

WELSH INFORMATION STANDARDS BOARD

DSC Notice:	DSCN 2023 / 32
Date of Issue:	9 th August 2023

<p>Welsh Health Circular / Official Letter:</p> <p>WHC/2022/005: Welsh Value in Health Centre – Data Requirements</p>	<p>Subject: Value in Health – Laterality - Hand</p>
<p>Sponsor: Dr Sally Lewis, National Clinical Lead for Value-Based and Prudent Healthcare</p>	
<p>Effective from: 1st July 2023</p>	
<p>DATA STANDARD CHANGE NOTICE</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 20th July 2023.</p> <p>WISB Reference: ISRN 2023 / 020</p>	
<p>Summary:</p> <p>To describe the content of Patient Reported Outcome Measures (PROMs) for the Laterality - Hand part of the applicable PROMs pathways as part of the Value in Health programme.</p>	
<p>Applies to:</p> <p>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</p> <p>E-mail: data.standards@wales.nhs.uk / 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:</p> <p>https://nhs.wales365.sharepoint.com/sites/DHC_DST/Lists/Information%20Standards%20Assurance%20Submission%20Log/AllItems.aspx</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 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)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.

Scope

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 **Laterality – Hand** 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

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

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 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 DSCN 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 **Laterality – Hand** PROMs tool.

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	Laterality - hand	New
Data item	Laterality	New
Data item	Handedness	New

Appendix B: Data Set Structure

Laterality - Hand

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	Laterality	LAHPX001X	Code from applicable value set
Data Item	Handedness	LAHPX002X	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

Laterality - Hand

Question Reference	Question Text	Data Item Name	Format	Value Set / Example								
LAHPX001X	On which side of your body is the affected hand?	Laterality	1-digit numeric	<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</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	Left	2	Right	3	Both	9	Unknown
1	Left											
2	Right											
3	Both											
9	Unknown											
LAHPX002X	Are you left or right handed?	Handedness	1-digit numeric	<table border="1"> <tr><td>1</td><td>Left</td></tr> <tr><td>2</td><td>Right</td></tr> <tr><td>3</td><td>Use both equally</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	Left	2	Right	3	Use both equally	9	Unknown
1	Left											
2	Right											
3	Use both equally											
9	Unknown											