

INFORMATION
ANALYSIS
DIRECTORATE



Patient Education / Self Management Programmes for People with Long Term Conditions (2013/14)



Department of
**Health, Social Services
and Public Safety**
www.dhsspsni.gov.uk

Published 19 March 2015

Reader Information

Theme	Social Care – Patient Education / Self Management
Document Purpose	For information
Authors / Statisticians	Philip Carson, Malcolm Megaw
Publication Date	19 th March 2015
Issued by	Community Information Branch Information & Analysis Directorate Department of Health Social Services & Public Safety Stormont Estate Belfast, BT4 3SQ Email cib@dhsspsni.gov.uk
Internet address	http://www.dhsspsni.gov.uk/index/statistics/pesmp-ltc-ni-13-14.pdf
Target Audience	Commissioners of programmes for long term conditions, Chief Executives of HSC Board and Trusts in Northern Ireland, voluntary care organisations, health care professionals, academics and social care stakeholders.
Main uses of document	The main uses of these data are to monitor a Programme for Government commitment, to inform and monitor related policy and to respond to ad-hoc queries and parliamentary/ assembly questions. The bulletin is also used by the Long Term Conditions Alliance Northern Ireland, academics/ researchers, the voluntary sector and those with an interest in long term conditions.
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Price	Free

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IAD comprises four statistical sections: Hospital Information, Community Information, Public Health Information & Research and Project Support Analysis.

This publication is produced by Community Information Branch.

Our Vision and Values

- *Provide up-to-date, quality information on children and adult social services and community health;*
- *to disseminate findings widely with a view to stimulating debate, promoting effective decision-making and improvement in service provision; and*
- *be an expert voice on social care information.*

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About Community Information Branch

The purpose of Community Information Branch (CIB) is to promote effective decision making in children and adult social services by providing quality information and analysis.

We collect, analyse, and publish a wide range of community information that is used to help monitor the delivery of personal social services policy. Information collected by CIB is used to assess HSC Trust performance, for corporate monitoring, policy evaluation, and to respond to parliamentary/assembly questions.

Information is widely disseminated through a number of regular key statistical publications and ad hoc reports, details of which are available online.

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1. Introduction

This publication provides statistical information on patient education / self management programmes for long term conditions collected from Health & Social Care (HSC) Trusts and independent programme providers. It details information on the type, provision, frequency and Trust area of the programmes delivered during the year 1 April 2013 to 31 March 2014.

The information included in this report should be considered as **experimental statistics** which have been produced as an aid to understanding the provision of patient education / self management programmes and to support a Programme for Government commitment.

The [Programme for Government \(PfG\) 2011-15](#) includes a commitment to enrol people who have a long term (chronic) condition, and who want to be enrolled, in a dedicated chronic condition management programme. This commitment seeks to ensure that people who have a long term condition have the information and skills they need to be able to self manage their condition as effectively as possible.

The number of people in Northern Ireland living with one or more long term condition is increasing¹. The Department is committed to improving the health and well-being and quality of life for people with long term conditions. It has produced a Policy Framework [“Living with Long Term Conditions”](#) to provide a strategic direction and driver for the commissioning, planning and delivery of services for adults in Northern Ireland with long term conditions. A key feature of the policy framework will be that people with long term conditions should be supported to self manage their condition effectively in order to maintain or enhance their health and well-being as well as their clinical, emotional and social outcomes.

Central to effective self management is providing information, education, advice and peer support for people with long term conditions in order to ensure they have the knowledge and skills to manage their own conditions more confidently, particularly when variations from the norm may occur, and to make daily decisions to improve their own health and well-being. **Source:** [PfG Commitment 44 Delivery Plan](#)

An initial data collection exercise was carried out during 2012 to establish a baseline on the number and type of patient education / self management programmes available in each HSC Trust during 2011/12. The original baseline information was produced in September 2013. Since then, arrangements have been put in place to facilitate the on-going collection of information on the provision of patient education and self management programmes. In July 2014 a regional summary report was published for the 2012/13 information collection.

This report is a regional summary of the information provided on the Patient Education / Self Management Programme questionnaire 2013/14. Information was provided by HSC Trusts and independent sector organisations who delivered programmes during 2013/14. The report summarises the key statistical information provided for the year 2013/14 and highlights how this compares with that of the 2011/12 baseline data collection and that collected for 2012/13.

¹ <http://www.northernireland.gov.uk/pfg-delivery-plans-commitment-44.pdf>

2. Key Findings

- In 2013/14, 12,741 participants availed of a patient education / self management programme. This is a 10% (1,210) increase on the number of participants recorded during 2012/13 (11,531).
- Out of the 12,741, 57% of participants at a patient education / self management programme were attending a programme provided specifically by one of the five HSC Trusts in Northern Ireland. This was down 3 percentage points from 60% in 2012/13.
- There were 36 programme types in place across Northern Ireland during 2013/14; this is up 20% (6) on those in place during 2012/13 (30).
- A total of 841 patient education / self management programmes were provided in 2013/14, an increase of 7% (57) on the number in 2012/13 (784). Of these 755 were condition specific programmes and 86 were generic programmes. In 2012/13 these figures were 733 and 51 respectively.
- The number of participants attending a programme specifically for cardiac, COPD, Type 1 diabetes or Type 2 diabetes in 2013/14 was 6,240. This was a 3% (192) decrease on the number of participants at programmes for the same conditions in 2012/13 (6,432).

2013/14
Participant Numbers
12,741

 **10%**

2013/14
Programme Frequency
841

 **7%**

4 Selected Conditions
Participant Numbers
6,240

 **3%**

3. Participants

In 2013/14, 12,741 participants attended a patient education / self management programme; an increase of 10% on the number of participants in 2012/13 (11,531). This increase can be attributed to the majority of programme providers recording an increase in participant numbers throughout the year, particularly Alzheimer’s Society (24%), Arthritis Care (134%), Cancer Focus NI (127%), South Eastern HSC Trust (22%) and Southern HSC Trust (25%) (Table 1).

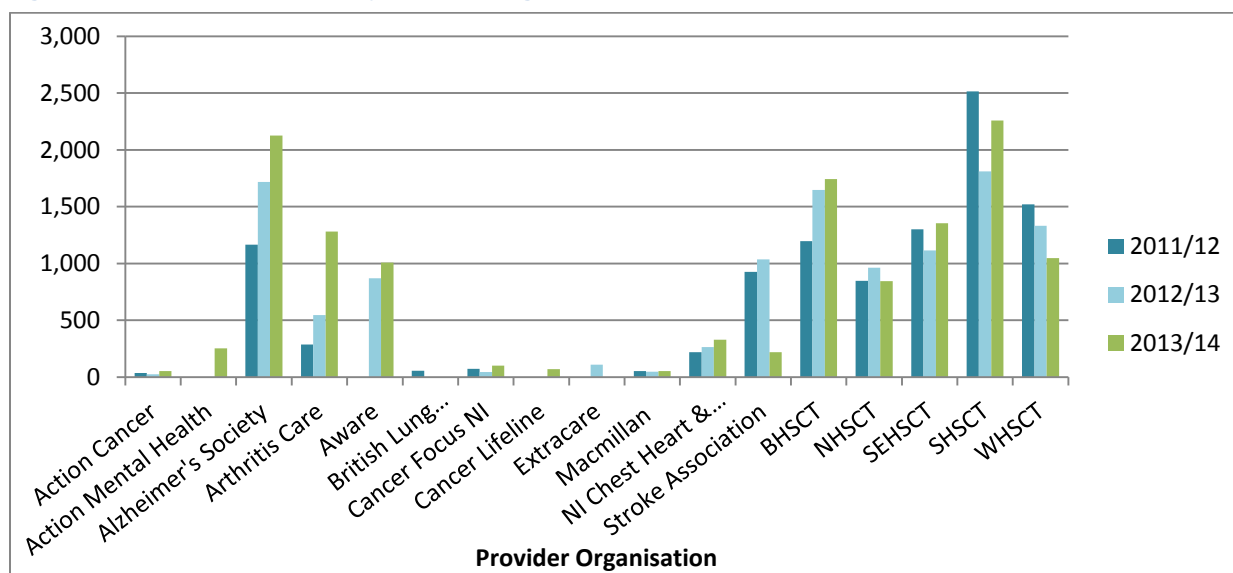
Participant numbers in programmes provided specifically by HSC Trusts (7,247) experienced a 6% (381) increase in 2013/14 over the number of participants in 2012/13 (6,866). The 7,247 participants at programmes provided specifically by HSC Trusts represented 57% of the total participant numbers in 2013/14. Of the independent sector organisations, Alzheimer’s Society provided programmes for the most participants (2,125); 17% of the total participant numbers (Figure 1).

Table 1. Annual Change in Participant Numbers by Provider Organisation (2011/12 – 2013/14)

Provider Organisation	2011/12	2012/13	2013/14	% Change 2012/13 – 2013/14
Action Cancer	35	26	52	100%
Action Mental Health	-	-	253	-
Alzheimer’s Society	1,165	1,718	2,125	24%
Arthritis Care	286	547	1,281	134%
Aware	-	871	1,008	16%
British Lung Foundation	57	-	-	-
Cancer Focus NI	72	45	102	127%
Cancer Lifeline	-	-	69	-
Extracare	-	110	-	-
Macmillan	53	46	54	17%
NI Chest Heart & Stroke	218	265	330	25%
Stroke Association ²	926	1,037	220	-79%
BHSCT	1,197	1,648	1,743	6%
NHSCT	846	962	845	-12%
SEHSCT	1,300	1,114	1,355	22%
SHSCT	2,514	1,810	2,258	25%
WHSCT	1,520	1,332	1,046	-21%
Total	10,189	11,531	12,741	10%

² The Stroke Association stated that the fall in participant numbers for 2013/14 is the result of a restructuring of their service delivery framework. This restructuring has led to participants on a particular programme stage no longer falling under the scope of this data collection.

Figure 1. Participant Numbers by Provider Organisation (2011/12 – 2013/14)³



There has also been an increase in the programme frequency of patient education / self management programmes in 2013/14. The 841 programmes that ran in 2013/14 represented an increase of 7% (57) on the programme frequency in 2012/13 (784). In 2013/14 the highest number of programmes and participants were in the Southern HSC Trust area, 236 and 3,369 respectively (Table 2).

Table 2. Programme Frequency and Participant Numbers by HSC Trust Area (2011/12 – 2013/14)

HSC Trust Area	2011/12		2012/13		2013/14	
	Programme Frequency	Participants	Programme Frequency	Participants	Programme Frequency	Participants
BHSCT	128	1,586	193	2,164	216	2,443
NHSCT	97	1,803	99	2,138	116	2,063
SEHSCT	98	1,502	104	1,633	92	1,975
SHSCT	156	3,351	204	2,579	236	3,369
WHSCT	146	1,947	117	2,146	111	1,845
Total	625	10,189	784	11,531⁴	841	12,741⁵

³ The Stroke Association stated that the fall in participant numbers for 2013/14 is the result of a restructuring of their service delivery framework. This restructuring has led to participants on a particular programme stage no longer falling under the scope of this data collection.

⁴ Aware, who provided 67 programmes for 871 participants with a Mental Health condition in 2012/13, were unable to provide figures broken down by HSC Trust area. As a result, the sum of HSC Trust Area figures will not match the total figure for Northern Ireland.

⁵ Aware, who provided 69 programmes for 1,008 participants and Cancer Focus who provided 1 programme for 38 participants, were unable to provide figures broken down by HSC Trust area. As a result, the sum of HSC Trust Area figures will not match the total figure for Northern Ireland.

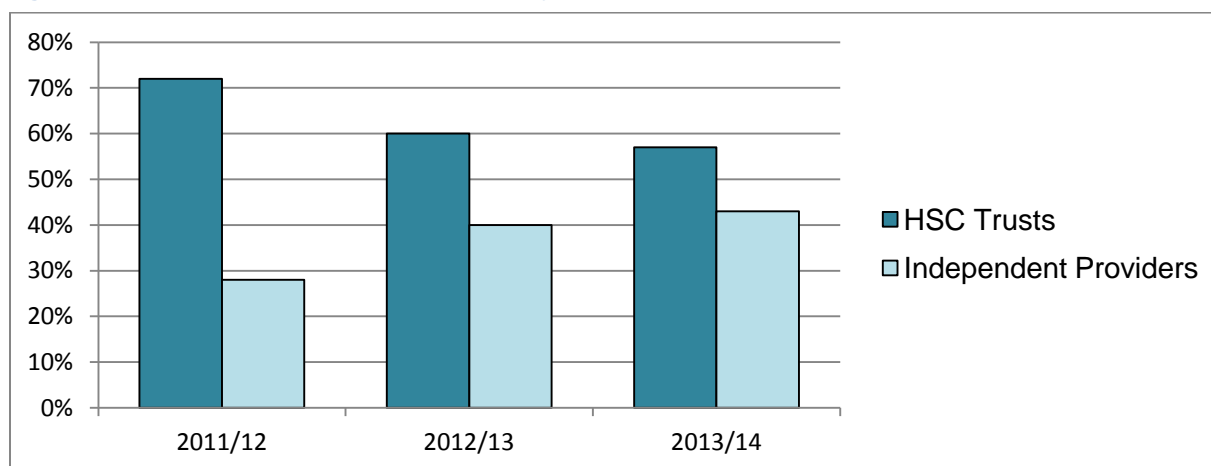
In 2013/14, 18% (2,325) of all participants attended a programme specifically for dementia. Programmes related specifically to cardiac conditions accounted for 17% (2,118) of all participants and Type 2 diabetes accounted for 14% (1,764) (Table 3).

Table 3. Participant Numbers by Programme Type and HSC Trust Area (2013/14)

Programme Type	BHSCT area	NHSCT area	SEHSCT area	SHSCT area	WHSCT area	Total
Condition Specific	2,339	1,937	1,888	3,070	1,577	11,857⁶
Arthritis	-	65	-	-	-	65
Cancer	172	38	48	25	50	371
Cardiac	568	471	447	341	291	2,118
Chronic Pain	344	311	280	272	85	1,292
COPD	296	255	300	262	271	1,384
Dementia	165	668	372	679	441	2,325
Diabetes Type 1	325	89	194	259	107	974
Diabetes Type 2	395	-	207	870	292	1,764
Mental Health	-	-	-	190	-	1,198
Neurological	14	-	-	-	-	14
Stroke	60	40	40	172	40	352
Generic	104	126	87	299	268	884
Total	2,443	2,063	1,975	3,369	1,845	12,741

Figure 2 shows that, when looking at the provider organisation, there has been an increase in the proportion of participants attending a programme provided by the independent sector from 2011/12 (28%) to 2013/14 (43%).

Figure 2. Proportions of Participant Numbers by Provider Sector (2011/12 - 2013/14)



⁶ Aware, who provided 69 programmes for 1,008 participants and Cancer Focus who provided 1 programme for 38 participants, were unable to provide figures broken down by HSC Trust area. As a result, the sum of HSC Trust Area figures will not match the total figure for Northern Ireland.

In 2013/14, 73% (9,357) of participants attended a programme that was either clinical or professional led. Of these, 98% of participants attended a condition specific programme. For both peer and jointly led programmes this figure fell to 79%; with 1,014 and 1,652 participants attending a condition specific programme respectively (Table 4).

Table 4. Participant Numbers by Programme Type and Programme Delivery (2013/14)

Programme Type	Clinical / Professional Led	Peer Led	Jointly Led	Total
Condition Specific	9,191	1,014	1,652	11,857
Arthritis	-	65	-	65
Cancer	310	-	61	371
Cardiac	2,118	-	-	2,118
Chronic Pain	343	949	-	1,292
COPD	1,113	-	271	1,384
Dementia	1,005	-	1,320	2,325
Diabetes Type 1	974	-	-	974
Diabetes Type 2	1,764	-	-	1,764
Mental Health	1,198	-	-	1,198
Neurological	14	-	-	14
Stroke	352	-	-	352
Generic	166	267	451	884
Total	9,357	1,281	2,103	12,741

In 2013/14, 60% (7,627) of participants attended a programme that was statutory funded. Voluntary funded programmes were provided for 32% (4,130) of participants with joint funded arrangements provided for 2% (293).

Table 5. Participant Numbers by Programme Type and Funding Arrangements (2013/14)

Programme Type	Statutory Funded	Voluntary Funded	Joint Funded	Other⁷	Total
Condition Specific	6,941	3,973	252	691	11,857
Arthritis	65	-	-	-	65
Cancer	96	243	32	-	371
Cardiac	1,501	617	-	-	2,118
Chronic Pain	547	745	-	-	1,292
COPD	1,129	255	-	-	1,384
Dementia	1,309	1,016	-	-	2,325
Diabetes Type 1	401	89	-	484	974
Diabetes Type 2	1,557	-	-	207	1,764
Mental Health	190	1,008	-	-	1,198
Neurological	14	-	-	-	14
Stroke	132	-	220	-	352
Generic	686	157	41	-	884
Total	7,627	4,130	293	691	12,741

⁷ Funding provided through Cooperation And Working Together (CAWT) - a partnership between the Health and Social Care Services in Northern Ireland and the Republic of Ireland which facilitates cross border collaborative working in health and social care.

4. Programmes

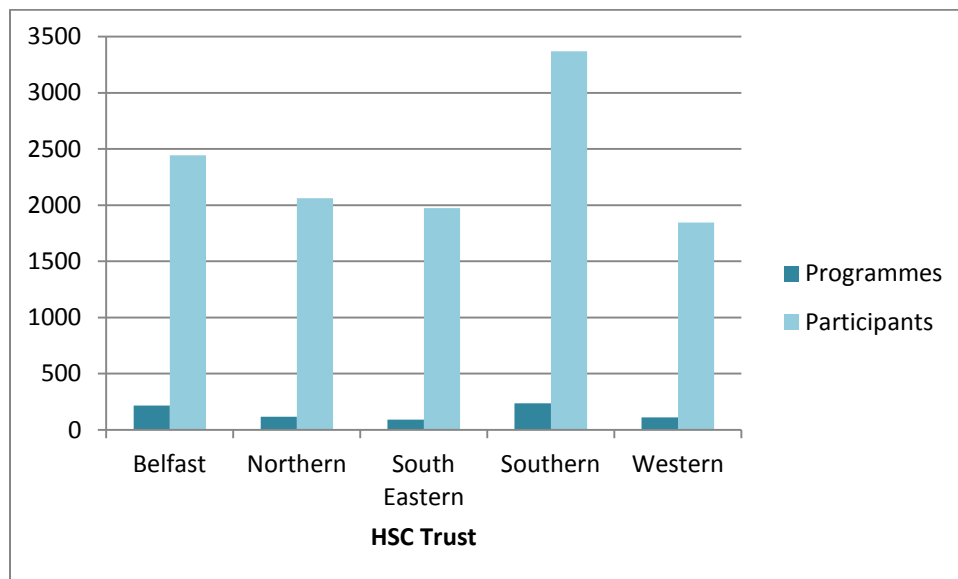
In 2013/14 an average of 15.1 participants attended each programme. Of the 841 programmes that were delivered, 24% (201) were for Type 2 diabetes and 14% (117) for Type 1 diabetes. Generic programmes, as opposed to those provided for specific conditions, accounted for 10% (86) of the total programmes in 2013/14 (Table 6).

Table 6. Programme Frequency and Participant Numbers by Programme (2013/14)

Programme Name	Programme Frequency	Participants
Arthritis	4	65
Challenging Arthritis	4	65
Cancer	38	371
Breast Cancer Transition Group	4	30
Fatigue Management	12	89
HOPE	6	54
Livewell Residential	1	38
Moving Forward	1	7
Postive Living Programme	4	52
Vital Nutrition	3	37
Zest for Life	7	64
Cardiac	81	2,118
Cardiac Rehabilitation	81	2,118
Chronic Pain	90	1,292
Challenging Pain	28	289
Coping with Pain	32	660
Pain Management Programme	30	343
COPD	70	1,384
Pulmonary Rehabilitation	70	1,384
Dementia	22	2,325
Carer Information Programme	10	2,125
Dementia Carer Group	12	200
Diabetes Type 1	117	974
BERTIE	7	44
CHOICE	65	580
DAFNE	29	215
SHAIRE	16	135
Diabetes Type 2	201	1,764
DAY	62	682
DESMOND	41	499
SET 2	7	76
Type 2 programme	81	395
X Pert	10	112
Mental Health	69	1,032
Anxiety Management	18	166
Living Life to the Full	69	1,008
Mood Management	3	24
Neurological	2	14
Dysarthria Group	1	7
Parkinson's Dysarthria Group	1	7
Stroke	40	352
Life After Stroke	16	220
Moving On/PREP	24	132
Generic	86	884
Challenging Your Condition	27	267
Managing the Challenge	25	253
Self Esteem	18	166
Taking Control	16	198
Total	841	12,741

Figure 3 illustrates the number of programmes and participants by HSC Trust area. Across HSC Trusts the average number of participants per programme varied from 21.5 in the South Eastern HSC Trust to 11.3 in the Belfast HSC Trust.

Figure 3. Number of Programmes and Participants by HSC Trust Area (2013/14)⁸



There has been an increase of 3% (22) in the number of condition specific programmes that took place during 2013/14 (755) from that in 2012/13 (733). The number of generic programmes (86) increased by 69% (35) from 2012/13 (51) (Table 7).

Table 7. Frequency of Programmes by Type and HSC Trust Area (2011/12 – 2013/14)⁹

HSC Trust Area	2011/12		2012/13		2013/14	
	Condition Specific	Generic	Condition Specific	Generic	Condition Specific	Generic
BHSCT	124	4	188	5	208	8
NHSCT	92	5	95	4	105	11
SEHSCT	95	3	102	2	82	10
SHSCT	145	11	191	13	205	31
WHSCT	119	27	90	27	85	26
Total	575	50	733	51	755	86

⁸ Aware, who provided 69 programmes for 1,008 participants and Cancer Focus who provided 1 programme for 38 participants, were unable to provide figures broken down by HSC Trust area. As a result, the sum of HSC Trust Area figures will not match the total figure for Northern Ireland.

⁹ The Challenging Pain programme with a frequency of 28 programmes and 289 participants was reclassified as a Chronic Pain programme in 2012/13. It was previously classified as a Generic programme.

Figure 4. Number of Programmes by Type (2011/12 – 2013/14)

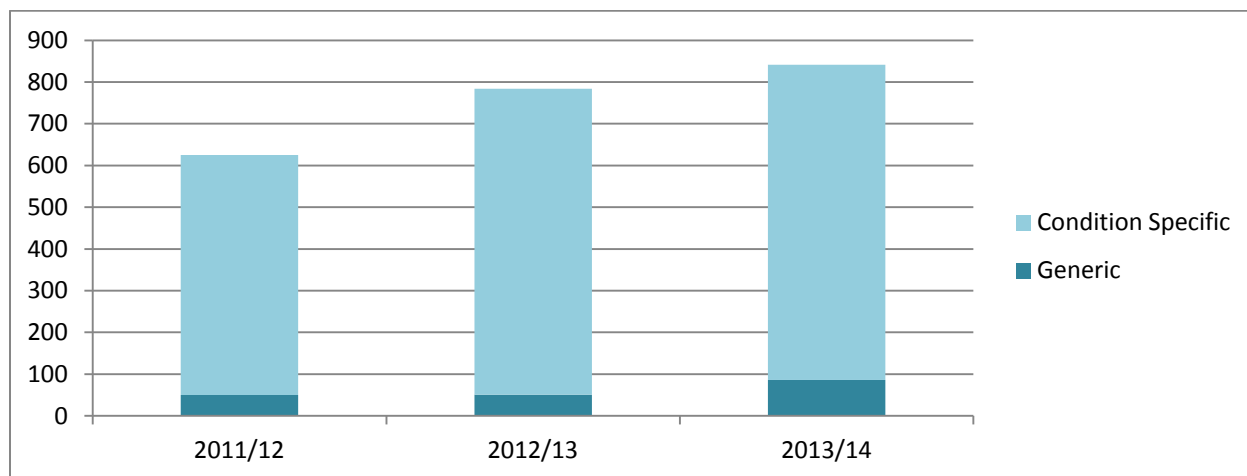
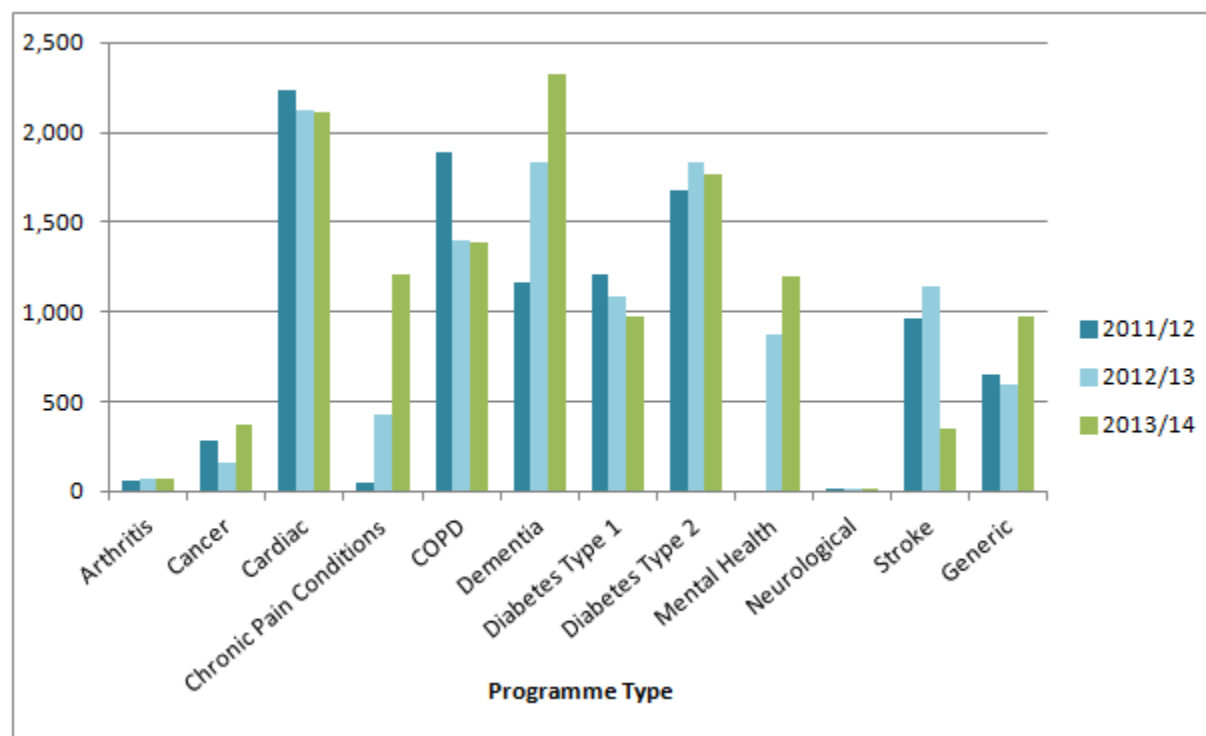


Figure 5 shows that within most programme types, participant numbers have stayed relatively stable. However, marked increases can be seen in the number of participants accessing programmes for chronic pain and dementia. Over the last three years large proportions of participants have been consistently accessing programmes related to cardiac, COPD and diabetes.

Figure 5. Participant Numbers by Programme Type (2011/12 – 2013/14)¹⁰



¹⁰ The Stroke Association stated that the fall in participant numbers for 2013/14 is the result of a restructuring of their service delivery framework. This restructuring has led to participants on a particular programme stage no longer falling under the scope of this data collection.

5. Selected Conditions

This section looks specifically at four selected conditions, cardiac, COPD, Type 1 diabetes and Type 2 diabetes. The number of participants attending a programme in relation to these conditions in 2013/14 (6,240) has fallen 3% (192) since 2012/13 (6,432). The number of participants at programmes related to the remaining conditions increased by 25%, and those attending generic programmes increased by 48%.

Table 8. Participant Numbers for 4 Selected Conditions by HSC Trust Area (2013/14)

	BHSCT area	NHSCT area	SEHSCT area	SHSCT area	WHSCT area	Total
Cardiac	568	471	447	341	291	2,118
COPD	296	255	300	262	271	1,384
Diabetes Type 1	325	89	194	259	107	974
Diabetes Type 2	395	-	207	870	292	1,764

Figure 6. Participant Numbers for 4 Selected Conditions (2013/14)

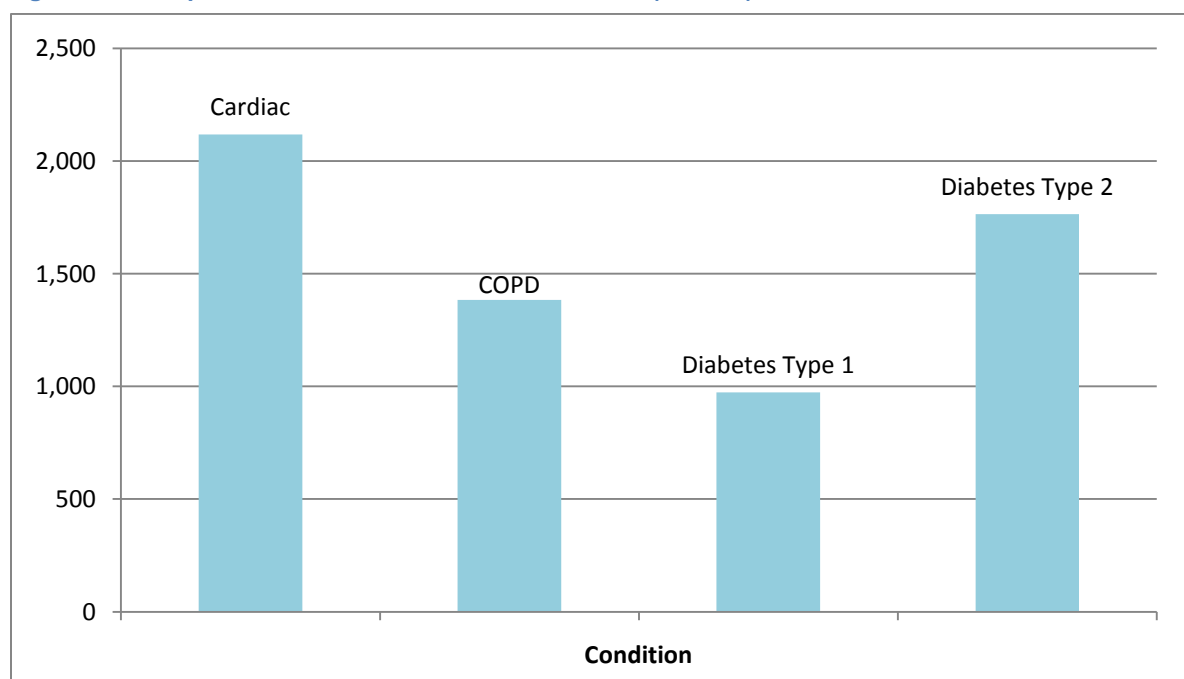


Table 8. Annual Change in Participant Numbers by Condition Addressed in Programme (2012/13 – 2013/14)

	2012/13	2013/14	% Change
4 Selected Conditions	6,432	6,240	-3%
Other Conditions	4,502	5,617	25%
Generic	597	884	48%

Appendix A. Technical Notes

Data Collection

The information presented in this publication derives from the third Patient Education / Self Management Programmes for Long Term Conditions questionnaire. Completed questionnaires were provided by each of the five HSC Trusts in Northern Ireland, as well as independent providers, to Community Information Branch (CIB) in the Department of Health, Social Services & Public Safety.

For this publication, the questionnaire covered the year ending 31 March 2014 and gathered information on the type, provision, frequency and Trust area of patient education / self management programmes delivered during the year. Further details about the scope of this audit can be found in the 2013/14 collection guidance notes which along with a copy of the questionnaire can be made available on request from [CIB](#).

Data Quality

On receipt of the Patient Education / Self Management Programmes questionnaire, statisticians in CIB conducted internal consistency checks. They also checked for variations from the baseline information collated for 2011/12 and the subsequent collection for 2012/13 both regionally and across providers. Queries arising from validation checks were presented to the independent organisations or HSC Trusts for clarification and if required returns could be amended and re-submitted. The HSC Trusts were also asked to provide appropriate explanations for any inconsistent or missing information.

The total number of people who attended a patient education / self management programme in 2013/14 can include any individuals who attended more than 1 programme during the year – there may therefore be an element of double counting.

The statistics presented in this bulletin were collected as an audit of programme provision and uptake for 2013/14 and are best described as experimental. Any future statistics covering this issue may be subject to revisions in coverage and methodology.

Data Presentation

Any instance of ‘ – ‘ represents either a zero figure or that the information is not available.

The total number of people who attended a patient education / self management programme in 2013/14 would include any individuals who attended more than 1 programme during the year – there may therefore be an element of double counting.

Amendments

The cut-off point for amendments to data was 24th December 2014. Any amendments notified by HSC Trusts or independent organisations after this date will not have been included.

Rounding Conventions

Percentages have been rounded to whole numbers and as a consequence some percentages may not sum to 100. 0% may reflect rounding down of values under 0.5%.

Revisions Policy

These data are revised by exception. If revisions are required, background circumstances are reported and revision dates are noted in subsequent publications of these series of statistics. The general revisions policy for Official Statistics produced by the DHSSPS can be found in the DHSSPS Statistics Charter on our website.

Main Uses of Data

Data presented in this publication helps to meet the information needs of the DHSSPS. Commitment 44 in the Programme for Government (PfG) 2011-15 is to 'Enrol people who have a long-term (chronic) condition, and who want to be enrolled, in a dedicated chronic condition management programme'. The figures included contribute to the Performance Indicators required to measure the provision of programmes and programme participation as well as identifying any further need of provision.

Contact

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<http://www.dhsspsni.gov.uk/index/statistics/feedback-statistics.htm>

The scope of collection was agreed between the Public Health Agency and DHSSPS and is summarised in the table below.

This data collection IS covering	This data collection IS NOT covering:	LTCs included in audit:
<p>Programmes for people with long term conditions.</p> <p>Programmes designed for:</p> <ul style="list-style-type: none"> • Adults; • Children/young people; • Carers. <p>Both HSC Trust <u>and</u> Independent sector provided / funded programmes.</p> <p>Programmes that have a formal / structured approach and are time limited.</p> <p>Programme format either structured group format or on-line format.</p>	<p>Any kind of “Support groups” for either physical or mental health long term conditions. By ‘support groups’ we mean informal, unstructured groups with no time limit.</p> <p>One-to-one reviews or appointments with health and social care professionals, e.g. GPs or other primary / community care professionals.</p>	<p>LTCs relating to physical health eg:</p> <ul style="list-style-type: none"> • Diabetes; • Cardiac; • COPD / respiratory; • Stroke / dementia / neurological; • Chronic Pain; • Arthritis / other Musculoskeletal; • Cancer. <p>LTCs relating to mental health.</p>

Abbreviations

BERTIE	Bournemouth Type 1 Intensive Education
BHSCT	Belfast Health and Social Care Trust
CHOICE	Carbohydrate Insulin Collaborative Education
COPD	Chronic Obstructive Pulmonary Disease
DAFNE	Dose Adjustment for Normal Eating
DAY	Diabetes And You
DESMOND	Diabetes Education & Self Management of Ongoing and Newly Diagnosed
DHSSPS	Department of Health, Social Services and Public Safety
HOPE	Help to Overcome Problems Effectively
NHSCT	Northern Health and Social Care Trust
SEHSCT	South Eastern Health and Social Care Trust
SET2	Southern Education Type 2
SHAIRE	Southern Health Adjusting Insulin Round Eating
SHSCT	Southern Health and Social Care Trust
WHSCT	Western Health and Social Care Trust

This and other statistical bulletins published by Community Information Branch are available to download on the DHSSPS website at:

<http://www.dhsspsni.gov.uk/index/statistics/socialcare.htm>

This publication can be requested in large print or other formats.