

**WELSH INFORMATION STANDARDS BOARD**

<b>DSC Notice:</b>	DSCN 2022 10
<b>Date of Issue:</b>	5 <sup>th</sup> May 2022

<p><b>Welsh Health Circular / Official Letter:</b></p> <p>WHC (2022)005: Value-Based Health Care Programme – Data Requirements</p>	<p><b>Subject:</b> Value in Health – PROMs Metadata</p>
<p><b>Sponsor:</b> Dr Sally Lewis, National Clinical Lead for Value-Based and Prudent Healthcare</p>	
<p><b>Effective from:</b> 1<sup>st</sup> May 2022</p>	
<p><b>DATA STANDARD CHANGE NOTICE</b></p> <p>A Data Standard 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) on 17<sup>th</sup> March 2022.</p> <p><b>WISB Reference:</b> ISRN 2020 / 001</p>	
<p><b>Summary:</b> To standardise the metadata used for Reported Outcome Measures (PROMs) as part of the Value in Health programme.</p>	
<p><b>Applies to:</b> 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.</p>	
<p>Please address enquiries about this Data Standard Change Notice to the Data Standards Team in Digital Health and Care Wales E-mail: <a href="mailto:data.standards@wales.nhs.uk">data.standards@wales.nhs.uk</a> / Tel: 029 2050 3593</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: <a href="https://nhs.wales365.sharepoint.com/sites/DHC_DST/Lists/Information%20Standards%20Assurance%20Submission%20Log/AllItems.aspx">https://nhs.wales365.sharepoint.com/sites/DHC_DST/Lists/Information%20Standards%20Assurance%20Submission%20Log/AllItems.aspx</a></p>	

## 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)005<sup>1</sup>. 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

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<sup>1</sup> <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. The use of existing standards described in the Document Metadata Standard<sup>2</sup> 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 introduce a standard set of metadata for PROMs records.

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<sup>2</sup><http://www.datadictionary.wales.nhs.uk/#!WordDocuments/nhswalesdocumentmetadastandard.htm>

## 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.

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**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.

<b>Data Definition Type</b>	<b>Name</b>	<b>Status</b>	<b>Page Number</b>
Patient Details	NHS Number	Existing	8
Patient Details	NHS Number Status Indicator	Existing	8
Patient Details	Local Patient Identifier	Existing	8
Patient Details	Patient Name (Forename)	Existing	8
Patient Details	Patient Name (Surname)	Existing	8
Patient Details	Date of Birth	Existing	8
Patient Details	Gender Identity	Existing	8
Patient Details	Postcode	Existing	8
Document Details	Originating System	Existing	8
Document Details	Originating Organisation	Existing	8
Event Details	Treatment Function	Existing	9
Event Details	Senior Responsible Professional Name	Existing	9
Event Details	Senior Responsible Professional Identifier Code System	Existing	9
Event Details	Senior Responsible Professional Identifier	Existing	9
PROMs Details	PROMs Site Code	New	9
PROMs Details	PROMs Issued Date	New	9
PROMs Details	PROMs Completion Date & Time	New	9
PROMs Details	PROMs Pathway ID	New	9
PROMs Details	PROMs Pathway Type	New	9
PROMs Details	PROMs Tool	New	10
PROMs Details	PROMs Trigger Classification	New	10
PROMs Details	PROMs Language	New	10
PROMs Details	Unique Form Identifier	New	10
PROMs Data Entry Details	Are you completing this questionnaire for someone else?	New	10
PROMs Data Entry Details	What is your relationship to the patient?	New	10
PROMs Data Entry Details	Physical impairment	New	10
PROMs Data Entry Details	Mental impairment	New	11
PROMs Data Entry Details	Under 16	New	11
PROMs Data Entry Details	No Language	New	11
PROMs Data Entry Details	Remote collection	New	12
PROMs Data Entry Details	Other reason	New	12
PROMs Data Entry Details	Laterality	New	12

## Appendix B: Data Set Structure - PROMs Metadata

Data Module	Item Reference	Name	Mandatory (M) / Optional (O)
Patient Details	MPDPX001X	NHS Number	O
Patient Details	MPDPX001A	NHS Number Status Indicator	M
Patient Details	MPDPX002X	Local Patient Identifier	M
Patient Details	MPDPX003X	Patient Name (Forename)	M (or optional where NHS No. is supplied and validated, i.e. with Status Indicator = 01)
Patient Details	MPDPX004X	Patient 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	M
Event Details	MEDPX001X	Treatment Function	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 Code	O
PROMs Details	MPRPX002X	PROMs Issued Date	M
PROMs Details	MPRPX003X	PROMs Completion Date & Time	M
PROMs Details	MPRPX004X	PROMs Pathway ID	O
PROMs Details	MPRPX005X	PROMs Pathway Type	M
PROMs Details	MPRPX006X	PROMs Tool	M
PROMs Details	MPRPX007X	PROMs Trigger Classification	M
PROMs Details	MPRPX008X	PROMs Language	M
PROMs Details	MPRPX009X	Unique Form Identifier	M

<b>Data Module</b>	<b>Item Reference</b>	<b>Name</b>	<b>Mandatory (M) / Optional (O)</b>
PROMs Data Entry Details	MDEPX001X	Are you completing this questionnaire for someone else?	M
PROMs Data Entry Details	MDEPX002X	What is your relationship to the patient?	M
PROMs Data Entry Details	MDEPX003A	Physical impairment	M
PROMs Data Entry Details	MDEPX003B	Mental impairment	M
PROMs Data Entry Details	MDEPX003C	Under 16	M
PROMs Data Entry Details	MDEPX003D	No Language	M
PROMs Data Entry Details	MDEPX003E	Remote collection	M
PROMs Data Entry Details	MDEPX003F	Other reason	M
PROMs Data Entry Details	MDEPX004X	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

Data Definition Type	Item Reference	Name	Format	Definition	Value Set / Example		
Patient Details	MPDPX001X	NHS Number	10-character alphanumeric	See <a href="#">NHS Wales Data Dictionary</a> for details of NHS Wales Document Metadata Standard	e.g. 0123456789		
Patient Details	MPDPX001A	NHS Number Status Indicator	2-digit numeric	See <a href="#">NHS Wales Data Dictionary</a> for existing standard	e.g. <table border="1" style="display: inline-table; vertical-align: middle;"> <tr> <td style="padding: 2px;">01</td> <td style="padding: 2px;">Number present &amp; traced</td> </tr> </table>	01	Number present & traced
01	Number present & traced						
Patient Details	MPDPX002X	Local Patient Identifier	10-character alphanumeric	See <a href="#">NHS Wales Data Dictionary</a> for details of NHS Wales Document Metadata Standard	e.g. 9876543210		
Patient Details	MPDPX003X	Patient Name (Forename)	35-character alphanumeric	See <a href="#">NHS Wales Data Dictionary</a> for details of NHS Wales Document Metadata Standard	e.g. John Use NULL for missing or N/A values		
Patient Details	MPDPX004X	Patient Name (Surname)	35-character alphanumeric	See <a href="#">NHS Wales Data Dictionary</a> for details of NHS Wales Document Metadata Standard	e.g. Smith Use NULL for missing or N/A values		
Patient Details	MPDPX005X	Date of Birth	CCYY-MM-DD	See <a href="#">NHS Wales Data Dictionary</a> for details of NHS Wales Document Metadata Standard	e.g. 1950-01-31		
Patient Details	MPDPX006X	Gender Identity	1-character alphanumeric	See <a href="#">NHS Wales Data Dictionary</a> for details of NHS Wales Core Reference Data Standard	e.g. F		
Patient Details	MPDPX007X	Postcode	8-character alphanumeric	See <a href="#">NHS Wales Data Dictionary</a> for details of NHS Wales Document Metadata Standard	e.g. AB12 3CD Use NULL for missing or N/A values		
Document Details	MDDPX001X	Originating System	6-digit alphanumeric	For PROMs, this would be the PROMs platform, e.g. DrDoctor, PKB, Amplitude, National Platform, etc. See <a href="#">NHS Wales Data Dictionary</a> for details of NHS Wales Document Metadata Standard	Please refer to the technical specification for details		
Document Details	MDDPX002X	Originating Organisation	5-character alphanumeric	See <a href="#">NHS Wales Data Dictionary</a> for details of NHS Wales Document Metadata Standard	e.g. 7A100		



Data Definition Type	Item Reference	Name	Format	Definition	Value Set / Example
Event Details	MEDPX001X	Treatment Function	3-digit numeric	This is the pathway specialty at the time the PROMs form is generated See <a href="#">NHS Wales Data Dictionary</a> for details of NHS Wales Document Metadata Standard	e.g. 100
Event Details	MEDPX002A	Senior Responsible Professional Name	100-character alphanumeric	See <a href="#">NHS Wales Data Dictionary</a> 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	See <a href="#">NHS Wales Data Dictionary</a> 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
Event Details	MEDPX002C	Senior Responsible Professional Identifier	8-character alphanumeric	See <a href="#">NHS Wales Data Dictionary</a> for details of NHS Wales Document Metadata Standard	e.g. 2345678 Use NULL for missing or N/A values
PROMs Details	MPRPX001X	PROMs Site Code	5-character alphanumeric	For PROMs, this is the code of the site where the PROMs form was initiated See <a href="#">NHS Wales Data Dictionary</a> for details of NHS Wales Document Metadata 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	2020-12-10
PROMs Details	MPRPX003X	PROMs Completion Date & Time	2020-12-10T13:30:10.999+00:00	The date and time the PROMs form was completed (or when the last item was recorded for incomplete records)	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 Pathway ID	20-character alphanumeric	An identifier that uniquely identifies the PROMs pathway for the individual patient completing the PROMs form All PROMs forms associated with the same patient and pathway/problem must have the same Pathway ID This could be the patient's clinical pathway ID or an identifier generated locally in the PROMs application	e.g. 00000000000000000001 Use NULL for missing or N/A values
PROMs Details	MPRPX005X	PROMs Pathway Type	3-character alphanumeric	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

Data Definition Type	Item Reference	Name	Format	Definition	Value Set / Example								
PROMs Details	MPRPX006X	PROMs Tool	3-character alphanumeric	The national code representing the PROMs tool associated with the PROMs record	e.g. OKS Please refer to the technical specification for details								
PROMs Details	MPRPX007X	PROMs Trigger Classification	2-digit numeric	The national code representing the classification of the PROMs trigger	e.g. 03 - Pre-op or prior to surgical intervention Please refer to the technical specification for details								
PROMs Details	MPRPX008X	PROMs Language	2-character alphanumeric	The code representing the language of the completed PROMs form	en=English cy=Welsh 71=Other								
PROMs Details	MPRPX009X	Unique Form Identifier	50-character alphanumeric	An identifier that uniquely identifies the record associated with a particular form instance. This should be unique to each record To be derived from: Originating Org, Local Patient ID, Completion Date/Time	e.g. 7A100999998888882020-01-31 00:00:00:000								
PROMs Data Entry Details	MDEPX001X	Are you completing this questionnaire for someone else?	1-digit numeric	To identify whether the patient required assistance to complete the form	e.g. 0 – No Please refer to the technical specification for details								
PROMs Data Entry Details	MDEPX002X	What is your relationship to the patient?	2-digit numeric	To describe the relationship of the person completing the form to the patient	e.g. 02 - Relative or carer on behalf of the patient Please refer to the technical specification for details								
		Why is your assistance needed?		To identify the reason why the patient required assistance to complete the form	[Question header, no returned data]								
PROMs Data Entry Details	MDEPX003A	Physical impairment	1-digit numeric	The patient has a physical impairment that prevents them from completing the questionnaire.	<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												

Data Definition Type	Item Reference	Name	Format	Definition	Value Set / Example								
PROMs Data Entry Details	MDEPX003B	Mental impairment	1-digit numeric	The patient has a mental impairment that prevents them from completing the questionnaire.	<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												
PROMs Data Entry Details	MDEPX003C	Under 16	1-digit numeric	The patient is under 16 years old	<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												
PROMs Data Entry Details	MDEPX003D	No Language	1-digit numeric	The patient does not speak English / Welsh	<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												

Data Definition Type	Item Reference	Name	Format	Definition	Value Set / Example								
PROMs Data Entry Details	MDEPX003E	Remote collection	1-digit numeric	Remote collection (e.g. telephone collection)	<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												
PROMs Data Entry Details	MDEPX003F	Other reason	1-digit numeric	Other reason	<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												
PROMs Data Entry Details	MDEPX004X	Laterality	1-digit numeric	To capture the anatomical side associated with the questionnaire being completed 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	<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												