

# WELSH INFORMATION GOVERNANCE & STANDARDS BOARD

<b>CDSC Notice:</b>	CDSCN 2010 / 01
<b>Date of Issue:</b>	4 <sup>th</sup> August 2010

<b>Ministerial / Official Letter:</b> Awaiting Confirmation	<b>Subject:</b> All Wales Specialist Palliative Care Data Set
<b>Sponsor:</b> Major Health Conditions & Clinical Support Services Team, Community, Primary Care & Health Services Directorate, WAG	
<b>Implementation Date:</b> 1 <sup>st</sup> October 2010	

## CLINICAL DATA SET CHANGE NOTICE

A Clinical Data Set Change Notice (CDSCN) is an information mandate for a new or revised information standard.

This CDSCN was approved by the Welsh Information Governance and Standards Board (WIGSB) at its meeting on the 17<sup>th</sup> June 2010

**WIGSB Reference:** IGRN 2008 / 037

### Summary:

To introduce the All Wales Specialist Palliative Care Data Set

**Data sets / returns affected:** All Wales Specialist Palliative Care Data Set

Please address enquiries about this Data Set Change Notice to the Data Standards Team in Health Solutions Wales E-mail: [data.standards@wales.nhs.uk](mailto:data.standards@wales.nhs.uk) Tel: 02920502539

The Welsh Information Governance and Standards Board is responsible for appraising information standards. Submission documents and WIGSB Outcomes relating to the approval of this standard can be found at: <http://howis.wales.nhs.uk/sites3/page.cfm?orgid=742&pid=24632>

## CLINICAL DATA SET CHANGE NOTICE

### Introduction

The aim of the all Wales Specialist Palliative Care Canisc Information project is to define, develop and implement the data collection required for the clinical care of patients referred to the specialist palliative care services. This project has been initiated in response to the recommendations in the Palliative Care Planning Group Report Wales: Report to the Minister for Health and Social Services (June 2008) chaired by Vivienne Sugar and Ilora Finlay's Implementation of Palliative Care Report (October 2008).

The business priority for this data set is to ensure rapid coordination of patient information from across organisations and to monitor specialist palliative care services in Wales. The All Wales Specialist Palliative Care Dataset is required to verify the work of individual providers and provide a consistent way to routinely capture clinical processes that reflect the quality of patient care as well as information that reflects throughput.

The approach adopted by the project is one of iterative development of a full set of data required for these purposes. Further expansion of the data required will be the subject of future change notices.

In due course reporting requirements to underpin monitoring of specialist palliative care services in Wales will be developed and introduced via future change notices.

It is recognised that the IT system capability to collect this data is currently under development and a programme of end-user training is underway across Wales. The timetable of actions set out below acknowledges this position.

Unlike national reporting data sets, the Palliative Care Data Set describes what data should be captured and available to support clinical care and monitor specialist palliative care services and why it should be captured. As it does not describe system data items or report specifications, it does not include data item formats. As this data set relates to operational business support rather than national database reporting, it will not be integrated into the existing patient level reporting data sets section of the NHS Wales Data Dictionary but will be held in a separate chapter/section.

### Description of Change

The introduce the All Wales Specialist Palliative Care Data Set

### Actions Required

LHBs should ensure the capture of these data items for all patients under the care of the specialist palliative care services from 1 October 2010.

**Canisc Developers** should ensure that the system can, and is available to, capture these data items in the timetable set out above.

	Data Item	Reason for collection	Options
<b>1. REGISTRATION / IDENTIFICATION OF PATIENT</b>			
One per patient			
1.1	NHS number	To assist in the accurate identification of patients .	
1.2	Date of birth	To assist in the accurate identification of patients. To enable age at referral to be established for analysis.	
1.3	Sex	To assist in the accurate identification of patients. To enable analysis of referral by sex.	<ul style="list-style-type: none"> <li>• Male</li> <li>• Female</li> <li>• Not specified</li> </ul>
1.4	Name and address of GP practice	To enable the specialist palliative care service to contact the GP practice and share patient information. To enable analysis of referral practice by GP practice.	
1.5	Ethnic Group	To enable analysis of referral by ethnic group to ensure an equitable service is being provided to the whole community.	<ul style="list-style-type: none"> <li>• Any white background</li> <li>• Mixed white and black Caribbean</li> <li>• Mixed white and black African</li> <li>• Mixed white and Asian</li> <li>• Any other mixed background</li> <li>• Indian and British Indian</li> <li>• Pakistani or British Pakistani</li> <li>• Bangladeshi or British Bangladeshi</li> <li>• Any other Asian background (other than Chinese)</li> <li>• Black Caribbean or black British Caribbean</li> <li>• Black African or black British African</li> <li>• Any other black background</li> <li>• Chinese</li> <li>• Any other ethnic group</li> <li>• Not stated</li> </ul>

1.6	Religion or belief	To assist in the provision of holistic care for the patient if the patient informs the service of their religion or belief.	
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	Data Item	Reason for collection	Options
<b>1. REGISTRATION / IDENTIFICATION OF PATIENT [continued]</b>			
1.7	Preferred language (spoken)	To alert the service if a patient's language is not English so that appropriate arrangements can be made to assist communication.	
<b>2. LOCAL PATIENT IDENTIFIER</b> One or more per patient			
2.1	Case record number at an organisation or service	To assist in the accurate identification of patients. To facilitate the location of patient information within other organisations caring for the patient.	
<b>3. PATIENT NAME</b> One or more per patient			
3.1	Patient name(s)	To assist in the accurate identification of patients to avoid duplicate registration. For this purpose, any name by which the patient is (or has been) known should be able to be accessed.	
3.2	Active name	To enable the specialist palliative care service to identify which is the name currently used by the patient.	
<b>4. PATIENT ADDRESS</b> One or more per patient			
4.1	Patient address(es)	To assist in the accurate identification of patients to avoid duplicate registration. For this purpose, any address including postcode at which the patient is (or has) lived with the start and end dates where relevant should be able to be accessed. To provide evidence of prevalence to assist commissioning and equity of access across providers.	
4.2	Current address	To indicate the address agreed with the patient at which the patient is currently residing to aid contact and communication. For this purpose, only one address can be current at a particular time.	

	Data Item	Reason for collection	Options
<b>4. PATIENT ADDRESS [continued]</b>			
4.3	Permanent or temporary address	To show whether any address is permanent or temporary to avoid duplicate registration if the patient is residing at a temporary residence.	
4.4	Active or inactive address	To indicate whether any address is currently active i.e. could be used by the patient as a residence, to assist in accurate identification and prevent duplicate registration if the patient has moved residence. For this purpose only one permanent address can be active at any one time: more than one temporary address can be active at any one time.	
4.5	Local Health Board	To provide data for planning as evidence of prevalence when used with numbers of patients in area and equity of services within LHB code area.	
<b>5. DIAGNOSIS</b>			
One or more per patient			
5.1	Diagnosis	To identify the underlying condition as defined by the Primary Professional which has caused the specialist palliative care team to be involved. To share the diagnosis with members of the specialist palliative care team To inform other multidisciplinary teams of specialist palliative care team involvement for this condition To allow analysis of caseload according to diagnosis . To provide information on patterns of use of services according to diagnosis.	Read Code

	Data Item	Reason for collection	Options
<b>6. REFERRAL</b>			
One or more per diagnosis			
6.1	Source of specialist palliative care referral	To identify patterns of referral.	<ul style="list-style-type: none"> <li>• Following an emergency admission</li> <li>• Primary Care: OOH</li> <li>• Primary Care: Community</li> <li>• Primary Care: Emergency</li> <li>• Another SPCT in the secondary/acute service</li> <li>• Planned non-SPCT in a secondary/acute service</li> <li>• Self-referral</li> <li>• Another SPCT non statutory</li> <li>• Other source of referral (will include referrals from Private Healthcare)</li> </ul>
6.2	Name of specialist palliative care team receiving referral	To identify the team giving care to the patient. To enable analysis by specialist palliative care team. To identify different specialist services involved in one individual's care.	
6.3	Primary professional name	To identify the health care professional ultimately responsible for patient care. To assist communication across specialist services	
6.4	Primary professional type	To identify the professional type of the primary professional To identify patients accessing care from a consultant led service.	
6.5	Date of specialist palliative care referral	To establish the date on which the referrer first initiates referral to the specialist palliative care team. To facilitate audit of responsiveness of service.	
6.6	Priority of specialist palliative care referral as defined by referrer	To assist in monitoring patients referred to the specialist palliative care team for urgent review of uncontrolled symptoms. To facilitate audit of responsiveness of service.	<ul style="list-style-type: none"> <li>• Urgent referral for uncontrolled symptoms</li> <li>• Other</li> </ul>

	Data Item	Reason for collection	Options
<b>7. FIRST ASSESSMENT</b>			
None or one per referral			
7.1	Date first assessed by a member of the specialist palliative care team	To facilitate audit of responsiveness of service.	
7.2	Reason for delay in being assessed	To enable reflection on service provision and consider service developments when necessary.	<ul style="list-style-type: none"> <li>• Patient choice</li> <li>• Clinical Reason</li> <li>• Logistic Reason</li> <li>• DNA - reason unspecified</li> <li>• Other, specify</li> <li>• Not known</li> </ul> <p>[multiple responses possible]</p>
<b>8. ALLERGIES AND ADVERSE REACTIONS</b>			
None, one or more per patient			
8.1	Alert type	To alert health care professionals that the patient has an allergy or has experienced an adverse reaction to a substance.	<ul style="list-style-type: none"> <li>• Allergy</li> <li>• Adverse reaction</li> </ul>
8.2	Cause of allergy or adverse reaction	To inform health care professionals of the substance which causes an allergy or adverse reaction to prevent future problems.	
8.3	Comment on allergy or adverse reaction	To alert health care professionals of any other relevant information about the nature of the allergy or adverse reaction.	



	Data Item	Reason for collection	Options
<b>9. DEATH</b>			
None or one per patient			
9.1	Date of death	To alert providers of care of the patient's death in order to prevent inappropriate contact. To enable reporting of deaths which occur while a patient is receiving specialist palliative care to the National Council for Palliative Care.	
9.2	Place of death	To enable reporting of place of death to the National Council for Palliative Care	<ul style="list-style-type: none"> <li>• Patient's home (including home of relative or carer)</li> <li>• Care home</li> <li>• Hospice/specialist palliative care unit</li> <li>• Community hospital</li> <li>• Acute hospital</li> <li>• Other</li> </ul>