

WELSH INFORMATION STANDARDS BOARD

DSC Notice:	DSCN 2025 / 04
Date of Issue:	7 th March 2025

<p>Welsh Health Circular/Official Letter: WHC (2022)005: Welsh Value in Health Centre – Data Requirements</p>	<p>Subject: Value in Health – Neck Disability Index (NDI)</p>
<p>Sponsor: Christopher Brown, National Director of Digital, Data, Technology, Innovation and Value</p>	
<p>Effective from: 1ST November 2024</p>	

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 Neck Disability Index (NDI) as part of the Value in Health programme.

Data sets / returns affected:

[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://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)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.

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 Neck Disability Index (NDI).

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

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 Module	Patient Details	MPDPX	See PROMs Metadata specification
Data Item	Q1	NDIPX001X	Code from applicable value set
Data Item	Q2	NDIPX002X	Code from applicable value set
Data Item	Q3	NDIPX003X	Code from applicable value set
Data Item	Q4	NDIPX004X	Code from applicable value set
Data Item	Q5	NDIPX005X	Code from applicable value set
Data Item	Q6	NDIPX006X	Code from applicable value set
Data Item	Q7	NDIPX007X	Code from applicable value set
Data Item	Q8	NDIPX008X	Code from applicable value set
Data Item	Q9	NDIPX009X	Code from applicable value set
Data Item	Q10	NDIPX010X	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.

Neck Disability Index (NDI)

Question Reference	Question Text	Data Item Name	Format	Value Set / Example														
NDIPX001X	Pain Intensity	Q1	1-digit numeric	<table border="1"> <tr> <td>0</td> <td>I have no neck pain at this moment.</td> </tr> <tr> <td>1</td> <td>The pain is very mild at the moment.</td> </tr> <tr> <td>2</td> <td>The pain is moderate at the moment.</td> </tr> <tr> <td>3</td> <td>The pain is fairly severe at the moment.</td> </tr> <tr> <td>4</td> <td>The pain is very severe at the moment.</td> </tr> <tr> <td>5</td> <td>The pain is the worst imaginable at the moment.</td> </tr> <tr> <td>9</td> <td>Unknown</td> </tr> </table>	0	I have no neck pain at this moment.	1	The pain is very mild at the moment.	2	The pain is moderate at the moment.	3	The pain is fairly severe at the moment.	4	The pain is very severe at the moment.	5	The pain is the worst imaginable at the moment.	9	Unknown
0	I have no neck pain at this moment.																	
1	The pain is very mild at the moment.																	
2	The pain is moderate at the moment.																	
3	The pain is fairly severe at the moment.																	
4	The pain is very severe at the moment.																	
5	The pain is the worst imaginable at the moment.																	
9	Unknown																	
NDIPX002X	Personal Care	Q2	1-digit numeric	<table border="1"> <tr> <td>0</td> <td>I can look after myself normally without causing extra neck pain.</td> </tr> <tr> <td>1</td> <td>I can look after myself normally, but it causes extra neck pain.</td> </tr> <tr> <td>2</td> <td>It is painful to look after myself, and I am slow and careful.</td> </tr> <tr> <td>3</td> <td>I need some help but manage most of my personal care.</td> </tr> <tr> <td>4</td> <td>I need help every day in most aspects of self-care.</td> </tr> </table>	0	I can look after myself normally without causing extra neck pain.	1	I can look after myself normally, but it causes extra neck pain.	2	It is painful to look after myself, and I am slow and careful.	3	I need some help but manage most of my personal care.	4	I need help every day in most aspects of self-care.				
0	I can look after myself normally without causing extra neck pain.																	
1	I can look after myself normally, but it causes extra neck pain.																	
2	It is painful to look after myself, and I am slow and careful.																	
3	I need some help but manage most of my personal care.																	
4	I need help every day in most aspects of self-care.																	

				<p>5 I do not get dressed. I wash with difficulty and stay in bed.</p> <p>9 Unknown</p>
NDIPX003X	Lifting	Q3	1-digit numeric	<p>0 I can lift heavy weights without causing extra neck pain.</p> <p>1 I can lift heavy weights, but it gives me extra neck pain.</p> <p>2 Neck pain prevents me from lifting heavy weights off the floor, but I can manage if items are conveniently positioned, i.e. on a table.</p> <p>3 Neck pain prevents me from lifting heavy weights, but I can manage light weights if they are conveniently positioned.</p> <p>4 I can lift only very light weights.</p> <p>5 I cannot lift or carry anything at all.</p> <p>9 Unknown</p>
NDIPX004X	Reading	Q4	1-digit numeric	<p>0 I can read as much as I want with no neck pain.</p> <p>1 I can read as much as I want with slight neck pain.</p> <p>2 I can read as much as I want with moderate neck pain.</p>

				<p>3 I can't read as much as I want because of moderate neck pain.</p> <p>4 I can't read as much as I want because of severe neck pain.</p> <p>5 I can't read at all.</p> <p>9 Unknown</p>
NDIPX005X	Headaches	Q5	1-digit numeric	<p>0 I have no headaches at all.</p> <p>1 I have slight headaches that come infrequently.</p> <p>2 I have moderate headaches that come infrequently.</p> <p>3 I have moderate headaches that come frequently.</p> <p>4 I have severe headaches that come frequently.</p> <p>5 I have headaches almost all the time.</p> <p>9 Unknown</p>
NDIPX006X	Concentration	Q6	1-digit numeric	<p>0 I can concentrate fully without difficulty.</p> <p>1 I can concentrate fully with slight difficulty.</p> <p>2 I have a fair degree of difficulty concentrating.</p> <p>3 I have a lot of difficulty concentrating.</p> <p>4 I have a great deal of difficulty concentrating.</p> <p>5 I can't concentrate at all.</p> <p>9 Unknown</p>

NDIPX007X	Work	Q7	1-digit numeric	<table border="1"> <tr><td>0</td><td>I can do as much work as I want.</td></tr> <tr><td>1</td><td>I can only do my usual work, but no more.</td></tr> <tr><td>2</td><td>I can do most of my usual work, but no more.</td></tr> <tr><td>3</td><td>I can't do my usual work.</td></tr> <tr><td>4</td><td>I can hardly do any work at all.</td></tr> <tr><td>5</td><td>I can't do any work at all.</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	0	I can do as much work as I want.	1	I can only do my usual work, but no more.	2	I can do most of my usual work, but no more.	3	I can't do my usual work.	4	I can hardly do any work at all.	5	I can't do any work at all.	9	Unknown
0	I can do as much work as I want.																	
1	I can only do my usual work, but no more.																	
2	I can do most of my usual work, but no more.																	
3	I can't do my usual work.																	
4	I can hardly do any work at all.																	
5	I can't do any work at all.																	
9	Unknown																	
NDIPX008X	Driving	Q8	1-digit numeric	<table border="1"> <tr><td>0</td><td>I can drive my car without neck pain.</td></tr> <tr><td>1</td><td>I can drive my car with only slight neck pain.</td></tr> <tr><td>2</td><td>I can drive as long as I want with moderate neck pain.</td></tr> <tr><td>3</td><td>I can't drive as long as I want because of moderate neck pain.</td></tr> <tr><td>4</td><td>I can hardly drive at all because of severe neck pain.</td></tr> <tr><td>5</td><td>I can't drive my car at all because of neck pain.</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	0	I can drive my car without neck pain.	1	I can drive my car with only slight neck pain.	2	I can drive as long as I want with moderate neck pain.	3	I can't drive as long as I want because of moderate neck pain.	4	I can hardly drive at all because of severe neck pain.	5	I can't drive my car at all because of neck pain.	9	Unknown
0	I can drive my car without neck pain.																	
1	I can drive my car with only slight neck pain.																	
2	I can drive as long as I want with moderate neck pain.																	
3	I can't drive as long as I want because of moderate neck pain.																	
4	I can hardly drive at all because of severe neck pain.																	
5	I can't drive my car at all because of neck pain.																	
9	Unknown																	
NDIPX009X	Sleeping	Q9	1-digit numeric	<table border="1"> <tr><td>0</td><td>I have no trouble sleeping.</td></tr> <tr><td>1</td><td>My sleep is slightly disturbed for less than 1 hour.</td></tr> <tr><td>2</td><td>My sleep is mildly disturbed for up to 1-2 hours.</td></tr> </table>	0	I have no trouble sleeping.	1	My sleep is slightly disturbed for less than 1 hour.	2	My sleep is mildly disturbed for up to 1-2 hours.								
0	I have no trouble sleeping.																	
1	My sleep is slightly disturbed for less than 1 hour.																	
2	My sleep is mildly disturbed for up to 1-2 hours.																	

				<p>3 My sleep is moderately disturbed for up to 2-3 hours.</p> <p>4 My sleep is greatly disturbed for up to 3-5 hours.</p> <p>5 My sleep is completely disturbed for up to 5-7 hours.</p> <p>9 Unknown</p>
NDIPX010X	Recreation	Q10	1-digit numeric	<p>0 I am able to engage in all my recreational activities with no neck pain at all.</p> <p>1 I am able to engage in all my recreational activities with some neck pain.</p> <p>2 I am able to engage in most, but not all of my recreational activities because of pain in my neck.</p> <p>3 I am able to engage in only a few of my recreational activities because of neck pain.</p> <p>4 I can hardly do recreational activities due to neck pain.</p> <p>5 I can't do any recreational activities due to neck pain.</p> <p>9 Unknown</p>