WELSH INFORMATION STANDARDS BOARD

DSC Notice:	DSCN 2025 / 03
Date of Issue:	7th March 2025

Welsh Health Circular/Official Letter: WHC (2022)005: Welsh Value in Health Centre – Data Requirements	**Subject:** Value in Health – Value in Health – T1 Distress Diabetes Scale-17 (T1-DDS)
Sponsor: Christopher Brown, National Director of Digital, Data, Technology, Innovation and Value	
Effective from: 1st November 2024	

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 23rd January 2025.

WISB Reference: ISRN 2024 / 021

Summary:
To describe the content of the T1 Distress Diabetes Scale-17 (T1-DDS) as part of the Value in Health programme.

Data sets / returns affected:
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. 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[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.

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
- Data Entry Details.

[1] https://www.gov.wales/welsh-value-health-centre-data-requirements-whc2022005

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).[2]

Description of Change

To introduce a standard coding structure for the T1 Distress Diabetes Scale-17 (T1-DDS).

Data Dictionary Version

Where applicable, this DSCN reflects changes introduced by DSCN and/or DDCN since the release of version 4.23 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.

[2] 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.

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	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
Data item	Q18	New
Data item	Q19	New
Data item	Q20	New
Data item	Q21	New
Data item	Q22	New
Data item	Q23	New
Data item	Q24	New
Data item	Q25	New
Data item	Q26	New
Data item	Q27	New
Data item	Q28	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	T1DPX001X	Code from applicable value set
Data Item	Q2	T1DPX002X	Code from applicable value set
Data Item	Q3	T1DPX003X	Code from applicable value set
Data Item	Q4	T1DPX004X	Code from applicable value set
Data Item	Q5	T1DPX005X	Code from applicable value set
Data Item	Q6	T1DPX006X	Code from applicable value set
Data Item	Q7	T1DPX007X	Code from applicable value set
Data Item	Q8	T1DPX008X	Code from applicable value set
Data Item	Q9	T1DPX009X	Code from applicable value set
Data Item	Q10	T1DPX010X	Code from applicable value set
Data Item	Q11	T1DPX011X	Code from applicable value set
Data Item	Q12	T1DPX012X	Code from applicable value set
Data Item	Q13	T1DPX013X	Code from applicable value set
Data Item	Q14	T1DPX014X	Code from applicable value set
Data Item	Q15	T1DPX015X	Code from applicable value set
Data Item	Q16	T1DPX016X	Code from applicable value set

Data Item	Q17	T1DPX017X	Code from applicable value set
Data Item	Q18	T1DPX018X	Code from applicable value set
Data Item	Q19	T1DPX019X	Code from applicable value set
Data Item	Q20	T1DPX020X	Code from applicable value set
Data Item	Q21	T1DPX021X	Code from applicable value set
Data Item	Q22	T1DPX022X	Code from applicable value set
Data Item	Q23	T1DPX023X	Code from applicable value set
Data Item	Q24	T1DPX024X	Code from applicable value set
Data Item	Q25	T1DPX025X	Code from applicable value set
Data Item	Q26	T1DPX026X	Code from applicable value set
Data Item	Q27	T1DPX027X	Code from applicable value set
Data Item	Q28	T1DPX028X	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

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
T1DPX001X	Feeling that I am not as skilled at managing diabetes as I should be.	Q1	1-digit numeric	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
T1DPX002X	Feeling that I don't eat as carefully as I probably should.	Q2	1-digit numeric	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
T1DPX003X	Feeling that I don’t notice the warning signs of hypoglycemia as well as I used to.	Q3	1-digit numeric	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
T1DPX004X	Feeling that people treat me differently when they find out I have diabetes.	Q4	1-digit numeric	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

T1DPX005X	Feeling discouraged when I see high blood glucose numbers that I can't explain.	Q5	1-digit numeric	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
T1DPX006X	Feeling that my family and friends make a bigger deal out of diabetes than they should.	Q6	1-digit numeric	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

T1DPX007X	Feeling that I can’t tell my diabetes doctor what is really on my mind.	Q7	1-digit numeric	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
T1DPX008X	Feeling that I am not taking as much insulin as I should.	Q8	1-digit numeric	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

T1DPX009X	Feeling that there is too much diabetes equipment and stuff I must always have with me.	Q9	1-digit numeric	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
T1DPX010X	Feeling like I have to hide my diabetes from other people.	Q10	1-digit numeric	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

T1DPX011X	Feeling that my friends and family worry more about hypoglycemia than I want them to.	Q11	1-digit numeric	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
T1DPX012X	Feeling that I don’t check my blood glucose level as often as I probably should.	Q12	1-digit numeric	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

T1DPX013X	Feeling worried that I will develop serious long-term complications, no matter how hard I try.	Q13	1-digit numeric	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
T1DPX014X	Feeling that I don’t get help I really need from my diabetes doctor about managing diabetes.	Q14	1-digit numeric	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

T1DPX015X	Feeling frightened that I could have a serious hypoglycemic event when I'm asleep.	Q15	1-digit numeric	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
T1DPX016X	Feeling that thoughts about food and eating control my life.	Q16	1-digit numeric	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

T1DPX017X	Feeling that my friends or family treat me as if I were more fragile or sicker than I really am.	Q17	1-digit numeric	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
T1DPX018X	Feeling that my diabetes doctor doesn't really understand what it's like to have diabetes.	Q18	1-digit numeric	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

T1DPX019X	Feeling concerned that diabetes may make me less attractive to employers.	Q19	1-digit numeric	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
T1DPX020X	Feeling that my friends or family act like "diabetes police" (bother me too much).	Q20	1-digit numeric	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

T1DPX021X	Feeling that I've got to be perfect with my diabetes management.	Q21	1-digit numeric	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
T1DPX022X	Feeling frightened that I could have a serious hypoglycemic event while driving.	Q22	1-digit numeric	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

T1DPX023X	Feeling that my eating is out of control.	Q23	1-digit numeric	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
T1DPX024X	Feeling that people will think less of me if they knew I had diabetes.	Q24	1-digit numeric	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

T1DPX025X	Feeling that no matter how hard I try with my diabetes, it will never be good enough.	Q25	1-digit numeric	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
T1DPX026X	Feeling that my diabetes doctor doesn't know enough about diabetes and diabetes care.	Q26	1-digit numeric	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

T1DPX027X	Feeling that I can’t ever be safe from the possibility of a serious hypoglycemic event.	Q27	1-digit numeric	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
T1DPX028X	Feeling that I don’t give my diabetes as much attention as I probably should.	Q28	1-digit numeric	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