WELSH INFORMATION STANDARDS BOARD

DSC Notice:	DSCN 2024 16 (AMD)
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 – Self-Administered Comorbidity Questionnaire (AMD)
Sponsor: Christopher Brown, National Director of Digital, Data, Technology, Innovation and Value	
Effective from: 1st April 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 23rd January 2025.

WISB Reference: ISRN 2024 / 017

Summary: To describe the content of Patient Reported Outcome Measures (PROMs) for the Self-Administered Comorbidity Questionnaire element of the PROMs pathways as part of the applicable Value in Health programme.

Data sets / returns affected:
Patient Reported Outcomes 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 uses 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 Outcome Measures (PROMs) and national clinical audit data, and data linkage to associate these records with sources of existing activity data, through data sets 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.

Due to the breadth and complexity of the information and associated processes, this will be achieved using an iterative approach. This DSCN sets out the specification for a standardised minimum data set of metadata to be applied to all (new and existing) PROMs data.

Standardised data is vital to effective central storage of PROMs data and, in particular, to the data linkage and analysis processes necessary to interpret the data to provide meaningful and consistent information via the aforementioned digital dashboards and data visualisation tools.

This DSCN describes the standard set of metadata items required to ensure that key commonalities are preserved and maintained across PROMs records. These standards are independent of the organisations and PROMs applications used to collect this information, and therefore support the seamless communication of PROMs information and enable comparative analysis at a population level.

The information specification set out in this DSCN describes the minimum metadata set to be applied to all new and existing PROMs records. These metadata describe the

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

components necessary to connect the patient, their completed questionnaires and the various touchpoints along their pathway, facilitating an end-to-end view of patient reported outcomes throughout the longitudinal record. By utilising common standards, linkages to activity and clinical information is also possible to provide a complete value-based view. Alignment with similar standards also allows effective storage and retrieval of PROMs records in clinical document repositories, and integration with clinical portals/workstations.

Scope

A PROMs form 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.

This data standard defines the information specification, and serves as a basis for the development of technical and interoperability standards which, in turn, define the data extraction and communication mechanisms necessary to unlock data from PROMs applications for both national and local purposes, to enable analysis at patient and population level. The detail of these technical standards is described in the associated technical specification documentation.

The scope of this standard is independent of the platform or source application used to capture PROMs information, however it is limited to the nationally-validated PROMs tools. The composition of the associated PROMs data sets is described in separate DSCNs, one for each PROMs tool, e.g. Oxford Knee Score.

The metadata items defined in this DSCN comprise 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 associated notices for each PROMs tool.

Furthermore, there are additional metadata items required for storage of PROMs records in a central document repository, e.g. the Welsh Care Records Service (WCRS). These are not a requirement for inclusion in the data set and central flow of data described in this DSCN, but the intention is for these to be added to that data set for consumption by the document repository, to enable access via the clinical record. For details of these items, please refer to the Document Metadata Standard.

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). Details of the implementation plan and central submission process are to be described in the associated technical specification.

Description of Change

This DSCN supersedes DSCN 2024 / 16.

Changes to the previous publication are highlighted as follows:
- <mark>Blue</mark> – new text
- <mark>Grey</mark> – existing text
- ~~Strikethrough~~ – text deletions

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 work collaboratively with DHCW and other provider organisations to develop the technical interoperability standards necessary for effective communication of PROMs data across systems and organisational boundaries; and ultimately

- To supply questionnaire and PROMs data to DHCW in accordance with the information specification described in this DSCN.

Digital Health and Care:

- To work collaboratively with provider organisations to develop the technical interoperability standards necessary for effective communication of questionnaire and PROMs data across systems and organisational boundaries; and ultimately

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

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	New
Data item	Heart Disease – Problem	New
Data item	Heart Disease – Treatment	New
Data item	Heart Disease – Activities	New
Data item	High blood pressure – Problem	New
Data item	High blood pressure – Treatment	New
Data item	High blood pressure – Activities	New
Data item	Lung disease – Problem	New
Data item	Lung disease – Treatment	New
Data item	Lung disease – Activities	New
Data item	Diabetes – Problem	New
Data item	Diabetes – Treatment	New
Data item	Diabetes – Activities	New
Data item	Ulcer or stomach disease – Problem	New
Data item	Ulcer or stomach disease – Treatment	New
Data item	Ulcer or stomach disease – Activities	New
Data item	Kidney disease – Problem	New
Data item	Kidney disease – Treatment	New
Data item	Kidney disease – Activities	New
Data item	Liver disease – Problem	New
Data item	Liver disease – Treatment	New
Data item	Liver disease – Activities	New
Data item	Anemia or other blood disease – Problem	New
Data item	Anemia or other blood disease – Treatment	New
Data item	Anemia or other blood disease – Activities	New
Data item	Cancer – Problem	New
Data item	Cancer – Treatment	New
Data item	Cancer – Activities	New
Data item	Depression – Problem	New
Data item	Depression –Treatment	New
Data item	Depression – Activities	New
Data item	Osteoarthritis, degenerative arthritis – Problem	New
Data item	Osteoarthritis, degenerative arthritis – Treatment	New
Data item	Osteoarthritis, degenerative arthritis – Activities	New
Data item	Back pain – Problem	New
Data item	Back pain – Treatment	New
Data item	Back pain – Activities	New
Data item	Rheumatoid arthritis – Problem	New

Data item	Rheumatoid arthritis – Treatment	New
Data item	Rheumatoid arthritis – Activities	New
Data item	Other medical problems (please write in)	New
Data item	Other medical problems – Problem	New
Data item	Other medical problems – Treatment	New
Data item	Other medical problems – Activities	New

Appendix B: Highlighted changes to be made to the NHS Wales Data Dictionary

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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	SACQPX	See PROMs Metadata specification
Data Item	Heart Disease – Problem	SACPX001A	Code from applicable value set
Data Item	Heart Disease – Treatment	SACPX001B	Code from applicable value set
Data Item	Heart Disease – Activities	SACPX001C	Code from applicable value set
Data Item	High blood pressure – Problem	SACPX002A	Code from applicable value set
Data Item	High blood pressure – Treatment	SACPX002B	Code from applicable value set
Data Item	High blood pressure – Activities	SACPX002C	Code from applicable value set
Data Item	Lung disease – Problem	SACPX003A	Code from applicable value set
Data Item	Lung disease – Treatment	SACPX003B	Code from applicable value set
Data Item	Lung disease – Activities	SACPX003C	Code from applicable value set
Data Item	Diabetes – Problem	SACPX004A	Code from applicable value set
Data Item	Diabetes – Treatment	SACPX004B	Code from applicable value set
Data Item	Diabetes – Activities	SACPX004C	Code from applicable value set
Data Item	Ulcer or stomach disease – Problem	SACPX005A	Code from applicable value set
Data Item	Ulcer or stomach disease – Treatment	SACPX005B	Code from applicable value set
Data Item	Ulcer or stomach disease – Activities	SACPX005C	Code from applicable value set

Data Type	Item Name	Reference	Data represents
Data Item	Kidney disease – Problem	SACPX006A	Code from applicable value set
Data Item	Kidney disease – Treatment	SACPX006B	Code from applicable value set
Data Item	Kidney disease – Activities	SACPX006C	Code from applicable value set
Data Item	Liver disease – Problem	SACPX007A	Code from applicable value set
Data Item	Liver disease – Treatment	SACPX007B	Code from applicable value set
Data Item	Liver disease – Activities	SACPX007C	Code from applicable value set
Data Item	Anemia or other blood disease – Problem	SACPX008A	Code from applicable value set
Data Item	Anemia or other blood disease – Treatment	SACPX008B	Code from applicable value set
Data Item	Anemia or other blood disease – Activities	SACPX008C	Code from applicable value set
Data Item	Cancer – Problem	SACPX009A	Code from applicable value set
Data Item	Cancer – Treatment	SACPX009B	Code from applicable value set
Data Item	Cancer – Activities	SACPX009C	Code from applicable value set
Data Item	Depression – Problem	SACPX010A	Code from applicable value set
Data Item	Depression – Treatment	SACPX010B	Code from applicable value set
Data Item	Depression – Activities	SACPX010C	Code from applicable value set
Data Item	Osteoarthritis, degenerative arthritis – Problem	SACPX011A	Code from applicable value set
Data Item	Osteoarthritis, degenerative arthritis – Treatment	SACPX011B	Code from applicable value set
Data Item	Osteoarthritis, degenerative arthritis – Activities	SACPX011C	Code from applicable value set
Data Item	Back pain – Problem	SACPX012A	Code from applicable value set
Data Item	Back pain – Treatment	SACPX012B	Code from applicable value set
Data Item	Back pain – Activities	SACPX012C	Code from applicable value set

Data Type	Item Name	Reference	Data represents
Data Item	Rheumatoid arthritis – Problem	SACPX013A	Code from applicable value set
Data Item	Rheumatoid arthritis – Treatment	SACPX013B	Code from applicable value set
Data Item	Rheumatoid arthritis – Activities	SACPX013C	Code from applicable value set
Data Item	Other medical problems (please write in)	SACPX014A	Free text
Data Item	Other medical problems – Problem	SACPX014C	Code from applicable value set
Data Item	Other medical problems – Treatment	SACPX014C	Code from applicable value set
Data Item	Other medical problems – Activities	SACPX014D	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

Question Reference	Question Text	Data Item Name	Format	Value Set / Example
SACPX001A	Heart Disease – Do you have the problem?	Heart Disease – Problem	1-digit numeric	0 No 1 Yes 9 Unknown
SACPX001B	Heart Disease – Do you receive treatment for it?	Heart Disease – Treatment	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown
SACPX001C	Heart Disease – Does it limit your activities?	Heart Disease – Activities	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown
SACPX002A	High blood pressure – Do you have the problem?	High blood pressure – Problem	1-digit numeric	0 No 1 Yes 9 Unknown
SACPX002B	High blood pressure – Do you receive treatment for it?	High blood pressure – Treatment	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown

Question Reference	Question Text	Data Item Name	Format	Value Set / Example
SACPX002C	High blood pressure – Does it limit your activities?	High blood pressure – Activities	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown
SACPX003A	Lung disease – Do you have the problem?	Lung disease – Problem	1-digit numeric	0 No 1 Yes 9 Unknown
SACPX003B	Lung disease – Do you receive treatment for it?	Lung disease – Treatment	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown
SACPX003C	Lung disease – Does it limit your activities?	Lung disease – Activities	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown
SACPX004A	Diabetes – Do you have the problem?	Diabetes – Problem	1-digit numeric	0 No 1 Yes 9 Unknown
SACPX004B	Diabetes – Do you receive treatment for it?	Diabetes – Treatment	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown

Question Reference	Question Text	Data Item Name	Format	Value Set / Example
SACPX004C	Diabetes – Does it limit your activities?	Diabetes – Activities	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown
SACPX005A	Ulcer or stomach disease – Do you have the problem?	Ulcer or stomach disease – Problem	1-digit numeric	0 No 1 Yes 9 Unknown
SACPX005B	Ulcer or stomach disease – Do you receive treatment for it?	Ulcer or stomach disease – Treatment	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown
SACPX005C	Ulcer or stomach disease – Does it limit your activities?	Ulcer or stomach disease – Activities	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown
SACPX006A	Kidney disease – Do you have the problem?	Kidney disease – Problem	1-digit numeric	0 No 1 Yes 9 Unknown
SACPX006B	Kidney disease – Do you receive treatment for it?	Kidney disease – Treatment	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown

Question Reference	Question Text	Data Item Name	Format	Value Set / Example
SACPX006C	Kidney disease – Does it limit your activities?	Kidney disease – Activities	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown
SACPX007A	Liver disease – Do you have the problem?	Liver disease – Problem	1-digit numeric	0 No 1 Yes 9 Unknown
SACPX007B	Liver disease – Do you receive treatment for it?	Liver disease – Treatment	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown
SACPX007C	Liver disease – Does it limit your activities?	Liver disease – Activities	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown
SACPX008A	Anemia or other blood disease – Do you have the problem?	Anemia or other blood disease – Problem	1-digit numeric	0 No 1 Yes 9 Unknown
SACPX008B	Anemia or other blood disease – Do you receive treatment for it?	Anemia or other blood disease – Treatment	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown

Question Reference	Question Text	Data Item Name	Format	Value Set / Example
SACPX008C	Anemia or other blood disease – Does it limit your activities?	Anemia or other blood disease – Activities	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown
SACPX009A	Cancer – Do you have the problem?	Cancer – Problem	1-digit numeric	0 No 1 Yes 9 Unknown
SACPX009B	Cancer – Do you receive treatment for it?	Cancer – Treatment	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown
SACPX009C	Cancer – Does it limit your activities?	Cancer – Activities	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown
SACPX010A	Depression – Do you have the problem?	Depression – Problem	1-digit numeric	0 No 1 Yes 9 Unknown
SACPX010B	Depression – Do you receive treatment for it?	Depression – Treatment	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown

Question Reference	Question Text	Data Item Name	Format	Value Set / Example
SACPX010C	Depression – Does it limit your activities?	Depression – Activities	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown
SACPX011A	Osteoarthritis, degenerative arthritis – Do you have the problem?	Osteoarthritis, degenerative arthritis – Problem	1-digit numeric	0 No 1 Yes 9 Unknown
SACPX011B	Osteoarthritis, degenerative arthritis – Do you receive treatment for it?	Osteoarthritis, degenerative arthritis – Treatment	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown
SACPX011C	Osteoarthritis, degenerative arthritis – Does it limit your activities?	Osteoarthritis, degenerative arthritis – Activities	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown
SACPX012A	Back pain – Do you have the problem?	Back pain – Problem	1-digit numeric	0 No 1 Yes 9 Unknown
SACPX012B	Back pain – Do you receive treatment for it?	Back pain – Treatment	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown

Question Reference	Question Text	Data Item Name	Format	Value Set / Example
SACPX012C	Back pain – Does it limit your activities?	Back pain – Activities	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown
SACPX013A	Rheumatoid arthritis – Do you have the problem?	Rheumatoid arthritis – Problem	1-digit numeric	0 No 1 Yes 9 Unknown
SACPX013B	Rheumatoid arthritis – Do you receive treatment for it?	Rheumatoid arthritis – Treatment	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown
SACPX013C	Rheumatoid arthritis – Does it limit your activities?	Rheumatoid arthritis – Activities	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown
SACPX014A	Other medical problems (please write in)	Other	100-character alphanumeric	Free text – use NULL for missing or N/A values
SACPX014B	Other medical problems – Do you have the problem?	Other medical problems (please write in) – Problem	1-digit numeric	0 No 1 Yes 9 Unknown

Question Reference	Question Text	Data Item Name	Format	Value Set / Example
SACPX014C	Other medical problems – Do you receive treatment for it?	Other medical problems (please write in) – Treatment	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown
SACPX014D	Other medical problems – Does it limit your activities?	Other medical problems (please write in) – Activities	1-digit numeric	0 No 1 Yes 8 N/A 9 Unknown