

**World Health
Organization**

Coding disease and death

There are few truer snapshots of a country's wellbeing than its health statistics. While broad economic indicators such as Gross Domestic Product may skew impressions of individual prosperity, data on disease and death reveal how a population is truly faring.

The [International Statistical Classification of Diseases and Related Health Problems](#) (ICD) is the bedrock for health statistics. It maps the human condition from birth to death: any injury or disease we encounter in life – and anything we might die of – is coded.

Not only that, the ICD also captures factors influencing health, or external causes of mortality and morbidity, providing a holistic look at every aspect of life that can affect health.

These health statistics form the basis for almost every decision made in health care today – understanding what people get sick from, and what eventually kills them, is at the core of mapping disease trends and epidemics, deciding how to programme health services, allocate health care spending, and invest in R&D.

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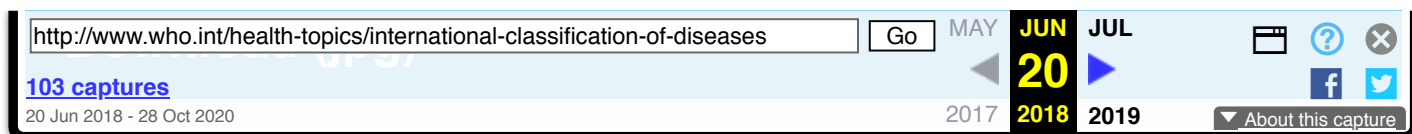
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Why is the ICD important? Watch our video

Crucially, in a world of 7.4 billion people speaking nearly 7000 languages, the ICD provides a common vocabulary for recording, reporting and monitoring health problems. Fifty years ago, it would be unlikely that a disease such as schizophrenia would be diagnosed similarly in Japan, Kenya and Brazil. Now, however, if a doctor in another country cannot read a person's medical records, they will know what the ICD code means.

Without the ICD's ability to provide standardized, consistent data, each country or region would have its own classifications that would most likely only be relevant where it is used. Standardization is the key that unlocks global health data analysis.



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Ready for the 21st century

On 18 June 2018, 18 years after the launch of ICD-10, WHO released a [version of ICD-11](#) to allow Member States time to plan implementation. This is anticipating the presentation of ICD-11 to the World Health Assembly in 2019 for adoption by countries. Over a decade in the making, this version is a vast improvement on ICD-10.

First, it has been updated for the 21st century and reflects critical advances in science and medicine. Second, it can now be well integrated with electronic health applications and information systems. This new version is fully electronic, significantly easier to implement which will lead to fewer mistakes, allows more detail to be recorded, all of which will make the tool much more accessible, particularly for low-resource settings.

A third, important feature is that ICD-11 has been produced through a transparent, collaborative manner, the scope of which is unprecedented in its history (*see Box: The revision process*). The complexity of the ICD has sometimes made it seem like an esoteric health tool requiring months of training – of the number of deaths reported in the world, those coded correctly were about one third. An overriding motive in this revision was to make the ICD easier to use (*see Box: Making the switch*).

BOX: The revision process

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The launch of ICD-11 revision took place in Toyko and since then, WHO has worked with a Joint Task Force to produce a version ready for release to countries. Through the revision, interested parties have been invited to send proposals, and WHO has received more than 10 000 so far.

BOX: Making the switch

The version given to the World Health Assembly in 2019 will go into effect on 1 January 2022. However, given the vast technical and technological adaptation and training required to move to a new system – thousands of coders from small primary health care clinics to large hospitals will need retraining – the switch from using ICD-10 to ICD-11 is unlikely to happen overnight.

While there will be a few early adopters, not many countries are likely to adapt that quickly – some countries are still using ICD-9, and a few are even using ICD-8. ICD-10 which was released in 1990 was first implemented by Thailand in 1994; the USA only switched to it in 2015.

The top 10 causes of death, 2016

Small code, big impact

The consequences that ICD coding has on provision of care, as well as health financing and insurance, means that clinicians, patient groups, and insurers, among others, take the use of the ICD extremely seriously – many groups often have strong positions on whether or not a condition should be included, or how it should be categorized.

For instance, some people working on stroke have long been pushing for it to be moved from circulatory diseases, where it has been for 6 decades, into neurological disease, where it now sits in ICD-11. Those advocating for the move cited key implications for treating the disease and reporting deaths as the main driver.

A critical point in engaging with the ICD is that inclusion or exclusion is not a judgement on the validity of a condition or the efficacy of treatment. Thus, the inclusion for the first time of traditional

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up cultural assumptions. For instance, ICD-6 published in 1948 classified homosexuality as a mental disorder, under the assumption that this supposed deviation from the norm reflected a personality disorder; homosexuality was later removed from the ICD and other disease classification systems in the 1970s.

Overview of ICD-11

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Gender incongruence

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Mental health



Gender incongruence, meanwhile, has also been moved out of mental disorders in the ICD, into sexual health conditions. The rationale being that while evidence is now clear that it is not a mental disorder, and indeed classifying it in this can cause enormous stigma for people who are transgender, there remain significant health care needs that can best be met if the condition is coded under the ICD.

For mental health conditions, ICD codes are especially important since the ICD is a diagnostic tool, and thus, these are the conditions that often garner much of the interest in the ICD. These include gaming disorder, which evidence shows is enough of a health problem that it requires tracking through the ICD. Other addictive behaviours such as hoarding disorder are now included in ICD-11, and conditions such as 'excessive sexual drive' has been reclassified as 'compulsive sexual behaviour disorder'.

A significant change in the mental disorders section of ICD-11 is the attempt of statisticians to simplify the codes as much as possible to allow for coding of mental health conditions by primary health care providers rather than by mental health specialists. This will be a critical move since the world still has a scarcity of mental health specialist – up to 9 out of 10 people needing mental health care don't receive it.

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The history of the ICD traces back to England in the 16th century. Every week, the London Bills of Mortality would announce deaths from distinctly medieval causes: scurvy, leprosy, and the big killer – plague. It wasn't until the late 19th century though, when Florence Nightingale, just returned from the Crimean War, advocated for the need for gathering statistics on causes of disease and death that data began to be collected more systematically.

Around the same time French statistician Jacques Bertillon introduced the Bertillon Classification of Causes of Death, which was adopted by several countries. In the 1940s, the World Health Organization took over Bertillon's system and expanded it to include statistics on causes of injury and disease, producing the first version of the International Statistical Classification of Diseases, Injuries and Causes of Death (ICD). This allowed for the first time the collection of both morbidity and mortality data to map both disease trends and causes of death.

Disease trends and the biggest killers

The data captured through ICD codes is of huge importance for countries. It allows for the mapping of disease trends and causes of death around the world, which are key indicators both of the health of a population, but also the social determinants that link closely to health, such as the education, nutrition, and public infrastructure - in short, a snapshot of where a country's vulnerabilities lie. A country in which people live in crowded, inadequate housing with no clean water are inevitably likely to have a higher incidence of diarrhoeal disease.

The [Global Health Observatory](#) is WHO's gateway to health-related statistics for over 1000 indicators. Data coded through the ICD populates the Global Health Observatory allowing WHO to report World Health Statistics annually. These statistics are critical in tracking progress towards key targets such as the Sustainable Development Goals.

Mortality data in the Global Health Observatory shows that while ischaemic heart disease and stroke are the top two killers worldwide, together accounting for 15 million deaths in 2015, zooming into the statistics by continent can show radically different pictures. In Africa, lower respiratory infections and HIV/AIDS cause the most deaths, whereas violence is in the top 10 causes of death in the Region of the Americas and the Eastern Mediterranean region.

Data clearly has huge significance in directing energy and resources in global health. Yet data also shows us a picture of what is happening in the world that is unhampered by bias or assumption. For instance, data from the [WHO's 2018 World Health Statistics](#) on global deaths on homicide and conflict show that the statistics do not always match the way these mortality data are reported in the media, for instance (*see graphic: Why data is important*)

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What shelf life will ICD-11 have?

The reason for revising the code every decade or so is this: countries can apply to develop their own adaptations. They are not allowed to change the basic code, but they can add detail – essentially producing more granular versions tailored to their health systems and circumstances.

Countries that create bespoke versions can then sell those to other countries, training them in its use. Practitioners of specialities such as dermatology or mental health may want to produce their own adaptations too.

As WHO tweaks the ICD through the years to take into account new understandings of medicine, countries are expected to follow suit. Many do not, however.

Every year, WHO takes slightly incompatible data from countries and makes them comparable.

Over the years though, version control slips too far and several slightly varying versions appear all over the world. Thus, a new version becomes necessary to reset the system.

ICD-11, however, has been produced electronically and therefore should act more as a living document to which everyone has access. Its agility should ensure considerable longevity.

Photo gallery



Tobacco addiction, Russia
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