

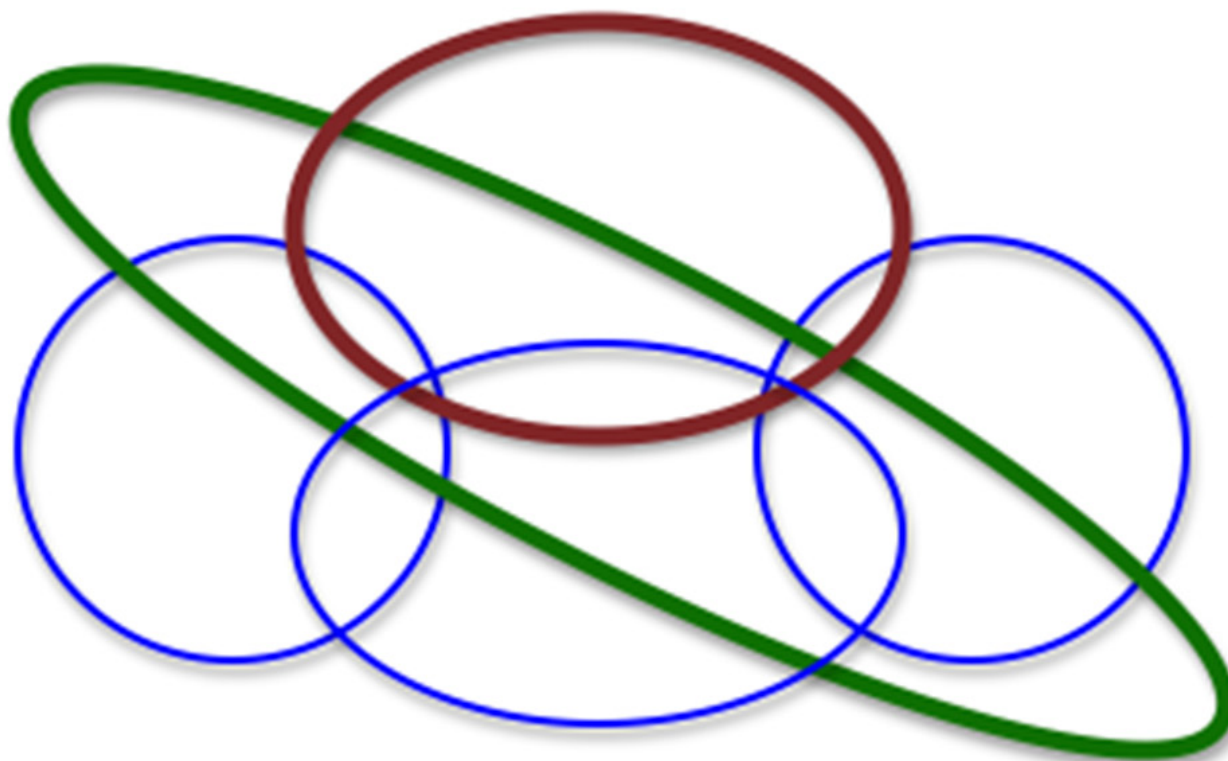
Responding
to Challenges



FIGHTING DIABETES
PRESERVING A LEGACY

Youth Living with Diabetes and Comorbidities

Available Surveillance Data – A Status Assessment



A 'Perfect Storm' for Youth

Clinical Innovation Support Paper #2017-09-01-SI

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about **SFBLF**



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

The primary 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.

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Executive Summary

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Organizations and individuals involved in surveillance studies were asked to comment on selected aspects of the evolving report, e.g., **International Diabetes Federation (Brussels)**, **JDRF Canada**, **CDC Division of Diabetes Translation (US)**, the **SEARCH project (US)**, **Statistics Canada**, **Canadian Institute for Health Information (CIHI)**, **Canadian Primary Care Sentinel Surveillance System (CPCSSN)**, **King’s College**, **Department of Primary Care and Public Health Sciences (UK)**, **Australian Diabetes Educators Association (ADEA)**. Sincere thanks to all who responded.

The views expressed in this report are those of the authors and do not necessarily represent the official position of the Sir Frederick Banting Legacy Foundation (SFBLF).

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The funders had no role in determining the focus or scope of the study, the preparation, review, or approval of the content or any decision regarding dissemination of the report.

Overview of the Report Content

This is the fifth research initiative by SFBLF since mid 2014 to help in the fight against diabetes with a focus on youth. These initiatives have been in response to various challenges arising from:

- The relative absence of surveillance data for diabetes in youth despite widespread agreement that diabetes is rising worldwide among that cohort.
- The increasing appearance of mental illness in combination with diabetes in youth.
- The need for increased awareness and early intervention to reduce risk and help prevent or delay the onset of Type 2 diabetes and complications for both Type 1 and Type 2 in youth.

This study is intended to encourage more aggressive and timely action by others with greater resources to seek improved surveillance insights for youth. The work was part of the SFBLF Annual Summer Intern program and undertaken through May to end of August, 2017.

The Research Focus, Genesis for, and Scope of, the study are described in Section 1.0

Surveillance 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. This paper expands on Why Surveillance Matters in Section 2.0

Surveillance is a difficult and costly undertaking and to be effective requires repetition on a consistent basis and frequency. Section 2.0 also includes consideration of Why Surveillance is Difficult, identifies key data elements that need to be collected and provides a categorization for surveillance studies.

Key Findings and Conclusions are reported in Sections 3.0 and 4.0 respectively. Section 5.0, Surveillance Landscape, includes more detail from a global perspective as well as for each of the four countries studied. References and other summaries can be found in Section 6.0, Appendices.

SCOPE OF THE RESEARCH

Additional details are provided in Section 1.0

Age Ranges

This study focused on children and adolescents, conveniently referred to throughout as ‘youth’, except where clear distinctions of age range are available

and relevant. The World Health Organization (WHO) defines children as 0–9 years of age and adolescents as 10–19 years of age.

Diseases/Conditions

Because there are relationships between and among overweight/obesity, diabetes and mental illness, the study sought surveillance data available for each of the three disease/conditions separately and for any of the combinations including related complications and comorbidities.

Evidence exists to support the view that certain ethnic and indigenous populations are more susceptible to diabetes than others. Each of the country summaries includes such perspectives.

Geography

Four countries only were selected for investigation; Australia, Canada, United Kingdom, United States. The study also examined the availability of surveillance data for the global, international perspective in order to create a context for the results arising for the selected countries.

Data Sources

The search was restricted primarily to reports and studies created by national government organizations in each country or by a third party organization with a government mandate to undertake national surveillance studies. Selected academic papers with a national or global focus were also examined including a few multi-national studies. Approximately 30 systems/processes and over 140 papers were reviewed. Some of that consideration was helped by our 2016 research.

Studies reporting on adults only were not included except to establish the global, international context. Surveillance studies with a specific regional, state, provincial or territorial scope within the selected countries were excluded except for those relating to indigenous groups.

The World Health Organization (WHO) Global Monitoring Framework for Non-communicable Diseases (NCD) includes a monitoring expectation for member states. Consequently, the literature search also considered NCD surveillance systems as possible sources of relevant data.

EXECUTIVE SUMMARY CONTINUED

Country Capability

Of primary importance were insights that described the established capability of the country to produce effective surveillance data; for example, what systems, processes, databases exist? Is surveillance for youth an established, routine process? To what extent are data made easily available not only for support of planning and resource allocation across the full spectrum of health system-related decision-making needs but also as information to inform the general public?

SUMMARY OF FINDINGS AND CONCLUSIONS

The expectation was that among the 4 countries could be found essential national surveillance data arising from established systems and processes and those, in turn, might identify approaches of value for consideration by others. The 'youth' population for the 4 countries exceeds 110 million (31.5%).

- 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. Frequency of surveillance studies varies widely across disease/conditions within and among the four countries.
- None of the 4 countries has cohesive, complete, national surveillance data sets (prevalence or incidence) for youth age 19 and under for all of the following base cases:
 - Diabetes by type, gender and age stratification
 - Overweight and obesity by gender and age stratification

c. Mental illness by type (or at least 'group'), gender and age stratification

- All have partial data sets and 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.
- Surveillance summaries for general public consumption tend to be susceptible to lack of precision in the use of related terminology. Some are prepared by the study organization but many are extracted and published online by national disease-specific advocacy organizations.
- Collaborative leadership for improved surveillance across and within countries is required.
- New initiatives are emerging and existing systems and processes have unexploited potential.
- Much remains to be done to improve the collective surveillance capability for youth. Meanwhile, many agencies and organizations at the global, national and 'sub-national' levels are taking valuable awareness-raising and strategic actions in a parallel quest to stem the rise of obesity, diabetes and mental disorders in youth.

At the end of the day, surveillance data for youth are valuable only if used to educate and ultimately, to identify and implement effective action that increases awareness, reduces risk, nurtures prevention, 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.

Research focus

- Describe and assess the status of surveillance data available for youth and young adults living with diabetes including diabetes-related complications, obesity or overweight and comorbid mental health issues.
- Describe consensus views regarding why surveillance matters and why assembling surveillance data is difficult.
- Describe initiatives in progress or planned to improve surveillance processes and data.

Why is this focus important and necessary?

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.

Surveillance is a difficult and costly undertaking and to be effective requires repetition on a consistent basis and frequency. Those conditions dictate the need for careful, informed planning and early action.

Diabetes is a worldwide pandemic among adults 20 to 79 years of age and the numbers are increasing worldwide. There is substantial documented evidence to support this statement beginning with the global perspectives provided by the International Diabetes Federation (IDF) and the World Health Organization (WHO) and reinforced by studies from many countries.

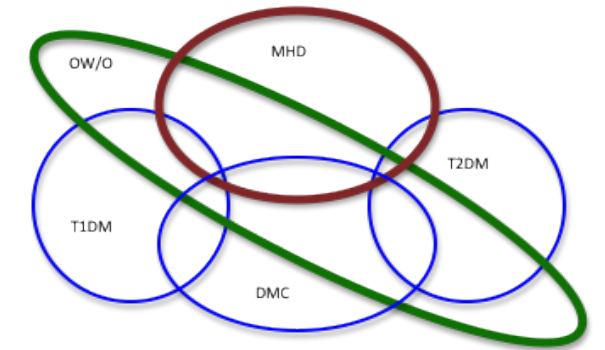
There are widely held opinions on the related trends applicable to youth age 19 years and under but the documented evidence base is sparse and inconsistent.

Specific trends frequently noted include, for example:

1.0 Overview of this study

A perfect storm for youth

What are the relative sizes [prevalence numbers and %] of these domains?



Trends and relationships

- 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.

OVERVIEW OF THIS STUDY CONTINUED

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.



None of the implications can be assessed effectively nor responses undertaken with confidence in the absence of documented evidence for the scale, scope, direction and pace of the trends.

Genesis of the Study

This is the fifth research initiative by SFBLF since mid 2014 to help in the fight against diabetes with a focus on youth. These initiatives have been in response to various challenges arising from:

- The relative absence of surveillance data for diabetes in youth despite widespread agreement that diabetes is rising worldwide among that cohort.
- The increasing appearance of mental illness in combination with diabetes in youth.
- The need for increased awareness and early intervention to reduce risk and help prevent or delay the onset of Type 2 diabetes and complications for both Type 1 and Type 2 in youth.

This study is intended to encourage more aggressive and timely action by others with greater resources to seek

improved surveillance insights for youth. The work was part of the SFBLF Annual Summer Intern program and undertaken through May to end of August 2017.

1. Count the children (2014-2016)

In 2014/15, SFBLF attempted to find surveillance data describing the prevalence and incidence of Type 1 and Type 2 diabetes in youth. National sources in Canada and various organizations at the provincial level were explored but a meaningful current national result proved elusive. For example, some studies had diabetes data by age and gender but not by type; some had diabetes by type and age but not by gender. Explorations were undertaken internationally with similar result.

In 2016, SFBLF considered the practicality of achieving improved surveillance insights by focusing on a smaller geography hoping to create an informative ‘diabetes demographic’ and a practical, cost-effective process that could be replicated by others.

To that end, SFBLF initiated the ‘Count the Children’ study and secured the assistance of two major school boards who represented, collectively, in excess of 80,000 students. Data collection documents were created along with a process designed to protect anonymity while giving the board administrative offices a mechanism by which an individual student could be identified if responses indicated follow-up might be prudent. After several months of deliberations, both boards advised they were unable to achieve the hoped for result.

2. Mental Health and Diabetes in Youth (2014-2016)

At the 3rd Annual Banting Legacy Transition Symposium (November 12, 2014), health care professionals (HCPs) in attendance identified a concern regarding the emergence of youth living with diabetes and also exhibiting mental health difficulties. HCPs expressed a wish to find help to enhance their training in order to deliver a higher quality of care for cases exhibiting such comorbidities.

SFBLF undertook a regional study in early 2015 that confirmed the need and results were reported at the 4th Annual Banting Legacy Transition Symposium (November 12, 2015). With the help of an international review team (Canada, Australia and the United States), SFBLF researched and developed a self-paced, narrated e-Learning course for HCPs and teachers, Mental Health and Diabetes in Youth, released in October 2016. The Australian Diabetes Educators Association (ADEA) accredited the course for their members.

Key objectives of the course are to nurture cross-discipline awareness and communication and identify the implications of the comorbidities for continuity of care and ‘transition’ support processes for youth living with diabetes.

(www.bantinglegacy.ca/e-learning)

3. Raising awareness, reducing risk (2016-2017)

The research for the course reinforced the absence of relevant surveillance data but also led to the realization that a Type 2 Diabetes Risk Self-Assessment Questionnaire for Youth (8 – 18) did not exist. With the help of some of the course review team members, such a tool was developed by SFBLF and released in December 2016.

In general, the 30 or more ‘adult’ risk questionnaires that exist worldwide are intended to be predictive and only work well in populations in which the risk scores were developed.

The SFBLF ‘risk questionnaire’ is not an evidence-based, predictive tool but rather, is intended to raise awareness among youth and their families and encourage further testing if the questionnaire ‘score’ suggests such would be prudent.

As of August 31, 2017, hundreds of visitors from 35 countries had downloaded the document from the SFBLF website. Subsequently, an online, self-scoring’ version, optimized for use with mobile devices, was developed and released in June 2017.

(www.bantinglegacy.ca/diabetes-risk)

4. Understanding Diabetes eLearning program (2017)

In 2017, SFBLF also developed an e-Learning course for youth and family members. The purpose of the course is to raise awareness and understanding of diabetes and related risks, to foster prevention and to help youth living with diabetes to prepare for the transition from paediatric to adult health care. Continuity of care is essential but there are practical ‘disconnects’ in many healthcare systems and it is very important that families work together to ensure the answers to critical questions are obtained well in advance of transition.

This free Course, released on July 1, 2017, consists of 3 narrated, graphics-supported modules, each approximately 18 minutes in length, that can be viewed at the learner’s pace, together or separately. For the hearing impaired, the narrated text is provided as a ‘sidebar’ for each screen.

(www.bantinglegacy.ca/understanding-diabetes)

OVERVIEW OF THIS STUDY CONTINUED

5. Surveillance data availability (2017)

In light of our experiences and the data collection challenges, SFBLF determined that one way we could help would be to prepare a study that would illustrate the surveillance challenges and data gaps and hopefully, encourage a sharper and more timely focus by others on the search for improved surveillance insights.

Scope of the Study

Age Ranges • Children 0 – 9 • Adolescents 10 – 19 • (Young adults 19-24)	Diseases/conditions • Diabetes • Obesity • Mental Illness • Diabetes complications • Combinations
Geography • Global context • Australia • Canada • United Kingdom • United States	Data sources • National Government • 3rd Party w/Gov’t mandate • Academic/Professional Orgs • Selected multi-national
COUNTRY CAPABILITY	

AGE RANGES

This study is focused on children and adolescents, conveniently referred to throughout as ‘youth’, except where clear distinctions of age range are available and relevant. The World Health Organization (WHO) defines children as 0 – 9 years of age and adolescents as 10 – 19 years of age. In most countries, all youth living with a chronic disease must eventually move from paediatric to adult health care. That ‘shift’ or transition can be problematic for continuity of care. Consequently, while this study did not address the transition problem, surveillance data for ‘up to’ the age 24 were sought in the hope papers addressing the transition issues might contain additional insights.

DISEASES/CONDITIONS

Because there are relationships between and among overweight/obesity, diabetes and mental health, this study sought surveillance data available for each of the three disease/conditions separately and for any of the combinations including related complications and comorbidities.

OVERVIEW OF THIS STUDY CONTINUED

Diabetes-related complications arise for both Type 1 and Type 2 diabetes and the earlier the onset of diabetes, the greater the risk of complications.

Evidence exists to support the view that certain ethnic and indigenous populations are more susceptible to diabetes than others. The study also sought supporting data for this aspect.

GEOGRAPHY

Four countries only were selected for investigation; Australia, Canada, United Kingdom, United States. However, the study also examined the availability of surveillance data for the global, international perspective to create a context for the results arising for the selected countries.

The four countries were selected because each has a well established healthcare system, a strong commitment to related medical research, an exemplary medical education system, one or more government agencies focused on disease prevention and health promotion, at least one non-government, national organization that supports and advocates for youth living with the chronic disease/conditions of interest for this study, and all but the UK have significant indigenous populations. The expectation was that among these countries could be found essential national surveillance data arising from established systems and processes and that in turn, might identify approaches of value for consideration by others.

DATA SOURCES

The search was restricted primarily to reports and studies created by national government organizations in each country or by a third party organization with a government mandate to undertake national surveillance studies. Selected academic papers with a national or global focus were also examined including a few multi-national studies. Approximately 30 national systems/processes and over 140 papers were reviewed of which 100 are included in the References section of this study. Some of the latter consideration was helped by our 2016 research.

Studies that reported on adults only were not included except to establish the global, international context. Likewise, surveillance studies with a specific regional, state, provincial or territorial scope within the selected countries were excluded except for those relating to indigenous groups.

Diabetes and mental illness are included in the WHO list

of Non-communicable Diseases (NCD), although mental illness is generally viewed as a ‘condition’ not a disease. Obesity is not included in the usual NCD list but is paired with diabetes as Target #7 in the WHO NCD Global Monitoring Framework. Consequently, the literature search also considered NCD surveillance systems as possible sources of relevant data for this study. In a few cases, studies that encompassed a number of countries such as those in the Organization for Economic Co-operation and Development (OECD) were considered as potential contributors to the global surveillance context. The four countries examined in this study are all members of OECD.

Key data source organizations reviewed

Global	
• International Diabetes Federation (IDF) • World Health Organization (WHO) • Selected Multi-national Organizations	
Australia • Australian Institute of Health and Welfare (AIHW) • Australian Bureau of Statistics (ABS) • National Diabetes Services Scheme (NDSS) • Diabetes Australia (DA)	Canada • Public Health Agency of Canada (PHAC) • Canadian Institute for Health Information (CIHI) • Statistics Canada (StatCan) • Canadian Primary Care Sentinel Surveillance Network (CPCSSN) • Canadian Mental Health Association (CMHA) • Diabetes Canada (DC)
United Kingdom • Royal College of Paediatrics and Child Health (RCPCH) • Public Health England (PHE) • National Health Service (NHS) • Office of National Statistics (ONS) • National Institute for Health and Care Excellence (NICE) • Diabetes UK (DUK)	United States • National Institutes of Health (NIH) • Centres for Disease Control and Prevention (CDC) • National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) • National Institute of Mental Health (NIMH) • American Diabetes Association (ADA)

COUNTRY CAPABILITY

Of primary importance were insights that described the established capability of the country to produce effective surveillance data; for example:

- What systems, processes, databases exist?
- Is surveillance an established, routine national process?

- To what extent are data made easily available not only for support of all aspects of healthcare planning and resource allocation but also as information to inform the general public?
- What plans or incentives exist to improve the availability and quality of surveillance data?

OVERVIEW OF THIS STUDY CONTINUED

CONTINUED

2.0 Perspectives on Surveillance

What is surveillance?

In this report, ‘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 as described in the scope of the study.

Why surveillance matters

GLOBAL AND NATIONAL VIEWS

“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

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 “more hazardous and lethal” 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

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

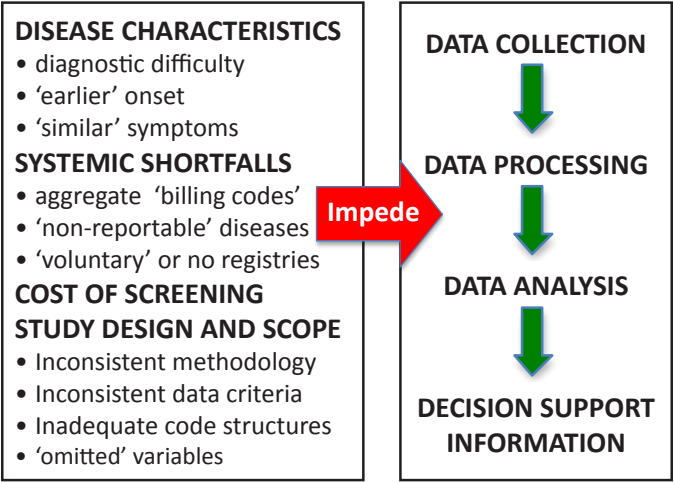
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PERSPECTIVES ON SURVEILLANCE CONTINUED

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.

Nature of the Surveillance Challenge



DISEASE/CONDITION-SPECIFIC CHALLENGES
All of the general surveillance challenges and deficiencies described above exist today for diabetes, diabetes-related complications and comorbidities such as mental illness. These diseases and conditions, separately and in combination, bring added complexity to the surveillance task.

- Type 2 diabetes in youth is a relatively new situation. Just a few decades ago, Type 2 was known as ‘adult onset’ diabetes. That is no longer an accurate label. One result is that Type 2 in youth has not received much attention from epidemiologists or researchers historically as compared with a focus on Type 1 in youth.
- The symptoms of Type 2 diabetes can remain invisible for a long time. It is estimated that 40% of people with Type 2 diabetes do not know they have it. Type 2 diabetes is progressive and cell damage can be in progress at time of diagnosis.
- There are over 400 diagnosable mental illnesses.

- There are bi-directional relationships between and among obesity, diabetes and mental illness.
- Some symptoms for selected mental health difficulties and diabetes are similar. One condition can ‘mask’ the other and lead to mis-diagnosis or missed diagnosis.

In the face of the above realities, the problem might seem intractable. Fortunately, a few international organizations and a growing number of countries, government agencies and various national not-for-profit organizations are focusing on how to improve surveillance insights applicable to youth. The same is happening at the provincial, state, territory and regional level.

What data needs to be collected?

The data required to create the information necessary to support the wide range of decision situations described above depends not only on the decision context but also on the analytical intent and who is asking the question. Those who set health system policy have different needs and perspectives from those who conduct basic medical research. Medical school curriculum planners need yet another set of data to help anticipate evolving educational needs and to create the requisite educational content. Those who seek clinical innovation through new or improved processes need data that will help confirm the effectiveness of the approaches.

The most basic data required for health care system capacity and capability planning and resource allocation have to be prevalence and incidence statistics by disease and condition type including comorbidities for all age ranges and with gender distinctions. Socioeconomic data, indigenous and ethnicity categories are important differentiators that need to be collected.

Designing and implementing prevention programs requires data on risk factors for a given disease or condition and a determination of which of these can be modified to achieve improved outcomes.

Age of onset is an important data element to collect in order to detect shifts that have a direct impact on immediate health care delivery needs but also to help anticipate the potential for increased appearance of disease-related complications. The earlier the onset, the longer the time available for complications to develop.

Comparative analyses require use of ‘common’ scope. For example, two very effective studies that otherwise

use different age ranges cannot easily be compared. Similarly, two studies on mental disorders in youth that include a different set of mental disorders or do not distinguish gender cannot be ‘compared’ in a conclusive fashion. The age demographic of a specific country or region can be very different from others. Comparing prevalence data as a percentage is therefore, potentially misleading and some kind of ‘age-adjusted’ calculation is required to support a more meaningful comparison.

What types of surveillance studies exist?

Surveillance studies are 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; all or some mental disorders; underweight, overweight, obese).

There are many ways to categorize extant surveillance studies. One approach is to categorize by disease/condition included, age range and gender distinctions and then by:

Geographic Scope: a. global b. multi-national c. national d. sub-national, e.g., region, province, state, territory and combinations e. urban or rural f. city, town	Data Acquisition Type: a. full count of selected demographic b. demographic sample assessed for ‘representativeness’ c. estimates based on mathematical models d. aggregates of previous ‘point-in-time’ studies e. extrapolations from a ‘like’ demographic or geographic entity f. electronic medical records
Frequency/Duration: a. one-time over defined period (e.g., months or years included} b. repeated with defined frequency (e.g., annually, every 5 years) c. periodic with no defined frequency d. continuous surveillance of a defined demographic sample e. continuous, self-reporting update of voluntary registries	Author/Sponsor: a. academic - individual or team b. professional – health care expert or team c. government or international agency d. disease/condition- specific advocacy group

PERSPECTIVES ON SURVEILLANCE CONTINUED

Related to the data collection need is the requirement for effective design of electronic data bases and collection processes. An often ill-considered aspect of such design is the ‘code structure’ to be used to label and classify data elements. A code structure, for example, that reflects known data ‘groups’ or categories can lead to ‘running out of codes’ with the ultimate outcome of the inherent data entry or visible reference convenience being diluted if not lost completely. Fortunately, modern information technology provides considerable flexibility to cope with unintended code structure consequences.

As an example, against the above schema, the IDF Diabetes Atlas could be categorized as:

- Disease/condition: aggregate diabetes
- Age range: 20 – 79 years
- Gender distinctions: partial
- Geographic scope: global
- Data acquisition type: ‘mixed’ - estimates based on mathematical models; extrapolations from a ‘like’ demographic or geographic entity
- Frequency/duration: repeated with defined frequency (every 2 years)
- Author/sponsor: disease/condition-specific advocacy group

POPULATION-BASED STUDIES

Population-based studies are widely used in epidemiology research. Underlying ‘study design’ is important and not without controversy regarding the relative efficacy of the result. In very broad terms, population-based studies include selection of a defined population, followed by specific observation of each member of the selected group. Challenges arise in the determination of whether or not such a group is then ‘representative’ of the broader population from which the sample was chosen and hence, the extent to which results arising from such a study can be generalized.

PERSPECTIVES ON SURVEILLANCE CONTINUED

The term ‘population-based’ is used frequently but does not necessarily mean exactly the same thing in all reported studies. Hence, in practical terms, three aspects need to be assessed: clarity of the definition of the population; specification of the ‘time-frame’ involved; and the applicability of the outcomes to the broader population. For example, results from a study based on all Grade 10 students in a given school system cannot be assumed to apply to all Grade 10 students. Design of epidemiology studies is a science in itself.

“The etymology of the word epidemiology arises from epi-demos, meaning upon the people. By definition, epidemiology has as one of its fundamental concepts, the population. But conflicting definitions in epidemiology are common where the names of study designs and concepts are concerned. Readers of epidemiologic literature should be aware that several terms are used idiosyncratically by epidemiologists.”

**Health Risk Science – Population-based studies,
McLaughlin Centre for Population**
Health Risk Assessment
University of Ottawa, Ottawa, Canada [GE5]

3.0 Key Findings

a. Total ‘youth’ population by country

The World Health Organization (WHO) defines children as 0 – 9 years of age and adolescents as 10 – 19 years of age. This report uses ‘youth’ to mean 0 – 19 years of age unless otherwise identified. In most countries, all youth living with a chronic disease must eventually move from paediatric to adult health care. That ‘shift’ or transition can be problematic for continuity of care. Consequently, while this study did not address the transition problem, surveillance data for ‘up to’ the age 24 were sought in the hope papers addressing the transition issues might contain additional insights. In the end, we elected to use any national surveillance study for the disease/conditions of interest as long as it related to all or some part of “19 and under” and was national in scope or intent.

We began by sizing the ‘youth’ population in the 4 countries. Even that proved somewhat elusive with respect to finding population data specifically for the 0 – 19 age range.

(as at July 2016)	AUS	CAN	UK	USA	TOTAL
Total Population	22,992,654	35,362,905	64,430,428	323,995,528	446,781,515
Children age 0 - 14	4,102,866	5,461,403	11,237,960	61,037,347	81,839,576
Adolescents/ young adults age 15 - 24	2,980,333	4,284,714	7,827,418	43,612,557	58,705,000
Total C, A, YA	7,083,199	9,746,117	19,065,378	104,649,904	140,544,576
Total C, A, YA as % of Total Population	30.81%	27.56%	29.59%	32.30%	31.46%
Children age 0 - 14					
Males	2,105,433	2,799,758	5,761,311	31,182,660	41,849,162
Females	1,997,433	2,661,645	5,476,649	29,854,687	39,990,414
Adolescents/ young adults age 15 - 24					
Males	1,528,993	2,204,127	3,997,150	22,360,342	30,090,612
Females	1,451,340	2,080,587	3,830,268	21,252,215	28,614,410
Total C, A, YA					
Males	3,634,426	5,003,885	9,758,461	53,543,002	71,939,774
Females	3,448,773	4,742,232	9,306,917	51,106,902	68,604,824

As illustrated in the Table above, the total population for the 4 countries reviewed was 446.8 million at July 2016 [GE4].

Of that total, there were 81.8 million children (0 – 14) and 58.7 million adolescents/young adults (15-24) for a total of 140.5 million or 31.46% of the combined total population. Apart from the significant presence, these young people represent the future. As such, their health and well-being deserve informed and persistent attention.

We were unable to find comparable statistics for adolescents (15-19) but assuming the proportion of 15–19 year olds is at least half of the 15-24 year old cohort or approximately 30 million, then the population of children and adolescents (0 – 19) in the 4 countries would be in the order of 110 million.

WHAT IF?

IDF estimated the worldwide prevalence of diabetes in adults (20-79) to be 8.8% in 2015. For the 4 countries reviewed, the comparable IDF estimates for adults range from a low of 6.2% (UK) to a high of 12.8% (US) [GL1]

Approximately 10% of all adult diabetes cases are Type 1 and 90% are Type 2 and it is estimated that 40% of adults living with Type 2 diabetes do not know they have it. [GL1]

There is no evidence available to support an estimate of worldwide diabetes prevalence for ‘youth’ (0-19) but

CONTINUED

KEY FINDINGS CONTINUED

what if that prevalence was say 3% and with the same ratio of Type 1 to Type 2?

For the 4 countries reviewed, that would produce estimated prevalence for youth (0-19) of 110 * 0.03 = 3.3 million living with diabetes of which 90% or approximately 2.97 million living with Type 2 and possibly 40% or 1.2 million of those unaware they have the condition.

We were unable to find surveillance data to test our “What if?” diabetes prevalence in youth hypothesis. Generally, what we could find reflected much lower estimates of prevalence but many of the studies were based on relatively ‘old’ data and noted that the estimates were “likely understated”.

b. Comparative Factors Summary

The following table was derived from the research undertaken by SFBLF in 2016 as part of developing the Mental Health and Diabetes in Youth e-Learning program. It is included here to illustrate and reinforce the importance of joint consideration of all disease/conditions included in this surveillance data availability study.

[See chart on next page]

c. Economic Burden of Disease

Disease comes with a major economic cost for countries not only in terms of provision of care but in lost productivity.

There is economic impact for national economies and employers but also for healthcare systems, individual and families.

A 2011 report prepared for the World Economic Forum by Harvard School of Public Health estimated the global economic burden of Non-communicable diseases (NCD) in 2010 and a projection through 2030. The estimates suggest a cumulative output loss of US\$ 47 trillion over the next two decades. NCDs included in that evaluation were cardiovascular disease, chronic respiratory disease, cancer, diabetes and mental health. The report also noted that cardiovascular disease and mental health conditions are the dominant contributors to the global economic burden of NCDs. [GL7]

Direct costs include hospitalizations, specialist, general practitioner, and medication costs and indirect costs, e.g., loss of economic input due to mortalities and long-term disability.

According to the IDF, the estimated total health expenditure globally due to diabetes alone in 2015 is

\$673 billion to 1,197 billion USD. For each of Australia, Canada, United Kingdom and the United States, the respective estimates are approximately \$15 billion, \$17 billion, \$13 billion, \$320 billion. [GL1]

d. National Surveillance Systems and Processes by Country

[relating to diabetes, obesity and mental illness in youth]

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.

WHO also reports on obesity and mental illness but surveillance data for youth are sparse. The following lists the key national systems or processes reviewed in this study.

AUSTRALIA

- National Diabetes Services Scheme (NDSS) – [Diabetes]
- National Health Survey (NHS) - [Obesity]
- National Survey of Mental Health and Wellbeing (NSMHWB) – [Mental Illness]
- Australasian Paediatric Endocrine Group (APEG) – [diabetes]
- National (insulin-treated) Diabetes Register (NDR) - [diabetes]

Australia Indigenous

- National Aboriginal and Torres Strait Islander Social Survey (NATSISS) – [Mental Illness]
- Aboriginal and Torres Strait Islander Health Survey (AATSIHS) – [Diabetes, obesity]

CANADA

- Canadian Chronic Disease Surveillance System (CCDSS) – [Diabetes, Mental Illness]
- Canadian Health Measures Survey (CHMS) – [Obesity, Diabetes, some mental illness]

CONTINUED

KEY FINDINGS CONTINUED

- Canadian Community Health Survey (CCHS) – [Obesity, diabetes]
- Canadian Paediatric Surveillance Program (CPSP) – [multiple diseases/conditions including diabetes and mental health difficulties such as eating disorders]
- Canadian Primary Care Sentinel Surveillance Network (CPCSSN) – [multiple diseases]
- Canadian Health Survey on Children and Youth (CHSCY) – [diabetes, obesity, mental illness; an emerging capability with successful pilot in 2016 and first application to be in 2018]

Canada - Indigenous

- First Nations Regional Health Survey – [diabetes and comorbidities]
- Aboriginal Peoples Survey – [general health indicators; variable content]

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b. Comparative Factors Summary

COMPARATIVE FACTOR	OBESITY	DIABETES – TYPE 1	DIABETES – TYPE 2	MENTAL DISORDERS
Global Prevalence	* 41 million under the age of 5 (2014)	* > 500,000 youth age 14 and under (2015)	* unknown but rising in youth worldwide	* 12.6% of children 4 – 17 years
Ability to Prevent	* most cases could be prevented	* cannot be prevented	* 70 % plus can be prevented/delayed	* many can be prevented
	* early intervention is critical both pre- and post-diagnosis; the latter to prevent or at least delay onset of complications and comorbidities			
Risk Factors	* unhealthy diet, inactivity and smoking are common risks			* many and varied
Age of Onset	* any age but increasingly in ‘youth’	* typically mid-teens but can be sooner or later	* increasingly appearing in ‘youth’	* 50% - 75% start before age 24
Early Onset Implications	* can be carried forward into adolescence and adulthood	* <i>increased risk of diabetes-related complications</i>	* <i>undiagnosed sets the stage for complications being present at diagnosis</i>	* <i>untreated can trigger a spiral into increasingly difficult recovery</i>
Persistence	* <i>does not need to be chronic</i>	* <i>chronic life-long condition</i>		* <i>many are episodic</i> * <i>some life-long</i>
Pre-Diagnostic Screening	* <i>population-wide screening not seen as cost-effective</i> * <i>focus on high-risk populations is seen as essential</i>			
Diagnostic Difficulty	* may be visually evident but still requires applicable BMI assessment	* determining diabetes type can be complex * determining mental disorders can be equally complex and potentially less certain * overlap in symptoms adds to complexity and uncertainty		
Post-Diagnostic Screening	* management plan dictates	* for comorbid mental disorders at time of diagnosis * subsequent as per management plan		* management plan dictates
Ability to Treat	* all can be treated and approaches require consideration of developmental stages * requires multi-disciplinary teams in various combinations plus family support			
Complications & Comorbidities	* Diabetes can lead to further medical complications if not managed well. * More than one mental disorder can be present simultaneously. * Diabetes and mental disorders can co-exist. * Abnormal weight or obesity can co-exist with diabetes and/or mental disorders.			
KNOWLEDGE BASE				
Prevention	* all require both population and individual level programs			
Surveillance	* all require improvement, especially for diabetes and for mental illness in youth			
Guidelines	* diagnostic and treatment guidelines exist but vary by country, region, medical discipline and are based on a mix of research evidence, expert consensus and extrapolation from other contexts			
Research	* each requires more aggressive evidence-based research applicable to youth and including a focus on complications, comorbidities and transition			

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KEY FINDINGS CONTINUED

UNITED KINGDOM (ENGLAND & WALES ONLY)

- National Paediatric Diabetes Audit (NPDA) – [diabetes, diabetes complications, diabetes comorbidities with obesity and mental illness]
- Diabetes Prevalence Model (DPM) – [diabetes]
- National Child Measurement Programme (NCMP) – [obesity]
- Mental Health of Children and Young People in Great Britain – [mental health]
- National Institute for Health and Care Excellence (NICE) – [performance and standards]

UNITED STATES

- SEARCH Project – [diabetes, complications and comorbidities]
- National Health and Nutrition Examination Survey (NHANES) – [obesity]
- Mental Health Surveillance Among Children – US – [mental illness]
- National Health Interview Survey (NHIS) – [multiple diseases/conditions]

United States Indigenous

- Special Diabetes Program for Indians (SDPI) [diabetes]
- Racial and Ethnic Approaches to Community Health (REACH) [general]
- National Health Status Report (NHS) Alaska Native Tribal Health Consortium [multiple]

QUALIFYING NOTES:

- In many cases, reports from the systems listed above are enhanced by data extracted from other supporting systems. For example, in the United States, the National Survey of Children's Health (NSCH).
- National systems exist in all 4 countries for surveillance of other diseases/conditions and/or general health indicators.
- All 4 countries have many supporting surveillance systems at the Provincial, State, Region or Territory level and these were not considered in this study.

e. Availability vs Capability

- Early research revealed 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 certainly have demonstrated the 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.
- In Section 5.0 Surveillance Landscape of this report, more details are provided by country to illustrate both the availability and nature of surveillance data and by implication, the apparent priority and perhaps, 'will' to conduct surveillance for youth and the disease/conditions of interest for this study.

f. 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.

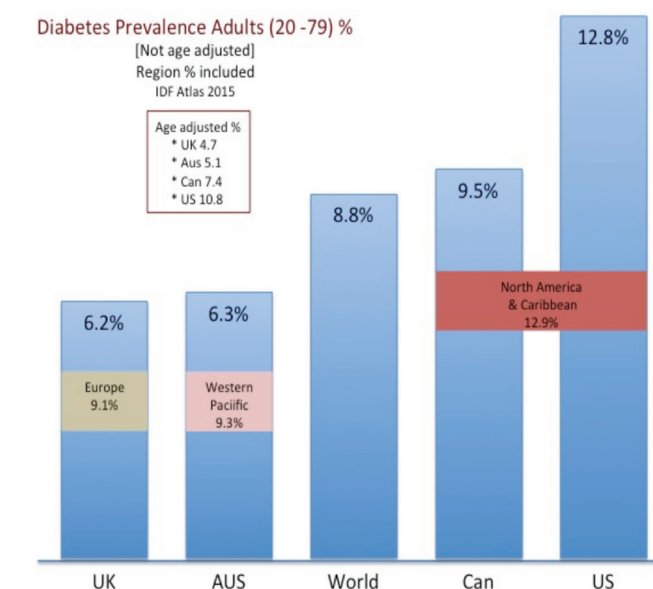
- Surveillance summaries assembled for general consumption tend to be susceptible to lack of precision in the use of related terminology. For example, a summary report on overweight and obesity may not include a clear description of the difference between "overweight" and "obesity" and may use one or 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.

g. Overview of available surveillance data - Global

FOR YOUTH AGE 19 AND UNDER

- 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:
 - Diabetes by type, gender and age stratification
 - Overweight/obesity by gender and age stratification
 - Mental Illness by type (or main group), gender and age stratification
- 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.
- 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].

- As described above, both the International Diabetes Federation (IDF) and the World Health Organization (WHO) produce global surveillance reports that include many countries and 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.



h. Overview of available surveillance data - Country

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

- 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.

CONTINUED

KEY FINDINGS CONTINUED

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:

- Diabetes by type, gender and age stratification
- Overweight/obesity by gender and age stratification
- 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.

i. Highlighted studies

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] as a convenience for the reader.

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.

KEY FINDINGS CONTINUED

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, 2017DOI: 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.

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CONTINUED

KEY FINDINGS CONTINUED

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."

4.0 Conclusions

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 and first application will be in 2018. 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.

CONTINUED

CONCLUSIONS CONTINUED

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.

CONCLUSIONS CONTINUED

CONTINUED

5.0 Surveillance Landscape - by geography

Introduction

This section provides additional details on the surveillance landscape for each of 'global' and the 4 countries reviewed. The focus is primarily on 'youth' but with reference to adult surveillance to establish context.

The 'global' perspectives are limited primarily to consideration of the surveillance studies generated by the International Diabetes Federation (IDF) and the World Health Organization (WHO) with brief consideration of multi-national and a very few 'survey' papers.

THE SURVEILLANCE LANDSCAPE SUMMARY FOR EACH COUNTRY INCLUDES:

- a. 'Youth' population estimate table
- b. Selected surveillance data table
- c. Surveillance capability
 - Reported opinions of capability
 - Summary assessment
 - Key national surveillance organizations
 - Key national surveillance systems/processes reviewed
 - Selected systems/processes – key characteristics
 - NCD 'Targets' surveillance and related capability (as reported by WHO)
- d. Selected national surveillance studies – additional details:
 - Diabetes
 - Obesity
 - Mental illness
 - Complications and comorbidities
 - Indigenous populations
- e. References – by disease/condition (for the country)

Surveillance Landscape - GLOBAL

a. Diabetes - Global

A global surveillance report on diabetes for 'youth' (0-19) could not be found.

IDF Diabetes Atlas 2015 - 7th Edition [GL1]

WHO Global Report on Diabetes 2016 [GL2]

- Both reports deal with adults and are included here as the available global 'benchmarks'. IDF Atlas also contains first-time estimates for children under age 14 living with T1DM by country with no age ranges or gender distinctions.

Parameter	IDF (pub 2015)	WHO (pub 2016)
age range	20-79	18-79
gender distinction	overviews only	partial by region
prevalence - %	8.8	8.5
prevalence - millions	415	422
# of countries included	220	177
# of Regions (country groups)	7	6
publication frequency	every 2 years	one time only

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, 2013 [GL8]

- A literature review reporting on 37 population-based studies selected from 145 potentially relevant studies and focusing on children (0-9) and/or adolescents (10-19) and drawn from the 1965 to 2008 time frame.
- Variations in incidence and prevalence rates of T2DM in children and adolescents were related to age of the study population, calendar time, geographical regions and ethnicity, resulting in a range of 0-330/100,000 person-years for incidence rates and 0-5,300/100,000 population for prevalence rates.
- The paper also reported wide variation in methodological characteristics, ascertainment rates, diagnostic tests and criteria used to diagnose T2DM.

International Comparisons: A Focus on Diabetes.

Ottawa, ON: CIHI: 2015 [GL3]

- Report includes summaries with a particular focus on both diabetes and obesity. It is not a surveillance study and draws prevalence data from other sources.
- A comparison of Canada's performance among all 34 OECD countries with a focus on 8 countries most often compared with Canada in the health system context (includes Australia, United Kingdom and United States) and for 5 dimensions of care: Health Status, Non-Medical Determinants of Health, Access to Care, Quality of Care and Patient Safety.

b. Overweight/obesity - Global

A global surveillance report on overweight/obesity for 'youth' (0-19) could not be found.

Obesity Atlas for the European Union: 2017,

World Obesity Federation, [GL17]

- Provides profiles for all EU members including the UK with separate reports for each of Wales, Scotland and N. Ireland
- Profiles include breakouts of overweight/obesity by gender and age range

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

- This is not a surveillance report. It is a worldwide 'prevention' initiative providing "policy recommendations to governments to prevent infants, children and adolescents from developing obesity, and to identify and treat pre existing obesity in children and adolescents."
- Contains recognition of the need for surveillance, "Governments should prioritize investment in building robust systems with specific indicators that measure childhood obesity and related determinants (such as fitness and nutrition) in a standardized manner." (p.38)
- Contains aggregate recommendations regarding implementation actions for each of WHO, other international organizations, member states, nongovernmental organizations, the private sector, philanthropic foundations and academic institutions.
- Contains general observations on prevalence, e.g., from p.2. of the report:

CONTINUED

- In 2014, an estimated 41 million children under 5 years of age were affected by overweight or obesity and of those, 48% lived in Asia and 25% in Africa.
- In Africa, the number of children who are overweight or obese has nearly doubled since 1990, increasing from 5.4 million to 10.3 million.
- The prevalence of infant, childhood and adolescent obesity may be plateauing in some settings, but in absolute numbers more overweight and obese children live in low- and middle-income countries than in high-income countries.
- Contains prevalence charts for the 6 WHO regions and the World Bank Income Groups.
- Report 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.

c. Mental Illness - Global

Depression & other common mental disorders, Global Health Estimates, WHO, 2017 [GL13]

- This surveillance report considers 2 broad groupings of mental disorders, Depressive Disorders and Anxiety Disorders. It includes data on males and females by age range starting at age 15 with 5 year increments to age 80+ along with ranges of uncertainty.
- It reports total prevalence by country grouped within the 6 Regional zones used by WHO. Total prevalence data for each group, Depressive and Anxiety Disorders, are provided but breakdown between males and females or age ranges are not provided at this level.

Parameter	Depression (2015)	Anxiety Disorders (2015)
age range	15 - 80+	15 - 80+
gender distinction	Yes	Yes
prevalence - Total %	4.4	3.6
prevalence - males %	3.6	2.6
prevalence - females %	5.1	4.6
prevalence - Total millions	322	264
incidence 2005 - 2015	18.4%	14.9%

Note: The numbers for each of these groups cannot be added since some people have more than one condition

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 is not a surveillance study but rather a worldwide review of available population-based epidemiological studies in mental disorders.
- * 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.
- * Two major limitations were identified: highly variable regional coverage and 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.
- * The study reported that 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.

Mental health care for children and adolescents worldwide: a review, Remschmidt, H. et al, World Psychiatry, 2005 Oct 4(3): 147-153 [GL16]

- * Focuses on systems of care available for youth with mental health issues and includes an estimate of global prevalence based on population studies in Europe and the United States.
- * The data reported are 6-month prevalence rates of all mental disorders in the general population (for boys and girls together); 16.3% in 8 year olds, 17.8% in 13 year olds, 16% in 18 year olds and 18.4% in 25 year olds.

OTHER MENTAL ILLNESS RELATED REPORTS:

Mental Health Action Plan 2013-2020, WHO, 2013, [GL4]

Mental Health: Strengthening our response,

WHO Fact Sheet No. 220, August 2014 [GL5]

- These 2 reports are not surveillance reports. They focus on broad policy and leadership needs for mental health promotion and mental illness prevention. They do reinforce the need for strengthening information systems, evidence and research for mental health.

d. Complications and Comorbidities – Global

Global surveillance reports for diabetes-related complications and for diabetes/mental disorders comorbidities for ‘youth’ (0-19) could not be found

Common diabetes-related complications include cardiovascular disease, nerve damage (neuropathy), kidney damage (nephropathy), eye damage (retinopathy), foot damage and skin conditions. [GE2]

The more common mental illness comorbidities found in youth living with diabetes are depression, diabetes stress, anxiety disorders and eating disorders. The screening guidelines recommended in several countries highlight the importance for medical practitioners to undertake such screening for youth living with diabetes. [GE3]

NIDDK International Conference Report on Diabetes and Depression: Current Understanding and Future Directions, Holt, R. I. G., et al, Diabetes Care Vol 37, Aug 2014; [GL11]

- A report arising from a conference of experts from 15 countries. It is not a surveillance report nor a review report but contains some prevalence and incidence data as well as several useful references to other studies that focused on children and adolescents.
- The majority of the content deals with diabetes in adults and the paper notes, “There are few studies of the prevalence of depressive disorders in pediatric populations”. However, elevated rates of depression, anxiety and distress in youth living with either T1DM or T2DM compared to the general population have been observed; e.g., for T1DM, rates ranging from 10 – 26% and for depression in adolescents with T2DM or populations with both T1DM and T2DM 8.6% - 14.8%

DAWN2TM 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.

Long-Term Complications and Mortality in Young-Onset Diabetes,

Constantino, M.I. et al, Diabetes Care 2013 Dec 36(12) 3863-3869 [GL19]

- Diabetes-related complications can occur with either type of diabetes. The earlier the onset of diabetes, the greater the risk of complications. The progressive nature of Type 2 diabetes 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 “more hazardous and lethal” than is Type 1 in youth.

e. Non-communicable Diseases - Global

Noncommunicable diseases country profiles 2014, WHO [GL14]

- The focus in these new profiles is on presenting information for each country related to their NCD mortality, risk factors and national systems capacity to prevent and control NCDs. The profiles include the number, rates and causes of deaths from NCDs and trends in NCD mortality since 2000; the prevalence of selected risk factors; and information describing current national responses to prevention and control of NCDs.

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

- This global status report on prevention and control of NCDs (2014), is framed around the nine voluntary global targets. The report provides data on the current situation, identifying bottlenecks as well as opportunities and priority actions for attaining the targets. The 2010 baseline estimates on NCD mortality and risk factors are provided so that countries can report on progress, starting in 2015. In addition, the report also provides the latest available estimates on NCD mortality (2012) and risk factors, 2010-2012.

Because of the focus provided by the WHO regarding on-going surveillance and monitoring of non-communicable diseases among WHO member states, a search was undertaken to see if within that context, there might be relevant surveillance data available for obesity, diabetes and mental illness in youth. To the extent such could be found, the details have been included in the appropriate subject matter sections for individual countries.

SURVEILLANCE LANDSCAPE - Global CONTINUED

Global or even multi-national surveillance data for non-communicable diseases in youth are very difficult to find. There are many related insights available for topics such as tobacco and alcohol use and various overviews for regions or even cities.

f. References related to Global – by disease/condition

DIABETES

GL1. *IDF Diabetes Atlas (2015)* 7th Edition <http://www.idf.org/idf-diabetes-atlas-seventh-edition>, retrieved December 4, 2015

GL2 *Global Report on Diabetes 2016*, WHO <http://www.who.int/diabetes/global-report/en> retrieved August 24, 2017

GL3 *International Comparison: A Focus on Diabetes*. Ottawa, ON: CIHI: 2015 https://secure.cihi.ca/free_products/oecd-diabetes-report-2015_en.pdf retrieved Mar 2, 2016

GL8 *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, <https://link.springer.com/article/10.1007%2Fs00125-013-2915-z>, retrieved June 22, 2017

OBESITY

GL12 *ECHO, Ending Childhood Obesity*, Final Report of the Commission, WHO, 2016 http://apps.who.int/iris/bitstream/10665/204176/1/9789241510066_eng.pdf?ua=1, retrieved February 2, 2016

GL17 *Obesity Atlas for the European Union: 2017*, World Obesity Federation, <http://www.worldobesity.org/data/countryprofiles/>, retrieved August 24/17

MENTAL ILLNESS

GL4 *Mental Health Action Plan 2013-2020*, WHO, 2013, http://www.who.int/mental_health/publications/action_plan/eng/, retrieved Feb 6/16

GL5 *Mental health: Strengthening our response*, WHO Fact Sheet No. 220, August 2014, <http://www.who.int/mediacentre/factsheets/fs220/en/>, retrieved Mar 15/16

GL9 *Diagnostic and Statistical Manual of Disorders (DSM)*, American Psychiatric Association, <https://www.psychiatry.org/psychiatrists/practice/dsm>, retrieved May 19/16

GL11 *NIDDK International Conference Report on Diabetes and Depression: Current Understanding and Future Directions*, Holt, R . I. G., et al, Diabetes Care Vol 37, Aug 2014;2067-2077 <http://care.diabetesjournals.org/content/37/8/2067.full.pdf+html>, retrieved Mar 20/16

GL13 *Depression and other common mental disorders, Global Health Estimates, 2017*, WHO <http://apps.who.int/iris/bitstream/10665/254610/1/WHO-MSD-MER-2017.2-eng.pdf>, retrieved July 24, 2017

GL16 *Mental health care for children and adolescents worldwide: a review*, Remschmidt, H. et al, World Psychiatry, 2005 Oct 4(3): 147-153, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1414760/>, retrieved July 24, 2017

GL18 *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 <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0065514#s5>, retrieved August 4, 2017

NONCOMMUNICABLE DISEASES

GL6 *Sustainable Development Goals*, United Nations, September 25, 2015, <http://www.un.org/sustainabledevelopment/sustainable-development-goals/>, retrieved, March 7/16

GL7 *The Global Economic Burden of Noncommunicable Diseases*, Bloom et al, January 2012, PGDA Working Paper No. 87, <http://www.hsph.harvard.edu/pgda/working.htm>, retrieved Feb 22, 2016

GL10 *International Classification of Diseases, ICD-10*, WHO, <http://www.who.int/classifications/icd/en/>, retrieved May 23/16

GL14 *Noncommunicable diseases country profiles 2014*, July 2014, <http://www.who.int/nmh/publications/ncd-profiles-2014/en/>, retrieved July 25, 2017

GL15 *Global Status Report on Noncommunicable diseases 2014*, WHO <http://www.who.int/nmh/publications/ncd-status-report-2014/en/>, retrieved July 25, 2017

SURVEILLANCE LANDSCAPE - Global CONTINUED

COMPLICATIONS AND COMORBIDITIES

GE1 *Psychological Challenges for Children Living with Diabetes*, Diana Naranjo & Korey Hood, Aug 2013, IDF DiabetesVoice, Vol 58, Special Issue 1, Sept 1, 2013 <http://www.idf.org/psychological-challenges-children-living-diabetes>, retrieved Mar 5/16

GE2 *Complications*, Mayo Clinic Staff (2016), <http://www.mayoclinic.org/diseases-conditions/diabetes/basics/complications/con-20033091>, retrieved May 8, 2017

GE3 *Mental Health Comorbidities of Diabetes*, JAMA, 2014 August 20; 312(7): 691-692, Ducat et al, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4439400/pdf/nihms684855.pdf>, retrieved May 27/16

GL19 *Long-Term Complications and Mortality in Young-Onset Diabetes*, Constantino. M.I. et al, Diabetes Care 2013 Dec 36(12) 3863-3869, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3836093/>, retrieved August 24, 2017

GL20 *DAWN2™ Study*, <http://www.dawnstudy.com/dawn2/about-dawn2.html>, retrieved August 24/17

Surveillance Landscape - AUSTRALIA

a. ‘Youth’ Population

Population	Males	Females	Total
Total Country [GE4]			24,673,782
Children age 0 - 14	2,105,433	1,997,433	4,102,866
Adolescents/young adults age 15 - 24	1,528,993	1,451,340	2,980,333
SFBLF estimate of adolescents 15 - 19	765,000	725,000	1,490,000
SFBLF estimate of youth (0 -19)	2,900.000	2,720,000	5,620,000

b. Selected Surveillance Data

Diabetes prevalence - adults 20 – 79 [IDF]	6.3%
Obesity prevalence – adults 20+ [WHO]	26.8%
Mental illness prevalence – depressive 15 – 80+ [WHO]	5.9%
Mental illness prevalence – anxiety 15 – 80+ [WHO]	7.0%
Diabetes prevalence – youth – 19 and under	not reported
Obesity prevalence – youth – 5 -17 [ABS]	27.4%
Mental illness prevalence – youth [AIHW]	14%

Note: estimates made by IDF and WHO do not necessarily match those made by national surveillance systems within a country

c. Surveillance Capability

REPORTED OPINIONS OF CAPABILITY

“A lack of clinical data that aid in the differentiation of type 1 and type 2 diabetes limit many population-based studies, and many studies do not capture undiagnosed cases of type 2” [A1]

“Confusion ... including among medical professionals, about the terminology used for different types of diabetes ... has led to misclassification” [A1]

“The continued high prevalence and burden of mental disorders in children and adolescent’s points to the need for continued investment in treatment and prevention, continuing mental health services reform at all levels, and further prioritising research into mental disorders in childhood and adolescence” [A9]

SUMMARY ASSESSMENT

- National processes exist but are widely variable in approach, content and frequency across disease/ conditions.
- Surveillance studies for diabetes-related complications and comorbidities in youth (0-19) are sparse; tend to be ‘embedded’ in broader studies and/or are not reported in a context specific to their diabetes connection.
- Significant differences in the criteria used to collect data for each disease/condition.
- Inconsistent use of age ranges and inclusion of gender distinctions within and across disease/ condition surveillance studies.
- Quality assessment of diabetes data bases published in 2014
- Age of data ranges from ‘current’ (1 to 4 years) to more than a decade old; studies published generally within 1 year
- Accredited researchers may have more timely and broader access to surveillance data
- Voluntary Diabetes Registry updated daily; ‘snapshots’ every 3 months.
- Reports for the general public are provided by originating organizations and by disease specific advocacy groups; often including helpful ‘infographics’.

KEY NATIONAL SURVEILLANCE ORGANIZATIONS

1. AIHW - Australian Institute of Health and Welfare
2. ABS - Australian Bureau of Statistics
3. NDSS - National Diabetes Services Scheme
4. DA- Diabetes Australia

SURVEILLANCE LANDSCAPE - Australia CONTINUED

KEY NATIONAL SURVEILLANCE SYSTEMS/ PROCESS REVIEWED [PRIMARY FOCUS]

- National Diabetes Services Scheme (NDSS) – [diabetes]
- National Health Survey (NHS) - [obesity, mental illness, diabetes]
- National Survey of Mental Health and Wellbeing (NSMHWB) – [mental illness]
- Australasian Paediatric Endocrine Group (APEG) – [diabetes]
- National (insulin-treated) Diabetes Register (NDR).- [diabetes]

Australia Indigenous

- National Aboriginal and Torres Strait Islander Social Survey (NATSISS) – [mental illness]
- Australian Aboriginal and Torres Strait Islander Health Survey (AATSIHS) – [multiple]
- Qualifying Notes:
 - i. In many cases, reports from the systems listed above may be enhanced by data extracted from other supporting systems.
 - ii. National systems exist for surveillance of other diseases/conditions and/or general health indicators.
 - iii. Supporting surveillance systems exist at State, Territory level and these were not considered in this study.

SELECTED SYSTEMS/PROCESSES - KEY CHARACTERISTICS

Recent Report	Age Range	Gender	Type
[A1] Type 2 diabetes in Australia’s children and young people: (2014); AIHW * first national report on T2DM in youth * includes assessment of 7 national data bases * prevalence and incidence * includes some comparisons with T1DM and also indigenous populations	0-18, 0-14, 10-24,10-39, 10-24, 15-19,20-24,30-34,35-39 and 40+	Yes	Type 2 specific with some T1DM
[A11] NDSS National Diabetes Service Scheme (2017) * voluntary diabetes registry with incentives * prevalence and incidence * T1DM and T2DM * Includes indigenous and ‘deprivation’ stats * continuous with published quarterly ‘snapshots’ and an ‘interactive’ map	Under 15 years old 0-20, 16-20 ,21-29, 21-39 40-59 and 60 +	Yes	Yes
[A10] National Health Survey: First Results 2014/15. ABS Dec 2015. * produced every 3 years * multiple diseases/conditions reported including overweight/obesity * sample size 15,000 * emphasis on 18 years plus	18 + 0-17 15-17	Yes	Partial
[A6] Prevalence, impact and burden (MHSA)-‘Young Minds Matter’ 2013/14 AIHW 2015 * second report; first in 1998 * Sample 6,310 parents; 2,967 11-17	* 4-17	Yes	‘Groups’

NCD ‘TARGETS’ - SURVEILLANCE CAPABILITY AND RELATED (AS REPORTED BY WHO)

2014 WHO NCD Country Profiles	AUS
1. Has an operational policy, strategy or action plan to reduce unhealthy diet and/or promote healthy diets	Yes
2. Has evidence-based national guidelines, protocols, standards for the management of major NCDs through a primary care approach	No
3. Has an NCD surveillance and monitoring system in place to enable reporting against the nine global NCD targets (adults 18+)	No

d. Selected national studies – additional details

DIABETES

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

- This is a seminal study and may be unique in the available surveillance literature not only because of the 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: NDSS, APEG, NDR plus the National Health Survey (NHS), the Australian Diabetes Study (AusDiab), the Medicare Benefits Schedule (MBS) and the Pharmaceutical Benefits Scheme (PBS). While the emphasis was on Type 2, the outcome also provides insight into the usefulness of these data bases as sources for Type 1 surveillance data.
- T2DM data (2002 – 2012) for age 10 – 39 in 5 year increments with gender distinctions and some comparative data for T1DM vs T2DM incidence plus a focus on Indigenous Australians
- Acknowledges that prevalence numbers are likely “underestimated”.

- Three systems are dominant: the National Diabetes Services Scheme (NDSS), the Australasian Paediatric Endocrine Group (APEG) and the National (insulin-treated) Diabetes Register (NDR). For many practical and data coverage reasons, the NHS, AusDiab, MBS and PBS data bases were judged to be unable to be used to monitor Type 2 diabetes in children and young people.
- APEG and NDR Data Bases are primarily sources for incidence data but each includes some prevalence data for a small age group. The APEG data base is a state-based system in which all states and territories collect data on insulin-treated diabetes in 0 – 14 year olds. Three states also collect data on non-insulin treated diabetes and 2 also collect data on 15 – 17 year olds. While the APEG has national coverage, the collected data are not compiled nationally.

NDSS – National Diabetes Services Scheme [A13]

- Includes data supporting both prevalence and incidence, applies to all ages and both T1DM and T2DM. The NDSS, established in 1987, is an Australian Government initiative administered by Diabetes Australia (DA). The NDSS provides education, information and a range of diabetes-related products at subsidised prices to people with diabetes who choose to register. The subsidised products include syringes, pen-needles, blood and urine test strips and insulin pump consumables.
- 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]
- “Statistical Snapshots” based on NDSS data are published every 3 months and reflect all types of diabetes as well as age ranges but do not report gender distinctions. 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]

OBESITY

National Health Survey (NHS) 2014/15 – First Results, ABS [A10]

- The 2014/15 National Health Survey is the most recent in a series of Australian-wide health surveys conducted by the ABS. This series is produced every 3 years. Data is extrapolated to be used in producing statistics to the larger community. The survey measures up to 2 residents, one adult (18 years and older) and one child (aged 0-17), those that are 15-17 years of age (self-reported) need the consent of a parent or guardian. From July 2014 to June 2015 nearly 15,000 private dwellings were elected via mail to partake in the survey and it included around 19,000 persons.
- Many diseases and conditions are reported including, diabetes (excluding gestational), overweight and obesity, and mental and behavioural conditions. The reported data are predominantly for adults age 18 and over but some details are provided for children 5 – 17 years of age.
- “Around one in four (27.4%) children aged 5 – 17 years were overweight or obese, comprised of 20.2% overweight and 7.4% obese similar to 2011-12 (25.7%)” . The Body Mass Index (BMI) data are broken out in aggregate between boys and girls for each of underweight, normal, overweight and obese. (p.40).
- The NHS 2014-15 also reported the prevalence of overweight/obesity by state and territory.

MENTAL ILLNESS

Prevalence, impact and burden (MHSA) - ‘Young Minds Matter’ 2013/14, AIHW (2015) [A6]

- “A program of population surveys, the National Survey of Mental Health and Wellbeing (NSMHWB), began in Australia in the late 1990s. These surveys provide evidence on the prevalence of mental illness in the Australian population, the amount of disability associated with mental disorders and the use of health services by people with mental disorders. These studies have 3 main components—a population-based survey of adults, a service-based survey of people with psychotic disorders, and a population-based survey of children”.
- Most recent survey (2007) of the adult population published in 2008 includes ages 16 – 85.

- A separate survey (2013-14) of children and adolescents published in 2015 includes ages 4 – 17 and is entitled Young Minds Matter.
- This report describes the prevalence of mental disorders by diagnostic scheduling amongst 4 - 17 year olds between 2013-2014 and notes changes from the 1998 survey. The data describe main disorder categories, i.e., Attention Deficit Hyperactivity Disorder (ADHD), anxiety disorders, major depressive disorders and conduct disorders by male and female break out including, combinations of two or more mental disorders in the previous 12 months.
- This 2013-14 report is the second survey with the first done in 1998. Up to 14% (1 in 7) of children and adolescents 4-17 years old were assessed as having mental health disorders within the survey time period. Of the 560,000 children and adolescents diagnosed ADHD was the most commonly found at (7%) followed by Anxiety disorders (nearly 7%), Major depressive disorder (3%) and Conduct disorders (2%). Approximately 4% of all 4-17 years old reported that they suffered with 2 or more mental health disorders at some time in the previous 12 months.
- For the full report see Lawrence et al. 2015. [A8]

COMPLICATIONS AND COMORBIDITIES

The National Health Survey includes surveillance data on high cholesterol, heart disease, hypertension, kidney disease, and mental illness all of which can be comorbid with diabetes. However, the study does not specifically report on the diabetes ‘connection’. [A10]

Diabetes among young Australians. Diabetes ser no.18. Cat.no. CVD 59, AIHW (2012) [14]

- Compared with other age groups, children aged 0-11 years had the highest rates of presentations for diabetes to hospital emergency departments in Victoria, New South Wales and Western Australia.
- People under 25 were hospitalised more often than those aged 25-30 for acute diabetes- related complications, such as ketoacidosis.
- The number of hospitalisations for ketoacidosis among people aged 0-24 increased over time from 2002-03 to 2009-10. These hospitalisations were associated with the presence of acute illnesses and a ‘history of non-compliance with medical treatment’, especially among people aged 12-24.

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SURVEILLANCE LANDSCAPE - Australia CONTINUED

- Serious but preventable long-term complications of diabetes were already evident in some people aged 19-30, including nerve damage, foot ulcers, eye and kidney disease.
- Diabetes was the underlying cause of death of 88 people aged 0-30, and an associated cause of death for a further 76 in 2001-07. Most of these deaths occurred in people aged 25-30.

INDIGENOUS POPULATIONS

National Aboriginal and Torres Strait Islander Social Survey (NATSISS)- 2014-15, ABS [A15]

- This is the 4th National social survey (building on 1994, 2002 and 2008) was conducted from September 2014 to June 2015 with a sample of 11,178 Aboriginal and Torres Strait Islander people living in private dwellings across Australia. The 2014–15 NATSISS is a multidimensional social survey which provides broad information across key areas of social concern for Aboriginal and Torres Strait Islander Australians, nationally, by state and territory and remoteness area including persons aged 15 years and over; children aged 4–14 years; and infants aged 0–3 years.

Australian Aboriginal and Torres Strait Islander Health Survey (AATSIHS): First Results, Australia, 2012-13 [A16]

- This survey, commenced in April 2012, collects information from the Aboriginal and Torres Strait Islander population in non-remote areas and remote areas, including discrete communities as part of the AHS (Australian Health Survey) that includes a nationally representative sample of around 13,000 Aboriginal and Torres Strait Islander people. A combination of existing ABS National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) together with two new elements - a National Aboriginal and Torres Strait Islander Nutrition and Physical Activity Survey (NATSINPAS) and a National Aboriginal and Torres Strait Islander Health Measures Survey (NATSIHMS), make up the AATSIHS (2012-13)

e. References related to Australia – by disease/condition category

DIABETES

- A1 **Type 2 diabetes in Australia’s children and young people: a working paper.** Diabetes Series no. 21. Cat no.. CVD 64. Canberra; AIHW <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129546359> retrieved Mar 2, 2016
- A2 **Diabetes – issues for children and teenagers**, State Gov’t of Victoria, Australia, Better Health Channel, <https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/diabetes-issues-for-children-and-teenagers> retrieved Mar 5/16
- A11 **National Diabetes Service Scheme (NDSS).** Diabetes Australia: (2017) <https://www.ndss.com.au/> retrieved July 22/17
- A12 **Diabetes Australia** <https://www.diabetesaustralia.com.au>, accessed July 22, 2017
- A13 **NDSS National Diabetes Service Scheme (2017) Statistical Snapshot** <https://www.ndss.com.au/data-snapshots> retrieved July 22,2017
- A14 **Diabetes among young Australians.** Diabetes series no. 18. Cat. no. CVD 59. Canberra: AIHW <http://www.aihw.gov.au/publication-detail/?id=60129542306&tab=2>, accessed Aug 27, 2017

MENTAL ILLNESS

- A3 **The Mental Health of Children and Adolescents**, Australian Government Department of Health, August 2015, Part 2, [http://www.health.gov.au/internet/main/publishing.nsf/Content/9DA8CA21306FE6EDCA257E2700016945/\\$File/pt2.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/9DA8CA21306FE6EDCA257E2700016945/$File/pt2.pdf), retrieved Mar 10/16
- A4 **The Roadmap for National Mental Health Reform 2012-2022**, Council of Australian Governments. <http://www.coag.gov.au/sites/default/files/The%20Roadmap%20for%20National%20Mental%20Health%20Reform%202012-2022.pdf>, retrieved Mar 15/16
- A5 **About Us**, Mental Health Australia, 2016, <https://mhaustralia.org/about-us>, retrieved Mar 15/16
- A6 **Prevalence, impact and burden (MHSA) – Young Minds Matter, 2013/14**, AIHW (2015), <https://mhsa.aihw.gov.au/background/prevalance/>, retrieved July 22/17

SURVEILLANCE LANDSCAPE - Australia CONTINUED

- A8 **The Mental Health of Children and Adolescents. Report on the second Australian Child and Adolescent Survey of Mental Health and Wellbeing**, Lawrence D, Johnson S, Hafekost J, Boterhoven De Haan K, Sawyer M, Ainley J, Zubrick SR (2015) Department of Health, Canberra. [http://www.health.gov.au/internet/main/publishing.nsf/ontent/9DA8CA21306FE6EDCA257E2700016945/\\$File/child2.pdf](http://www.health.gov.au/internet/main/publishing.nsf/ontent/9DA8CA21306FE6EDCA257E2700016945/$File/child2.pdf), Retrieved July 22/17
- A9 **Young Minds Matter** – An overview and background for the survey cited as [A6] www.youngmindsmatter.org.au retrieved July 22/17

MULTIPLE DISEASES/CONDITIONS (INCLUDING OBESITY)

- A7 **Australian Health Survey: updated results, 2011- 2012.** ABS cat. no. 4364.055.003. Canberra: <http://aihw.gov.au> retrieved July 16,2017
- A10 **National Health Survey: First Results 2014/15.** ABS cat.no. 4364.0.55.001 Canberra <http://www.abs.gov.au/ausstats/abs@.nsf/PrimaryMainFeatures/4364.0.55.001?OpenDocument>Retrieved July 22/17

INDIGENOUS SURVEILLANCE

- A15 **National Aboriginal and Torres Strait Islander Social Survey (NATSISS) - 2014-15**, <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/4714.0~201415~Main%20Features~Population%20context~2>, accessed August 27, 2017
- A16 **Australian Aboriginal and Torres Strait Islander Health Survey (AATSIHS): First Results, Australia, 2012-13** <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4727.0.55.001main+features802012-13> retrieved: August 18/2017

GENERAL

- GE4 **The World FactBook (2017):** Central Intelligence Agency [CIA] <https://www.cia.gov/library/publications/the-world-factbook/geos/xx.html>, Retrieved Aug 7/17

Surveillance Landscape - CANADA

SURVEILLANCE LANDSCAPE - Canada CONTINUED

a. 'Youth' Population

Population	Males	Females	Total
Total [GE4]			35,362,905
Children age 0 - 14	2,799,758	2,661,645	5,461,403
Adolescents/young adults age 15 - 24	2,204,127	2,080,587	4,284,714
SFBLF estimate of adolescents 15 - 19	1,100,000	1,000,000	2,100,000
SFBLF estimate of youth (0 -19)	3,900.000	3,700,000	7,600,000

Note: In Canada, adults are defined as 18 +

b. Selected Surveillance Data

Diabetes prevalence - adults 20 – 79 [IDF]	9.5%
Obesity prevalence – adults 20+ [WHO]	26.2%
Mental illness prevalence – depressive 15 – 80+ [WHO]	4.7%
Mental illness prevalence – anxiety 15 – 80+ [WHO]	4.9%
Diabetes prevalence – age 12 and over [CCHS]	6.7%
Obesity prevalence – youth 0-19 [CPCSSN]	6% to 28.4%
Mental illness prevalence – youth 12–19 [CMHA]	10% to 20%

- Despite the number of systems and inherent overlaps, significant gaps persist.
- Significant differences in the criteria used to collect the data across provinces and compared to national systems.
- Inconsistent use of age ranges and inclusion of gender distinctions within and across disease/condition surveillance studies.
- StatCan is the dominant source of surveillance data. Relevant reports and study results are provided in many formats, e.g. Fact Sheets, CANSIM data tables and report summaries. It can be difficult to find and integrate these sources to assemble a collective understanding.
- CIHI have many data bases of relevance that can be accessed only by formal, fee-based requests for CIHI analysts to extract and assemble.

KEY NATIONAL SURVEILLANCE ORGANIZATIONS

- 1 PHAC – Public Health Agency of Canada
- 2 StatCan – Statistics Canada
- 3 CIHI – Canadian Institute for Health Information
- 4 CMHA – Canadian Mental Health Association
- 5 DC – Diabetes Canada (formerly Canadian Diabetes Association)

KEY NATIONAL SURVEILLANCE SYSTEMS/ PROCESS REVIEWED [PRIMARY FOCUS]

- Canadian Chronic Disease Surveillance System (CCDSS) – [Diabetes, Mental Illness]
- Canadian Health Measures Survey (CHMS) – [Obesity, Diabetes, some mental illness]

- Canadian Community Health Survey (CCHS) – [Obesity, diabetes]
- Canadian Paediatric Surveillance Program (CPSP) – [multiple diseases/conditions including diabetes and mental health difficulties such as eating disorders]
- Canadian Primary Care Sentinel Surveillance Network (CPCSSN) [multiple diseases]
- Canadian Health Survey on Children and Youth (CHSCY) – [diabetes, obesity, mental illness; an emerging capability with successful pilot in 2016 and first application to be in 2018]

Canada - Indigenous

- First Nations Regional Health Survey – [diabetes and comorbidities]
- Aboriginal Peoples Survey – [general health indicators; variable content]

Qualifying Notes:

- i. Reports from the systems listed above may be enhanced by data extracted from other supporting systems.
- ii. National systems exist for surveillance of other diseases/conditions and/or general health indicators.
- iii. Supporting surveillance systems exist at the provincial, territory level and these were not considered in this study.

SELECTED SYSTEMS/PROCESSES - KEY CHARACTERISTICS

Recent Report	Age Range	Gender	Type
[C1] Diabetes in Canada: Facts and figures from a public health perspective, PHAC, 2011 * population-based study using 2008/09 data from CCDSS and several other sources * est for T1 not available in Canada (at the time) * breakouts by province/territory * age ranges included in reports are inconsistent	* 1–9, 10–19 and 5 yr increments thereafter to 85	Yes	No but overall estimates
[C15] Canadian Health Measures Survey (CHMS), StatCan * continuous survey with 2 year cycle for reports of selected disease/conditions * disease/conditions include diabetes, obesity * personal interview and medical screening * sample size typically 6,000	* 3-79	Yes	For some diseases
[C8] Canadian Community Health Survey (2014). StatCan * reports annually within 6 months of end of collection * disease/conditions include diabetes, obesity * sample 120,000 18+; 10,000 12-17 * voluntary participation	* 12- 17, 18 and over	Summary	No
[C17] CCPCSSN (2016) * electronic medical records based surveillance * selected samples * several disease/conditions * obesity study reported in 2016	* 19 and under	Yes	Yes
[C5] CMHA Fast Facts about Mental Illness (2013)	* 12 -19, 15-24	Yes	partial
[C10]. StatCan Overweight and obesity in children and adolescents: results from the 2009 to 2011 Canadian Health Measures Survey	* age 5 – 11, 12 - 17	Yes	Yes

c. Surveillance Capability

REPORTED OPINIONS OF CAPABILITY

“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]

SUMMARY ASSESSMENT

- National as well as provincial processes exist for surveillance of overweight/obesity, diabetes and mental illness in ‘youth’ but with differing details and frequency.
- Canada has many national surveillance systems but the studies are done with varying or cyclical frequency, tend to report aggregate summaries and most reflect somewhat untimely data.
- Generally, available national surveillance data are published within 12 months of reports being completed irrespective of data age.

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NCD ‘TARGETS’ - SURVEILLANCE CAPABILITY AND RELATED (AS REPORTED BY WHO)

2014 WHO NCD Country Profiles	AUS
1. Has an operational policy, strategy or action plan to reduce unhealthy diet and/or promote healthy diets	Yes
2. Has evidence-based national guidelines, protocols, standards for the management of major NCDs through a primary care approach	Yes
3. Has an NCD surveillance and monitoring system in place to enable reporting against the nine global NCD targets (adults 18+)	No

d. Selected national studies – additional details

NATIONAL SYSTEMS

Canadian Chronic Disease Surveillance System (CCDSS) [C2]

The CCDSS is a collaborative network of provincial and territorial chronic disease surveillance systems, supported by the Public Health Agency of Canada. It identifies chronic disease cases from provincial and territorial administrative health databases, including physician billing claims and hospital discharge abstract records, linked to provincial and territorial health insurance registry. Data on all residents who are eligible for provincial or territorial health insurance (about 97% of the Canadian population) are captured in the health insurance registry; thus, the CCDSS coverage is near-universal. Case definitions are applied to these linked databases and data are then aggregated at the provincial and territorial level before being submitted to the Public Health Agency of Canada for reporting at the provincial, territorial and national levels.

The CCDSS summarizes data on residents of Canada who have accessed the Canadian health care system. Agencies such as StatCan and PHAC use the CCDSS as a data source for compiling various reports. Age ranges reported depend on disease/condition and the frequency of reporting is undefined, periodic.

Canadian Health Measures Survey (CHMS) [C15]

The Canadian Health Measures Survey (CHMS) is a national survey that is led by Statistics Canada, in partnership with Health Canada and the Public Health Agency of Canada, which collects information from Canadians about their general health. The CHMS is the most comprehensive, direct health measures survey conducted in Canada and is designed to represent the Canadian population. Through personal interviews and the collection of physical measurements, the survey provides baseline data on indicators of environmental exposures, chronic diseases, infectious diseases, fitness, and nutritional status, as well as risk factors and protective characteristics related to these areas. The physical measurements include such factors as height and weight, blood pressure, physical fitness and lung function measures, as well as many measures based on blood and urine samples including environmental chemicals.

Canadian Community Health Survey – (CCHS) [C8]

The CCHS collects information on health status, health care use and determinants of health. This is a sample survey with a cross-sectional design intended to provide reliable estimates at the regional level. In 2007, changes were made to the survey design to improve its effectiveness and flexibility. Since then, data collection occurs every year rather than every two years as was the case prior to 2007.

The CCHS contacts 120,000 households per year to cover the population aged 18 and over and 10,000 respondents to cover the population aged 12 to 17 years. It can be a valuable source for studying rare characteristics in detail such as obese diabetic youth with mental illness. Participation is voluntary. The CCHS releases all data collected in the previous calendar year within 6 months from the end of collection, usually mid-June.

Canadian Primary Care Sentinel Surveillance Network (CPCSSN) [C20]

CPCSSN has a primary care electronic medical record data base which includes de-identified health data on about 1.5 million Canadians. Children and adolescents (< 18 yr) represent about 25% of the patients in the database. CPCSSN has validated case definitions for the chronic diseases of interest for this study.

Canadian Paediatric Surveillance Program (CPSP) [C16]

The Canadian Paediatric Surveillance Program (CPSP), a joint project of the Public Health Agency of Canada and the Canadian Paediatric Society, contributes to the improvement of the health of children and youth in Canada by national surveillance and research into childhood disorders that are high in disability, morbidity and economic costs to society, despite their low frequency. The CPSP gathers data from over 2,500 paediatricians and paediatric subspecialists each month to monitor rare diseases and conditions in Canadian children.

Canadian Health Survey on Children and Youth (CHSCY) [C12]

Canadian Health Survey on Children and Youth (CHSCY). A successful pilot test of the CHSCY was conducted in fall 2016 and the first cycle of CHSCY data will be collected in late 2018. The CHSCY will include all children and youth age 1-17 living in the provinces and territories and includes self-reported diagnoses of diabetes, height, weight and more details on possible mental health conditions. The sample size will be 50,000.

Diabetes

Canadian Chronic Disease Surveillance System (CCDSS) [C2]

- This system presents Canadian national data available about people with diabetes and those at risk of developing type 2 diabetes, including data that describe the disparities in the burden of disease and access to supports as related to social determinants of health. Priorities of the report include: prevention of diabetes and its complications in Aboriginal communities, reducing the stigma related to diabetes, support for improved diabetes foot care and support for children with diabetes in school.
- The last report from CCDSS containing age stratified data on diabetes prevalence was published in 2011.

Canadian Community Health Survey (2014). Statistics Canada. [C8]

- The most recent surveillance report dealing with diabetes prevalence in youth age 12 and over.
- Study asked survey respondents aged 12 and over to report if they had been diagnosed with Diabetes by a health professional. Rates included type 1, type 2 and gestational diabetes but these distinctions were

not reported. Aggregate gender breakout by broad age groups is included with trend analysis over the period of 2001 to 2014.

- As at 2014, for Canadians aged 12 or older 6.7% or 2 million people reported that they had diabetes. This rate was not higher than for 2013, but was an increase from the rates between 2001/09 to 2011 combined.
- Males and females had almost the same rates for diabetes prevalence up to the age of 44 years of age. Overall, males had higher rates of diabetes for all age ranges except for the range of 12-34 years of age.

The most recent surveillance report dealing with diabetes incidence in youth is a 2008 report from the Canadian Paediatric Surveillance Program (CPSP) focused on Type 2 incidence in youth. [C18]. That study is currently being repeated by a Canadian research team led by Shazhan Amed (UBC) and is expected to complete in 2018. [C7]

2015 Report on Diabetes – Driving Change: Canadian Diabetes Association [C2]

- This is not a surveillance study but draws heavily on existing surveillance studies reflecting data from 1999 to 2014. As such, the summaries included provide a helpful ‘roadmap’ to understanding the many surveillance systems and their relationships, specifically;
- Canadian Chronic Disease Surveillance System 1999/2000 to 2010/11
- Canadian Community Health Survey (2007 and 2014)
- Canadian Health Measures Survey 2012/13
- Aboriginal Peoples Survey 2012
- First Nations Regional Health Survey 2008/2010
- Survey on Living with Chronic Disease in Canada diabetes component 2011

Obesity

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

* The most recent report on overweight/obesity prevalence in children/youth less than 20 years of age used electronic medical records for the period 2004-2013 and included 8,261 children and was published in 2016. Sample size was close to 4 times larger than the national survey sample.

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SURVEILLANCE LANDSCAPE - Canada CONTINUED

* In 2013, 28.4% of children aged 5-19 years, and 6% of children aged 0-5 years, were categorized as overweight or obese. Between 2008 and 2013, the total number of 18-month well baby visit billing codes was 1152; 6.9% of this group were categorized as overweight or obese; 19.2% were categorized as having risk of overweight.

Canadian Community Health Survey (CCHS) – Nutrition, 2014 and 2015, StatCan Table 105-2024, July 31, 2017 [C11]

- Reports on BMI for children and adolescents with gender breakdown for ages 5 to 17 years using WHO BMI classification.
- Total obese prevalence 12.5%; males 14.5% and females 9.5%

Mental Illness

Fast Facts about Mental Illness (2013)

CMHA [C5]

- This report describes the prevalence of mental disorders among 15 -24, 12 -19, 16-30 and 25-44 years old in 2013 The data describe main disorder categories, i.e., major depressive episode, suicide, schizophrenia, anxiety disorders and mortality outcomes.
- Prevalence estimates 10-20% of Canadian youth are affected by a mental illness or disorder, where 3.2 million, 12-19 year old are at risk for developing depression.
- 5% of males and 12 % of female youths aged 12-19 have experienced a major depressive episode
- In 2013 suicide accounted for 24% of all deaths among 15-24 year old, suicide is the leading cause of death in both men and women from adolescence to middle age .
- 1 out of 5 children who need mental health services receives them

Complications and Comorbidities

Surveillance data regarding diabetes-related complications can be found embedded in main diabetes studies as can data for some comorbidities. Surveillance studies with a primary focus on these perspectives could not be found.

INDIGENOUS POPULATIONS.

Aboriginal Peoples Survey [C19]

- The Aboriginal Peoples Survey (APS) is a national survey conducted by Statistics Canada and administered every 5 years. The survey collects data from First Nations people living off-reserve, Métis

and Inuit aged 6 years and older. the 2017 Survey is in progress.

First Nations Regional Health Survey [C13]

- The First Nations Regional Health Survey16 is the only First Nations-governed cross-sectional national health survey of First Nations living on-reserve and in northern First Nations communities in Canada; so far, two phases have been conducted, in 2002/2003 and 2008/2010. The survey collects detailed data on the health and well being of First Nations adults (18 years +), youth aged 12-17 and children under the age of 12 on the health and well-being of First Nations adults (aged 18 years and older) who live on-reserve and are Registered Indians or recognized by their band as members of their community. Fact sheets are provided on a wide range of diseases/ conditions including diabetes.

e. References related to Canada – by disease/condition category

DIABETES

- C1 *Diabetes in Canada: Facts and figures from a public health perspective (Chap 5)*, PHAC, Dec 15, 2011, <http://www.phac-aspc.gc.ca/cd-mc/publications/diabetes-diabete/facts-figures-faits-chiffres-2011/chap5-eng.php>, retrieved, May 15/16
- C2 *DC 2015 Report on Diabetes – Driving Change:* Toronto, ON: Canadian Diabetes Association; 2015 <http://www.diabetes.ca/getmedia/5a7070f0-77ad-41ad-9e95-ec1bc56ebf85/2015-report-on-diabetes-driving-change-english.pdf.aspx>, retrieved August 24/17
- C7 *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), Amed, S et al., <http://www.cpsp.cps.ca/uploads/studies/Non-type-1-diabetes-protocol.pdf> retrieved August 24/17
- C18 *Type 2 Diabetes, Medication-Induced Diabetes, and Monogenic Diabetes in Canadian Children*, Amed. S. et al, Diabetes Care, Vol 33, No. 4, April 2010. http://www.academia.edu/20225763/Type_2_Diabetes_Medication-Induced_Diabetes_and_Monogenic_Diabetes_in_Canadian_Children_A_prospective_national_surveillance_study, accessed Aug 27, 2017

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SURVEILLANCE LANDSCAPE - Canada CONTINUED

OBESEITY

- C10 Overweight and obesity in children and adolescents: results from the 2009 to 2011 Canadian Health Measures Survey, Roberts, K.C, et al, StatCan, August 2012 http://www.statcan.gc.ca/access_acces/alternative_alternatif.action?l=eng&loc=11706-eng.pdf, retrieved July 29/17
- C11 *Canadian Community Health Survey (CCHS) – Nutrition , 2014 and 2015*, StatCan Table 105-2024, July 31, 2017, <http://www5.statcan.gc.ca/cansim/>
- C17 *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. DOI:10.9778/cmajo.20150108, <http://cmajopen.ca/content/4/3/E538.full>, accessed Aug 27, 2017

MENTAL ILLNESS

- C3 *Report from the Canadian Chronic Diseases Surveillance System: Mental Illness in Canada, 2015*. Public Health Agency of Canada <http://healthycanadians.gc.ca/publications/diseases-conditions-maladies-affections/mental-illness-2015-maladies-mentales/index-eng.php>, retrieved, Mar 11/16
- C4 *Changing Directions, Changing Lives: The Mental Health Strategy for Canada*, Mental Health Commission of Canada 2013, <http://www.mentalhealthcommission.ca/English/node/721>, retrieved Feb 20/16
- C5 *Fast Facts about Mental Illness*, Canadian Mental Health Association, <http://www.cmha.ca/media/fast-facts-about-mental-illness/#.VuXOnMenPHg>, retrieved Feb 20/16
- C6 *Child and youth mental disorders: Prevalence and evidence-based interventions*. Waddell C, Shepherd CA, Schwartz C, Barican J. Vancouver, BC: Children’s Health Policy Centre, Simon Fraser University; 2014. <http://childhealthpolicy.ca/wp-content/uploads/2014/06/14-06-17-Waddell-Report-2014.06.16.pdf> retrieved Mar 19/16
- C14 *Taking the Next Step Forward: Building a responsive mental health and addictions system for emerging adults*, Mental Health Commission of Canada, 2015. <https://www.mentalhealthcommission.ca/English/document/76936/taking-next-step-forward>, accessed Aug 27, 2017

MULTIPLE DISEASES/CONDITIONS

- C8 *Canadian Community Health Survey (2014)*. Statistics Canada. <http://www.statcan.gc.ca/daily-quotidien/150617/dq150617b-eng.pdf> retrieved August 24/17
- C9 *Canadian Health Measures Survey 2012-2013*. Statistics Canada <http://www.statcan.gc.ca/daily-quotidien/141029/dq141029c-eng.htm> retrieved August 24/17
- C12 *Canadian Health Survey on Children and Youth (CHSCY)*, Statistics Canada, 2016 <http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=5233>, accessed, Aug 17, 2017
- C15 Canadian Health Measures Survey (CHMS) <https://www.canada.ca/en/health-canada/services/environmental-workplace-health/environmental-contaminants/human-biomonitoring-environmental-chemicals/canadian-health-measures-survey.html>, accessed Aug 27, 2017
- C16 Canadian Paediatric Surveillance Program (CPSP) <http://www.cpsp.cps.ca/about-apropos>, accessed Aug 27, 2017
- C20 Canadian Primary Care Sentinel Surveillance Network (CPCSSN) <http://cpcssn.ca>, accessed, Aug 27, 2017

INDIGENOUS SURVEILLANCE

- C13 *National Report on Adults, Youth and Children Living in First Nations Communities*. Regional Health Survey (RHS) Phase 2 (2008/10) Ottawa: The First Nations Information Governance Centre, June 2012. http://fnigc.ca/sites/default/files/docs/first_nations_regional_health_survey_rhs_2008-10_-_national_report.pdf.avut, retrieved August 21, 2017
- C19 Aboriginal Peoples Survey, StatCan <https://www.aadnc-aandc.gc.ca/eng/1321384019753/1322059098232>, accessed Aug 27, 2017

GENERAL

- GE4 *The World FactBook (2017)*: Central Intelligence Agency [CIA] <https://www.cia.gov/library/publications/the-world-factbook/geos/xx.html>, Retrieved Aug 7/17

Surveillance Landscape
UNITED KINGDOM (England & Wales)

a. ‘Youth’ Population

Population	Males	Females	Total
Total [GE4]			64,430,428
Children age 0 - 14	5,761,311	5,476,649	11,237,960
Adolescents/young adults age 15 - 24	3,997,150	3,830,268	7,827,418
SFBLF estimate of adolescents 15 - 19	2,000,000	1,900,000	3,900,000
SFBLF estimate of youth (0 -19)	7,800,000	7,400,000	15,200,000

b. Selected Surveillance Data
(England & Wales only)

Diabetes prevalence - adults 20 – 79 [IDF]	6.2%
Obesity prevalence – adults 20+ [WHO]	26.9%
Mental illness prevalence – depressive 15 – 80+ [WHO]	4.5%
Mental illness prevalence – anxiety 15 – 80+ [WHO]	4.2%
Diabetes prevalence – youth – 24 and under [NPDA]	28,439
Obesity prevalence – youth – 2 -15 [KCL]	26.0% - 37.8%
Mental illness prevalence – youth 5 – 16 [ONS]	10%

Note: estimates made by IDF and WHO do not necessarily match those made by national surveillance systems within a country

c. Surveillance Capability

REPORTED OPINIONS OF CAPABILITY

“Paediatric diabetes care in England and Wales has improved dramatically but still lags behind some of our European counterparts... There is more work to be done” [UK7]

“Contributing to proof-of-concept for use of primary care electronic health records to evaluate children’s obesity suggests these may provide a valuable resource for monitoring obesity trends” [UK12]

SUMMARY ASSESSMENT

Surveillance data for youth are not reported uniformly across the UK geographic areas of England, Wales, Scotland and N. Ireland but in various combinations, e.g, England only, England and Wales only, Scotland only, etc.

Consequently, this summary focuses on England and Wales.

- National as well as regional processes exist for surveillance of overweight/obesity, diabetes and mental illness in ‘youth’ but with different scope and frequency.
- Surveillance for each of diabetes and obesity is much stronger and more timely than for mental illness.
- Significant differences in the criteria used to collect the data across regions and compared to national systems.
- Inconsistent use of age ranges and inclusion of gender distinctions within and across disease/condition surveillance studies.
- Generally, available national surveillance data are published within 12 months of reports being completed. However, the last available national study on the prevalence of mental illness in children and youth was published in 2004.
- National registries for diabetes, obesity and mental illness could not be found.

KEY NATIONAL SURVEILLANCE ORGANIZATIONS

1. RCPCH – Royal College of Paediatrics and Child Health
2. PHE – Public Health England
3. NHS Digital – National Health Service
4. KCL - King’s College London, Dept of Primary Care and PHS
5. ONS – Office of National Statistics
6. DUK – Diabetes UK
7. NICE – National Institute for Health and Care Excellence

CONTINUED

SURVEILLANCE LANDSCAPE - United Kingdom (England & Wales only) CONTINUED

KEY NATIONAL SURVEILLANCE SYSTEMS/ PROCESS REVIEWED [PRIMARY FOCUS]

- National Paediatric Diabetes Audit (NPDA) – [diabetes, diabetes complications, diabetes comorbidities with obesity and mental illness]
- Diabetes Prevalence Model (DPM) – [diabetes]
- National Child Measurement Programme (NCMP) – [obesity]
- Mental Health of Children and Young People in Great Britain – [mental health]
- National Institute for Health and Care Excellence (NICE) – [performance and standards]

Qualifying Notes:

- i. Reports from the systems listed above may be enhanced by data extracted from other supporting systems.
- ii. National systems exist for surveillance of other diseases/conditions and/or general health indicators.
- iii. Supporting surveillance systems exist at the regional level and these were not considered in this study.

SELECTED SYSTEMS/PROCESSES - KEY CHARACTERISTICS

Recent Report	Age Range	Gender	Type
[UK7] National Paediatric Diabetes Audit 2015 – 2016 (pub Feb 2017) [England & Wales] RCPCH * annual study * incidence and prevalence * includes complications, mental illness, obesity * includes benchmarking and recommendations for surveillance improvement	* 24 and under * 0-4, 5-9, 10-14, 15-19, 20-24	Yes	Yes
[UK11] Diabetes Prevalence Model (2016) PHE * mathematical model * England only	* 16 and above * 7 age groupings	Yes	Yes
[UK12] Childhood Obesity trends 1994 – 2013 (pub Jan 2015), KCL * investigated EMR as a surveillance source * 370,544 children and 507,483 BMI records	* 2 to 15 * 2-5, 6-10, 11-15	Yes	No
[UK15] National Child Measurement Programme England 2015/16 (NHS Digital, 2016) & Child Measurement Programme Wales 2014/15 * annual study * measures abnormal weight and obesity for school ‘entering’ cohort (ages 4-5) and year 6 (ages 10-11)	* 4 to 5 both countries * 10 – 11 England	Yes	uw, ow, obese
[UK14] Mental health of children and young people in Great Britain, 2004, ONS (pub 2005) * reports main disorder categories * Data age (2004 c/w 1999) makes it unlikely the reported results remain relevant	* 5 to 16	Yes	partial

CONTINUED

SURVEILLANCE LANDSCAPE - United Kingdom (England & Wales only) CONTINUED

NCD ‘TARGETS’ - SURVEILLANCE CAPABILITY AND RELATED (AS REPORTED BY WHO)

2014 WHO NCD Country Profiles	UK
1. Has an operational policy, strategy or action plan to reduce unhealthy diet and/or promote healthy diets	Yes
2. Has evidence-based national guidelines, protocols, standards for the management of major NCDs through a primary care approach	Yes
3. Has an NCD surveillance and monitoring system in place to enable reporting against the nine global NCD targets (adults 18+)	No

d. Selected national studies – additional details

DIABETES

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

- The primary source for national diabetes surveillance data for children and youth is the Royal College of Paediatrics and Child Health (RCPCH) who 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 data are reported with 5 year age range increments and gender distinctions.
- 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.

- 2015/16 Audit - ages 0 to 24; 28,439 children and young people living with diabetes; an increase of 757 from 2014/15

Diabetes Prevalence Model (September 2016), PHE, [UK11]

- This model provides estimates of total (diagnosed and undiagnosed) diabetes prevalence for people aged 16 years and over in England but does not identify diabetes type.
- The most recently published data released in 2016 estimates that “3.8 million people in England aged over 16 had diabetes in 2015 (diagnosed and undiagnosed). This is equal to 8.6% of the population of this age group.”.
- Diabetes prevalence is higher in men than in women, 9.6% vs 7.6%.
- Findings of the model suggest that 1 in 4 people with diabetes, an estimated 940,000, are unaware of their condition.

OBESITY

National Child Measurement Programme, England 2015/16 school year, Nov 3, 2016, NHS Digital [UK15]

- The National Child Measurement Programme (NCMP) annually measures over one million children and now holds ten years of reliable data. The Programme collects height and weight measurements for children entering the school system (aged 4 to 5 years) and those in year 6 (aged 10 -11 years) primarily in state maintained schools in England. A similar programme is implemented for Wales but ages 4 to 5 years only.
- The report includes BMI rates with breakdowns by child age and sex as well as other distinctions, for example, underweight, overweight and obese and breakouts by ethnicity, region and deprivation gap but not for ‘combinations’ such as diabetes and obesity or obesity and mental illness.
- Obesity prevalence was more than twice as high in year 6 (19.8%) vs the entering year (9.3%)
- Over one fifth of entering children were overweight or obese. In year 6, it was over one third.

SURVEILLANCE LANDSCAPE - United Kingdom (England & Wales only) CONTINUED

- Prevalence of obesity in boys entering (13.1%) and in year 6 (21.7%) was greater than for girls in both cases (12.6% and 17.9% respectively).
- The prevalence of obesity has increased for both the entering cohort and the year 6 cohort since the 2014/15 study.

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 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.
- The study concluded that more than a third of UK children are overweight or obese, but the prevalence may have stabilized between 2004 and 2013 [the second decade of the data].
- In the older age group (11 – 15 years), the upward trend was still evident, highlighting the need for interventions to focus on this age group.

MENTAL ILLNESS

Mental health of children and young people in Great Britain, 2004, ONS, 2005 [UK14]

- Describes the prevalence of mental disorders among 5-16 year olds in 2004 and notes changes from the 1999 survey. The data describe main disorder categories, i.e., emotional, conduct, hyperkinetic and autism spectrum disorders (and some subgroups where sample size permits).
- In 2004, one in ten children and young people (10 per cent) aged 5-16 had a clinically diagnosed mental disorder: 4% emotional disorder (anxiety or depression), 6% conduct disorder, 2% hyperkinetic disorder, and 1% a less common disorder (autism, tics, eating disorder). Some children (2%) had more than one type of disorder.
- There were no changes between 1999 and 2004 in the overall proportions of children with a mental disorder other than a modest decline from 3% to 2% in boys aged 5-10 who had an emotional disorder.
- Given the age of this study, it is highly unlikely that the data remain representative of the current reality.

Mental Health advocates

Despite the absence of current data, there are charitable

organizations in the UK that advocate on behalf of young people living with mental health issues and publish relevant statistics; e.g., Young Minds [UK18], the Mental Health Foundation [UK17] and the Centre for Mental Health [UK16].

The Guardian newspaper published an opinion item as part of their 2014 Christmas charity appeal summarizing the “state of mental health among young people” in the UK and supporting the view of the Chief Medical Officer’s annual report advocating the need for more up-to-date, comprehensive national statistics. [UK13]

COMPLICATIONS AND COMORBIDITIES

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

- As noted above, the NPDA also reports on diabetes-related complications and comorbidities for obesity and mental illness.
- Diabetes-related complications, for which detailed surveillance data are provided for each of T1DM and T2DM, include cardiovascular disease, eye disease, kidney disease, thyroid and coeliac disease
- For mental illness comorbidity, 30% of T1DM and 33.8% of T2DM cases required referral to expert psychology services.
- For obesity comorbidity, the prevalence of overweight or obesity in T1DM cases for ages 4-5 was 33.7% and hence higher than the 22.1% reported in the NCMP study and for ages 10-11 was also 33.7% but lower than the 34.1% NCMP result.
- For T2DM cases, comorbid overweight was 7.3% and obese 78.5%

INDIGENOUS POPULATIONS

There are no ‘indigenous’ populations in the UK similar to populations such as First Nations (Canada), Aboriginal (Australia), American Indians (United States) for which abnormal prevalence or incidence of diabetes has been reported.

e. References related to United Kingdom – by category

DIABETES

UK1 Diabetes Burnout, Diabetes UK, <http://www.diabetes.co.uk/emotions/diabetes-burnout.html>, retrieved Feb 14/16

SURVEILLANCE LANDSCAPE - United Kingdom (England & Wales only) CONTINUED

UK2 *From the pond into the sea: Children’s transition to adult health services*, June 2014, Care Quality Commission, Citygate, Gallowgate, UK, https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report.pdf, retrieved Mar 30/16

UK3 *Time to question the NHS diabetes prevention programme*: The BMJ, 19 September 2015 <http://www.bmj.com/bmj/section.pdf/905402?path=/bmj/351/8025/Editorials.full.pdf> , accessed July 27, 2017

UK4 *Know Diabetes. Fight Diabetes*, Diabetes UK (2014) <https://www.diabetes.org.uk/> retrieved: May 26/2017

UK5 Public Health England (2016) <http://www.gov.uk/government/organisations/public-health-england>, retrieved July 17, 2017

UK6 *Diabetes UK Position Statement 2015 (2016)*, [https://www.diabetes.org.uk/Documents/About%20Us/What%20we%20say/Position%20Statement%20-%20Early%20identification%20of%20people%20with%20Type%20%20diabetes%20\(Nov%202015\).pdf](https://www.diabetes.org.uk/Documents/About%20Us/What%20we%20say/Position%20Statement%20-%20Early%20identification%20of%20people%20with%20Type%20%20diabetes%20(Nov%202015).pdf) retrieved August 24, 2017

UK7 *National Paediatric Diabetes Audit 2015 – 2016 Report 1: Care Processes and Outcomes*, February 2017, http://www.rcpch.ac.uk/system/files/protected/page/Complete%20NPDA%202015-16%20report%20FINAL_0.pdf, retrieved July 17, 2017

UK8 National Children & Young People’s Diabetes Network, <http://www.cypdiabetesnetwork.nhs.uk>, retrieved August 24, 2017

UK9 National Institute for Health and Care Excellence, <https://www.nice.org.uk>, retrieved August 24, 2017

UK10 *Diabetes Prevalence 2016* (November), Diabetes UK, <https://www.diabetes.org.uk/Professionals/Position-statements-reports/Statistics/Diabetes-prevalence-2016/>, retrieved July 18, 2017

UK11 *Diabetes Prevalence Model (September 2016)*, PHE, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/612306/Diabetesprevalencemodelbriefing.pdf, retrieved July 18, 2017

OBESITY

UK12 *Childhood Obesity trends .. 1994 – 2013*, Cornelia H M van Jaarsveld, Martin C. Gulliford, Arch Dis Child 2015;100:214-219. doi:10.1136/archdischild-2014-307151, <http://adc.bmj.com/content/archdischild/100/3/214.full.pdf>, retrieved July 18, 2017

UK15 *National Child Measurement Programme, England 2015/16 school year*, Nov 3, 2016, NHS Digital, <http://www.content.digital.nhs.uk/catalogue/PUB22269/nati-chil-meas-prog-eng-2015-2016-rep.pdf>, retrieved July 19, 2017.

MENTAL HEALTH

UK13 *What is the state of children’s mental health today?*, The Guardian, 2014, <https://www.theguardian.com/society/christmas-charity-appeal-2014-blog/2015/jan/05/-sp-state-children-young-people-mental-health-today>, retrieved July 18, 2017

UK14 *Mental health of children and young people in Great Britain*, 2004, ONS, 2005, <http://content.digital.nhs.uk/catalogue/PUB06116/ment-heal-chil-youn-peop-gb-2004-rep1.pdf>, retrieved July 19, 2017

UK16 Centre for Mental Health, <https://www.centreformentalhealth.org.uk/about-us>, retrieved August 24, 2017

UK17 Mental Health Foundation, <https://www.mentalhealth.org.uk/publications/surviving-or-thriving-state-uks-mental-health>, retrieved August 24, 2017

UK18 Young Minds, <https://youngminds.org.uk>, retrieved August 24, 2017

GENERAL

GE4 *The World FactBook (2017)*: Central Intelligence Agency [CIA] <https://www.cia.gov/library/publications/the-world-factbook/geos/xx.html>, Retrieved Aug 7/17

Surveillance Landscape - UNITED STATES

a. ‘Youth’ Population

Population	Males	Females	Total
Total [GE4]			326,709,838
Children age 0 - 14	31,182,660	29,854,687	61,037,347
Adolescents/young adults age 15 - 24	22,360,342	21,252,215	43,612,557
SFBLF estimate of adolescents 15 - 19	11,200,000	10,100,000	21,300, 000
SFBLF estimate of youth (0 -19)	43,400,000	40,000,000	83,400,000

b. Selected Surveillance Data

Diabetes prevalence - adults 20 – 79 [IDF]	12.8%
Obesity prevalence – adults 20+ [WHO]	33.0%
Mental illness prevalence – depressive 15 – 80+ [WHO]	5.9%
Mental illness prevalence – anxiety 15 – 80+ [WHO]	6.3%
Diabetes prevalence – youth – 24 and under [NPDA]	increasing
Obesity prevalence – youth – 2 -15 [KCL]	17%
Mental illness prevalence – youth 5 – 16 [ONS]	13% - 20%

Note: estimates made by IDF and WHO do not necessarily match those made by national surveillance systems within a country

c. Surveillance Capability

REPORTED OPINIONS OF CAPABILITY

“Despite concern about an “epidemic,” there are limited data on trends in prevalence of either type 1 or type 2 diabetes across US race and ethnic groups”. [us8]

“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]

“Research addressing the prevention of obesity and T2DM among youth is urgently needed” [us12]

SUMMARY ASSESSMENT

- National processes exist but are widely variable in approach, content and frequency across disease/ conditions.
- There are many government and related collaborative organizations involved with surveillance and it can be

difficult to interpret which organization or study is the source organization for several aspects of reported surveillance data, especially, for data relating to surveillance of indigenous populations.

- Significant differences in the criteria used to collect data for each disease/condition.
- Age ranges and gender distinctions within and across disease/condition as reported are inconsistent.
- Data ‘age’ is highly variable; results of major studies are published within 18 months to 3 years of study completion irrespective of the age of the sampled data.
- National registries for diabetes, obesity or mental illness in youth are not evident.
- Reports for the general public are provided by originating organizations and by disease-specific advocacy groups.; often including helpful ‘infographics’

KEY NATIONAL SURVEILLANCE ORGANIZATIONS

1. CDC – Centres for Disease Control and Prevention
2. NIDDK – National Institute of Diabetes and Digestive and Kidney Diseases
3. NIMH – National Institute of Mental Health
4. ADA – American Diabetes Association

KEY NATIONAL SURVEILLANCE SYSTEMS/ PROCESS REVIEWED [PRIMARY FOCUS]

- SEARCH Project – [diabetes, complications and comorbidities]
- National Diabetes Statistics Report [diabetes]
- National Health and Nutrition Examination Survey (NHANES) – [obesity]

SURVEILLANCE LANDSCAPE - United States CONTINUED

- Mental Health Surveillance Among Children – US – [mental illness]
 - National Health Interview Survey (NHIS) – [multiple diseases/conditions]

United States Indigenous

 - Special Diabetes Program for Indians (SDPI) [diabetes]
 - American Community Survey US Bureau of the Census [multiple diseases/conditions]
 - Racial and Ethnic Approaches to Community Health (REACH) [general]
- National Health Status Report (NHS) Alaska Native Tribal Health Consortium [multiple]

Qualifying Notes:

 - i. Reports from the systems listed above may be enhanced by data extracted from other supporting systems.
 - ii. National systems exist for surveillance of other diseases/conditions and/or general health indicators.
 - iii. Supporting surveillance systems exist at the state, territory level and these were not considered in this study.

SELECTED SYSTEMS/PROCESSES - KEY CHARACTERISTICS

Recent Report	Age Range	Gender	Type
[US8], [US14] SEARCH project (2014, 2017) * includes consideration of complications and comorbidities * ‘representative’ samples from 20,000 * continuing with periodic reports	T1DM 0 –19 T2DM 15-19	Yes	Yes
[US1] National Diabetes Statistics Report 2017 * Centre for Disease Control and Prevention* multiple data sources * periodic reports	18 years and older; some data for under age 18 derived from SEARCH	Yes	No
[US5] Mental Health Surveillance Among Children – US, 2005-2011, (May 2013) * Centre for Disease Control and Prevention * first national study for US children aged 3 -17 and based on data from 2005 – 2011	3–17 12–17	Yes	Yes
[US11] National Health and Nutrition Examination Survey (NHANES) (June 2016) [obesity] * samples ‘grouped’ counties	2-5 6-11	Yes	Yes
* combines interviews and physical examinations * reports every 2 years	12-19		

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SURVEILLANCE LANDSCAPE - United States CONTINUED

NCD ‘TARGETS’ - SURVEILLANCE CAPABILITY AND RELATED (AS REPORTED BY WHO)

2014 WHO NCD Country Profiles	USA
1. Has an operational policy, strategy or action plan to reduce unhealthy diet and/or promote healthy diets	Yes
2. Has evidence-based national guidelines, protocols, standards for the management of major NCDs through a primary care approach	Yes
3. Has an NCD surveillance and monitoring system in place to enable reporting against the nine global NCD targets (adults 18+)	Yes

d. Selected national studies – additional details

DIABETES

National, population based data for the prevalence of diabetes in youth under age 20, in aggregate or stratified by selected demographics or combinations, are generated from a representative sample defined and administered in the context of the SEARCH project.

These data, in turn, are cited in the National Diabetes Statistics Report, a periodic report published by CDC that focuses primarily on the US population age 18+. The United States Diabetes Surveillance System (USDSS), operated by the CDC Division of Diabetes Translation, includes data on adults only (18 years plus).

SEARCH for Diabetes in Youth is a national multi-center study aimed at understanding more about diabetes among children and young adults in the United States. SEARCH was launched in 2000 and will continue at least through 2020. There are more than 20,000 study participants. [US10]

National Diabetes Statistics Report 2017: Centre for Disease Control and Prevention [US1]

- The National Diabetes Statistics Report is a periodic publication of the CDC and includes information on prevalence and incidence of diabetes, prediabetes, risk factors for complications, acute and long-term complications, deaths and costs. It focuses primarily on adults age 18+.
- The most recent report, published in 2017, is based on a wide array of data sources including CDC,

the Indian Health Service (IHS), the Agency for Healthcare Research and Quality (AHRQ), the U.S. Census bureau and many published studies. Most estimates in the report do not differentiate between T1DM and T2DM but the report states, “since T2DM accounts for 90% to 95% of all diabetes cases, the data presented are likely to be more characteristic of T2DM”.

Prevalence of Type 1 and Type 2 Diabetes Among Children and Adolescents From 2001 to 2009, Dabelea, Dana, et al JAMA. 2014;311(17) pp 1778-1786 (pub 2014) [US8]

- A SEARCH study published in 2014 estimated changes in the prevalence of type 1 and type 2 diabetes in US youth by sex, age, and race/ethnicity between 2001 and 2009. The total population base for each of the 2001 and 2009 data points was just over 3.3 million youth in 4 geographic areas and 1 managed health care plan. Age ranges considered were 0-19 for T1DM and 10-19 for T2DM.
- The study reported that during the 2001 to 2009 period, in 5 areas of the United States, T1DM in youth age 0-19 increased by 21.1% and for T2DM in youth age 10-19 by 30.5% but that, “further studies are required to determine why”.
- The report also stated, “Despite concern about an “epidemic,” there are limited data on trends in prevalence of either type 1 or type 2 diabetes across US race and ethnic groups”.

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, 2017DOI: 10.1056/NEJMoa161018 [US14]

- The 2014 SEARCH study was updated to cover the period 2002 – 2012 and reported in April 2017. It concluded that incidence of both T1DM and T2DM continues to increase, particularly among youths of minority racial and ethnic groups.
- After adjustment for age, sex, and race or ethnic group, the relative annual increase in the incidence of type 1 diabetes was 1.8% (0-19) and that of type 2 diabetes was 4.8% (10–19).
- This study identified that type 2 incidence increased significantly in all racial and ethnic groups except non-Hispanic whites. In the earlier SEARCH study (2

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SURVEILLANCE LANDSCAPE - United States CONTINUED

data points), an increase in prevalence was not seen among Asian or Pacific Islander youths or among Native American youths. 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.

OBESITY

Trends in Obesity Prevalence Among Children and Adolescents in the United States, 1988-1994 Through 2013-2014. Ogden, C.L., et al, JAMA, 2016. 315(21): p. 2292-2299 [US11]

- The most recent published study (June, 2016), based on data from the 2013-2014 National Health and Nutrition Examination Survey (NHANES) provides prevalence % for children/youth 2 to 19 years. There were a total of 6,878 participants in the study. It includes breakouts by male, female and race/ethnic groups.
- The study concludes, “In this nationally representative study of US children and adolescents aged 2 to 19 years, the prevalence of obesity in 2011-2014 was 17% and extreme obesity was 5.8%. Between 1988-1994 and 2013-2014, the prevalence of obesity increased until 2003-2004 and then decreased in children age 2 to 5 years, increased until 2007-2008 and then levelled off in children aged 6 to 11 years, and increased among adolescents aged 12 to 19 years.” The NHANES is released every 2 years.

MENTAL ILLNESS

Mental Health Surveillance Among Children – US, 2005-2011, CDC (May 16/13) [US5]

- This first national study for US children aged 3 -17 is based on data from 2005 – 2011, provides prevalence % for children/youth 3-17 and 12-17 and includes breakouts for a selected list of mental disorders with varying age stratifications and with incidence data for some. Report estimates that 13% - 20% of children living in the US experience a mental disorder in a given year.
- Prevalence data are difficult to interpret or compare because of comorbidities, distinctions between ‘common’ mental disorders and ‘seriously debilitating mental illness’ and the use of different age ranges, for example.
- The study cited above includes identification of many deficiencies in existing surveillance data collection systems and concludes that, “More comprehensive

surveillance is needed to develop a public health approach that will both help prevent mental disorders and promote mental health among children”. No plans for future studies are identified.

COMPLICATIONS AND COMORBIDITIES

Association of Type 1 Diabetes vs Type 2 Diabetes Diagnosed During Childhood and Adolescence With Complications During Teenage Years and Young Adulthood, Dabelea, Dana et al, JAMA 2017;317(8):825-835. doi:10.10001/jama.2017.0686 [US9]

- This study assessed 1,746 T1DM and 272 T2DM patients younger than 20 years and concluded the prevalence of complications and comorbidities was higher among those with type 2 compared with type 1, but frequent in both groups.
- Complications included diabetic kidney disease, retinopathy, peripheral neuropathy, arterial stiffness, hypertension and cardiovascular autonomic neuropathy. Save for the latter, patients with T2DM had higher age-adjusted prevalence vs those with T1DM.

Obesity and Type 2 Diabetes in Children: Epidemiology and Treatment, Pulgaron, E.R., et al, Curr Diab Rep 2014 Aug 14(8): 508 doi: 10.1007/s11892-014-0508-y, [US12]

- This is a review paper and not a surveillance study but draws on many underlying studies. and states the most common comorbidity of T2D in youth is obesity. Cited studies indicate that over 85% of children with T2D are either overweight or obese at diagnosis and in a comparison of youth with type 1 and T2D, 96% of those with T2D, versus 24% of children with type 1 diabetes, were overweight or obese at diagnosis.
- The report notes that, “Research addressing the prevention of obesity and T2DM among youth is urgently needed”.

Mental-Health Risks of Diabetes Underrecognized, Melville, N.A., Medscape, July 18, 2014 [US13]

- This is not a surveillance study and reflects a mix of adult and youth considerations but does place a focus on the importance of addressing comorbid diabetes and mental disorders.

INDIGENOUS POPULATIONS

- The dominant indigenous populations in the United States are identified as American Indians and Alaskan Natives. Census numbers include individuals who identified with one group separately, individuals reporting both groups and individuals reporting one or other but with an additional ethnic relationship. As a result population statistics variously reported for ‘indigenous’ US people can reflect a wide range.
- The National Diabetes Statistics report produced by CDC [US1] includes data on American Indians and Alaskan Native adults and also includes some data for indigenous youth extracted from the SEARCH project. For example, the 2017 Report included SEARCH data (2011-12) showing American Indian youth (0-19) had the lowest incidence of Type 1 diabetes while American Indian youth (10-19) had the highest incidence of Type 2 diabetes.
- The SEARCH study noted that their sample participants may not be fully representative of the indigenous youth populations. [US14]
- A Federal surveillance program, “Special Diabetes Program for Indians (SPDI)”, was established in 1997 but is due to expire in 2017. [US17]
- The US Department of Health and Human Services, Indian Health Service, provides data on treatment and care for American Indians/Alaska Natives through a program of the American Diabetes Association. That report noted that between 1994 and 2004, there was a 68% increase in diabetes in American Indian and Alaska Native youth aged 15-19 years.[US19]
- The Alaskan Native Tribal Health Consortium provides state-wide reports on Alaska Native Health status. [US18]

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Description of Key Organizations

Global

IDF – International Diabetes Federation [www.idf.org]

The IDF is an umbrella organization of over 230 national diabetes associations in 165 countries and territories. It represents the interests of the growing number of people with diabetes and those at risk. The Federation has been leading the global diabetes community since 1950.

The International Diabetes Federation is divided into seven regions, with the aim of strengthening the work of national diabetes associations and enhancing the collaboration between them. IDF is associated with the Department of Public Information of the United Nations and has official relationships with the World Health Organization (WHO) and the Pan American Health Organization (PAHO).

The World Diabetes Day awareness campaign is led by IDF and was launched in 1991 by IDF and WHO. It is held on November 14, the birthday of Sir Frederick Banting, co-discoverer of insulin and Canada’s first Nobel Laureate. World Diabetes Day became an official United Nations Day in 2006 with the passage of UN Resolution 61/225.

WHO - The World Health Organization [www.who.int]

WHO was formed on 7 April 1948 – a date now celebrated every year as World Health Day. The organization has more than 7000 people working in 150 country offices, in 6 regional offices and at headquarters in Geneva. WHO staff work side by side with governments and other partners to ensure the highest attainable level of health for all people. The primary role is to direct and coordinate international health within the United Nations’ system.

The main areas of work are health systems, promoting health through the life-course, noncommunicable diseases, communicable diseases, corporate services, preparedness, surveillance and response.

Australia

AIHW – Australian Institute of Health and Welfare [www.aihw.gov.au]

The AIHW is a major national agency within the Australian Government Department of Health producing independent, relevant and reliable health and welfare information and statistics to support better decisions,

leading to better health and wellbeing for Australians. The AIHW informs policy development and public discussion by producing reports, datasets and other products— adding to the evidence base that is critical to good policy making and effective service delivery.

ABS – Australian Bureau of Statistics [www.abs.gov.au]

Australian Bureau of Statistics (ABS) is Australia’s national statistical agency, providing trusted official statistics on a wide range of economic, social, population and environmental matters of importance to Australia. The National Health Survey (NHS), run every 3 years, is one such study.

NDSS – National Diabetes Services Scheme [www.ndss.com.au]

National Diabetes Service Scheme (NDSS) and the related registrant database is an initiative of the Australian Government and is administered with the assistance of Diabetes Australia. NDSS national diabetes data snapshots are updated every three months, and provide key statistics for all types of diabetes including type 1 and Type 2, gestational diabetes, and insulin therapy.

DA – Diabetes Australia [www.diabetesaustralia.com.au]

Diabetes Australia (DA) is a not-for-profit organization established in 1984 and is the national body for people affected by all types of diabetes and those at risk. Through leadership, prevention, management and research, Diabetes Australia is committed to reducing the impact of diabetes. DA works in partnership with diabetes health professionals and educators, researchers and healthcare providers, states and territories to minimise the impact of diabetes on the Australian community.

Canada

PHAC - Public Health Agency of Canada [www.phac-aspc.gc.ca]

The Public Health Agency of Canada is an agency of the Government of Canada and is responsible for public health, emergency preparedness, and response and infectious and chronic disease control and prevention. It was formed by Order in Council in 2004 and subsequently by legislation that came into force December 15, 2006

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DESCRIPTION OF KEY ORGANIZATIONS CONTINUED

and it is member of the Federal Health Portfolio (along with Health Canada, the Canadian Institute of Health Research, and other organizations).

The mission of PHAC is to promote and protect the health of Canadians through leadership, partnership, innovation and action in public health.

StatCan - Statistics Canada
[www.statcan.gc.ca]

The mission of Statistics Canada is to serve Canada with high-quality statistical information that matters. Statistics Canada produces statistics that help Canadians better understand their country—its population, resources, economy, society and culture.

In addition to conducting a Census every five years, there are about 350 active surveys on virtually all aspects of Canadian life.

In Canada, providing statistics is a federal responsibility. As Canada’s central statistical office, Statistics Canada is legislated to serve this function for the whole of Canada and each of the provinces and territories.

Statistics Canada is a member of the United Nations Statistical Commission.

CIHI - Canadian Institute for Health Information
[www.cihi.ca]

The Canadian Institute for Health Information is an independent, not-for-profit organization that provides essential information on Canada’s health system and the health of Canadians. They have offices in Ottawa, Toronto, Montreal and Victoria.

The mandate of CIHI is to deliver comparable and actionable information to accelerate improvements in health care, health system performance and population health across the continuum of care.

CIHI promotes data quality and standards, manages health system databases and develops comparable measures for the performance of Canada’s health systems. CIHI also focuses on vulnerable populations such as seniors; children and youth; recipients of mental health and addictions services; and First Nations, Inuit and Métis.

CIHI works with a broad range of health organizations and partners across the country, including ministries of health, StatCan and Health Canada.

CMHA - Canadian Mental Health Association
[www.cmha.ca]

Founded in 1918, CMHA is a national charity that helps

maintain and improve mental health for all Canadians. With more than 10,000 staff and volunteers in more than 100 community locations across Canada, CMHA provides vital services and support to well over half a million Canadians every year. As the nation-wide leader and champion for mental health, CMHA helps people access the community-based resources they need to build resilience and support recovery from mental illness in their own communities.

As a nation-wide, voluntary organization, the Canadian Mental Health Association promotes the mental health of all and supports the resilience and recovery of people experiencing mental illness. The CMHA accomplishes this mission through advocacy, education, research and service.

DC - Diabetes Canada (formerly Canadian Diabetes Association) [www.diabetes.ca]

The Canadian Diabetes Association became Diabetes Canada on February 13, 2017 to “shed the light on the diabetes epidemic Canada is facing”.

Diabetes Canada will be the driving force to build awareness of the disease and its implications, which are often misunderstood.

Diabetes Canada will be the national voice for millions of Canadians living with diabetes or prediabetes.

The mission of Diabetes Canada is to lead the fight against diabetes by helping those affected by diabetes live healthy lives, preventing the onset and consequences of diabetes, and discovering a cure.

MHCC – Mental Health Commission of Canada
[www.mentalhealthcommission.ca]

The Mental Health Commission of Canada leads the development and dissemination of innovative programs and tools to support the mental health and wellness of Canadians. Through its unique mandate from the Government of Canada, the MHCC supports federal, provincial, and territorial governments as well as organizations in the implementation of sound public policy. Funded by Health Canada, the MHCC convenes stakeholders, develops and influences sound public policy, and seeks to inspire collective action. Examples include the justice system, primary health care, workplace, housing, and others that impact the lives of Canadians living with a mental health problem or illness and their families.

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DESCRIPTION OF KEY ORGANIZATIONS CONTINUED

The MHCC provides its recommendations to governments, service providers, community leaders and many others, and works with these partners to implement them. Focus areas include Caregiving, Children and Youth, Diversity, E-Mental Health, First Nations, Inuit and Metis, First Responders, Housing and Homelessness, Knowledge Exchange Centre, Mental Health and the Law, Mental Health and First Aid, Mental Health Indicators for Canada, Mental Health Matters, Mental Health Strategy for Canada, Peer Support, Recovery, Seniors (65+), Stigma and Discrimination, Suicide Prevention and the Workplace.

United Kingdom
(England and Wales)

RCPCH - Royal College of Paediatrics and Child Health [www.rcpch.ac.uk]

The National Paediatric Diabetes Audit is published by the Royal College of Paediatrics and Child Health (RCPCH). “The report provides an analysis of data submitted by healthcare professionals caring for infants, children and young people with diabetes in England and Wales [over the annual reporting period]. It includes details of the prevalence of diabetes, compliance with care processes recommended by the National Institute for Health and Care Excellence, and recommendations for improvements in care for the growing number of children with this life-long disease”.

PHE – Public Health England
[www.gov.uk/government/organizations/public-health-england]

“Public Health England exists to protect and improve the nation’s health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health”.

NICE - National Institute for Health and Care Excellence [www.nice.org.uk]

The National Institute for Health and Care Excellence provides national guidance and advice to improve health and social care. The legislated mandate for NICE applies to England only but certain NICE products and services are provided under special agreements to Wales, Scotland and Northern Ireland. NICE is not a disease- or condition-

specific organization. Diabetes and other endocrinal, nutritional and metabolic conditions (including obesity) as well as mental health and behavioural conditions are included among NICE focus areas. NICE is not a surveillance data collection organization per se but the standards and expectations established by NICE provide a backdrop for measuring performance in the healthcare system and this indirectly encourages collection of relevant surveillance data by others.

NCYPDN - National Children & Young People’s Diabetes Network [www.cypdiabetesnetwork.nhs.uk]

“The National Children & Young People’s Diabetes Network (NCYPDN) is working towards agreed standards of care, outcomes and process of quality assurance to establish the delivery of a world class service. The aim of the network will be achieved with support from an extended group of relevant stakeholders from national and international associations/groups that advocate for better care of children and young people with diabetes.” Among the aims and objectives are:

- * explore the requirement for and support the development of regional and subsequently a national registry for Children and Young People with Diabetes
- * achieve 100% data submission to the national Paediatric Diabetes Audit.

DUK – Diabetes UK [www.diabetes.org.uk]

Diabetes UK is a charity registered in England, Wales and Scotland and is the leading UK charity for people affected by diabetes. Diabetes UK works to support those living with diabetes, prevent Type 2 diabetes, make research breakthroughs, and ultimately find a cure.

United States

NIH - National Institutes of Health [www.nih.gov]

NIH, the nation’s medical research agency, includes 27 Institutes and Centers and is a component of the U.S. Department of Health and Human Services. NIH is the primary federal agency conducting and supporting basic, clinical, and translational medical research, and is investigating the causes, treatments, and cures for both common and rare diseases. CDC, NIDDK and NIMH are all part of the very large and complex NIH organization. NIH is the largest biomedical research agency in the world.

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DESCRIPTION OF KEY ORGANIZATIONS CONTINUED**CDC – Centres for Disease Control and Prevention [www.cdc.gov]**

CDC works to protect America from health, safety and security threats, both foreign and in the U.S. CDC conducts critical science and provides health information that protects the US against expensive and dangerous health threats, and responds when these arise.

NIDDK - The National Institute of Diabetes and Digestive and Kidney Diseases [www.niddk.nih.gov]

NIDDK conducts and supports research on many of the most common, costly, and chronic conditions to improve health. The Institute's research interests include: diabetes and other endocrine and metabolic diseases; digestive diseases, nutrition, and obesity; and kidney, urologic, and hematologic diseases.

NIMH - National Institute of Mental Health [www.nimh.nih.gov]

The National Institute of Mental Health is the lead federal agency for research on mental disorders. NIMH is one of the 27 Institutes and Centers that make up the National Institutes of Health.

ADA - American Diabetes Association [www.diabetes.org]

ADA supports, promotes and works with others in the diabetes community to advance knowledge and translate discoveries about diabetes and its complications into practical solutions that make everyday life better for people living with or at risk for diabetes.