



Patient Education / Self Management Programmes for People with Long Term Conditions (2023/24)





Reader Information

Theme Social Care – Patient Education / Self Management

Document Purpose For information

Authors / Statisticians Louise Walker, Lee Beattie, Terence McShane,

Malcolm Megaw

Publication Date 4th June 2025

Issued by Community Information Branch Information & Analysis Directorate

Department of Health Stormont Estate

Belfast, BT4 3SQ

Email cib@health-ni.gov.uk

Internet address https://www.health-ni.gov.uk/topics/doh-statistics-and-

research/patient-education-programmes

Target Audience Commissioners of programmes for long term conditions,

Chief Executives of HSC Board and Trusts in Northern Ireland, voluntary care organisations, health care professionals, academics and social care stakeholders.

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.

Copyright This publication is Crown copyright and may be

reproduced free of charge in any format or medium. Any material used must be acknowledged, and the title of the

publication specified.

Price Free

We would greatly welcome any feedback that you have regarding the content of this publication. Please send any comments you may have to cib@health-ni.gov.uk.

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 <u>Code of Practice</u> for Official Statistics.

https://www.healthni.gov.uk/topics/doh-statisticsand-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 decisionmaking 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.

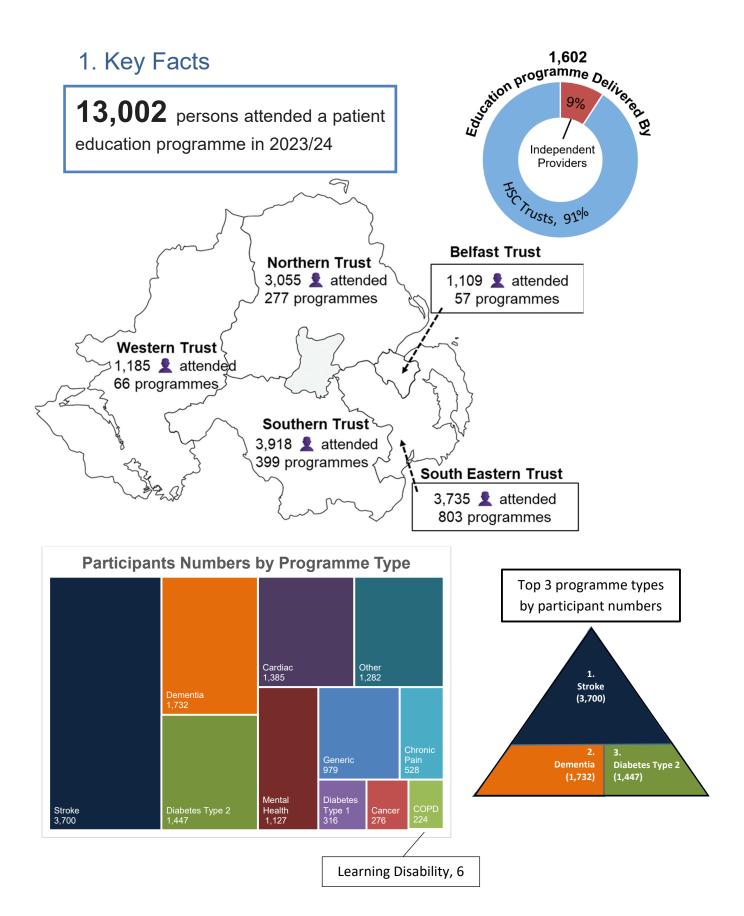
We collect, analyse, and publish a wide range of community information that is used to help monitor the delivery of personal social services policy. Information collected by CIB is used to assess HSC Trust performance, for corporate monitoring, policy evaluation, and to respond to parliamentary/assembly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

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

Contents

1. Key Facts 6
2. Programmes
COVID-19 impact on Patient Education / Self Management Programmes7
3. Programmes9
Programme Frequency by HSC Trust Area9
Programme Frequency by Programme Type
Programme Frequency by Provider Organisation 10
4. Conditions
Number of Participants by Programme Type 12
Number of Participants by Condition 14
5. Participants
Participant Numbers by HSC Trust Area16
Participant Numbers by Programme Type18
Participants by Programme Delivery 19
Participants by Funding Arrangement 20
6. Tables21
Table 1: Programme Frequency by HSC Trust Area (2019/20 - 2023/24) ^{1,} 21
Table 2: Programme Frequency by Programme Type and HSC Trust Area (2023/24) 22
Table 3: Frequency of Programmes by Type and HSC Trust Area (2019/20-2023/24) -
Condition Specific [,] 23
Table 4: Frequency of Programmes by Type and HSC Trust Area (2019/20-2023/24) -
Generic 24
Table 5: Programme Frequency by Provider Organisation (2023/24)25
Table 6: Participants Numbers by HSC Trust Area (2019/20-2023/24) 26
Table 7: Participants Numbers by Programme Type and HSC Trust Area (2023/24) - 27
Table 8: Participant Numbers by Condition (2019/20 – 2023/24) 28
Table 9: Participants Numbers by Provider Organisation (2019/20-2023/24) 29
Table 10: Participants Numbers by Programme Type and Programme Delivery
(2023/24) 30

Table 11: Participants Numbers by Programme Type and	Funding Arrangements
(2023/24)	31
Appendix A: Background	32
Appendix B: Technical Notes	33
Data Collection	33
Data Quality	33
Data Presentation	33
Amendments	35
Rounding Conventions	35
Revisions Policy	35
Main Uses of Data	35
Contact	35
User Feedback	35
Abbreviations	36



2. Programmes

COVID-19 impact on Patient Education / Self Management Programmes

When considering historical data, 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 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 from 2020/21 to 2023/24, and due to the likely impact of COVID-19 on programme provision in these years, imputing figures based on prior years would have likely been inaccurate. Therefore, Belfast HSC Trust data is unavailable for 2020/21, 2021/22, 2022/23, and 2023/24.
 - AWARE was unable to provide a 2019/20, 2020/21, or 2023/24 return, however AWARE NI did have programmes recorded on Trust returns. Cancer Focus and Macmillan were unable to provide returns from 2020/21 to 2023/24. Cancer Lifeline was unable to submit a 2020/21 return. This was likely 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 was 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 restrictions due to the COVID-19 pandemic have eased, if the format has been successful, and if this suits the structure of the programme. Some programme providers noted in 2021/22 that they have incorporated a hybrid structure of online and face to face delivery.

3. Programmes

Programme Frequency by HSC Trust Area

In 2023/24 there were 78 different patient education / self management programmes in place across Northern Ireland. These programmes ran a total of 1,602 times within HSC Trust areas throughout the year, ranging from 803 in the South Eastern HSC Trust area to 57 in the Belfast HSC Trust area (Figure 1).

South Eastern 50% 803
Southern 25% 399
Northern 17% 277
Western 4% 66
Belfast 4% 57
Programme Frequency

Figure 1 Programme Frequency by HSC Trust Area (2023/24)

Programme Frequency by Programme Type

Between 2019/20 and 2020/21 the frequency of programmes regionally decreased by 63% (-779). Belfast HSC Trust were unable to provide data for publications from 2020/21 to 2023/24, however some programmes were run in this HSC Trust by other providers. Across the HSC Trusts, reduction in programme frequency from 2019/20 reflects the impact of COVID-19 on the services and some programmes returning in person and online in recent years. Across Northern Ireland programme frequency almost doubled in 2023/24 (1602) compared to the previous year (804). However, due to the impact of COVID-19 on programme scheduling in 2019/20 and 2020/21 and changes made to how programmes were delivered, extreme caution should be taken when comparing data from before 2019/20 and that for subsequent years, 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).

Programmes

800

400

200

2019/20 2020/21 2021/22 2022/23 2023/24

Belfast Northern South Eastern Southern Western

Figure 2 Programme Frequency by HSC Trust Area (2019/20 – 2023/24)

Programme Frequency by Provider Organisation

During 2023/24, patient education / self management programmes ran 1,538 times within HSCT trust areas with an additional 64 run regionally. Of the 1,602 times that programmes ran, 96% were condition specific and 4% were generic. The most frequent programme type in 2023/24, covering a single condition, was Cardiac (363), accounting for nearly one quarter (23%) of all programmes run (Figure 3; Table 2). Mental Health was the most frequent programme type in 2022/23.

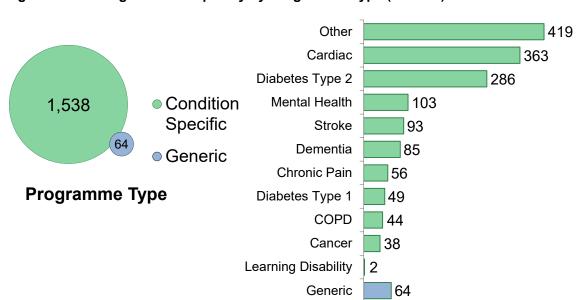


Figure 3 Programme Frequency by Programme Type (2023/24)

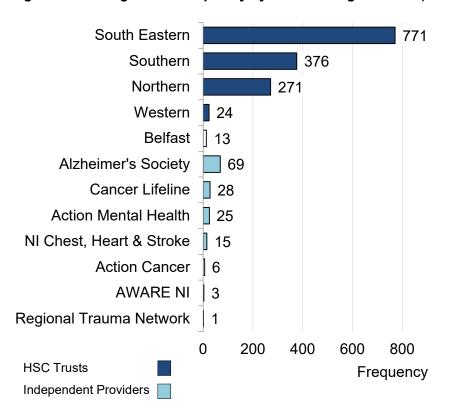


Figure 4 Programme Frequency by Provider Organisation (2023/24)

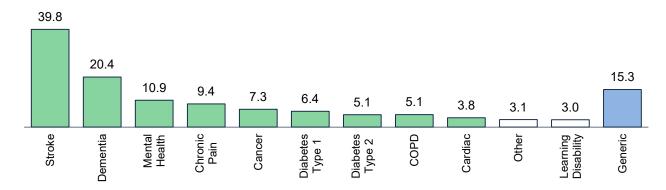
Just over nine in ten (91%) of programmes run during 2023/24 were provided by HSC Trusts (Figure 4). Of those programmes run by independent providers, Alzheimer's Society provided the most (69; Table 5).

4. Conditions

Average Number of Participants per Programme by Condition

The average number of participants per programme, by condition, ranged from 39.8 for those attending Stroke programmes, to 3 for Learning Disability programmes (Figure 5). The overall regional average number of participants per programme was 8.1.

Figure 5 Average Number of Participants per Programme by Condition (2023/24)*



Stroke specific programmes were the most frequented patient education / self management programmes in 2023/24, with nearly 1 in 3 participants.



Number of Participants by Programme Type

Over the last 5 years, large numbers of participants have been continually accessing programmes related to type 2 diabetes, dementia, cardiac, stroke, and mental health as shown in (Figure 6; Table 7). However, across the programme types, the reduction in participants from 2019/20 reflects the impact of COVID-19 on these services.

^{*} 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.

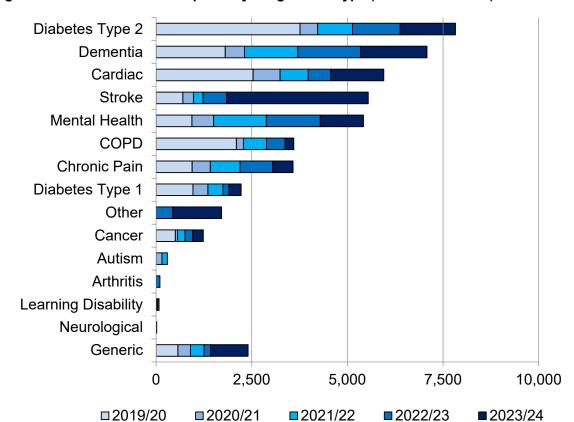


Figure 6 Number of Participants by Programme Type (2019/20 – 2023/24)*

^{*} 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.

Number of Participants by Condition

The annual number of participants attending chronic condition education programmes had remained high until 2019/20, with ongoing refinement and validation of data in this area accounting for some of the annual variance. Figure 7 shows the high attendance in Diabetes Type 2, Cardiac and COPD programmes in 2019/20. However, due to the impact of COVID-19 on programme scheduling since 2019/20, and subsequent resource issues experienced by organisations in submitting complete returns, extreme caution should be taken when comparing data from 2020/21 to 2023/24 against previous trend data, with the below figures included for illustrative purposes.

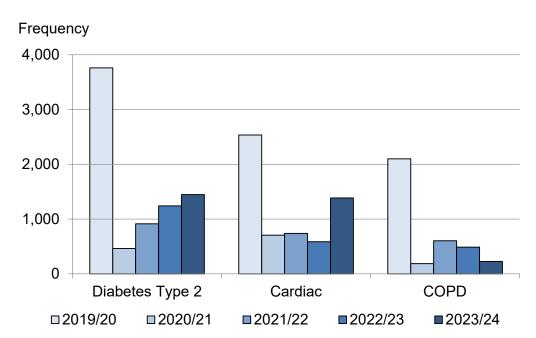
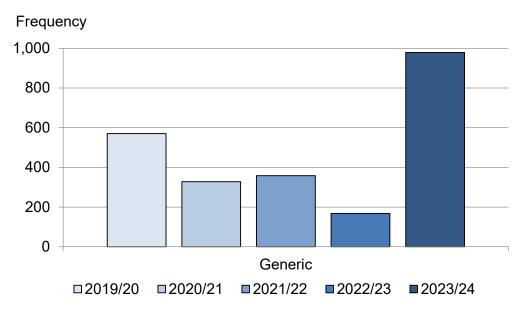


Figure 7 Number of Participants by Condition (2019/20 – 2023/24)*

^{*} 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.

Over the last 5 years, an average of 481 participants have attended generic education programmes (Figure 8; Table 8). 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, 2020/21, and 2021/22, and subsequent resource issues experienced by organisations in submitting complete returns, extreme caution should be taken when comparing to previous trend data, with the below figures included for illustrative purposes.

Figure 8 Number of Participants by Condition (2019/20 – 2023/24) - Generic*



^{*} 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.

5. Participants

Participant Numbers by HSC Trust Area

In 2023/24, 13,002 participants attended a patient education / self management programme, ranging from 3,918 in the Southern HSC Trust area to 1,109 in the Belfast HSC Trust area (Figure 9; Table 6). Belfast HSC Trust were unable to provide data for the 2023/24 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.

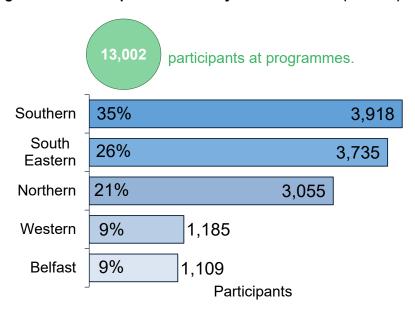


Figure 9 Participant Numbers by HSC Trust Area (2023/24)*

Nearly 1 in 3 of all participants attended a patient education / self management programme in the Southern Trust area in 2023/24.



Between 2019/20 and 2023/24 participant numbers decreased by 12% (-1,820) regionally, however, increases were seen in South Eastern (19%; 607) and Southern (15%; 504) HSC Trusts. Across the HSC Trusts, reduction in participant numbers reflects the impact of COVID-19 on the services. Regional participant numbers increased in 2023/24 by 66% (5,149) compared to the previous year. However, due to the impact of COVID-19 on programme scheduling from 2019/20 to 2021/22, and subsequent resource issues experienced by organisations in submitting complete returns, as well as the introduction of more online programmes, extreme caution should be taken when comparing 2019/20 to 2023/24 against previous trend data, with the below figures

^{*} 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.

included for illustrative purposes. Belfast HSC Trust were unable to provide data for the 2020/21, 2021/22, 2022/23, and 2023/24 publications, however some programmes were run in this HSC Trust by other providers. 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 10; Table 6).

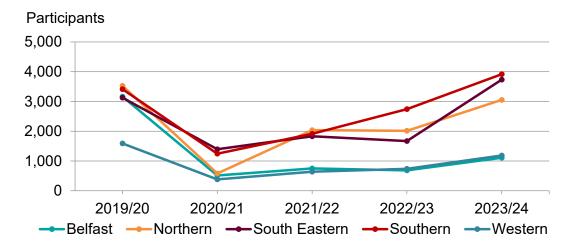


Figure 10 Participant Numbers by HSC Trust Area (2019/20 – 2023/24)*

Participant Numbers by HSC Provider

Of the 13,002 participants attending within Trusts and regionally, 79% were attending a programme delivered by HSC Trusts and 21% a programme by independent providers. In 2023/24. The South Eastern Trust had the greatest number of participants (3,447), of all the HSC Trust providers, and 27% 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 2022/23 and 2023/24 publications, however some programmes were run in this HSC Trust by other providers.

While the Alzheimer's Society had the greatest number of participants (1,396), of all the independent sector providers, and 11% of the total regional participant numbers (Figure 11; Table 9), 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.

^{*} 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.

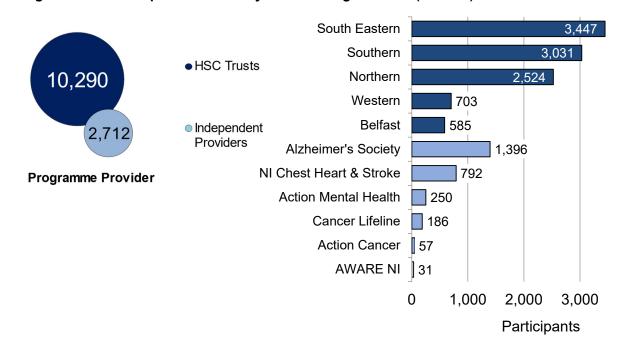
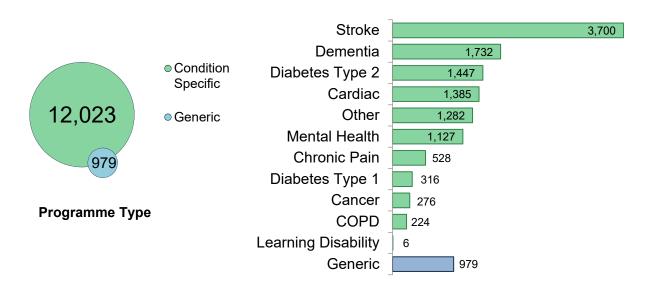


Figure 11 Participant Numbers by Provider Organisation (2023/24)

Participant Numbers by Programme Type

Of the 13,002 participants at programmes, 93% were attending a condition specific programme with 7% attending a generic programme. Figure 12 shows that the programme types with the most participants were stroke programmes (28%) and dementia programmes (13%).





Participants by Programme Delivery

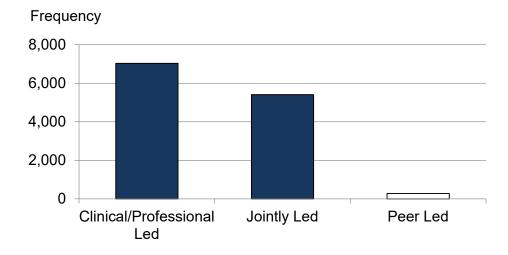
Prior to 2020/21, the top 6 conditions by participant numbers had programmes available across all 5 HSC Trust areas with the exception of cardiac specific programmes reported in the Western HSC Trust area. However, due to the impact of the COVID-19 pandemic, in 2023/24, only 3 of the top 6 conditions had a programme available in all HSC Trusts. These were stroke, dementia, and other. Cardiac programmes were only recorded in South Eastern and Southern HSC Trusts. There were no diabetes or mental health programmes recorded for Belfast or Western HSC Trusts.

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 2023/24 publication, however some programmes were run in this HSC Trust by other providers.

In 2023/24, 55% (7,035) of participants attended a programme that was either clinically or professionally led; this was lower than the proportion in 2021/22 (70%). Participants at jointly led programmes accounted for 42% (5,410) of the total, with the remaining 2% (280) of participants attending a programme that was peer led.

Of the participants at clinically or professionally led programmes in 2023/24, 87% (6,935) were attending a condition specific programme. This was the case for 89% (4,808) of those at jointly led programmes. All 280 participants at peer led programmes 72% were attending condition specific programmes (Table 10).

Figure 13 Number of Participants by Programme Delivery (2023/24)*



.

^{*} In 2023/24 there were 277 participants without programme delivery information recorded.

Participants by Funding Arrangement

In 2023/24, 45% (5,817) of participants attended a programme that was statutory funded, a percentage decrease of 6% since the previous year, although this represents an increase of 960 participants. Joint funded programmes were provided for 16% of participants; with <1% of participants attending voluntary funded programmes. 39% were at programmes utilising other funding arrangements¹ (Table 11).

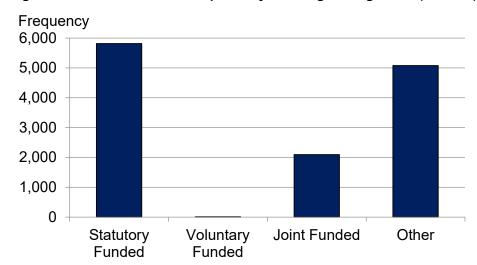


Figure 14 Number of Participants by Funding Arrangement (2023/24)*1

^{*} 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.

¹ 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 (2019/20 - 2023/24) 1,2

HSC Trust	2019/20	2020/21	2021/22	2022/23	2023/24
Belfast	305	63	79	95	57
Northern	249	76	196	192	277
South Eastern	288	138	169	183	803
Southern	240	135	211	268	399
Western	163	54	74	66	66
Northern Ireland	1,245	466	729	804	1,602

¹ 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, 2021/22, 2022/23, or 2023/24 and due to the likely impact of COVID-19 on programme provision in these years, imputing figures based on prior years would have been inappropriate. Therefore, Belfast HSC Trust data is unavailable for 2020/21, 2021/22, 2022/23, and 2023/24; however some programmes were run in this HSC Trust by other providers.

⁻ In 2019/20, it wasn't possible for WHSCT to submit a validated return ahead of the publication deadline so their diabetes programmes were estimated based on previous returns.

⁻ AWARE was unable to provide a 2019/20 return. AWARE, Cancer Focus, Cancer Lifeline and Macmillan Cancer Support were unable to submit a 2020/21 return due to COVID-19 pressures, and Cancer Focus, and Macmillan Cancer Support were unable to submit returns from 2021/22 to 2023/24.

⁻ Northern HSC Trust cardiac programmes were not included in 2021/22 as they were delivered on a one-to-one basis. This type of programme delivery is typically not included in the patient education programme criteria.

⁻ South Eastern HSC Trust did not record programme numbers for their pulmonary rehabilitation programmes in 2021/22.

⁻ 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.

² 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 <u>Appendix B</u>.

Table 2: Programme Frequency by Programme Type and HSC Trust Area (2023/24)³

Programme Type	Belfast	Northern	South Eastern	Southern	Western	Total
Condition Specific	55	276	801	344	62	1,538
Cancer	29	5	1	1	2	38
Cardiac	-	-	358	5	-	363
Chronic Pain	-	-	1	30	25	56
COPD	-	-	1	43	-	44
Dementia	12	20	28	15	10	85
Diabetes Type 1	-	8	20	21	-	49
Diabetes Type 2	-	183	37	66	-	286
Learning Disability	-	-	-	-	2	2
Mental Health	-	17	50	36	-	103
Other	1	22	286	103	7	419
Stroke	13	21	19	24	16	93
Generic	2	1	2	55	4	64
Total	57	277	803	399	66	1,602

³ Belfast HSC Trust were unable to provide data for the 2023/24 publication, however some programmes were run in this HSC Trust by other providers. AWARE, Cancer Focus and Macmillan were unable to provide returns for 2023/24.

Table 3: Frequency of Programmes by Type and HSC Trust Area (2019/20-2023/24) – Condition Specific^{4,5}

HSC Trust	2019/20	2020/21	2021/22	2022/23	2023/24
Belfast	301	58	78	95	55
Northern	247	71	191	192	276
South Eastern	286	136	167	183	801
Southern	220	120	196	253	344
Western	152	46	64	66	62
Northern Ireland	1,206	431	696	789	1,538

⁴ 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, 2021/22, 2022/23, or 2023/24 and due to the likely impact of COVID-19 on programme provision in these years, imputing figures based on prior years would have been inappropriate. Therefore, Belfast HSC Trust data is unavailable from 2020/21 to 2023/24; 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.

⁻ In 2019/20, it wasn't possible for WHSCT to submit a validated return ahead of the publication deadline so their diabetes programmes were estimated based on previous returns.

⁻ AWARE was unable to provide a 2019/20 return. AWARE, Cancer Focus, Cancer Lifeline and Macmillan Cancer Support were unable to submit a 2020/21 return due to COVID-19 pressures, and Cancer Focus, and Macmillan Cancer Support were unable to submit returns from 2021/22 to 2023/24.

⁻ Northern HSC Trust cardiac programmes were not included in 2021/22 as they were delivered on a one-to-one basis. This type of programme delivery is typically not included in the patient education programme criteria.

⁻ South Eastern HSC Trust did not record programme numbers for their pulmonary rehabilitation programmes in 2021/22.

⁻ 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.

⁵ 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 and HSC Trust Area (2019/20-2023/24) – Generic⁴

HSC Trust	2019/20	2020/21	2021/22	2022/23	2023/24
Belfast	4	5	1	-	2
Northern	2	5	5	-	1
South Eastern	2	2	2	-	2
Southern	20	15	15	15	55
Western	11	8	10	-	4
Northern Ireland	39	35	33	15	64

⁴ 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, 2021/22, 2022/23, or 2023/24, and due to the likely impact of COVID-19 on programme provision in these years, imputing figures based on prior years would have been inappropriate. Therefore, Belfast HSC Trust data is unavailable from 2020/21 to 2023/24; 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 (2023/24)⁵

Provider Organisation	2023/24
AWARE NI	3
Action Cancer	6
Action Mental Health	25
Alzheimer's Society	69
Cancer Lifeline	28
NI Chest, Heart & Stroke	15
Regional Trauma Network	1
BHSCT	13
NHSCT	271
SEHSCT	771
SHSCT	376
WHSCT	24
Total	1,602

 $^{^{5}}$ Belfast HSC Trust were unable to provide data for the 2023/24 publication, however some programmes were run in this HSC Trust by other providers.

AWARE, Cancer Focus and Macmillan were unable to provide returns for 2023/24.

Table 6: Participants Numbers by HSC Trust Area (2019/20-2023/24)⁶

HSC Trust	2019/20	2020/21	2021/22	2022/23	2023/24
Belfast	3,163	515	750	685	1,109
Northern	3,528	582	2,038	2,014	3,055
South Eastern	3,128	1,395	1,830	1,671	3,735
Southern	3,414	1,246	1,915	2,744	3,918
Western	1,589	383	638	739	1,185
Northern Ireland	14,822	4,121	7,171	7,853	13,002

⁶ 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, 2021/22, 2022/23, or 2023/24, and due to the likely impact of COVID-19 on programme provision in these years, imputing figures based on prior years would have been inappropriate. Therefore, Belfast HSC Trust data is unavailable from 2020/21 to 2023/24; 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.

⁻ In 2019/20, it wasn't possible for WHSCT to submit a validated return ahead of the publication deadline so their diabetes programmes were estimated based on previous returns.

⁻ AWARE was unable to provide a 2019/20 return. AWARE, Cancer Focus, Cancer Lifeline and Macmillan Cancer Support were unable to submit a 2020/21 return due to COVID-19 pressures, and Cancer Focus, and Macmillan Cancer Support were unable to submit a returns from 2021/22 to 2023/24.- Northern HSC Trust cardiac programmes were not included in 2021/22 as they were delivered on a one-to-one basis. This type of programme delivery is typically not included in the patient education programme criteria.

Northern HSC Trust did not record participant numbers for their autism programme 'Emotional Regulation' in 2021/22.

⁻ South Eastern HSC Trust did not record programme numbers for their pulmonary rehabilitation programmes in 2021/22.

⁻ 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 7: Participants Numbers by Programme Type and HSC Trust Area (2023/24)⁷

Programme Type	Belfast	Northern	South Eastern	Southern	Western	Total
Condition Specific	952	2,986	3,661	3,384	1,040	12,023
Cancer	197	43	11	8	17	276
Cardiac	-	-	1,252	133	-	1,385
Chronic Pain	-	-	14	264	250	528
COPD	-	-	10	214	-	224
Dementia	145	788	146	591	62	1,732
Diabetes Type 1	-	51	150	115	-	316
Diabetes Type 2	-	641	314	492	-	1,447
Learning Disability	-	-	-	-	6	6
Mental Health	-	482	329	316	-	1,127
Other	25	323	559	229	146	1,282
Stroke	585	658	876	1,022	559	3,700
Generic	157	69	74	534	145	979
Total	1,109	3,055	3,735	3,918	1,185	13,002

⁷ Belfast HSC Trust were unable to provide data for the 2023/24 publication, however some programmes were run in this HSC Trust by other providers. AWARE, Cancer Focus and Macmillan were unable to provide returns for 2023/24.

Table 8: Participant Numbers by Condition (2019/20 – 2023/24)8

Programme Type	2019/20	2020/21	2021/22	2022/23	2023/24
Condition Specific	14,252	3,793	6,813	7,767	12,023
Arthritis	-	-	-	100	-
Autism	-	155	140	-	-
Cancer	503	57	197	200	276
Cardiac	2,535	706	738	586	1,385
Chronic Pain	944	473	778	856	528
COPD	2,099	185	603	486	224
Dementia	1,810	500	1,396	1,640	1,732
Diabetes Type 1	964	390	397	155	316
Diabetes Type 2	3,761	461	913	1,241	1,447
Learning Disability	-	23	18	32	6
Mental Health	936	566	1,381	1,408	1,127
Neurological	-	-	-	18	-
Other	-	-	-	429	1,282
Stroke	700	277	252	616	3,700
Generic	570	328	358	168	979
Total	14,822	4,121	7,171	7,935	13,002

⁸ 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, 2021/22, 2022/23, or 2023/24 and due to the likely impact of COVID-19 on programme provision in these years, imputing figures based on prior years would have been inappropriate. Therefore, Belfast HSC Trust data is unavailable from 2020/21 to 2023/24; 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.

⁻ In 2019/20, it wasn't possible for WHSCT to submit a validated return ahead of the publication deadline so their diabetes programmes were estimated based on previous returns.

⁻ AWARE was unable to provide a 2019/20 return. AWARE, Cancer Focus, Cancer Lifeline and Macmillan Cancer Support were unable to submit a 2020/21 return due to COVID-19 pressures, and Cancer Focus, and Macmillan Cancer Support were unable to submit returns from 2021/22 to 2023/24.

⁻ Northern HSC Trust cardiac programmes were not included in 2021/22 as they were delivered on a one-to-one basis. This type of programme delivery is typically not included in the patient education programme criteria.

⁻ Northern HSC Trust did not record participant numbers for their autism programme 'Emotional Regulation' in 2021/22.

⁻ 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 9: Participants Numbers by Provider Organisation (2019/20-2023/24)⁹

Provider Organisation	2019/20	2020/21	2021/22	2022/23	2023/24
AWARE NI	-	-	369	575	31
Action Cancer	97	47	61	94	57
Action Mental Health	318	91	162	200	250
Alzheimer's Society	1,769	460	941	1,640	1,396
Cancer Focus NI	17	-	-	-	-
Cancer Lifeline	15	-	100	72	186
Macmillan Cancer Support	37	-	-	-	-
NI Chest Heart & Stroke	868	421	396	636	792
Stroke Association	92	53	27	100	-
Versus Arthritis	614	351	538	360	-
BHSCT	2,552	-	-	-	585
NHSCT	2,981	414	1,481	1,430	2,524
SEHSCT	2,362	1,195	1,382	786	3,447
SHSCT	2,198	878	1,452	1,854	3,031
WHSCT	902	211	262	188	703
Total	14,822	4,121	7,171	7,935	13,002

⁹ 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, 2021/22, 2022/23, or 2023/24 and due to the likely impact of COVID-19 on programme provision in these years, imputing figures based on prior years would have been inappropriate. Therefore, Belfast HSC Trust data is unavailable from 2020/21 to 2023/24; 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.

⁻ In 2019/20, it wasn't possible for WHSCT to submit a validated return ahead of the publication deadline so their diabetes programmes were estimated based on previous returns.

⁻ AWARE was unable to provide a 2019/20 return. AWARE, Cancer Focus, Cancer Lifeline and Macmillan Cancer Support were unable to submit a 2020/21 return due to COVID-19 pressures, and Cancer Focus, and Macmillan Cancer Support were unable to submit returns from 2021/22 to 2023/24.

⁻ Northern HSC Trust cardiac programmes were not included in 2021/22 as they were delivered on a one-to-one basis. This type of programme delivery is typically not included in the patient education programme criteria.

⁻ Northern HSC Trust did not record participant numbers for their autism programme 'Emotional Regulation' in 2021/22.

⁻ 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 10: Participants Numbers by Programme Type and Programme Delivery (2023/24)¹⁰

Programme Type	Clinical / Professional Led	Jointly Led	Peer Led	Total
Condition Specific	6,935	4,808	280	12,023
Cancer	273	3	-	276
Cardiac	1,201	184	-	1,385
Chronic Pain	467	61	-	528
COPD	224	-	-	224
Dementia	482	1,250	-	1,732
Diabetes Type 1	166	109	41	316
Diabetes Type 2	1,447	-	-	1,447
Learning Disability	6	-	-	6
Mental Health	954	72	101	1,127
Other	1,057	87	138	1,282
Stroke	658	3,042	-	3,700
Generic	100	602	-	702
Total	7,035	5,410	280	12,725

AWARE, Cancer Focus and Macmillan were unable to provide returns for 2023/24.

¹⁰ In 2023/24 there were 277 participants without programme delivery information recorded. Belfast HSC Trust were unable to provide data for the 2023/24 publication, however some programmes were run in this HSC Trust by other providers.

Table 11: Participants Numbers by Programme Type and Funding Arrangements (2023/24)¹¹

Programme Type	Statutory Funded	Voluntary Funded	Joint Funded	Other ¹²	Total
Condition Specific	5,509	11	2,095	4,408	12,023
Cancer	70	3	203	-	276
Cardiac	1,334	-	-	51	1,385
Chronic Pain	514	-	-	14	528
COPD	224	-	-	-	224
Dementia	481	-	1,251	-	1,732
Diabetes Type 1	275	-	-	41	316
Diabetes Type 2	756	-	641	50	1,447
Learning Disability	6	-	-	-	6
Mental Health	1,001	-	-	126	1,127
Other	848	8	-	426	1,282
Stroke	-	-	-	3,700	3,700
Generic	308	-	-	671	979
Total	5,817	11	2,095	5,079	13,002

 11 Belfast HSC Trust were unable to provide data for the 2023/24 publication, however some programmes were run in this HSC Trust by other providers.

AWARE, Cancer Focus and Macmillan were unable to provide returns for 2023/24.

¹² 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 2023 to 31 March 2024.

The <u>Programme for Government (PfG) 2011-15</u> included a commitment to enrol people who have a long term (chronic) condition, and who want to be enrolled, in a dedicated chronic condition management programme. The commitment sought to ensure that people who have a long term condition have the information and skills they need to be able to self manage their condition as effectively as possible.

The number of people in Northern Ireland living with one or more long term condition is increasing⁴. 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 2023/24. Information was provided by HSC Trusts and independent sector organisations who delivered programmes during 2023/24. The report summarises the key statistical information provided for the year 2023/24 and how this compares with that collected in previous years.

⁴ 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 four of the five HSC Trusts in Northern Ireland, as well as independent providers, to Community Information Branch (CIB) in the Department of Health. Belfast HSCT did not provide a completed questionnaire in 2023/24.

For this publication, the questionnaire covered the year ending 31 March 2024 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 <u>collection guidance notes along with a copy of the questionnaire</u>.

Data Quality

On receipt of the Patient Education / Self Management Programmes questionnaire, statisticians in CIB conduct internal consistency checks. They also check for variations from the baseline information collated for 2019/20 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 2023/24 and are best described as <u>experimental</u>. Any future statistics covering this issue may be subject to revisions in coverage and methodology.

Data Presentation

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

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

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

Data Validation Issues

Please note the following limitations for 2019/20 data

- Please note that a number of organisations advised of disruption to programmes due to the impact of COVID-19.
- 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 in 2019/20, but a complete return was provided in 2020/21.
- 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.

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 frequency (1) remained the same.

- Belfast HSC Trust did not complete a return ahead of publication in 2020/21, 2021/22, 2022/23 or 2023/24, and due to the likely impact of COVID-19 on programme provision in these years, imputing figures based on prior years would have likely been inappropriate. Therefore, submitted Belfast HSC Trust data is unavailable for 2020/21, 2021/22, 2022/23, and 2023/24.
- 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.
- Cancer Focus, and Macmillan Cancer Support were unable to submit a return in 2021/22, 2022/23, or 2023/24, likely due to COVID-19 pressures.
- Some new programmes could not be validated in time for the 2021/22 publication so were not included, but are part of ongoing data quality work to include all relevant programmes.

In Northern HSC Trust these were new autism, long covid, and cancer programmes. In South Eastern HSC Trust these were new autism programmes.

In 2021/22 AWARE and Northern HSC Trust recorded that they had delivered regional online mental health programmes. These are not yet included in the Northern Ireland totals as further data validation work is required to incorporate regional programmes into this publication.

Northern HSC Trust cardiac programmes were not included in 2021/22 as they were delivered on a one-to-one basis. This type of programme delivery is typically not included in the patient education programme criteria.

Northern HSC Trust did not record participant numbers for their autism programme 'Emotional Regulation' in 2021/22.

South Eastern HSC Trust noted that the DESMOND (Virtual) diabetes programme was stood down from January to March 22 due to winter pressures, and there was a reduced ability to deliver the programme in 2021/22, due to staff redeployment related to COVID 19.

South Eastern HSC Trust did not record programme numbers for their pulmonary rehabilitation programmes in 2021/22.

Data Validation Issues

Western HSC Trust noted issues in the provision of their pulmonary rehabilitation programmes in 2021/22 due to issues with technology and participant engagement leading to participant dropout.

Western HSC Trust noted staffing issues in the provision of their diabetes programmes in 2021/22.

Amendments

The cut-off point for amendments to data was 1st April 2025. 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) 2011-2015 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

Louise Walker on 028 905 22162 or via email: cib@health-ni.gov.uk.

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.

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

This data collection IS covering	This data collection IS NOT covering:	LTCs included in audit:
Programmes for people with long term conditions. Programmes designed for:	Any kind of "Support groups" for either physical or mental health long term conditions. By 'support groups' we mean informal, unstructured groups with no time limit. One-to-one reviews or appointments with health and social care professionals, e.g. GPs or other primary / community care professionals.	LTCs relating to physical health eg: Diabetes; Cardiac; COPD / respiratory; Stroke / dementia / neurological; Chronic Pain; Arthritis / other Musculoskeletal; Cancer. LTCs relating to mental health.

Abbreviations

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

Abbreviations	Full term
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: Department of Health (Social care statistics). This publication can be requested in large print or other formats.					
are available to download on the DoH website at: Department of Health (Social care statistics).					
are available to download on the DoH website at: Department of Health (Social care statistics).					
are available to download on the DoH website at: Department of Health (Social care statistics).					
are available to download on the DoH website at: Department of Health (Social care statistics).					
are available to download on the DoH website at: Department of Health (Social care statistics).					
are available to download on the DoH website at: Department of Health (Social care statistics).					
are available to download on the DoH website at: Department of Health (Social care statistics).					
are available to download on the DoH website at: Department of Health (Social care statistics).					
are available to download on the DoH website at: Department of Health (Social care statistics).					
are available to download on the DoH website at: Department of Health (Social care statistics).					
are available to download on the DoH website at: Department of Health (Social care statistics).					
are available to download on the DoH website at: Department of Health (Social care statistics).					
are available to download on the DoH website at: Department of Health (Social care statistics).					
are available to download on the DoH website at: Department of Health (Social care statistics).					
are available to download on the DoH website at: Department of Health (Social care statistics).					
are available to download on the DoH website at: Department of Health (Social care statistics).					
				ty Information Br	anch
This publication can be requested in large print or other formats.	Department of Health (Social care statistic	<u>s).</u>		
	This publication can b	e requested in large	print or other for	mats.	