

## WELSH INFORMATION STANDARDS BOARD

<b>DSC Notice:</b>	DSCN 2017 / 08
<b>Date of Issue:</b>	21 <sup>st</sup> November 2017

<b>Ministerial / Official Letter:</b> N/A	<b>Subject:</b> Children and Young People Neurodevelopment Assessment – Wait Times
<b>Sponsor:</b> Dr Liz Davies, Deputy Director, Mental Health and Vulnerable Groups Division, Welsh Government	
<b>Implementation Date:</b> 1 <sup>st</sup> November 2017	
<div><b>DATA STANDARDS CHANGE NOTICE</b></div> <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) in TBC</p> <p><b>WISB Reference:</b> ISRN 2017 / 009</p>	
<b>Summary:</b> <p>To introduce a data collection to monitor performance against the 26 week waiting time target for referral to neurodevelopment assessments of ADHD and ASD for children and young people (aged 17 years 6 months and under at time of referral).</p>	
<b>Data sets / returns affected:</b> <ul style="list-style-type: none"><li>None – new standard</li></ul>	
<p>Please address enquiries about this Data Standards Change Notice to the Data Standards Team in NHS Wales Informatics Service</p> <p>E-mail: <a href="mailto:data.standards@wales.nhs.uk">data.standards@wales.nhs.uk</a> / Tel: 029 2050 2539</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="http://howis.wales.nhs.uk/sites3/page.cfm?orgid=742&amp;pid=24632">http://howis.wales.nhs.uk/sites3/page.cfm?orgid=742&amp;pid=24632</a></p>	

## **DATA STANDARDS CHANGE NOTICE**

### Introduction

The creation of this standard originates from the inconsistent management of the neurodevelopment assessment process across Wales.

The standard will be put in place to ensure timely access of neurodevelopmental (ADHD and ASD only) assessments for children and young people age 17 years 6 months and under.

The Together for Children and Young People (T4CYP) service improvement programme was launched by the Health Minister in February 2015 to improve the emotional and mental health of children and young people in Wales. Led through a multi-agency board, 7 work streams were established to engage with clinical colleagues in the NHS and stakeholders to reshape services in line with the principles of prudent health care. One of these is the neurodevelopmental work stream.

Welsh Government's Together for Mental Health Delivery Plan, Priority Area 8 includes the following requirement:

8.1 To enable people experiencing neurodevelopmental conditions, (such as autistic spectrum disorder and attention deficit hyperactivity disorder) to access timely assessment and treatment that supports their continued social and personal development.

The Welsh Government has also provided funding to WLGA to develop, implement and deliver an all Wales, all age, Autism Service. The collection of this data will help develop evidence based local service needs.

### Description of Change

To introduce a data collection to monitor access to referral for neurodevelopment assessments of ADHD and ASD for children and young people (aged 17 years 6 months and under at time of referral).

Health Boards to report (to the Welsh Government) monthly on waiting times for referral for neurodevelopmental assessment.

The provided data will reflect current wait i.e. census/snapshot at the end of the reporting period. Wait will not be measured retrospectively on receipt of treatment (i.e. how long did the patient wait).

### Data Dictionary Version

Where applicable, this DSCN reflects changes introduced by DSCN and/or DDCN since the release of version 4.9 of the NHS Wales Data Dictionary.

The changes introduced by such DSCNs will be published in version 4.10 of the NHS Wales Data Dictionary.

## Actions Required

### Local Health Boards / Trust:

- Ensure arrangements are in place to enable the collection of the information required in accordance with the definitions set out in this DSCN.
- Ensure that proformas are submitted monthly to the Welsh Government Delivery & Performance Division ([HSS.Performance@gov.wales](mailto:HSS.Performance@gov.wales)).

### Actions for the Welsh Government Delivery & Performance Division:

- On an annual basis, make the form available for Mental Health Services to complete and notify them of the deadline for the submission of data.

## **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>New/Retired/Changed</b>	<b>Page Number</b>
Aggregate Proforma	Children and Young People Neurodevelopment Assessment – Wait Times	New	5

## **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.

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### **Children and Young People Neurodevelopment Assessment – Wait Times**

#### **Return Submission Details**

This form should be completed by each Local Health Board (LHB) and submitted to the Welsh Government Delivery & Performance Division:

[HSS.Performance@gov.wales](mailto:HSS.Performance@gov.wales)

Local Health Boards to submit one completed pro forma per month, by the dates provided in the Definitions and Guidance section of the form.

Information should be provided in relation to those children and young people who are waiting for an Attention Deficit Hyperactivity Disorder (ADHD) or Autistic Spectrum Disorder (ASD) neurodevelopmental assessment only.

Only children and young people aged 17 years 6 months and under at the time the referral was received by the Neurodevelopmental Service should be included in the waiting times and not the age at which any subsequent intervention begins. For example, if a patient was 17 years and 5 months old when they were referred for an assessment, but was 18 years old when they started an intervention or was discharged, they would still be reported within this pro forma

Local Health Boards are to report on a provider basis (i.e. for the services they provide as a Health Board) and not on a resident basis (i.e. for the residents of their Health Board).

The latest version of each form is available on the Welsh Government's Performance Management Website:

<http://howis.wales.nhs.uk/sitesplus/407/home>

Any further queries regarding the data collection forms should be directed to the Delivery & Performance Division, Welsh Government, on 03000 258871, or e-mail:

[HSS.Performance@gov.wales](mailto:HSS.Performance@gov.wales)

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### **Information Requirements November 2017 onwards**

#### **Number of patients who are waiting to start an ADHD or ASD neurodevelopment assessment**

This is the number of patients who are currently waiting to start an ADHD or ASD neurodevelopment assessment as at each census snapshot (i.e. the last calendar day of each month)

Waits should be categorised into the following time bands:

- Patients waiting up to and including 84 days ( $\leq 11$  weeks)
- Patients waiting 85 days and over and up to and including 126 days (12-17 weeks)
- Patients waiting 127 days and over and up to and including 182 days (18 - 25 weeks)
- Patients waiting 183 days and over and up to and including 252 days (26 - 35 weeks)
- Patients waiting 253 days and over and up to and including 364 days (36 - 51 weeks)
- Patients waiting 365 days and over ( $\geq 52$  weeks)

When calculating wait times, the following guidance applies:

*Clock start point* is the date which the referral for an ADHD or ASD neurodevelopmental assessment is received by the Neurodevelopmental Service.

*Clock stop point* is the date of the first face to face appointment of the assessment process (this may be with or without the patient being present e.g. with the parent or guardian only).

*Could Not Attend (CNA) and Did Not Attend (DNA)*

The process to be followed in relation to offering further dates for assessment to children or young people who could not attend or did not attend their assessment will be determined locally. For the purposes of these returns:

CNA – The clock start point is reset to the date at which the patient notified the service that they were unable to attend the appointment. There are no restrictions applied regarding the maximum number of times a date can be reset.

DNA – The clock start point is reset to the date the patient did not attend the appointment. There are no restrictions applied regarding the maximum number of times a date can be reset.

#### *Adjustments*

Where the patient is unavailable for medical or social reasons, an adjustment should be made to the wait time to take account of the period of unavailability.

#### *Cancellations by the Neurodevelopment Service*

If the Neurodevelopment Service cancels a patient's appointment, the waiting times clock continues and a new appointment must be booked i.e. the clock is not reset.

**Note:** Where there is a requirement to obtain additional information in support of a referral, such as information from a social worker, the clock should not be stopped.