MINISTRY OF HEALTH
MANATŪ HAUORA

New Zealand Government

Summary of the Review of Public Comment Feedback on the Draft HISO 10038.4 Cancer MDM Data Standard

Released 2021

Citation: Ministry of Health. 2021. *Summary of the Review of Public Comment Feedback on the Draft HISO 10038.4 Cancer MDM Data Standard*. Wellington: Ministry of Health.

Published in April 2021 by the Ministry of Health
PO Box 5013, Wellington 6140, New Zealand

ISBN 978-1-99-100707-0 (online)
HP 7657

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Background

In 2017, cancer multidisciplinary meeting (MDM) subject matter experts developed the draft HISO 10038.4 Cancer MDM Data Standard (the draft standard), in consultation with stakeholders. The draft standard defined a consistent way of capturing data to support interoperability between hospital systems as well as informed decision-making during an MDM.

In 2019, the draft standard was updated to reflect the release of the **New Zealand Cancer Action Plan 2019–2029**, with a number of other changes made to enhance the standard.

HISO approved the release of the draft standard for public comment in February 2020. Due to the impact of COVID-19, Te Aho o Te Kahu (the Cancer Control Agency) asked that the release of the standard be delayed. The Ministry of Health (the Ministry) sought public comment on the standard from 18 May 2020 and, after receiving requests for the period to be extended, closed the submission on 24 July 2020. The Ministry received 34 submissions.

The following sections summarise the responses received as a result of the public consultation process and provides an overview of the decisions made by the MDM subject matter experts. This document includes:

- the source of the responses and the number of responses received
- the summary of the responses and the outcome of the working group's review.

1 Source of responses and number of responses received

Table 1 lists the responses received from the public consultation by organisation type. In some instances, collated feedback was submitted by a group of individuals representing one organisation.

Table 1: Submissions received by organisation type

Response type	Number of responses	Number of individual comments received
Academic	3	17
Cancer networks (includes regional and cancer tumour networks)	8	146
Colleges (eg, The Royal New Zealand College of General Practitioners)	2	19
District health boards (DHBs) (some DHBs provided multiple submissions)	18	175
Other	3	24
Total responses	**34**	**381**

2 Summary of responses and outcomes

Table 2 provides an overview of the feedback received from respondents in the public comment process and the outcomes agreed by the MDM subject matter experts (the experts).

Note: Where feedback has been covered under 'General comments', it has not been repeated in the specific sections.

Table 2: Summary of feedback received from public consultation

Brief overview of feedback	Outcome
General comments	
We received mixed feedback around the development of the draft Cancer MDM Data Standard (the standard). Some respondents felt the standard was comprehensive and aspirational and supported the approach of consistent and well-documented cancer multidisciplinary meetings (MDMs). Respondents noted the substantial amount of minimum information that needed to be captured. Some respondents felt the standard was too ambitious, potentially time consuming and would be a burden for clinical and MDM coordinators. Capturing the level of detail required, or pulling the information from the various electronic systems, would take time and effort and potentially be detrimental to the core functions of an MDM. The standard relies on integrated systems, and this is a current challenge for most MDMs. Respondents also felt that the standard should identify the information to be captured specifically for the MDM process, which is a single moment of a patient's pathway, and should not be for the purposes of a data collection.	The subject matter experts (the experts) acknowledged the feedback received and noted that the standard was developed as a key enabler to support decision-making during the MDM process. Data items were selected primarily for their relevance in facilitating discussion and decision-making. However, the experts also acknowledged that some data elements did not support decision-making in an MDM. These elements were removed (see the discussion under specific sections below for further details). The experts reviewed the obligations within the standard, based on the understanding that some current systems are unable to auto populate but might be able to support interoperability in the future. They identified and made mandatory the key 'minimum' data elements that are necessary to support MDM decision-making. They retained other data elements but changed those elements to 'optional' to support organisations updating or implementing new MDM systems. The experts acknowledged that the standard was not applicable for paediatric cancer and felt that this could be addressed separately. Thus, they updated the 'out of scope' list to include paediatric cancers.

Brief overview of feedback	Outcome
Some respondents advised that they already capture much of the information documented in some of the sections at MDMs. Some respondents advised the standard was not applicable for paediatric cancer.	
Introduction	
Respondents felt that equity should be reflected in the standard's introduction as MDMs aim to support collaborative decision-making.	The introduction section of the standard was revised to ensure it referred to high-quality data as a key enabler for informed decision-making during the MDM process. It was also updated to include reference to the importance of collecting this information for those with poorer health care experiences and/or outcomes.
3.1 Patient details	
Respondents felt that the fields that need to be captured should be auto populated from other electronic systems. This idea was supported by feedback from the pilot site that implemented the standard.	The fields identified in the standard are currently captured in some tumour-specific MDMs. The pilot site was able to auto populate some of the data fields.
3.2 General practitioner details	
There was mixed feedback on the inclusion of these data elements as not everyone is assigned a specific general practitioner (GP) (especially in rural areas).	As a patient would most likely be enrolled in a general practice, the GP details were removed from the standard. The remaining fields have been made 'optional'.
3.3 Core referral information and key questions	
Respondents felt the standard needed to reflect the ability to capture pathology and radiology separately, as well as other types of investigation.	As a result of the feedback, pathology and radiology were separated and data elements were included for collecting other investigations.
Some respondents queried the inclusion of the term 'Key questions' as they felt this may become a risk for the patient and clinicians if referrals are 'parked' or not accepted due to lack of response.	The experts disagreed with the respondents' queries around 'Key questions' as the purpose of this data element is to ensure there are 'no surprises' and the pathologist/radiologist is not caught out by a question from left field. These questions are used to guide and focus the pathologist/radiologist's review.
3.4 Clinical background	
Respondents recommended including comorbidities (and a list of SNOMED CT terms) to support discussions around determining recommended treatments.	The experts agreed that comorbidity details are important for making decisions on treatment and should be included. A list of SNOMED CT terms and identifiers for comorbidities has been included in the appendices and forms the base for future development.

Brief overview of feedback	Outcome
3.5 Family history	
General feedback indicated that the family history data fields proposed for collection are irrelevant for decision-making during the MDM process. This type of information is neither accessible, readily available nor known by clinicians or patients. Moreover, capturing this information could potentially breach the privacy of individuals not central to the MDM discussion.	Experts agreed that the family history section should be removed from the standard as it did not support decision-making during the MDM process.
3.6 Current presentation	
Respondents felt that faster cancer treatment data is captured elsewhere in a patient's record and is not relevant to clinical planning.	The experts agreed that all Faster Cancer Treatment data elements should be removed.
3.7 Staging	
Respondents felt that not all cancers can be staged using AJCC TNM staging. They believed there must be customised staging for these types of cancers.	The experts acknowledged that AJCC staging is not applicable to all cancers. They reviewed the list of other staging systems to include the most common staging systems, and this list will be revised in a future edition.
• **TNM staging support** Responses: Agreed/supported (15), opposed (3), no comment (16), comments received (7). Overall, respondents supported the use of TNM staging. However, they felt it is not applicable to some tumour groups (eg, breast, gynaecology oncology and most childhood cancers).	The experts changed the obligation for data elements that capture TNM data so that values do not have to be recorded for those cancers where they are not applicable.
3.8 Pathology/radiology review	
Respondents felt this section needs to be able to capture other investigations as not all are pathology/radiology. Some existing systems are capturing this information.	Concordance for other investigations will not be included in this section as concordance reviews are only completed on pathology or radiology.
3.9 MDM meeting details	
The pilot site indicated that they were unable to map clinicians, clinical role, quorum specialty and MDM facility from the HPI. The standard does not provide the ability to understand what the minimum quorum would be for each meeting.	Auto population would depend on the implementation of the HPI standard and the interoperability between the systems. As the quorum details are part of the MDM's terms of reference, the experts agreed that the data elements should be replaced by an indicator to identify if the quorum has been met.

Brief overview of feedback	Outcome
3.10 MDM discussion and recommendations	
Respondents felt that the data elements would not provide enough information to identify whether prioritised patients received equitable care.	The experts determined that the focus on equity of care and prioritisation of patients would be handled elsewhere, eg, within an MDM terms of reference or clinical processes.
The standard needs to include the ability to capture free text fields for 'other' when the data element options provided are not applicable.	Additional fields were included to provide the ability to capture additional information where 'other' has been recorded as a response to a data element.
Respondents requested the inclusion of appropriate SNOMED CT lists for tumour-specific investigations and referral specialties.	The experts agreed that SNOMED CT lists should be developed. Due to the volume of terms for some data elements, these will need to be applied to the standard post publication.
3.11 Post-MDM patient consultation	
Respondents felt this information does not contribute to the core purpose of the MDM. Capturing information about the discussion with the patient occurs after an MDM.	The experts agreed that this section does not contribute to the decision-making at an MDM, and it was removed.
4. Adoption roadmap	
Respondents indicated that they would welcome support in the implementation phases of an MDM IT system. Systems that integrate with other clinical systems would be required to reduce duplication and manual entry. Some respondents noted that, as technology evolves, systems will need to be agile otherwise there will be legacy systems that are not fit for purpose, creating fragmentation and inefficiencies. Having tumour-specific standards would also further support the adoption of this standard.	The experts noted the respondents' comments. This section has been removed in the revised standard.