

## WELSH INFORMATION STANDARDS BOARD

<b>DSC Notice:</b>	DSCN 2025 / 02
<b>Date of Issue:</b>	7 <sup>th</sup> March 2025

<p><b>Welsh Health Circular/Official Letter:</b> WHC (2022)005: Welsh Value in Health Centre – Data Requirements</p>	<p><b>Subject:</b> Value in Health - Distress Diabetes Scale-17 (DDS-17)</p>
<p><b>Sponsor:</b> Christopher Brown, National Director of Digital, Data, Technology, Innovation and Value</p>	
<p><b>Effective from:</b> 1<sup>st</sup> November 2024</p>	
<p><b>DATA STANDARDS CHANGE NOTICE</b></p> <p>A Data Standards 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) at its meeting on 23<sup>rd</sup> January 2025.</p> <p><b>WISB Reference: ISRN 2024 / 021</b></p>	
<p><b>Summary:</b> To describe the content of the Distress Diabetes Scale-17 (DDS-17) as part of the Value in Health programme.</p>	
<p><b>Data sets / returns affected:</b> <a href="https://wales.nhs.uk">Patient Reported Outcome Measures (PROMs) (wales.nhs.uk)</a></p>	
<p>Please address enquiries about this Data Standards Change Notice to the Data Standards Team in Digital Health and Care Wales</p> <p>E-mail: <a href="mailto:data.standards@wales.nhs.uk">data.standards@wales.nhs.uk</a></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><a href="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</a></p>	

# 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. 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 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.

## Scope

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.

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

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

- 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). Implementation details can be found in the overarching PROMs Standard Operating Model (PSOM).<sup>2</sup>

### Description of Change

To introduce a standard coding structure for the Distress Diabetes Scale-17 (DDS-17).

### Data Dictionary Version

Where applicable, this DSCN reflects changes introduced by DSCN and/or DDCN since the release of version 4.22 of the NHS Wales Data Dictionary.

The changes introduced by such DSCNs will be published in version 4.25 of the NHS Wales Data Dictionary.

### 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:

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

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<sup>2</sup> <https://vbhc.nhs.wales/digital-health/data-products/>

**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.

<b>Data Definition Type</b>	<b>Name</b>	<b>Status</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 module	Data Entry Questions	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
Data item	Q7	New
Data item	Q8	New
Data item	Q9	New
Data item	Q10	New
Data item	Q11	New
Data item	Q12	New
Data item	Q13	New
Data item	Q14	New
Data item	Q15	New
Data item	Q16	New
Data item	Q17	New

## 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 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	DDSPX001X	Code from applicable value set
Data Item	Q2	DDSPX002X	Code from applicable value set
Data Item	Q3	DDSPX003X	Code from applicable value set
Data Item	Q4	DDSPX004X	Code from applicable value set
Data Item	Q5	DDSPX005X	Code from applicable value set
Data Item	Q6	DDSPX006X	Code from applicable value set
Data Item	Q7	DDSPX007X	Code from applicable value set
Data Item	Q8	DDSPX008X	Code from applicable value set
Data Item	Q9	DDSPX009X	Code from applicable value set
Data Item	Q10	DDSPX010X	Code from applicable value set
Data Item	Q11	DDSPX011X	Code from applicable value set
Data Item	Q12	DDSPX012X	Code from applicable value set
Data Item	Q13	DDSPX013X	Code from applicable value set
Data Item	Q14	DDSPX014X	Code from applicable value set
Data Item	Q15	DDSPX015X	Code from applicable value set
Data Item	Q16	DDSPX016X	Code from applicable value set

Data Item	Q17	DDSPX017X	Code from applicable value set
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- **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														
DDSPX001X	Feeling that my doctor doesn't know enough about diabetes and diabetes care.	Q1	1-digit numeric	<table border="1"> <tr><td>1</td><td>Not a problem</td></tr> <tr><td>2</td><td>A slight problem</td></tr> <tr><td>3</td><td>A moderate problem</td></tr> <tr><td>4</td><td>A somewhat serious problem</td></tr> <tr><td>5</td><td>A serious problem</td></tr> <tr><td>6</td><td>A very serious problem</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	Not a problem	2	A slight problem	3	A moderate problem	4	A somewhat serious problem	5	A serious problem	6	A very serious problem	9	Unknown
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DDSPX002X	Feeling that diabetes is taking up too much of my mental and physical energy every day.	Q2	1-digit numeric	<table border="1"> <tr><td>1</td><td>Not a problem</td></tr> <tr><td>2</td><td>A slight problem</td></tr> <tr><td>3</td><td>A moderate problem</td></tr> <tr><td>4</td><td>A somewhat serious problem</td></tr> <tr><td>5</td><td>A serious problem</td></tr> <tr><td>6</td><td>A very serious problem</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	Not a problem	2	A slight problem	3	A moderate problem	4	A somewhat serious problem	5	A serious problem	6	A very serious problem	9	Unknown
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DDSPX003X	Not feeling confident in my day-to-day ability to manage diabetes.	Q3	1-digit numeric	<table border="1"> <tr><td>1</td><td>Not a problem</td></tr> <tr><td>2</td><td>A slight problem</td></tr> <tr><td>3</td><td>A moderate problem</td></tr> <tr><td>4</td><td>A somewhat serious problem</td></tr> <tr><td>5</td><td>A serious problem</td></tr> <tr><td>6</td><td>A very serious problem</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	Not a problem	2	A slight problem	3	A moderate problem	4	A somewhat serious problem	5	A serious problem	6	A very serious problem	9	Unknown
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DDSPX004X	Feeling angry, scared and/or depressed when I think about living with diabetes.	Q4	1-digit numeric	<table border="1"> <tr><td>1</td><td>Not a problem</td></tr> <tr><td>2</td><td>A slight problem</td></tr> <tr><td>3</td><td>A moderate problem</td></tr> <tr><td>4</td><td>A somewhat serious problem</td></tr> <tr><td>5</td><td>A serious problem</td></tr> <tr><td>6</td><td>A very serious problem</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	Not a problem	2	A slight problem	3	A moderate problem	4	A somewhat serious problem	5	A serious problem	6	A very serious problem	9	Unknown
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DDSPX005X	Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes.	Q5	1-digit numeric	<table border="1"> <tr><td>1</td><td>Not a problem</td></tr> <tr><td>2</td><td>A slight problem</td></tr> <tr><td>3</td><td>A moderate problem</td></tr> <tr><td>4</td><td>A somewhat serious problem</td></tr> <tr><td>5</td><td>A serious problem</td></tr> <tr><td>6</td><td>A very serious problem</td></tr> </table>	1	Not a problem	2	A slight problem	3	A moderate problem	4	A somewhat serious problem	5	A serious problem	6	A very serious problem		
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DDSPX006X	Feeling that I am not testing my blood sugars frequently enough.	Q6	1-digit numeric	<table border="1"> <tr> <td>1</td> <td>Not a problem</td> </tr> <tr> <td>2</td> <td>A slight problem</td> </tr> <tr> <td>3</td> <td>A moderate problem</td> </tr> <tr> <td>4</td> <td>A somewhat serious problem</td> </tr> <tr> <td>5</td> <td>A serious problem</td> </tr> <tr> <td>6</td> <td>A very serious problem</td> </tr> <tr> <td>9</td> <td>Unknown</td> </tr> </table>	1	Not a problem	2	A slight problem	3	A moderate problem	4	A somewhat serious problem	5	A serious problem	6	A very serious problem	9	Unknown
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DDSPX007X	Feeling that I will end up with serious long-term complications, no matter what I do.	Q7	1-digit numeric	<table border="1"> <tr> <td>1</td> <td>Not a problem</td> </tr> <tr> <td>2</td> <td>A slight problem</td> </tr> <tr> <td>3</td> <td>A moderate problem</td> </tr> <tr> <td>4</td> <td>A somewhat serious problem</td> </tr> <tr> <td>5</td> <td>A serious problem</td> </tr> <tr> <td>6</td> <td>A very serious problem</td> </tr> <tr> <td>9</td> <td>Unknown</td> </tr> </table>	1	Not a problem	2	A slight problem	3	A moderate problem	4	A somewhat serious problem	5	A serious problem	6	A very serious problem	9	Unknown
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DDSPX008X	Feeling that I am often failing with my diabetes routine.	Q8	1-digit numeric	<table border="1"> <tr> <td>1</td> <td>Not a problem</td> </tr> <tr> <td>2</td> <td>A slight problem</td> </tr> <tr> <td>3</td> <td>A moderate problem</td> </tr> <tr> <td>4</td> <td>A somewhat serious problem</td> </tr> <tr> <td>5</td> <td>A serious problem</td> </tr> </table>	1	Not a problem	2	A slight problem	3	A moderate problem	4	A somewhat serious problem	5	A serious problem				
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DDSPX009X	Feeling that friends or family are not supportive enough of self-care efforts (e.g. planning activities that conflict with my schedule, encouraging me to eat the "wrong" foods).	Q9	1-digit numeric	<table border="1"> <tr> <td>1</td> <td>Not a problem</td> </tr> <tr> <td>2</td> <td>A slight problem</td> </tr> <tr> <td>3</td> <td>A moderate problem</td> </tr> <tr> <td>4</td> <td>A somewhat serious problem</td> </tr> <tr> <td>5</td> <td>A serious problem</td> </tr> <tr> <td>6</td> <td>A very serious problem</td> </tr> <tr> <td>9</td> <td>Unknown</td> </tr> </table>	1	Not a problem	2	A slight problem	3	A moderate problem	4	A somewhat serious problem	5	A serious problem	6	A very serious problem	9	Unknown
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DDSPX010X	Feeling that diabetes controls my life.	Q10	1-digit numeric	<table border="1"> <tr> <td>1</td> <td>Not a problem</td> </tr> <tr> <td>2</td> <td>A slight problem</td> </tr> <tr> <td>3</td> <td>A moderate problem</td> </tr> <tr> <td>4</td> <td>A somewhat serious problem</td> </tr> <tr> <td>5</td> <td>A serious problem</td> </tr> <tr> <td>6</td> <td>A very serious problem</td> </tr> <tr> <td>9</td> <td>Unknown</td> </tr> </table>	1	Not a problem	2	A slight problem	3	A moderate problem	4	A somewhat serious problem	5	A serious problem	6	A very serious problem	9	Unknown
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DDSPX011X	Feeling that my doctor doesn't take my concerns seriously enough.	Q11	1-digit numeric	<table border="1"> <tr><td>1</td><td>Not a problem</td></tr> <tr><td>2</td><td>A slight problem</td></tr> <tr><td>3</td><td>A moderate problem</td></tr> <tr><td>4</td><td>A somewhat serious problem</td></tr> <tr><td>5</td><td>A serious problem</td></tr> <tr><td>6</td><td>A very serious problem</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	Not a problem	2	A slight problem	3	A moderate problem	4	A somewhat serious problem	5	A serious problem	6	A very serious problem	9	Unknown
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DDSPX012X	Feeling that I am not sticking closely enough to a good meal plan.	Q12	1-digit numeric	<table border="1"> <tr><td>1</td><td>Not a problem</td></tr> <tr><td>2</td><td>A slight problem</td></tr> <tr><td>3</td><td>A moderate problem</td></tr> <tr><td>4</td><td>A somewhat serious problem</td></tr> <tr><td>5</td><td>A serious problem</td></tr> <tr><td>6</td><td>A very serious problem</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	Not a problem	2	A slight problem	3	A moderate problem	4	A somewhat serious problem	5	A serious problem	6	A very serious problem	9	Unknown
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DDSPX013X	Feeling that friends or family don't appreciate how difficult living with diabetes can be.	Q13	1-digit numeric	<table border="1"> <tr><td>1</td><td>Not a problem</td></tr> <tr><td>2</td><td>A slight problem</td></tr> <tr><td>3</td><td>A moderate problem</td></tr> <tr><td>4</td><td>A somewhat serious problem</td></tr> <tr><td>5</td><td>A serious problem</td></tr> <tr><td>6</td><td>A very serious problem</td></tr> </table>	1	Not a problem	2	A slight problem	3	A moderate problem	4	A somewhat serious problem	5	A serious problem	6	A very serious problem		
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DDSPX014X	Feeling overwhelmed by the demands of living with diabetes.	Q14	1-digit numeric	<table border="1"> <tr><td>1</td><td>Not a problem</td></tr> <tr><td>2</td><td>A slight problem</td></tr> <tr><td>3</td><td>A moderate problem</td></tr> <tr><td>4</td><td>A somewhat serious problem</td></tr> <tr><td>5</td><td>A serious problem</td></tr> <tr><td>6</td><td>A very serious problem</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	Not a problem	2	A slight problem	3	A moderate problem	4	A somewhat serious problem	5	A serious problem	6	A very serious problem	9	Unknown
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DDSPX015X	Feeling that I don't have a doctor who I can see regularly enough about my diabetes.	Q15	1-digit numeric	<table border="1"> <tr><td>1</td><td>Not a problem</td></tr> <tr><td>2</td><td>A slight problem</td></tr> <tr><td>3</td><td>A moderate problem</td></tr> <tr><td>4</td><td>A somewhat serious problem</td></tr> <tr><td>5</td><td>A serious problem</td></tr> <tr><td>6</td><td>A very serious problem</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	Not a problem	2	A slight problem	3	A moderate problem	4	A somewhat serious problem	5	A serious problem	6	A very serious problem	9	Unknown
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DDSPX016X	Not feeling motivated to keep up my diabetes self-management.	Q16	1-digit numeric	<table border="1"> <tr><td>1</td><td>Not a problem</td></tr> <tr><td>2</td><td>A slight problem</td></tr> <tr><td>3</td><td>A moderate problem</td></tr> <tr><td>4</td><td>A somewhat serious problem</td></tr> <tr><td>5</td><td>A serious problem</td></tr> </table>	1	Not a problem	2	A slight problem	3	A moderate problem	4	A somewhat serious problem	5	A serious problem				
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DDSPX017X	Feeling that friends or family don't give me the emotional support that I would like.	Q17	1-digit numeric	<table border="1"> <tr> <td>1</td> <td>Not a problem</td> </tr> <tr> <td>2</td> <td>A slight problem</td> </tr> <tr> <td>3</td> <td>A moderate problem</td> </tr> <tr> <td>4</td> <td>A somewhat serious problem</td> </tr> <tr> <td>5</td> <td>A serious problem</td> </tr> <tr> <td>6</td> <td>A very serious problem</td> </tr> <tr> <td>9</td> <td>Unknown</td> </tr> </table>	1	Not a problem	2	A slight problem	3	A moderate problem	4	A somewhat serious problem	5	A serious problem	6	A very serious problem	9	Unknown
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