WELSH INFORMATION STANDARDS BOARD

DSC Notice:	DSCN 2022 / 49
Date of Issue:	5TH December 2022

Welsh Health Circular / Official Letter: WHC/2022/005: Welsh Value in Health Centre – Data Requirements **Sponsor**: Dr Sally Lewis, National Clinical Lead for Value-Based and Prudent Healthcare **Effective from:** 1st November 2022	**Subject:** Value in Health – Data Entry Questions

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 20th October 2022.

WISB Reference: ISRN 2022 / 038

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.
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

<u>Introduction</u>

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 use
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 validated or standardised patient
questionnaires including 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[1]. 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.

<u>Scope</u>

A 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.

Standardised data is vital to effective central storage of 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 provides a standard coding structure and process for the central submission,
storage and communication of data for **Data Entry Questions** PROMs questions.

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.

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[1] https://gov.wales/welsh-value-health-centre-data-requirements-whc2022005

The scope of this standard is independent of the platform or source application used to capture information, however it is limited to the nationally-validated or standardised questionnaires and PROMs tools. The composition of these questionnaires is described in separate DSCNs, one for each questionnaire.

Also defined is a set of metadata items which underpin the data in an associated PROMs Metadata Standard. This comprises 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 metadata specification and associated notices for related validated/standardised questionnaires and PROMs tools.

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 coding structure for the **Data Entry Questions** PROMs questions.

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 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	New
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: Data Set Structure

Data Entry Questions

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

Data Entry Questions

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	e.g. 0 – No Please refer to the technical specification for details
MDEPX002X	What is your relationship to the patient?	Relationship To Patient	2-digit numeric	e.g. 02 - Relative or carer on behalf of the patient Please refer to the technical specification for details
	Why is your assistance needed?	Why Assistance Needed		[Question header, no returned data]
MDEPX003A	Physical impairment	Physical impairment	1-digit numeric	0 No* 1 Yes 8 N/A 9 Unknown *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'
MDEPX003B	Mental impairment	Mental impairment	1-digit numeric	0 No* 1 Yes 8 N/A 9 Unknown *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'

Question Reference	Question Text	Data Item Name	Format	Value Set / Example
MDEPX003C	Under 16	Under 16	1-digit numeric	0 No* 1 Yes 8 N/A 9 Unknown *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'
MDEPX003D	No Language	No Language	1-digit numeric	0 No* 1 Yes 8 N/A 9 Unknown *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'
MDEPX003E	Remote collection	Remote collection	1-digit numeric	0 No* 1 Yes 8 N/A 9 Unknown *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'

Question Reference	Question Text	Data Item Name	Format	Value Set / Example
MDEPX003F	Other reason	Other reason	1-digit numeric	0 No* 1 Yes 8 N/A 9 Unknown *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'