

WELSH INFORMATION STANDARDS BOARD

DSC Notice:	DSCN 2025 / 19
Date of Issue:	15 th October 2025

Welsh Health Circular/Official Letter: WHC (2022) 005: Welsh Value in Health Centre – Data Requirements	Subject: Value in Health – Quality of Life in Epilepsy (QOLIE-31)
Sponsor: Christopher Brown, National Director of Value Transformation	
Standard Type: PROMs	
Effective Date: 04/09/2025	

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 18th September 2025.

WISB Reference: ISRN 2025 / 016

Summary:

To introduce a new data set for Quality of Life in Epilepsy (QOLIE-31), 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 \(PROMs\) \(wales.nhs.uk\)](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. 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.

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 Quality of Life in Epilepsy (QOLIE-31).

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.

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	5
Data module	Document Details	Existing	5
Data module	Event Details	Existing	5
Data module	PROMs Details	Existing	5
Data module	Data Entry Details	Existing	5
Data item	Q1	New	5
Data item	Q2	New	5
Data item	Q3	New	5

Data item	Q4	New	5
Data item	Q5	New	5
Data item	Q6	New	5
Data item	Q7	New	5
Data item	Q8	New	5
Data item	Q9	New	5
Data item	Q10	New	5
Data item	Q11	New	5
Data item	Q12	New	5
Data item	Q13	New	5
Data item	Q14	New	5
Data item	Q15	New	6
Data item	Q16	New	6
Data item	Q17	New	6
Data item	Q18	New	6
Data item	Q19	New	6
Data item	Q20	New	6
Data item	Q21	New	6
Data item	Q22	New	6
Data item	Q23	New	6
Data item	Q24	New	6
Data item	Q25	New	6
Data item	Q26	New	6
Data item	Q27	New	6
Data item	Q28	New	6
Data item	Q29	New	6
Data item	Q30	New	6
Data item	Q31	New	6
Data item	QOLIE-31 Seizure Worry	New	6
Data item	QOLIE-31 Overall Quality of Life	New	6
Data item	QOLIE-31 Emotional Well-Being	New	6
Data item	QOLIE-31 Energy/Fatigue	New	6
Data item	QOLIE-31 Cognitive	New	7
Data item	QOLIE-31 Medication Effects	New	7
Data item	QOLIE-31 Social Function	New	7
Data item	QOLIE-31 Overall Score	New	7

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	QOL1PX001X	Code from applicable value set
Data item	Q2	QOL1PX002X	Code from applicable value set
Data item	Q3	QOL1PX003X	Code from applicable value set
Data item	Q4	QOL1PX004X	Code from applicable value set
Data item	Q5	QOL1PX005X	Code from applicable value set
Data item	Q6	QOL1PX006X	Code from applicable value set
Data item	Q7	QOL1PX007X	Code from applicable value set
Data item	Q8	QOL1PX008X	Code from applicable value set
Data item	Q9	QOL1PX009X	Code from applicable value set
Data item	Q10	QOL1PX010X	Code from applicable value set
Data item	Q11	QOL1PX011X	Code from applicable value set
Data item	Q12	QOL1PX012X	Code from applicable value set
Data item	Q13	QOL1PX013X	Code from applicable value set
Data item	Q14	QOL1PX014X	Code from applicable value set

Data Type	Item Name	Reference	Data represents
Data item	Q15	QOL1PX015X	Code from applicable value set
Data item	Q16	QOL1PX016X	Code from applicable value set
Data item	Q17	QOL1PX017X	Code from applicable value set
Data item	Q18	QOL1PX018X	Code from applicable value set
Data item	Q19	QOL1PX019X	Code from applicable value set
Data item	Q20	QOL1PX020X	Code from applicable value set
Data item	Q21	QOL1PX021X	Code from applicable value set
Data item	Q22	QOL1PX022X	Code from applicable value set
Data item	Q23	QOL1PX023X	Code from applicable value set
Data item	Q24	QOL1PX024X	Code from applicable value set
Data item	Q25	QOL1PX025X	Code from applicable value set
Data item	Q26	QOL1PX026X	Code from applicable value set
Data item	Q27	QOL1PX027X	Code from applicable value set
Data item	Q28	QOL1PX028X	Code from applicable value set
Data item	Q29	QOL1PX029X	Code from applicable value set
Data item	Q30	QOL1PX030X	Code from applicable value set
Data item	Q31	QOL1PX031X	Scale 0-100
Data item	QOLIE-31 Seizure Worry	QOL1PX032X	Calculated score
Data item	QOLIE-31 Overall Quality of Life	QOL1PX033X	Calculated score
Data item	QOLIE-31 Emotional Well-Being	QOL1PX034X	Calculated score
Data item	QOLIE-31 Energy/Fatigue	QOL1PX035X	Calculated score

Data Type	Item Name	Reference	Data represents
Data item	Q31	QOL1PX031X	Scale 0-100
Data item	QOLIE-31 Seizure Worry	QOL1PX032X	Calculated score
Data item	QOLIE-31 Overall Quality of Life	QOL1PX033X	Calculated score
Data item	QOLIE-31 Emotional Well-Being	QOL1PX034X	Calculated score
Data item	QOLIE-31 Energy/Fatigue	QOL1PX035X	Calculated score
Data item	QOLIE-31 Cognitive	QOL1PX036X	Calculated score
Data item	QOLIE-31 Medication Effects	QOL1PX037X	Calculated score
Data item	QOLIE-31 Social Function	QOL1PX038X	Calculated score
Data item	QOLIE-31 Overall Score	QOL1PX039X	Calculated score

- **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

Question Reference	Question Text	Item Name	Format	Value Set / Example																						
QOL1PX001X	1. Overall, how would you rate your quality of life?	Q1	2-digit numeric	<table border="1"> <tr> <td>10</td> <td>Best Possible Quality of Life</td> </tr> <tr> <td>9</td> <td></td> </tr> <tr> <td>8</td> <td></td> </tr> <tr> <td>7</td> <td></td> </tr> <tr> <td>6</td> <td></td> </tr> <tr> <td>5</td> <td></td> </tr> <tr> <td>4</td> <td></td> </tr> <tr> <td>3</td> <td></td> </tr> <tr> <td>2</td> <td></td> </tr> <tr> <td>1</td> <td></td> </tr> <tr> <td>0</td> <td>Worst Possible Quality of Life (as bad as or worse than being dead)</td> </tr> </table>	10	Best Possible Quality of Life	9		8		7		6		5		4		3		2		1		0	Worst Possible Quality of Life (as bad as or worse than being dead)
10	Best Possible Quality of Life																									
9																										
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2																										
1																										
0	Worst Possible Quality of Life (as bad as or worse than being dead)																									

				99	Unknown
QOL1PX002X	These questions are about how you FEEL and how things have been for you during the past 4 weeks . For each question, please indicate the one answer that comes closest to the way you have been feeling.				Rubric – no return value
QOL1PX003X	(How much of the time during the past 4 weeks...) 2. Did you feel full of pep?	Q2	1-digit numeric	1	All of the time
				2	Most of the time
				3	A good bit of the time
				4	Some of the time
				5	A little of the time
				6	None of the time
				9	Unknown
QOL1PX004X	(How much of the time during the past 4 weeks...) 3. Have you been a very nervous person?	Q3	1-digit numeric	1	All of the time
				2	Most of the time
				3	A good bit of the time
				4	Some of the time
				5	A little of the time
				6	None of the time
				9	Unknown

QOL1PX005X	<p>(How much of the time during the past 4 weeks...)</p> <p>4. Have you felt so down in the dumps that nothing could cheer you up?</p>	Q4	1-digit numeric	<table border="1"> <tr><td>1</td><td>All of the time</td></tr> <tr><td>2</td><td>Most of the time</td></tr> <tr><td>3</td><td>A good bit of the time</td></tr> <tr><td>4</td><td>Some of the time</td></tr> <tr><td>5</td><td>A little of the time</td></tr> <tr><td>6</td><td>None of the time</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	All of the time	2	Most of the time	3	A good bit of the time	4	Some of the time	5	A little of the time	6	None of the time	9	Unknown
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QOL1PX006X	<p>(How much of the time during the past 4 weeks...)</p> <p>5. Have you felt calm and peaceful?</p>	Q5	1-digit numeric	<table border="1"> <tr><td>1</td><td>All of the time</td></tr> <tr><td>2</td><td>Most of the time</td></tr> <tr><td>3</td><td>A good bit of the time</td></tr> <tr><td>4</td><td>Some of the time</td></tr> <tr><td>5</td><td>A little of the time</td></tr> <tr><td>6</td><td>None of the time</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	All of the time	2	Most of the time	3	A good bit of the time	4	Some of the time	5	A little of the time	6	None of the time	9	Unknown
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QOL1PX007X	<p>(How much of the time during the past 4 weeks...)</p> <p>6. Did you have a lot of energy?</p>	Q6	1-digit numeric	<table border="1"> <tr><td>1</td><td>All of the time</td></tr> <tr><td>2</td><td>Most of the time</td></tr> <tr><td>3</td><td>A good bit of the time</td></tr> <tr><td>4</td><td>Some of the time</td></tr> <tr><td>5</td><td>A little of the time</td></tr> <tr><td>6</td><td>None of the time</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	All of the time	2	Most of the time	3	A good bit of the time	4	Some of the time	5	A little of the time	6	None of the time	9	Unknown
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QOL1PX008X	(How much of the time during the past 4 weeks...) 7. Have you felt downhearted and blue?	Q7	1-digit numeric	<table border="1"> <tr><td>1</td><td>All of the time</td></tr> <tr><td>2</td><td>Most of the time</td></tr> <tr><td>3</td><td>A good bit of the time</td></tr> <tr><td>4</td><td>Some of the time</td></tr> <tr><td>5</td><td>A little of the time</td></tr> <tr><td>6</td><td>None of the time</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	All of the time	2	Most of the time	3	A good bit of the time	4	Some of the time	5	A little of the time	6	None of the time	9	Unknown	
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QOL1PX009X	(How much of the time during the past 4 weeks...) 8. Did you feel worn out?	Q8	1-digit numeric	<table border="1"> <tr><td>1</td><td>All of the time</td></tr> <tr><td>2</td><td>Most of the time</td></tr> <tr><td>3</td><td>A good bit of the time</td></tr> <tr><td>4</td><td>Some of the time</td></tr> <tr><td>5</td><td>A little of the time</td></tr> <tr><td>6</td><td>None of the time</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	All of the time	2	Most of the time	3	A good bit of the time	4	Some of the time	5	A little of the time	6	None of the time	9	Unknown	
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QOL1PX010X	(How much of the time during the past 4 weeks...) 9. Have you been a happy person?	Q9	1-digit numeric	<table border="1"> <tr><td>1</td><td>All of the time</td></tr> <tr><td>2</td><td>Most of the time</td></tr> <tr><td>3</td><td>A good bit of the time</td></tr> <tr><td>4</td><td>Some of the time</td></tr> <tr><td>5</td><td>A little of the time</td></tr> <tr><td>6</td><td>None of the time</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	All of the time	2	Most of the time	3	A good bit of the time	4	Some of the time	5	A little of the time	6	None of the time	9	Unknown	
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QOL1PX011X	(How much of the time during the past 4 weeks...) 10. Did you feel tired?	Q10	1-digit numeric	<table border="1"> <tr><td>1</td><td>All of the time</td></tr> <tr><td>2</td><td>Most of the time</td></tr> <tr><td>3</td><td>A good bit of the time</td></tr> <tr><td>4</td><td>Some of the time</td></tr> <tr><td>5</td><td>A little of the time</td></tr> <tr><td>6</td><td>None of the time</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	All of the time	2	Most of the time	3	A good bit of the time	4	Some of the time	5	A little of the time	6	None of the time	9	Unknown	
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QOL1PX012X	(How much of the time during the past 4 weeks...) 11. Have you worried about having another seizure?	Q11	1-digit numeric	<table border="1"> <tr><td>1</td><td>All of the time</td></tr> <tr><td>2</td><td>Most of the time</td></tr> <tr><td>3</td><td>A good bit of the time</td></tr> <tr><td>4</td><td>Some of the time</td></tr> <tr><td>5</td><td>A little of the time</td></tr> <tr><td>6</td><td>None of the time</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	All of the time	2	Most of the time	3	A good bit of the time	4	Some of the time	5	A little of the time	6	None of the time	9	Unknown	
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QOL1PX013X	(How much of the time during the past 4 weeks...) 12. Did you have difficulty reasoning and solving problems (such as making plans, making decisions, learning new things)?	Q12	1-digit numeric	<table border="1"> <tr><td>1</td><td>All of the time</td></tr> <tr><td>2</td><td>Most of the time</td></tr> <tr><td>3</td><td>A good bit of the time</td></tr> <tr><td>4</td><td>Some of the time</td></tr> <tr><td>5</td><td>A little of the time</td></tr> <tr><td>6</td><td>None of the time</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	All of the time	2	Most of the time	3	A good bit of the time	4	Some of the time	5	A little of the time	6	None of the time	9	Unknown	
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QOL1PX014X	(How much of the time during the past 4 weeks...) 13. Has your health limited your social activities (such as visiting with friends or close relatives)?	Q13	1-digit numeric	<table border="1"> <tr><td>1</td><td>All of the time</td></tr> <tr><td>2</td><td>Most of the time</td></tr> <tr><td>3</td><td>A good bit of the time</td></tr> <tr><td>4</td><td>Some of the time</td></tr> <tr><td>5</td><td>A little of the time</td></tr> <tr><td>6</td><td>None of the time</td></tr> <tr><td>0</td><td>Unknown</td></tr> </table>	1	All of the time	2	Most of the time	3	A good bit of the time	4	Some of the time	5	A little of the time	6	None of the time	0	Unknown	
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QOL1PX015X	14. How has the QUALITY OF YOUR LIFE been during the past 4 weeks (that is, how have things been going for you)?	Q14	1-digit numeric	<table border="1"> <tr><td>1</td><td>Very well: could hardly be better</td></tr> <tr><td>2</td><td>Pretty good</td></tr> <tr><td>3</td><td>Good & bad parts about equal</td></tr> <tr><td>4</td><td>Pretty bad</td></tr> <tr><td>5</td><td>Very bad: could hardly be worse</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	Very well: could hardly be better	2	Pretty good	3	Good & bad parts about equal	4	Pretty bad	5	Very bad: could hardly be worse	9	Unknown			
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QOL1PX016X	The following question is about MEMORY .			Rubric – no return value															
QOL1PX017X	15. In the past 4 weeks, have you had any trouble with your memory?	Q15	1-digit numeric	<table border="1"> <tr><td>1</td><td>Yes, a great deal</td></tr> <tr><td>2</td><td>Yes, somewhat</td></tr> <tr><td>3</td><td>Only a little</td></tr> <tr><td>4</td><td>No, not at all</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	Yes, a great deal	2	Yes, somewhat	3	Only a little	4	No, not at all	9	Unknown					
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QOL1PX018X	Circle one number for how often in the past 4 weeks you have had trouble remembering			Rubric – no return value															

	or how often this memory problem has interfered with your normal work or living.																	
QOL1PX019X	16. Trouble remembering things people tell you	Q16	1-digit numeric	<table border="1"> <tr><td>1</td><td>All of the time</td></tr> <tr><td>2</td><td>Most of the time</td></tr> <tr><td>3</td><td>A good bit of the time</td></tr> <tr><td>4</td><td>Some of the time</td></tr> <tr><td>5</td><td>A little of the time</td></tr> <tr><td>6</td><td>None of the time</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	All of the time	2	Most of the time	3	A good bit of the time	4	Some of the time	5	A little of the time	6	None of the time	9	Unknown
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6	None of the time																	
9	Unknown																	
QOL1PX020X	The following questions are about CONCENTRATION problems you may have. Circle one number for how often in the past 4 weeks you had trouble concentrating or how often these problems interfered with your normal work or living.			Rubric – no return value														
QOL1PX021X	17. Trouble concentrating on reading	Q17	1-digit numeric	<table border="1"> <tr><td>1</td><td>All of the time</td></tr> <tr><td>2</td><td>Most of the time</td></tr> <tr><td>3</td><td>A good bit of the time</td></tr> <tr><td>4</td><td>Some of the time</td></tr> <tr><td>5</td><td>A little of the time</td></tr> <tr><td>6</td><td>None of the time</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	All of the time	2	Most of the time	3	A good bit of the time	4	Some of the time	5	A little of the time	6	None of the time	9	Unknown
1	All of the time																	
2	Most of the time																	
3	A good bit of the time																	
4	Some of the time																	
5	A little of the time																	
6	None of the time																	
9	Unknown																	
QOL1PX022X	18. Trouble concentrating on doing one thing at a time	Q18	1-digit numeric	<table border="1"> <tr><td>1</td><td>All of the time</td></tr> <tr><td>2</td><td>Most of the time</td></tr> </table>	1	All of the time	2	Most of the time										
1	All of the time																	
2	Most of the time																	

				<table border="1"> <tr><td>3</td><td>A good bit of the time</td></tr> <tr><td>4</td><td>Some of the time</td></tr> <tr><td>5</td><td>A little of the time</td></tr> <tr><td>6</td><td>None of the time</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	3	A good bit of the time	4	Some of the time	5	A little of the time	6	None of the time	9	Unknown		
3	A good bit of the time															
4	Some of the time															
5	A little of the time															
6	None of the time															
9	Unknown															
QOL1PX023X	The following questions are about problems you may have with certain ACTIVITIES. Circle one number for how much during the past 4weeks your epilepsy or antiepileptic medication has caused trouble with...			Rubric – no return value												
QOL1PX024X	19. Leisure time (such as hobbies, going out)	Q19	1-digit numeric	<table border="1"> <tr><td>1</td><td>A great deal</td></tr> <tr><td>2</td><td>A lot</td></tr> <tr><td>3</td><td>Somewhat</td></tr> <tr><td>4</td><td>Only a little</td></tr> <tr><td>5</td><td>Not at all</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	A great deal	2	A lot	3	Somewhat	4	Only a little	5	Not at all	9	Unknown
1	A great deal															
2	A lot															
3	Somewhat															
4	Only a little															
5	Not at all															
9	Unknown															
QOL1PX025X	20. Driving	Q20	1-digit numeric	<table border="1"> <tr><td>1</td><td>A great deal</td></tr> <tr><td>2</td><td>A lot</td></tr> <tr><td>3</td><td>Somewhat</td></tr> <tr><td>4</td><td>Only a little</td></tr> <tr><td>5</td><td>Not at all</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	A great deal	2	A lot	3	Somewhat	4	Only a little	5	Not at all	9	Unknown
1	A great deal															
2	A lot															
3	Somewhat															
4	Only a little															
5	Not at all															
9	Unknown															
QOL1PX026X	The following questions relate to the way you FEEL about your seizures .			Rubric – no return value												

QOL1PX027X	21. How fearful are you of having a seizure during the next month?	Q21	1-digit numeric	<table border="1"> <tr><td>1</td><td>Very fearful</td></tr> <tr><td>2</td><td>Somewhat fearful</td></tr> <tr><td>3</td><td>Not very fearful</td></tr> <tr><td>4</td><td>Not fearful at all</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	Very fearful	2	Somewhat fearful	3	Not very fearful	4	Not fearful at all	9	Unknown
1	Very fearful													
2	Somewhat fearful													
3	Not very fearful													
4	Not fearful at all													
9	Unknown													
QOL1PX028X	22. Do you worry about hurting yourself during a seizure?	Q22	1-digit numeric	<table border="1"> <tr><td>1</td><td>Worry a lot</td></tr> <tr><td>2</td><td>Occasionally worry</td></tr> <tr><td>3</td><td>Don't worry at all</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	Worry a lot	2	Occasionally worry	3	Don't worry at all	9	Unknown		
1	Worry a lot													
2	Occasionally worry													
3	Don't worry at all													
9	Unknown													
QOL1PX029X	23. How worried are you about embarrassment or other social problems resulting from having a seizure during the next month?	Q23	1-digit numeric	<table border="1"> <tr><td>1</td><td>Very worried</td></tr> <tr><td>2</td><td>Somewhat worried</td></tr> <tr><td>3</td><td>Not very worried</td></tr> <tr><td>4</td><td>Not at all worried</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	Very worried	2	Somewhat worried	3	Not very worried	4	Not at all worried	9	Unknown
1	Very worried													
2	Somewhat worried													
3	Not very worried													
4	Not at all worried													
9	Unknown													
QOL1PX030X	24. How worried are you that medications you are taking will be bad for you if taken for a long time?	Q24	1-digit numeric	<table border="1"> <tr><td>1</td><td>Very worried</td></tr> <tr><td>2</td><td>Somewhat worried</td></tr> <tr><td>3</td><td>Not very worried</td></tr> <tr><td>4</td><td>Not at all worried</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	Very worried	2	Somewhat worried	3	Not very worried	4	Not at all worried	9	Unknown
1	Very worried													
2	Somewhat worried													
3	Not very worried													
4	Not at all worried													
9	Unknown													
QOL1PX031X	For each of these PROBLEMS, circle one number for how much they bother you on a scale of 1 to 5 where 1 = Not at all bothersome, and 5 =Extremely bothersome.			Rubric – no return value										

QOL1PX032X	25. Seizures	Q25	1-digit numeric	<table border="1"> <tr><td>1</td><td>Not at all bothersome</td></tr> <tr><td>2</td><td></td></tr> <tr><td>3</td><td></td></tr> <tr><td>4</td><td></td></tr> <tr><td>5</td><td>Extremely bothersome</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	Not at all bothersome	2		3		4		5	Extremely bothersome	9	Unknown
1	Not at all bothersome															
2																
3																
4																
5	Extremely bothersome															
9	Unknown															
QOL1PX033X	26. Memory difficulties	Q26	1-digit numeric	<table border="1"> <tr><td>1</td><td>Not at all bothersome</td></tr> <tr><td>2</td><td></td></tr> <tr><td>3</td><td></td></tr> <tr><td>4</td><td></td></tr> <tr><td>5</td><td>Extremely bothersome</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	Not at all bothersome	2		3		4		5	Extremely bothersome	9	Unknown
1	Not at all bothersome															
2																
3																
4																
5	Extremely bothersome															
9	Unknown															
QOL1PX034X	27. Work limitations	Q27	1-digit numeric	<table border="1"> <tr><td>1</td><td>Not at all bothersome</td></tr> <tr><td>2</td><td></td></tr> <tr><td>3</td><td></td></tr> <tr><td>4</td><td></td></tr> <tr><td>5</td><td>Extremely bothersome</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	Not at all bothersome	2		3		4		5	Extremely bothersome	9	Unknown
1	Not at all bothersome															
2																
3																
4																
5	Extremely bothersome															
9	Unknown															
QOL1PX035X	28. Social limitations	Q28	1-digit numeric	<table border="1"> <tr><td>1</td><td>Not at all bothersome</td></tr> <tr><td>2</td><td></td></tr> </table>	1	Not at all bothersome	2									
1	Not at all bothersome															
2																

				<table border="1"> <tr><td>3</td><td></td></tr> <tr><td>4</td><td></td></tr> <tr><td>5</td><td>Extremely bothersome</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	3		4		5	Extremely bothersome	9	Unknown				
3																
4																
5	Extremely bothersome															
9	Unknown															
QOL1PX031X	29. Physical effects of antiepileptic medication	Q29	1-digit numeric	<table border="1"> <tr><td>1</td><td>Not at all bothersome</td></tr> <tr><td>2</td><td></td></tr> <tr><td>3</td><td></td></tr> <tr><td>4</td><td></td></tr> <tr><td>5</td><td>Extremely bothersome</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	Not at all bothersome	2		3		4		5	Extremely bothersome	9	Unknown
1	Not at all bothersome															
2																
3																
4																
5	Extremely bothersome															
9	Unknown															
QOL1PX032X	30. Mental effects of antiepileptic medication	Q30	1-digit numeric	<table border="1"> <tr><td>1</td><td>Not at all bothersome</td></tr> <tr><td>2</td><td></td></tr> <tr><td>3</td><td></td></tr> <tr><td>4</td><td></td></tr> <tr><td>5</td><td>Extremely bothersome</td></tr> <tr><td>9</td><td>Unknown</td></tr> </table>	1	Not at all bothersome	2		3		4		5	Extremely bothersome	9	Unknown
1	Not at all bothersome															
2																
3																
4																
5	Extremely bothersome															
9	Unknown															
QOL1PX033X	31. How good or bad do you think your health is? On the thermometer scale below, the best imaginable state of health is 100 and the worst imaginable state is 0. Please indicate how you feel about	Q31	3-digit numeric	<p>Scale value 0-100 e.g. 80</p> <p>Use NULL for unknown or N/A values</p>												

	your health by circling one number on the scale. Please consider your epilepsy as part of your health when you answer this question.			
QOL1PX034X	QOLIE-31 Seizure Worry	QOLIE-31 Seizure Worry	Decimal (to as many decimal places as possible, i.e. no rounding)	Score (0-100) based on QOLIE-31 scoring method, e.g. 67 Use NULL for missing, unknown or N/A values
QOL1PX035X	QOLIE-31 Overall Quality of Life	QOLIE-31 Overall Quality of Life	Decimal (to as many decimal places as possible, i.e. no rounding)	Score (0-100) based on QOLIE-31 scoring method, e.g. 50 Use NULL for missing, unknown or N/A values
QOL1PX036X	QOLIE-31 Emotional Well-Being	QOLIE-31 Emotional Well-Being	Decimal (to as many decimal places as possible, i.e. no rounding)	Score (0-100) based on QOLIE-31 scoring method, e.g. 50 Use NULL for missing, unknown or N/A values
QOL1PX037X	QOLIE-31 Energy/Fatigue	QOLIE-31 Energy/Fatigue	Decimal (to as many decimal places as possible, i.e. no rounding)	Score (0-100) based on QOLIE-31 scoring method, e.g. 50 Use NULL for missing, unknown or N/A values

QOL1PX038X	QOLIE-31 Cognitive	QOLIE-31 Cognitive	Decimal (to as many decimal places as possible, i.e. no rounding)	Score (0-100) based on QOLIE-31 scoring method, e.g. 60.83 Use NULL for missing, unknown or N/A values
QOL1PX039X	QOLIE-31 Medication Effects	QOLIE-31 Medication Effects	Decimal (to as many decimal places as possible, i.e. no rounding)	Score (0-100) based on QOLIE-31 scoring method, e.g. 50 Use NULL for missing, unknown or N/A values
QOL1PX001X	QOLIE-31 Social Function	QOLIE-31 Social Function	Decimal (to as many decimal places as possible, i.e. no rounding)	Score (0-100) based on QOLIE-31 scoring method, e.g. 48 Use NULL for missing, unknown or N/A values
QOL1PX002X	QOLIE-31 Overall Score	QOLIE-31 Overall Score	Decimal (to as many decimal places as possible, i.e. no rounding)	Score (0-100) based on QOLIE-31 scoring method, e.g. 53.865 Use NULL for missing, unknown or N/A values



Llywodraeth Cymru
Welsh Government