

INFORMATION  
ANALYSIS  
DIRECTORATE



# Patient Education / Self Management Programmes for People with Long Term Conditions (2019/20)



Department of  
**Health**

An Roinn Sláinte

Mánnystrie O Poustie

[www.health-ni.gov.uk](http://www.health-ni.gov.uk)

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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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# About Us



Statistics and research for the **Department of Health** is provided by the Information and Analysis Directorate (IAD). IAD is responsible for compiling, processing, analysing, interpreting and disseminating a wide range of statistics covering health and social care.



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/doh-statistics-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**

- *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.*

## **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.

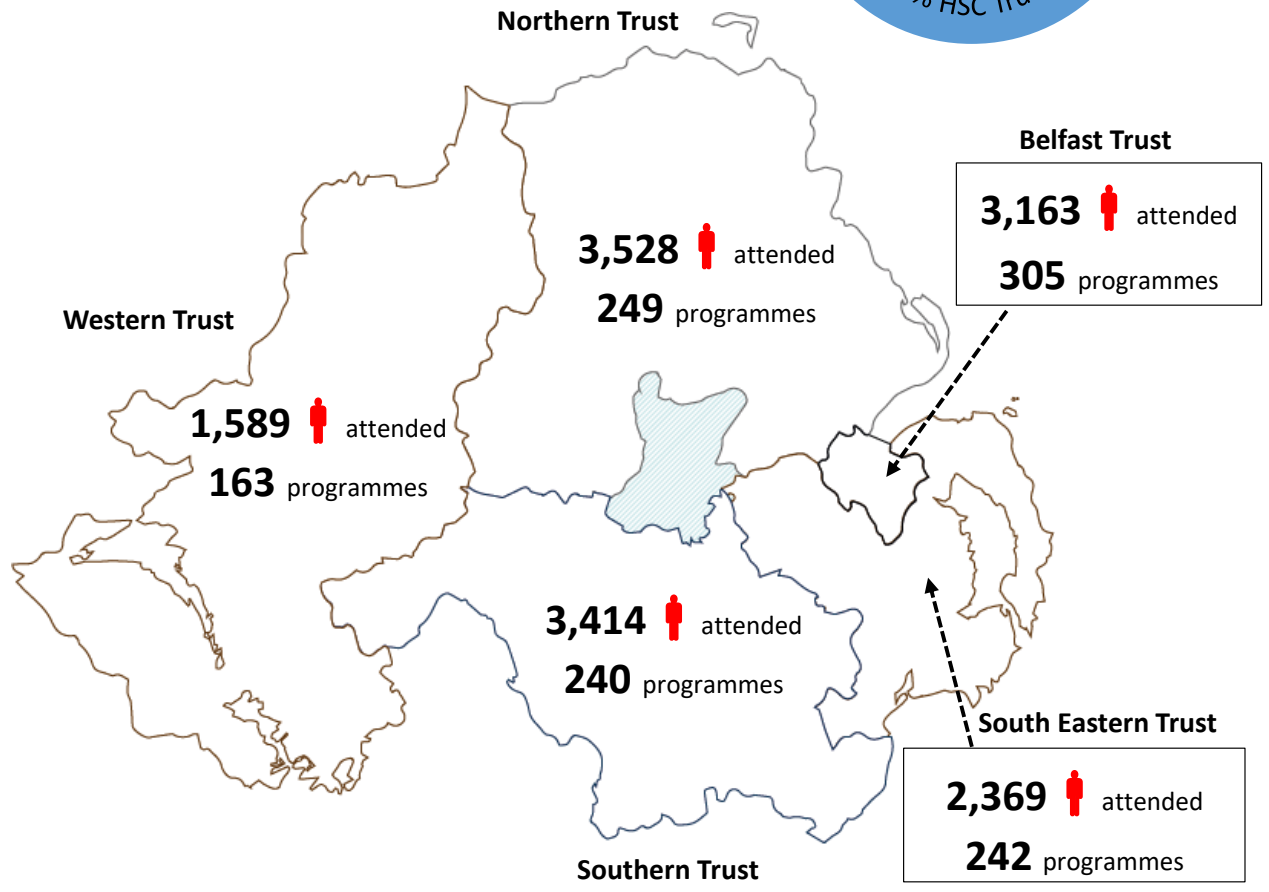
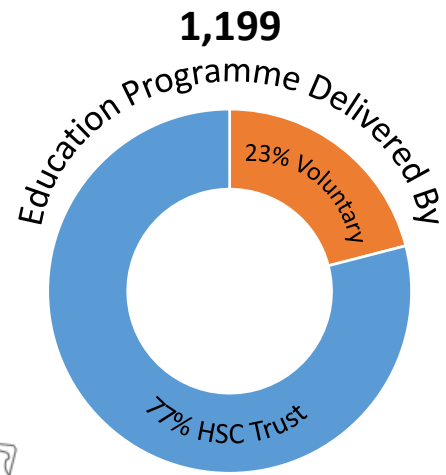
Information is widely disseminated through a number of regular key statistical publications and ad hoc reports, details of which are available online.

# Contents

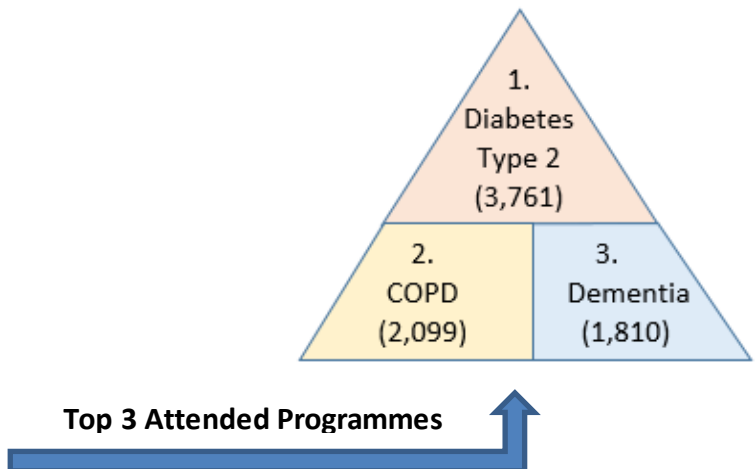
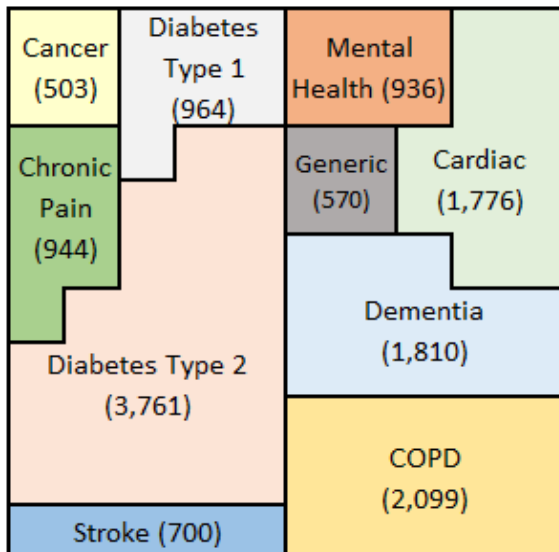
<b>1. Key Facts.....</b>	<b>5</b>
<b>2. Programmes.....</b>	<b>6</b>
<b>3. Conditions.....</b>	<b>8</b>
<b>4. Participants.....</b>	<b>10</b>
<b>5. Diabetes.....</b>	<b>14</b>
<b>6. COPD.....</b>	<b>16</b>
<b>7. Tables.....</b>	<b>18</b>
Table 1. Programme Frequency by HSC Trust Area (2015/16-2019/20).....	18
Table 2. Programme Frequency by Programme Type and HSC Trust Area (2019/20).....	19
Table 3. Frequency of Programmes by Type HSC Trust Area (2015/16-2019/20).....	20
Table 4. Programme Frequency by Provider Organisation (2019/20).....	21
Table 5. Participants Numbers by HSC Trust Area (2015/16-2019/20).....	22
Table 6. Participants Numbers by Programme Type and HSC Trust Area (2019/20).....	23
Table 7. Annual Change in participant Numbers by Provider Organisation (2015/16-2019/20)....	24
Table 8. Participants Numbers by Provider Organisation (2015/16-2019/20).....	25
Table 9. Participants Numbers by Programme Type and Programme Delivery (2019/20).....	26
Table 10. Participants Numbers by Programme Type and Funding Arrangements (2019/20).....	27
<b>Appendix A. Background.....</b>	<b>28</b>
<b>Appendix B. Technical Notes .....</b>	<b>29</b>

# 1. Key Facts

**14,063** persons attended a patient education programme in 2019/20



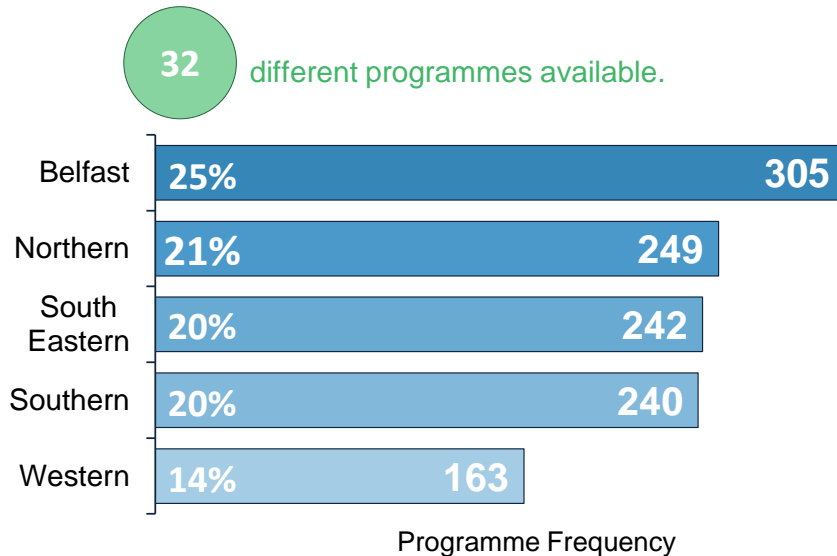
## Participants Numbers by Programme Type



## 2. Programmes

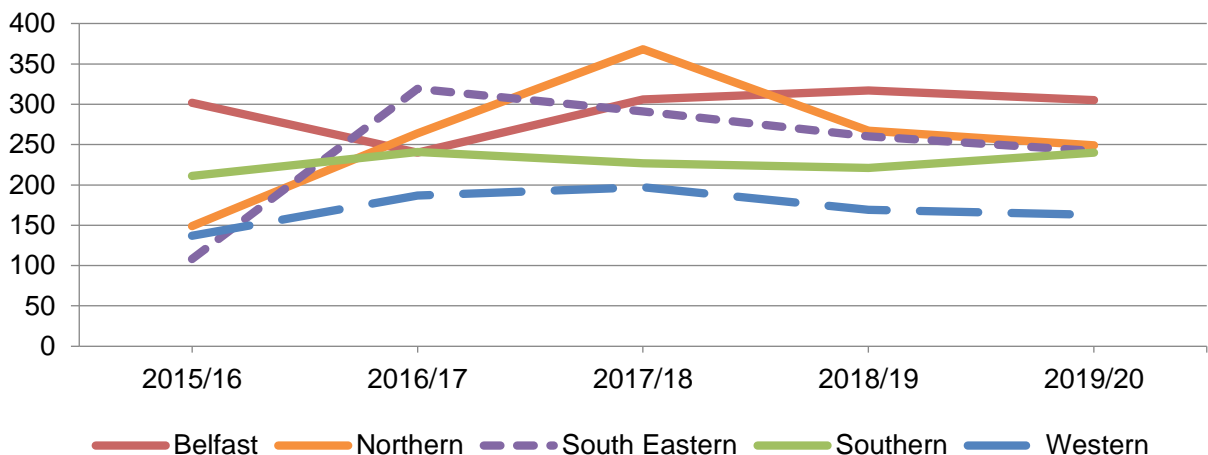
In 2019/20 there were 32 different patient education / self management programmes in place across Northern Ireland. These programmes ran a total of 1,199 times throughout the year ranging from 305 in the Belfast HSC Trust area to 163 in the Western HSC Trust area (Figure 1).

**Figure 1. Programme Frequency by HSC Trust Area (2019/20)\***



Since 2015/16, the frequency of programmes regionally has risen by 32%, reflecting an increase across all HSC Trust areas. Please note that ongoing refinement and validation of data in this area may account for some of the annual change. In the main, programme frequency by HSC Trust area was similar in 2018/19 to 2019/20 (Figure 2) (Table 1).

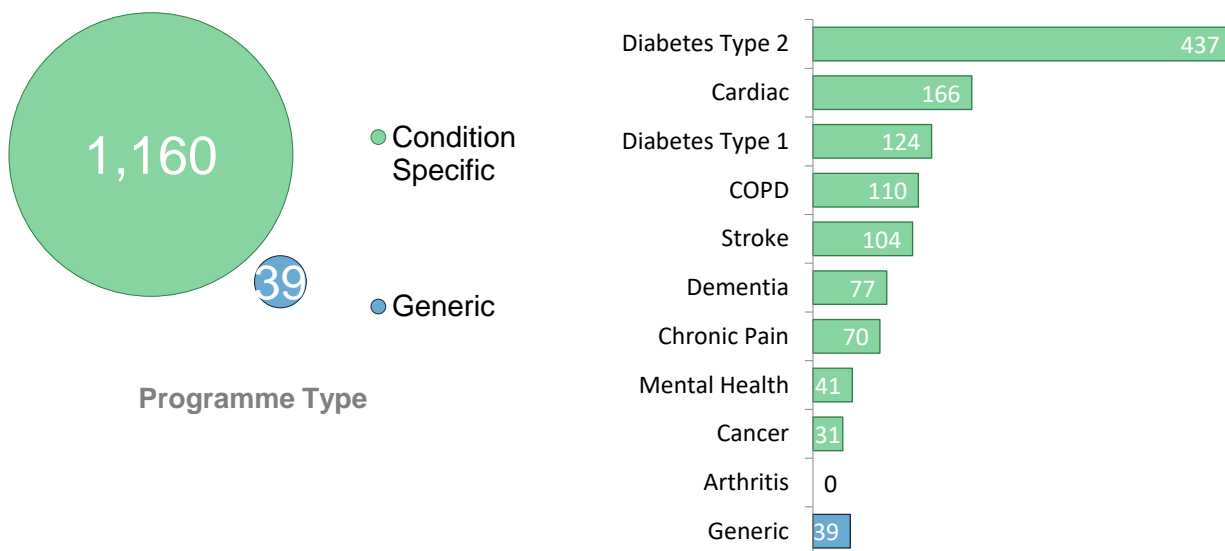
**Figure 2. Programme Frequency by HSC Trust Area (2015/16 – 2019/20)**



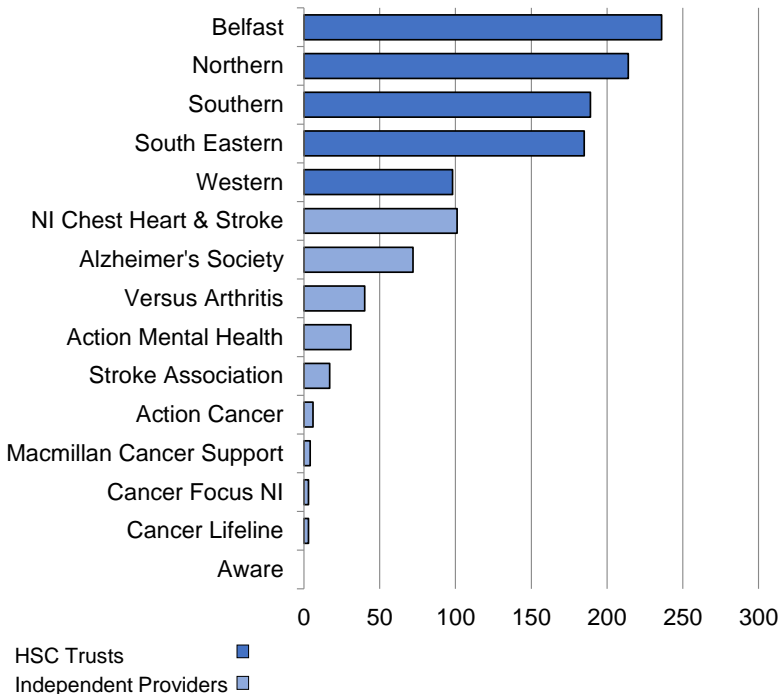
\* Data should be interpreted with care due to impact of COVID pandemic, please see Technical Guidance for detail.

During 2019/20, of the 1,199 times that programmes ran, 97% were condition specific and 3% were generic. Similar to 2018/19, the most frequent programme in 2019/20 was diabetes type 2 (437), accounting for more than a third (36%) of all programmes run (Figure 3) (Table 2).

**Figure 3. Programme Frequency by Programme Type (2019/20)**



**Figure 4. Programme Frequency by Provider Organisation (2019/20)\***



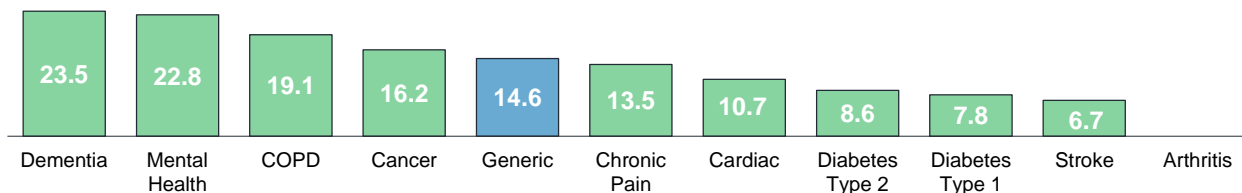
Just over 3 in 4 (77%) programmes run during 2019/20 were provided by HSC Trusts (Figure 4). Of those programmes run by independent providers, NI Chest Heart and Stroke provided the most (101) (Table 4).

\* Data should be interpreted with care due to impact of COVID pandemic, please see Technical Guidance for detail.

### 3. Conditions

The average number of participants per programme, by condition, ranged from just under 24, 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 public facing, with multiple members of the same family attending, resulting in high attendance. The overall regional average number of participants per programme was 11.7.

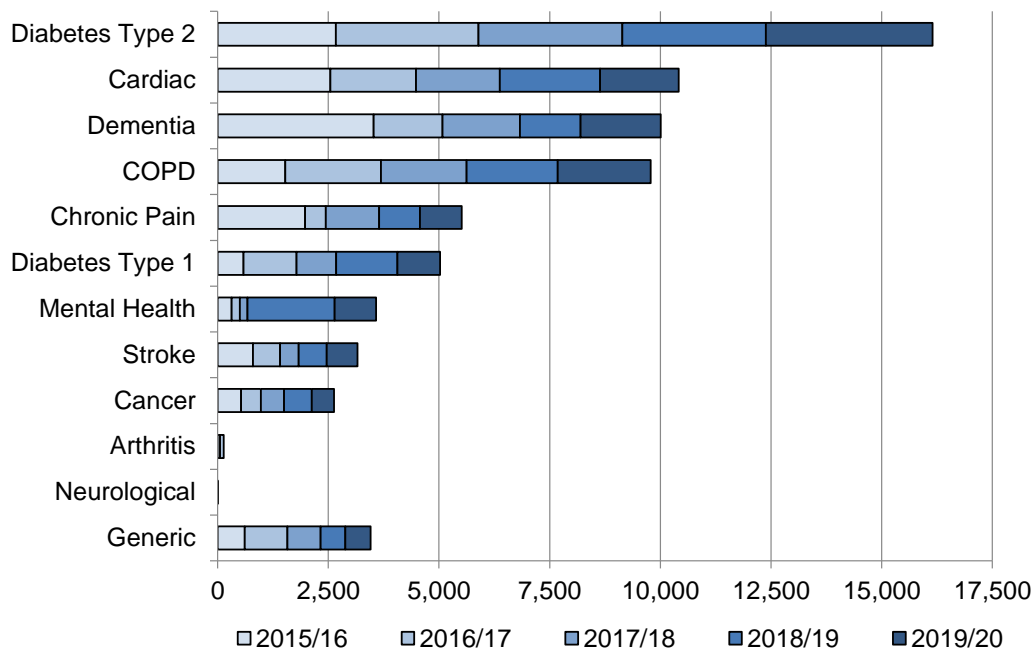
**Figure 5. Average Number of Participants per Programme by Condition (2019/20)**



Just over 1 in 4 participants at a patient education / self management programme in 2019/20 attended a diabetes type 2 specific programme.

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

**Figure 6. Number of Participants by Programme Type (2015/16 – 2019/20)\***

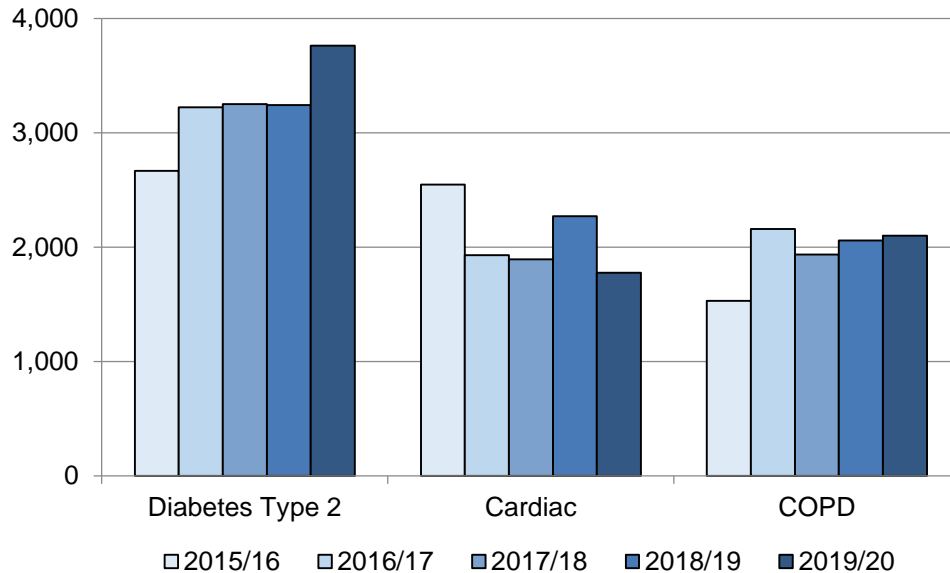


\* Due to ongoing data validation, figures from 2018/19 have been revised. Further information can be found in the Data Presentation section of [Appendix B](#).



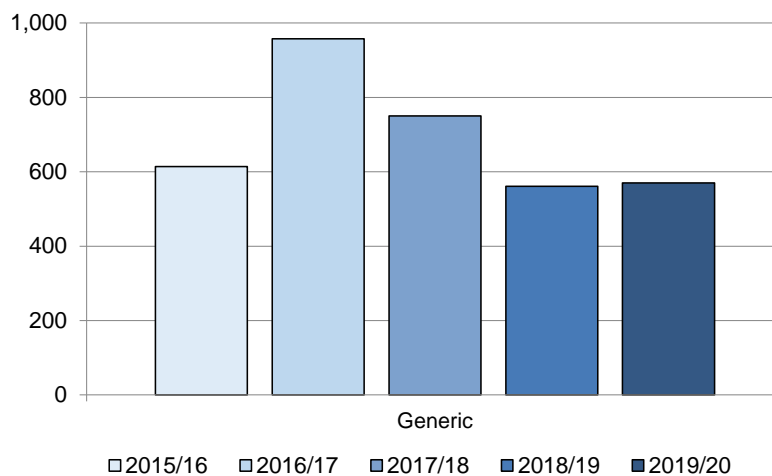
The annual number of participants attending chronic condition education programmes has remained high, with ongoing refinement and validation of data in this area accounting for some of the annual variance. Due to the impact of COVID 19 on programme scheduling in 2019/20, and subsequent resource issues experienced by organisations in submitting complete returns, it is not robust to compare 2019/20 against previous trend data, with the below figures included for illustrative purposes. Figure 7 shows the regular high attendance Diabetes Type 2, Cardiac and COPD programmes since 2015/16.

**Figure 7. Number of Participants by Condition (2015/16 – 2019/20)\***



Over the last 5 years, on average of 691 participants have attended generic education 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 (2015/16 – 2019/20)\***



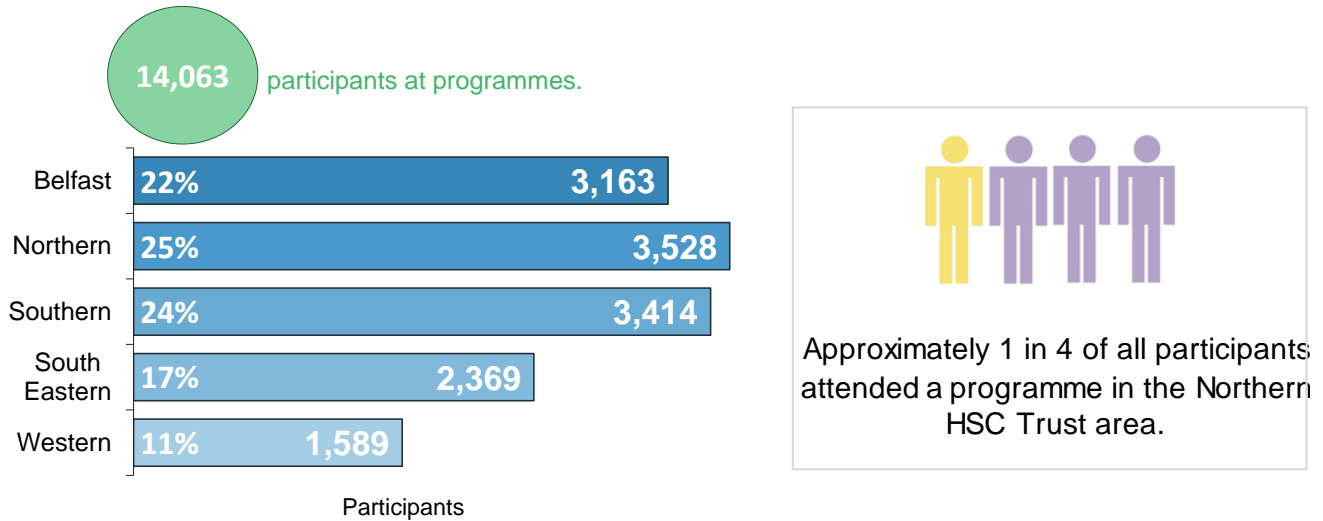
\* Due to ongoing data validation, figures from 2018/19 have been revised. Further information can be found in the Data Presentation section of [Appendix B](#). Ongoing data validation highlights the need to view early year's data with care, as the return was still in development, and organisations may have partially submitted/ not submitted, and/or variance in interpretation when completing questionnaire.

# 4. Participants

## Participants by HSC Trust Area

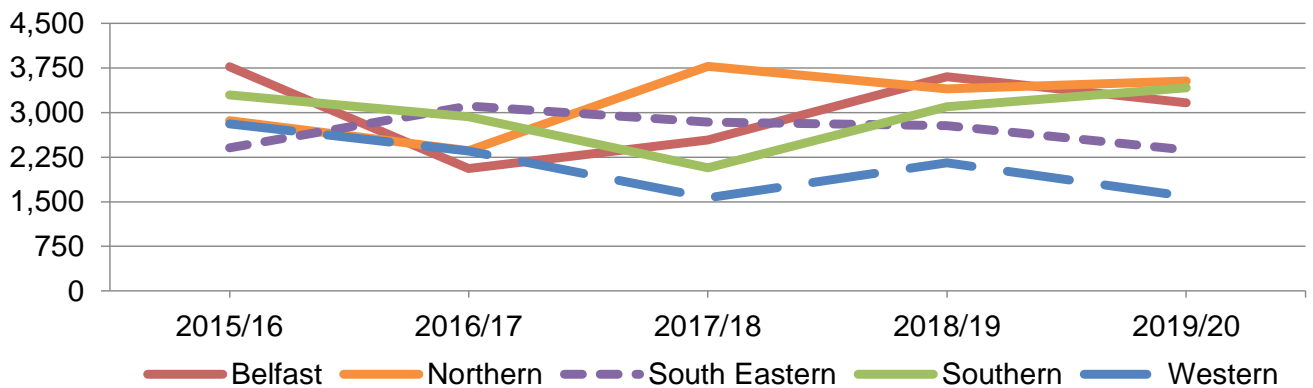
In 2019/20, 14,063 participants attended a patient education / self management programme ranging from 3,528 in the Northern HSC Trust area to 1,589 in the Western HSC Trust area (Figure 9) (Table 5). Data should be interpreted with care due to impact of COVID pandemic, please see Technical Guidance for detail.

**Figure 9. Participant Numbers by HSC Trust Area (2019/20)**



Decreased participant numbers at patient education / self management programmes in 2019/20 is likely to reflect the impact of COVID 19 pandemic on providing programmes, and the subsequent impact on staff resources which have affected the ability of providers to submit complete returns. Where 2019/20 information could be provided, it is in line with 2018/19.

**Figure 10. Participant Numbers by HSC Trust Area (2015/16 – 2019/20)\***

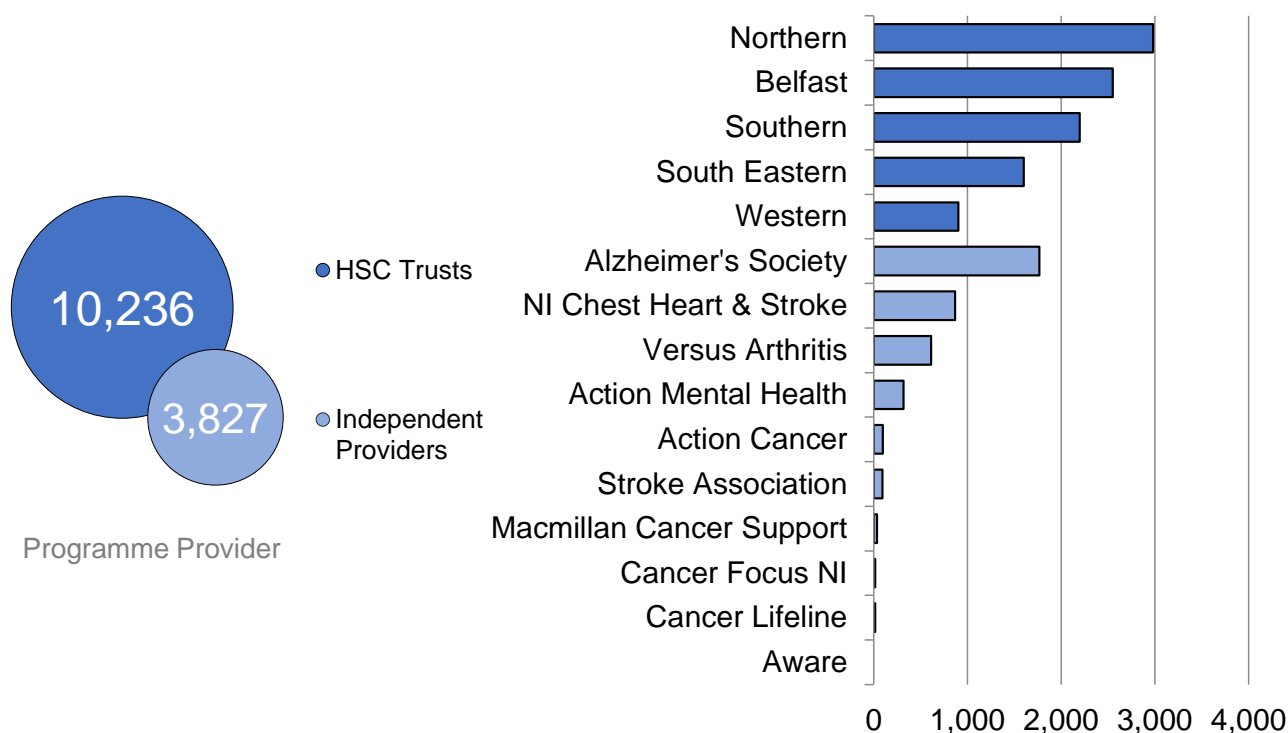


\* Due to ongoing data validation, figures from 2018/19 have been revised. Further information can be found in the Data Presentation section of [Appendix B](#).

Of the 14,063 participants, 73% were attending a programme delivered by HSC Trusts and 27% a programme by independent sector organisations. In 2019/20, participant numbers at programmes provided by HSC Trusts (10,236) showed a 7% (1,793) decrease over the number of participants in 2018/19\* (10,980). Although data should be interpreted with care due to impact of COVID pandemic, please see Technical Guidance for detail.

While the Alzheimer’s Society had the greatest number of participants (1,769), of all the independent sector providers, and 13% of the total regional participant numbers (Figure 11) (Table 8), it should be noted that some of the Alzheimer’s Society programmes are public facing, with multiple members of the same family attending, resulting in high attendance. 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 11. Participant Numbers by Provider Organisation (2019/20)**

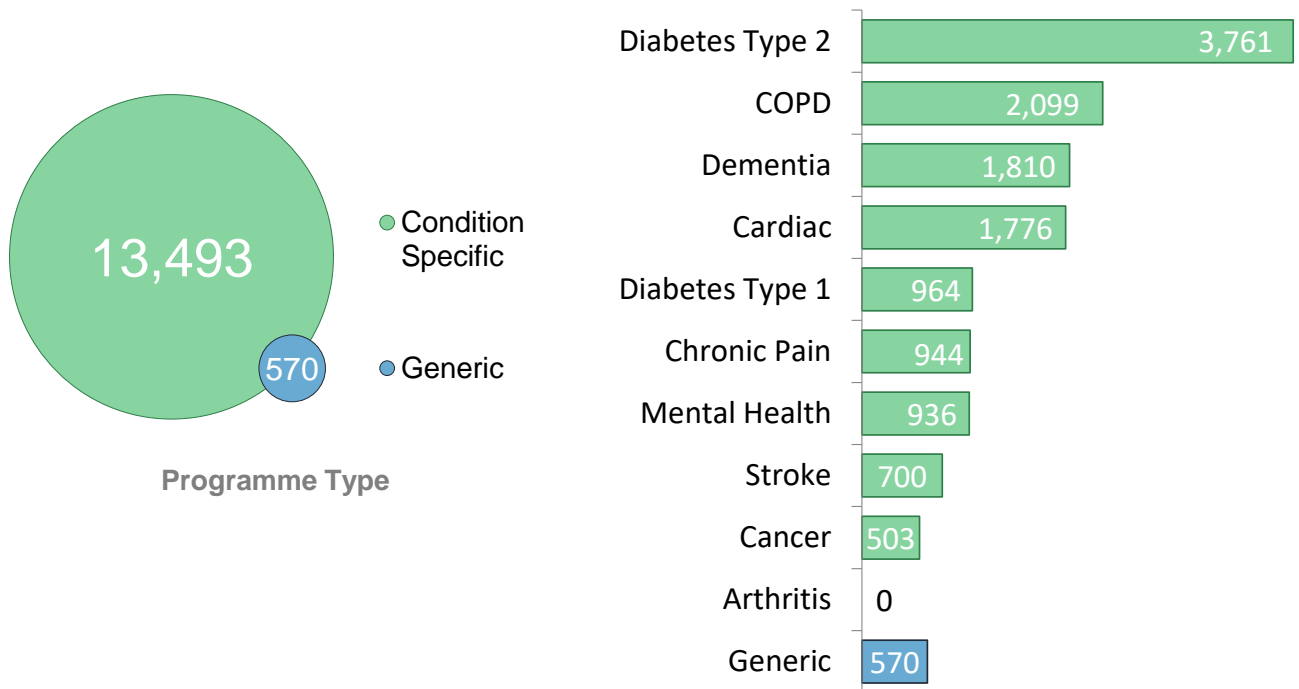


\* Due to ongoing data validation, figures from 2018/19 have been revised. Further information can be found in the Data Presentation section of [Appendix B](#).

## Participants by Programme Type

Of the 14,063 participants at programmes, 96% were attending a condition specific programme with 4% attending a generic programme. Figure 12 shows that the majority of participants (27%) attended a programme related to diabetes type 2; followed by COPD (15%).

**Figure 12. Participant Numbers by Programme Type (2019/20)**



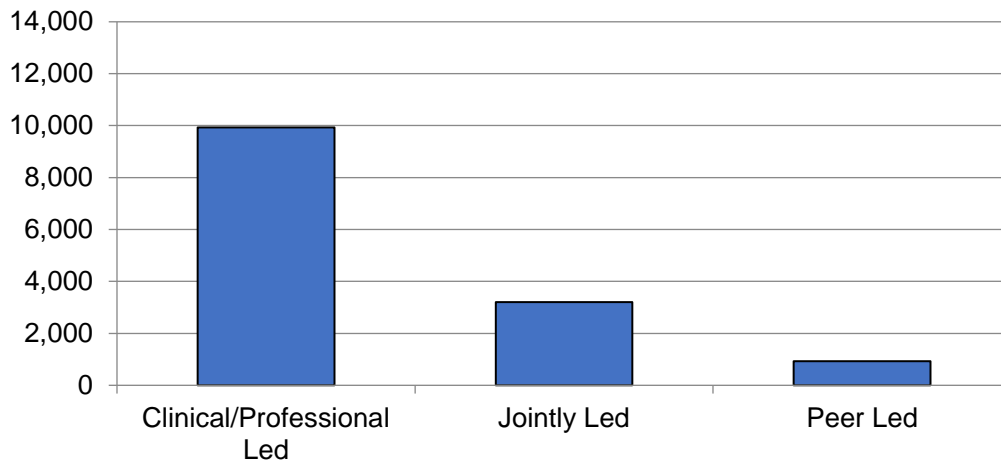
The top 6 conditions, by participant numbers, had programmes available across all 5 HSC Trust areas with one exception. There were no cardiac specific programmes reported in the Western HSC Trust area; however Northern Ireland Chest Heart and Stroke (NICHHS) provided the generic 'Taking Control' programme in this area during 2019/20 (Table 6). Data should be interpreted with care due to impact of COVID pandemic, please see Technical Guidance for detail.

## Participants by Programme Delivery

In 2019/20, 71% (9,933) of participants attended a programme that was either clinically or professionally led; this was lower than the proportion in 2018/19 (83%). Participants at jointly led programmes accounted for 23% (3,198) of the total, with the remaining 7% (932) of participants attending a programme that was peer led.

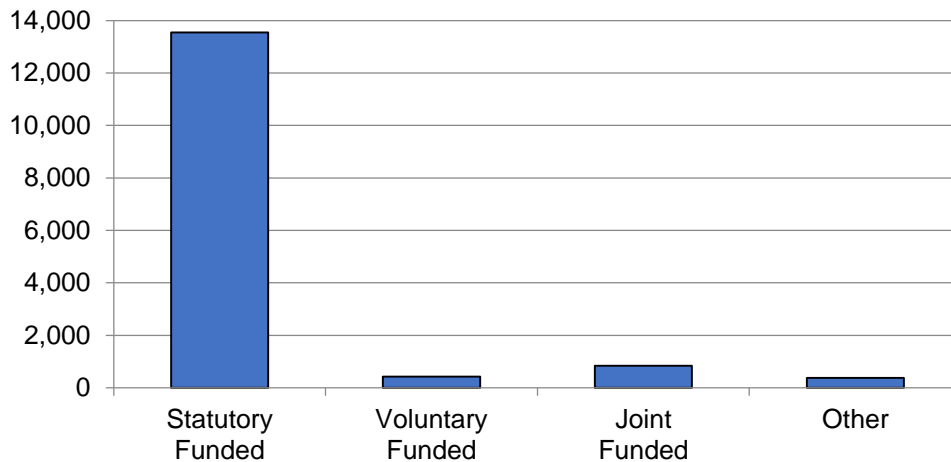
Of the participants at clinically or professionally led programmes in 2019/20, 99% (9,821) were attending a condition specific programme. 92% (2,938) of those at a jointly led programme and 79% (734) at a peer led programme (Table 9) were attending condition specific programmes.

**Figure 13. Number of Participants by Programme Delivery (2019/20)**



In 2019/20, 69% (9,645) of participants attended a programme that was statutory funded, a percentage decrease of 2% (-391) since the previous year. Jointly funded programmes were provided for 27% of participants; with 2% of participants each attending voluntary funded programmes and 3% at programmes utilising other funding arrangements<sup>1</sup> (Table 10).

**Figure 14. Number of Participants by Funding Arrangement (2019/20)<sup>1</sup>**



<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.

## 5. Diabetes

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

Standardised Prescription Rate for Diabetes by ICP Rate against Northern Ireland Average

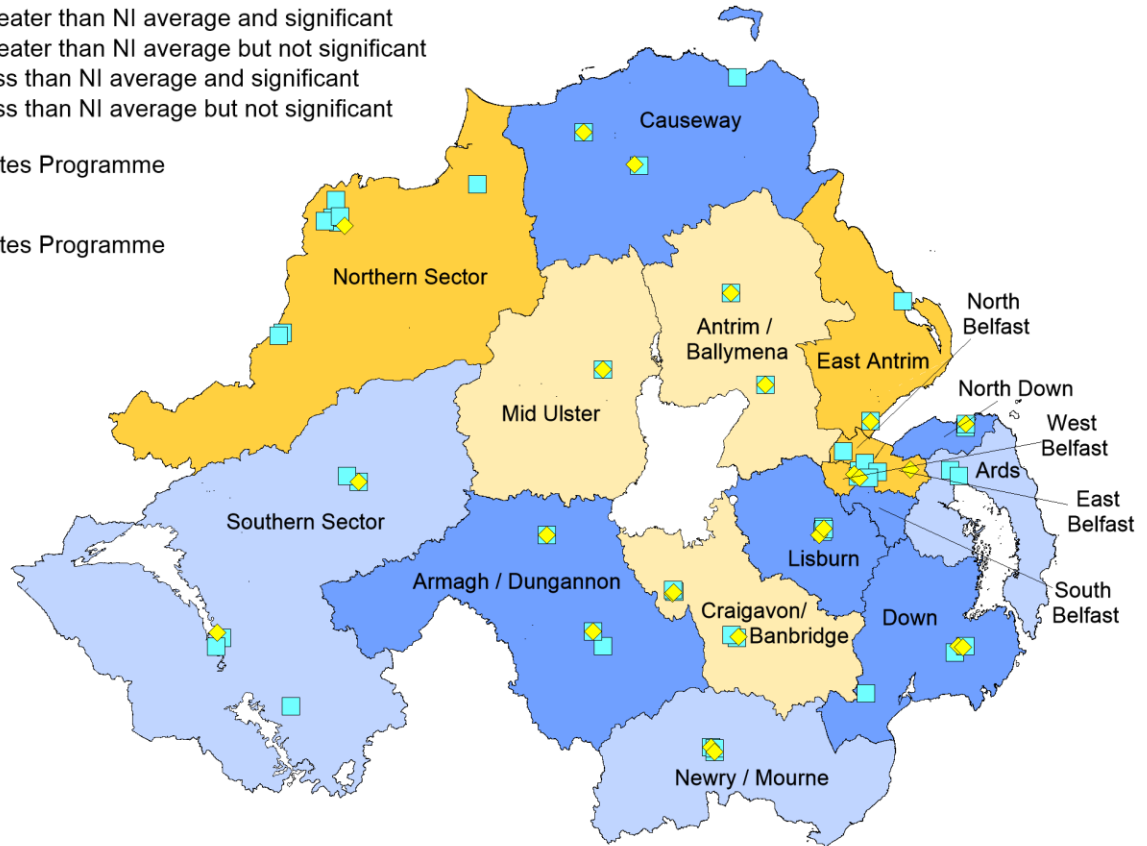
- Rate is greater than NI average and significant
- Rate is greater than NI average but not significant
- Rate is less than NI average and significant
- Rate is less than NI average but not significant

Type 1 Diabetes Programme

◆ Location

Type 2 Diabetes Programme

■ Location



Source: BSO, DoH

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Using 2019 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 (Down) where the SPR was less than the Northern Ireland average, but not significant in 2018, while the SPR for this ICP has remained less than the average, it is significantly less than average in 2019.

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

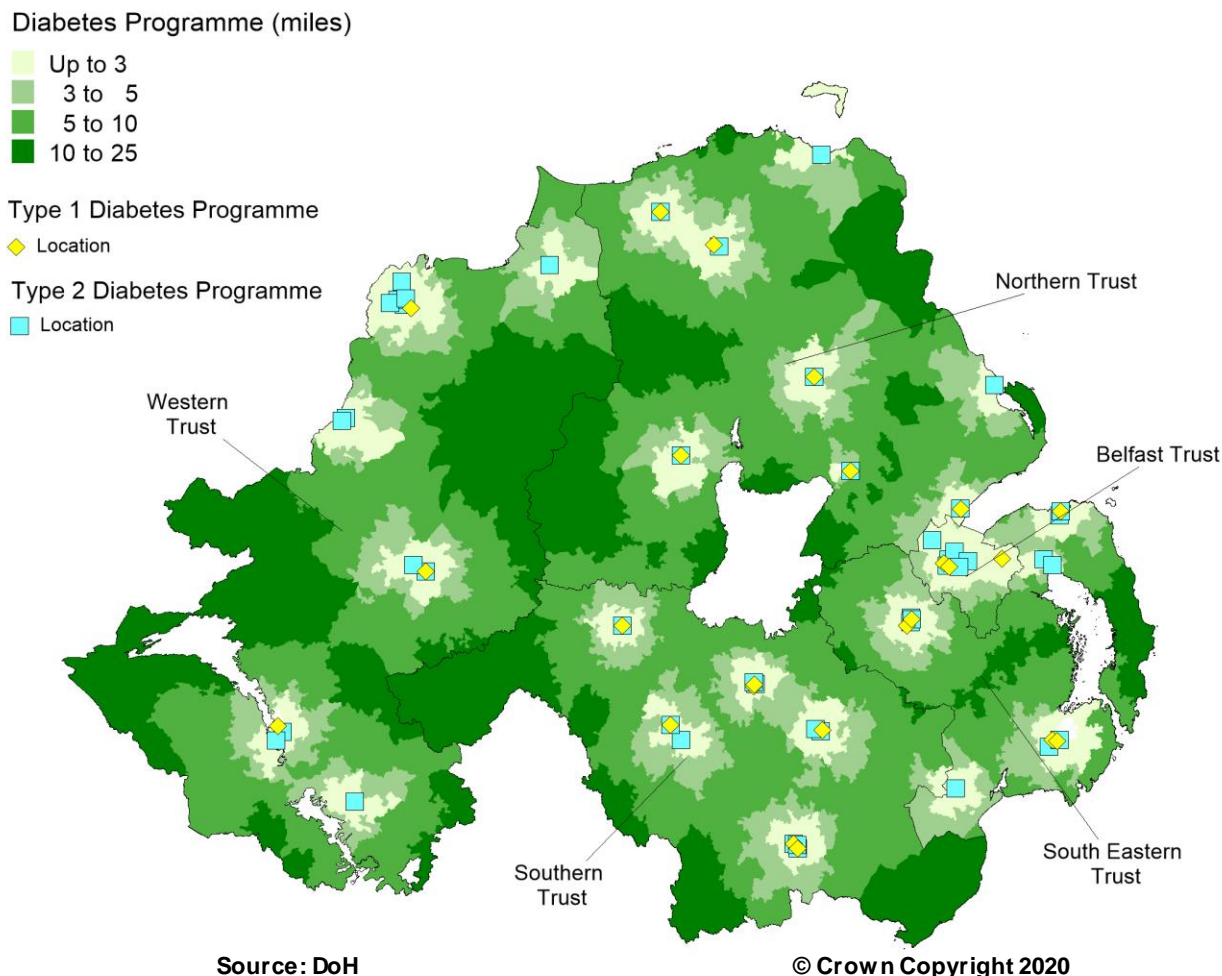


Figure 16 illustrates the locations of patient education / self management programmes for both Type 1 and Type 2 diabetes that ran during 2019/20 and their proximity to census output population areas in Northern Ireland. More than half (56%) of the population in Northern Ireland lived within 3 miles 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 2019/20 were located in similar locations as in the previous year. However, Type 1 Diabetes programmes did not run in Larne in the Northern HSC Trust in 2019/20, while in South Eastern HSC Trust one programme location moved from Ards to Bangor. There was greater provision of Type 2 programme locations in the South Eastern HSC Trust, with Type 2 programmes running in Castlewellan. Type 1 Diabetes programmes did not run in Killeel in Southern HSC Trust in 2019/20 while in Western HSC Trust one programme location moved from Irvinestown to Lisnaskea. Southern HSC Trust advised that they also ran a number of online sessions this year. Belfast Trust Type 1 & 2 Diabetes programme locations reflect some historic programme locations as location information was not provided for all programmes in place during 2019/20.

\* Further information can be found in the Maps section of [Appendix B](#).



## 6. COPD

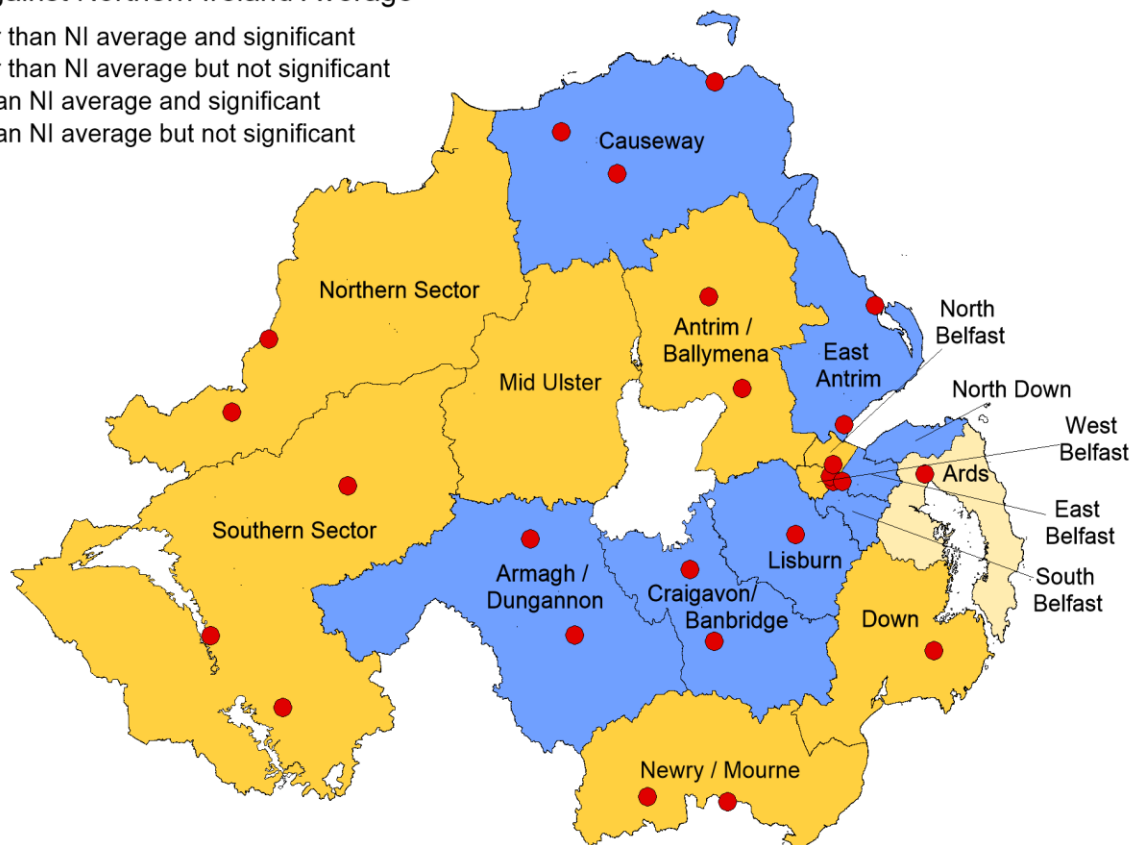
**Figure 17. Standardised Prescription Rate for COPD, by ICP Rate Against Northern Ireland Average; with COPD Programme Locations**

Standardised Prescription Rate for COPD  
by ICP Rate Against Northern Ireland Average

- Rate is greater than NI average and significant
- Rate is greater than NI average but not significant
- Rate is less than NI average and significant
- Rate is less than NI average but not significant

COPD Programme

- Location



Source: BSO, DoH

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**Please Note, the above calculated 2019 SPR are not comparable with previously reported SPR rates (pre 2018) in the Patient Education Programme Publication series, due to a break in methodology.**

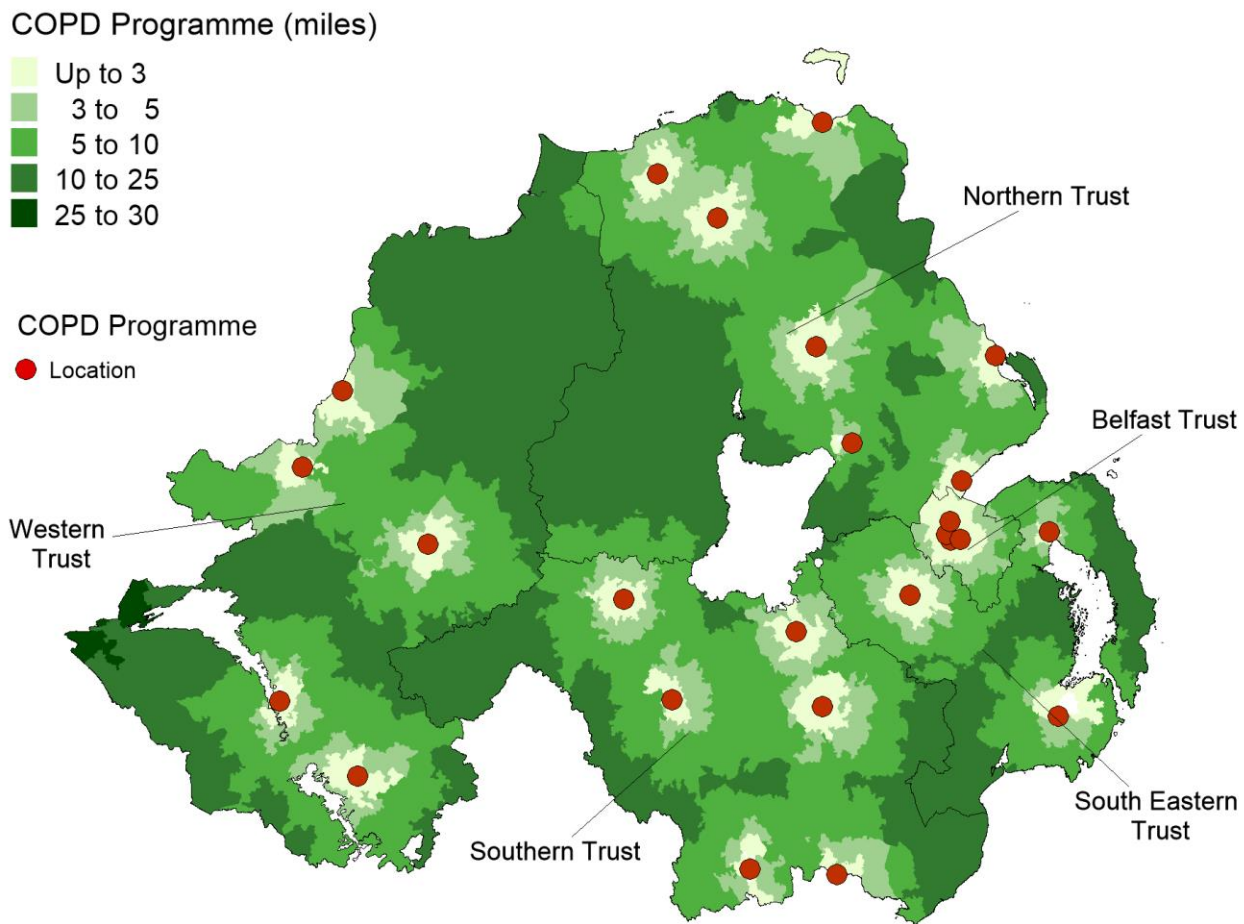
Figure 17 uses COPD specific prescription data to compare the SPR against the regional average. All but one ICP area had a rate that was either significantly greater or less than the Northern Ireland average. The Ards ICP area had a lower rate which was not significant when compared to the regional average.

The North Down and East Belfast (SPR rates significantly lower than the NI average) ICP areas had no provision for a COPD specific programme during 2019/20, similar to the previous year. The Mid Ulster ICP area (SPR significantly greater than the NI average) had no provision for a COPD specific programme during 2019/20 which differs from previous programme location data, however this may be a consequence of partially submitted returns\*. Figure 18 overleaf provides more information on the access to programmes.

\* Further information can be found in the Maps section of [Appendix B](#).



**Figure 18. Proximity of Census Output Areas to COPD Programmes**



Source: DoH

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Figure 18 illustrates the locations of programmes for COPD that ran during 2019/20 and their proximity to census output population areas. Approximately 41% of the population in Northern Ireland lived within 3 miles of a COPD programme in 2019/20, with approximately 1 in 1000 persons located more than 25 miles away from a programme. With no programme located in the North Down, East Belfast or Mid Ulster 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 2019/20 were located in similar locations as in 2018/19. However, programmes did not run in Limavady or Londonderry in the Northern Trust in 2019/20, while in Southern HSC Trust one programme location moved from Kilkeel to Warrenpoint.

\* Further information can be found in the Maps section of [Appendix B](#).

## 7. Tables

**Table 1. Programme Frequency by HSC Trust Area (2015/16 – 2019/20)<sup>2, 3</sup>**

HSC Trust Area	Programme Frequency				
	2015/16	2016/17	2017/18	2018/19	2019/20
Belfast	302	240	306	317	305
Northern	149	264	368	267	249
South Eastern	108	319	291	260	242
Southern	211	241	227	221	240
Western	137	187	197	169	163
<b>Total</b>	<b>908</b>	<b>1,251</b>	<b>1,389</b>	<b>1,234</b>	<b>1,199</b>

<sup>2</sup> - Please note that a number of organisations advised of disruption to programmes due to the impact of COVID 2019.

- BHSC 2019/20 figures have been imputed based on the 2018/19 return, as a completed 2019/20 return was not received ahead of publication.
- AWARE was unable to provide a 2019/20 return due to COVID 19 impacted staff resources.
- SEHSC were unable to provide a complete data return of cardiac programmes ahead of publication'
- WHSC diabetes programmes was estimated based on previous return, as it wasn't possible to submit a validated 2019/20 return ahead of publication deadline.

<sup>3</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 (2019/20)<sup>4</sup>**

Programme Type	HSC Trust Area					Total
	Belfast	Northern	South Eastern	Southern	Western	
<b>Condition Specific</b>	<b>301</b>	<b>247</b>	<b>240</b>	<b>220</b>	<b>152</b>	<b>1,160</b>
Arthritis	0	0	0	0	0	0
Cancer	18	5	1	2	5	31
Cardiac	28	36	96	6	0	166
Chronic Pain	15	20	8	4	23	70
COPD	32	18	20	20	20	110
Dementia	27	11	29	6	4	77
Diabetes Type 1	24	31	19	18	32	124
Diabetes Type 2	140	84	50	117	46	437
Mental Health	0	21	0	20	0	41
Stroke	17	21	17	27	22	104
<b>Generic</b>	<b>4</b>	<b>2</b>	<b>2</b>	<b>20</b>	<b>11</b>	<b>39</b>
<b>Total</b>	<b>305</b>	<b>249</b>	<b>242</b>	<b>240</b>	<b>163</b>	<b>1,199</b>

<sup>4</sup> - Please note that a number of organisations advised of disruption to programmes due to the impact of COVID 2019.

- BHSCT 2019/20 figures have been imputed based on the 2018/19 return, as a completed 2019/20 return was not received ahead of publication.

- AWARE was unable to provide a 2019/20 return due to COVID 19 impacted staff resources.

- SEHSCT were unable to provide a complete data return of cardiac programmes ahead of publication'

- WHSCT diabetes programmes was estimated based on previous return, as it wasn't possible to submit a validated 2019/20 return ahead of publication deadline.

**Table 3. Frequency of Programmes by Type and HSC Trust Area (2015/16 – 2019/20)<sup>5, 6</sup>**

HSC Trust Area	2015/16		2016/17		2017/18		2018/19		2019/20	
	Condition Specific	Generic	Condition Specific	Generic	Condition Specific	Generic	Condition Specific	Generic	Condition Specific	Generic
Belfast	295	7	234	6	298	8	312	5	301	4
Northern	149	0	264	0	361	7	267	0	247	2
South Eastern	100	8	276	43	288	3	257	3	240	2
Southern	199	12	228	13	200	27	206	15	220	20
Western	110	27	161	26	171	26	147	22	152	11
<b>Total</b>	<b>854</b>	<b>54</b>	<b>1,163</b>	<b>88</b>	<b>1,318</b>	<b>71</b>	<b>1,189</b>	<b>45</b>	<b>1,160</b>	<b>39</b>

<sup>5</sup> - Please note that a number of organisations advised of disruption to programmes due to the impact of COVID 2019.

- BHSC 2019/20 figures have been imputed based on the 2018/19 return, as a completed 2019/20 return was not received ahead of publication.
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- WHSC diabetes programmes was estimated based on previous return, as it wasn't possible to submit a validated 2019/20 return ahead of publication deadline.

<sup>6</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 (2019/20)<sup>7</sup>**

<b>Provider Organisation</b>	<b>2019/20</b>
Action Cancer	6
Action Mental Health	31
Alzheimer's Society	72
Aware	-
Cancer Focus NI	3
Cancer Lifeline	3
Macmillan Cancer Support	4
NI Chest Heart & Stroke	101
Stroke Association	17
Versus Arthritis	40
BHSCT	236
NHSCT	214
SEHSCT	185
SHSCT	189
WHSCT	98
<b>Total</b>	<b>1,199</b>

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<sup>7</sup> - Please note that a number of organisations advised of disruption to programmes due to the impact of COVID 2019.

- BHSCT 2019/20 figures have been imputed based on the 2018/19 return, as a completed 2019/20 return was not received ahead of publication.

- AWARE was unable to provide a 2019/20 return due to COVID 19 impacted staff resources.

- SEHSCT were unable to provide a complete data return of cardiac programmes ahead of publication'

- WHSCT diabetes programmes was estimated based on previous return, as it wasn't possible to submit a validated 2019/20 return ahead of publication deadline.

**Table 5. Participant Numbers by HSC Trust Area (2015/16 – 2019/20)<sup>8, 9, 10</sup>**

HSC Trust Area	Participants				
	2015/16	2016/17	2017/18	2018/19	2019/20
Belfast	3,773	2,056	2,541	3,602	3,163
Northern	2,865	2,359	3,778	3,397	3,528
South Eastern	2,410	3,110	2,842	2,778	2,369
Southern	3,295	2,933	2,070	3,101	3,414
Western	2,809	2,353	1,566	2,155	1,589
<b>Total</b>	<b>15,192</b>	<b>12,811</b>	<b>12,797</b>	<b>15,033</b>	<b>14,063</b>

<sup>8</sup> - Please note that a number of organisations advised of disruption to programmes due to the impact of COVID 2019.

- BHSCCT 2019/20 figures have been imputed based on the 2018/19 return, as a completed 2019/20 return was not received ahead of publication.

- AWARE was unable to provide a 2019/20 return due to COVID 19 impacted staff resources.

- SEHSCCT were unable to provide a complete data return of cardiac programmes ahead of publication'

- WHSCCT diabetes programmes was estimated based on previous return, as it wasn't possible to submit a validated 2019/20 return ahead of publication deadline.

<sup>9</sup> Due to ongoing data validation, figures for 2018/19 have been revised. Further information can be found in Technical [Appendix B](#).

<sup>10</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 (2019/20)<sup>11</sup>**

Programme Type	HSC Trust Area					Total
	Belfast	Northern	South Eastern	Southern	Western	
<b>Condition Specific</b>	<b>3,095</b>	<b>3,490</b>	<b>2,333</b>	<b>3,122</b>	<b>1,453</b>	<b>13,493</b>
Arthritis	0	0	0	0	0	0
Cancer	372	42	14	28	47	503
Cardiac	443	636	580	117	0	1,776
Chronic Pain	213	282	146	67	236	944
COPD	712	284	477	269	357	2,099
Dementia	161	335	422	788	104	1,810
Diabetes Type 1	255	204	189	99	217	964
Diabetes Type 2	827	946	357	1,303	328	3,761
Mental Health	0	638	0	298	0	936
Stroke	112	123	148	153	164	700
<b>Generic</b>	<b>68</b>	<b>38</b>	<b>36</b>	<b>292</b>	<b>136</b>	<b>570</b>
<b>Total</b>	<b>3,163</b>	<b>3,528</b>	<b>2,369</b>	<b>3,414</b>	<b>1,589</b>	<b>14,063</b>

<sup>11</sup> - Please note that a number of organisations advised of disruption to programmes due to the impact of COVID 2019.

- BHSCT 2019/20 figures have been imputed based on the 2018/19 return, as a completed 2019/20 return was not received ahead of publication.

- AWARE was unable to provide a 2019/20 return due to COVID 19 impacted staff resources.

- SEHSCT were unable to provide a complete data return of cardiac programmes ahead of publication'

- WHSCT diabetes programmes was estimated based on previous return, as it wasn't possible to submit a validated 2019/20 return ahead of publication deadline.

**Table 7. Participant Numbers by Condition (2015/16 – 2019/20)<sup>12, 13</sup>**

<b>Provider Organisation</b>	<b>2015/16</b>	<b>2016/17</b>	<b>2017/18</b>	<b>2018/19</b>	<b>2019/20</b>
<b>Condition Specific</b>	<b>14,578</b>	<b>11,853</b>	<b>12,047</b>	<b>14,472</b>	<b>13,493</b>
Arthritis	56	83	0	0	0
Cancer	531	443	526	625	503
Cardiac	2,548	1,929	1,894	2,271	1,776
Chronic Pain	1,977	466	1,204	921	944
COPD	1,530	2,160	1,934	2,057	2,099
Dementia	3,522	1,555	1,752	1,369	1,810
Diabetes Type 1	587	1,194	898	1,378	964
Diabetes Type 2	2,668	3,223	3,252	3,243	3,761
IBD	36	0	0	0	0
Lymphoedema	6	0	0	0	0
Mental Health	314	188	168	1,974	936
Neurological	7	0	0	0	0
Stroke	796	612	419	634	700
<b>Generic</b>	<b>614</b>	<b>958</b>	<b>750</b>	<b>561</b>	<b>570</b>
<b>Total</b>	<b>15,192</b>	<b>12,811</b>	<b>12,797</b>	<b>15,033</b>	<b>14,063</b>

<sup>12</sup> - Please note that a number of organisations advised of disruption to programmes due to the impact of COVID 2019.

- BHSCT 2019/20 figures have been imputed based on the 2018/19 return, as a completed 2019/20 return was not received ahead of publication.

- AWARE was unable to provide a 2019/20 return due to COVID 19 impacted staff resources.

- SEHSCT were unable to provide a complete data return of cardiac programmes ahead of publication'

- WHSCT diabetes programmes was estimated based on previous return, as it wasn't possible to submit a validated 2019/20 return ahead of publication deadline.

<sup>13</sup> Due to ongoing data validation, figures for 2018/19 have been revised. Further information can be found in Technical [Appendix B](#).



**Table 8. Participant Numbers by Provider Organisation (2015/16 – 2019/20)<sup>14, 15</sup>**

<b>Provider Organisation</b>	<b>2015/16</b>	<b>2016/17</b>	<b>2017/18</b>	<b>2018/19</b>	<b>2019/20</b>
Action Cancer	67	60	77	80	97
Action Mental Health	260	217	185	296	318
Alzheimer's Society	3,469	1,422	1,752	1,364	1,769
Aware	-	-	-	735	-
Cancer Focus NI	69	85	96	30	17
Cancer Lifeline	68	49	38	22	15
Macmillan Cancer Support	254	30	41	54	37
NI Chest Heart & Stroke	452	519	639	750	868
Stroke Association	478	258	53	85	92
Versus Arthritis <sup>2</sup>	468	357	704	637	614
BHSCT	2,866	1,775	1,726	2,552	2,552
NHSCT	1,967	2,087	2,919	2,996	2,981
SEHSCT	1,629	2,862	2,331	2,134	1,603
SHSCT	1,850	1,795	1,447	1,993	2,198
WHSCT	1,295	1,295	789	1,305	902
<b>Total</b>	<b>15,192</b>	<b>12,811</b>	<b>12,797</b>	<b>15,033</b>	<b>14,063</b>

<sup>14</sup> - Please note that a number of organisations advised of disruption to programmes due to the impact of COVID 2019.

- BHSCT 2019/20 figures have been imputed based on the 2018/19 return, as a completed 2019/20 return was not received ahead of publication.

- AWARE was unable to provide a 2019/20 return due to COVID 19 impacted staff resources.

- SEHSCT were unable to provide a complete data return of cardiac programmes ahead of publication'

- WHSCT diabetes programmes was estimated based on previous return, as it wasn't possible to submit a validated 2019/20 return ahead of publication deadline.

<sup>15</sup> Due to ongoing data validation, figures for 2018/19 have been revised. Further information can be found in Technical [Appendix B](#).

**Table 9. Participant Numbers by Programme Type and Programme Delivery (2019/20)<sup>16</sup>**

<b>Programme Type</b>	<b>Clinical / Professional Led</b>	<b>Peer Led</b>	<b>Jointly Led</b>	<b>Total</b>
<b>Condition Specific</b>	<b>9,821</b>	<b>734</b>	<b>2,938</b>	<b>13,493</b>
Arthritis	0	0	0	0
Cancer	466	0	37	503
Cardiac	1,776	0	0	1,776
Chronic Pain	210	734	0	944
COPD	1,922	0	177	2,099
Dementia	41	0	1,769	1,810
Diabetes Type 1	836	0	128	964
Diabetes Type 2	3,640	0	121	3,761
Mental Health	838	0	98	936
Stroke	92	0	608	700
<b>Generic</b>	<b>112</b>	<b>198</b>	<b>260</b>	<b>570</b>
<b>Total</b>	<b>9,933</b>	<b>932</b>	<b>3,198</b>	<b>14,063</b>

<sup>16</sup> - Please note that a number of organisations advised of disruption to programmes due to the impact of COVID 2019.

- BHSC 2019/20 figures have been imputed based on the 2018/19 return, as a completed 2019/20 return was not received ahead of publication.

- AWARE was unable to provide a 2019/20 return due to COVID 19 impacted staff resources.

- SEHSC were unable to provide a complete data return of cardiac programmes ahead of publication'

- WHSC diabetes programmes was estimated based on previous return, as it wasn't possible to submit a validated 2019/20 return ahead of publication deadline.

**Table 10. Participant Numbers by Programme Type and Funding Arrangements (2019/20)<sup>17\*</sup>**

<b>Programme Type</b>	<b>Statutory Funded</b>	<b>Voluntary Funded</b>	<b>Joint Funded</b>	<b>Other*</b>	<b>Total</b>
<b>Condition Specific</b>	<b>9,271</b>	<b>87</b>	<b>3,711</b>	<b>424</b>	<b>13,493</b>
Arthritis	0	0	0	0	0
Cancer	401	87	15	0	503
Cardiac	1,776	0	0	0	1,776
Chronic Pain	944	0	0	0	944
COPD	1,922	0	0	177	2,099
Dementia	398	0	1,412	0	1,810
Diabetes Type 1	843	0	0	121	964
Diabetes Type 2	2,689	0	946	126	3,761
Mental Health	298	0	638	0	936
Stroke	0	0	700	0	700
<b>Generic</b>	<b>374</b>	<b>196</b>	<b>0</b>	<b>0</b>	<b>570</b>
<b>Total</b>	<b>9,645</b>	<b>283</b>	<b>3,711</b>	<b>424</b>	<b>14,063</b>

\*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.

<sup>17</sup> - Please note that a number of organisations advised of disruption to programmes due to the impact of COVID 2019.

- BHSCT 2019/20 figures have been imputed based on the 2018/19 return, as a completed 2019/20 return was not received ahead of publication.

- AWARE was unable to provide a 2019/20 return due to COVID 19 impacted staff resources.

- SEHSCT were unable to provide a complete data return of cardiac programmes ahead of publication'

- WHSCT diabetes programmes was estimated based on previous return, as it wasn't possible to submit a validated 2019/20 return ahead of publication deadline.

# 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 2019 to 31 March 2020.

The [Programme for Government \(PfG\) 2011-15](#) 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 2019/20. Information was provided by HSC Trusts and independent sector organisations who delivered programmes during 2019/20. The report summarises the key statistical information provided for the year 2019/20 and how this compares with that collected in previous years.

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<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 2020 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 2015/16 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 2019/20 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 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 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

<p>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.</p>
<p>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.</p>
<p>In the 2017/18 publication, Action Mental Health's figures for the '<i>Managing the Challenge</i>' programme were reflected in the WHSCT figures. In the 2019/20 publication this activity was revised to show that 185 participants, attending 23 programme, were delivered by Action Mental Health.</p>
<p>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.</p>
<p>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.</p>
<p>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.</p>
<p>Please note the following limitations for 2019/20 data</p> <ul style="list-style-type: none"> <li>- Please note that a number of organisations advised of disruption to programmes due to the impact of COVID 2019.</li> <li>- BHSCT 2019/20 figures have been imputed based on the 2018/19 return, as a completed 2019/20 return was not received ahead of publication.</li> <li>- AWARE was unable to provide a 2019/20 return due to COVID 19 impacted staff resources.</li> <li>- SESHCT were unable to provide a complete data return of cardiac programmes ahead of publication'</li> <li>- WHSCT diabetes programmes was estimated based on previous return, as it wasn't possible to submit a validated 2019/20 return ahead of publication deadline.</li> </ul>
<p>In the 2019/20 publication the number of participants attending 'Active Minds' delivered by the Northern Health and Social Care Trust (NHSCT) was revised from 25 to 5, as the sum of participants by sessions, rather than programme was submitted in 2018/19. The programme frequently (1) remained the same.</p>

## Amendments

The cut-off point for amendments to data was 2<sup>nd</sup> Dec 2020. 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 SPR from 2018/19 onward 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.

## 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.

<b>This data collection <u>IS</u> covering</b>	<b>This data collection <u>IS NOT</u> covering:</b>	<b>LTCs included in audit:</b>
Programmes for people with long term conditions. Programmes designed for: <ul style="list-style-type: none"><li>• Adults;</li><li>• Children/young people;</li></ul>	Any kind of "Support groups" for either physical or mental health long term conditions. By 'support groups' we mean informal,	LTCs relating to physical health eg: <ul style="list-style-type: none"><li>• Diabetes;</li><li>• Cardiac;</li></ul>

<ul style="list-style-type: none"> <li>• Carers.</li> </ul> <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>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>	<ul style="list-style-type: none"> <li>• COPD / respiratory;</li> <li>• Stroke / dementia / neurological;</li> <li>• Chronic Pain;</li> <li>• Arthritis / other Musculoskeletal;</li> <li>• Cancer.</li> </ul> <p>LTCs relating to mental health.</p>
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### 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>

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