

WELSH INFORMATION STANDARDS BOARD

DSC Notice:	DSCN 2022 / 39 (AMD)
Date of Issue:	11 th October 2024

Welsh Health Circular/Official Letter: WHC (2022)005: Welsh Value in Health Centre – Data Requirements	Subject: Value in Health – Oxford Elbow Score (OES) (AMD)
Sponsor: Dr Sally Lewis, National Clinical Lead for Value-Based and Prudent Healthcare	
Effective from: 1 st September 2024	
DATA STANDARDS CHANGE NOTICE A Data Standards 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) at its meeting on 19th September 2024. WISB Reference: ISRN 2024 / 017	
Summary: To describe the content of Patient Reported Outcome Measures (PROMs) for the Oxford Elbow Score element of the applicable PROMs pathways as part of the Value in Health programme.	
Data sets / returns affected: Patient Reported Outcomes Measures (PROMs) (wales.nhs.uk)	
Please address enquiries about this Data Standards Change Notice to the Data Standards Team in Digital Health and Care Wales E-mail: data.standards@wales.nhs.uk / Tel: 02920502539	
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 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 reported outcomes throughout the longitudinal record. By utilising common standards,

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

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 / 39.

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	Oxford Elbow Score	Existing
Data item	Side effected	Existing
Data item	Lifting	Existing
Data item	Carrying	Existing
Data item	Self-care	Existing
Data item	Dressing	Existing
Data item	Confidence	Existing
Data item	Thinking	Existing
Data item	Night pain	Changed
Data item	Sleeping	Existing
Data item	Activities	Existing
Data item	Leisure activities	Existing
Data item	Worst pain	Existing
Data item	Usual pain	Existing
Data item	Pain Score	Existing
Data item	Elbow function Score	Existing
Data item	Social-psychological Score	Existing

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 PROM's Metadata specification
Data Module	Document Details	MDDPX	See PROM's Metadata specification
Data Module	Event Details	MEDPX	See PROM's Metadata specification
Data Module	PROMs Details	MPRPX	See PROM's Metadata specification
Data Module	Data Entry Details	MDEPX	See PROM's Metadata specification
Data Item	Side Effected	OESPX001X	Code from applicable value set
Data Item	Lifting	OESPX002X	Code from applicable value set
Data Item	Carrying	OESPX003X	Code from applicable value set
Data Item	Self-care	OESPX004X	Code from applicable value set
Data Item	Dressing	OESPX005X	Code from applicable value set
Data Item	Confidence	OESPX006X	Code from applicable value set
Data Item	Thinking	OESPX007X	Code from applicable value set
Data Item	Night pain	OESPX008X	Code from applicable value set
Data Item	Sleeping	OESPX009X	Code from applicable value set
Data Item	Activities	OESPX010X	Code from applicable value set
Data Item	Leisure activities	OESPX011X	Code from applicable value set
Data Item	Worst pain	OESPX012X	Code from applicable value set
Data Item	Usual pain	OESPX013X	Code from applicable value set

Data Type	Item Name	Reference	Data represents
Data Item	Pain Score	OESPX014X	Calculated Score
Data Item	Elbow function Score	OESPX015X	Calculated Score
Data Item	Social-psychological Score	OESPX016X	Calculated Score

- 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		
OESPX001X	On which side of your body is the affected elbow for which you are receiving treatment?	Side Affected	1-digit numeric	1	Left	
				2	Right	
				3	Both	
				9	Unknown	
	Problems with your Elbow. During the past 4 weeks:			Heading text – no return value		
	Tick (✓) one box for every question.			Rubric – no return value		
OESPX002X	Have you had difficulty lifting things in your home, such as putting out the rubbish, because of your elbow problem?	Lifting	1-digit numeric	4	No difficulty	
				3	A little bit of difficulty	
				2	Moderate difficulty	
				1	Extreme difficulty	
				0	Impossible to do	
				9	Unknown	
OESPX003X	Have you had difficulty carrying bags of shopping, because of your elbow problem?	Carrying	1-digit numeric	4	No difficulty	
				3	A little bit of difficulty	
				2	Moderate difficulty	
				1	Extreme difficulty	
				0	Impossible to do	
				9	Unknown	

Question Reference	Question Text	Data Item Name	Format	Value Set / Example	
OESPX004X	Have you had any difficulty washing yourself all over, because of your elbow problem?	Self-care	1-digit numeric	4	No difficulty
				3	A little bit of difficulty
				2	Moderate difficulty
				1	Extreme difficulty
				0	Impossible to do
				9	Unknown
OESPX005X	Have you had any difficulty dressing yourself, because of your elbow problem?	Dressing	1-digit numeric	4	No difficulty
				3	A little bit of difficulty
				2	Moderate difficulty
				1	Extreme difficulty
				0	Impossible to do
				9	Unknown
OESPX006X	Have you felt that your elbow problem is "controlling your life"?	Confidence	1-digit numeric	4	No, not at all
				3	Occasionally
				2	Some days
				1	Most days
				0	Every day
				9	Unknown

Question Reference	Question Text	Data Item Name	Format	Value Set / Example	
OESPX007X	How much has your elbow problem been "on your mind"?	Thinking	1-digit numeric	4	Not at all
				3	A little of the time
				2	Some of the time
				1	Most of the time
				0	All of the time
				9	Unknown
OESPX008X	Have you been troubled by pain from your elbow in bed at night?	Night pain	1-digit numeric	4	Not at all
				3	1 or 2 times a night 1 or 2 nights
				2	Some nights
				1	Most nights
				0	Every night
				9	Unknown
OESPX009X	How often has your elbow pain interfered with your sleeping?	Sleeping	1-digit numeric	4	Not at all
				3	Occasionally
				2	Some of the time
				1	Most of the time
				0	All of the time
				9	Unknown

Question Reference	Question Text	Data Item Name	Format	Value Set / Example	
OESPX010X	How much has your elbow problem interfered with your usual work or everyday activities?	Activities	1-digit numeric	4	Not at all
				3	A little bit
				2	Moderately
				1	Greatly
				0	Totally
				9	Unknown
OESPX011X	Has your elbow problem limited your ability to take part in leisure activities that you enjoy doing?	Leisure activities	1-digit numeric	4	No, not at all
				3	Occasionally
				2	Some of the time
				1	Most of the time
				0	All of the time
				9	Unknown
OESPX012X	How would you describe the worst pain you have from your elbow?	Worst pain	1-digit numeric	4	No pain
				3	Mild pain
				2	Moderate pain
				1	Severe pain
				0	Unbearable
				9	Unknown

Question Reference	Question Text	Data Item Name	Format	Value Set / Example													
OESPX013X	How would you describe the pain you usually have from your elbow?	Usual pain	1-digit numeric	<table><tr><td>4</td><td>No pain</td></tr><tr><td>3</td><td>Mild pain</td></tr><tr><td>2</td><td>Moderate pain</td></tr><tr><td>1</td><td>Severe pain</td></tr><tr><td>0</td><td>Unbearable</td></tr><tr><td>9</td><td>Unknown</td></tr></table>	4	No pain	3	Mild pain	2	Moderate pain	1	Severe pain	0	Unbearable	9	Unknown	
4	No pain																
3	Mild pain																
2	Moderate pain																
1	Severe pain																
0	Unbearable																
9	Unknown																
OESPX014X	Pain Score	Pain Score	Decimal (to as many decimal places as possible, i.e. no rounding)	Score (0-100) based on OES scoring method, e.g. 50. Use NULL for missing, unknown or N/A values													
OESPX015X	Elbow function Score	Elbow function Score	Decimal (to as many decimal places as possible, i.e. no rounding)	Score (0-100) based on OES scoring method, e.g. 50. Use NULL for missing, unknown or N/A values													
OESPX016X	Social-psychological Score	Social-psychological Score	Decimal (to as many decimal places as possible, i.e. no rounding)	Score (0-100) based on OES scoring method, e.g. 50. Use NULL for missing, unknown or N/A values													