A Practical Implementation Guide to ICD-11 for Mortality

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Introduction

WHO has produced a report entitled "ICD-11 Implementation or Transition Guide" to assist countries in making the transition from ICD-10 (or earlier revisions) to ICD-11.[1] The report covers the landscape of activities required as part of implementation, but necessarily does not go into great detail on any one of the activities, leaving countries to complete ICD-11 implementation as best suits their needs. However, countries also require practical advice gained from experience in undertaking similar large-scale activities involving multiple partners. The aim of this "practical guide" is to provide useful tips gleaned from past experience and real-world examples from countries that have already begun ICD-11 implementation, all while retaining the essential elements contained in the WHO report.

Why implement ICD-11?

Countries considering the implementation of ICD-11 may wonder why the change is necessary. If they have been using ICD-10 for mortality coding, the coding team is accustomed to the coding rules and the codes themselves. They are able to work smoothly and efficiently, producing data as needed for analysis and public health planning. Analysts similarly are used to working within the confines of ICD-10 to produce tables, graphs and reports. Such countries may question the need to implement another revision of the International Classification of Diseases.

Countries that have never used the ICD for mortality coding may question the need for any coding system. They may have a simple list of common diseases or causes of death that suffice for their needs. ICD-11 may seem to be very complex and too difficult to implement.

ICD-11 appears to be very different from ICD-10. The code structure is completely new, some causes will require combined codes, and some causes have been moved to different chapters. Implementing ICD-11 may mean a steep learning curve for coding teams and analysts. The process will take time, it will call for careful planning and will require budget support. So why do it?

Rationale for ICD-11

 ICD-11 incorporates the latest in medical information, enables the user to capture much more detail and offers various features to facilitate its use:

- The ICD is revised periodically to reflect advances in medical knowledge and understanding. The classification was greatly in need of updating, given that more than 30 years have passed since ICD-10 was implemented (in 1990). Changes contained in ICD-11 include revisions in the sub-categories of specific diseases, such as diabetes, infections related to HIV, and others. Other changes refer to broad categories

of diseases, such as the movement of cerebrovascular diseases to the chapter on diseases of the nervous system, based on consideration of the cardiovascular section of the classification by a team of cerebrovascular experts.

- New coding conventions will enable greater detail to be reported than previously possible, for example, the use of code combinations for post-coordination of causes of death. Extension codes also are useful for reporting more detail. They are used to a certain extent for mortality coding but will be used primarily for morbidity coding. They offer such advantages for disease reporting that your ministry of health may well insist on implementing ICD-11 for both morbidity and mortality.

- If a country chooses not to implement ICD-11, over time it will become more difficult to maintain international comparability for your mortality data, as more and more countries move to ICD-11.

- ICD-11 offers a suite of electronic tools to facilitate implementation and use of the classification:
  - The *Translation Tool* provides a mechanism for translators to work collaboratively on the translation of ICD-11.
  - Countries can use the ICD-11 *Field Implementation Test program (ICD-11 FIT)* to assess readiness of coders and other staff for ICD-11 implementation.
  - The ICD-11 *Coding Tool* facilitates the selection of the appropriate code for diagnostic expressions. As a cause is entered, the *Coding Tool* draws on the list of terms in the *Index* to generate a list of possible diagnoses and associated ICD-11 codes, ranked according to match accuracy. The coder can then select the most appropriate expression and code to represent the cause.
  - Coders can review detailed sections of ICD-11 using the *Browser* – the electronic equivalent of Volume 1 from previous revisions of the ICD.
  - There will be no need to purchase expensive ICD manuals, as both the Coding Tool and Browser will be available free of charge, either online or via download.
  - Countries can use the *Training Tool* to develop specific ICD-11 training programs for coders, IT personnel, analysts and staff.
  - *DORIS* automated coding tool (see description below).
  - Countries can use *ANACOD3*, updated to accommodate ICD-11 codes, to evaluate the quality of cause of death data.
  - WHO's suite of electronic tools comes with *API* (Application Programming Interface) software to facilitate the integration of these tools into an existing mortality data system.

Automated solutions for mortality coding

- **DORIS (Digital Open Rule Integrated Cause of Death Selection) Tool**

DORIS is a software tool developed by WHO to facilitate coding causes of death and the identification of underlying causes of death. This tool examines the information provided on the death certificates and assists in automatically selecting the underlying cause of death following the mortality coding rules of the international classification of Diseases (ICD) reference guide. It is designed to facilitate coding, even in low-resource settings. The first release version of the DORIS automated mortality coding tool (Release 1.0) is available to

be used by countries. Initial reviews of the release version have identified shortcomings of the system, but WHO will continue to improve DORIS.

DORIS is available in two versions:

- o **DORIS Web Version** is a web-based application accessible through a web browser. It applies the ICD mortality rules on individual death certificates for the cause of death selection. The web version can be accessed at: https://icd.who.int/doris/tool.
- o **DORIS Desktop Version for batch processing** is a desktop software that can be installed on local computers. It is designed to allow batch processing of large volumes of death certificates. Whether working in text or code mode, this software analyzes thousands of death certificates and supports multiple Excel, CSV, and JSON formats. Because of limitations in the *Coding Tool* however, certificates coded using batch processing will require careful post-processing review.

- **Iris version 6 for automated mortality coding**
  Iris is an automated coding software that allows death certificates to be coded according to ICD-10 rules and standards. Iris has been implemented in several European Union countries, as well as by the Office for National Statistics in England and Wales and by Statistics Canada. The Australian Bureau of Statistics and the Fijian Statistical Office use it in the Asia-Pacific region. The Philippines is the first country in Asia to implement Iris. Morocco is the first country in Africa to implement fully automated Iris.

  Work on Iris version 6 for ICD-11 began in 2022, once major updates and other changes to ICD-11 were completed and ICD-11 reached a relatively stable state. The official release of Iris for ICD-11 is planned for October 2025. A test version of Iris for ICD-11 was released in October 2023 as part of an extensive period of testing and development of Iris version 6 for ICD-11.

  Iris version 6 for ICD-11 will retain all of the features of Iris for ICD-10:
  - o User-friendly **interface**;
  - o Country-specific **dictionary** (to be developed by each country) that <u>exactly</u> maps diagnostic terms to ICD codes (Statistics Canada is developing an English language dictionary).
  - o **Standardization** permits conversion of non-standard diagnostic expressions in the dictionary to standard expressions, to reduce dictionary size and improve coding precision.
  - o **Time interval standardization** ensures time intervals are used as part of mapping diagnostic expressions to ICD codes;
  - o **Decision Tables** ensure diagnostic expressions are ordered in correct causal sequence;

- Unicausal Decision Tables can be printed as a PDF file for use in coder training; Multicausal Decision Tables are released in PDF format on the Iris website.
    - **Decision Table Browser** facilitates Decision Table maintenance;
  - **MUSE** (Multicausal and Unicausal Selection Engine) employs Decision Tables and other Iris tables to ensure correct application of causal and modification rules, application of multiple cause coding rules, and correct selection of the underlying cause of death;
  - **Causal and modification rules** are identified on the Iris interface as part of the underlying cause selection process;
  - **Code entry mode** accepts ICD codes for diagnostic terms entered on the death certificate; Iris then selects the underlying cause of death;
  - **Text entry mode** enables the user to enter diagnostic expressions from the death certificate in free text. The dictionary then converts the text into ICD codes;
  - **Automated batch coding** of the Medical Certificates of Causes of Death (MCCD) portion of death certificates;

Iris version 6 for ICD-11 will also include some new features:

  - Possible incorporation of the WHO *Coding Tool* for optional use, limited to *Coding Tool* exact matches of diagnostic terms to ICD-11 codes
  - Depending on user interest, development of a **web version** of Iris V6 to facilitate access to Iris.

As with the ICD-10 version of Iris, **implementation** of Iris version 6 for ICD-11 will require more work than for DORIS. Much of the additional work concerns the development of an Iris dictionary and standardization rules that map diagnostic expressions precisely to ICD-11 codes. However, the opposite is true when it comes to the **use** of the two coding systems: When used for automated coding, Iris will match diagnoses to codes more precisely than DORIS. As a result, certificates coded by DORIS in automated batch mode will require significantly more post-processing review than will certificates coded by Iris.

Getting Started on ICD-11 Implementation

A good approach to implementation planning is to begin by ensuring all participating partners have a clear understanding of how the current death registration system/cause of death collection operate and are aware of areas needing improvement. Business process mapping (BPM), an approach that uses mapping tools and group discussion to describe processes, identify problems and propose solutions, has been very effective in describing these processes in many low and middle-income countries. Furthermore, by bringing together all stakeholders, BPM provides an excellent setting for orientation and group discussion of plans for ICD-11 implementation.

The Dominican Republic, Ecuador and Trinidad and Tobago have used BPM to assess the current death registration/cause of death collection systems and discuss ICD-11 implementation roadmap development. The roadmap will cover all the steps in ICD-11 implementation and will prove helpful as implementation unfolds and decisions have to be made on processes, actors and IT solutions.

Budget

Regardless of the implementation process developed, adequate funding will be required and should be identified at the beginning of the process. Typically, one government ministry or department provides the majority of the funding, often the ministry of health, although the majority funder could be the central statistics office, the ministry of planning or the civil registration office. The identification of the majority funder usually takes place at a higher level, but the mapping activity can inform the budget process by providing insight into the amount of funding required for implementation. In addition, the group format of BPM provides a setting for stakeholders to identify additional contributions to implementation, in funding or in kind.

National Implementation Taskforce

In almost all cases, ICD-11 implementation for mortality will be part of a larger implementation effort organized by the Ministry of Health, covering usage for both morbidity and mortality coding. The *National Implementation Taskforce* will include all stakeholders for both morbidity and mortality. To ensure high-level support, the *National Taskforce* should include senior members of the various participating agencies, including representatives of organizations that will be involved in mortality implementation. Specifically, the *National Taskforce* should include representatives from the ministry of health, the organization charged with coding, the organization producing mortality statistics, the national statistical organization, private healthcare groups, physician associations and hospital associations. *National Taskforce* participants representing mortality interests should either serve on the *Mortality Project Management Team* (see next section) or should report regularly to the *Mortality Project Management Team* on developments from the *National Taskforce* that will affect ICD-11 implementation for mortality.

The broad representation recommended for the *National Taskforce* reflects the fragmentation of responsibilities common to most national civil registration and vital statistics systems, resulting in the need for coordination of efforts. In this sense the *National Taskforce* has much in common with national committees on vital and health statistics. A report on national

committees emphasizes their coordination role and notes the various roles such committees can play, including the implementation of international recommendations.[2]   In effect, countries that have a national committee in place can make use of that committee in designing and implementing the *National Implementation Taskforce*.

Some countries have implemented the most recent ICD revision for mortality but not for morbidity, or the reverse. But in most cases, you will want to use the same ICD revision used by the Ministry of Health for morbidity coding. This is because, despite efforts to map codes from the current revision to the new revision, differences in tabulations of cases or deaths by cause group will remain, as we will see in the discussion of dual coding.

Project Manager and Team for Mortality Implementation

Although less complex than implementation for morbidity, nonetheless the implementation of ICD-11 for mortality should be carefully planned. The planning should include a *Terms of Reference* (TOR) statement including the purpose, manager and membership, meeting schedule and level of administrative support. An example TOR is provided in Annex 2.

ICD-11 implementation for mortality should involve a project manager and core team that will be responsible for planning and oversight. The team should include key individuals and decisionmakers for each step in the process. A member of the mortality team should serve on the *National implementation Taskforce* and should ensure the national team is informed of plans for ICD-11 mortality implementation as well as progress on the various implementation steps. The mortality project manager and team should develop a detailed implementation plan, covering each step in the process, a detailed timeframe/GANTT chart and a budget. As part of implementation, the manager and team should be responsible for determining when each step in the process has been completed before moving to the next step. The planning process should include a careful assessment of the current status of mortality coding and consider needs to ensure a successful implementation of ICD11.

Key individuals to include in your project team should be selected from the following groups:
 - Vital Statistics, Director's Office
 - MOH Planning and Measurement Group
 - Registrar General
 - IT/Data Processing Group
 - Lead of the Cause of Death Coding Team
 - Vital Statistics Analysis Group
 - National Statistics Office

Remember that implementation of an ICD revision is a long-term process, typically taking 2 years or more and requiring multiple steps. For this reason, you should begin the process for mortality implementation well in advance of the expected release date for ICD-11-coded mortality data.

Preliminary Activities

Much of the preliminary work will focus on the compatibility of the new revision with the language used to report causes of death by physicians in your country. WHO has already completed translation of ICD11 from the original English into Spanish, French, Portuguese and other languages, so most countries will not require translation into additional languages. An important step in implementation however, will be to determine the need for any additional terms or other modifications to WHO's ICD-11 electronic tools to facilitate the coding of cause of death terminology used by physicians in your country.

Specific activities should include the following:

- Complete the ICD-11 translation into your language, if needed, using the *Translation Tool*. The tool allows various translators to work collaboratively on the translation. Inform WHO of any errors found in the WHO translation;
- Use the *Coding Tool* to see if the acronyms or diagnostic terms commonly used by your physicians are present in ICD-11. At the same time, ensure that those acronyms or diagnostic terms refer to the appropriate disease;
- Develop a list of the 50 (or 100) most common diagnostic terms found on death certificates in your country. Use the *Coding Tool* to determine if those terms are present in ICD-11. If additional terms, synonyms and acronyms are needed for the *Coding Tool*, inform WHO early on in the implementation process.   Any proposed changes to the *Coding* Tool have to be evaluated by two different expert groups within WHO before being added to the index. This is a useful process, but it does take time, so submit your proposed changes well in advance of the start date for ICD-11 coding. See the *ICD-11 proposal process* section below for details on how to submit proposed changes to ICD-11.
- Check the ICD-10 – ICD-11 mapping to ensure terms are mapped correctly from one revision to the other. Inform WHO via the WHO Regional Office for your region of any errors or additions to the mapping that you have identified.

In 2016, WHO recommended changes to the content of the Medical Certificate of Cause of Death (MCCD) in the first edition of the *Reference Guide*. As part of the implementation of ICD-11, WHO now is providing specifications for the introduction of an electronic MCCD. While it would be good for countries to consider making changes to the existing national MCCD and/or implementing an electronic MCCD, these changes should take place before and not during ICD-11 implementation. Making multiple changes to the recording instrument while simultaneously implementing ICD-11 may make it difficult to identify the source of problems when problems appear in the implementation process. In addition, these changes will have implications for the required IT infrastructure and personnel as well as training needs for both IT personnel and

coders and will necessarily add to the complexity of the implementation process. If updating of the MCCD and/or development of an electronic MCCD are deemed essential, they should be developed, tested and in use well before ICD-11 implementation begins.

ICD-11 update proposal process

As part of preparation for ICD-11, Statistics Canada identified a set of common diagnostic terms and checked to see if they were present in the 11th revision. They were surprised to find that a substantial proportion of the terms could not be located. Because of the time required for approval of update proposals, Canada is submitting proposals well in advance of their proposed implementation date for ICD-11.

As mentioned above, you may find that some changes to ICD-11 are called for. Those changes may be primarily the addition of terms commonly used on death certificates in your country that cannot be found via the *Coding Tool*, terms from ICD-10 that are not mapped correctly to ICD-11, or changes to the *Reference Guide* that are required. For all such changes, the update proposal process is the same: proposals should be entered on the *Proposal Platform*, a part of the *ICD-11 Maintenance Platform* (https://icd.who.int/dev11). Before any change can be made to the classification or the *Reference Guide*, the proposal must be reviewed by two groups, the Mortality Reference Group (MRG) and the Classification and Statistics Advisory Committee (CSAC), with approval contingent on a vote to approve by CSAC members. The MRG is a group composed of international experts on cause of death classification, all of whom are employed by national governments and who volunteer their time to serve on the MRG. The CSAC is a WHO committee tasked with keeping the ICD-11 in line with current knowledge in the areas of classification and statistics.

Planning for Training

A variety of staff involved in ICD-11 implementation will require training, including the Project Manager. Two sections below provide details on training requirements for key groups - coders and IT staff - but others will require training as well. The ICD-11 implementation process should include careful planning for training needs, identifying who needs to be trained, who will do the training, what training method or approach should be applied, funding availability and so on.

Mexico provides an example of the sort of education planning that should go into the ICD-11 implementation process. With support from PAHO, the Mexican ICD Collaborating Center (CEMECE) agreed to use outside funding to begin ICD-11 implementation, including development of detailed plans for training. An evaluation committee was established, composed of 9 CEMECE members with extensive experience in teaching ICD coding. To promote the use of ICD-11 for mortality and morbidity coding, trainees were recruited from the individual Mexican states. The training methodology required all trainees to prepare to present on technical material distributed in advance, with only one trainee randomly selected to do the actual presentation. Because of covid restrictions, the 95 initial trainees received remote training classes every 2 weeks for one year. The final set of 42 trainees from 21 Mexican states received 9 days of in-person training using the same training approach. While other countries may prefer to use experienced trainers or may choose a different training method, the essential is to address the basic issues: assure funding, identify the training to be conducted and the individuals to be trained, and select trainers who fit the desired training approach

Coding Staff and Tools:

> Coder training on ICD-11 is an essential part of implementation planning and should include the following:
> - Use of the *Training Tool* for introductory training;
> - Determine timing for in-person coder training
> - Ensure training date is coordinated with beginning of ICD-11 coding
> - Recruit new coders (if needed) before in-person training
> - Determine need for automated coding training
> - Ensure that training produces coders capable of manual ICD-11 coding, as even automated coding systems produce rejects requiring manual coding.

Coders will require training on the characteristics and usage of ICD-11. The Project Manager and senior member of the IT team should attend at least part of the coder training to improve their understanding of the system and help them to foresee potential roadblocks to implementation. Coder training should include instruction on use of the WHO suite of electronic tools [*Browser:(,https://icd.who.int/browse/2024-01/mms/en) Coding Tool: (https://icd.who.int/ct/icd11_mms/en/release), DORIS*). The *Training Tool* (https://icdcdn.who.int/icd11training/index.html) will provide some of the information to be used in training, but in-person training by a nosologist (expert coding trainer) will be necessary as well. The Project Manager and team should identify the need and proposed date for coder training by a nosologist early in project planning. There are not many good-quality nosologists available, so their participation should be arranged well in advance. Remember also that the timing of ICD-11 coder training should not take place until coders are ready to begin coding with ICD-11. Depending on the timing of ICD-11 implementation, the project team will need to determine if ICD-10 refresher training is needed in the interim. The Project Manager and team should determine if training on an automated coding system will also be needed. Finally, the manager should contact the MOH to determine if the MOH will require morbidity coder training, so that can be coordinated.

The Project Manager and team also should consider reinforcement of the existing coding team, if necessary. This assessment should take into account the size of any existing coding backlog, the current number of coders and their average daily output, the estimated number of deaths in future years, and any possible coder retirements in the near future. If additional coders are needed, they should be recruited, provided with introductory training and included in the in-person ICD-11 coder training.

IT System and Tools

Similar to the coders, IT staff will need ICD-11 training tailored to their needs. The Training Tool can provide some of what they will need. Selected IT staff should be invited to attend certain portions of the in-person coder training; this will both provide useful information and afford them the opportunity to ask questions to clear up possible confusion or misunderstandings. IT participants on the Project Team can inform the Manager of additional training that will be required.

The existing IT infrastructure should be carefully evaluated to ensure the capacity exists to take advantage of the many electronic features of ICD-11:

- Determine the availability of individual computers for coding staff. ICD-11 coding will work best if each coder is equipped with a computer or terminal;
    - o Document the need for additional computers;
    - o Consider use of dumb terminals versus computers
- Determine the quality of internet access for coding staff. If access is poor, ICD-11 tools will have to be downloaded and operated locally;
    - o Document the need for improved internet access, if needed;
- If an automated coding system is desired, consider engaging an expert consultant to determine the capacity of existing IT staff to implement an automated system;
    - o Determine availability of expert consultants;
    - o Determine availability of qualified IT staff to implement automated system;

In addition, the existing mortality data system will require modification:

- At a minimum, the existing system will need to be updated to accommodate the larger number of characters in ICD-11 codes and any additional variables that are to be added to the existing MCCD;
- The addition of external systems also may raise interoperability concerns, for example:
    - o automated coding system (Iris, DORIS);
    - o District Health Information System 2 (DHIS2).

Data Quality and Comparability

The Project Management Team should take advantage of the extended implementation period, as recommended above, to put in place a number of activities to ensure data quality under ICD-11. These activities should include further enhancement of ICD-11, dual coding of causes of death (ICD-10 and ICD-11), staff training on the use of ANACOD3 to evaluate cause of death quality, more in-depth studies on cause of death quality, and planning for routine analysis of annual mortality data.

ICD-11 improvement

As part of the transition to ICD-11, the coding team should extend ICD-10 to ICD-11 mapping, initiated as part of preliminary activities, to identify any additional errors in codes mapped from ICD-10 to ICD-11. As before, these errors should be reported promptly to WHO. At the same time, the coding team should identify any synonyms or acronyms used in your country that are not included in the Coding Tool – and inform WHO of these items as well.

Dual coding of causes of death

An essential element of the transition to ICD-11 is the implementation of dual coding of causes of death in ICD-10 and ICD-11. Dual coding (or bridge coding) studies are designed to show the impact of the transition from ICD-10 to ICD-11 on the resulting cause of death statistics. Implementation of a new ICD revision can lead to disruptions in cause of death levels and discontinuities in trends. These changes can result from a more detailed list of diseases in the new revision, additions to or modification of ICD chapters, and changes to coding rules including rules for the selection of the underlying cause of death. A change in cause of death coding rules implemented in ICD-10 led to a major disruption in trends for pneumonia and smaller changes for diseases likely to be mentioned with pneumonia.[3] Fortunately, only very minor changes in rules for the selection of the underlying cause of death were allowed in ICD-11.

The impact of the transition to a new ICD revision can be described by the comparability ratio. For a given cause of death, this ratio is calculated by dividing the number of deaths classified by the new revision by the number of deaths classified by the previous revision. The comparability ratio represents the net effect of the new revision on cause of death statistics. Countries should begin their dual coding study by selecting deaths already coded in ICD-10. To measure the entire impact of the transition to ICD-11, the ICD-10-coded deaths should be selected across each of the ICD chapters. These deaths will then be coded in ICD-11 in order to calculate the comparability ratio for each cause of death. The number of deaths selected for dual coding should be as large as possible, first to ensure the results are statistically reliable, and second to include as many causes of death as practical in the study.   Hence dual coding should begin relatively early in the transition process to ensure sufficient numbers of deaths are dual-coded. If coding in your country is entirely manual, it will be challenging to generate a sufficient number of dual-coded death records for a comprehensive dual coding study. In that case, dual coding should be limited to specific causes of death that underwent major modification in ICD-11, in particular, diseases that are among your country's leading causes of death.

You should plan to produce a report on the dual/bridge coding study, including a table with comparability ratios for selected causes of death. A good example of a dual coding report documenting the change from ICD-9 to ICD-10 was produced by the US National Center for Health Statistics (NCHS) and can be found on the NCHS website: https://www.cdc.gov/nchs/data/nvsr/nvsr49/nvsr49_02.pdf.[3] See Annex 3 for additional information on the US dual coding study.

The availability of automated coding systems that can function in both ICD revisions will greatly facilitate dual coding studies. The speed and consistency of automated coding systems mean that dual coding studies can be implemented relatively quickly, can include a larger number of certificates and causes of death, and will reduce the need for an extended overlap of manual coding in both ICD revisions. The dual coding report mentioned above also serves as an example of a dual coding study based on automated coding. If, however, the dual coding study is carried out using DORIS in automated mode, countries should be aware that the results will need to be carefully reviewed. This is because of issues concerning DORIS's ability in

automated mode to match diagnostic terms from the MCCD to the correct disease and ICD-11 code.

Results of dual coding studies should be used to highlight changes in cause of death levels and trends resulting from implementation of ICD-11. The changes should be presented to data users, in particular key users within the Ministry of Health, in advance of the release of cause of death statistics based on ICD-11 coding. Advanced knowledge of these changes will help users identify those changes that are artifacts of the transition and not actual changes in the incidence of specific causes of death. This will be important for public health planning and communication with the public.

Cause of death quality

Assessing the quality of cause of death data will require routine analysis of mortality data, combined with specific attention to the cause of death data certified by physicians and coded by the coding team. The Project Management Team should determine the need for training on vital statistics analysis as part of a program for routine analysis and publication of mortality data. Analysts also should receive training on the WHO cause of death quality software, *ANACOD3.* These two activities are mutually supportive, as routine analysis of mortality data includes some measures of cause of death quality, while *ANACOD3* includes a number of demographic measures and complex calculations such as life expectancy and life tables, which are essential elements in vital statistics reports. A more advanced assessment of the quality of cause of death certification may be possible in countries maintaining detailed patient medical records. If available in your country, these records can be used to assess the accuracy of cause of death certification by physicians. These studies are costly and time-consuming to implement however, so they should not be considered as part of the ICD-11 implementation assessment. A good example of such a study took place in New York City.[4,5]

Routine Data Analysis and Dissemination

The Project Management Team should develop a plan for routine analysis of vital statistics data and dissemination of the results. The publication of an annual report on vital statistics should be the responsibility of the organization identified as the source of official vital statistics for the country. Depending on the existing vital statistics legislation, this responsibility may be vested in the central statistics office, an independent vital statistics organization, or the ministry of health. It is important to ensure that only one source exists for official vital measures for the country. There should be a plan for dissemination of the results of annual vital statistics reports, special studies and other vital statistics information. These reports should be made available promptly to all of the organizations represented on the National Implementation Taskforce as well as all the relevant international organizations. The reports should be posted on easily-accessible websites and announcements of their availability should be broadly distributed.

Final report

Complex processes such as implementation of an ICD revision often require modification of plans after the process has started. To ensure that all the challenges encountered and the changes made to implementation plans are documented, the Project Manager or a senior member of the Mortality Implementation Team should keep a log of all such events in a notebook designated for this purpose.

The Project Management Team should conclude the ICD-11 implementation process with the preparation of a final report, describing all the steps involved in the implementation of ICD-11, results of the implementation, errors or challenges encountered in the process and lessons learned. The structure and updating process included in the 11th revision of the ICD are designed to ensure that future revisions will not be required, but that may or may not be true. ICD-10 developed the first update procedure for the classification, yet ultimately it was decided that an 11th revision was called for. In addition, the updating process itself may lead to substantial changes to ICD-11, which in turn may require some of the procedures included in the present implementation process. Finally, the large amount of work involved in the implementation of ICD-11 deserves a report on activities undertaken, to document the various steps and to provide guidance for the implementation of any future changes to the International Classification of Diseases.

References

1. Geneva: World Health Organization; 2019. *ICD-11 Implementation or Transition Guide*. License: CC BY-NC-SA 3.0 IGO. Retrieved June 1, 2023 at: https://icd.who.int/docs/ICD-11%20Implementation%20or%20Transition%20Guide_v105.pdf
2. Coordinating Role of National Committees on Vital and Health Statistics, *Technical Papers*, International Institute for Vital Registration and Statistics, No 6, January 1980. Bethesda.
   Retrieved June 6, 2023:
   https://www.cdc.gov/nchs/data/isp/006_Coordinating_Role_of_National_Committtees_on_Vital_Health_Stat.pdf.
3. Anderson RN, Miniño AM, Hoyert DL, Rosenberg HM. Comparability of cause of death between ICD–9 and ICD–10: Preliminary estimates. *National vital statistics reports*; vol 49 no. 2. Hyattsville, Maryland: National Center for Health Statistics. 2001. Retrieved June 6, 2023: https://www.cdc.gov/nchs/data/nvsr/nvsr49/nvsr49_02.pdf.
4. Agarwal R, Norton JM, Konty K, Zimmerman R, Glover M, Lekiachvili A, et al. Overreporting of deaths from coronary heart disease in New York City hospitals, 2003. Prev Chronic Dis 2010;7(3):A47.
5. Madsen A, Begier E. Improving quality of cause of death reporting in New York City. Prev Chronic Dis 2013; 10: 130227.

Annex 1: Implementation Activities and Timeline

Main Activity	Specific Actions	Year 1				Year 2			
		Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
Preparation for Implementation Activities	Develop TOR for Project Team	X							
	Develop detailed implementation plan	X							
Preliminary Activities	Complete translation of ICD11 and tools	X	X	X	X	X	X	X	X
	Add local terms to dictionary	X	X	X	X	X	X	X	X
	Check ICD-10 to ICD-11 mapping	X	X	X	X	X	X	X	X
	Engage nosologist for ICD-11 training		X						
Coding Team	Plan ICD11 training for coders, IT team, analysts		X	X	X				
	Recruit new coders if needed		X	X	X				
	Multiple cause, underlying cause coder training			X	X	X	X		
	Browser, Coding Tool and DORIS training			X	X	X	X		
	Automated coding system training*								
IT System	Carry out IT needs assessment	X	X						
	Determine computer equipment needs for coders, advocate	X	X	X	X				
	Assess internet access, advocate for improvement	X	X	X	X				
	IT staff to attend part of coder training		X	X	X				
	Modify information system to meet ICD-11 requirements			X	X	X	X	X	X

	Determine interoperability between existing information system and ICD-11 tools			X	X	X	X	X	X

Annex 1: Implementation Activities and Timeline (cont.)

Main Activity	Specific Actions	Year 1				Year 2			
		Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
Data Quality and Comparability	Continued use of ICD-10 to ICD-11 mapping			X	X	X	X	X	X
	Addition of local terms to ICD-11 dictionary			X	X	X	X	X	X
	Dual/bridge coding study ICD-10 to ICD-11					X	X	X	X
	ANACOD3 training for cause of death quality assessment			X	X				
	Monitor cause of death quality indicators					X	X	X	X
	Training on vital statistics analysis and report writing				X	X	X	X	X

* Implementation of automated coding will depend on decision of each D4H country.

Annex 2: Terms of Reference example

Terms of Reference

Working Group 4: ICD-10 Coding Support

Bloomberg Data for Health CRVS Component

Objective

The principal purpose of this working group is to provide guidance and implementation advice to countries that wish to implement or improve the coding of causes of death according to ICD-10 coding rules. Guidance and implementation advice will include assistance with both manual and automated cause of death coding.

To achieve these objectives the group will:

- Provide recommendations and guidance aligned with D4H project implementation strategies;
- Coordinate with D4H partners who will provide IT assistance required for implementation of automated coding;
- Maintain lines of communication with WHO, the Mortality Reference Group, and the Iris Institute regarding cause of death coding issues;
- Stay abreast of global best practices on ICD-10 coding of causes of death.

Terms of Reference

The Working Group will advise and assist with implementation of ICD-10 coding of causes of death as requested by D4H country project teams. This will include the following:

- Develop ICD-10 coding training materials and training agenda for implementation of ICD-10 coding in D4H countries;
- Assist/advise TAG members with the acquisition of necessary training materials, including ICD-10 coding manuals and electronic decision tables;
- Advise TAG members on design of coding strategy for country implementation;
- Identify D4H staff or consultants with appropriate ICD-10 expertise to serve as coding instructors, for both manual and automated coding;
- Liaise with Swiss TPH staff or consultants regarding IT training and technical assistance needed for implementation of automated coding;
- Collaborate with the Australian Bureau of Statistics on the IRIS implementation assistance they provide to UoM countries;
- Propose monitoring and evaluation guidelines.

Communication

To provide the proposed support, the working group will:

- Acknowledge requests for assistance within one business day (Monday/Friday) and provide an initial response within five business days;
- Maintain communication with working group members via email regarding project design and implementation discussions and recommendations.

Members

- Sam Notzon, CDC Foundation
- Saman Gamage, University of of Melbourne
- Rasika Rampihtage, University of Melbourne
- Rodela Khan
- Hafiz Chowdhury, University of Melbourne
- Yusuf Hemed, private consultant

Annex 3: Summary of the ICD-9 to ICD-10 Comparability Study, United States, 2001

The United States transition from ICD-9 to ICD-10 began with deaths occurring in 1999. As part of the implementation of ICD-10, the US National Center for Health Statistics carried out a dual coding (bridge coding) study to describe the effects of this transition on mortality statistics. The study involved the dual classification of the underlying cause of deaths for a single set of deaths under ICD-9 and ICD-10. The deaths used in the study were a nonrandom sample of 1.8 million deaths occurring in 1996, those that could be coded in time for the dual coding study. For this reason, the NCHS publication summarizing the results of this study was deemed a preliminary comparability study.[3]

Major changes to the ICD were introduced with the Tenth Revision of the ICD. To begin, ICD-10 is much more detailed than ICD-9 (8,000 categories for classifying causes of death as compared to only 5,000 categories in ICD-9). For example, ICD-9 used a single code to classify myocardial infarction (410) with no 4th digit to provide any additional detail. By contrast, ICD-10 uses six different codes (I21.0 – I21.4 and I21.9) to specify the site of the infection. ICD-10 also created special perinatal codes for diseases previously assigned to decedents of any age. Thus for deaths less than 28 days of age, ICD-10 assigns the code P6.0 for uremia, while the code N19 is used for uremia deaths at all other ages. Second, as part of the increased detail in ICD-10, the classification replaced the 4-digit numeric codes used in ICD-9 with alphanumeric 4-digit codes. Each of the 21 chapters of ICD-10 is assigned a letter or letters; codes within each chapter all begin with the designated letter or letters. Chapters of ICD-10 have been added or rearranged. For example, ICD-9 chapter VI, diseases of the nervous system and sense organs was divided into ICD-10 chapter VI (Diseases of the Nervous System), chapter VII (Diseases of the Eye and Adnexa, and chapter VIII (Diseases of the Ear and Mastoid Process). Within chapters, cause of death titles have been changed and regrouped.

ICD-10 also introduced changes in international selection and modification rules for the ICD. One of the most important was a change in the direct sequel rule and its effect on pneumonia. The direct sequel rule (Rule 3) governs selection of the underlying cause of death, requiring replacement of the condition selected by the General Principle, Rule 1 or Rule 2 if that condition was the consequence of another reported condition. In ICD-10 however, a change in the wording of the direct sequel rule required it to be applied much more broadly than in ICD-9. Because pneumonia is often the consequence of another condition or injury, pneumonia was much less likely to be selected as the underlying cause of death in ICD-10. Another consequence of the rule change was to slightly increase the selection of other conditions, such as various heart diseases, cerebrovascular diseases, complications of diabetes, malignant neoplasms and some external causes of death.

Other rule changes affected chapter XVIII, the ill-defined disease chapter in ICD-10. The most important change was to exempt SIDS (Sudden Infant Death Syndrome) from the rule stipulating that for any condition from chapter XVIII selected as underlying condition, if one or more other conditions are present on the MCCD, the underlying cause should be re-selected without taking into account the condition from chapter XVIII. The result was to make SIDS more likely to be selected in ICD-10. The other change in ICD-10 was to treat certain other

conditions not in chapter XVIII as ill-defined, such as unspecified cardiac arrest (I46.9), unspecified hypotension (I95.9), Acute respiratory failure (J96.0) and others.

Data

This study is based on death certificate information from a nonrandom sample of 1.8 million 1996 US death certificates. This 80 percent sample (1.8 million out of a total of 2.3 million certificates) represents all the 1996 certificates that could be coded in time for the study. Remaining 1996 certificates were rejected by the MMDS system for manual coding, and only a small number of those could be manually coded in time to be included. Rejected certificates primarily included causes that required careful examination, such as rare causes, maternal deaths, some external causes and deaths due to complications of surgeries. For this reason, the comparability file contains only small numbers of deaths with these causes. As a result, comparability ratios for these causes were not included in the report.

Methods

A dual coding study requires underlying cause of death data to be coded in both ICD revisions, while ensuring that selection and modification rules for each revision are applied. For the US study, the underlying cause of death data were coded twice, first with the ICD-9 version of the automated coding system – the Mortality Medical Data System (MMDS) - and subsequently with the MMDS for ICD-10. The resulting information was used to create the ICD-9 to ICD-10 comparability file.

The comparability file contained the information needed to calculate comparability ratios, which describe the impact on mortality of the change from ICD-9 to ICD-10. For each cause of death, the comparability ratio was calculated as the number of deaths due to that cause in ICD-10, divided by the number of deaths assigned to that cause in ICD-9. ICD-10 changes that resulted in an increase in the number of deaths coded to a particular cause produced comparability ratios greater than 1.0, while changes reducing the number of deaths assigned to a given cause would result in a comparability ratio of less than 1.

Results

The Tenth Revision of the ICD incorporated a number of important changes to the classification as well as to the selection and modification rules, as mentioned above. The changes produced discontinuities, some of substantial size, in cause of death trends between the last year of ICD-9 and the first year of ICD-10. The cause of death ratios in the report were essential to understand those discontinuities for mortality analysis, public health planning and policy development.

The most unexpected impact on comparability ratios was for influenza and pneumonia (ratio = 0.6982), as the change in wording of the direct sequence rule was not expected to have that large an effect on the selection of pneumonia as the underlying cause. While the number of deaths assigned to influenza under ICD-10 coding was similar to the total when coded in ICD-9, the number of pneumonia deaths declined by nearly 22,000 when the revised direct sequel rule was applied. Deaths no longer assigned to pneumonia were primarily assigned to diseases of

the heart, cerebrovascular diseases, malignant neoplasms, chronic lower respiratory diseases, septicemia, malnutrition, and chronic liver disease and cirrhosis.

Other diseases reporting substantial changes in comparability ratios included Alzheimer's Disease (1.5536, and an increase of 10,586 deaths), nephrotic syndrome and nephrosis (1.2320), septicemia (1.1949), viral hepatitis (0.8343), tuberculosis (0.8547), and human immunodeficiency virus (HIV) (1.0637).

Comparability ratios were relatively small for some diseases but the impact was disproportionately large on the number of deaths. For example, the US study reported an overall decrease in the selection of diseases of the heart under ICD-10 (ratio of 0.9858, or 1.5 % fewer deaths). While the change was small on a percent basis the reduction in the absolute number of such deaths was large (8,841), owing to the importance of this cause group in the US. Other changes with an outsized effect on the absolute number of deaths included cerebrovascular diseases (ratio = 1.0588 and an increase of 7,624), chronic lower respiratory diseases (1.0478 and an increase of 4,304), and malignant neoplasms (1.0068 and an increase of 3,144).

The reason for the increase or decrease in deaths under ICD-10 varied from one cause to another. For example, diseases of the heart were slightly less likely to be selected under ICD-10 because of the change in Rule A. Under Rule A in ICD-10, cardiac arrest is treated as an ill-defined disease and therefore ignored in the selection of the underlying cause if another more specific cause is listed on the certificate. Some deaths were added to the heart category, most the result of the change of the direct sequence rule affecting pneumonia. The increase in the number of malignant neoplasm deaths was due primarily to the change in the direct sequence rule, although some deaths were shifted from malignant neoplasms to HIV or neoplasms of uncertain behavior. Most of the 23 percent increase in nephritis, nephrotic syndrome and nephrosis can be attributed to changes in the classification of renal failure. End-stage renal disease, classified as an unspecified disorder of the kidney and grouped with "all other diseases" in ICD-9 was reclassified as end-stage renal disease and grouped with renal failure in ICD-10. The 6 percent increase in deaths due to HIV in ICD-10 was largely attributed to changes in highly improbable sequences. Under ICD-9, only selected malignant neoplasms could be part of a valid sequence with HIV. Other malignant neoplasms listed with HIV would be considered highly improbable and the malignant neoplasms, rather than HIV, would be selected as the underlying cause. In ICD-10 any malignant neoplasm reported as due to HIV was considered acceptable and HIV was selected as the underlying cause. Other deaths were added to HIV because of the change in the direct sequel rule and its impact on other diseases (infectious diseases and vital hepatitis) when reported as due to HIV. The NCHS report describes ICD-10 coding changes for a number of additional diseases. Readers with an interest in those changes should refer to the NCHS report.

Impact of ICD-10 implementation on mortality trends by cause of death

As noted above, application of the changes in coding rules including selection of the underlying cause of death led to significant changes in the number of deaths coded to various causes.

This can be best illustrated with a review of the 10 leading causes of death in 1996, as coded with ICD-9 and ICD-10. Although the top 5 leading causes remained the same (Diseases of the heart, Malignant neoplasms, Cerebrovascular diseases, Chronic lower respiratory diseases, and Accidents (Unintentional injuries)) there were important changes in the remaining five leading causes of death. Influenza and pneumonia, ranked 6th in 1996 with iCD-9 coding, fell to the 7th position following the changes in coding rules in ICD-10. Diabetes mellitus moved up from the 7th to the 6th leading cause of death under ICD-10. Alzheimer's disease, previously not part of the 10 leading causes, moved to the 8th leading cause thanks to changes included in ICD-10. HIV and suicide moved from 8th and 9th to 9th and 10th positions, respectively. Chronic liver disease and cirrhosis, ranked 10th when coded under iCD-9, was no longer one of the 10 leading causes of death under ICD-10.

Keeping in mind these and other discontinuities in cause of death trends helped to ensure correct interpretation of real mortality changes and the ensuing effects on mortality analysis, public health planning and policy development.