

WELSH INFORMATION STANDARDS BOARD

DSC Notice:	DSCN 2024 / 04
Date of Issue:	9 th January 2024

<p>Welsh Health Circular / Official Letter:</p> <p>WHC (2022)005: Welsh Value in Health Centre – Data Requirements</p>	<p>Subject: Value in Health – PROMs Metadata</p>
<p>Sponsor: Dr Sally Lewis, National Clinical Lead for Value-Based and Prudent Healthcare</p>	
<p>Effective from: 9th January 2024</p>	

DATA STANDARD CHANGE NOTICE

A Data Standard Change Notice (DSCN) is an information mandate for a new or revised information standard.

This DSCN was approved by the Welsh Information Standards Board (WISB) on 21st December 2023

WISB Reference: ISRN 2023 / 037

Summary:

To standardise the metadata used for Reported Outcome Measures (PROMs) as part of the Value in Health programme.

Applies to:

This Standard applies to all bodies that commission or provide health and care services in Wales in partnership with the NHS including their relevant system suppliers.

Please address enquiries about this Data Standard Change Notice to the Data Standards Team in Digital Health and Care Wales

E-mail: data.standards@wales.nhs.uk / Tel: 029 2050 3593

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:

https://nhswales365.sharepoint.com/sites/DHC_DST/Lists/Information%20Standards%20Assurance%20Submission%20Log/AllItems.aspx

DATA STANDARD 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 reported outcomes throughout

¹ <https://gov.wales/welsh-value-health-centre-data-requirements-whc2022005> (NHS Wales users only)

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

To standardise the metadata used for Reported Outcome Measures (PROMs) as part of the Value in Health programme.

This update to the previous Standard² describes changes identified as a result of a review. Changes are marked in the usual way.

Actions Required

Local Health Boards / Trust:

- To capture PROMs metadata in accordance with the information specification described in this DSCN; and
- To work with DHCW to develop mechanisms which enable central data collection of PROMs data to include these metadata items.

Digital Health and Care Wales:

- To work with health boards and trusts to develop technical solutions to allow PROMs metadata to be collected locally; and
- To work with health boards and trusts to develop mechanisms which enable the metadata to be collected centrally and stored in a standardised way.

² <https://dhw.nhs.wales/information-services/information-standards/data-standards/data-standards-files/data-standard-change-notice-docs/dscns-2022/20221114-dscn-48-vih-proms-metadata-v2pdf/>

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 shown in the sequence in which it appears in this DSCN.

Data Definition Type	Name	Status	Page Number
Patient Details	NHS Number	Changed	8
Patient Details	NHS Number Status Indicator	Changed	8
Patient Details	Local Person Identifier	Changed	8
Patient Details	Local Person Identifier Origination	New	8
Patient Details	Given Name	Changed	8
Patient Details	Family Name	Changed	8
Patient Details	Date of Birth	Changed	8
Patient Details	Gender Identity	Changed	8
Patient Details	Postcode	Changed	8
Document Details	Originating System	Changed	9
Document Details	Originating Organisation Code	Changed	9
Event Details	Treatment Specialty Code	Changed	9
Event Details	Senior Responsible Professional Name	Changed	9
Event Details	Senior Responsible Professional Identifier Code System	Changed	9
Event Details	Senior Responsible Professional Identifier	Changed	10
PROMs Details	Event Location Code	Changed	10
PROMs Details	PROMs Issued Date	Existing	10
PROMs Details	PROMs Completion Date & Time	Changed	10
PROMs Details	Referral Identifier	Changed	10
PROMs Details	Referral Identifier Origination	New	10
PROMs Details	PROMs Pathway Type	Changed	11
PROMs Details	PROMs Tool	Changed	11
PROMs Details	PROMs Trigger Event Type	Changed	11
PROMs Details	PROMs Language	Changed	11
PROMs Details	Local PROMs Pathway Type	New	11
PROMs Details	Local PROMs Tool	New	11
PROMs Details	PROMs Data Standard Version	New	11
PROMs Details	PROMs Trigger Event Date	New	11
PROMs Data Entry Details	Pathway Laterality	New	12
PROMs Data Entry Details	PROMs Laterality	Changed	12
Data item	PROMs Trigger Event Type	New	13

Appendix B: Data Set Structure - PROMs Metadata

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.

Data Module	Item Reference	Name	Mandatory (M) / Optional (O)
Patient Details	MPDPX001X	NHS Number	M (where available)
Patient Details	MPDPX001A	NHS Number Status Indicator	M
Patient Details	MPDPX002A	Local Person Identifier Origination	O
Patient Details	MPDPX002X	Local Patient Person Identifier	M
Patient Details	MPDPX003X	Patient Given Name (Forename)	M (or optional where NHS No. is supplied and validated, i.e. with Status Indicator = 01)
Patient Details	MPDPX004X	Patient Family Name (Surname)	M (or optional where NHS No. is supplied and validated, i.e. with Status Indicator = 01)
Patient Details	MPDPX005X	Date of Birth	M
Patient Details	MPDPX006X	Gender Identity	M (or optional where NHS No. is supplied and validated, i.e. with Status Indicator = 01)
Patient Details	MPDPX007X	Postcode	M (or optional where NHS No. is supplied and validated, i.e. with Status Indicator = 01)
Document Details	MDDPX001X	Originating System	M
Document Details	MDDPX002X	Originating Organisation Code	M
Event Details	MEDPX001X	Treatment Function Specialty Code	M
Event Details	MEDPX002A	Senior Responsible Professional Name	M (or optional where Identifier and Code System are supplied)
Event Details	MEDPX002B	Senior Responsible Professional Identifier Code System	M (or optional where Name is supplied)
Event Details	MEDPX002C	Senior Responsible Professional Identifier	M (or optional where Name is supplied)
PROMs Details	MPRPX001X	PROMs Site Event Location Code	O
PROMs Details	MPRPX002X	PROMs Issued Date	M
PROMs Details	MPRPX003X	PROMs Completion Date & Time	M
PROMs Details	MPRPX004X	PROMs Pathway Referral ID Identifier	O
PROMs Details	MPRPX004A	Referral Identifier Origination	O

Data Module	Item Reference	Name	Mandatory (M) / Optional (O)
PROMs Details	MPRPX005X	PROMs Pathway Type	M
PROMs Details	MPRPX006X	PROMs Tool	M
PROMs Details	MPRPX007X	PROMs Trigger Classification Event Type	M
PROMs Details	MPRPX008X	PROMs Language	M
PROMs Details	MPRPX009X	Local PROMs Pathway Type	O
PROMs Details	MPRPX010X	Local PROMs Tool	O
PROMs Details	MPRPX012X	PROMs Data Standard Version	M
PROMs Details	MPRPX013X	PROMs Trigger Event Date	Mandatory for healthcare pathway activity-based event types, e.g. referrals, outpatient appointments, interventions, etc. (i.e. not mandatory for event types not directly resulting from these, such as clinician or patient initiated event types)
PROMs Details	MPRPX014X	Pathway Laterality	M
PROMs Data Entry Details	MDEPX004X	PROMs Laterality	M

For mandatory items where data is not available, please use the 'unknown' and 'N/A' values as defined in the information specification below.

Appendix C: Information Specification – PROMs Metadata

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.

Data Definition Type	Item Reference	Name	Format	Definition	Value Set / Example		
Patient Details	MPDPX001X	NHS Number	10-character alphanumeric	See NHS Wales Data Dictionary for details of NHS Wales Document Metadata Standard existing standard	e.g. 0123456789		
Patient Details	MPDPX001A	NHS Number Status Indicator	2-digit numeric N/A – code from associated value set	See NHS Wales Data Dictionary for details of existing standard	e.g. <table border="1" style="display: inline-table; vertical-align: middle;"> <tr> <td style="text-align: center;">01</td> <td style="text-align: center;">Number present & traced</td> </tr> </table>	01	Number present & traced
01	Number present & traced						
Patient Details	MPDPX002A	Local Person Identifier Origination	N/A – code from associated value set	The issuing system for the Local Person Identifier, e.g. PAS See NHS Wales Data Dictionary for details of NHS Wales Document Metadata Standard	Please refer to the technical specification for details Use NULL for missing or N/A values		
Patient Details	MPDPX002X	Local Patient Person Identifier	10-character alphanumeric	See NHS Wales Data Dictionary for details of NHS Wales Document Metadata Standard existing standard	e.g. 9876543210		
Patient Details	MPDPX003X	Patient Given Name (Forename)	35-character alphanumeric	See NHS Wales Data Dictionary for details of NHS Wales Document Metadata Standard existing standard	e.g. John Use NULL for missing or N/A values		
Patient Details	MPDPX004X	Patient Family Name (Surname)	35-character alphanumeric	See NHS Wales Data Dictionary for details of NHS Wales Document Metadata Standard existing standard	e.g. Smith Use NULL for missing or N/A values		
Patient Details	MPDPX005X	Date of Birth	CCYY-MM-DD yyyy-mm-dd	See NHS Wales Data Dictionary for details of NHS Wales Document Metadata Standard existing standard	e.g. 1950-01-31		
Patient Details	MPDPX006X	Gender Identity	1-character alphanumeric N/A – code from associated value set	See NHS Wales Data Dictionary for details of NHS Wales Core Reference Data Standard	e.g. F		
Patient Details	MPDPX007X	Postcode	8-character alphanumeric	See NHS Wales Data Dictionary for details of NHS Wales Document Metadata Core Reference Data Standard	e.g. AB12 3CD Use NULL for missing or N/A values		

Data Definition Type	Item Reference	Name	Format	Definition	Value Set / Example
Document Details	MDDPX001X	Originating System	6-character alphanumeric N/A – code from associated value set	For PROMs, this would be the PROMs platform that collects the PROMs information from the patient, e.g. DrDoctor, PKB, Amplitude, National Platform, etc. See NHS Wales Data Dictionary for details of NHS Wales Document Metadata Standard	Please refer to the technical specification for details Use NULL for missing or N/A values
Document Details	MDDPX002X	Originating Organisation Code	5-character alphanumeric N/A – code from associated value set	The code for the organisation from which the record originates See NHS Wales Data Dictionary for details of NHS Wales Document Metadata Core Reference Data Standard	e.g. 7A100
Event Details	MEDPX001X	Treatment Function Specialty Code	3-digit numeric N/A – code from associated value set	This is the code for the pathway specialty at the time the PROMs form is generated See NHS Wales Data Dictionary for details of NHS Wales Document Metadata Standard	e.g. 100
Event Details	MEDPX002A	Senior Responsible Professional Name	100-character alphanumeric	The name of the person who has overall responsibility for the health/care event to which the record relates. Where possible, the standardised display format convention should be used, i.e. <FAMILY_NAME>“, „<Given_name>“, „<Title> See NHS Wales Data Dictionary for details of NHS Wales Document Metadata Standard	e.g. JONES, Alan N, Dr Use NULL for missing or N/A values
Event Details	MEDPX002B	Senior Responsible Professional Identifier Code System	100-character alphanumeric N/A – code from associated value set	An identifier that uniquely identifies the Senior Responsible Professional. This is their professional registration code See NHS Wales Data Dictionary for details of NHS Wales Document Metadata Standard	e.g. GMC Use NULL for missing or N/A values Please refer to the technical specification for details

Data Definition Type	Item Reference	Name	Format	Definition	Value Set / Example
Event Details	MEDPX002C	Senior Responsible Professional Identifier	8-character alphanumeric N/A – code from associated value set	The code system for the Senior Responsible Professional Identifier See NHS Wales Data Dictionary for details of NHS Wales Document Metadata Core Reference Data Standard	e.g. 2345678 Use NULL for missing or N/A values
PROMs Details	MPRPX001X	PROMs Site Event Location Code	5-character alphanumeric N/A – code from associated value set	The code for the location where the health/care event took place For PROMs, this is the code of the site where the PROMs form was initiated See NHS Wales Data Dictionary for details of NHS Wales Document Metadata Core Reference Data Standard	e.g. 7A1A1 Use NULL for missing or N/A values
PROMs Details	MPRPX002X	PROMs Issued Date	yyyy-mm-dd	This is the date and time the PROMs form was issued to the patient	e.g. 2020-12-10
PROMs Details	MPRPX003X	PROMs Completion Date & Time	yyyy-mm-ddThh:mm:ss.ss+hh:mm	The date and time the PROMs form was completed (or when the last item was recorded for incomplete records) If only the date component is captured, this can be provided without a time component, i.e. yyyy-mm-dd	For PROMs, this is the date when the form is completed by the patient, e.g. 2020-12-10T13:30:10.999+00:00
PROMs Details	MPRPX004X	PROMs Referral Pathway ID Identifier	50-36-character alphanumeric	A locally-produced identifier which uniquely identifies the referral record An identifier that uniquely identifies the PROMs pathway for the individual patient completing the PROMs form All PROMs forms/questionnaires associated with the same referral patient and pathway/problem must have the same Pathway ID/Referral Identifier This could be the patient's clinical pathway ID or an identifier generated locally in the PROMs application	Use NULL for missing or N/A values
PROMs Details	MPRPX004A	Referral Identifier Origination	N/A – code from associated value set	The issuing system for the Referral Identifier, e.g. PAS	Please refer to the technical specification for details Use NULL for missing or N/A values

Data Definition Type	Item Reference	Name	Format	Definition	Value Set / Example
PROMs Details	MPRPX005X	PROMs Pathway Type	3-character alphanumeric N/A – code from associated value set	The type of pathway that the PROM is associated to, e.g. lung cancer, heart failure, cataract, etc.	e.g. KNA Please refer to the technical specification for details For local pathways, use OTH - Other
PROMs Details	MPRPX006X	PROMs Tool	4-character alphanumeric N/A – code from associated value set	The national code representing the PROMs tool associated with the PROMs record The 4th character of the code indicates the version number for the tool	e.g. OKS2 Please refer to the technical specification for details For local tools, use OTH - Other
PROMs Details	MPRPX007X	PROMs Trigger Classification Event Type	2-digit numeric N/A – code from associated value set	The national code representing the classification of the PROMs trigger type of healthcare or administrative event that triggers a requirement for a questionnaire (or onboarding process) to be completed ³	e.g. 03 – Pre-op or prior to surgical intervention 14 - Pre-op assessment Please refer to the technical specification for details
PROMs Details	MPRPX008X	PROMs Language	2-character alphanumeric N/A – code from associated value set	The code representing the language of the completed PROMs form	en=English cy=Welsh 71=Other
PROMs Details	MPRPX009X	Local PROMs Pathway Type	10-character alphanumeric	A locally-defined code to identify the PROMs pathway This is only required for local pathways	e.g. ZZKNA
PROMs Details	MPRPX010X	Local PROMs Tool	10-character alphanumeric	A locally-defined code to identify the PROMs tool This is only required for local tools	e.g. ZZOKS1
PROMs Details	MPRPX012X	PROMs Data Standard Version	N/A – code from associated value set	The version of the data standard used for the PROMs tool This is usually the DSC Notice reference number found at the top right corner of the associated DSCN	e.g. 2023028 for EORTC QLQ LC13 Please refer to the technical specification for details
PROMs Details	MPRPX013X	PROMs Trigger Event Date	yyyy-mm-dd	The date of the event that triggers a requirement for a questionnaire (or onboarding process) to be completed, irrespective of the date that the PROMs form was triggered/issued	e.g. 2020-12-10 for a PROMs form triggered by a surgical event taking place on 10 th December 2020

³ Definitions for each of the coded items used in the value set for PROMs Trigger Event Type can be found in [Appendix D](#)

Data Definition Type	Item Reference	Name	Format	Definition	Value Set / Example										
PROMs Details	MPRPX014X	Pathway Laterality	1-digit numeric	<p>To capture the anatomical side associated with the healthcare referral / pathway record</p> <p>Note that if a patient had been referred onto a pathway for interventions to both left and right sides and the Referral Identifier was common to both, then the Pathway Laterality would be 'both left and right'</p>	<table border="1"> <tr><td>1</td><td>Left</td></tr> <tr><td>2</td><td>Right</td></tr> <tr><td>3</td><td>Both left and right</td></tr> <tr><td>8</td><td>N/A</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	Left	2	Right	3	Both left and right	8	N/A	9	Unknown
1	Left														
2	Right														
3	Both left and right														
8	N/A														
9	Unknown														
PROMs Data Entry Details	MDEPX004X	PROMs Laterality	1-digit numeric	<p>To capture the anatomical side associated with the questionnaire being completed</p> <p>Note that if a patient completes a questionnaire for both left and right sides, two records should be generated and labelled as per the specified value set</p> <p>Note also that this item is intended to capture the laterality specified as part of the patient's PROMs pathway record as opposed to any patient reported laterality information which would be captured within the form itself</p>	<table border="1"> <tr><td>1</td><td>Left</td></tr> <tr><td>2</td><td>Right</td></tr> <tr><td>8</td><td>N/A</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	Left	2	Right	8	N/A	9	Unknown		
1	Left														
2	Right														
8	N/A														
9	Unknown														

Appendix D: Value sets and definitions

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.

PROMs Trigger Event Type

Definition: A type of healthcare or administrative event that triggers a requirement for a questionnaire (or onboarding process) to be completed.

Format: 2-digit numeric

Code	Description	Definition
10	Onboarding	To be used for onboarding purposes, i.e. when registering a patient to receive a questionnaire in the future.
11	Primary care	For a questionnaire that is to be completed in primary care, prior to a referral to secondary care.
12	Referral	When a questionnaire is to be completed following acceptance of a referral.
13	Outpatient appointment	When a questionnaire is to be completed following the booking of an outpatient appointment
14	Pre-op assessment	When a questionnaire is to be completed following the booking of a pre-op assessment appointment. This is the pre-admission outpatient appointment scheduled just before the admission to assess the patient's fitness to undergo surgery.
15	Intervention	When a questionnaire is to be completed after a health/care intervention. This only applies following receipt of confirmation that the relevant intervention, e.g. surgery, took place.
16	Discharge	When a questionnaire is to be completed at the point of discharge, where a patient may be placed on a 'see on symptoms' or 'patient-initiated follow-up' pathway.
17	Clinician-initiated	This trigger event type is used when none of the other triggers apply and a questionnaire is to be completed at an undefined stage in the pathway at the request of a clinician.
18	Patient-initiated	This trigger event type is used when none of the other triggers apply and a questionnaire is completed at an undefined stage in the pathway.
71	Other	For use when no specific trigger event type applies.
91	Unknown	For use when the reason for triggering the questionnaire is unknown.