

WELSH INFORMATION STANDARDS BOARD

DSC Notice:	DSCN 2022 / 49 (AMD)
Date of Issue:	11 th October 2024

<p>Welsh Health Circular/Official Letter: WHC (2022)005: Welsh Value in Health Centre – Data Requirements</p>	<p>Subject: Value in Health – Data Entry Questions (AMD)</p>
<p>Sponsor: Dr Sally Lewis, National Clinical Lead for Value-Based and Prudent Healthcare</p>	
<p>Effective from: 1st September 2024</p>	
<p>DATA STANDARDS CHANGE NOTICE</p> <p>A Data Standards Change Notice (DSCN) is an information mandate for a new or revised information standard.</p> <p>This DSCN was approved by the Welsh Information Standards Board (WISB) at its meeting on 19th September 2024.</p> <p>WISB Reference: ISRN 2024 / 017</p>	
<p>Summary: To describe the content of Patient Reported Outcome Measures (PROMs) for the Data Entry Questions element of the PROMs pathways as part of the applicable Value in Health programme.</p>	
<p>Data sets / returns affected: Patient Reported Outcomes Measures (PROMs) (wales.nhs.uk)</p>	
<p>Please address enquiries about this Data Standards Change Notice to the Data Standards Team in Digital Health and Care Wales</p> <p>E-mail: data.standards@wales.nhs.uk / Tel: 02920502539</p>	
<p>The Welsh Information Standards Board is responsible for appraising information standards. Submission documents and WISB Outcomes relating to the approval of this standard can be found at:</p> <p>https://nhswales365.sharepoint.com/sites/DHC_DST/Lists/Information%20Standards%20Assurance%20Submission%20Log/AllItems.aspx</p>	

DATA STANDARDS CHANGE NOTICE

Introduction

The Value in Health (or VIH) programme was commissioned by Welsh Government to “Improve the health outcomes of the people in Wales, in a financially sustainable way, through the creation of a data-driven system, which seeks to provide timely information to citizens, clinical teams and organisations to inform decision-making.”

Part of this programme includes the development of digital products capable of providing outcome-based analytical information at the point of care, as well as for secondary uses analyses. In particular, these products aim to:

- Provide an analytical tool to allow clinicians to view data at population level and make informed decisions based on relationships they identify between diagnoses, treatments and outcomes/survival;
- Improve accessibility of national audit data and make this visible throughout the year rather than via the annual statutory reporting process;
- Improve data quality by making the data more visible and using measures to highlight data issues;
- Make historical data available to enable the identification of patterns and trends over time; and
- Provide drill-through functionality to allow clinicians to drill down to record level and identify corresponding patient records in operational systems.

This is to be achieved through the central collection of Patient Reported Outcome Measures (PROMs) and national clinical audit data, and data linkage to associate these records with sources of existing activity data, through data sets such as Admitted Patient Care (APC ds), Outpatient activity (OP ds) and Emergency Department Data Set (EDDS).

The mandate for the necessary patient reported and clinical outcome data was issued to NHS Wales by Welsh Government via WHC (2022)005¹. This describes the requirement in the context of national strategy for health and social care, and the necessity for services to adapt to the evolving healthcare needs of the ageing population to create a service that is flexible and more effective in dealing with these emerging challenges.

Due to the breadth and complexity of the information and associated processes, this will be achieved using an iterative approach. This DSCN sets out the specification for a standardised minimum data set of metadata to be applied to all (new and existing) PROMs data.

Standardised data is vital to effective central storage of PROMs data and, in particular, to the data linkage and analysis processes necessary to interpret the data to provide meaningful and consistent information via the aforementioned digital dashboards and data visualisation tools.

This DSCN describes the standard set of metadata items required to ensure that key commonalities are preserved and maintained across PROMs records. These standards are independent of the organisations and PROMs applications used to collect this information, and therefore support the seamless communication of PROMs information and enable comparative analysis at a population level.

The information specification set out in this DSCN describes the minimum metadata set to be applied to all new and existing PROMs records. These metadata describe the components necessary to connect the patient, their completed questionnaires and the various touchpoints along their pathway, facilitating an end-to-end view of patient

¹ <https://gov.wales/welsh-value-health-centre-data-requirements-whc2022005>

reported outcomes throughout the longitudinal record. By utilising common standards, linkages to activity and clinical information is also possible to provide a complete value-based view. Alignment with similar standards also allows effective storage and retrieval of PROMs records in clinical document repositories, and integration with clinical portals/workstations.

Scope

A PROMs form can be issued to a patient at any point along their treatment pathway. Usually this occurs prior to, and at regular intervals following their treatment, as a means of measuring and monitoring the effectiveness of their treatment following an intervention, from the patient's perspective.

This data standard defines the information specification and serves as a basis for the development of technical and interoperability standards which, in turn, define the data extraction and communication mechanisms necessary to unlock data from PROMs applications for both national and local purposes, to enable analysis at patient and population level. The detail of these technical standards is described in the associated technical specification documentation.

The scope of this standard is independent of the platform or source application used to capture PROMs information; however, it is limited to the nationally validated PROMs tools. The composition of the associated PROMs data sets is described in separate DSCNs, one for each PROMs tool, e.g. Oxford Knee Score.

The metadata items defined in this DSCN comprise the following components or data modules:

- Patient Details;
- Document Details;
- Event Details;
- PROMs Details; and
- Data Entry Details.

This DSCN should be read in conjunction with the associated notices for each PROMs tool.

Furthermore, there are additional metadata items required for storage of PROMs records in a central document repository, e.g. the Welsh Care Records Service (WCRS). These are not a requirement for inclusion in the data set and central flow of data described in this DSCN, but the intention is for these to be added to that data set for consumption by the document repository, to enable access via the clinical record. For details of these items, please refer to the Document Metadata Standard.

Effective Date

This data standard is effective from the date of publication. Only those data flows that comply with the standard, and associated technical standards, will be processed for central storage and consumption by ViH products, and nationally developed views managed centrally by Digital Health and Care Wales (DHCW). Details of the implementation plan and central submission process are to be described in the associated technical specification.

Description of Change

This DSCN supersedes DSCN 2022 / 49.

Changes to the previous publication are highlighted as follows:

- **Blue** – new text
- **Grey** – existing text
- ~~Strikethrough~~ – text deletions

Data Dictionary Version

Where applicable, this DSCN reflects changes introduced by DSCN and/or DDCN since the release of version 4.21 of the NHS Wales Data Dictionary.

The changes introduced by such DSCNs will be published in version 4.22 of the NHS Wales Data Dictionary.

Actions Required

Local Health Boards / Trust:

- To work collaboratively with DHCW and other provider organisations to develop the technical interoperability standards necessary for effective communication of PROMs data across systems and organisational boundaries; and ultimately
- To supply questionnaire and PROMs data to DHCW in accordance with the information specification described in this DSCN.

Digital Health and Care:

- To work collaboratively with provider organisations to develop the technical interoperability standards necessary for effective communication of questionnaire and PROMs data across systems and organisational boundaries; and ultimately
- To supply questionnaire and PROMs data to health boards and trusts in accordance with the information specification described in this DSCN.

Appendix A: Table reflecting areas that are impacted as a result of this DSCN

The following table shows where there are changes to the scope and/or definitions of applicable data sets, data items, terms and other associated areas that are linked with the changes documented within this DSCN.

Each data definition type is listed in alphabetical order and is shown in the sequence in which it appears in this DSCN.

Data Definition Type	Name	Status
Data module	Patient Details	Existing
Data module	Document Details	Existing
Data module	Event Details	Existing
Data module	PROMs Details	Existing
Data module	Data Entry Details	Existing
Data module	Data Entry Questions	Existing
Data item	Completing Questionnaire	Changed
Data item	Relationship To Patient	Changed
Data item	Physical impairment	Changed
Data item	Mental impairment	Changed
Data item	Under 16	Changed
Data item	No Language	Changed
Data item	Remote collection	Changed
Data item	Other reason	Changed

Appendix B: Highlighted changes to be made to the NHS Wales Data Dictionary

Changes to the NHS Wales Data Dictionary are detailed below, with new text being highlighted in **blue** and deletions are shown with a **strikethrough**. The text shaded in **grey** shows existing text copied from the NHS Wales Data Dictionary.

Data Type	Item Name	Reference	Data represents
Data Module	Patient Details	MPDPX	See PROMs Metadata specification
Data Module	Document Details	MDDPX	See PROMs Metadata specification
Data Module	Event Details	MEDPX	See PROMs Metadata specification
Data Module	PROMs Details	MPRPX	See PROMs Metadata specification
Data Module	Data Entry Details	MDEPX	See PROMs Metadata specification
Data Item	Completing Questionnaire	MDEPX001X	Code from applicable value set
Data Item	Relationship To Patient	MDEPX002X	Code from applicable value set
Data Item	Physical impairment	MDEPX003A	Code from applicable value set
Data Item	Mental impairment	MDEPX003B	Code from applicable value set
Data Item	Under 16	MDEPX003C	Code from applicable value set
Data Item	No Language	MDEPX003D	Code from applicable value set
Data Item	Remote collection	MDEPX003E	Code from applicable value set
Data Item	Other reason	MDEPX003F	Code from applicable value set

- **Please note that all data modules/items are mandatory, but the information specifications contain details for populating items where there is no data, e.g. 8 – N/A, 9 – Unknown, etc.**
- **Note also that a data record should be submitted as long as there is data for 1 or more questions. For questions where an answer has not been supplied, a value of NULL, N/A or unknown should be provided against the relevant data item in accordance with the specification described below.**

Appendix C: Information Specification

Changes to the NHS Wales Data Dictionary are detailed below, with new text being highlighted in **blue** and deletions shown with a **strikethrough**. Text shaded in grey denotes existing content.

Question Reference	Question Text	Data Item Name	Format	Value Set / Example																
MDEPX001X	Are you completing this questionnaire for someone else?	Completing Questionnaire	1-digit numeric	<p>e.g. 0 – No Please refer to the technical specification for details</p> <table border="1"> <tr> <td>0</td> <td>No*</td> </tr> <tr> <td>1</td> <td>Yes</td> </tr> <tr> <td>9</td> <td>Unknown</td> </tr> </table> <p>*Note that a value of '0 – no' should only be recorded if there is an option for the patient to explicitly answer 'no' to the question, otherwise use '9 – unknown'</p>	0	No*	1	Yes	9	Unknown										
0	No*																			
1	Yes																			
9	Unknown																			
MDEPX002X	What is your relationship to the patient?	Relationship To Patient	2-digit numeric 1-digit numeric	<p>e.g. 02 – Relative or carer on behalf of the patient Please refer to the technical specification for details</p> <table border="1"> <tr> <td>1</td> <td>Spouse/Partner</td> </tr> <tr> <td>2</td> <td>Parent/Guardian</td> </tr> <tr> <td>3</td> <td>Other family member</td> </tr> <tr> <td>4</td> <td>Friend</td> </tr> <tr> <td>5</td> <td>Social-care professional</td> </tr> <tr> <td>6</td> <td>Healthcare professional</td> </tr> <tr> <td>7</td> <td>Other</td> </tr> <tr> <td>9</td> <td>Unknown</td> </tr> </table>	1	Spouse/Partner	2	Parent/Guardian	3	Other family member	4	Friend	5	Social-care professional	6	Healthcare professional	7	Other	9	Unknown
1	Spouse/Partner																			
2	Parent/Guardian																			
3	Other family member																			
4	Friend																			
5	Social-care professional																			
6	Healthcare professional																			
7	Other																			
9	Unknown																			
	Why is your assistance needed?	Why Assistance Needed		[Question header, no returned data]																

Question Reference	Question Text	Data Item Name	Format	Value Set / Example								
MDEPX003A	Physical impairment	Physical impairment	1-digit numeric	<table border="1"> <tr> <td>0</td> <td>No*</td> </tr> <tr> <td>1</td> <td>Yes</td> </tr> <tr> <td>8</td> <td>N/A</td> </tr> <tr> <td>9</td> <td>Unknown</td> </tr> </table> <p>*Note that a value of '0 – no' should only be recorded if there is an option for the patient to explicitly answer 'no' to the question, otherwise use '9 – unknown'</p>	0	No*	1	Yes	8	N/A	9	Unknown
0	No*											
1	Yes											
8	N/A											
9	Unknown											
MDEPX003B	Mental impairment	Mental impairment	1-digit numeric	<table border="1"> <tr> <td>0</td> <td>No*</td> </tr> <tr> <td>1</td> <td>Yes</td> </tr> <tr> <td>8</td> <td>N/A</td> </tr> <tr> <td>9</td> <td>Unknown</td> </tr> </table> <p>*Note that a value of '0 – no' should only be recorded if there is an option for the patient to explicitly answer 'no' to the question, otherwise use '9 – unknown'</p>	0	No*	1	Yes	8	N/A	9	Unknown
0	No*											
1	Yes											
8	N/A											
9	Unknown											
MDEPX003C	Under 16	Under 16	1-digit numeric	<table border="1"> <tr> <td>0</td> <td>No*</td> </tr> <tr> <td>1</td> <td>Yes</td> </tr> <tr> <td>8</td> <td>N/A</td> </tr> <tr> <td>9</td> <td>Unknown</td> </tr> </table> <p>*Note that a value of '0 – no' should only be recorded if there is an option for the patient to explicitly answer 'no' to the question, otherwise use '9 – unknown'</p>	0	No*	1	Yes	8	N/A	9	Unknown
0	No*											
1	Yes											
8	N/A											
9	Unknown											

Question Reference	Question Text	Data Item Name	Format	Value Set / Example								
MDEPX003D	No Language	No Language	1-digit numeric	<table border="1"> <tr><td>0</td><td>No*</td></tr> <tr><td>1</td><td>Yes</td></tr> <tr><td>8</td><td>N/A</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table> <p>*Note that a value of '0 - no' should only be recorded if there is an option for the patient to explicitly answer 'no' to the question, otherwise use '9 - unknown'</p>	0	No*	1	Yes	8	N/A	9	Unknown
0	No*											
1	Yes											
8	N/A											
9	Unknown											
MDEPX003E	Remote collection	Remote collection	1-digit numeric	<table border="1"> <tr><td>0</td><td>No*</td></tr> <tr><td>1</td><td>Yes</td></tr> <tr><td>8</td><td>N/A</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table> <p>*Note that a value of '0 - no' should only be recorded if there is an option for the patient to explicitly answer 'no' to the question, otherwise use '9 - unknown'</p>	0	No*	1	Yes	8	N/A	9	Unknown
0	No*											
1	Yes											
8	N/A											
9	Unknown											
MDEPX003F	Other reason	Other reason	1-digit numeric	<table border="1"> <tr><td>0</td><td>No*</td></tr> <tr><td>1</td><td>Yes</td></tr> <tr><td>8</td><td>N/A</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table> <p>*Note that a value of '0 - no' should only be recorded if there is an option for the patient to explicitly answer 'no' to the question, otherwise use '9 - unknown'</p>	0	No*	1	Yes	8	N/A	9	Unknown
0	No*											
1	Yes											
8	N/A											
9	Unknown											