

## WELSH INFORMATION STANDARDS BOARD

<b>DSC Notice:</b>	DSCN 2025 / 10 (AMD)
<b>Date of Issue:</b>	30 <sup>th</sup> July 2025

<p><b>Welsh Health Circular/Official Letter:</b> WHC (2022) 005: Welsh Value in Health Centre – Data Requirements</p> <p><b>Sponsor:</b> Christopher Brown, National Director of Value Transformation</p> <p><b>Standard Type:</b> PROM</p> <p><b>Effective Date:</b> 03/07/2025</p>	<p><b>Subject:</b> Value in Health – Zarit Caregiver Burden Interview Additional Questions – Zarit 6 AQ (AMD)</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 17<sup>th</sup> July 2025.

**WISB Reference:** ISRN 2025 / 015

**Summary:**

To introduce a new data set Zarit Caregiver Burden Interview Additional Questions – Zarit 6 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/patient-reported-outcome-measures)

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](mailto: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://nhswales365.sharepoint.com/sites/DHC\\_DST/Lists/Information%20Standards%20Assurance%20Submission%20Log/AllItems.aspx](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 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)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.

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 Zarit Caregiver Burden Interview Additional Questions – Zarit 6 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.

## Zarit Caregiver Burden Interview Additional Questions – Zarit 6 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).<sup>2</sup>

## **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.

<b>Data Definition Type</b>	<b>Name</b>	<b>New/Retired/Changed/Existing</b>	<b>Page Number</b>
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 item	Q1	New	
Data item	Q2	New	
Data item	Q3	New	

## 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	ZAQ1PX001X	Free text
Data Item	Q2	ZAQ1PX002X	Free text
Data Item	Q3	ZAQ1PX003X	Code from applicable value set
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	ZAQ1PX001X	Free text
Data Item	Q2	ZAQ1PX002X	Free text
Data Item	Q3	ZAQ1PX003X	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.

### **Appendix C: Information Specification**

Changes to the Standard are detailed below, with new text being highlighted in **blue** and deletions shown with a **strikethrough**. Text shaded in grey denotes existing content.

<b>Question Reference</b>	<b>Question Text</b>	<b>Item Name</b>	<b>Format</b>	<b>Value Set / Example</b>								
<b>ZAQ1PX001X</b>	Please enter your first name:	Q1	100-character alphanumeric	Free text – use NULL for missing or N/A values								
<b>ZAQ1PX002X</b>	Please enter your year of birth:	Q2	100-character alphanumeric	Free text – use NULL for missing or N/A values								
<b>ZAQ1PX003X</b>	Have you ever completed one of these assessments before?	Q3	1-digit numeric	<table border="1"> <tr> <td>0</td> <td>No</td> </tr> <tr> <td>1</td> <td>Yes</td> </tr> <tr> <td>2</td> <td>Unsure</td> </tr> <tr> <td>9</td> <td>Unknown</td> </tr> </table>	0	No	1	Yes	2	Unsure	9	Unknown
0	No											
1	Yes											
2	Unsure											
9	Unknown											
	<p>To ensure we can provide you with the right care going forward, it is important that we understand the needs of you and your carer. We therefore request that you pass this to them if you are happy to do so.</p> <p>Dear carer</p>			[Question header, no returned data]								

	<p>We're asking you to complete an assessment to help us make better recommendations for the care of your loved one. By understanding how you feel, together we can make better decisions about the support needed.</p> <p>The information you provide will be made available to the patient's clinical team as part of the patient's medical record but will not be treated in the strictest of confidence.</p> <p>Please click next to continue to the assessment</p>			
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