

INFORMATION  
ANALYSIS  
DIRECTORATE



# Patient Education / Self Management Programmes for People with Long Term Conditions (2020/21)



Department of  
**Health**

An Roinn Sláinte  
Máinnstríe O Poustie

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



Northern Ireland  
Statistics  
& Research  
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# About Us



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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](#).

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

This publication is produced by Community Information Branch.

## Our Vision and Values

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

## 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.

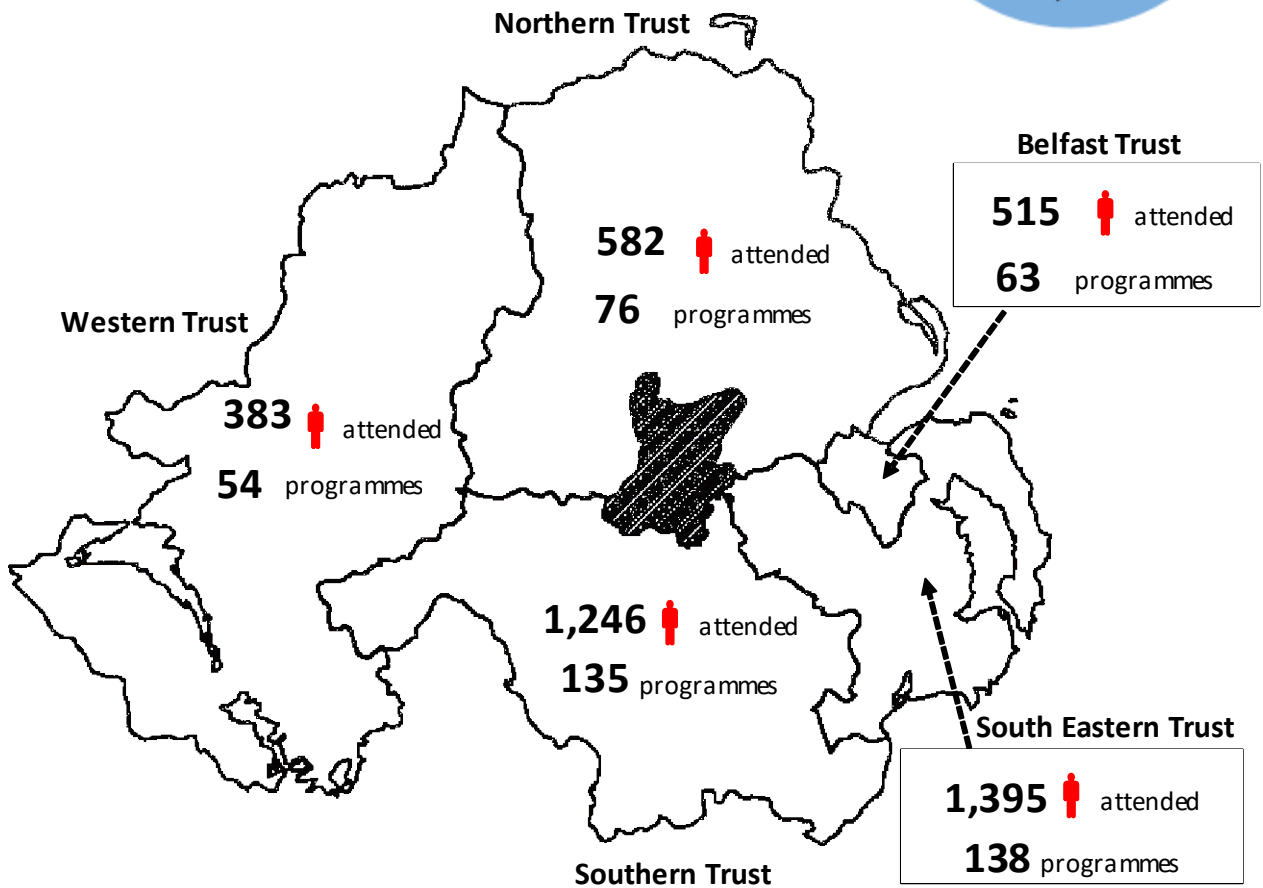
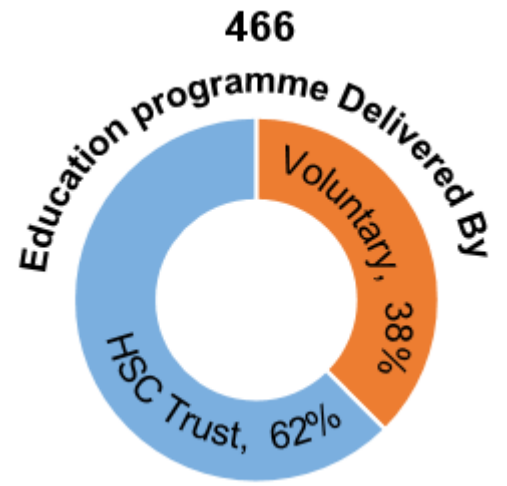
# Contents

<b>1. Key Facts .....</b>	<b>6</b>
<b>2. Programmes.....</b>	<b>7</b>
COVID-19 impact on Patient Education / Self Management Programmes -----	7
<b>3. Programmes.....</b>	<b>9</b>
Programme Frequency by HSC Trust Area -----	9
Programme Frequency by Programme Type-----	9
Programme Frequency by Provider Organisation-----	10
<b>4. Conditions .....</b>	<b>12</b>
Number of Participants by Programme Type -----	12
Number of Participants by Condition -----	14
<b>5. Participants.....</b>	<b>16</b>
Participant Numbers by HSC Trust Area -----	16
Participant Numbers by Programme Type -----	18
Participants by Programme Delivery-----	19
Participants by Funding Arrangement -----	20
<b>6. Tables.....</b>	<b>21</b>
Table 1: Programme Frequency by HSC Trust Area (2016/17 -2020/21), -----	21
Table 2: Programme Frequency by Programme Type and HSC Trust Area (2020/21)-	22
Table 3: Frequency of Programmes by Type HSC Trust Area (2016/17-2020/21) – Condition Specific, -----	23
Table 4: Frequency of Programmes by Type HSC Trust Area (2016/17-2020/21) – Generic-----	24
Table 5: Programme Frequency by Provider Organisation (2020/21) -----	25
Table 6: Participants Numbers by HSC Trust Area (2016/17-2020/21), -----	26
Table 7: Participants Numbers by Programme Type and HSC Trust Area (2020/21),	27
Table 8: Participant Numbers by Condition (2016/17 – 2020/21),-----	28
Table 9: Participants Numbers by Provider Organisation (2016/17-2020/21), -----	29
Table 10: Participants Numbers by Programme Type and Programme Delivery (2020/21) -----	30

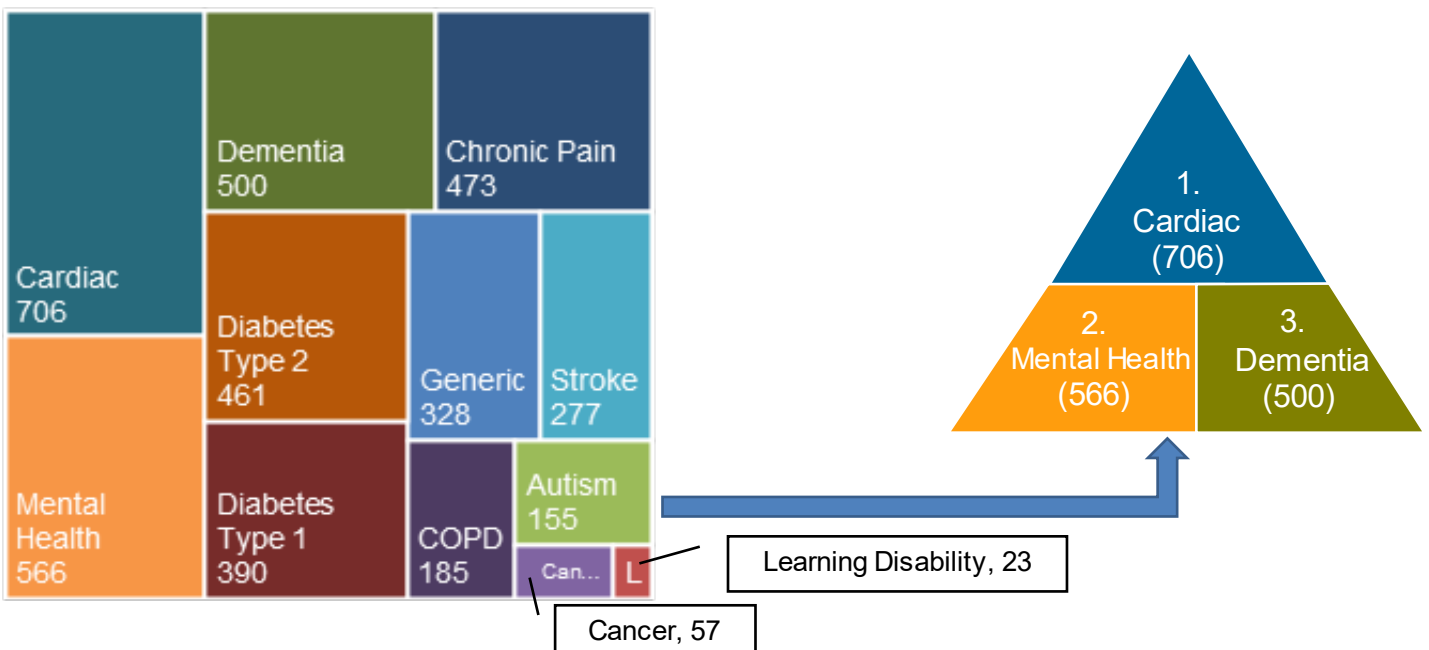
<b>Table 11: Participants Numbers by Programme Type and Funding Arrangements (2020/21),</b>	<b>-----31</b>
<b>Appendix A: Background.....</b>	<b>32</b>
<b>Appendix B: Technical Notes.....</b>	<b>33</b>
<b>Data Collection-----</b>	<b>33</b>
<b>Data Quality-----</b>	<b>33</b>
<b>Data Presentation -----</b>	<b>33</b>
<b>Amendments-----</b>	<b>34</b>
<b>Rounding Conventions -----</b>	<b>35</b>
<b>Revisions Policy-----</b>	<b>35</b>
<b>Main Uses of Data-----</b>	<b>35</b>
<b>Contact -----</b>	<b>35</b>
<b>User Feedback -----</b>	<b>35</b>
<b>Abbreviations -----</b>	<b>36</b>

# 1. Key Facts

**4,121** persons attended a patient education programme in 2020/21



Participants Numbers by Programme Type



## 2. Programmes

### COVID-19 impact on Patient Education / Self Management Programmes

Health & Social Care (HSC) Trusts and community and voluntary organisations have reported changes to their provision of Patient Education / Self Management Programmes from 2020 onward due to the impact of COVID-19. The following points indicate the background to these changes and may apply to all, or only a single HSC Trust or community/voluntary organisation. It is not possible to apportion specific issues to specific changes in reported provision, unless specified.

- A number of organisations advised of disruption to programmes due to the impact of COVID-19. Particular issues in programme provision, or data submission include;
  - Belfast HSC Trust figures for 2019/20 figures were imputed based on their 2018/19 return, as a completed 2019/20 return was not received ahead of publication. Belfast HSC Trust did not complete a return ahead of publication in 2020/21, and due to the likely impact of COVID-19 on programme provision in this year, imputing figures based on prior years would have likely been inaccurate. Therefore, Belfast HSC Trust data is unavailable for 2020/21.
  - AWARE was unable to provide a 2019/20 return, and AWARE, Cancer Focus, Cancer Lifeline and Macmillan Cancer Support were unable to submit a 2020/21 return due to COVID-19 pressures.
- Face-to-face patient education / self management programmes were suspended at various points to reduce the risk of contact and transmission of the virus.
- While many patient education / self management programmes continued to be provided virtually during the COVID-19 pandemic, some programmes were less able to continue for various reasons e.g.
  - Staff were redeployed to other areas.
  - Due to staff sickness and absence.
  - Voluntary and community sector programme delivery were impacted by the effect of the COVID-19 pandemic on resources, and fundraising.
  - Some programmes were less suited to virtual attendance than others.
- Some programmes which were previously provided face-to-face in different HSC Trust areas, moved to a regional online format. Resultantly, the sum of figures presented by HSC Trust area in this publication may not match the total figures presented for Northern Ireland.
- There was variation in the number of virtual programmes able to be provided and participants able to attend. In some cases it was recommended that the number of participants per session should be capped, according to the type of programme offered. For other programmes where the number of participants did

not have a limit, a greater number of participants could attend than in previous face-to-face sessions.

- Some programme providers detailed the following reasons for low uptake of virtual patient education / self management programmes:
  - People without suitable internet access or familiarity with technology may not have been able to access the online programmes.
  - Some older people that would usually attend face to face programmes did not engage online.
  - For some programmes, setting up online programme provision took time, and programmes were not available until towards the end of the year.
  - Some people preferred to wait until a face-to-face session was offered in the future.
- Some programme providers indicated that their programmes may continue to be run online in the future, even after the COVID-19 pandemic has ended, if the format has been successful, and if this suits the structure of the programme.

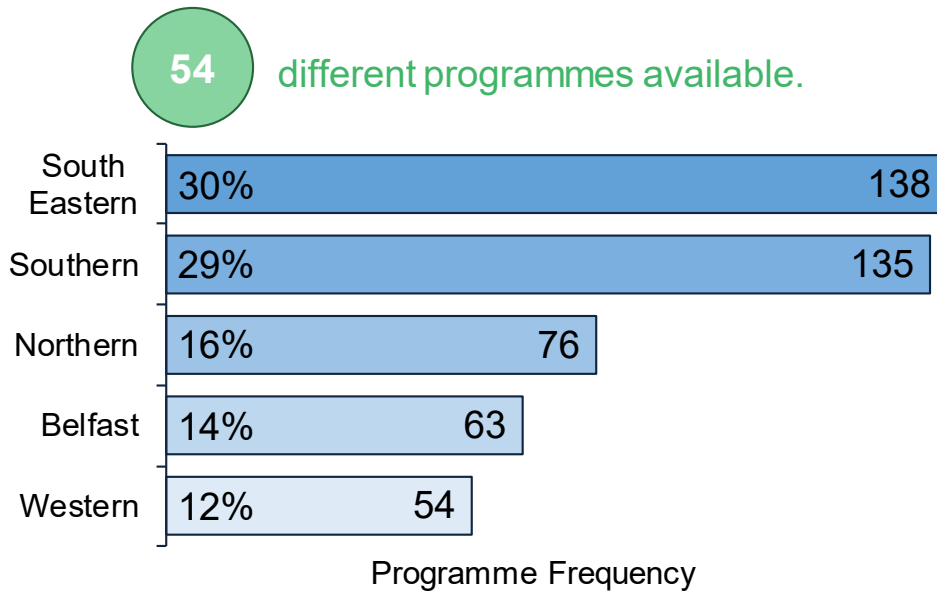


### 3. Programmes

#### Programme Frequency by HSC Trust Area

In 2020/21 there were 54 different patient education / self management programmes in place across Northern Ireland. These programmes ran a total of 466 times throughout the year ranging from 138 in the South Eastern HSC Trust area to 54 in the Western HSC Trust area (Figure 1).

**Figure 1 Programme Frequency by HSC Trust Area (2020/21)\***

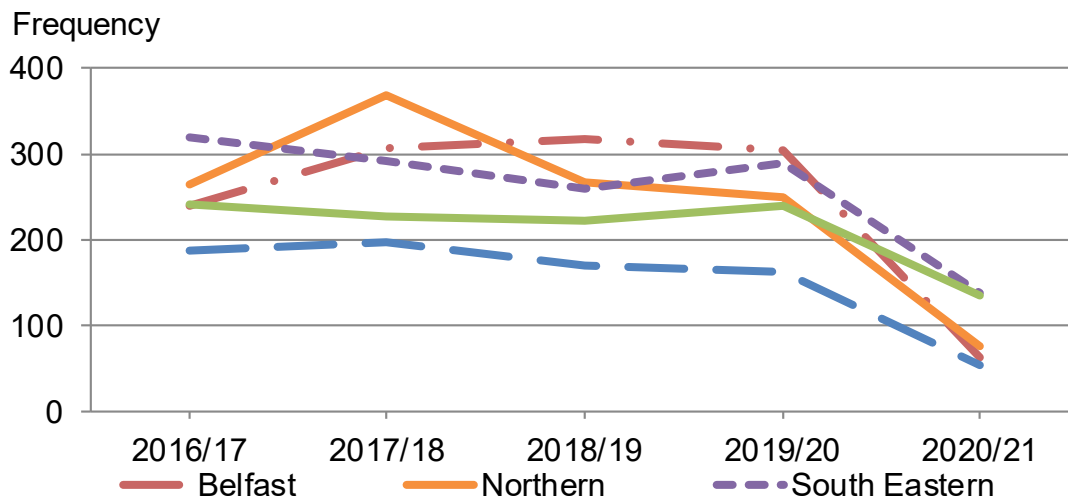


#### Programme Frequency by Programme Type

Between 2016/17, and 2019/20 the frequency of programmes regionally decreased by <1%, reflecting small decreases across most HSC Trust areas. Belfast HSC Trust were unable to provide data for the 2020/21 publication, however some programmes were run in this HSC Trust by other providers. Across the HSC Trusts, reduction in programme frequency reflects the impact of COVID-19 on the services. Regional programme frequency decreased in 2020/21 by 63% (-779) compared to the prior year. However, due to the impact of COVID-19 on programme scheduling in 2019/20 and 2020/21, and subsequent resource issues experienced by organisations in submitting complete returns, extreme caution should be taken when comparing 2019/20 and 2020/21 against previous trend data, with the below figures included for illustrative purposes. Please note that ongoing refinement and validation of data in this area may account for some of the annual change displayed in the below trend lines. (Figure 2) (Table 1).

\* Data should be interpreted with care due to impact of COVID-19 pandemic, please see 'COVID-19 impact on Patient Education / Self Management Programmes' and 'Appendix B Technical Notes' for detail.

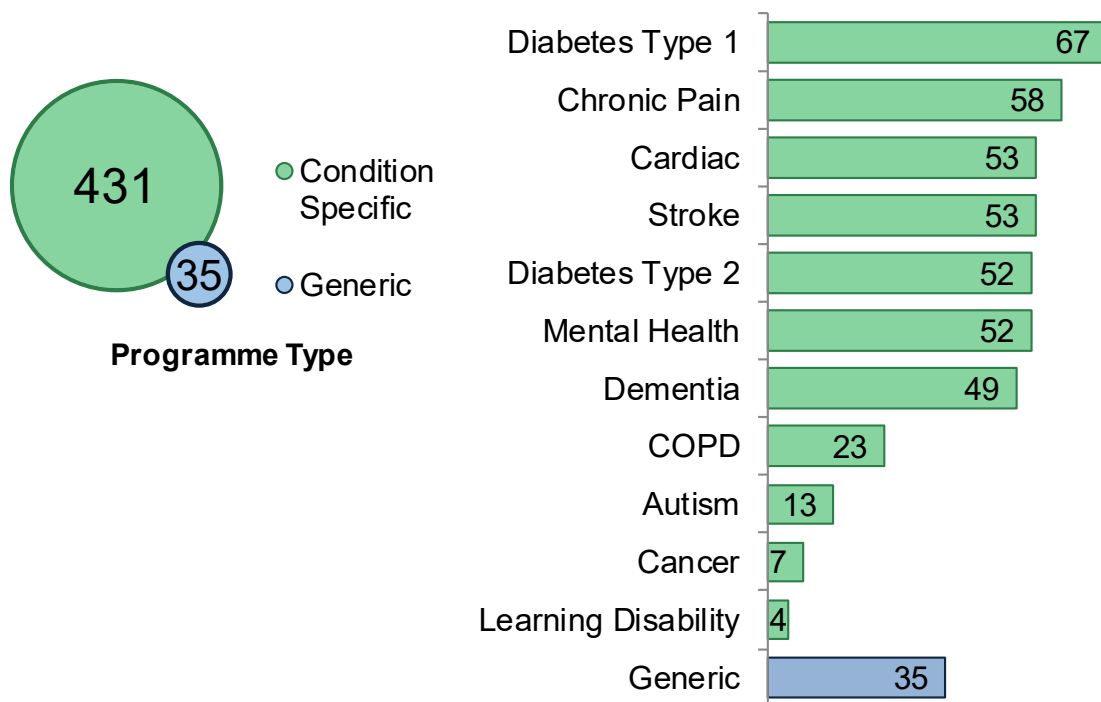
**Figure 2 Programme Frequency by HSC Trust Area (2016/17 – 2020/21)\***



### Programme Frequency by Provider Organisation

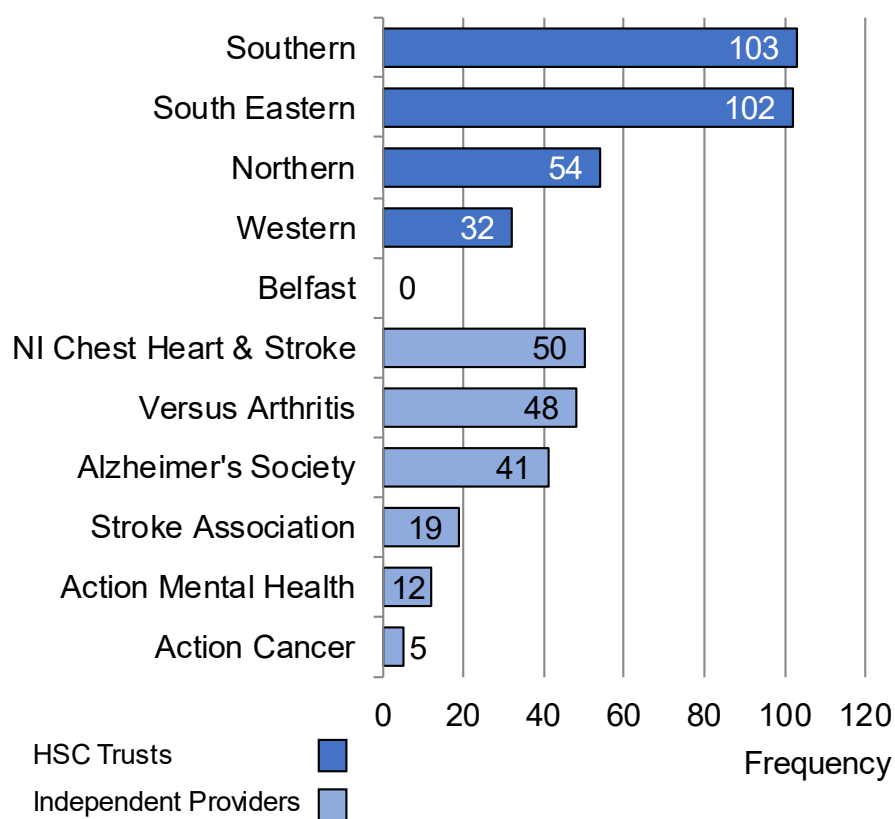
During 2020/21, of the 466 times that programmes ran, 93% were condition specific and 7% were generic. In comparison to 2019/20 where the most frequent programme was diabetes type 2, the most frequent programme in 2020/21 was diabetes type 1 (67), accounting for about a seventh (14%) of all programmes ran (Figure 3) (Table 2).

**Figure 3 Programme Frequency by Programme Type (2020/21)\***



\* Data should be interpreted with care due to impact of COVID-19 pandemic, please see 'COVID-19 impact on Patient Education / Self Management Programmes' and 'Appendix B Technical Notes' for detail.

**Figure 4 Programme Frequency by Provider Organisation (2020/21)\***



Just under two thirds (62%) programmes run during 2020/21 were provided by HSC Trusts (Figure 4). Of those programmes run by independent providers, NI Chest Heart and Stroke provided the most (50) (Table 4).

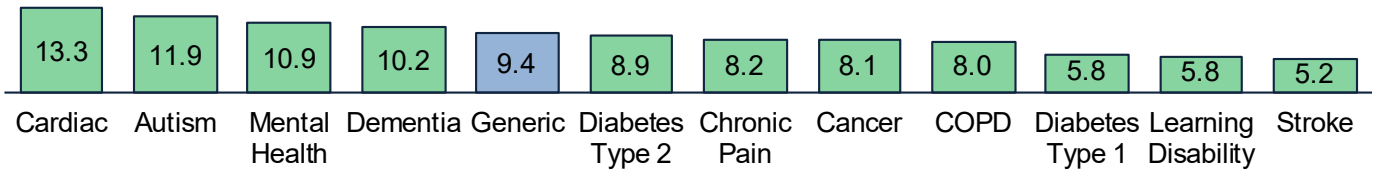
\* Data should be interpreted with care due to impact of COVID-19 pandemic, please see 'COVID-19 impact on Patient Education / Self Management Programmes' and 'Appendix B Technical Notes' for detail.

## 4. Conditions

### Average Number of Participants per Programme by Condition

The average number of participants per programme, by condition, ranged from just over 13, for those attending Cardiac programmes, to just over 5 for stroke programmes (Figure 5). The overall regional average number of participants per programme was 8.8.

**Figure 5 Average Number of Participants per Programme by Condition (2020/21)\***



Just over 1 in 11 participants at a patient education / self management programme in 2020/21 attended a diabetes type 1 specific programme (the most frequent programme in 2020/21).

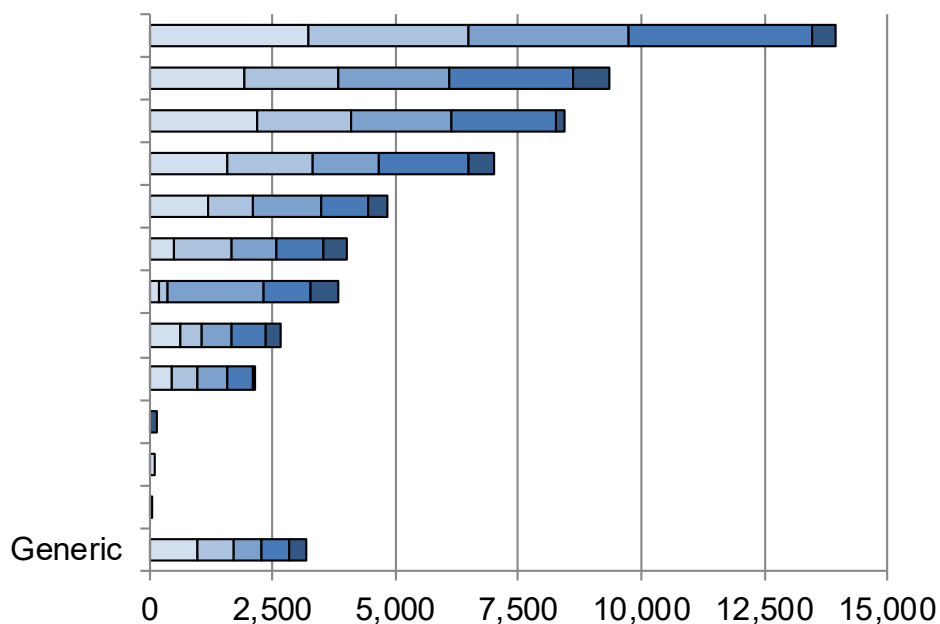


### Number of Participants by Programme Type

Over the last 5 years, large numbers of participants have been continually accessing programmes related to diabetes type 2, cardiac, COPD, and dementia as shown in (Figure 6) (Table 7). However, across the programme types, the reduction in participants reflects the impact of COVID-19 on these services. Due to the impact of COVID-19 on programme scheduling in 2019/20 and 2020/21, and subsequent resource issues experienced by organisations in submitting complete returns, extreme caution should be taken when comparing 2019/20 and 2020/21 against previous trend data, with the below figures included for illustrative purposes.

\* Data should be interpreted with care due to impact of COVID-19 pandemic, please see 'COVID-19 impact on Patient Education / Self Management Programmes' and 'Appendix B Technical Notes' for detail.

**Figure 6 Number of Participants by Programme Type (2016/17 – 2020/21)\*<sup>1</sup>**



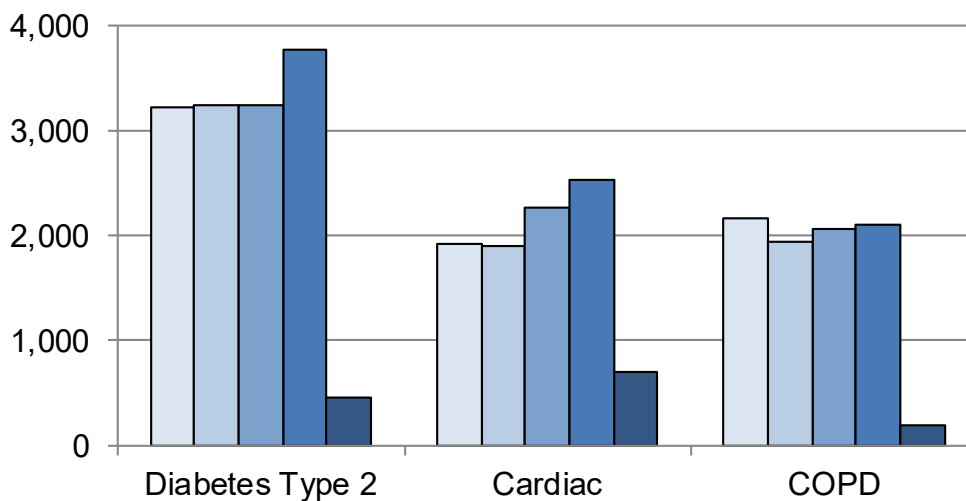
\* Data should be interpreted with care due to impact of COVID-19 pandemic, please see 'COVID-19 impact on Patient Education / Self Management Programmes' and 'Appendix B Technical Notes' for detail.

<sup>1</sup> Due to ongoing data validation, figures from 2018/19 were revised in 2019/20. Further information can be found in the Data Presentation section of Appendix B.

## Number of Participants by Condition

The annual number of participants attending chronic condition education programmes had remained high in previous years, with ongoing refinement and validation of data in this area accounting for some of the annual variance. Figure 7 shows the regular high attendance in Diabetes Type 2, Cardiac and COPD programmes since 2016/17. However, due to the impact of COVID-19 on programme scheduling in 2019/20 and 2020/21, and subsequent resource issues experienced by organisations in submitting complete returns, extreme caution should be taken when comparing 2019/20 and 2020/21 against previous trend data, with the below figures included for illustrative purposes.

**Figure 7** Number of Participants by Condition (2016/17 – 2020/21)<sup>2</sup>

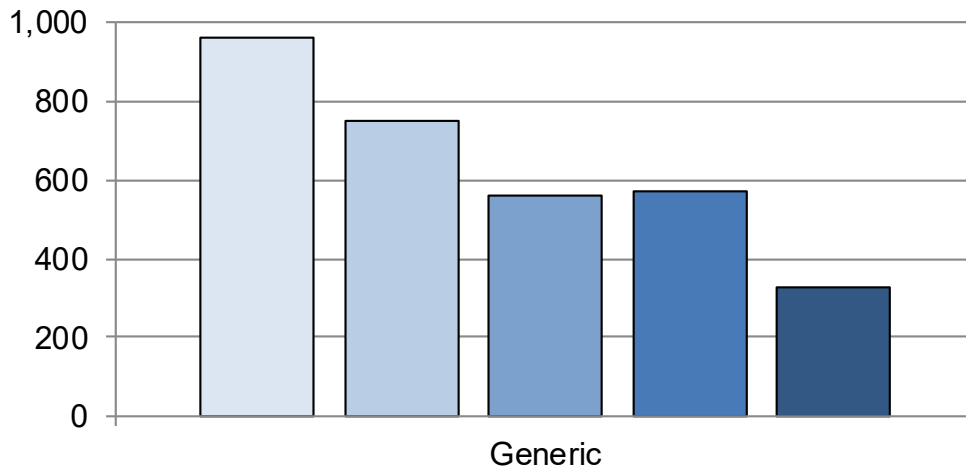


\* Data should be interpreted with care due to impact of COVID-19 pandemic, please see 'COVID-19 impact on Patient Education / Self Management Programmes' and 'Appendix B Technical Notes' for detail.

<sup>2</sup> Due to ongoing data validation, figures from 2018/19 were revised in 2019/20. Further information can be found in the Data Presentation section of Appendix B.

Over the last 5 years, an average of 633 participants have attended generic education programmes (Figure 8) (Table 7). Likely reasons for this may include greater derived benefit from tailored educational programmes. As before, due to the impact of COVID-19 on programme scheduling in 2019/20 and 2020/21, and subsequent resource issues experienced by organisations in submitting complete returns, extreme caution should be taken when comparing 2019/20 and 2020/21 against previous trend data, with the below figures included for illustrative purposes.

**Figure 8**      **Number of Participants by Condition (2016/17 – 2020/21) - Generic<sup>\*3</sup>**



\* Data should be interpreted with care due to impact of COVID-19 pandemic, please see 'COVID-19 impact on Patient Education / Self Management Programmes' and 'Appendix B Technical Notes' for detail.

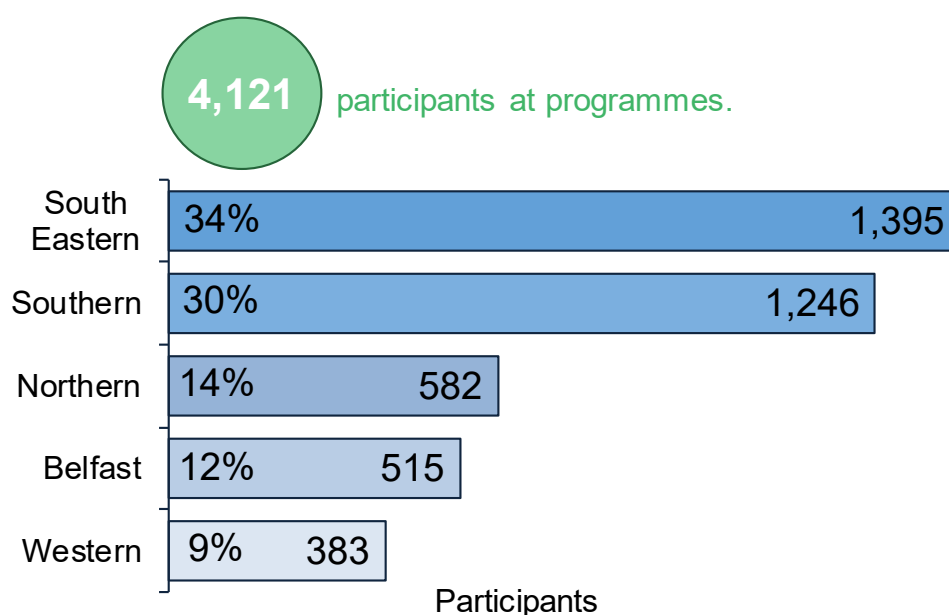
<sup>3</sup> Due to ongoing data validation, figures from 2018/19 were revised in 2019/20. Further information can be found in the Data Presentation section of Appendix B.

## 5. Participants

### Participant Numbers by HSC Trust Area

In 2020/21, 4,121 participants attended a patient education / self management programme ranging from 1,395 in the South Eastern HSC Trust area to 383 in the Western HSC Trust area (Figure 9) (Table 5). Belfast HSC Trust were unable to provide data for the 2020/21 publication, however some programmes were run in this HSC Trust by other providers. Data should be interpreted with care due to impact of COVID-19 pandemic, please see Technical Guidance for detail.

**Figure 9 Participant Numbers by HSC Trust Area (2020/21)\***



Approximately 1 in 3 of all participants attended a patient education / self management programme in the South Eastern Trust area in 2020/21



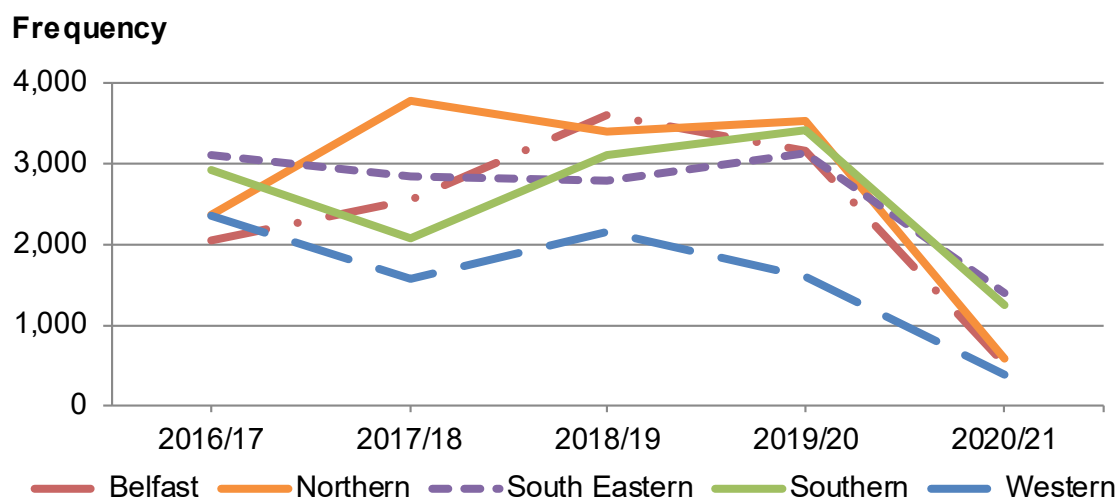
Between 2016/17 and 2019/20 participant numbers regionally increased by 16% (2,011), reflecting small increases across all HSC Trust areas, apart from Western HSC Trust which recorded a decrease of 32% (-764). Belfast HSC Trust were unable to provide data for the 2020/21 publication, however some programmes were run in this HSC Trust by other providers. Across the HSC Trusts, reduction in participant numbers reflects the impact of COVID-19 on the services. Regional participant numbers decreased in 2020/21 by 72% (-10,701) compared to the prior year. However, due to the impact of COVID-19 on programme scheduling in 2019/20 and 2020/21, and subsequent resource issues experienced by organisations in submitting complete returns, extreme caution should be taken when comparing 2019/20 and 2020/21 against previous trend data, with the below figures included for illustrative purposes. Please note that ongoing refinement and

\* Data should be interpreted with care due to impact of COVID-19 pandemic, please see 'COVID-19 impact on Patient Education / Self Management Programmes' and 'Appendix B Technical Notes' for detail.



validation of data in this area may account for some of the annual change displayed in the below trend lines. (Figure 2) (Table 1).

**Figure 10 Participant Numbers by HSC Trust Area (2016/17 – 2020/21)\*<sup>4</sup>**



## Participant Numbers by HSC Provider

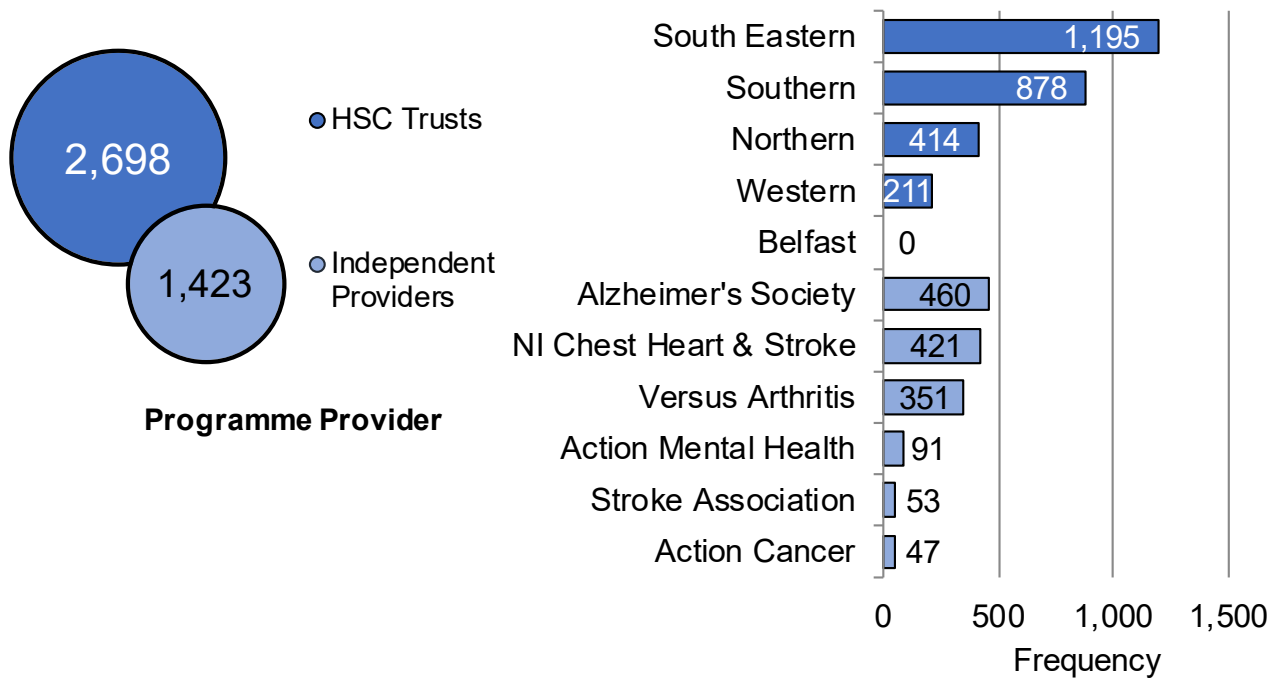
Of the 4,121 participants, 65% were attending a programme delivered by HSC Trusts and 35% a programme by independent sector organisations. In 2020/21, participant numbers at programmes provided by HSC Trusts (2,698) showed a 74% (-7,538) decrease over the number of participants in 2020/21 (10,236). The South Eastern Trust had the greatest number of participants (1,195), of all the HSC Trust providers, and 29% of the total regional participant numbers. Although data should be interpreted with care due to impact of COVID-19 pandemic, please see Technical Guidance for detail. In addition, Belfast HSC Trust were unable to provide data for the 2020/21 publication.

While the Alzheimer's Society had the greatest number of participants (460), of all the independent sector providers, and 11% 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 higher 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.

\* Data should be interpreted with care due to impact of COVID-19 pandemic, please see 'COVID-19 impact on Patient Education / Self Management Programmes' and 'Appendix B Technical Notes' for detail.

<sup>4</sup> Due to ongoing data validation, figures from 2018/19 were revised in 2019/20. Further information can be found in the Data Presentation section of Appendix B.

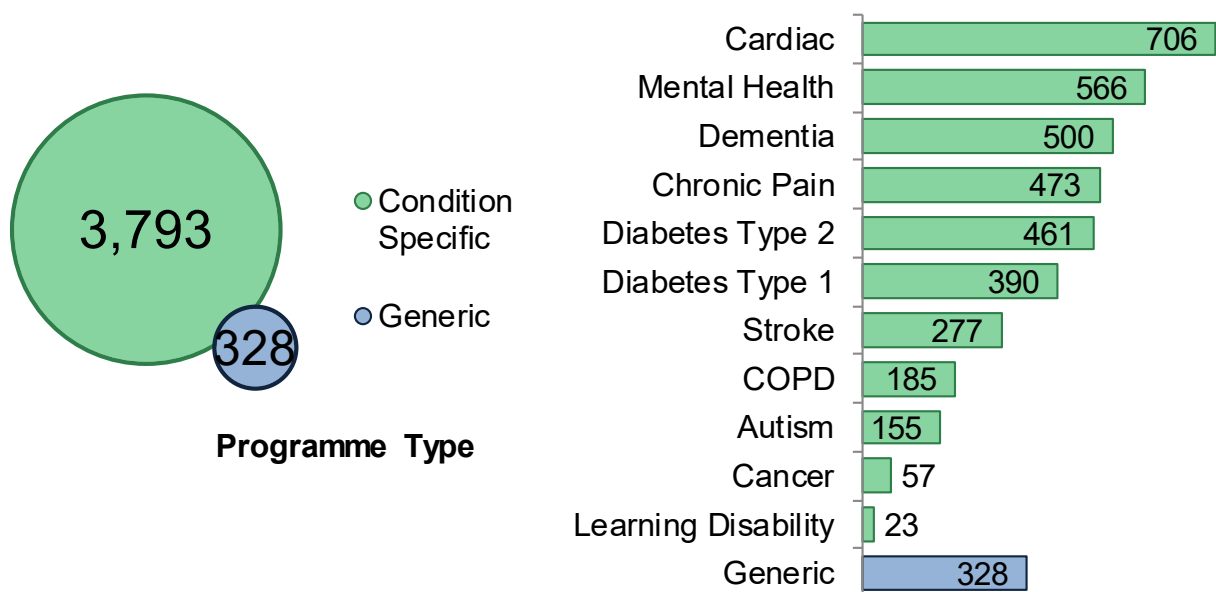
**Figure 11 Participant Numbers by Provider Organisation (2020/21)\***



### Participant Numbers by Programme Type

Of the 4,121 participants at programmes, 92% were attending a condition specific programme with 8% attending a generic programme. Figure 12 shows that the majority of participants (17%) attended a cardiac programme; followed by mental health programmes (14%).

**Figure 12 Participant Numbers by Programme Type (2020/21)\***



\* Data should be interpreted with care due to impact of COVID-19 pandemic, please see 'COVID-19 impact on Patient Education / Self Management Programmes' and 'Appendix B Technical Notes' for detail.

## Participants by Programme Delivery

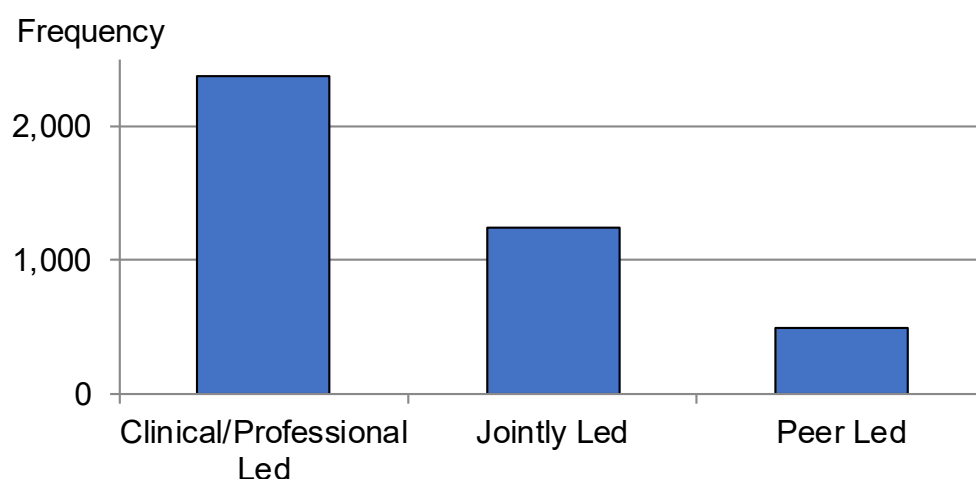
In previous years the top 6 conditions, by participant numbers, had programmes available across all 5 HSC Trust areas with the exception of cardiac specific programmes reported in the Western HSC Trust area. However, due to the impact of the COVID-19 pandemic, this year the only condition of the 2020/21 top 6 with a programme available in all HSC Trusts was chronic pain. Cardiac programmes were only recorded in South Eastern HSC Trust, no mental health programmes were recorded for Belfast and Western HSC Trusts, and programmes for dementia and type 2 diabetes ran in all HSC Trusts except Western HSC Trust and Belfast HSC Trust, respectively. (Table 6).

Data should be interpreted with care due to impact of COVID-19 pandemic, please see Technical Guidance for detail. Belfast HSC Trust were unable to provide data for the 2020/21 publication, however some programmes were run in this HSC Trust by other providers.

In 2020/21, 58% (2,384) of participants attended a programme that was either clinically or professionally led; this was lower than the proportion in 2019/20 (71%). Participants at jointly led programmes accounted for 30% (1,248) of the total, with the remaining 12% (489) of participants attending a programme that was peer led.

Of the participants at clinically or professionally led programmes in 2020/21, 100% (2,384) were attending a condition specific programme. 76% (19) of those at a jointly led programme and 82% (9) at a peer led programme (Table 9) were attending condition specific programmes.

**Figure 13 Number of Participants by Programme Delivery (2020/21)\***

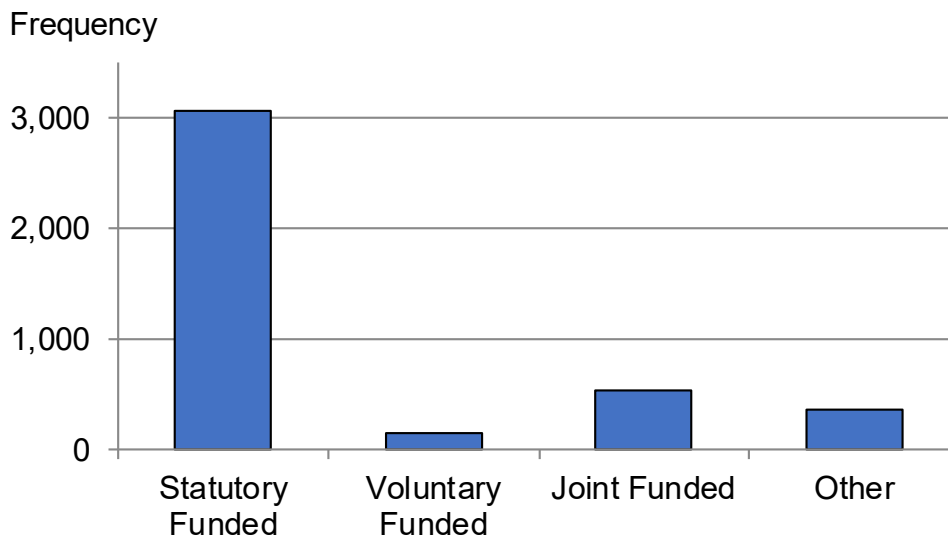


\* Data should be interpreted with care due to impact of COVID-19 pandemic, please see 'COVID-19 impact on Patient Education / Self Management Programmes' and 'Appendix B Technical Notes' for detail.

## Participants by Funding Arrangement

In 2020/21, 74% (3,062) of participants attended a programme that was statutory funded, a percentage increase of 5% (-6,583) since the previous year. Jointly funded programmes were provided for 13% of participants; with 4% of participants each attending voluntary funded programmes and 9% at programmes utilising other funding arrangements<sup>5</sup> (Table 10).

**Figure 14** Number of Participants by Funding Arrangement (2020/21)<sup>5</sup>



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\* Data should be interpreted with care due to impact of COVID-19 pandemic, please see 'COVID-19 impact on Patient Education / Self Management Programmes' and 'Appendix B Technical Notes' for detail.

<sup>5</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.

## 6. Tables

Table 1: Programme Frequency by HSC Trust Area (2016/17 -2020/21)<sup>1, 2</sup>

HSC Trust	2016/17	2017/18	2018/19	2019/20	2020/21
Belfast	240	306	317	305	63
Northern	264	368	267	249	76
South Eastern	319	291	260	242	138
Southern	241	227	221	240	135
Western	187	197	169	163	54
<b>Northern Ireland</b>	<b>1,251</b>	<b>1,389</b>	<b>1,234</b>	<b>1,199</b>	<b>466</b>

<sup>1</sup> Please note that a number of organisations advised of disruption to programmes due to the impact of COVID-19.

- Belfast HSC Trust figures for 2019/20 figures were imputed based on their 2018/19 return, as a completed 2019/20 return was not received ahead of publication. Belfast HSC Trust did not complete a return ahead of publication in 2020/21, and due to the likely impact of COVID-19 on programme provision in this year, imputing figures based on prior years would have likely been inaccurate. Therefore, Belfast HSC Trust data is unavailable for 2020/21; however some programmes were run in this HSC Trust by other providers.

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

- AWARE was unable to provide a 2019/20 return, and AWARE, Cancer Focus, Cancer Lifeline and Macmillan Cancer Support were unable to submit a 2020/21 return due to COVID-19 pressures.

- A number of organisations advised of disruption to programmes due to the impact of COVID-19. For many organisations there was a reduction in the number of programmes provided and participants attending. Please see 'COVID-19 impact on Patient Education / Self Management Programmes' and 'Appendix B Technical Notes' for detail.

<sup>2</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 (2020/21)<sup>3</sup>

Programme Type	Belfast	Northern	South Eastern	Southern	Western	Total
<b>Condition Specific</b>	<b>58</b>	<b>71</b>	<b>136</b>	<b>120</b>	<b>46</b>	<b>431</b>
Autism	-	2	11	-	-	<b>13</b>
Cancer	2	2	1	1	1	<b>7</b>
Cardiac	-	-	53	-	-	<b>53</b>
Chronic Pain	18	13	12	8	7	<b>58</b>
COPD	-	-	8	11	4	<b>23</b>
Dementia	27	8	10	4	-	<b>49</b>
Diabetes Type 1	-	15	21	13	18	<b>67</b>
Diabetes Type 2	-	4	6	32	10	<b>52</b>
Learning Disability	-	-	2	2	-	<b>4</b>
Mental Health	-	14	1	37	-	<b>52</b>
Stroke	11	13	11	12	6	<b>53</b>
<b>Generic</b>	<b>5</b>	<b>5</b>	<b>2</b>	<b>15</b>	<b>8</b>	<b>35</b>
<b>Total</b>	<b>63</b>	<b>76</b>	<b>138</b>	<b>135</b>	<b>54</b>	<b>466</b>

<sup>3</sup> Please note that a number of organisations advised of disruption to programmes due to the impact of COVID-19.

- Belfast HSC Trust did not complete a return ahead of publication in 2020/21, and due to the likely impact of COVID-19 on programme provision in this year, imputing figures based on prior years would have likely been inaccurate. Therefore, Belfast HSC Trust data is unavailable for 2020/21; however some programmes were run in this HSC Trust by other providers.

- AWARE, Cancer Focus, Cancer Lifeline and Macmillan Cancer Support were unable to submit a 2020/21 return due to COVID-19 pressures.

- A number of organisations advised of disruption to programmes due to the impact of COVID-19. For many organisations, there was a reduction in the number of programmes provided and participants attending. Please see 'COVID-19 impact on Patient Education / Self Management Programmes' and 'Appendix B Technical Notes' for detail.

Table 3: Frequency of Programmes by Type HSC Trust Area (2016/17-2020/21) – Condition Specific<sup>4, 5</sup>

HSC Trust	2016/17	2017/18	2018/19	2019/20	2020/21
Belfast	234	298	312	301	58
Northern	264	361	267	247	71
South Eastern	276	288	257	286	136
Southern	228	200	206	220	120
Western	161	171	147	152	46
<b>Northern Ireland</b>	<b>1,163</b>	<b>1,318</b>	<b>1,189</b>	<b>1,206</b>	<b>431</b>

<sup>4</sup> Please note that a number of organisations advised of disruption to programmes due to the impact of COVID-19.

- Belfast HSC Trust figures for 2019/20 figures were imputed based on their 2018/19 return, as a completed 2019/20 return was not received ahead of publication. Belfast HSC Trust did not complete a return ahead of publication in 2020/21, and due to the likely impact of COVID-19 on programme provision in this year, imputing figures based on prior years would have likely been inaccurate. Therefore, Belfast HSC Trust data is unavailable for 2020/21; however some programmes were run in this HSC Trust by other providers.

- SEHSCT were unable to provide a complete data return of cardiac programmes ahead of publication in 2019/20, however in 2020/21 a full cardiac return was completed.

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- AWARE was unable to provide a 2019/20 return, and AWARE, Cancer Focus, Cancer Lifeline and Macmillan Cancer Support were unable to submit a 2020/21 return due to COVID-19 pressures.

- A number of organisations advised of disruption to programmes due to the impact of COVID-19. For many organisations there was a reduction in the number of programmes provided and participants attending. Please see 'COVID-19 impact on Patient Education / Self Management Programmes' and 'Appendix B Technical Notes' for detail.

<sup>5</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: Frequency of Programmes by Type HSC Trust Area (2016/17-2020/21) – Generic<sup>6</sup>

HSC Trust	2016/17	2017/18	2018/19	2019/20	2020/21
Belfast	6	8	5	4	5
Northern	-	7	-	2	5
South Eastern	43	3	3	2	2
Southern	13	27	15	20	15
Western	26	26	22	11	8
<b>Northern Ireland</b>	<b>88</b>	<b>71</b>	<b>45</b>	<b>39</b>	<b>35</b>

<sup>6</sup> Please note that a number of organisations advised of disruption to programmes due to the impact of COVID-19.

- Belfast HSC Trust figures for 2019/20 figures were imputed based on their 2018/19 return, as a completed 2019/20 return was not received ahead of publication. Belfast HSC Trust did not complete a return ahead of publication in 2020/21, and due to the likely impact of COVID-19 on programme provision in this year, imputing figures based on prior years would have likely been inaccurate. Therefore, Belfast HSC Trust data is unavailable for 2020/21; however some programmes were run in this HSC Trust by other providers.

- A number of organisations advised of disruption to programmes due to the impact of COVID-19. For many organisations there was a reduction in the number of programmes provided and participants attending. Please see 'COVID-19 impact on Patient Education / Self Management Programmes' and 'Appendix B Technical Notes' for detail.



Table 5: Programme Frequency by Provider Organisation (2020/21)<sup>7</sup>

Provider Organisation	2020/21
Action Cancer	5
Action Mental Health	12
Alzheimer's Society	41
NI Chest Heart & Stroke	50
Stroke Association	19
Versus Arthritis	48
BHSCT	-
NHSCT	54
SEHSCT	102
SHSCT	103
WHSCT	32
<b>Total</b>	<b>466</b>

<sup>7</sup> Please note that a number of organisations advised of disruption to programmes due to the impact of COVID-19.

- Belfast HSC Trust did not complete a return ahead of publication in 2020/21, and due to the likely impact of COVID-19 on programme provision in this year, imputing figures based on prior years would have likely been inaccurate. Therefore, Belfast HSC Trust data is unavailable for 2020/21; however some programmes were run in this HSC Trust by other providers.

- AWARE, Cancer Focus, Cancer Lifeline and Macmillan Cancer Support were unable to submit a 2020/21 return due to COVID-19 pressures.

- A number of organisations advised of disruption to programmes due to the impact of COVID-19. For many organisations there was a reduction in the number of programmes provided and participants attending. Please see 'COVID-19 impact on Patient Education / Self Management Programmes' and 'Appendix B Technical Notes' for detail.

Table 6: Participants Numbers by HSC Trust Area (2016/17-2020/21)<sup>8, 9</sup>

HSC Trust	2016/17	2017/18	2018/19	2019/20	2020/21
Belfast	2,056	2,541	3,602	3,163	515
Northern	2,359	3,778	3,397	3,528	582
South Eastern	3,110	2,842	2,778	3,128	1,395
Southern	2,933	2,070	3,101	3,414	1,246
Western	2,353	1,566	2,155	1,589	383
<b>Northern Ireland</b>	<b>12,811</b>	<b>12,797</b>	<b>15,033</b>	<b>14,822</b>	<b>4,121</b>

<sup>8</sup> Please note that a number of organisations advised of disruption to programmes due to the impact of COVID-19.

- Belfast HSC Trust figures for 2019/20 figures were imputed based on their 2018/19 return, as a completed 2019/20 return was not received ahead of publication. Belfast HSC Trust did not complete a return ahead of publication in 2020/21, and due to the likely impact of COVID-19 on programme provision in this year, imputing figures based on prior years would have likely been inaccurate. Therefore, Belfast HSC Trust data is unavailable for 2020/21; however some programmes were run in this HSC Trust by other providers.

- SEHSCT were unable to provide a complete data return of cardiac programmes ahead of publication in 2019/20, however in 2020/21 a full cardiac return was completed.

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

- AWARE was unable to provide a 2019/20 return, and AWARE, Cancer Focus, Cancer Lifeline and Macmillan Cancer Support were unable to submit a 2020/21 return due to COVID-19 pressures.

- A number of organisations advised of disruption to programmes due to the impact of COVID-19. For many organisations there was a reduction in the number of programmes provided and participants attending. Please see 'COVID-19 impact on Patient Education / Self Management Programmes' and 'Appendix B Technical Notes' for detail.

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

Table 7: Participants Numbers by Programme Type and HSC Trust Area (2020/21)<sup>10, 11</sup>

Programme Type	Belfast	Northern	South Eastern	Southern	Western	Total
<b>Condition Specific</b>	<b>465</b>	<b>530</b>	<b>1,371</b>	<b>1,120</b>	<b>307</b>	<b>3,793</b>
Autism	-	10	145	-	-	<b>155</b>
Cancer	23	10	9	7	8	<b>57</b>
Cardiac	-	-	706	-	-	<b>706</b>
Chronic Pain	108	143	101	73	48	<b>473</b>
COPD	-	-	103	46	36	<b>185</b>
Dementia	286	40	34	140	-	<b>500</b>
Diabetes Type 1	-	82	187	59	62	<b>390</b>
Diabetes Type 2	-	13	37	298	113	<b>461</b>
Learning Disability	-	-	13	10	-	<b>23</b>
Mental Health	-	170	4	392	-	<b>566</b>
Stroke	48	62	32	95	40	<b>277</b>
<b>Generic</b>	<b>50</b>	<b>52</b>	<b>24</b>	<b>126</b>	<b>76</b>	<b>328</b>
<b>Total</b>	<b>515</b>	<b>582</b>	<b>1,395</b>	<b>1,246</b>	<b>383</b>	<b>4,121</b>

<sup>10</sup> Please note that a number of organisations advised of disruption to programmes due to the impact of COVID-19.

- Belfast HSC Trust did not complete a return ahead of publication in 2020/21, and due to the likely impact of COVID-19 on programme provision in this year, imputing figures based on prior years would have likely been inaccurate. Therefore, Belfast HSC Trust data is unavailable for 2020/21; however some programmes were run in this HSC Trust by other providers.

- AWARE, Cancer Focus, Cancer Lifeline and Macmillan Cancer Support were unable to submit a 2020/21 return due to COVID-19 pressures.

- A number of organisations advised of disruption to programmes due to the impact of COVID-19. For many organisations, there was a reduction in the number of programmes provided and participants attending. Please see 'COVID-19 impact on Patient Education / Self Management Programmes' and 'Appendix B Technical Notes' for detail.

<sup>11</sup> Due to ongoing data validation, figures for 2018/19 have been revised. Further information can be found in the Technical notes in [Appendix B](#).

Table 8: Participant Numbers by Condition (2016/17 – 2020/21)<sup>12, 13</sup>

Programme Type	2016/17	2017/18	2018/19	2019/20	2020/21
<b>Condition Specific</b>	<b>11,853</b>	<b>12,047</b>	<b>14,472</b>	<b>14,252</b>	<b>3,793</b>
Arthritis	83	-	-	-	-
Autism	-	-	-	-	155
COPD	2,160	1,934	2,057	2,099	185
Cancer	443	526	625	503	57
Cardiac	1,929	1,894	2,271	2,535	706
Chronic Pain	466	1,204	921	944	473
Dementia	1,555	1,752	1,369	1,810	500
Diabetes Type 1	1,194	898	1,378	964	390
Diabetes Type 2	3,223	3,252	3,243	3,761	461
Learning Disability	-	-	-	-	23
Mental Health	188	168	1,974	936	566
Stroke	612	419	634	700	277
<b>Generic</b>	<b>958</b>	<b>750</b>	<b>561</b>	<b>570</b>	<b>328</b>
<b>Total</b>	<b>12,811</b>	<b>12,797</b>	<b>15,033</b>	<b>14,822</b>	<b>4,121</b>

<sup>12</sup> Please note that a number of organisations advised of disruption to programmes due to the impact of COVID-19.

- Belfast HSC Trust figures for 2019/20 figures were imputed based on their 2018/19 return, as a completed 2019/20 return was not received ahead of publication. Belfast HSC Trust did not complete a return ahead of publication in 2020/21, and due to the likely impact of COVID-19 on programme provision in this year, imputing figures based on prior years would have likely been inaccurate. Therefore, Belfast HSC Trust data is unavailable for 2020/21; however some programmes were run in this HSC Trust by other providers.

- SEHSCT were unable to provide a complete data return of cardiac programmes ahead of publication in 2019/20, however in 2020/21 a full cardiac return was completed.

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

- AWARE was unable to provide a 2019/20 return, and AWARE, Cancer Focus, Cancer Lifeline and Macmillan Cancer Support were unable to submit a 2020/21 return due to COVID-19 pressures.

- A number of organisations advised of disruption to programmes due to the impact of COVID-19. For many organisations there was a reduction in the number of programmes provided and participants attending. Please see 'COVID-19 impact on Patient Education / Self Management Programmes' and 'Appendix B Technical Notes' for detail.

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

Table 9: Participants Numbers by Provider Organisation (2016/17-2020/21)<sup>14, 15</sup>

Provider Organisation	2016/17	2017/18	2018/19	2019/20	2020/21
Action Cancer	60	77	80	97	47
Action Mental Health	217	185	296	318	91
Alzheimer's Society	1,422	1,752	1,364	1,769	460
Aware	-	-	735	-	-
Cancer Focus NI	85	96	30	17	-
Cancer Lifeline	49	38	22	15	-
Macmillan Cancer Support	30	41	54	37	-
NI Chest Heart & Stroke	519	639	750	868	421
Stroke Association	258	53	85	92	53
Versus Arthritis	357	704	637	614	351
BHSCT	1,775	1,726	2,552	2,552	-
NHSCT	2,087	2,919	2,996	2,981	414
SEHSCT	2,862	2,331	2,134	2,362	1,195
SHSCT	1,795	1,447	1,993	2,198	878
WHSCT	1,295	789	1,305	902	211
<b>Total</b>	<b>12,811</b>	<b>12,797</b>	<b>15,033</b>	<b>14,822</b>	<b>4,121</b>

<sup>14</sup> Please note that a number of organisations advised of disruption to programmes due to the impact of COVID-19.

- Belfast HSC Trust figures for 2019/20 figures were imputed based on their 2018/19 return, as a completed 2019/20 return was not received ahead of publication. Belfast HSC Trust did not complete a return ahead of publication in 2020/21, and due to the likely impact of COVID-19 on programme provision in this year, imputing figures based on prior years would have likely been inaccurate. Therefore, Belfast HSC Trust data is unavailable for 2020/21; however some programmes were run in this HSC Trust by other providers.

- SEHSCT were unable to provide a complete data return of cardiac programmes ahead of publication in 2019/20, however in 2020/21 a full cardiac return was completed.

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

- AWARE was unable to provide a 2019/20 return, and AWARE, Cancer Focus, Cancer Lifeline and Macmillan Cancer Support were unable to submit a 2020/21 return due to COVID-19 pressures.

- A number of organisations advised of disruption to programmes due to the impact of COVID-19. For many organisations there was a reduction in the number of programmes provided and participants attending. Please see 'COVID-19 impact on Patient Education / Self Management Programmes' and 'Appendix B Technical Notes' for detail.

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

Table 10: Participants Numbers by Programme Type and Programme Delivery (2020/21)<sup>16</sup>

Programme Type	Clinical / Professional Led	Peer Led	Jointly Led	Total
<b>Condition Specific</b>	<b>2,375</b>	<b>410</b>	<b>1,008</b>	<b>3,793</b>
Arthritis	122	-	33	<b>155</b>
Cancer	57	-	-	<b>57</b>
Cardiac	706	-	-	<b>706</b>
Chronic Pain	128	297	48	<b>473</b>
COPD	149	-	36	<b>185</b>
Dementia	40	-	460	<b>500</b>
Diabetes Type 1	328	-	62	<b>390</b>
Diabetes Type 2	348	113	-	<b>461</b>
Mental Health	23	-	-	<b>23</b>
Stroke	421	-	145	<b>566</b>
Other	53	-	224	<b>277</b>
<b>Generic</b>	<b>9</b>	<b>79</b>	<b>240</b>	<b>328</b>
<b>Total</b>	<b>2,384</b>	<b>489</b>	<b>1,248</b>	<b>4,121</b>

<sup>16</sup> Please note that a number of organisations advised of disruption to programmes due to the impact of COVID-19.

- Belfast HSC Trust did not complete a return ahead of publication in 2020/21, and due to the likely impact of COVID-19 on programme provision in this year, imputing figures based on prior years would have likely been inaccurate. Therefore, Belfast HSC Trust data is unavailable for 2020/21; however some programmes were run in this HSC Trust by other providers.

- AWARE, Cancer Focus, Cancer Lifeline and Macmillan Cancer Support were unable to submit a 2020/21 return due to COVID-19 pressures.

- A number of organisations advised of disruption to programmes due to the impact of COVID-19. For many organisations, there was a reduction in the number of programmes provided and participants attending. Please see 'COVID-19 impact on Patient Education / Self Management Programmes' and 'Appendix B Technical Notes' for detail.

Table 11: Participants Numbers by Programme Type and Funding Arrangements (2020/21)<sup>17, 18</sup>

Programme Type	Statutory Funded	Voluntary Funded	Joint Funded	Other <sup>16</sup>	Total
<b>Condition Specific</b>	<b>2,931</b>	<b>4</b>	<b>492</b>	<b>366</b>	<b>3,793</b>
Autism	145	-	-	10	155
Cancer	53	4	-	-	57
Cardiac	706	-	-	-	706
Chronic Pain	473	-	-	-	473
COPD	180	-	-	5	185
Dementia	360	-	140	-	500
Diabetes Type 1	292	-	62	36	390
Diabetes Type 2	448	-	13	-	461
Learning Disability	23	-	-	-	23
Mental Health	251	-	-	315	566
Stroke	-	-	277	-	277
<b>Generic</b>	<b>131</b>	<b>150</b>	<b>47</b>	<b>-</b>	<b>328</b>
<b>Total</b>	<b>3,062</b>	<b>154</b>	<b>539</b>	<b>366</b>	<b>4,121</b>

<sup>17</sup> Please note that a number of organisations advised of disruption to programmes due to the impact of COVID-19.

- Belfast HSC Trust did not complete a return ahead of publication in 2020/21, and due to the likely impact of COVID-19 on programme provision in this year, imputing figures based on prior years would have likely been inaccurate. Therefore, Belfast HSC Trust data is unavailable for 2020/21; however some programmes were run in this HSC Trust by other providers.

- AWARE, Cancer Focus, Cancer Lifeline and Macmillan Cancer Support were unable to submit a 2020/21 return due to COVID-19 pressures.

- A number of organisations advised of disruption to programmes due to the impact of COVID-19. For many organisations, there was a reduction in the number of programmes provided and participants attending. Please see 'COVID-19 impact on Patient Education / Self Management Programmes' and 'Appendix B Technical Notes' for detail.

<sup>18</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 2020 to 31 March 2021.

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 ongoing 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 2020/21. Information was provided by HSC Trusts and independent sector organisations who delivered programmes during 2020/21. The report summarises the key statistical information provided for the year 2020/21 and how this compares with that collected in previous years.

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<sup>4</sup> [Programme for Government 2011 - 2015 | Northern Ireland Executive](#)



## 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 2021 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.

Data Validation Issues
Aware did not provide figures for 2015/16-2017/18.
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

<b>Data Validation Issues</b>
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 ' <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.
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.
Please note the following limitations for 2019/20 data <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-19.</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>- SEHSCT were unable to provide a complete data return of cardiac programmes ahead of publication in 2019/20, but a complete return was provided in 2020/21.</li> <li>- WHSCT diabetes programmes were estimated based on previous return, as it wasn't possible to submit a validated 2019/20 return ahead of publication deadline.</li> </ul>
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.
- Belfast HSC Trust did not complete a return ahead of publication in 2020/21, and due to the likely impact of COVID-19 on programme provision in this year, imputing figures based on prior years would have likely been inaccurate. Therefore, Belfast HSC Trust data is unavailable for 2020/21.
- A number of organisations advised of disruption to programmes due to the impact of COVID-19. For many organisations there was a reduction in the number of programmes provided and participants attending. Please see 'COVID-19 impact on Patient Education / Self Management Programmes' for detail.
- Cancer Focus, Cancer Lifeline, and Macmillan Cancer Support were unable to submit a return due to COVID-19 pressures in 2020/21.

## Amendments

The cut-off point for amendments to data was 28<sup>th</sup> February 2022. 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.

## 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.

Please send any comments you have to [cib@health-ni.gov.uk](mailto:cib@health-ni.gov.uk).

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

<b>This data collection IS covering</b>	<b>This data collection IS NOT 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><li>• Carers.</li></ul> Both HSC Trust <u>and</u> Independent sector	Any kind of "Support groups" for either physical or mental health long term conditions. By 'support groups' we mean informal, unstructured groups with no time limit.  One-to-one reviews or appointments with health and social care	LTCs relating to physical health eg: <ul style="list-style-type: none"><li>• Diabetes;</li><li>• Cardiac;</li><li>• COPD / respiratory;</li><li>• Stroke / dementia / neurological;</li></ul>

<p>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>professionals, e.g. GPs or other primary / community care professionals.</p>	<ul style="list-style-type: none"> <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

Abbreviations	Full term
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

<b>Abbreviations</b>	<b>Full term</b>
HOPE	Help to Overcome Problems Effectively
IBD	Inflammatory Bowel Disease
NHSCT	Northern Health and Social Care Trust
PUMPS	Insulin Pump Education Programme
SEHSCT	South Eastern Health and Social Care Trust
SET2	Southern Education Type 2
SHAIRE	Southern Health Adjusting Insulin Round Eating
SHSCT	Southern Health and Social Care Trust
WHSCT	Western Health and Social Care Trust

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