies at much lower cost than other sources. Australia have also completed a detailed analysis of the quality of their many national diabetes surveillance data bases as potential sources for

improved surveillance and as a result, have sharpened their focus and identified significant improvements that must be made. [A1]

- * In the most recent study from the US SEARCH team the authors note, “The sample size accrued over a period of 11 years may have been the basis for identifying [diabetes] trends not previously observable”. [US14],
- * In Canada, a new study on the incidence of non-insulin dependent diabetes among youth less than 18 years of age was begun in June 2017 and is expected to take 2 years. This study will include a comparison with a similar study done in 2008. [C7]

2. ‘Integrated’ studies are required and these are emerging:

- * The NPDA (UK) system already encompasses diabetes by type with gender and age range distinctions and attention to diabetes-related complications, obesity and some aspects of mental illness as well as many other factors directly related to care delivery. [UK7]
- * A new system in Canada, the Canadian Health Survey on Children and Youth (CHSCY), has the potential for dramatic improvement. A successful pilot was completed in 2016 but first application has been delayed until 2019. This new survey will include ages 1-17 and will also seek data on diabetes, obesity and mental illness. The sample size will be 50,000. [C12]

3. There is inherent potential in existing systems and processes:

- * In all 4 countries, systems and processes for producing surveillance data for obesity and mental illness exist but with varied application to youth. All of these systems may have the potential to be improved in support of youth. Assessments to consider expanding age ranges surveyed and including age range stratification, disease type and gender distinctions as well as more frequent application might prove beneficial and lead to cost-effective enhancements.

4. Collaborative leadership is required:

- * All 4 countries have frequently noted in their reports that significant improvement in surveillance for youth is required.
- * If the 4 countries reviewed were to collaborate to establish a few common ‘standards’ for surveillance of youth, it would not take too many years for that collective to produce dramatic improvement in overall understanding of the challenges existing and emerging for youth. Such collaboration might lead also to identification of improvement actions of mutual benefit not only for surveillance but also for prevention programs, research priorities and medical education curricula.
- * Specific standards that would make a substantial difference are common or at least ‘core’ age ranges, inclusion of gender distinctions, age stratification, disease ‘type’, age of onset, ethnicity, the most common diabetes-related complications and a specific list of mental illness disorders most often seen comorbid with diabetes in youth. There are over 400 diagnosable mental disorders and in company with the attendant diagnostic difficulty, this creates major impediments for surveillance. A short, focused list such as depression, anxiety, diabetes stress and eating disorders would relieve some of that challenge while adding substantial value.
- * Implementation of such standards at the next level of government, i.e., province, state,

territory would contribute significantly as well. Canada and Australia, for example, have systems and processes at that level which reflect a degree of ‘commonality’ of surveillance criteria but, in general, it remains problematic to aggregate those studies to produce reliable national conclusions.

- * There is some evidence to suggest that even within countries, there is opportunity for improved collaboration among the various national agencies directly involved with aspects of surveillance in order to improve capability for surveillance of diabetes, obesity and mental illness and the combinations in youth.

5. Surveillance data are valuable only if used to educate and/or cause essential action:

- * At the end of the day, what matters is having information that supports decision-making for healthcare system priority setting, resource allocations, establishing research priorities, creating and confirming enhanced diagnostic and treatment guidelines, adjusting medical education curricula, designing, implementing and ‘testing’ improved processes and avoiding or reducing healthcare costs.
- * Surveillance data for youth are only valuable if used to identify and implement effective action that increases awareness, reduces risk, improves the quality, delivery and continuity of healthcare, including access to such services and in the process, contributes to sustained and enhanced quality of life and well-being.

6. Lack of surveillance data is not hindering broad qualitative initiatives:

- * While much remains to be done to improve the collective surveillance capability for youth, many agencies and organizations at the global and national level are taking valuable awareness-raising and strategic actions in a parallel quest to stem the rise of obesity, diabetes and mental disorders in youth.
- * The following short list of major reports illustrates those initiatives. None of these are surveillance studies although some contain significant excerpts from surveillance reports:

Global Status Report on Noncommunicable diseases. 2014, WHO [GL15]

ECHO, Ending Childhood Obesity, Final Report of the Commission, WHO, 2016 [GL12]

2015 Report on Diabetes – Driving Change: Toronto, ON: Canadian Diabetes Association; 2015 [C2]

From the pond into the sea: Children’s transition to adult health services, June 2014, Care Quality Commission, Citygate, Gallowgate, UK, [UK2]

Changing Directions, Changing Lives: The Mental Health Strategy for Canada, Mental Health Commission of Canada 2013 [C4]

Taking the Next Step Forward: Building a responsive mental health and addictions system for emerging adults, Mental Health Commission of Canada, 2015. [C14]

The Roadmap for National Mental Health Reform 2012-2022, Council of Australian Governments. [A4]

National Institute of Mental Health, Strategic Plan for Research 2015, United States [US15]

HHS Disparities Action Plan to Reduce Racial and Ethnic Health Disparities 2008 -2015, US Dept of HHS, Office of Minority Health [US16]

DAWN2 Study [GL20]

The DAWN2 study is not a surveillance study (Diabetes Attitudes Wishes and Needs) but does address key “psychosocial challenges faced by people with diabetes and the people helping them”. This study is a global partnership involving 15,000 people living with diabetes or caring for people with diabetes in 17 countries across 4 continents. The country profiles reported for each of the 17 countries include measures of depression in diabetes and diabetes stress. Age ranges are not reported. Canada, UK and US are participants but Australia is not.

Highlighted studies from around the world

The following 10 studies and surveys illustrate helpful approaches and initiatives that contribute to potential for improvement in the collective surveillance capability and resulting knowledge. They have been extracted from the Surveillance Landscape segments [see Section 5.0] of the SFBLF report.

Self-assessment of country capability

* *Type 2 diabetes in Australia’s children and young people: a working paper. Diabetes Series no. 21. Cat no. CVD 64. Canberra; 2014, AIHW [A1]*

* This Australian initiative is a seminal study and may be unique in the available surveillance literature not only because of a detailed focus on both prevalence and incidence of T2DM in youth but also because it asks and answers a key question, “Does Australia have an appropriate data source to monitor type 2 diabetes in children and young people?”

* Includes an assessment of the quality of 7 major data bases as sources of surveillance data. The outcome also provides insight into the usefulness of these data bases as sources for T1DM surveillance data.

Comprehensive, annual reporting with continuing country capability self-assessment

* *National Paediatric Diabetes Audit 2015-2016 Report 1: Care Processes & Outcomes [UK7].*

* The primary source for national diabetes surveillance data for children and youth in the UK is the Royal College of Paediatrics and Child Health (RCPCH). They track diabetes prevalence and incidence in children and young people up to the age of 24 years and under the care of a consultant Paediatrician.

* The Audit addresses incidence and prevalence of all types of diabetes including diabetes-related complications amongst children and young people receiving care from a Paediatric Diabetes Unit (PDU) in England and Wales. The Audit measures which key care processes are being received and enables benchmarking against standards of care specified by NICE.

* In addition to reporting on diabetes-related complications and comorbidities for obesity and mental illness, the NPDA includes much more, e.g., perspectives on ethnicity, relationship of care outcomes to ‘deprivation’, HbA1c control targets, completion of required health checks based on NICE guidelines, treatment regimen, and structured education for patients.

* Equally importantly, the Audit includes recommendations for action to improve both quality of care delivery and quality and completeness of surveillance data.

Identifying/confirming the ‘incidence reality’ for T2DM in youth

* *Incidence trends of type 2 diabetes, medication - induced diabetes, and monogenic diabetes in Canadian children A comparison, Canadian Paediatric Surveillance Program (CPSP) study: one decade later (2017-19) [C7]*

* This new Canadian study, begun in June 2017, will provide valuable insights into the trend for T2DM in youth. It includes a more in-depth diagnostic approach than might be found in other studies.

* *Incidence Trends of Type 1 and Type 2 Diabetes among Youths, 2002 -2012, Mayer-Davis, EJ. et al, N Engl J Med 2017; 376:1419-1429 April 13, 2017 DOI: 10.1056/NEJMoa161018 [US14]*

* This is the most recent study published (June 2017) by the US SEARCH team. Among the many findings reported, is an illustration of the value of a continuing focus on a defined demographic. In particular, the authors note that the sample size accrued over a period of 11 years may have been the basis for identifying trends not previously observable.

Assessing the value of electronic medical records as a surveillance data source

* *Prevalence of toddler, child and adolescent overweight and obesity derived from primary care electronic medical records: an observational study, Biro, S, et al, CMAJ Open 2016. [C17]*

* This recent Canadian study (2016) reports on overweight/obesity prevalence in children/youth less than 20 years of age. Conducted as part of the Canadian Primary Care Sentinel Surveillance Network (CPCSSN), the study used electronic medical records for the period 2004-2013 and included 8,261 children. Sample size was close to 4 times larger than the national survey sample.

* *Childhood Obesity trends 1994 – 2013, Cornelia H M van Jaarsveld, Martin C. Gulliford, Kings College London, Arch Dis Child 2015;100:214-219. doi:10.1136/archdischild-2014-307151 [UK12]*

* This UK study used primary care electronic health records to evaluate the prevalence of overweight and obesity in 2 – 15 year old children in England and compared trends between 1994 and 2013. Data were analyzed for 370,544 children with 507,483 BMI records.

Use of a voluntary ‘registry’ to expand surveillance data availability

* *NDSS – National Diabetes Services Scheme [A13]*

* This Australian government initiative (AIHW), administered by Diabetes Australia (DA) is the only example of a national diabetes registry found among the 4 countries reviewed. It is updated daily and is supported with an interactive national ‘map’ with “Data Snapshots” published every 3 months.

* Participation in the NDSS data base registry is voluntary and registration must be supported by a diagnosis from a doctor or CDE. However, there is an economic incentive to register since supplies available through the NDSS are less expensive than other options. Despite that, there remain many reasons why the NDSS is not a complete reflection of the prevalence of diabetes since it does not capture undiagnosed cases and not all people with diagnosed diabetes may choose to participate. [A1]

- * As of March 31, 2017 there were 1,240,151 people with diabetes registered on the NDSS of whom, 108,708 registered in the previous 12 months and that included 67,122 new cases of Type 2. [A11]

Existence of a national long range plan to improve surveillance

- * *Towards a Public Health Surveillance Strategy for England*, PHE, December 2012 [UK19]

- * This is the only example of a formal, national surveillance strategy document found among the 4 countries reviewed. It provides, “*an overview of the vision, rationale and plans for delivery of a surveillance strategy for Public Health England, as part of Public Health England's broader information strategy. It also sets out the key benefits and challenges in delivering such a strategy*”.

“Surveillance of surveillance”

- * *Global trends in the incidence and prevalence of type 2 diabetes in children and adolescents: a systematic review and evaluation of methodological approaches*, Farsani, S. F., et al, JAMA, Vol 56, Issue 7, pp 1471 – 1488, July 2013, [GL8]

- * This survey identified 145 potentially relevant studies among which 37 population-based studies met the inclusion criteria for incidence and prevalence of type 2 diabetes in children and adolescents.

- * Results reported the, “*variations in the incidence and prevalence rates of type 2 diabetes in children and adolescents were mainly related to age of the study population, calendar time, geographical regions and ethnicity, resulting in a range of 0–330 per 100,000 person-years for incidence rates, and 0–5,300 per 100,000 population for prevalence rates. Furthermore, a substantial variation in the methodological characteristics was observed for response rates (60–96%), ascertainment rates (53–99%), diagnostic tests and criteria used to diagnose type 2 diabetes*”.

- * *Global Epidemiology of Mental Disorders: What Are We Missing?* Baxter, A. J., et al, PLoS ONE 8(6):e65514. doi:10.1371/journal.pone.0065514, June 24, 2013 [GL18]

- * This study, published in June 2013, “*reviews the coverage and limitations in global epidemiological data for mental disorders and suggests strategies to strengthen the data.*”

- * “*Of the 77,000 data sources identified, fewer than 1% could be used for deriving national estimates of prevalence, incidence, remission, and mortality in mental disorders. The two major limitations were (1) highly variable regional coverage, and (2) important methodological issues that prevented synthesis across studies, including the use of varying case definitions, the selection of samples not allowing generalization, lack of standardized indicators, and incomplete reporting. North America and Australasia had the most complete prevalence data for mental disorders while coverage was highly variable across Europe, Latin America, and Asia Pacific, and poor in other regions of Asia and Africa. Nationally-representative data for incidence, remission, and mortality were sparse across most of the world.*”

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