



# Patient Education / Self Management Programmes for People with Long Term Conditions (2018/19)



# Reader Information

Theme Social Care – Patient Education / Self Management

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research/patient-education-programmes

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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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 Code of Practice for Official Statistics.

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.

#### **Our Vision and Values**

## **About Community Information Branch**

- 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.

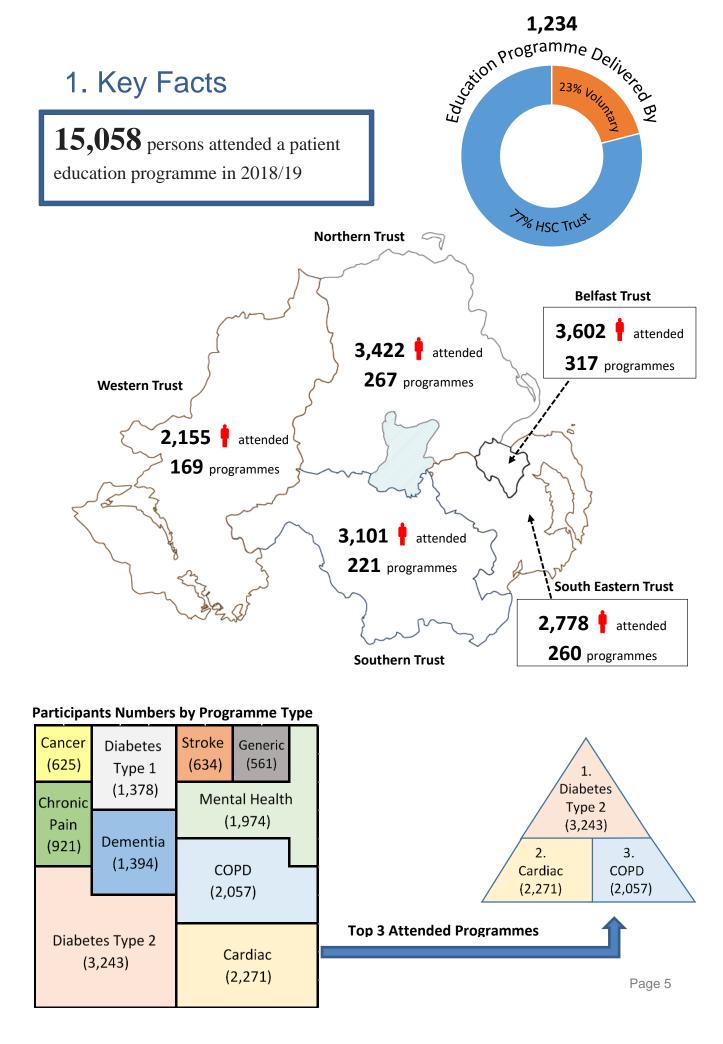
The purpose of Community Information Branch (CIB) is to promote effective decision making in children and adult social services by providing quality information and analysis.

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.

# Contents

1.	Key Facts	5
2.	Programmes	6
3.	Conditions	8
4.	Participants	.10
Dia	abetes	.14
CC	OPD	.16
5.	Tables	18
	Table 1. Programme Frequency by HSC Trust Area (2014/15-2018/19)	18
	Table 2. Programme Frequency by Programme Type and HSC Trust Area (2018/19)	19
	Table 3. Frequency of Programmes by Type HSC Trust Area (2014/15-2018/19)	20
	Table 4. Programme Frequency by Provider Organisation (2018/19)	21
	Table 5. Participants Numbers by HSC Trust Area (2014/15-2018/19)	22
	Table 6. Participants Numbers by Programme Type and HSC Trust Area (2018/19)	23
	Table 7. Annual Change in participant Numbers by Provider Organisation (2014/15-2018/19)	24
	Table 8. Participants Numbers by Provider Organisation (2014/15-2018/19)	25
	Table 9. Participants Numbers by Programme Type and Programme Delivery (2018/19)	26
	Table 10. Participants Numbers by Programme Type and Funding Arrangements (2018/19)	27
Αp	ppendix A. Background	28
۸n	pondiy B. Tachnical Notes	20



# 2. Programmes

In 2018/19 there were 40 different patient education / self management programmes in place across Northern Ireland. These programmes ran a total of 1,234 times throughout the year ranging from 317 in the Belfast HSC Trust area to 169 in the Western HSC Trust area (Figure 1).

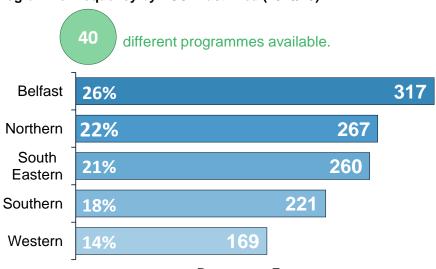


Figure 1. Programme Frequency by HSC Trust Area (2018/19)

Programme Frequency

Since 2014/15, the frequency of programmes regionally has risen by 44%, reflecting an increase across all HSC Trust areas. In the main, programme frequency by HSC Trust area was similar in 2017/18\* to 2018/19 (Figure 2) (Table 1). Please note that ongoing refinement and validation of data in this area may account for some of the annual change.

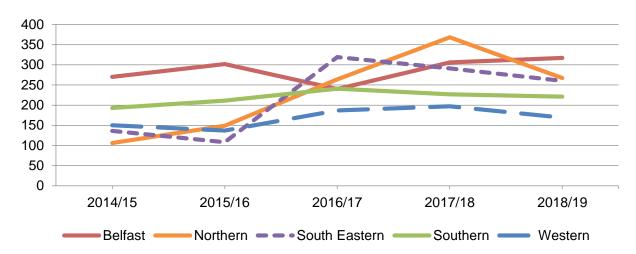


Figure 2. Programme Frequency by HSC Trust Area (2014/15 - 2018/19)\*

<sup>\*</sup> Due to ongoing data validation, figures from 2017/18 have been revised. Further information can be found in the Data Presentation section of Appendix B.

During 2018/19, of the 1,234 times that programmes ran, 96% were condition specific and 4% were generic. Similar to 2017/18\*, the most frequent programme in 2018/19 was diabetes type 2 (401), accounting for approximately 3 in 10 (32%) of all programmes ran (Figure 3) (Table 2).

Figure 3. Programme Frequency by Programme Type (2018/19)

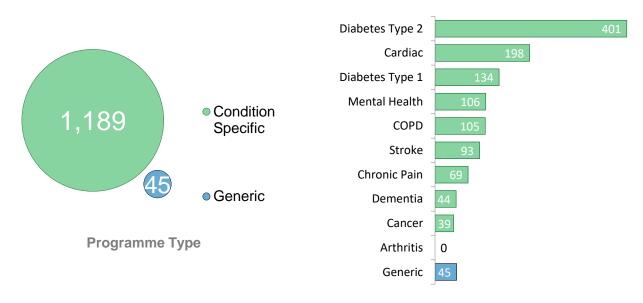
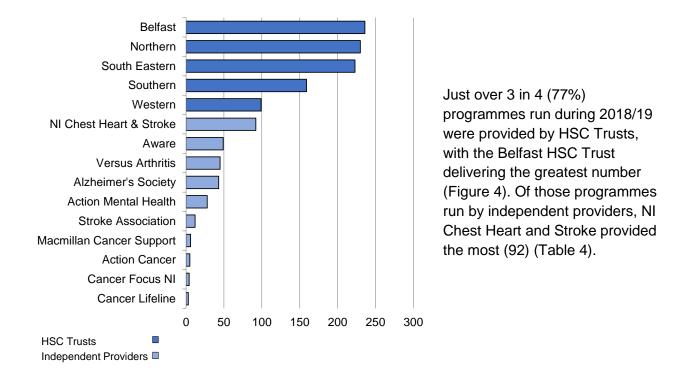


Figure 4. Programme Frequency by Provider Organisation (2018/19)

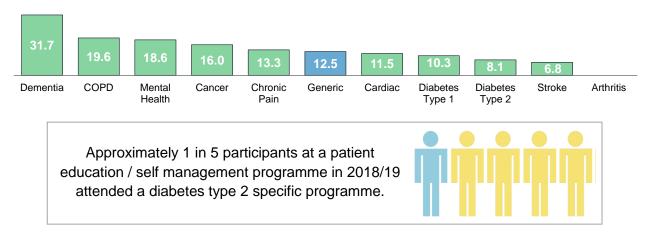


<sup>\*</sup> Due to ongoing data validation, figures from 2017/18 have been revised. Further information can be found in the Data Presentation section of <a href="Appendix B">Appendix B</a>.

# 3. Conditions

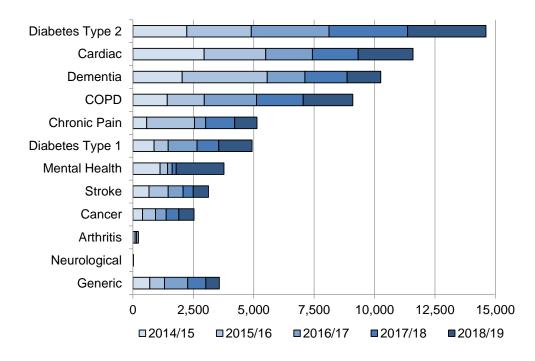
The average number of participants per programme, by condition, ranged from just under 32, for those attending Dementia programmes, to just under 7 for stroke programmes (Figure 5). A reason for the extremely high attendance rate for Alzheimer's Society is the fact that some of the programmes are open to the public, resulting in very high attendance. The overall regional average number of participants per programme was 12.2.

Figure 5. Average Number of Participants per Programme by Condition (2018/19)



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 (2014/15 – 2018/19)\*



<sup>\*</sup> Due to ongoing data validation, figures from 2017/18 have been revised. Further information can be found in the Data Presentation section of <a href="Appendix B">Appendix B</a>.

From 2014/15, the number of annual participants at chronic condition education programmes has risen. Across the years, consistent increases have been observed for diabetes, and cancer-related programmes (Figure 7), with approximately twice as many attending diabetes (49%) and cancer (56%) programmes in 2018/19 compared 2014/15. The work of the regional diabetes network to develop and promote the diabetes education programme portfolio may be a factor in increasing attendance at diabetes programmes.

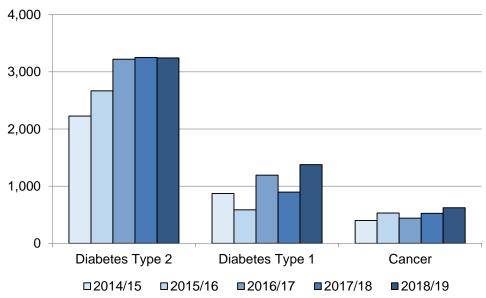


Figure 7. Number of Participants by Condition (2014/15 - 2018/19)\*

Since 2014/15, the number of participants attending generic education programmes has decreased (-19%), in favour of condition specific programmes (Figure 8) (Table 7). Likely reasons for this may include greater derived benefit from tailored educational programmes.

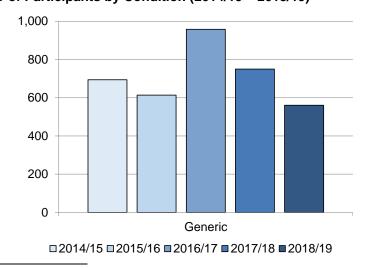


Figure 8. Number of Participants by Condition (2014/15 - 2018/19)\*

<sup>\*</sup> Due to ongoing data validation, figures from 2017/18 have been revised. Further information can be found in the Data Presentation section of <a href="Appendix B">Appendix B</a>. Ongoing data validation highlights the need to view early year's data with care, as the return was still in development, and organisations may have partially submitted/ not submitted, and/or variance in interpretation when completing questionnaire.

# 4. Participants

## Participants by HSC Trust Area

In 2018/19, 15,058 participants attended a patient education / self management programme ranging from 3,602 in the Belfast HSC Trust area to 2,155 in the Western HSC Trust area (Figure 9) (Table 5). While participant numbers increased by 18% (2,261) compared to 2017/18\*, this can be mainly attributed to improved representational reporting, with returns received from organisations who had previously failed to submit.

15,058 participants at programmes. **Belfast** 24% 3,602 3,422 Northern 23% 21% 3,101 Southern Approximately 1 in 4 of all participants South 18% 2,778 attended a programme in the Belfast Eastern HSC Trust area. Western **Participants** 

Figure 9. Participant Numbers by HSC Trust Area (2018/19)

Since 2014/15, overall participant numbers at patient education / self management programmes have increased by 16% (1,989) (Figure 10) (Table 5). Some fluctuation in participant numbers since 2016/17 can be attributed to the reporting lag/data validation in capturing the spectrum of emerging educational programmes.

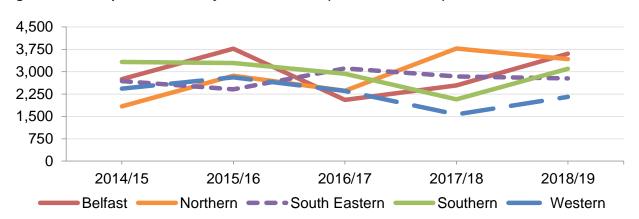


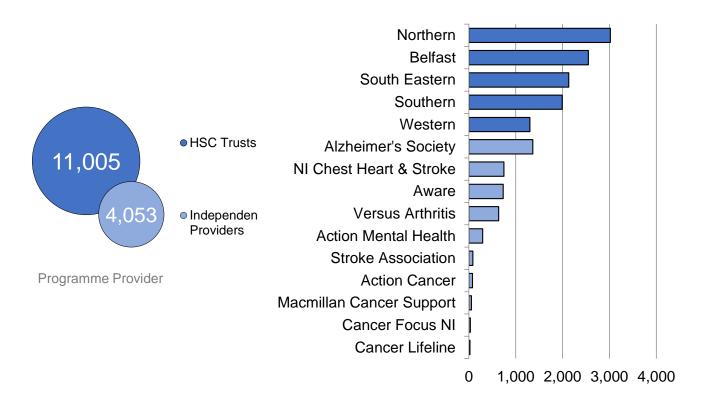
Figure 10. Participant Numbers by HSC Trust Area (2014/15 - 2018/19)\*

<sup>\*</sup> Due to ongoing data validation, figures from 2017/18 have been revised. Further information can be found in the Data Presentation section of Appendix B.

Of the 15,058 participants, 73% were attending a programme delivered by HSC Trusts and 27% a programme by independent sector organisations. In 2018/19, participant numbers at programmes provided by HSC Trusts (11,005) showed a 19% (1,793) increase over the number of participants in 2017/18\* (9,212).

While the Alzheimer's Society had the greatest number of participants (1,364), of all the independent sector providers, and 9% of the total regional participant numbers (Figure 11) (Table 8)\*, it should be noted that some of their programmes are open to the public, resulting in very high attendance at single events. Some fluctuation in participant numbers since 2016/17 can be attributed to the reporting lag/data validation in capturing the spectrum of emerging educational programmes.





<sup>\*</sup> Due to ongoing data validation, figures from 2017/18 have been revised. Further information can be found in the Data Presentation section of <a href="Appendix B">Appendix B</a>.

Of the 15,058 participants at programmes, 96% were attending a condition specific programme with 4% attending a generic programme. Figure 12 shows that the majority of participants (22%) attended a programme related to diabetes type 2; followed by cardiac (15%). Fluctuation in participant numbers most likely can be attributed to the reporting lag/data validation in capturing the spectrum of emerging educational programmes.

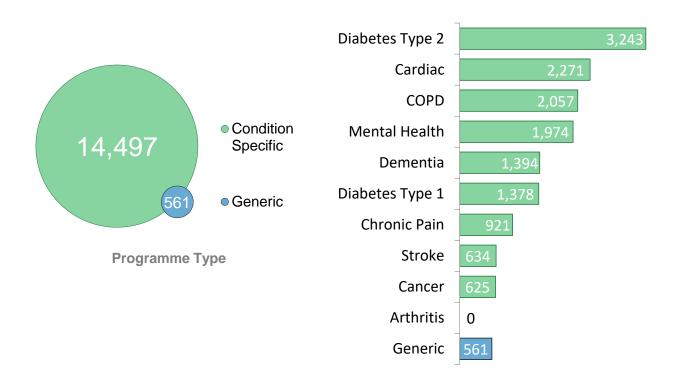


Figure 12. Participant Numbers by Programme Type (2018/19)

The top 6 conditions, by participant numbers, had programmes available across all 5 HSC Trust areas with one exception. There were no cardiac specific programmes reported in the Western HSC Trust area; however Northern Ireland Chest Heart and Stroke (NICHS) provided the generic 'Taking Control' programme in this area during 2018/19 (Table 6). The number of participants at a condition specific programme has increased by 17% (2,122) since 2014/15 (Table 7).

In 2018/19, 83% (12,500) of participants attended a programme that was either clinically or professionally led; this was greater than the proportion in 2017/18\* (79%). Participants at jointly led programmes accounted for 11% (1,625) of the total, with the remaining 6% (933) of participants attending a programme that was peer led.

Of the participants at clinically or professionally led programmes in 2018/19, over 99% (12,489) were attending a condition specific programme. 88% (1,424) of those at a jointly led programme and 63% (584) at a peer led programme (Table 9) were attending condition specific programmes.

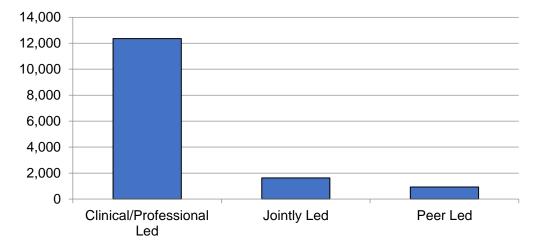


Figure 13. Number of Participants by Programme Delivery (2018/19)

In 2018/19, 67% (10,036) of participants attended a programme that was statutory funded, a decrease of 7% (724) since the previous year\*. Jointly funded programmes were provided for 23% of participants; with 2% of participants each attending voluntary funded programmes and 9% at programmes utilising other funding arrangements<sup>1</sup> (Table 10).

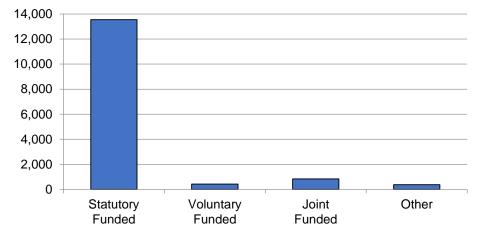


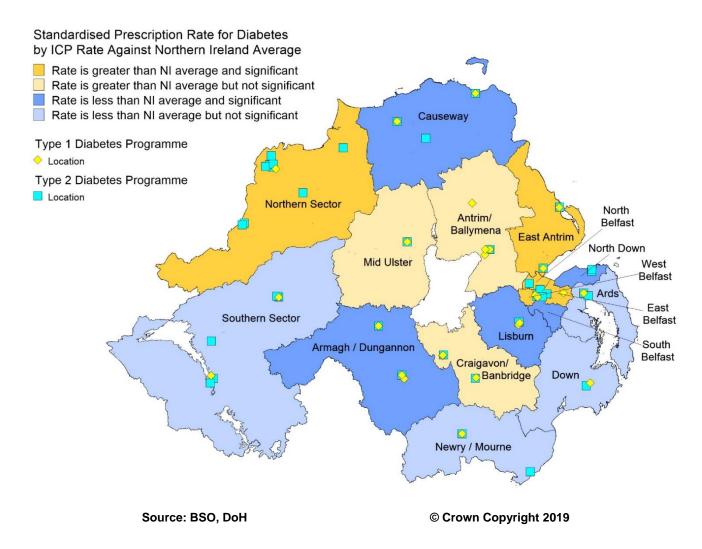
Figure 14. Number of Participants by Funding Arrangement (2018/19)<sup>1</sup>

<sup>\*</sup> Due to ongoing data validation, figures from 2017/18 have been revised. Further information can be found in the Data Presentation section of Appendix B.

<sup>&</sup>lt;sup>1</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 2018 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 (Armagh/Dungannon) where the SPR was less than the Northern Ireland average, but not significant in 2017/18, this now has a SPR that is less than the average and is a significant finding.

Diabetes Programme (miles) Up to 3 3 to 5 5 to 10 Northern Trust 10 to 25 Type 1 Diabetes Programme Location Type 2 Diabetes Programme Location **Belfast Trust** Western Trust South Eastern Trust Southern Trust

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 2018/19 and their proximity to census output population areas in Northern Ireland. More than half (56%) of the population in Northern Ireland lived within 3 miles of a diabetes programme. Approximately 1 in 12 (8%) 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 2018/19 were located in similar locations as in the previous year. However, there was greater provision of Type 2 programmes in the South Eastern HSC Trust, with two new Type 2 programmes running in Downpatrick, Newtownards and Lisburn. There was one less Type 1 programme which ran in the West of the Belfast HSC Trust, compared to previous years, which may be a consequence of partially submitted returns\*.

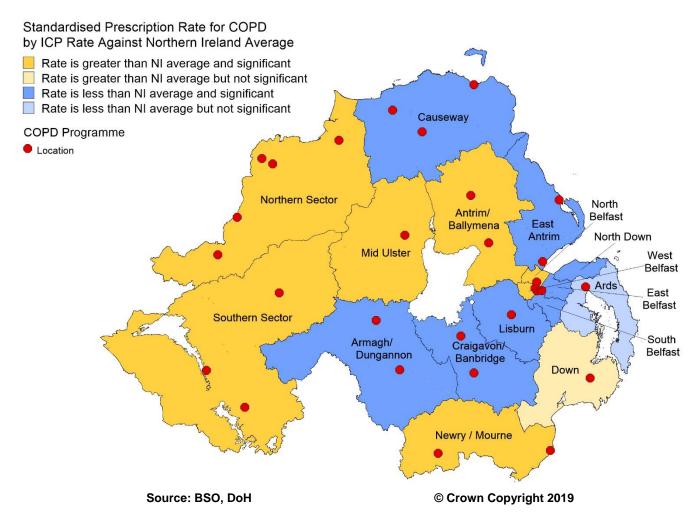
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Source: DoH

<sup>\*</sup> Further information can be found in the Maps section of Appendix B.

## **COPD**

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



Please Note, the above calculated 2018 SPR are not comparable with previously reported SPR rates in the Patient Education Programme Publication series, due to a break in methodology.

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. The Down ICP area had a higher rate, and the Ards ICP are had a lower rate, both of which were not significant when compared to the regional average.

The North Down (SPR less than the NI average) ICP area had no provision for a COPD specific programme during 2018/19. East Belfast ICP area (SPR significantly less than the NI average) had no provision for a COPD specific programme during 2018/19. This differs from previous programme location data, where West Belfast was not recorded as providing a COPD specific programme, however this may be a consequence of partially submitted returns\*. Figure 18 overleaf provides more information on the access to programmes.

<sup>\*</sup> Further information can be found in the Maps section of Appendix B.

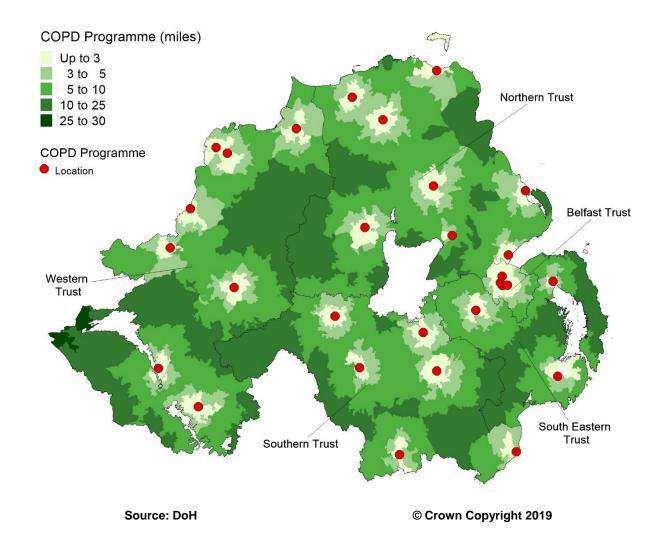


Figure 18. Proximity of Census Output Areas to COPD Programmes

Figure 18 illustrates the locations of programmes for COPD that ran during 2018/19 and their proximity to census output population areas. Approximately 45% of the population in Northern Ireland lived within 3 miles of a COPD programme in 2018/19 with approximately 1 in 1000 persons located more than 25 miles away from a programme. With no programme located in the North Down or East Belfast ICP areas (Figure 17), the map above, in conjunction with Figure 17, shows how the majority of these ICP areas are located no more than 10 miles from a COPD programme.

COPD programmes during 2018/19 were located in similar locations as in 2017. An additional programme was provided in Northern Trust, around Ballymena. Provision in the Belfast Trust\* increased from 1 to 2 programmes in both the North and South of the Trust, while one programme moved from the East, to the West of the Trust. However, please note differing programme location data may be a consequence of previous partially submitted Belfast returns.

<sup>\*</sup> Further information can be found in the Maps section of Appendix B.

# 5. Tables

Table 1. Programme Frequency by HSC Trust Area (2014/15 - 2018/19)\*^

	Programme Frequency						
HSC Trust Area	2014/15	2015/16	2016/17	2017/18	2018/19		
Belfast	270	302	240	306	317		
Northern	106	149	264	368	267		
South Eastern	136	108	319	291	260		
Southern	193	211	241	227	221		
Western	150	137	187	197	169		
Total	856	908	1,251	1,389	1,234		

<sup>\*</sup> Due to ongoing data validation, figures from 2016/17 and 2017/18 have been revised. Further information can be found in the Data Presentation section of Appendix B

<sup>^</sup> 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. Further information can be found in the Data Presentation section of Appendix B.

Table 2. Programme Frequency by Programme Type and HSC Trust Area (2018/19)

	HSC Trust Area					
Programme Type	Belfast	Northern	South Eastern	Southern	Western	Total
Condition Specific	312	267	257	206	147	1,189
Arthritis	ı	-	1	ı	-	-
Cancer	19	12	ı	4	4	39
Cardiac	28	39	124	7	-	198
Chronic Pain	15	23	12	10	9	69
COPD	32	29	15	9	20	105
Dementia	22	9	4	6	3	44
Diabetes Type 1	24	22	27	25	36	134
Diabetes Type 2	140	91	54	73	43	401
Mental Health	20	24	3	45	14	106
Stroke	12	18	18	27	18	93
Generic	5	-	3	15	22	45
Total	317	267	260	221	169	1,234

Table 3. Frequency of Programmes by Type and HSC Trust Area (2014/15 - 2018/19)\*^

	2014/15		2015/16		2016/17		2017/18		2018/19	
HSC Trust Area	Condition Specific	Generic	Condition Specific	Generic						
Belfast	263	7	295	7	234	6	298	8	312	5
Northern	103	3	149	0	264	0	361	7	267	0
South Eastern	127	9	100	8	276	43	288	3	257	3
Southern	180	13	199	12	228	13	200	27	206	15
Western	125	25	110	27	161	26	171	26	147	22
Total	799	57	854	54	1,163	88	1,318	71	1,189	45

<sup>\*</sup> Due to ongoing data validation, figures from 2016/17 and 2017/18 have been revised. Further information can be found in the Data Presentation section of Appendix B.

<sup>^</sup> 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. Further information can be found in the Data Presentation section of Appendix B.

Table 4. Programme Frequency by Provider Organisation (2018/19)\*

Provider Organisation	2018/19
Action Cancer	5
Action Mental Health	28
Alzheimer's Society	43
Aware	49
Cancer Focus NI	4
Cancer Lifeline	3
Macmillan Cancer Support	6
NI Chest Heart & Stroke	92
Stroke Association	12
Versus Arthritis*	45
BHSCT	236
NHSCT	230
SEHSCT	223
SHSCT	159
WHSCT	99
Total	1,234

<sup>\*</sup> Versus Arthritis was formerly known as Arthritis Care

Table 5. Participant Numbers by HSC Trust Area (2014/15 - 2018/19)\*^

	Participants Participants						
<b>HSC Trust Area</b>	2014/15	2015/16	2016/17	2017/18	2018/19		
Belfast	2,751	3,773	2,056	2,541	3,602		
Northern	1,838	2,865	2,359	3,778	3,422		
South Eastern	2,683	2,410	3,110	2,842	2,778		
Southern	3,327	3,295	2,933	2,070	3,101		
Western	2,432	2,809	2,353	1,566	2,155		
Total	13,069	15,192	12,811	12,797	15,058		

<sup>\*</sup> Due to ongoing data validation, figures from 2016/17 and 2017/18 have been revised. Further information can be found in the Data Presentation section of Appendix B.

<sup>^</sup> 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. Further information can be found in the Data Presentation section of Appendix B.

Table 6. Participant Numbers by Programme Type and HSC Trust Area (2018/19)

	HSC Trust Area					
Programme Type	Belfast	Northern	South Eastern	Southern	Western	Total
Condition Specific	3,517	3,422	2,767	2,887	1,904	14,497
Arthritis	-	1	1	1	-	-
Cancer	382	155	ı	43	45	625
Cardiac	443	667	1,031	130	-	2,271
Chronic Pain	202	279	211	130	99	921
COPD	712	407	392	193	353	2,057
Dementia	300	183	250	555	106	1,394
Diabetes Type 1	255	197	247	141	538	1,378
Diabetes Type 2	827	982	453	567	414	3,243
Mental Health	300	437	45	982	210	1,974
Stroke	96	115	138	146	139	634
Generic	85	-	11	214	251	561
Total	3,602	3,422	2,778	3,101	2,155	15,058

Table 7. Participant Numbers by Condition (2014/15 – 2018/19)\*,1

Provider Organisation	2014/15	2015/16	2016/17	2017/18	2018/19
Condition Specific	12,375	14,578	11,853	12,047	14,497
Arthritis	87	56	83	-	-
Cancer	400	531	443	526	625
Cardiac	2,950	2,548	1,929	1,894	2,271
Chronic Pain	567	1,977	466	1,204	921
COPD	1,423	1,530	2,160	1,934	2,057
Dementia	2,038	3,522	1,555	1,752	1,394
Diabetes Type 1	873	587	1,194	898	1,378
Diabetes Type 2	2,228	2,668	3,223	3,252	3,243
IBD	-	36	-	-	-
Lymphoedema	6	6	-	-	-
Mental Health	1,123	314	188	168	1,974
Neurological	14	7	-	-	-
Stroke	666	796	612	419	634
Generic	694	614	958	750	561
Total	13,069	15,192	12,811	12,797	15,058

<sup>\*</sup> Due to ongoing data validation, figures from 2016/17 and 2017/18 have been revised. Further information can be found in the Data Presentation section of <a href="https://example.com/AppendixB">Appendix B</a>.

<sup>&</sup>lt;sup>1</sup> Data for Mental Health programmes for all years are provisional due to ongoing data quality work.

Table 8. Participant Numbers by Provider Organisation (2014/15 – 2018/19)\*, 2

Provider Organisation	2014/15	2015/16	2016/17	2017/18	2018/19
Action Cancer	62	67	60	77	80
Action Mental Health	278	260	217	185	296
Alzheimer's Society	2,026	3,469	1,422	1,752	1,364
Aware	1,123	1	1	1	735
Cancer Focus NI	96	69	85	96	30
Cancer Lifeline	64	68	49	38	22
Macmillan Cancer Support	130	254	30	41	54
NI Chest Heart & Stroke	532	452	519	639	750
Stroke Association	324	478	258	53	85
Versus Arthritis <sup>2</sup>	540	468	357	704	637
BHSCT	1,824	2,866	1,775	1,726	2,552
NHSCT	997	1,967	2,087	2,919	3,021
SEHSCT	1,953	1,629	2,862	2,331	2,134
SHSCT	1,969	1,850	1,795	1,447	1,993
WHSCT	1,151	1,295	1,295	789	1,305
Total	13,069	15,192	12,811	12,797	15,058

<sup>\*</sup> Due to ongoing data validation, figures from 2016/17 and 2017/18 have been revised. Further information can be found in the Data Presentation section of Appendix B.

Table 9. Participant Numbers by Programme Type and Programme Delivery (2018/19)

Programme Type	Clinical / Professional Led	Peer Led	Jointly Led	Total
Condition Specific	12,489	584	1,424	14,497
Arthritis	-	-	-	-
Cancer	571	-	54	625
Cardiac	2,271	-	-	2,271
Chronic Pain	337	584	-	921
COPD	1,704	-	353	2,057
Dementia	1,394	-	-	1,394
Diabetes Type 1	1,378	-	-	1,378
Diabetes Type 2	3,051	-	192	3,243
Mental Health	1,698	-	276	1,974
Stroke	85	-	549	634
Generic	11	349	201	561
Total	12,500	933	1,625	15,058

Table 10. Participant Numbers by Programme Type and Funding Arrangements (2018/19)\*

Programme Type	Statutory Funded	Voluntary Funded	Joint Funded	Other*	Total
Condition Specific	9,614	108	3,453	1,322	14,497
Arthritis	-	-	i	•	-
Cancer	479	108	38	-	625
Cardiac	2,271	-	-	-	2,271
Chronic Pain	921	-	-	-	921
COPD	1,704	-	-	353	2,057
Dementia	330	-	1,064	-	1,394
Diabetes Type 1	1,196	-	-	182	1,378
Diabetes Type 2	1,874	-	982	387	3,243
Mental Health	839	-	735	400	1,974
Stroke		-	634	-	634
Generic	422	139	-	-	561
Total	10,036	247	3,453	1,322	15,058

<sup>\*</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 2018 to 31 March 2019.

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>4</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 "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.

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 2018/19. Information was provided by HSC Trusts and independent sector organisations who delivered programmes during 2018/19. The report summarises the key statistical information provided for the year 2018/19 and how this compares with that collected in previous years.

<sup>&</sup>lt;sup>4</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 2019 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 collection guidance notes along with a copy of the questionnaire.

## **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 2014/15 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 re-submitted. 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 2018/19 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.

During 2012/13-2013/14 Aware were unable to provide figures broken down by HSC Trust area. Aware did not provide figures for 2015/16-2017/18.

During 2014/15 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 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.

Data for Mental Health programmes in 2014/15 has been revised to reflect Aware – 'Living Life to the Full' programmes which ran in each of the 5 HSC Trusts, e.g. 25 courses ran in Belfast HSC Trust with 325

participants, 10 courses ran in Northern HSC Trust with 135 participants, 17 courses ran in South Eastern HSC Trust with 221 participants, 12 courses ran in Southern HSC Trust with 156 participants, and 22 courses ran in Northern HSC Trust with 286 participants.

During 2015/16 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 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.

For 2016/17 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. 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.

In 2016/17 Alzheimer's Society did not provide information for programmes that ran in the Belfast, Northern and South Eastern HSC Trusts. Programmes in these areas accounted for approximately 1,300 participants during 2015/16. In 2017/18, programmes in these areas accounted for approximately 1,243 participants.

In the 2017/18 publication, Action Mental Health's figures for the 'Managing the Challenge' programme were reflected in the WHSCT figures. In the 2018/19 publication this activity was revised to show that 185 participants, attending 23 programme, were delivered by Action Mental Health.

For 2017/18 the Belfast HSC Trust did not provide programme frequency figures, therefore their data has been imputed based on 2016/17. Data estimates for Belfast Trust in 2016/17 are noted above.

In the 2018/19 publication, data pertaining to 'Talking Therapies' and 'Recovery by Discovery' programmes, in BHSCT and SHSCT, respectively, for 2016/17 and 2017/18 were removed from trend analysis. This was a result of further learning on how the programmes were delivered, leading to revised evaluation against the criteria outlined in the questionnaire.

In the revised 2018/19 publication, all activity delivered by Action Mental Health, which had been previously reflected within Western HSC Trust activity, is reported separately.

#### **Amendments**

The cut-off point for amendments to data was 30th July 2019. 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.

#### **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

## Standardised Prescription Rate (SPR)

A full explanation of the methodology used in the presentation of maps in this report can be made available on request from CIB. BNF codes are used to categorise medicinal items against particular conditions. Following review, BSO have changed how they record some BNF codes, resulting in a different subset of codes being employed to underpin the COPD Standardised Prescription Rate (SPR) in 2017/18, compared to 2018/19. Consequently the 2018/19 SPR is not comparable with the COPD SPR from previous publication cycles due to this break in methodology.

## **Location Points**

Due to partial and non- submissions, by BHSCT, in 2016/17 and 2017/18, respectively, it cannot be validated if these locations points were still in use as COPD and diabetes education programme venues prior to 2018/19.

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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	This data collection	LTCs included in audit:
<u>IS</u> covering	IS NOT covering:	
Programmes for people with	Any kind of "Support	LTCs relating to physical
long term conditions.	groups" for either physical	health eg:
Programmes designed for:	or mental health long term conditions. By 'support	Diabetes;
<ul><li>Adults;</li></ul>	groups' we mean informal,	Cardiac;
<ul><li>Children/young people;</li><li>Carers.</li></ul>	unstructured groups with no time limit.	COPD / respiratory;
Both HSC Trust <u>and</u> Independent sector provided /	One-to-one reviews or appointments with health	<ul> <li>Stroke / dementia / neurological;</li> </ul>
funded programmes.	and social care	Chronic Pain;
	professionals, e.g. GPs or	

Programmes that have a formal / structured approach and are	other primary / community care professionals.	Arthritis / other     Musculoskeletal;
time limited.		Cancer.
Programme format either structured group format or on-		LTCs relating to mental health.
line format.		

## **Abbreviations**

BERTIE	Bournemouth Type 1 Intensive Education
BHSCT	Belfast Health and Social Care Trust
BNF	British National Formulary
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

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

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

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