

# **Dementia Post Diagnostic Support: NHS Board Performance 2014/15**

**Publication date – 24 January 2017**

---

## Contents

Contents.....	1
Introduction .....	2
Main points.....	3
Results and Commentary.....	4
1. Delivery against the LDP Standard.....	4
1.1 Delivering expected rates of dementia diagnosis.....	4
1.2 Delivering twelve months of post-diagnostic support .....	6
2. In Focus: Demographics.....	8
Glossary.....	11
List of Tables.....	12
Contact.....	13
Further Information.....	13
Rate this publication.....	13
Appendices .....	14
A1 – Publication Metadata (including revisions details).....	14
A2 – Early Access details (including Pre-Release Access) .....	16
A3 – ISD and Official Statistics .....	17

## Introduction

This publication provides developmental statistics on performance against the Dementia Post-Diagnostic Support LDP Standard for financial year 2014/15.

### Dementia Post-Diagnostic Support

In 2010's 'Scotland's National Dementia Strategy', the Scottish Government made a commitment to improving post-diagnostic support (PDS) for those receiving a diagnosis of dementia. The Scottish Government endorsed a 12 month PDS model that used [The Five Pillars](#) methodology developed by Alzheimer Scotland, and concluded with a person-centred support plan.

### Policy

In order to effectively monitor performance of PDS delivery, a national Local Delivery Plan ([LDP Standard](#)) (formerly known as a HEAT Target) was introduced in April 2013. It guaranteed to deliver expected rates of dementia diagnosis and by 2015/16, all people newly diagnosed with dementia will have a minimum of a year's worth of post-diagnostic support coordinated by a link worker, including the building of a person-centred support plan.

### Data Collection

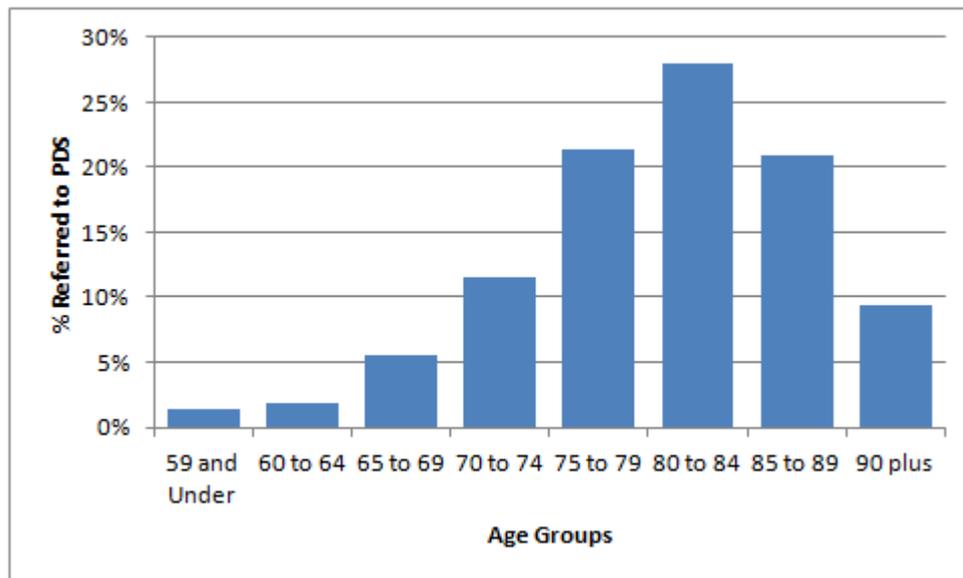
NHS Boards currently provide monthly submissions containing PDS data from their local services to ISD. These data submissions contain information on the patient journey through PDS including diagnosis information, link worker allocation, first substantive contact, progress through the five pillars and discharge details. This data, in combination with the recently published incidence figures in the ['Estimated and Projected Diagnosis Rates for Dementia in Scotland: 2014 to 2020'](#) report will form the basis of the LDP Standard calculation.

This is the first publication to report on performance against the LDP Standard, and will do so for patients who have a recorded diagnosis of dementia within the 2014/15 financial year. There is no specific threshold or target in which NHS Boards are expected to be attaining to as the PDS services are still within their infancy and it is anticipated there is likely further developments required.

## Main points

- An estimated 2 out of 5 new cases of dementia in Scotland in financial year 2014/15 were referred for PDS.
- 73% of patients diagnosed with dementia in 2014/15 who were referred for post-diagnostic support completed treatment successfully.

**Age distribution of those referred to the PDS service**



- Age groups achieved between 70% to 78% against the LDP Standard
- The differences in distribution of referrals by areas of deprivation ranged from 17% in the most deprived areas to 23% in lesser deprived areas.
- Performance against LDP Standard within areas of deprivation ranged from 70% for those in lesser deprived areas to 76% for those in more deprived areas.

## Results and Commentary

### 1. Delivery against the LDP Standard

Performance against the LDP Standard will be reported in two parts, each addressing a separate element to the Standard:-

1. To deliver expected rates of dementia diagnosis
2. All people newly diagnosed with dementia will have a minimum of a year's worth of post-diagnostic support coordinated by a link worker, including the building of a person-centred support plan

#### 1.1 Delivering expected rates of dementia diagnosis

The Scottish Government recently commissioned the research 'Estimated and Projected Diagnosis Rates for Dementia in Scotland: 2014-2020'. Within the paper it is estimated 16,712 people were diagnosed with dementia in 2014. The number of individuals diagnosed with dementia is projected to steadily increase to 19,473 by 2020. These published rates were applied to up to date population estimates within National Records Scotland (NRS) for financial year 2014/15 and then compared to how many people were referred to a PDS service.

**Table 1. Percentage of estimated new incidences referred for PDS treatment, by NHS Board; for financial year 2014/15**

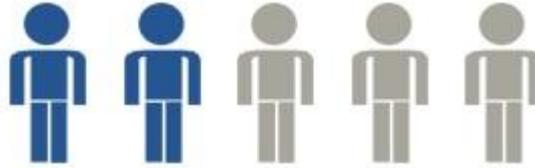
	Estimated Diagnosed Incidence of Dementia <sup>1</sup>	Number of People Referred to a PDS Service	% of New Diagnosed Incidences Referred to PDS
<b>Scotland</b>	<b>16,661</b>	<b>6660</b>	<b>40%</b>
NHS Ayrshire & Arran	1,129	609	54%
NHS Borders	444	119	27%
NHS Dumfries & Galloway	607	330	54%
NHS Fife	1,193	374	31%
NHS Forth Valley	897	365	41%
NHS Grampian	1,711	396	23%
NHS Greater Glasgow & Clyde	3,392	1560	46%
NHS Highland	1,162	424	36%
NHS Lanarkshire	1,973	993	50%
NHS Lothian	2,391	609	25%
NHS Orkney	78	15	19%
NHS Shetland	70	49	70%
NHS Tayside	1,499	769	51%
NHS Western Isles	114	48	42%

Source: Monthly PDS submissions by NHS Boards; 'Estimated and Projected Diagnosis Rates of Dementia in Scotland: 2014 to 2020'; NRS population estimates. All as at December 2016.

#### Notes

1. These incidence figures were derived from taking most up to date NRS population estimates for 2014/15 and applying rates as indicated in the cited research
2. Incidence figures are subject to the rates supplied in the Scottish Government's publication and therefore, are subject to any limitations highlighted in the report also.

The LDP Standard calls for expected rates of dementia diagnosis to be met, and that all those diagnosed should receive post-diagnostic support. The Dementia PDS submissions indicate that 6,660 people were referred for PDS in financial year 2014/15. This would indicate that approximately 2 out of 5 people who were diagnosed with dementia in 2014/15 were referred for PDS.



## 1.2 Delivering twelve months of post-diagnostic support

This section looks to report on how many of those referred to the PDS service received their entitled care over the minimum twelve month period. The timeframe for the delivery of PDS was agreed to commence on the first substantive contact between a link worker and a patient and had to occur within twelve months of diagnosis.

Table 2 below indicates where a patient has either completed their PDS; stopped PDS due to circumstances out with the services control; still undergoing PDS treatment; or where PDS was not successfully completed.

The criteria for each of the categories are as follows:-

- PDS was considered complete where cases did not fit any of the alternative categories.
- Uncontrollable circumstances included the patient moving to a different NHS Board or the patient dying within the twelve month period of their treatment.
- PDS currently ongoing is where a patient is still receiving PDS treatment.
- PDS was considered not successful if a first substantive contact had not occurred twelve months after diagnosis or where PDS was stopped prior to the twelve months where this was within the service's control.

**Table 2. Completion of PDS for those referred to the service, by NHS Board; for financial year 2014/15**

	Total Referred to PDS	PDS Completed	PDS Stopped due to Uncontrollable Circumstances <sup>1</sup>	PDS Still Ongoing	PDS Not Successfully Completed <sup>2</sup>
<b>Scotland</b>	<b>6660</b>	<b>4031</b>	<b>776</b>	<b>36</b>	<b>1817</b>
NHS Ayrshire & Arran	609	278	55	1	275
NHS Borders	119	111	5	0	3
NHS Dumfries & Galloway	330	213	58	1	58
NHS Fife	374	229	57	0	88
NHS Forth Valley	365	187	40	3	135
NHS Grampian	396	222	45	1	128
NHS Greater Glasgow & Clyde	1560	985	179	16	380
NHS Highland	424	250	57	1	116
NHS Lanarkshire	993	562	105	4	322
NHS Lothian	609	326	62	6	215
NHS Orkney	15	15	0	0	0
NHS Shetland	49	25	9	2	13
NHS Tayside	769	628	101	1	39
NHS Western Isles	48	0	3	0	45

Sources: Monthly PDS submissions by NHS Boards as at December 2016.

Notes

1. A patient moving to a different NHS Board or dying were classified as uncontrollable circumstances
2. Where PDS was stopped prior to 12 months for reasons that were not classed as 'uncontrollable' (eg. lack of funding)

An NHS Board was considered to have delivered against the LDP Standard where PDS treatment was completed or where it was stopped due to uncontrollable circumstances. Those

who were still undergoing PDS were excluded from performance analysis and those who had not successfully completed PDS were classed as a fail against the LDP Standard.

Table 3 below shows, as a percentage, the performance of NHS Boards against the LDP Standard.

**Table 3. NHS Board performance against the LDP Standard for financial year 2014/15**

	Total Referred to PDS <sup>1</sup>	Delivered Successfully Against the Standard <sup>2</sup>	% of Standard Achieved
<b>Scotland</b>	<b>6624</b>	<b>4807</b>	<b>73%</b>
NHS Ayrshire & Arran	608	333	55%
NHS Borders	119	116	97%
NHS Dumfries & Galloway	329	271	82%
NHS Fife	374	286	76%
NHS Forth Valley	362	227	63%
NHS Grampian	395	267	68%
NHS Greater Glasgow & Clyde	1544	1164	75%
NHS Highland	423	307	73%
NHS Lanarkshire	989	667	67%
NHS Lothian	603	388	64%
NHS Orkney	15	15	100%
NHS Shetland	47	34	72%
NHS Tayside	768	729	95%
NHS Western Isles	48	3	6%

Sources: Monthly PDS submissions by NHS Boards as at December 2016

Notes

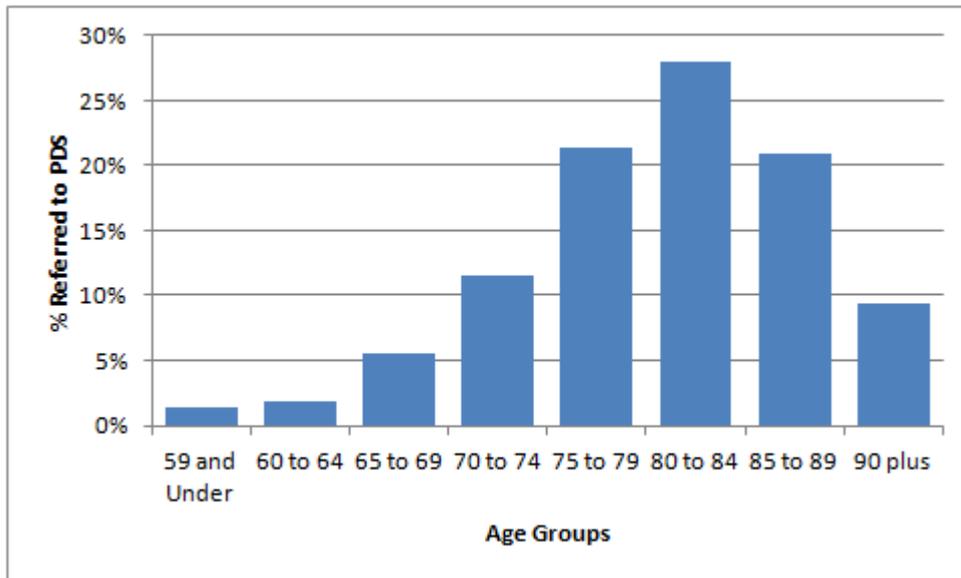
1. Number of those referred for PDS, but excludes those currently undergoing PDS as uncertain at this point whether they will meet the requirements of the LDP Standard
2. Those who have received 12 months PDS support or had PDS stopped due to patient death or move

Overall, at a national level, Scotland achieved 73% against the LDP Standard meaning almost 3 out of 4 people referred received successful PDS. Three NHS Boards performed above 90%, with NHS Orkney achieving 100%. The majority of NHS Boards delivered successful PDS within 60-80% of newly diagnosed cases. NHS Western Isles performance of 6% could be largely attributed to their funding being ceased in the summer of 2015.

## 2. In focus: Demographics

This section reports the demographics of those who have been referred to dementia PDS services. The age and deprivation status of those using the service were identified as two areas of interest to explore further. The graphs below show the distribution of those referred to PDS services by age group and level of deprivation.

**Chart 1. Distribution of those referred to the PDS service by age group**

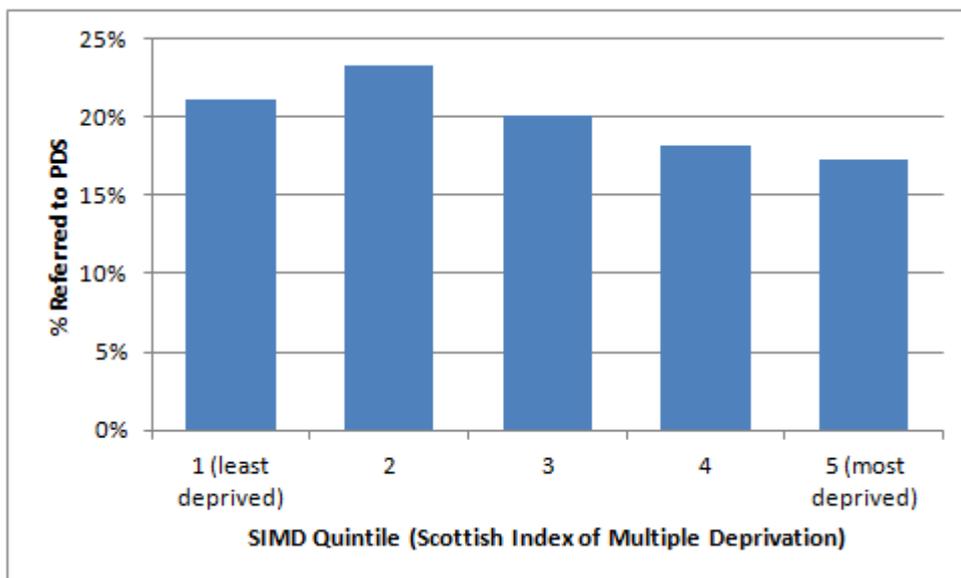


Sources: Monthly PDS submissions by NHS Boards as at December 2016.

Notes

1. 224 cases excluded due to incomplete data

**Chart 2. Distribution of those referred to the PDS service by deprivation**



Sources: Monthly PDS submissions by NHS Boards as at December 2016.

Notes

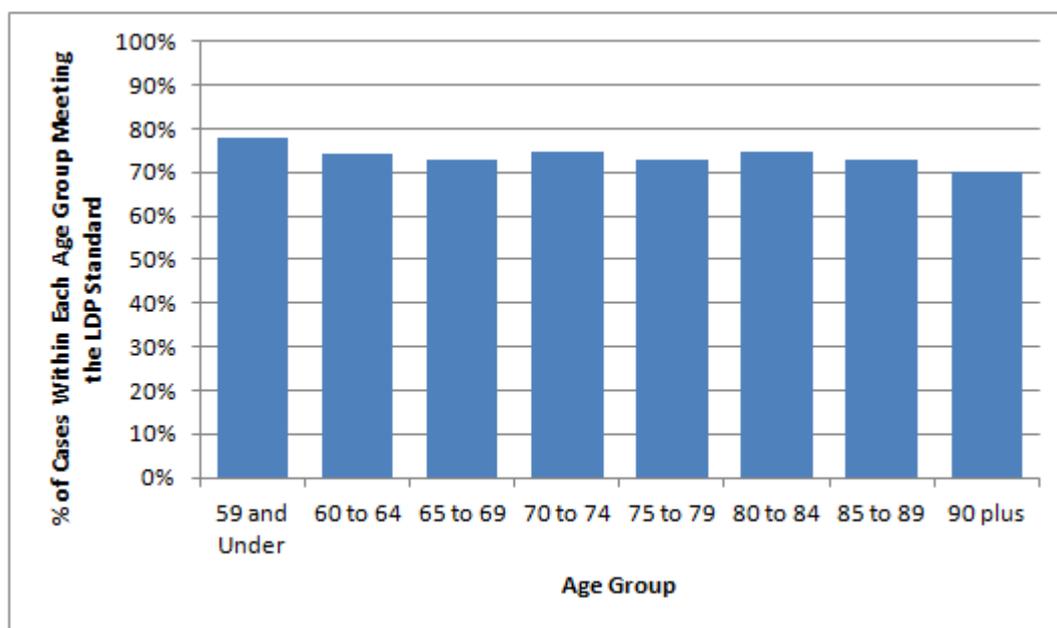
1. 182 cases excluded due to incomplete data

From the charts we can decipher that the older you get the more likely you would be referred to PDS. Those aged between 80 to 84 years were the highest referred age group to PDS services in the financial year 2014/15 by containing 28% of all referrals. Those 59 years and under age group had the least referred with 1% of the total referrals.

The Scottish Index of Multiple Deprivation (SIMD) quintiles were used to analyse and compare levels of deprivation. The differences in distribution by deprivation areas ranged from 17% in the most deprived areas (SIMD Quintile 5) to 23% in lesser deprived areas (SIMD Quintile 2).

Further analysis was conducted to assess the success against the LDP Standard within each of the age groups and levels of deprivation.

**Chart 3. Percentage of cases within age groups that met the LDP Standard**

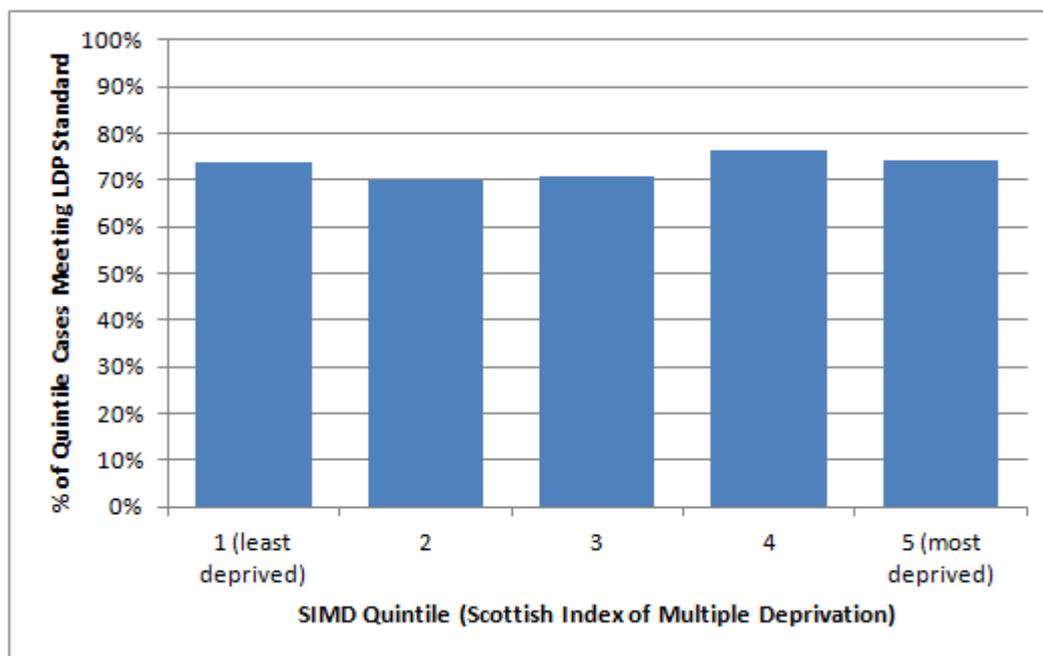


Sources: Monthly PDS submissions by NHS Boards as at December 2016.

Notes

1. 223 cases excluded due to incomplete data

**Chart 4. Percentage of cases within areas of deprivation that met the LDP Standard**



Sources: Monthly PDS submissions by NHS Boards as at December 2016.

Notes

- 1. 181 cases excluded due to incomplete data

Success of the LDP Standard by age or deprivation varied very little. Those 59 years or under had a success rate of 78%, with those 90 or over having the least success of all age groups at 70%. All remaining age groups ranged between a 73-75% rate of success.

Within the areas of deprivation, the smallest success was seen within those in lesser deprived areas (SIMD quintile 2) with a 70% success rate. Those in more deprived areas (SIMD Quintile 4) had the largest success rate with 76% of those referred within these areas successfully meeting the LDP Standard.

## Glossary

**Five Pillars Model** – This is a model developed by Alzheimers Scotland that is used to help support those diagnosed with dementia. The five pillars are: supporting community connections, peer support, planning for future care, understanding the illness and managing symptoms, and planning for future decision making. Further information on each of the pillars can be found on the Alzheimer Scotland website [here](#).

**Incidence** – When referring to new incidence, it is meant as a newly developed case of a particular illness or disease. For the purposes of this topic, new incidence would be those where the onset of dementia has occurred.

**LDP Standard** – Formerly known as HEAT Targets, Local Delivery Plan (LDP) Standards are priorities agreed between Scottish Government and NHS Boards. Performance on Dementia PDS is one of the current LDP Standards. Further information can be found on the Scottish Government website [here](#).

**Link worker** – A specialist in providing post-diagnostic support for those with dementia. Link workers could be employed by the NHS or by Alzheimers Scotland.

**Post-Diagnostic Support (PDS)** - Support commissioned by Scottish Government that anyone diagnosed with dementia as of April 2013 would be entitled to a 12 months worth of post-diagnostic support. This support would follow the Five Pillars methodology set out by Alzheimers Scotland and would conclude with a person-centred support plan.

**Referral** – When someone has received a new diagnosis of dementia, they would then be referred to a service that provides post-diagnostic support in order for them to be allocated a link worker who will provide this post-diagnostic support.

**SIMD Quintile** – The Scottish Index of Multiple Deprivation Quintiles. A method of ranking concentrated areas of Scotland into five categories of deprivation starting with SIMD Quintile 1 being those in the least deprived areas up to SIMD Quintile 5 for those most deprived.

## List of Tables

Table No.	Name	Time period	File & size
1	<a href="#">Dementia Post-Diagnostic Support Tables</a>	2014/15	Excel [31kb]

## Contact

### **Laura Marchbank**

Principal Information Analyst

[laura.marchbank@nhs.net](mailto:laura.marchbank@nhs.net)

[0141 282 2160](tel:01412822160)

### **Lee Wilson**

Senior Information Analyst

[lwilson21@nhs.net](mailto:lwilson21@nhs.net)

0141 282 2335

## General Enquiries

[NSS.ISDDementiaPDS@nhs.net](mailto:NSS.ISDDementiaPDS@nhs.net)

## Further Information

Further information can be found on the [ISD website](#)

## Rate this publication

Please [provide feedback](#) on this publication to help us improve our services.

## Appendices

### A1 – Publication Metadata (including revisions details)

Metadata Indicator	Description
Publication title	Dementia Post Diagnostic Support: NHS Board Performance 2014/15
Description	Reporting on NHS Board performance in delivering 12 months worth of PDS to those newly diagnosed with dementia during the 2014/15 financial year.
Theme	Health and Social Care
Topic	Dementia Post-Diagnostic Support
Format	PDF Report with excel tables
Data source(s)	NHS Boards
Date that data are acquired	December 2016
Release date	24 <sup>th</sup> January 2017
Frequency	To be determined.
Timeframe of data and timeliness	Data has been collected from NHS Boards from April 2013 until present.
Continuity of data	Data collection for PDS began in April 2013.
Revisions statement	N/A
Revisions relevant to this publication	N/A
Concepts and definitions	Concepts and definitions for the Dementia PDS work can be found within the ISD website.
Relevance and key uses of the statistics	Relevant to monitoring performance of PDS services since the implementation of the LDP Standard. Statistics used to inform NHS Boards so as to better improve delivery of PDS services to those newly diagnosed with dementia.
Accuracy	NHS Boards have the responsibility of accurately collecting information on the delivery of Dementia Post-Diagnostic Support and providing ISD with this information. It is expected by ISD that quality assurance methods and measures are in place and implemented to ensure information is accurate and correct. ISD conduct data quality checks upon receipt of the data.
Completeness	Overall, submissions from NHS Boards are submitted on time. Until November 2016 only 13 out of 14 NHS Boards were submitting due to lack of funding in NHS Western Isles. The National Minimum Dataset is very well submitted by all NHS Boards and are usually of a good standard.

Comparability	As the delivery of PDS services is still in its infancy, it is expected that local services will be in various phases of development depending on factors such as availability of resource etc. Therefore, it is advised that this publication is not used to compare NHS Boards against each other.
Accessibility	It is the policy of ISD Scotland to make its web sites and products accessible according to <a href="#">published guidelines</a> .
Coherence and clarity	The report is available as a PDF File wit tables clearly linked for ease of use
Value type and unit of measurement	Numbers, percentages
Disclosure	The <a href="#">ISD protocol on Statistical Disclosure Protocol</a> is followed.
Official Statistics designation	Non-Official Statistics
UK Statistics Authority Assessment	N/A
Last published	N/A
Next published	To be determined.
Date of first publication	December 2016
Help email	Laura.Marchbank@nhs.net
Date form completed	

## **A2 – Early Access details (including Pre-Release Access)**

### **Pre-Release Access**

Under terms of the "Pre-Release Access to Official Statistics (Scotland) Order 2008", ISD are obliged to publish information on those receiving Pre-Release Access ("Pre-Release Access" refers to statistics in their final form prior to publication). The standard maximum Pre-Release Access is five working days. Shown below are details of those receiving standard Pre-Release Access.

### **Standard Pre-Release Access:**

Scottish Government Health Department

NHS Board Chief Executives

NHS Board Communication leads

## A3 – ISD and Official Statistics

### About ISD

Scotland has some of the best health service data in the world combining high quality, consistency, national coverage and the ability to link data to allow patient based analysis and follow up.

Information Services Division (ISD) is a business operating unit of NHS National Services Scotland and has been in existence for over 40 years. We are an essential support service to NHSScotland and the Scottish Government and others, responsive to the needs of NHSScotland as the delivery of health and social care evolves.

**Purpose:** To deliver effective national and specialist intelligence services to improve the health and wellbeing of people in Scotland.

**Mission:** Better Information, Better Decisions, Better Health

**Vision:** To be a valued partner in improving health and wellbeing in Scotland by providing a world class intelligence service.

### Official Statistics

Information Services Division (ISD) is the principal and authoritative source of statistics on health and care services in Scotland. ISD is designated by legislation as a producer of 'Official Statistics'. Our official statistics publications are produced to a high professional standard and comply with the Code of Practice for Official Statistics. The Code of Practice is produced and monitored by the UK Statistics Authority which is independent of Government. Under the Code of Practice, the format, content and timing of statistics publications are the responsibility of professional staff working within ISD.

ISD's statistical publications are currently classified as one of the following:

- National Statistics (ie assessed by the UK Statistics Authority as complying with the Code of Practice)
- National Statistics (ie legacy, still to be assessed by the UK Statistics Authority)
- Official Statistics (ie still to be assessed by the UK Statistics Authority)
- other (not Official Statistics)

Further information on ISD's statistics, including compliance with the Code of Practice for Official Statistics, and on the UK Statistics Authority, is available on the [ISD website](#).