WELSH INFORMATION STANDARDS BOARD

DSC Notice:	DSCN 2025 / 11 (AMD)
Date of Issue:	30th July 2025

Welsh Health Circular/Official Letter: WHC (2022) 005: Welsh Value in Health Centre – Data Requirements	**Subject:** Value in Health - Zarit Caregiver Burden Interview – Zarit 6 (AMD)
Sponsor: Christopher Brown, National Director of Value Transformation	
Standard Type: PROM	
Effective Date: 03/07/2025	

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 17th July 2025.

WISB Reference: ISRN 2025 / 015

Summary:
To introduce a new data set for Zarit Caregiver Burden Interview – Zarit 6, 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)

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://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[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.

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 – Zarit 6.

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 – Zarit 6

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	
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	
Data item	Q4	New	
Data item	Q5	New	
Data item	Q6	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	ZAR1PX001X	Code from applicable value set
Data Item	Q2	ZAR1PX002X	Code from applicable value set
Data Item	Q3	ZAR1PX003X	Code from applicable value set
Data Item	Q4	ZAR1PX004X	Code from applicable value set
Data Item	Q5	ZAR1PX005X	Code from applicable value set
Data Item	Q6	ZAR1PX006X	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.

Question Reference	Question Text	Item Name	Format	Value Set / Example
ZAR1PX001X	Because of the time I spend with him/her, I do not have enough time for myself	Q1	1-digit numeric	0 Never 1 Rarely 2 Sometimes 3 Quite frequently 4 Nearly always 9 Unknown
ZAR1PX002X	I feel stressed between caring for him/her and trying to meet other responsibilities for my family or work	Q2	1-digit numeric	0 Never 1 Rarely 2 Sometimes 3 Quite frequently 4 Nearly always 9 Unknown

ZAR1PX003X	I feel that he/she currently affects my relationship with other family members or friends in a negative way	Q3	1-digit numeric	0 Never 1 Rarely 2 Sometimes 3 Quite frequently 4 Nearly always 9 Unknown
ZAR1PX004X	I feel strained when I am around the person I care for	Q4	1-digit numeric	0 Never 1 Rarely 2 Sometimes 3 Quite frequently 4 Nearly always 9 Unknown
ZAR1PX005X	I feel that my health has suffered because of my involvement with the person I care for	Q5	1-digit numeric	0 Never 1 Rarely 2 Sometimes 3 Quite frequently 4 Nearly always 9 Unknown
ZAR1PX006X	I feel that I have lost control of my own life since this person's illness	Q6	1-digit numeric	0 Never 1 Rarely 2 Sometimes 3 Quite frequently 4 Nearly always 9 Unknown