



# Patient Education / Self Management Programmes for People with Long Term Conditions (2016/17)



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The statisticians within IAD are outposted from the Northern Ireland Statistics & Research Agency (NISRA) and the statistics are produced in accordance with the principles and protocols set out in the <u>Code of Practice for Official Statistics</u>.

https://www.health-ni.gov.uk/topics/dohstatistics-and-research 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.

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- 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 decisionmaking and improvement in service provision; and
- be an expert voice on social care information.

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.

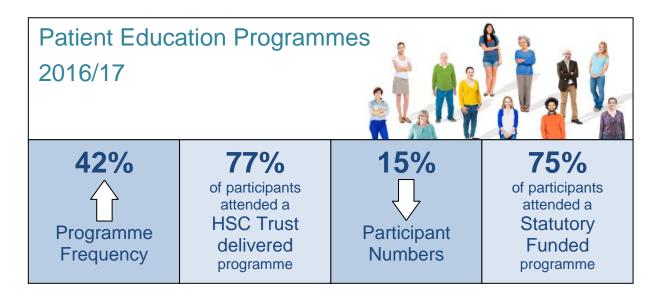
We collect, analyse, and publish a wide range of community information that is used to help monitor the delivery of personal social services policy. Information collected by CIB is used to assess HSC Trust performance, for corporate monitoring, policy evaluation, and to respond to parliamentary/assembly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



- There were 41 patient education / self management programmes provided a total of 1,291<sup>1</sup> times with 12,910<sup>2,3</sup> participants in 2016/17.
- Programme frequency has increased by 42% when compared to 2015/16 (908).
   Participant numbers have decreased by 15% (2,282) in 2016/17<sup>2,3</sup> when compared to 2015/16 (15,192).
- Approximately 1 in 4 participants attended a diabetes type 2 specific programme with 17% and 15% of participants attending a programme for COPD and cardiac conditions respectively.
- Of the 12,910<sup>2,3</sup> participants, 77% were attending a patient education / self management programme delivered by the five HSC Trusts.
- 9,642 participants (75%) attended a programme that was statutory funded.

<sup>&</sup>lt;sup>1</sup> The Belfast HSC Trust were unable to provide programme frequency figures for their CHOICE and PUMPS programmes therefore an estimated figure has been used. Further information can be found in the Data Presentation section of <u>Appendix B</u>.

<sup>&</sup>lt;sup>2</sup> Alzheimer's Society did not provide information for programmes that ran in the Belfast, Northern and South Eastern HSC Trusts during 2016/17. Programmes in these areas accounted for approximately 1,300 participants in 2015/16.

<sup>&</sup>lt;sup>3</sup> The Belfast HSC Trust did not provide information for cardiac rehabilitation programmes during 2016/17. During 2015/16 this programme accounted for approximately 570 participants.

# 2. Programmes

In 2016/17 there were 41 different patient education / self management programmes in place across Northern Ireland. These programmes ran a total of 1,291 times throughout the year ranging from 319 in the South Eastern HSC Trust area to 187 in the Western HSC Trust area.

The number of different programmes available this year was 4 more than the previous year (37). Programme frequency increased by 42% in 2016/17 (1,291) when compared to 2015/16 (908) (Figure 1).

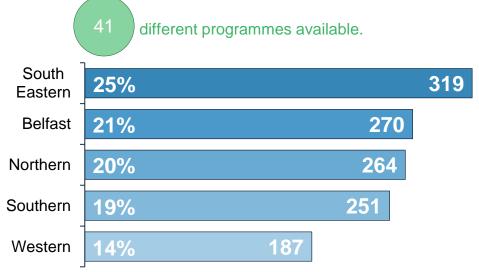
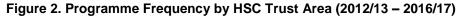
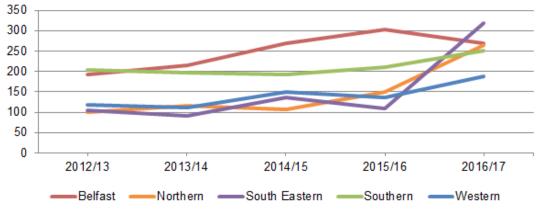


Figure 1. Programme Frequency by HSC Trust Area (2016/17)<sup>4</sup>



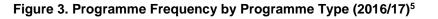
Since 2012/13, the frequency of programmes regionally has risen by 65%, reflecting an increase across all HSC Trust areas. There was a large increase in the frequency of programmes provided in the South Eastern HSC Trust compared to last year. This can be attributed to the frequency of Cardiac Rehabilitation programmes being available for 2016/17 (Figure 2) (Table 1).

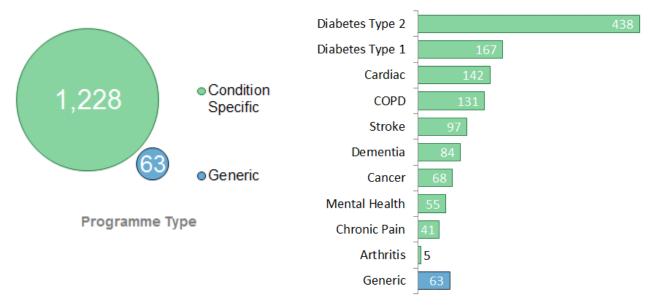




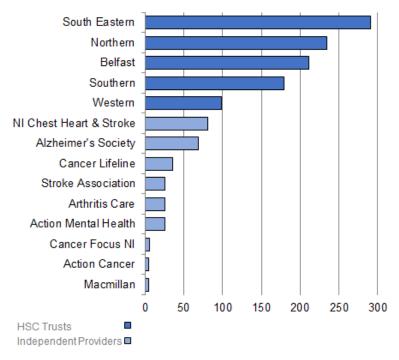
<sup>&</sup>lt;sup>4</sup> The Belfast HSC Trust were unable to provide programme frequency figures for their CHOICE and PUMPS programmes therefore an estimated figure has been used. Further information can be found in the Data Presentation section of <u>Appendix B</u>.

During 2016/17, of the 1,291 times that programmes ran, 95% were condition specific and 5% were generic. Similar to 2015/16, the most frequent programme in 2016/17 was diabetes type 2 (438), accounting for just over a third (34%) of all programmes run (Figure 3) (Table 2).





### Figure 4. Programme Frequency by Provider Organisation (2016/17)<sup>5</sup>

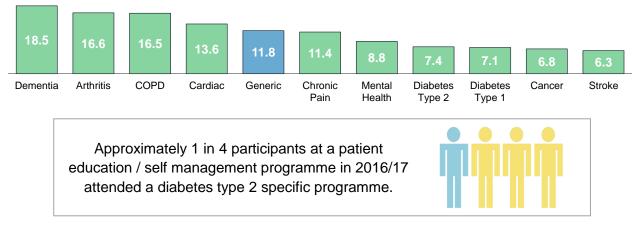


Nearly 4 in 5 (78%) programmes run during 2016/17 were provided by HSC Trusts, with the South Eastern HSC Trust delivering the greatest number (Figure 4). Of those programmes run by independent providers, NI Chest Heart & Stroke (NICHS) provided the most (81), followed by Alzheimer's Society (69). Compared to 2015/16, the frequency of condition specific and generic programmes both increased by 44% and 17%, respectively (Table 3).

<sup>&</sup>lt;sup>5</sup> The Belfast HSC Trust were unable to provide programme frequency figures for their CHOICE and PUMPS programmes therefore an estimated figure has been used. Further information can be found in the Data Presentation section of <u>Appendix B</u>.

# 3. Conditions

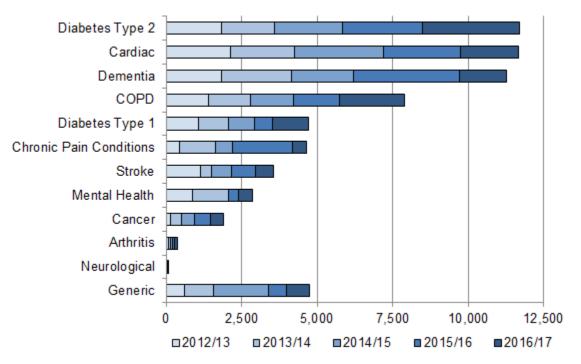
The average number of participants per programme, by condition, ranged from just over 18.5, for those attending dementia programmes, to just over 6 for stroke programmes (Figure 5). The overall average number of participants per programme was 10.0.





Over the last 5 years, large numbers of participants have been continually accessing programmes related to diabetes type 2, cardiac and dementia as shown in (Figure 6) (Table 7).

Figure 6. Number of Participants by Programme Type (2011/12 – 2015/16)



<sup>&</sup>lt;sup>6</sup> The Belfast HSC Trust were unable to provide programme frequency figures for their CHOICE and PUMPS programmes therefore an estimated figure has been used. Further information can be found in the Data Presentation section of <u>Appendix B</u>.

Between 2012/13 and 2016/17 the number of annual participants at programmes for diabetes type 2 has increased by 76%. There has been a 55% increase in the number attending COPD programmes and the number of participants at diabetes type 1 programmes has increased by 10% (Figure 7). An increase in participants attending chronic pain, cancer and arthritis programmes has also been seen since 2012/13.

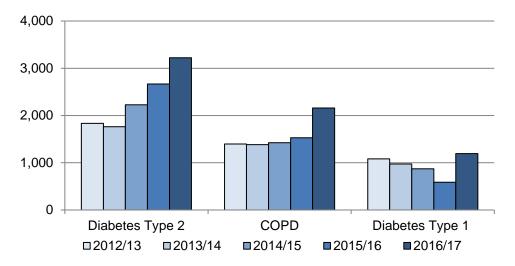


Figure 7. Number of Participants by Condition (2012/13 – 2016/17)

Over the past 5 years, participant numbers have decreased at those programmes tailored to cardiac, dementia and stroke (Figure 8) (Table 7). Any annual analysis of participant numbers and programme frequency should be considered in conjunction with each other, and also take account of any caveats in the information as set out in the footnotes.

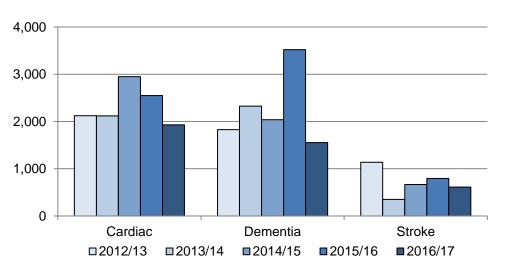


Figure 8. Number of Participants by Condition (2012/13 – 2016/17) 7,8,9

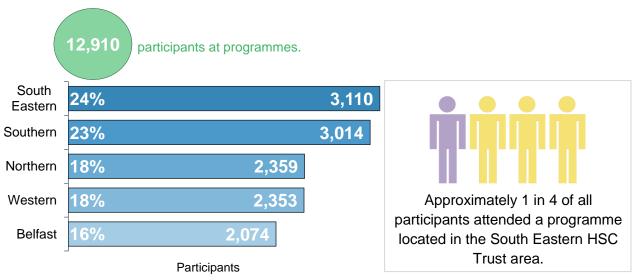
<sup>8</sup> Alzheimer's Society did not provide information for programmes that ran in the Belfast, Northern and South Eastern HSC Trusts during 2016/17. Programmes in these areas accounted for approximately 1,300 participants in 2015/16.
<sup>9</sup> The decrease in participants at programmes for stroke in 2013/14 can be attributed to a restructuring of the Stroke Association's service framework.

<sup>&</sup>lt;sup>7</sup> The Belfast HSC Trust did not provide information for cardiac rehabilitation programmes during 2016/17. During 2015/16 this programme accounted for approximately 570 participants.

# 4. Participants

### Participants by HSC Trust Area

In 2016/17, 12,910 participants<sup>10,11</sup> attended a patient education / self management programme ranging from 3,110 in the South Eastern HSC Trust area to 2,074 in the Belfast HSC Trust area (Figure 9). This represented a decrease of 15% (2,282) compared to 2015/16 (15,192). Annual changes should be treated with caution, please see related footnotes. Compared to 2015/16, when the South Eastern HSC Trust area had the least number of participants at programmes, there were a larger number of people accessing programmes for all conditions in the area.



### Figure 9. Participant Numbers by HSC Trust Area (2016/17)<sup>10,11</sup>

Since 2012/13, participant numbers at patient education / self management programmes has increased by 12% (1,379). Participant numbers have increased in each of the HSC Trust areas over the past 5 years with the exception of the Belfast HSC Trust area (Figure 10) (Table 5). Annual changes should be treated with caution, please see related footnotes.

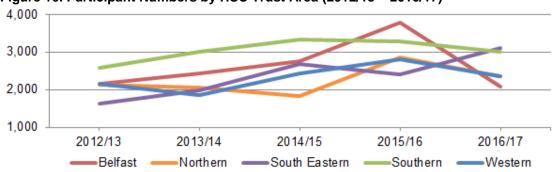


Figure 10. Participant Numbers by HSC Trust Area (2012/13 – 2016/17)<sup>10,11</sup>

<sup>&</sup>lt;sup>10</sup> The Belfast HSC Trust did not provide information for cardiac rehabilitation programmes during 2016/17. During 2015/16 this programme accounted for approximately 570 participants.

<sup>&</sup>lt;sup>11</sup> Alzheimer's Society did not provide information for programmes that ran in the Belfast, Northern and South Eastern HSC Trusts during 2016/17. Programmes in these areas accounted for approximately 1,300 participants in 2015/16.

Of the 12,910 participants, 77% were attending a programme delivered by HSC Trusts and 23% a programme by independent sector organisations. In 2016/17, participant numbers at programmes provided by HSC Trusts (9,895) showed a 3% (288) increase over the number of participants in 2015/16 (9,607). The South Eastern HSC Trust provided programmes for 22% of all participants.

The Alzheimer's Society<sup>12</sup> had 1,422 participants at programmes they provided during 2016/17, the most of all the independent sector organisations who provided programmes, and 11% of the total participant numbers (Figure 11).

The proportion of participants at programmes provided by HSC Trusts and independent sector providers has remained relatively stable across the last 5 years (Table 8), however, figures for 2016/17 do not include participants at Alzheimer's Society programmes in the Belfast, Northern and South Eastern HSC Trusts.

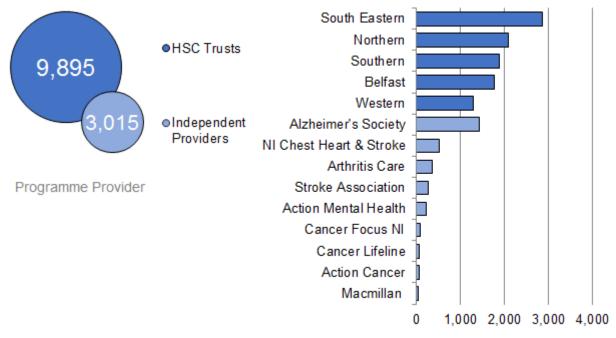
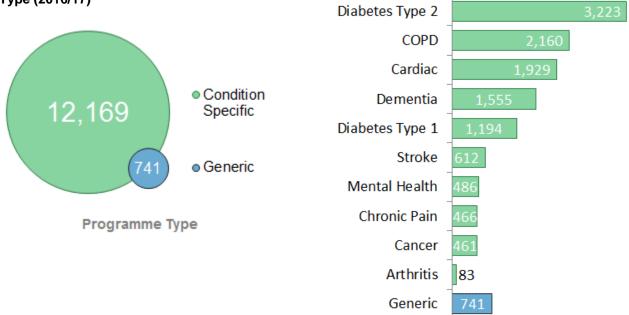
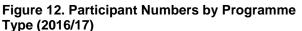


Figure 11. Participant Numbers by Provider Organisation (2016/17)

<sup>&</sup>lt;sup>12</sup> Alzheimer's Society did not provide information for programmes that ran in the Belfast, Northern and South Eastern HSC Trusts during 2016/17. Programmes in these areas accounted for approximately 1,300 participants in 2015/16.

Of the 12,910 participants at programmes, 94% were attending a condition specific programme with 6% attending a generic programme. Figure 12 shows that the majority of participants (25%) attended a programme related to diabetes type 2; followed by COPD (17%). During 2016/17 dementia programmes accounted for the most participants; however the number of participants at dementia specific programmes has fallen by 56% since then<sup>13</sup>. Annual changes should be treated with caution, please see related footnotes.





The top 6 conditions, by participant numbers, had programmes available across all 5 HSC Trust areas with two exceptions. There were no cardiac specific programmes reported in the Belfast and Western HSC Trust areas; however NICHS provided the generic 'Taking Control' programme in these areas during 2016/17. Also, there were no dementia specific programmes reported in the Belfast and Western HSC Trust areas (Table 6)<sup>13</sup>. The number of participants at a condition specific programme has increased by 11% (1,235) in the 5 years since 2012/13 (Table 7).

<sup>&</sup>lt;sup>13</sup> Alzheimer's Society did not provide information for programmes that ran in the Belfast, Northern and South Eastern HSC Trusts during 2016/17. Programmes in these areas accounted for approximately 1,300 participants in 2015/16.

In 2016/17, 75% (9,710) of participants attended a programme that was either clinically or professionally led; this was greater than the proportion in 2015/16 (61%). Participants at jointly led programmes accounted for 19% (2,462) of the total, with the remaining 6% (738) of participants attending a programme that was peer led.

Of the participants at clinically or professionally led programmes in 2016/17, 96% (9,369) were attending a condition specific programme. 93% (2,297) of those at a jointly led programme and 68% (503) at a peer led programme (Table 9) were attending condition specific programmes.

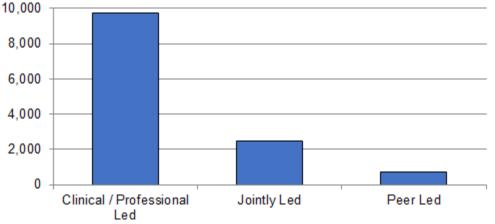


Figure 13. Number of Participants by Programme Delivery (2016/17)

In 2016/17, 75% (9,642) of participants attended a programme that was statutory funded, a decrease of 29% (3,904) since the previous year. Jointly funded programmes were provided for 16% of participants; with 6% of participants each attending voluntary funded programmes and 4% at programmes utilising other funding arrangements<sup>14</sup> (Table 10).

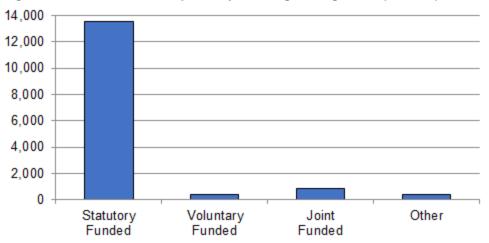
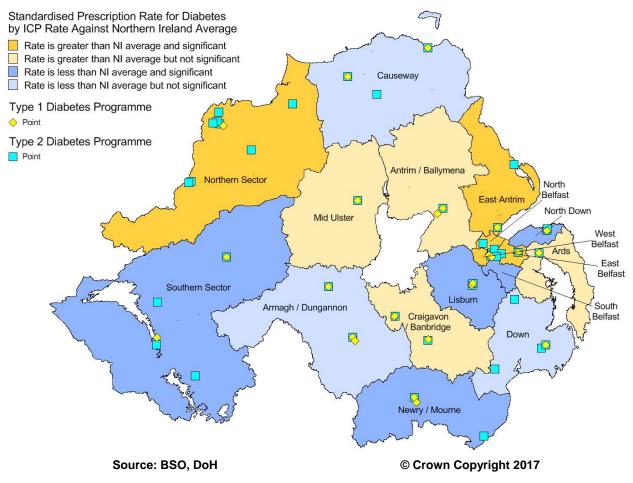


Figure 14. Number of Participants by Funding Arrangement (2016/17)<sup>14</sup>

<sup>&</sup>lt;sup>14</sup> Funding may be provided through other sources such as 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.

### Diabetes

## Figure 15. Standardised Prescription Rate for Diabetes, by ICP Rate Against Northern Ireland Average; with Diabetes Programme Locations



Using 2016 diabetes specific prescription data, the map above shows whether the Standardised Prescription Rate (SPR) for a discrete Integrated Care Partnership (ICP) Area is significantly greater or less than the Northern Ireland SPR. In addition, programme location data for both diabetes Type 1 and Type 2 focused education programmes have been added. When comparing to the previous year, those areas where the SPR was greater than the Northern Ireland average have remained as such. There was one ICP (Ards) where the SPR was less than the Northern Ireland average, it is not a significant finding.

#### Figure 16. Proximity of Census Output Areas to Diabetes Programmes

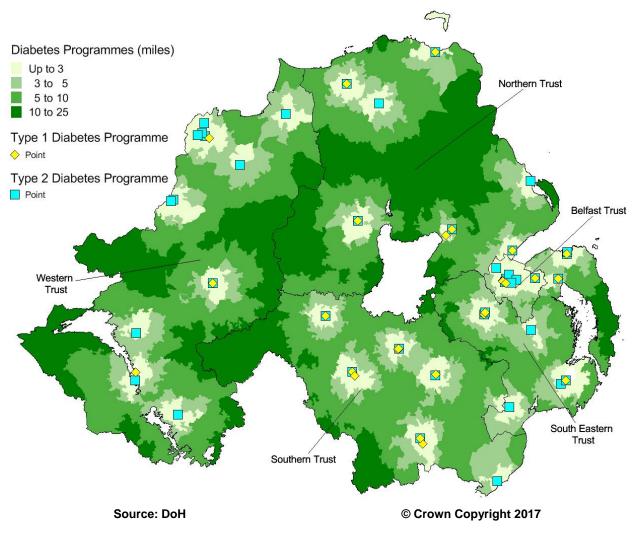


Figure 16 illustrates the locations of patient education / self management programmes for both Type 1 and Type 2 diabetes that ran during 2016/17 and their proximity to census output areas in Northern Ireland. Approximately half (50%) of the population in Northern Ireland lived within 3 miles of a diabetes programme. Almost 1 in 10 (9%) people in Northern Ireland lived more than 10 miles from a diabetes programme, with no one located more than 25 miles away from a programme. Diabetes programmes during 2016/17 were located in similar locations as in the previous year, however there was additional provision of programmes in the south of the South Eastern HSC Trust.

### COPD

Figure 17. Standardised Prescription Rate for COPD, by ICP Rate Against Northern Ireland Average; with Diabetes Programme Locations

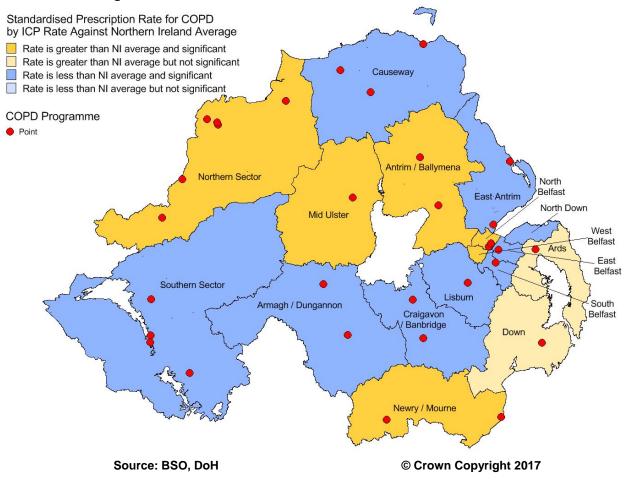


Figure 17 uses COPD specific prescription data to compare the SPR against the regional average. All but two ICP areas had a rate that was either significantly greater or less than the Northern Ireland average. Only the Ards and Down ICP areas had a rate than was not significant when compared to the regional average (both greater). As was the case in 2015/16, the North Down ICP area (SPR less than the NI average) was the only one with no provision for a COPD specific programme during 2016/17. Figure 18 overleaf provides more information on the access to programmes.



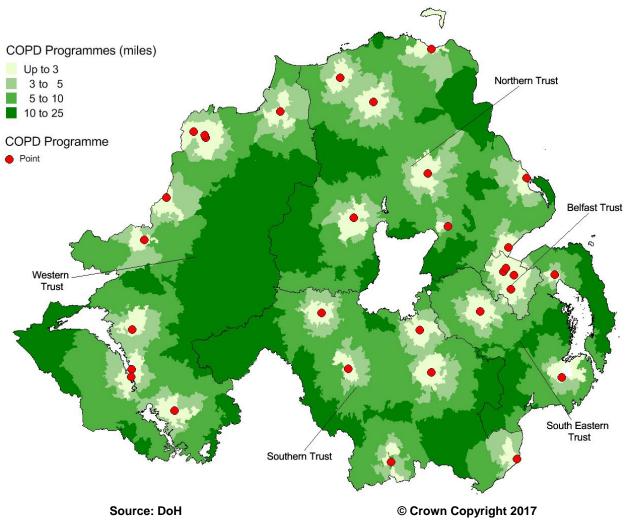


Figure 18 illustrates the locations of programmes for COPD that ran during 2016/17 and their proximity to census output areas. Approximately 42% of the population in Northern Ireland lived within 3 miles of a COPD programme in 2016/17 with no one located more than 25 miles away from a programme. With no programme located in the North Down ICP area (Figure 17), the map above, in conjunction with Figure 17, shows how the majority of the ICP area is located less than 10 miles from a COPD programme. COPD programmes during 2016/17 were located in similar locations as in the previous year, however there was additional provision of programmes in the east of the Southern HSC Trust around Banbridge.

### 5. Tables

	Programme Frequency						
HSC Trust Area	2012/13	2012/13 2013/14 2014/15 2015/16					
Belfast	193	216	270	302	270		
Northern	99	116	106	149	264		
South Eastern	104	92	136	108	319		
Southern	204	197	193	211	251		
Western	117	111	150	137	187		
Total	784	802	856	908	1,291		

Table 1. Programme Frequency by HSC Trust Area (2012/13 – 2016/17)<sup>15</sup>

<sup>&</sup>lt;sup>15</sup> The Belfast HSC Trust were unable to provide programme frequency figures for their CHOICE and PUMPS programmes therefore an estimated figure has been used. Further information can be found in the Data Presentation section of <u>Appendix B</u>.

Programme Type	Belfast	Northern	South Eastern	Southern	Western	Total
Condition Specific	264	264	276	238	186	1,228
Arthritis	-	5	-	-	-	5
Cancer	48	10	1	3	6	68
Cardiac	-	36	87	19	-	142
Chronic Pain	9	17	-	7	8	41
COPD	40	31	33	15	12	131
Dementia	-	-	15	27	42	84
Diabetes Type 1	22	16	88	21	20	167
Diabetes Type 2	133	128	33	86	58	438
Stroke	12	21	19	30	15	97
Mental Health	-	-	-	30	25	55
Generic	6	-	43	13	1	63
Total	270	264	319	251	187	1,291

Table 2. Programme Frequency by Programme Type and HSC Trust Area (2016/17)<sup>16</sup>

<sup>&</sup>lt;sup>16</sup> The Belfast HSC Trust were unable to provide programme frequency figures for their CHOICE and PUMPS programmes therefore an estimated figure has been used. Further information can be found in the Data Presentation section of <u>Appendix B</u>.

	201	2012/13		2013/14 2014/15 201		5/16	2010	6/17		
HSC Trust Area	Condition Specific	Generic	Condition Specific	Generic	Condition Specific	Generic	Condition Specific	Generic	Condition Specific	Generic
Belfast	188	5	208	8	238	32	295	7	264	6
Northern	95	4	105	11	93	13	149	0	264	0
South Eastern	102	2	82	10	110	26	100	8	276	43
Southern	191	13	169	28	168	25	199	12	238	13
Western	90	27	85	26	103	47	110	27	186	1
Total	733	51	719	83	713	143	854	54	1,228	63

Table 3. Frequency of Programmes by Type and HSC Trust Area (2012/13 – 2016/17)<sup>17</sup>

Table 4. Programme Frequency by Provider Organisation (2016/17)<sup>17</sup>

Provider Organisation	2016/17
Action Cancer	5
Action Mental Health	25
Alzheimer's Society	69
Arthritis Care	26
Cancer Focus NI	6
Cancer Lifeline	36
Macmillan Cancer Support	4
NI Chest Heart & Stroke	81
Stroke Association	26
BHSCT	211
NHSCT	234
SEHSCT	291
SHSCT	179
WHSCT	98
Total	1,291

<sup>&</sup>lt;sup>17</sup> The Belfast HSC Trust were unable to provide programme frequency figures for their CHOICE and PUMPS programmes therefore an estimated figure has been used. Further information can be found in the Data Presentation section of <u>Appendix B</u>.

	Participants							
HSC Trust Area	2012/13	2013/14	2014/15	2015/16	2016/17			
Belfast	2,164	2,443	2,751	3,773	2,074			
Northern	2,138	2,063	1,838	2,865	2,359			
South Eastern	1,633	1,975	2,683	2,410	3,110			
Southern	2,579	3,013	3,327	3,295	3,014			
Western	2,146	1,845	2,432	2,809	2,353			
Total	11,531	12,385	13,069	15,192	12,910			

Table 5. Participant Numbers by HSC Trust Area (2012/13 – 2016/17)<sup>18,19</sup>

<sup>&</sup>lt;sup>18</sup> The Belfast HSC Trust did not provide information for cardiac rehabilitation programmes during 2016/17. During 2015/16 this programme accounted for approximately 570 participants.

<sup>&</sup>lt;sup>19</sup> Alzheimer's Society did not provide information for programmes that ran in the Belfast, Northern and South Eastern HSC Trusts during 2016/17. Programmes in these areas accounted for approximately 1,300 participants in 2015/16.

Programme Type	Belfast	Northern	South Eastern	Southern	Western	Total
Condition Specific	1,985	2,359	2,664	2,829	2,332	12,169
Arthritis	-	83	-	-	-	83
Cancer	242	131	6	26	56	461
Cardiac	-	540	1,017	372	-	1,929
Chronic Pain	97	213	-	93	63	466
COPD	631	414	546	202	367	2,160
Dementia	-	-	133	738	684	1,555
Diabetes Type 1	166	117	570	186	155	1,194
Diabetes Type 2	770	741	255	747	710	3,223
Mental Health	-	-	-	269	217	486
Stroke	79	120	137	196	80	612
Generic	89	-	446	185	21	741
Total	2,074	2,359	3,110	3,014	2,353	12,910

Table 6. Participant Numbers by Programme Type and HSC Trust Area (2016/17)<sup>20,21</sup>

<sup>&</sup>lt;sup>20</sup> The Belfast HSC Trust did not provide information for cardiac rehabilitation programmes during 2016/17. During 2015/16 this programme accounted for approximately 570 participants.

<sup>&</sup>lt;sup>21</sup> Alzheimer's Society did not provide information for programmes that ran in the Belfast, Northern and South Eastern HSC Trusts during 2016/17. Programmes in these areas accounted for approximately 1,300 participants in 2015/16.

Provider Organisation	2012/13	2013/14	2014/15	2015/16	2016/17
Condition Specific	10,934	11,772	11,252	14,578	12,169
Arthritis	70	65	87	56	83
Cancer	154	371	400	531	461
Cardiac	2,121	2,118	2,950	2,548	1,929
Chronic Pain Conditions	428	1,207	567	1,977	466
COPD	1,396	1,384	1,423	1,530	2,160
Dementia	1,828	2,325	2,038	3,522	1,555
Diabetes Type 1	1,081	974	873	587	1,194
Diabetes Type 2	1,834	1,764	2,228	2,668	3,223
IBD	-	-	-	36	-
Lymphoedema	-	-	6	6	-
Mental Health	871	1,198	-	314	486
Neurological	14	14	14	7	-
Stroke	1,137	352	666	796	612
Generic	597	969	1,817	614	741
Total	11,531	12,741	13,069	15,192	12,910

Table 7. Annual Change in Participant Numbers by Provider Organisation (2012/13 – 2016/17)<sup>22,23</sup>

<sup>&</sup>lt;sup>22</sup> The Belfast HSC Trust did not provide information for cardiac rehabilitation programmes during 2016/17. During 2015/16 this programme accounted for approximately 570 participants.

<sup>&</sup>lt;sup>23</sup> Alzheimer's Society did not provide information for programmes that ran in the Belfast, Northern and South Eastern HSC Trusts during 2016/17. Programmes in these areas accounted for approximately 1,300 participants in 2015/16.

		-			
Provider Organisation	2012/13	2013/14	2014/15	2015/16	2016/17
Action Cancer	26	52	62	67	60
Action Mental Health	-	253	278	260	217
Alzheimer's Society	1,718	2,125	2,026	3,469	1,422
Arthritis Care	547	1,281	540	468	357
Aware	871	1,008	1,123	-	-
Cancer Focus NI	45	102	96	69	85
Cancer Lifeline	-	69	64	68	67
Extracare	110	-	-	-	-
Macmillan	46	54	130	254	30
NI Chest Heart & Stroke	265	330	532	452	519
Stroke Association	1,037	220	324	478	258
BHSCT	1,648	1,743	1,824	2,866	1,775
NHSCT	962	845	997	1,967	2,087
SEHSCT	1,114	1,355	1,953	1,629	2,862
SHSCT	1,810	1,902	1,969	1,850	1,876
WHSCT	1,332	1,046	1,151	1,295	1,295
Total	11,531	12,385	13,069	15,192	12,910

Table 8. Participant Numbers by Provider Organisation (2012/13 – 2016/17)<sup>24,25,26</sup>

<sup>&</sup>lt;sup>24</sup> Alzheimer's Society did not provide information for programmes that ran in the Belfast, Northern and South Eastern HSC Trusts during 2016/17. Programmes in these areas accounted for approximately 1,300 participants in 2015/16.

<sup>&</sup>lt;sup>25</sup> 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 the questionnaire.

<sup>&</sup>lt;sup>26</sup> The Belfast HSC Trust did not provide information for cardiac rehabilitation programmes during 2016/17. During 2015/16 this programme accounted for approximately 570 participants.

Programme Type	Clinical / Professional Led	Peer Led	Jointly Led	Total
Condition Specific	9,369	503	2,297	12,169
Arthritis	-	83	-	83
Cancer	424	-	37	461
Cardiac	1,475	-	454	1,929
Chronic Pain	427	39	-	466
COPD	2,160	-	-	2,160
Dementia	133	360	1,062	1,555
Diabetes Type 1	1,173	21	-	1,194
Diabetes Type 2	3,223	-	-	3,223
Mental Health	-	-	486	486
Stroke	354	-	258	612
Generic	341	235	165	741
Total	9,710	738	2,462	12,910

 Table 9. Participant Numbers by Programme Type and Programme Delivery (2016/17)

Programme Type	Statutory Funded	Voluntary Funded	Joint Funded	Other <sup>27</sup>	Total
Condition Specific	9,045	336	2,061	727	12,169
Arthritis	64	19	-	-	83
Cancer	197	264	-	-	461
Cardiac	1,929	-	-	-	1,929
Chronic Pain	439	27	-	-	466
COPD	1,793	-	-	367	2,160
Dementia	133	-	1,062	360	1,555
Diabetes Type 1	1,168	26	-	-	1,194
Diabetes Type 2	2,482	-	741	-	3,223
Mental Health	486	-	-	-	486
Stroke	354	-	258	-	612
Generic	597	144	-	-	741
Total	9,642	480	2,061	727	12,910

 Table 10. Participant Numbers by Programme Type and Funding Arrangements (2016/17)

<sup>&</sup>lt;sup>27</sup> Funding may be provided through other sources such as 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.

# Appendix A. Background

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 2016 to 31 March 2017.

The <u>Programme for Government (PfG) 2011-15</u> included 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. The commitment sought 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 increasing<sup>28</sup>. 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 <u>"Living with Long Term Conditions</u>" 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.

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 and annual publications have continued since.

This report is a regional summary of the information provided on the Patient Education / Self Management Programme questionnaire 2016/17. Information was provided by HSC Trusts and independent sector organisations who delivered programmes during 2016/17. The report summarises the key statistical information provided for the year 2016/17 and how this compares with that collected in previous years.

<sup>&</sup>lt;sup>28</sup> https://www.northernireland.gov.uk/publications/programme-government-2011-2015

# Appendix B. Technical Notes

### **Data Collection**

The information presented in this publication derives from the 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.

For this publication, the questionnaire covered the year ending 31 March 2017 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 2016/17 collection guidance notes which along with a copy of the questionnaire can be made available on request from <u>CIB</u>.

### **Data Quality**

On receipt of the Patient Education / Self Management Programmes questionnaire, statisticians in CIB conduct internal consistency checks. They also check for variations from the baseline information collated for 2011/12 and the subsequent collections both regionally and across providers. Queries arising from validation checks are presented to the independent organisations or HSC Trusts for clarification and if required returns can be amended and resubmitted. The HSC Trusts are also asked to provide appropriate explanations for any inconsistent or missing information.

The statistics presented in this bulletin were collected as an audit of programme provision and uptake for 2016/17 and are best described as <u>experimental</u>. 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 would include any individuals who attended more than 1 programme during the year – there may therefore be an element of double counting.

As some information was not available by HSC Trust area, or programmes have been provided regionally, the sum of HSC Trust area figures may not match the total figure for Northern Ireland. In addition, there are some instances where data was unavailable but an estimate could be derived. Details of these can be found in the table below.

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.

Aware, who provided 69 programmes for 1,008 participants, were unable to provide figures broken down by HSC Trust area during 2013/14.

Cancer Focus, who provided 1 programme for 38 participants, were unable to provide figures broken down by HSC Trust area during 2013/14.

Cancer Focus, who provided 1 programme for 38 participants, were unable to provide figures broken down by HSC Trust area during 2014/15.

There were 10 programmes provided during 2014/15 for which the programme frequency was unavailable

due to the rolling and ongoing nature of the programmes. These include Cardiac Rehabilitation, Pulmonary Rehabilitation, CrISP and CrISP/DIP programmes run over multiple HSC Trust areas. Cancer Focus, who provided 1 programme for 40 participants, were unable to provide figures broken down by HSC Trust area during 2015/16.

There were 3 programmes provided during 2015/16 for which the programme frequency was unavailable due to the rolling and ongoing nature of the programmes. These include Cardiac Rehabilitation, Pain Management Programme and CrISP/DIP/CIP programmes run over multiple HSC Trust areas.

The Belfast HSC Trust were unable to provide programme frequency figures for their CHOICE and PUMPS programmes therefore an estimated figure has been used. The figure for CHOICE is derived from the average participants at CHOICE programmes provided by other HSC Trusts in 2016/17. The figure for PUMPS is derived from the average participants at diabetes type 1 programmes provided by other HSC Trusts in 2016/17. These averages are used to estimate the programme frequency based on the number of participants reported.

### Amendments

The cut-off point for amendments to data was 16th October 2017. 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 DoH can be found in the DoH Statistics Charter on our website.

### Revisions to Data

The Challenging Pain programme was reclassified as a Condition Specific, Chronic Pain programme in 2012/13. It was previously classified as a Generic programme.

There were 3 programmes with a frequency of 39 programmes and 356 participants removed from the 2013/14 figures as they have been subsequently deemed not to fall under the scope of the questionnaire. These were specifically the Anxiety Management, Mood Management and Self Esteem programmes.

The Aware programme, Living Life to the Full, has been reclassified as a Generic programme in 2014/15. It was previously classified as a Condition Specific, Mental Health programme.

### Main Uses of Data

Data presented in this publication helps to meet the information needs of the DoH. 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.

### Maps

A full explanation of the methodology used in the presentation of maps in this report can be made available on request from CIB.

### Contact

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### User Feedback

Any comments you have regarding this or any other publication produced by CIB are welcome. Your views help us to improve the service we provide to users of this information and to the wider public.

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

This data collection <u>IS</u> covering	This data collection <u>IS NOT</u> covering:	LTCs included in audit:
<ul> <li>Programmes for people with long term conditions.</li> <li>Programmes designed for: <ul> <li>Adults;</li> <li>Children/young people;</li> <li>Carers.</li> </ul> </li> <li>Both HSC Trust <u>and</u> Independent sector provided / funded programmes.</li> <li>Programmes that have a formal / structured approach and are time limited.</li> <li>Programme format either structured group format or on- line format.</li> </ul>	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. One-to-one reviews or appointments with health and social care professionals, e.g. GPs or other primary / community care professionals.	LTCs relating to physical health eg: Diabetes; Cardiac; COPD / respiratory; Stroke / dementia / neurological; Chronic Pain; Arthritis / other Musculoskeletal; Cancer. LTCs relating to mental health.

### Abbreviations

BERTIE	Bournemouth Type 1 Intensive Education
BHSCT	Belfast Health and Social Care Trust
BSO	Business Services Organisation
CHOICE	Carbohydrate Insulin Collaborative Education
COPD	Chronic Obstructive Pulmonary Disease
CrISP	Carer Information and Support Programme

DIP	Dementia Information Programme
DM	Diabetes Mellitus
DAFNE	Dose Adjustment for Normal Eating
DAY	Diabetes And You
DESMOND	Diabetes Education & Self Management of Ongoing and Newly Diagnosed
DoH	Department of Health
HOPE	Help to Overcome Problems Effectively
IBD	Inflammatory Bowel Disease
NHSCT	Northern Health and Social Care Trust
PUMPS	Insulin Pump Education Programme
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

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https://www.health-ni.gov.uk/topics/dhssps-statistics-and-research-social-services/socialcare-statistics

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