

WELSH INFORMATION STANDARDS BOARD

DSC Notice:	DSCN 2025 / 18
Date of Issue:	15 th October 2025

<p>Welsh Health Circular/Official Letter: WHC (2022) 005: Welsh Value in Health Centre – Data Requirements</p> <p>Sponsor: Christopher Brown, National Director of Value Transformation</p> <p>Standard Type: PROMs</p> <p>Effective Date: 04/09/2025</p>	<p>Subject: Value in Health – LYMPROM Additional Questions (LYMPROM-AQ)</p>
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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 18th September 2025.

WISB Reference: ISRN 2025 / 016

Summary:

To introduce a new data set for LYMPROM Additional Questions (LYMPROM-AQ), as part of the Value in Health programme, to establish a standardised structure for the collection and storage of all data items and corresponding values included within this DSCN.

Applies to:

[Patient Reported Outcome Measures \(PROMs\) \(wales.nhs.uk\)](https://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

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://nhs.wales365.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 use analyses. 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 data, including that collected via Patient-Reported Outcome Measures (PROMs) and national clinical audit data, and data linkage to associate these records with sources of existing activity data, 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.

Questionnaire tools, including PROMs, 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.

Description of Change

To introduce a standard coding structure for the LYMPROM Additional Questions (LYMPROM-AQ).

Actions Required

Local Health Boards / Trust:

- To supply patient-reported data to DHCW in accordance with the information specification described in this DSCN.

Digital Health and Care Wales:

To supply patient-reported data to health boards and trusts in accordance with the information specification described in this DSCN.

LYMPROM ADDITIONAL QUESTIONS (LYMPROM-AQ)

Scope

The scope of this standard is independent of the platform or source application used to capture patient-reported data. The composition of the associated PROMs data sets is described in separate DSCNs, one for each tool, e.g. Oxford Knee Score.

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 valid from the date of publication. In the case of PROMs, any Health Board wanting to develop new processes for collecting, storing or sharing PROMs information should adhere to the standard in accordance with their own implementation plans. 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). Implementation details can be found in the overarching PROMs Standard Operating Model (PSOM).²

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.

Key:

- **New:** The creation of a new data item not already described in an existing standard.
- **Retired:** The entire data item is no longer in use.
- **Changed:** An existing data item has been modified; this includes a change to the definition or its value set.
- **Existing:** The inclusion of a data item that is already in use in an existing standard, but no changes have been made to its definition or value set.

Data Definition Type	Name	New/Retired/Changed/Existing	Page Number
Data module	Patient Details	Existing	4

Data module	Document Details	Existing	4
Data module	Event Details	Existing	4
Data module	PROMs Details	Existing	4
Data module	Data Entry Details	Existing	4
Data module	LYMPROM-AQ	New	4
Data item	Q1	New	4
Data item	Q2	New	4
Data item	Q3	New	4
Data item	Q4	New	4
Data item	Q5A	New	4
Data item	Q5B	New	4
Data item	Q5C	New	4
Data item	Q5D	New	4
Data item	Q5E	New	5

Appendix B: Highlighted changes to be made to the Standard

Changes to the Standard 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 previous Standard.

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	Q1	LAQ1PX001X	Code from applicable value set
Data Item	Q2	LAQ1PX002X	Code from applicable value set
Data Item	Q3	LAQ1PX003X	Code from applicable value set
Data Item	Q4	LAQ1PX004X	Code from applicable value set
Data Item	Q5A	LAQ1PX005A	Code from applicable value set
Data Item	Q5B	LAQ1PX005B	Code from applicable value set
Data Item	Q5C	LAQ1PX005C	Code from applicable value set
Data Item	Q5D	LAQ1PX005D	Code from applicable value set
Data Item	Q5E	LAQ1PX005E	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 if 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.**

Question Reference	Question Text	Item Name	Format	Value Set / Example										
LAQ1PX001X	Have you had an appointment (in person, video or over the telephone) with a lymphoedema therapist on the last year?	Q1	1-digit numeric	<table border="1"> <tr><td>0</td><td>Yes</td></tr> <tr><td>1</td><td>No</td></tr> <tr><td>2</td><td>Unsure</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	0	Yes	1	No	2	Unsure	9	Unknown		
0	Yes													
1	No													
2	Unsure													
9	Unknown													
LAQ1PX002X	Have you completed a LYMPROM© in the last 2 weeks?	Q2	1-digit numeric	<table border="1"> <tr><td>0</td><td>Yes</td></tr> <tr><td>1</td><td>No</td></tr> <tr><td>2</td><td>Unsure</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	0	Yes	1	No	2	Unsure	9	Unknown		
0	Yes													
1	No													
2	Unsure													
9	Unknown													
LAQ1PX003X	Are you underdoing intensive treatment? i.e attending a few times a week for bandaging and MLD?	Q3	1-digit numeric	<table border="1"> <tr><td>0</td><td>Yes</td></tr> <tr><td>1</td><td>No</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	0	Yes	1	No	9	Unknown				
0	Yes													
1	No													
9	Unknown													
LAQ1PX004X	How do you identify?	Q4	1-digit numeric	<table border="1"> <tr><td>0</td><td>Female</td></tr> <tr><td>1</td><td>Male</td></tr> <tr><td>2</td><td>Other</td></tr> <tr><td>3</td><td>Prefer not to say</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	0	Female	1	Male	2	Other	3	Prefer not to say	9	Unknown
0	Female													
1	Male													
2	Other													
3	Prefer not to say													
9	Unknown													
	Where is your swelling (lymphoedema)? Please select all that apply.			Rubric – no return value										
LAQ1PX005A	Arm/hand	Q5A	1-digit numeric	<table border="1"> <tr><td>0</td><td>Not present</td></tr> </table>	0	Not present								
0	Not present													

				<table border="1"> <tr> <td>1</td> <td>Present</td> </tr> <tr> <td>9</td> <td>Unknown</td> </tr> </table>	1	Present	9	Unknown		
1	Present									
9	Unknown									
LAQ1PX005B	Leg/foot	Q5B	1-digit numeric	<table border="1"> <tr> <td>0</td> <td>Not present</td> </tr> <tr> <td>1</td> <td>Present</td> </tr> <tr> <td>9</td> <td>Unknown</td> </tr> </table>	0	Not present	1	Present	9	Unknown
0	Not present									
1	Present									
9	Unknown									
LAQ1PX005C	Head/neck	Q5C	1-digit numeric	<table border="1"> <tr> <td>0</td> <td>Not present</td> </tr> <tr> <td>1</td> <td>Present</td> </tr> <tr> <td>9</td> <td>Unknown</td> </tr> </table>	0	Not present	1	Present	9	Unknown
0	Not present									
1	Present									
9	Unknown									
LAQ1PX005D	Genitals	Q5D	1-digit numeric	<table border="1"> <tr> <td>0</td> <td>Not present</td> </tr> <tr> <td>1</td> <td>Present</td> </tr> <tr> <td>9</td> <td>Unknown</td> </tr> </table>	0	Not present	1	Present	9	Unknown
0	Not present									
1	Present									
9	Unknown									
LAQ1PX005E	Breast/chest	Q5E	1-digit numeric	<table border="1"> <tr> <td>0</td> <td>Not present</td> </tr> <tr> <td>1</td> <td>Present</td> </tr> <tr> <td>9</td> <td>Unknown</td> </tr> </table>	0	Not present	1	Present	9	Unknown
0	Not present									
1	Present									
9	Unknown									

