

Engagement Report

Home Oxygen Assessment Service

NHS County Durham CCG
NHS Newcastle and Gateshead CCG
(Gateshead locality only)
NHS South Tyneside CCG
NHS Sunderland CCG
NHS Tees Valley CCG

August 2021



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Introduction

Background

Between 28th May 2021 and 30th July 2021 (9 weeks) NHS Tees Valley Clinical Commissioning Group (CCG) launched a period of public engagement to gather service user's views about the Home Oxygen Assessment Service.

The Home Oxygen Assessment Service is currently commissioned by NHS Tees Valley CCG (all localities except Hartlepool and Stockton-on-Tees), NHS Sunderland CCG, NHS County Durham CCG, NHS South Tyneside CCG and the Gateshead locality of Newcastle and Gateshead CCG from Air Liquide.

The current service model focuses on oxygen prescription and ongoing assessment of oxygen need. A typical pathway incorporates an initial assessment, reviews at four weeks, three months and six months and annual reviews thereafter. The provider is only commissioned to carry out these activities and can only signpost to other services where required.

It is expected that the majority of patients on long term oxygen are also supported by community respiratory teams, leading to two independent teams supporting this group of patients and potential duplication therefore of clinical activity, or not making best use of clinical time whilst supporting individual patients.

Current Service

The current service consists of a team of 13 specialist nurses responsible for assessing and reviewing patient's oxygen needs. The clinical team is supported by an admin team based in South Shields.

Referrals to the service are usually made by GPs but can be made by other healthcare professionals. When patients with respiratory problems and any other conditions are thought to need oxygen they are referred to the service for an oxygen assessment. The team of specialist nurses will assess if oxygen is appropriate and if so order the supply, provide support and follow up.

The team reviews all patients receiving home oxygen to make sure their oxygen supply is appropriate for their condition and provide ongoing care and support. The majority of oxygen assessments take place in the home. This is supported by ambulatory assessment clinics at Middlesbrough, Sunderland and Durham. The team works closely with GPs, hospital consultants, community healthcare teams and home oxygen equipment providers.

There are currently approximately 3,302 patients accessing the service.

CCG	Patients
NHS COUNTY DURHAM CCG	1111
NHS TEES VALLEY CCG	921
NHS SUNDERLAND CCG	703
NHS NEWCASTLE GATESHEAD CCG	290
NHS SOUTH TYNESIDE CCG	277
	3302

Patient Engagement

The CCG is keen to understand the views and experience of patients who have used the Oxygen at Home Service, how they access it, any barriers to service, what 'good' looks like etc. This is in order that they can build a more detailed picture of the service and feed this into work ongoing across the region via Integrated Care Partnerships (ICPs) that are looking closely at the way services are configured.

The approach to engagement should present a 'plain English' narrative about the current service and the meaning of the engagement – why you should get involved?

Therefore, the approach to the engagement will consider:

- Definition of the current Home Oxygen Assessment Service and how it works
- Any challenges and solutions to improve the service
- Patient outcomes and experience from the current service
- Any relevant patient data

Methodology

Communications and Engagement

The North of England Commissioning Support Unit (NECSU) was tasked with the planning and delivery of the engagement activity, on behalf of NHS Tees Valley CCG (all localities except Hartlepool and Stockton-on-Tees), NHS Sunderland CCG, NHS County Durham CCG, NHS South Tyneside CCG and the Gateshead locality of Newcastle and Gateshead CCG.

The objectives of the activity were:

- To fully understand the needs and priorities of patients using Home Oxygen Assessment Services, as well as the views of other relevant stakeholders, that can feed into any future planning around service models.
- Continue to meet NHS legal duties for engagement, equality and best practice in engagement and communications, in line with previous engagement activity.

In order to achieve this, the engagement method employed was a postal survey sent out to a sample set of 50% of service users from each locality.

County Durham - 565
South Tyneside - 143
Sunderland - 350
Gateshead - 155
Tees Valley - 485

A total of 1,698 surveys were posted. This was supported by an online version of the survey.

Communications activity

The following supporting communication activity took place:

- Promoted via the Tees Valley CCG website – news post shared with partner CCGs
- Stakeholder briefing issued

Total sample

The total sample from the engagement methods was 705 paper returns and 23 online returns.

Quantitative analysis: the survey was structured to include both closed and free text (open) questions giving respondents the opportunity to comment on their experience in more detail. All free text responses were assigned a code, and codes grouped into categories to allow a quantitative representation of the feedback. For all questions, responses have been presented as a proportion of the number of individuals who responded to each question.

Summary of findings

Use of home oxygen

- 63.34% have been using oxygen for more than three years
- 97.32% use their oxygen without problems as advised by their clinician

Information about home oxygen

- 89.8% said the Home Oxygen Nurse explained in detail the reasons why oxygen had been prescribed
- 92.68% said it was not necessary to have more information
- 96.12% said the information and leaflets were clear and easy understand
- Respondents wanted more leaflets and some said they have never received any leaflets

Involvement

- 70.70% felt the Nurse involved them in treatment decisions
- 91.69% didn't feel it was necessary to be more involved in decision-making

Timing

- 96.83% said the time they waited for an assessment was reasonable
- Most people had their assessment at hospital or soon after discharge
- Some assessments had been delayed/cancelled due to COVID
- Some said they did not have an assessment or haven't seen anyone
- Although there were slightly more people who had had their last review in the last 0-3 months (194 out of 708 responses), there were 161 people who had not had a review in 12 months

Privacy and dignity

- 97.04% said their privacy and dignity was respected during assessment

Customer service

- 93.98% said the customer service team were courteous, helpful and knowledgeable
- 92.42% knew who and how to call with any questions
- Most people rated the response from the service high with a positive experience

Equipment

- 96.78% were satisfied with the training given to them for the safe use of their equipment
- 60% use aids to carry their oxygen
- 77% said the weight of their portable equipment was manageable
- 39.19% said it was not.
- 92.61% said their portable equipment allowed them to leave home
- 98.70% said they didn't have any problems storing oxygen cylinders.

- 66% said their oxygen helped them to increase the amount of time spent doing physical exercise or other activities
- 33% expressed it did not

Quality of life

- When asked about the impact of home oxygen on quality of life, the most important things were;
 - Not having to be admitted to hospital due to breathing problems
 - Not having to call the emergency services due to breathing problems
 - Being able to breathe well and not being short of breath
 - The explanation for using the equipment

Service improvement

- When asked how the service could be improved, the most important things were
 - Being able to get advice from the service at any time during the day
 - Being able to be referred to other healthcare professionals/services
 - More information on the safe use of oxygen
- Some respondents would like more visits, more regular follow ups or said they haven't had a visit or a recent visit
- There was nothing that the service needs to stop doing
- 92.28% said that they didn't feel there was any duplication between the Home Oxygen Assessment Service nurses and nurses from the respiratory team at the hospital.
- Most said they were not in contact with hospital respiratory team

Customer experience

- When asked to rate their overall experience most respondents had a positive experience
- Most said they were happy/or the service was excellent
- Most did not have any other feedback
- Some said they would prefer contact more often/regular check-ups and that reviews assessments were important

Feedback from the patient survey

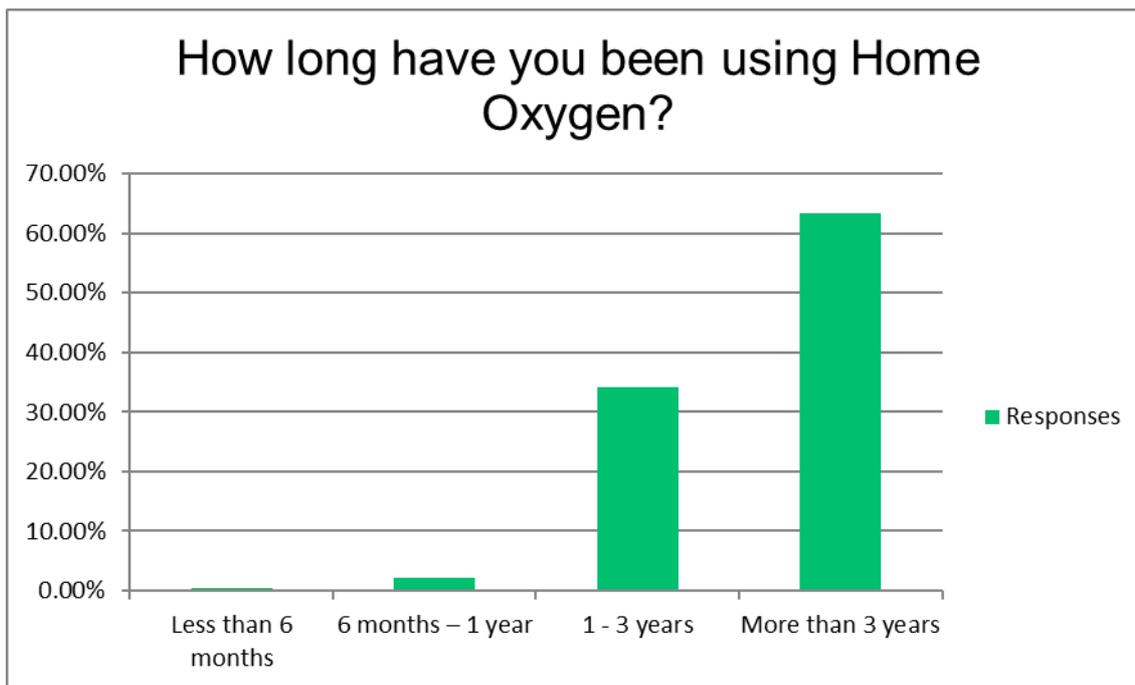
Demographics

A total of 728 individuals completed the survey either online or on paper. The key demographics of the sample are provided below with a full breakdown available in the Appendix.

- 97% of respondents were service users and 3% carers
- The highest proportions were aged 65+ (76.90%), 55 – 64 (13.45%)
- 56% were female and 43% male
- 97% of respondents had a disability, long-term illness or health condition
- 98% were white British

Use of Home Oxygen

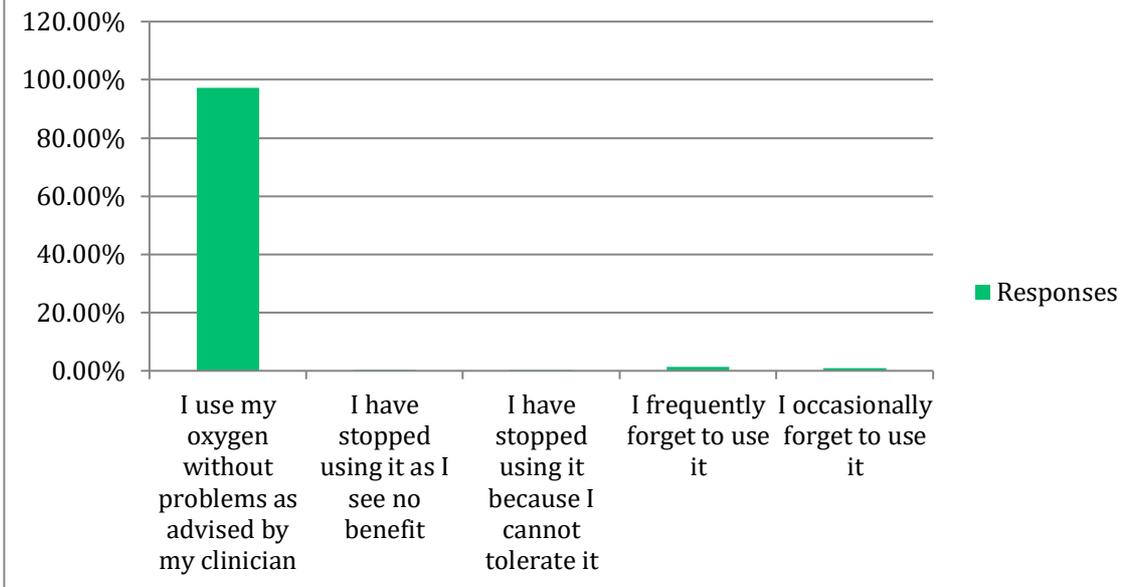
The majority of respondents to the survey have been using oxygen for more than three years (63.34%). The vast majority 97.32% said they used their oxygen without problems as advised by their clinician



Answer choices	Responses %	Responses
Less than 6 months	42%	3
6 months – 1 year	2.11%	15
1 - 3 years	34.13%	243
More than 3 years	63.34%	451

Total responses – 712

How often do you use your oxygen?

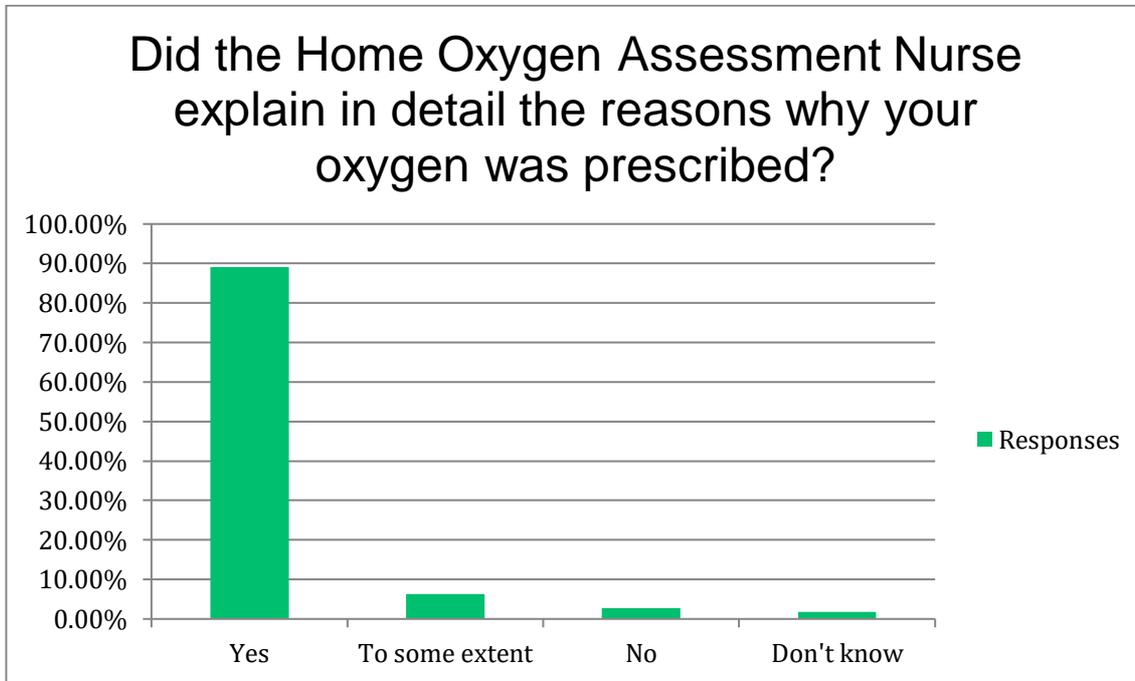


Answer Choices	Responses %	Responses
I use my oxygen without problems as advised by my clinician	97.32%	689
I have stopped using it as I see no benefit	0.28%	2
I have stopped using it because I cannot tolerate it	0.14%	1
I frequently forget to use it	1.27%	9
I occasionally forget to use it	0.99%	7

Total responses – 708

Information about Home Oxygen

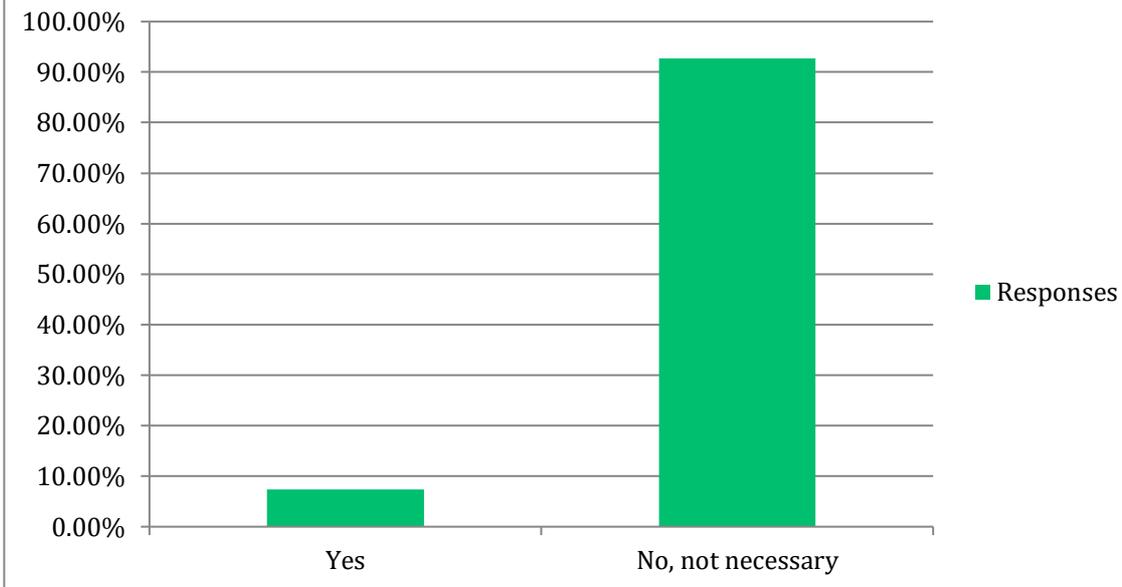
Most respondents (89.8%) felt that the Home Oxygen Nurse explained in detail the reasons why oxygen had been prescribed to them, with most people (92.68%) responding to say that it was not necessary to have more information when asked if they would have liked to have more. When asked if the information and leaflets given to them was clear and easy understand, the majority (96.12%) felt that it was.



Answer Choices	Responses %	Responses
Yes	89.08%	636
To some extent	6.30%	45
No	2.80%	20
Don't know	1.82%	13

Total responses – 714

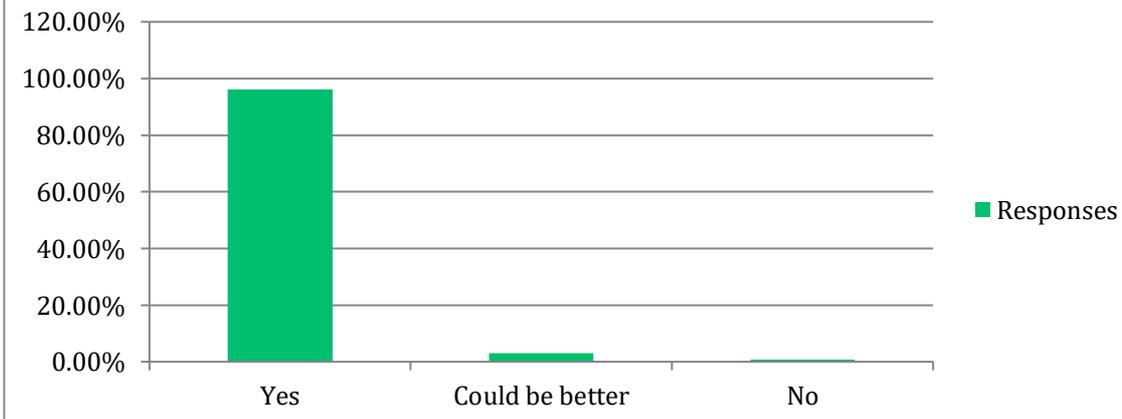
Would you have liked more information?



Answer choices	Responses %	Responses
Yes	7.32%	52
No, not necessary	92.68%	658

Total responses - 710

Do you think the information and leaflets given to you by the Home Oxygen Assessment Nurse is clear and easy to understand?



Answer choices	Responses %	Responses
Yes	96.12%	669
Could be better	3.02%	21
No	0.86%	6

Total responses – 696

When asked how the information and leaflets could be better, 28 people responded.

Free text question responses. Do you think the information and leaflets given to you by the Home Oxygen Assessment Nurse is clear and easy to understand? (N=28)

Respondents were asked how the information and leaflets given to them by the Home Oxygen Assessment Nurse could be better. In total, 28 respondents provided 29 comments. The themes that appeared more often are discussed, followed by a table outlining all the themes and a 'other' category.

Theme	Comments
More leaflets are required or received no leaflets	7
Unsure or don't know	4
More information is required, such as contact information, how to use the new machine, information regarding flying and more information regarding portable oxygen	4
No improvement is needed	3
Large print option	2
Haven't had an assessment or seen a nurse	2
Other comments – not themed	7

Seven comments indicated that they would like to receive more leaflets or that they have not received any leaflets.

"More leaflets"

Four comments indicated that they are unsure or don't know if they received any leaflets.

"Unsure if received."

Four comments discussed a requirement for more information and or explanation.

"More information about portable oxygen."

Three comments indicated that no improvement to the information or leaflets is needed.

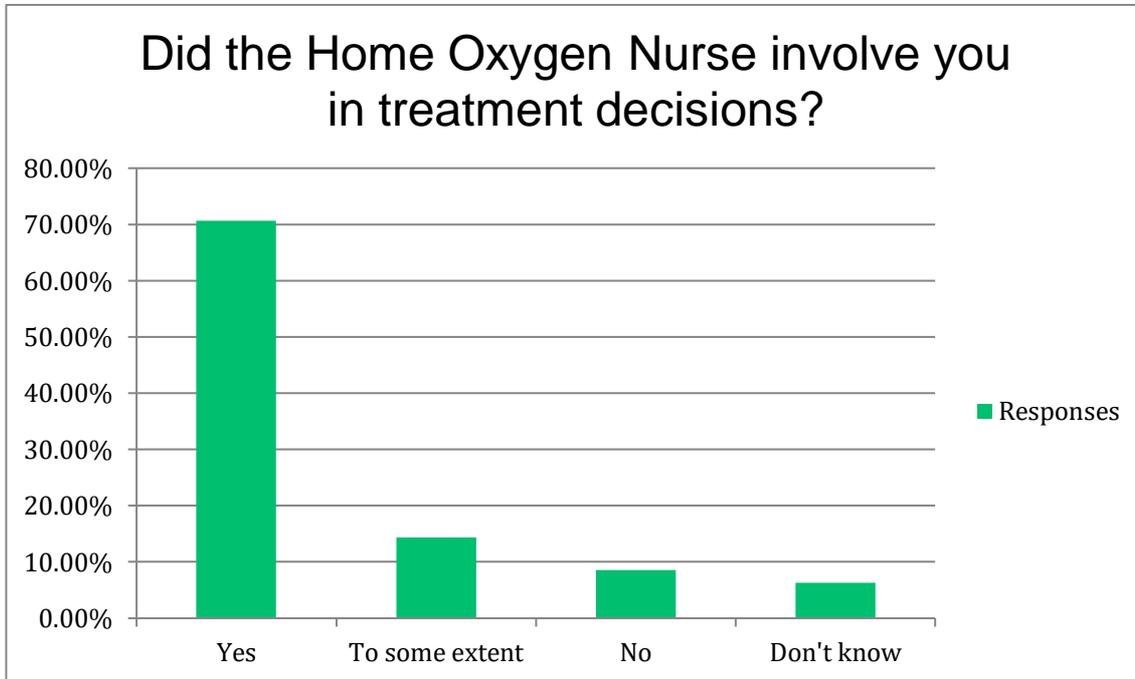
"It could not be better than it is."

The following seven comments could not be themed and are therefore in the 'other' category.

Comments
<i>"Well only got one and it was only one page"</i>
<i>"Scale it down so not as much to read"</i>
<i>"Think appointment card could be filled in better, with details more precise of last visit!"</i>
<i>"Explain what oxygen should be set at"</i>
<i>"Not had any information for a long time, no nurse, man brought new machine lugged it in and left no explanation."</i>
<i>"A bit shocking in places (as a reminder of how short my life will be)"</i>
<i>"I have dementia and short-term memory recall"</i>

Involvement

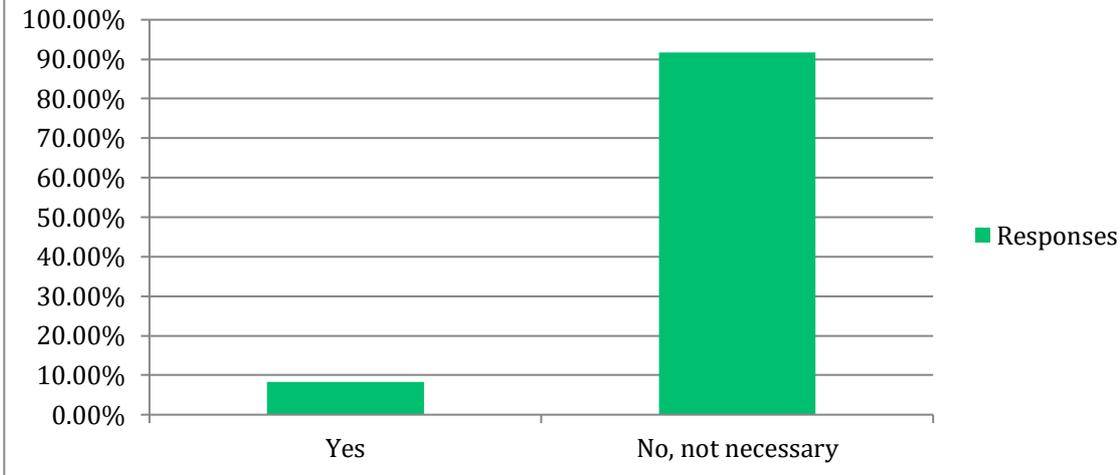
Although most respondents (70.70%) felt that the Nurse involved them in treatment decisions 102 out of 710 people who answered this question (14.37%) expressed that they were involved to 'some extent' in treatment decisions. The majority (91.69%) did not feel it was necessary to be more involved in the decision-making process.



Answer choices	Responses %	Responses
Yes	70.70%	502
To some extent	14.37%	102
No	8.59%	61
Don't know	6.35%	45

Total responses – 710

Would you have liked the opportunity for more involvement in the decision making process?



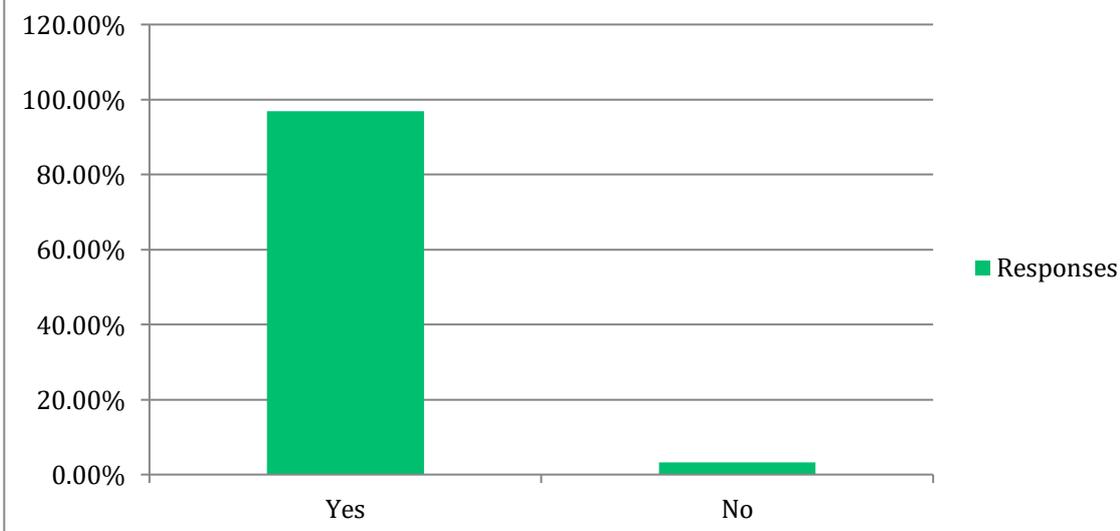
Answer choices	Responses %	Responses
Yes	8.31%	59
No, not necessary	91.69%	651

Total responses - 710

Timing

Most respondents (96.83%) said the time they waited for an assessment was reasonable. When asked when their last review was the answers were evenly spread with roughly 20% in each answer choice, 0-3 months, 3-6 months, over 6 months and over 12 months. Although there were slightly more people who had had their last review in the last 0-3 months (194 out of 708 responses), there were 161 people who had not had a review in 12 months.

Was the time you waited for an assessment reasonable?



Answer choices	Responses %	Responses
Yes	96.83%	672
No	3.17%	22

Total responses – 694

Free text question responses. Was the time you waited for an assessment reasonable? (N=45)

Respondents were asked to state how long they waited for an assessment. In total, 45 respondents provided 46 comments. The themes that appeared more often are discussed, followed by a table outlining all of the themes.

Theme	Comments
At hospital or soon after discharge	9
Delayed/cancelled due to COVID	7
N/A, did not have an assessment or haven't seen anyone	7
No more than a few weeks	4
About 1 month	3
Can't remember	3
Takes too long	2
Other comments – not themed	11

Nine comments indicated that they received their assessment either at the hospital or soon after discharge.

“Assessment made while in hospital by consultant.”

Seven comments indicated that their assessment was delayed or cancelled due to the COVID-19 pandemic.

“Understandable delay due to current circumstances.”

Seven comments indicated that this question was not applicable, or they did not have an assessment.

“Didn't have assessment was prescribed oxygen for covid-19.”

Four comments indicated that they had to wait no more than a few weeks for their assessment.

“I didn't wait more than 2 weeks.”

The following 11 comments could not be themed and are therefore in the 'other' category.

Comments
<i>"3 months"</i>
<i>"eventually got home oxygen due to an emergency already waited 6 months"</i>
<i>"quite a while after leaving hospital"</i>
<i>"Assessment straight away"</i>
<i>"about 1 year. When I found I had chronic lymphocytic 19-96 leukaemia, I also knew my breathing wasn't right, I was not attention seeking I knew something wasn't right."</i>
<i>"Close to 2 years since I have seen an oxygen nurse then I got a call saying a nurse will come in a week, I received no letter just a call!"</i>
<i>"Unsure of difference between home oxygen nurse and respiratory nurse"</i>
<i>"Seen by consultant etc."</i>
<i>"Did not know until turned up"</i>
<i>"Got from the GP surgery"</i>
<i>"There was an initial mix up but as I was being seen by the hospital team there were no issues"</i>

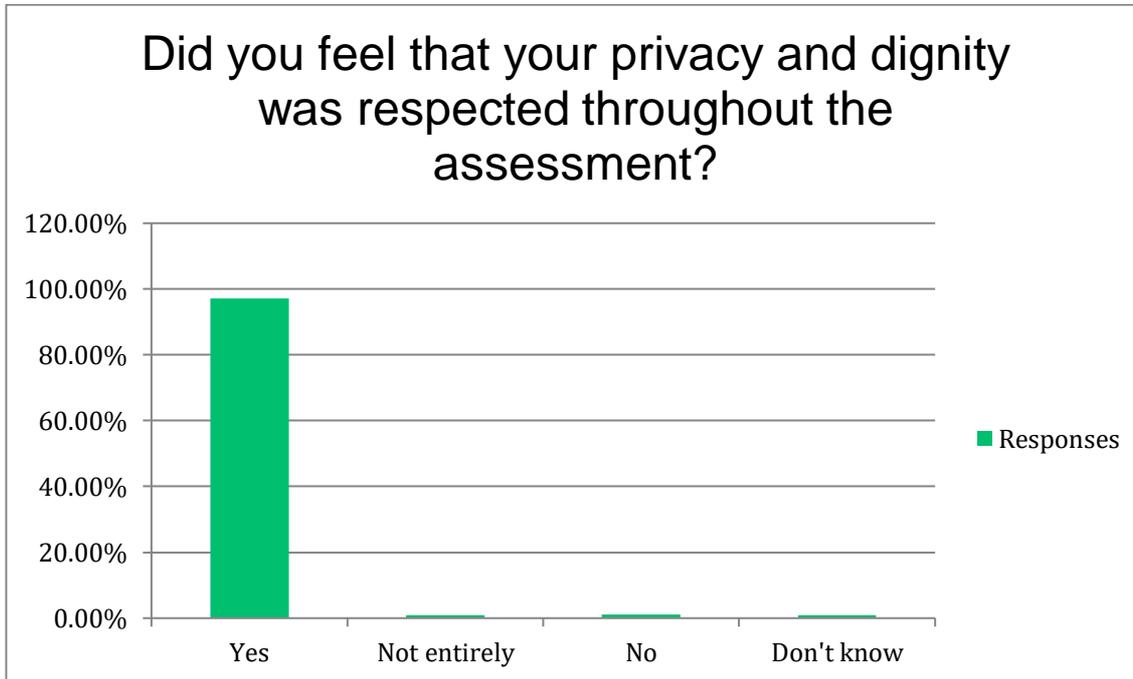


Answer choices	Responses %	Responses
0 - 3 months ago	27.40%	194
3 - 6 months ago	18.36%	130
Over 6 months	22.46%	159
Over 12 months	22.74%	161
Don't know	9.04%	64

Total responses - 708

Privacy and dignity

The vast majority (97.04%) said their privacy and dignity was respected throughout their assessment.



Answer choices	Responses %	Responses
Yes	97.04%	689
Not entirely	0.85%	6
No	1.13%	8
Don't know	0.99%	7

Total responses – 710

Out of the 8 respondents who answered no, 6 respondents left feedback to the question; if you answered no, could you explain what happened to make you feel that your privacy and dignity were not respected.

Free text question responses. Did you feel that your privacy and dignity was respected throughout the assessment? (N=6)

Respondents were asked to explain what happened to make them feel that their privacy and dignity was not respected throughout the assessment. In total, six respondents provided six comments. The theme that appeared more often is discussed, followed by a 'other' category.

Theme	Comments
N/A - didn't have an assessment	4
Other comments – not themed	2

Four comments indicated that this question was not applicable as they did not have an assessment.

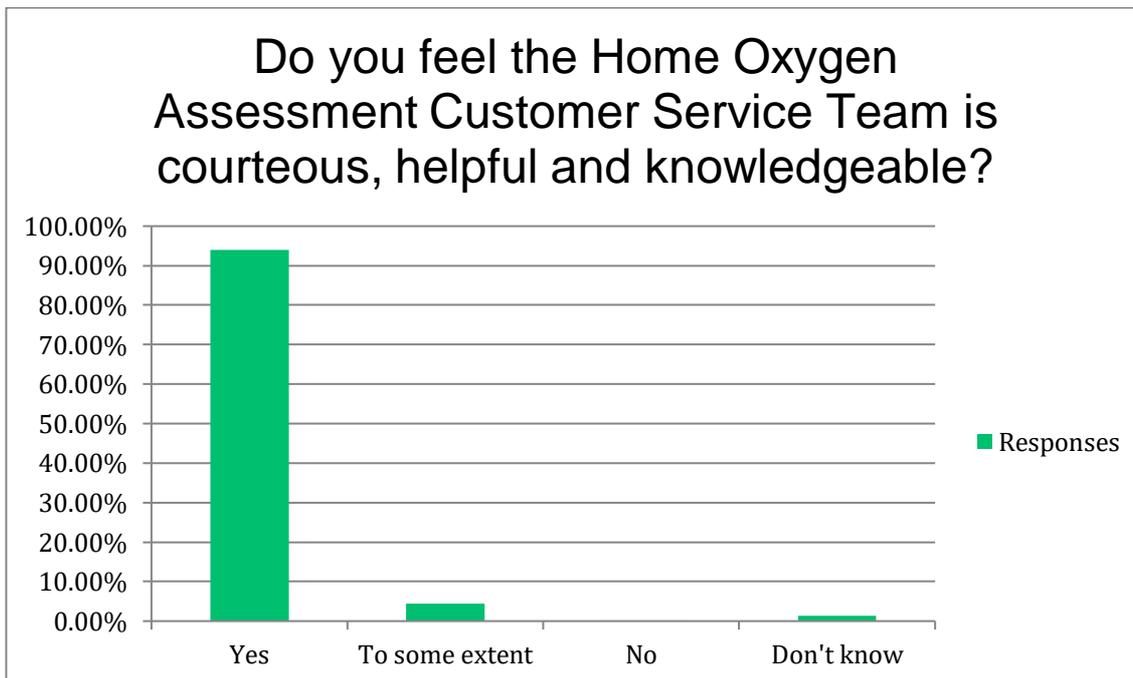
“Didn’t have an assessment”

The following two comments could not be themed and are therefore in the ‘other’ category.

Comments
<i>“Only the oxygen tank was checked and a few pamphlets left”</i>
<i>“can’t remember”</i>

Customer Service

The majority of respondents (93.98%) felt that the customer service team were courteous, helpful and knowledgeable and most people (92.42%) knew who and how to call with any questions, problems or concerns.



Answer choices	Responses %	Responses
Yes	93.98%	671
To some extent	4.48%	32
No	0.14%	1
Don't know	1.40%	10

Total responses – 714

Out of 714 respondents to this question, 80 people left a comment when asked to leave comments about the team in a free text box.

Free text question responses. Do you feel the Home Oxygen Assessment Customer Service Team is courteous, helpful and knowledgeable? (N=80)

Respondents were asked to add any comments they have about the Team. In total, 80 respondents provided 123 comments. The themes that appeared more often are discussed, followed by a table outlining all the themes and a ‘other’ category.

Theme	Comments
<i>The team are helpful, explain everything are informative and answer all questions</i>	32
<i>The team are friendly/nice/cheerful/polite/pleasant</i>	31
<i>Very good or excellent team or service</i>	16
<i>The team are easy to speak to, or they are comfortable to speak to – they are understanding</i>	8
<i>The team are kind/caring/reassuring or put you at ease</i>	8
<i>They are professional and knowledgeable</i>	5
<i>Respondents have confidence in the team</i>	2
<i>Haven't been seen by a nurse in 1.5 years or since COVID started</i>	2
<i>COVID-19 – taking longer for reviews, or they are more difficult</i>	2
<i>The team are abrupt</i>	2
<i>They are efficient or give good time when servicing equipment</i>	2
<i>Other comments – not themed</i>	15

Additionally, 32 comments indicated that staff are helpful.

“The oxygen assessment team have been very kind and helpful, explaining the process in understandable language”

31 comments indicated that the team are friendly, nice, cheerful, polite or pleasant.

“I wish every other service teams were as friendly and helpful as your team”

Furthermore, 16 comments indicated that the team or service are very good or excellent.

“The team that attend to me are excellent”

The following 15 comments could not be themed and are therefore in the ‘other’ category.

Comments
<i>“Different since change of provider.”</i>
<i>“The nurse carrying out the assessment did not portray a friendly manner, no social interaction and at times made the visit uncomfortable.”</i>
<i>“I usually have the same nurse and she is very knowledgeable about my condition this is good continuity of care.”</i>
<i>“I met my new oxygen nurse a few weeks ago and she was lovely.”</i>
<i>“No relationship or knowledge of your condition is ever really formed. Have seen quite a few different nurses. I have only contacted the oxygen team in order to request CO2 check but was told she was ‘too busy’ to come out. My community respiratory nurse knows me to know I am not a pest. She came out and did the test immediately for me. My next appointment with the oxygen would have been this November. My Co2 was high. Did feel your service was to say the least poor! Respiratory team is very good. Oxygen team needs to improve.”</i>
<i>“Safety checks are cursory, probably because I have use o2 for a long time”</i>
<i>“Always there when I need them.”</i>
<i>“They seem to have done a great job under restrictions”</i>

"They can't be expected to know every condition that requires oxygen therapy. On the times I have to explain my condition (chronic cluster headaches) they always like to learn something new and are very grateful for the insight."

"My last contact was if you need help call us and we will visit you. That was a long time ago and no contact since."

"Feels like a visit made to 'tick' the box tokenism."

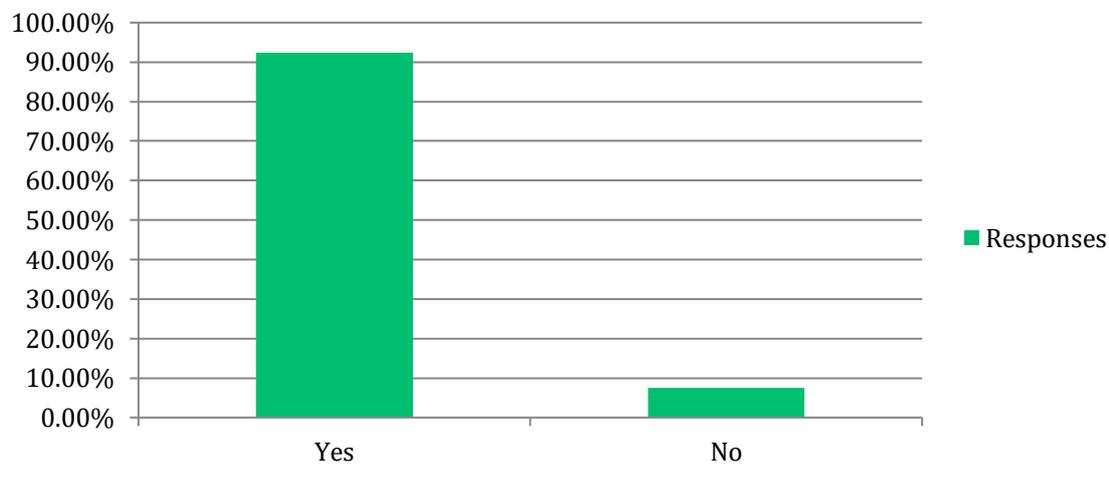
"Forms did not arrive until 4th July. Sorry for unavoidable delay."

"I have osteoporosis."

"Oxygen."

"I have had oxygen supplied since DOLBY took over from Brit. Ox. I'm on my second as could not get 1st one registered (x3) so that machine was replaced and was told 2nd one had DEFINITELY BEEN REGISTERED."

Would you know how and who to call with any questions, problems or concerns regarding your home oxygen service?



Answer choices	Responses %	Responses
Yes	92.42%	658
No	7.58%	54

Total responses - 712

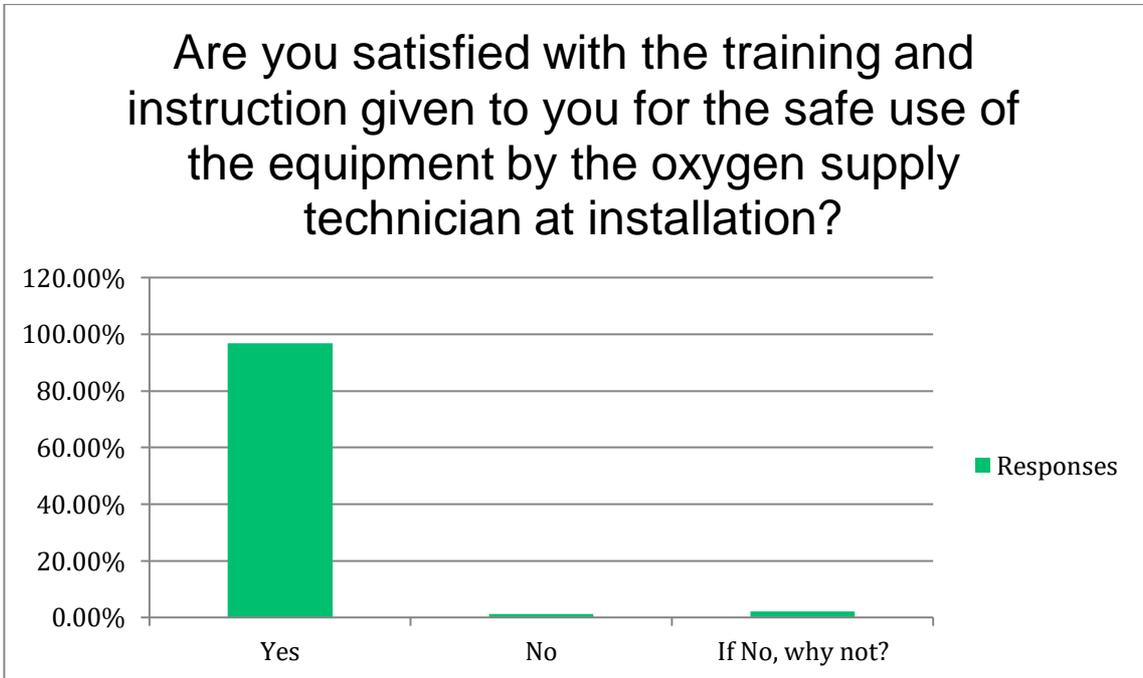
When asked to rate how happy they have been with the response from the Home Oxygen service when they have called the service, the ratings were as follows (on a scale of 10, with 1 being poor and 10 being excellent). The majority of people rated the service a 7,8,9 or 10 which is towards the positive as opposed to the negative end of the scale which suggests people are fairly positive about the response they receive when calling the service.

Rating	Responses %	Responses
1 (Poor)	1.45%	9
2	0.16%	1
3	0.16%	1
4	0.00%	0
5	1.13%	7
6	0.64%	4
7	1.77%	11
8	9.34%	58
9	9.98%	62
10 (Excellent)	48.63%	302

Total responses – 621

Equipment

The majority of respondents (96.78%) expressed that they were satisfied with the training given to them for the safe use of their equipment by the oxygen supply technician during installation. Although 8 people said they were not satisfied (1.12%), 15 people answered the question, 'if no, why not'?



Answer choices	Responses %	Responses
Yes	96.78%	691
No	1.12%	8
If no, why not	2.10%	15

Total responses – 714

Free text question responses. Are you satisfied with the training and instruction given to you for the safe use of the equipment by the oxygen supply technician at installation? (N=15)

Respondents were asked if they were not satisfied, why not. In total, 15 respondents provided 16 comments. The themes that appeared more often are discussed, followed by a table outlining the themes and a 'other' category.

Theme	Comments
Respondent received no training	5
Can't remember	2
Other comments – not themed	9

Five comments indicated that they have not had any training.

“Did not get any.”

An additional two comments indicated that they could not remember if they had any training.

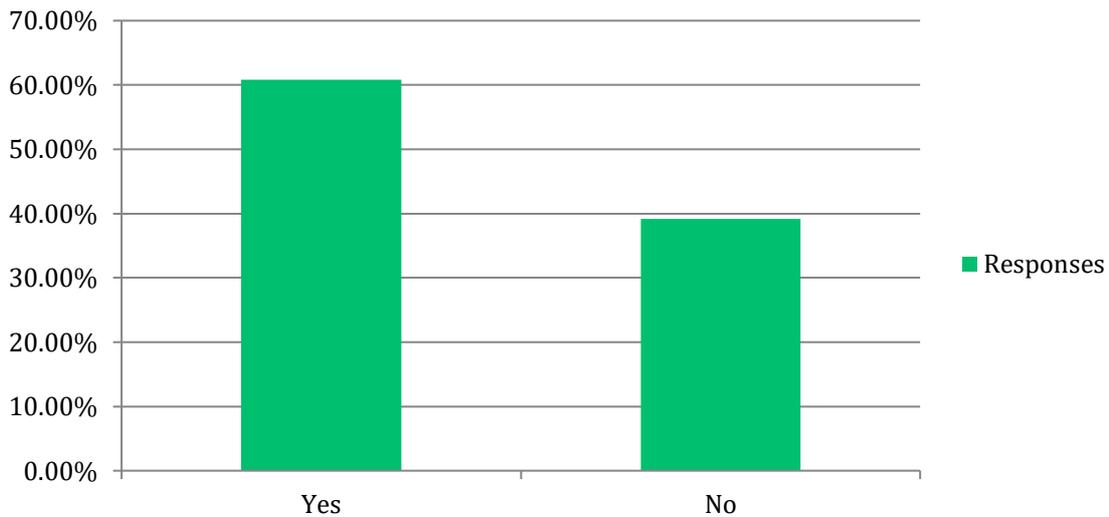
“Can't remember training / instruction.”

The following nine comments could not be themed and are therefore in the 'other' category.

Comments
<i>“Didn't explain how secure oxygen cylinder to the trolley [sic]”</i>
<i>“They did not give any recently.”</i>
<i>“I was still in hospital and it was explained to my husband”</i>
<i>“I was told to use vac cleaner on the back of the concentrator which I was not shown how to do.”</i>
<i>“She did not see me carrying my oxygen bottle upstairs”</i>
<i>“Not helpful don't leave enough canulas. When contacted sent out wrong length of canula.”</i>
<i>“New tubing needed for upstairs but not reported after service their machine cannot be used at present”</i>
<i>“Would appreciate if they checked we are comfortable and understand my memory isn't always the best and partner hard of hearing. New equipment is sometimes a challenge”</i>
<i>“The drive/supply technician is very helpful and goes that extra mile he's very good. [name removed]”</i>

Just over 60% respondents use aids to carry their oxygen. Of those that do just over 77% said the weight of their portable equipment was manageable but still 112 people (39.19%) said it was not. Most respondents (92.61%) said that their portable equipment allowed them to leave home and 98.70% said they did not have any problems storing their oxygen cylinders.

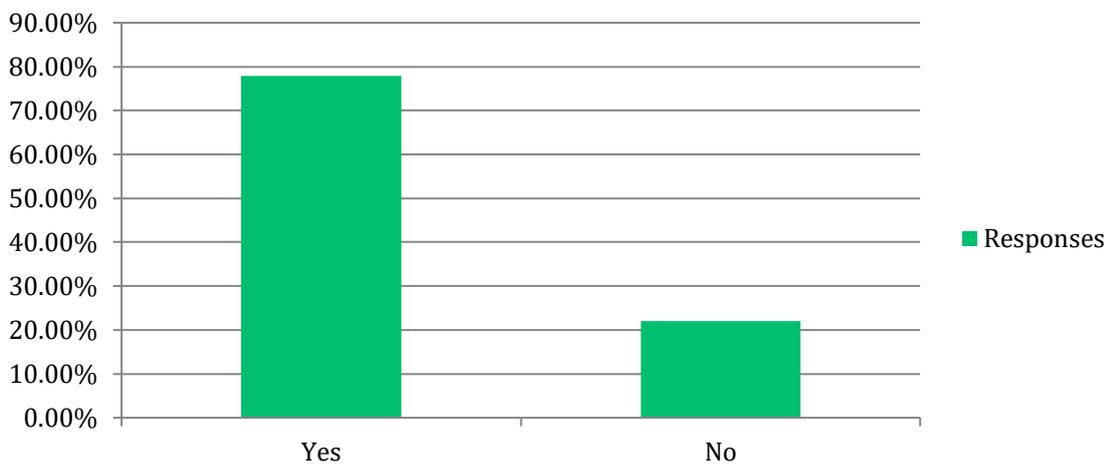
Do you use any aids to carry your oxygen?



Answer choices	Responses %	Responses
Yes	60.81%	433
No	39.19%	279

Total responses - 712

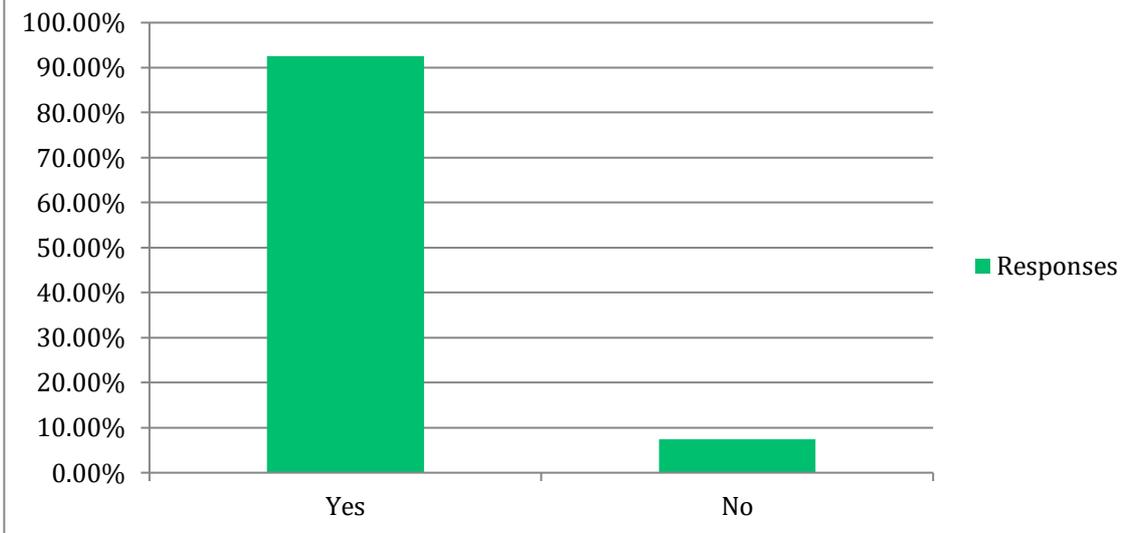
If you answered Yes to Q15 is the weight of the portable equipment manageable for you?



Answer choices	Responses %	Responses
Yes	77.95%	396
No	22.05%	112

Total responses - 508

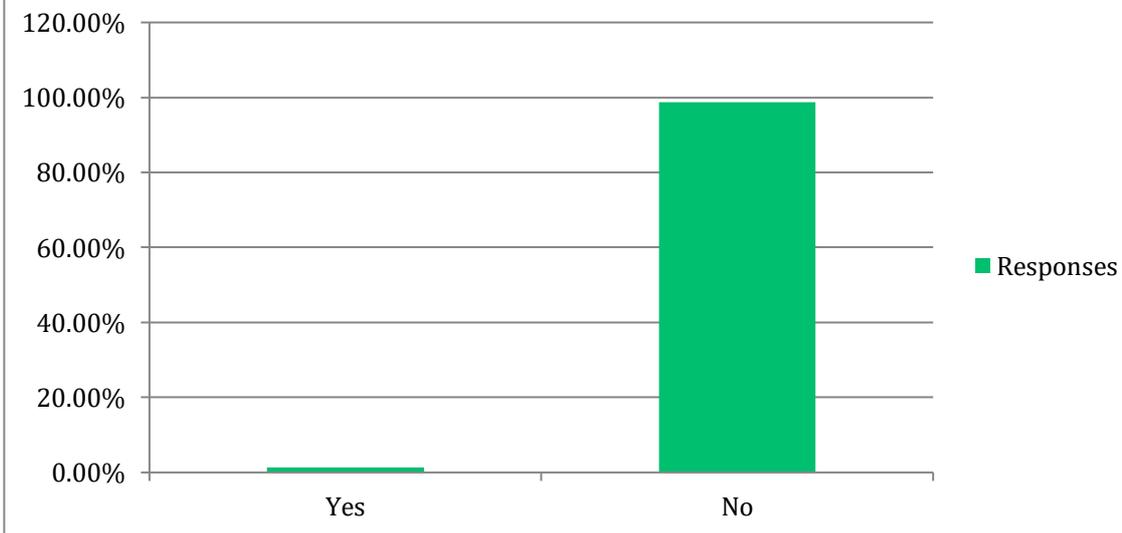
Does the portable equipment allow you to leave your home?



Answer choices	Responses %	Responses
Yes	92.61%	564
No	7.39%	45

Total responses – 609

Do you have any problems with the storage of your oxygen cylinders?

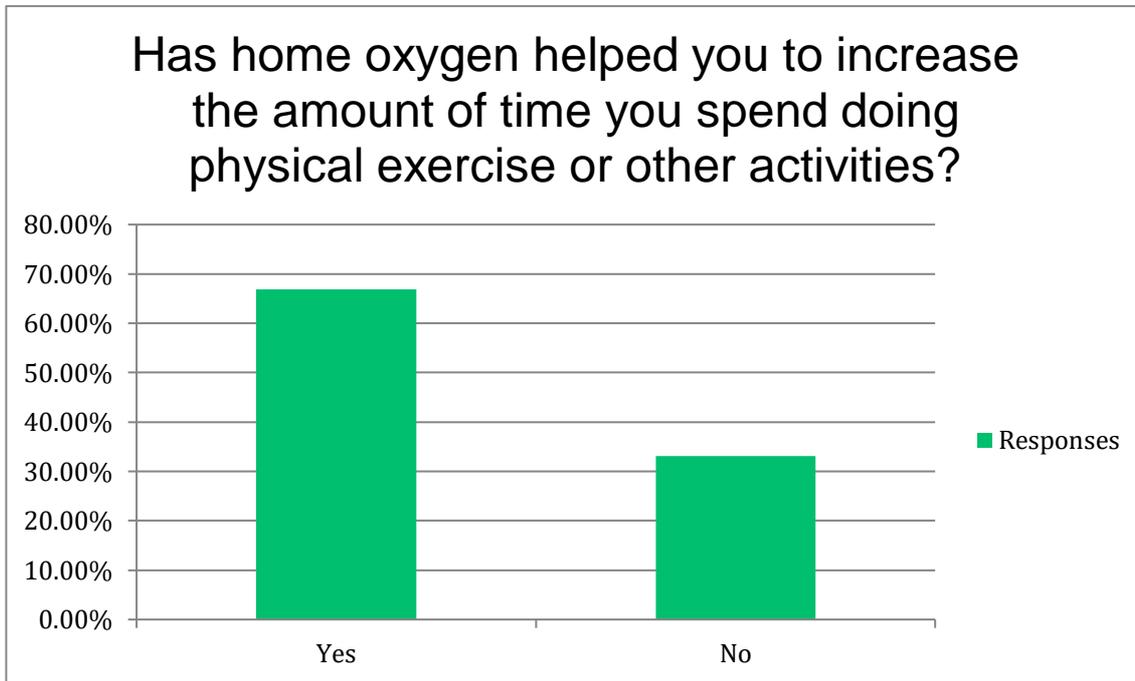


Answer choices	Responses %	Responses
Yes	1.30%	9
No	98.70%	684

Total responses - 693

Quality of Life

Just over 66% of respondents said their home oxygen had helped them to increase the amount of time they spent doing physical exercise or other activities which still leaves over 33% expressing that it did not.



Answer choices	Responses %	Responses
Yes	66.86%	454
No	33.14%	225

Total responses – 679

Respondents were asked to think about the impact of home oxygen on their quality of life and asked to score a series of statements using the following scores (1 for very important, 2 for quite important, 3 for little importance, 4 for no relevance to you).

Please see table below.

Scores	1 (very important)		2		3		4 (little relevance)		Total
	%	Count	%	Count	%	Count	%	Count	
Being able to breathe well and not being short of breath	76.80%	533	13.11%	91	3.89%	27	6.20%	43	694
Being able to do my daily activities	58.37%	394	25.93%	175	7.56%	51	8.15%	55	675
Not having to be admitted to hospital due to breathing problems	79.83%	558	9.73%	68	2.86%	20	7.58%	53	699
Not having to call the emergency services due to breathing problems	77.52%	538	10.66%	74	3.31%	23	8.50%	59	694
Having emotional wellbeing	63.79%	428	24.14%	162	5.22%	35	6.86%	46	671
The time it takes for the Home Oxygen Service Assessment nurse to attend to me	60.89%	397	24.08%	157	6.29%	41	8.74%	57	652
The explanation for using the equipment	72.35%	484	18.24%	122	3.29%	22	6.13%	41	669
Reduces the fear of death	66.62%	441	18.58%	123	5.14%	34	9.67%	64	662
The shame I feel when people see me with the oxygen equipment	24.28%	161	17.35%	115	27.90%	185	30.47%	202	663
The independence that the oxygen equipment gives to me	69.96%	482	15.38%	106	4.64%	32	10.01%	69	689
To be able to maintain contact with other people	68.41%	470	16.74%	115	4.66%	32	10.19%	70	687
								Answers	705

If we look at what was most important to people regarding impact of home oxygen on their quality of life (score 1 as very important) they are ranked as follows:

Ranking	Statement	1 (very important)
1	Not having to be admitted to hospital due to breathing problems	79.83%
2	Not having to call the emergency services due to breathing problems	77.52%
3	Being able to breathe well and not being short of breath	76.80%
4	The explanation for using the equipment	72.35%
5	The independence that the oxygen equipment gives to me	69.96%
6	To be able to maintain contact with other people	68.41%
7	Reduces the fear of death	66.62%
8	Having emotional wellbeing	63.79%
9	The time it takes for the Home Oxygen Service Assessment nurse to attend to me	60.89%
10	Being able to do my daily activities	58.37%
11	The shame I feel when people see me with the oxygen equipment	24.28%

Service Improvement

Respondents were asked to think about how the service could be improved and asked to score a series of statements using the following scores (1 for very important, 2 for quite important, 3 for little importance, 4 for no relevance to you).

Scores	1		2		3		4		Total
Being able to get advice from the service at any time during the day	66.12%	447	23.08%	156	5.03%	34	5.77%	39	676
More information on how to manage holiday oxygen	36.79%	241	22.90%	150	13.89%	91	26.41%	173	655
More information on the safe use of oxygen	47.47%	309	25.81%	168	13.36%	87	13.36%	87	651
Being able to be referred to other healthcare professionals/services e.g. pulmonary rehab	56.12%	367	21.56%	141	8.26%	54	14.07%	92	654
Easier access to information leaflets	36.32%	239	32.22%	212	15.20%	100	16.26%	107	658
Access to online resources	28.24%	172	21.84%	133	11.82%	72	38.10%	232	609
More frequent visits from the Home Oxygen Assessment Nurse	34.54%	229	33.79%	224	17.95%	119	13.73%	91	663
Less frequent visits from the Home Oxygen Assessment Nurse	14.39%	82	27.54%	157	29.12%	166	28.95%	165	570
Service accessible by video/app	12.36%	75	15.16%	92	13.51%	82	58.98%	358	607
Any other ideas - please tell us here									42
Answers									694

If we look at what was most important to people regarding how the service could be improved (score 1 as very important) they are ranked as follows:

Ranking	Statement	1 (very important)
1	Being able to get advice from the service at any time during the day	66.12%
2	Being able to be referred to other healthcare professionals/services e.g. pulmonary rehab	56.12%
3	More information on the safe use of oxygen	47.47%
4	More information on how to manage holiday oxygen	36.79%
5	Easier access to information leaflets	36.32%
6	More frequent visits from the Home Oxygen Assessment Nurse	34.54%
7	Access to online resources	28.24%
8	Less frequent visits from the Home Oxygen Assessment Nurse	14.39%
9	Service accessible by video/app	12.36%

When asked for other ideas as to how to improve the service, 42 people answered the question. Their responses were as follows;

Free text question responses. Thinking about how the service could be improved, please score the statements below. (N=42)

Respondents were asked for any other ideas. In total, 42 respondents provided 43 comments. The themes that appeared more often are discussed, followed by a table outlining all the themes and a 'other' category.

Theme	Comments
Everything is fine or they are satisfied	9
They would like more visits, more regular follow ups or they haven't had a visit or a recent visit.	6
None or not applicable	4
Not everyone is equipped with digital skills/smart tech	3
Receive oxygen for cluster headaches only so question is not applicable	2
Keep up the good work	2
Other comments – not themed	17

Nine comments indicated that they were satisfied or that everything is fine

“Everything is fine with my home oxygen service”

Respondents also suggested that they would either like more visits/follow ups – that they either haven't received any or that they weren't recent (6 comments).

“Could do with more visits”

An additional four comments indicated that this question is not applicable to them, with a further two comments suggesting this is because they receive oxygen for cluster headaches.

“A lot of this is N/A to my situation which is cluster headaches”

Three comments indicated that not everyone is equipped with technology or the digital skills to use it.

“Not everyone is equipped with digital skills and smart tech”

The following 17 comments could not be themed and are therefore in the 'other' category.

Comments
<i>"Find pulmonary rehab sessions helpful and enjoyable - have attended several times"</i>
<i>"It would be nice if you could do something about the noise the concentrator creates"</i>
<i>"Stickers to inform people that liquid oxygen is being stored outside"</i>
<i>"Some info on exercise I can do"</i>
<i>"I have had huge issues with the oxygen supplier. There is nowhere I can go to complain. There should be an online department I can go to."</i>
<i>"Need accessible easy read info as [name removed] poor literacy skills"</i>
<i>"To receive the requested number of O2 cylinders. Due to shortage this not happening. Although do come on later date."</i>
<i>"CF team deals with all my care"</i>
<i>"The portable cylinder could be bigger"</i>
<i>"All points fully covered by nurse [name removed]. Very professional, makes a big difference"</i>
<i>"give timeslots and possible weekends for home visits for nurses and maintenance as some patients still do work full time"</i>
<i>"I was still in hospital when installed"</i>
<i>"Practical advice regarding going out/socialising"</i>
<i>"A small device which carries the oxygen bottles with a handle would be nice. You can put it behind you. Carrying heavy weights makes you more breathless"</i>
<i>"My condition is progressive if the oxygen helps me help my own it is sufficient"</i>
<i>"Why ask the home visit question twice"</i>
<i>"This question is very misleading as on the whole I'm satisfied with the service but all the questions on the left are important"</i>

When asked if there was anything the Home Oxygen Assessment service needs to **stop** doing as it isn't helping you keep well or live a full life independently, 328 people answered the question. Their responses were as follows;

Free text question responses. Is there anything the Home Oxygen Assessment service needs to stop doing as it isn't helping you keep well or live a full life independently? (N=328)

Respondents were asked for any other ideas. In total, 328 respondents provided 329 comments. The themes that appeared more often are discussed, followed by a table outlining all the themes and then a 'other' category.

Theme	Comments
No	304
Oxygen cylinders are too heavy - not able to walk for long time	3
Issues with Dolby Visisol	2
Don't know	2
Yes – needs to do more	2
Listen to patients more - do what is needed - Stop thinking of everyone as the same, everyone has different needs and issues	2
Other comments – not themed	12

The majority of comments (304 comments) indicated that there was nothing that the Home Oxygen Assessment service needs to stop doing.

"No need to stop anything, very satisfactory."

Three comments indicated that the oxygen cylinders are too heavy.

"Trying to carry oxygen slinger far too heavy! So not able to walk far and be out for long."

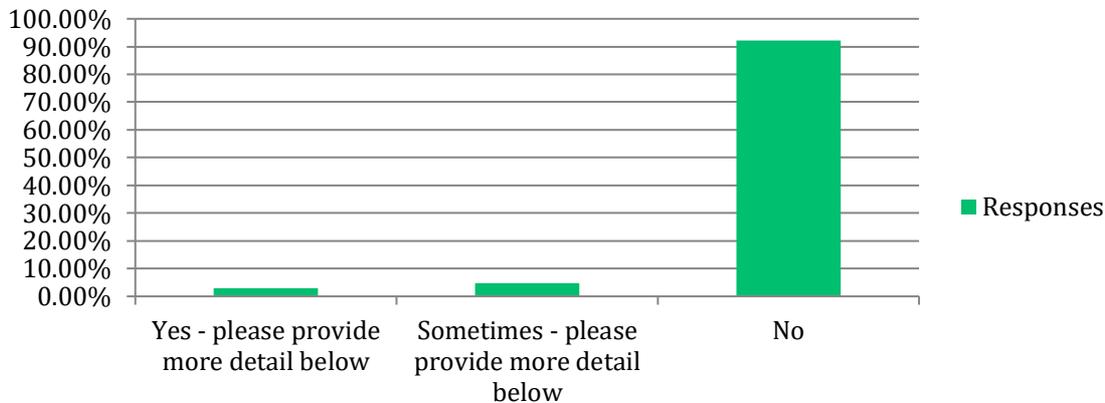
Additionally, two comments indicated issues with Dolby Vivisol.

"Just Dolby Vivisol"

The following 12 comments could not be themed and are therefore in the 'other' category.

Comments
<i>"The carry bag of the small cylinder is very hard to use as the dial that shows volume can't be left seen when on, the off switch area is turned on."</i>
<i>"...basically the dolby bottles don't fit the BOAC bag"</i>
<i>"Blood test from the ear"</i>
<i>"All aspects to service provide safety and feeling of wellbeing"</i>
<i>"To accept [sic] return of equipment that I no longer in use (Demand breathing circuit example)"</i>
<i>"When ordering my cylinders then not bringing the right amount"</i>
<i>"Need help with turning on valve controls. They are very tight / stiff"</i>
<i>"Yes stop calling to see me as I was burned on my ear and neck with jelly that was put on my ear I would not like to see them again"</i>
<i>"Sending letter and newsletters"</i>
<i>"Don't need home visits as often"</i>
<i>"At the moment I don't use the small bottle very often but I still need the big ones"</i>
<i>"slowly getting there"</i>

Do you feel that there is any duplication with the Home Oxygen Assessment Service nurses and the nurses from the respiratory team at the hospital?



Answer choices	Responses %	Responses
Yes	3.02%	18
Sometimes	4.70%	28
No	92.28%	550

Total responses - 596

The overall majority of respondents (92.28%) said that they did not feel there was any duplication between the Home Oxygen Assessment Service nurses and nurses from the respiratory team at the hospital.

For each answer choice respondents were asked to provide more detail.

Free text question responses. Do you feel that there is any duplication with the Home Oxygen Assessment Service nurses and the nurses from the respiratory team at the hospital? (N=80)

Respondents were asked if they felt any duplication with the Home Oxygen Assessment Service nurses and the nurses from the respiratory team at the hospital. In total, 80 respondents provided 81 comments. The themes that appeared more often are discussed, followed by a table outlining all the themes and a 'other' category.

Theme	Comments
Not in contact with hospital respiratory team	15
Happy with service	8
N/A	7
Nothing to add	4
Not seen a nurse for 12+ months	4
Supplement or complement each other - good balance	4
Only use oxygen for cluster headaches	4
Same advice or tests given	3
Both excellent or helpful	3
Unsure	3

Haven't seen assessment nurse since they first received oxygen	2
Better communication between the two services	2
Hospital team more thorough or more detailed	2
Don't see nurses enough or have little contact	2
Other comments – not themed	18

15 comments indicated that they are not in contact with the hospital respiratory team.

"I do not see any nurses from the hospital respiratory team"

An additional eight comments indicated that they are happy with the service they receive.

"Very happy with service"

The following 18 comments could not be themed and are therefore in the 'other' category.

Comments
<i>"My GP does check-ups on me not the hospital as much"</i>
<i>"Been discharged from hospital as no treatment other than oxygen can help"</i>
<i>"As far as I can tell there is no connection between the hospital and the assessment service except for the issuance of requirement"</i>
<i>"I would like my oxygen nurse at the RVI hospital to call me more often"</i>
<i>"sessions in pulmonary rehab"</i>
<i>"Difference in flow rate"</i>
<i>"Unable to process the difference"</i>
<i>"Breathing information sometimes confusing knowing which service is which"</i>
<i>"I feel more confidence in the hospital team"</i>
<i>"Sometimes respiration nurse has been and give instruction re o2 the home oxygen nurse comes next day"</i>
<i>"Are better than hospital staff"</i>
<i>"I feel that the home oxygen service sees you in your home surroundings"</i>
<i>"nasal cannulas have to be replaced every 3 weeks. Can they be sent on a regular basis instead of having to ring up every 3 weeks"</i>
<i>"Until lockdown I attended a breathe easy group. as of then I get visits for my respiration nurse on any problems I can phone they are based in my area."</i>
<i>"NO duplication because I don't have a home oxygen nurse"</i>
<i>"Engineers turning up when they say they will for routine maintenance"</i>
<i>"Would be nice to have the info as to delivery time am or pm"</i>
<i>"Only use m/c when I sleep"</i>

Customer Experience

On a scale of 1 to 10 (1 being poor to 10 being excellent) respondents were asked to rate their overall experience of the Home Oxygen Assessment service?

Rating	Respondents %	Respondents
1 (poor)	4.17%	29
2	0.58%	4
3	0.43%	3
4	0.29%	2
5	2.73%	19
6	1.01%	7
7	2.16%	15
8	10.79%	75
9	17.99%	125
10 (excellent)	59.86%	416

Total respondents - 695

The weighted average is 8.89

People who have not had a positive experience have rated the service a 1 (29 people). Those who are undecided have picked somewhere in the middle a 5 (19 people) but on the whole the % go up as the rating goes up to a 10 being excellent. Therefore, taken as an overall data set, respondents have a positive experience of the service.

Respondents were asked to share any other feedback that they would like the CCGs to consider as part of the service review. 145 people answered the question. Their responses were as follows:

Free text question responses. Please share any other feedback that you would like us to consider as part of this review (N=145)

Respondents were asked to share any other feedback they would like considered. In total, 145 respondents provided 153 comments. The themes that appeared more often are discussed, followed by a table outlining all the themes.

Theme	Comments
All good/ok/happy/excellent	34
Nothing/ N/A	29
Prefer contact more often/regular check-ups – reviews assessments are vital	8
Thank you/grateful	7
Amazing/excellent/polite nurses/staff	7
Provided with more information and for the to answer any questions I have, such as on the oxygen, exercise I can do, advice on using the equipment, how to get pipe oxygen	7
Use o2 for cluster headaches	5
Keep up the good work	3
Would like an estimated delivery time - AM/PM	3
Smaller/lighter cylinder to carry	3
Have sufficient o2 supply/deliver right amount	3

Dad's portable o2 machine replaced - not returned until September - not going out much	3 [duplicated]
They are professional	2
Complaints about oxygen supplier	2
New container has smaller capacity - more frequent deliveries/harder to use	2
Had to cancel appointment and no new appointment was provided	2
With oxygen - can live normal life	2
Faulty equipment/improve quality of the equipment	2
Other comments – not themed	29

34 comments indicated that they were happy with the service, or the service was ok, good or excellent.

"I found this service second to none and can only go by personal experience – I can't find fault with it"

29 comments indicated that they had no feedback.

"Nothing"

Respondents also suggested that regular contact, check-ups reviews or assessments are vital (8 comments).

"Review by nurse vital in the past year mam has been changed from as required oxygen use at high flow rate to being on 16 hours/day following review of 3/12 rate due to co2 retention. This highlights the important of an oxygen assessment nurse to us as a family"

Seven comments indicated that they were grateful for the service or thanked the service.

"The home oxygen keeps me alive. Thank you"

The following 29 comments could not be themed and are therefore in the 'other' category.

Comments
<i>"Would like to be more mobile outside of home, to be able to visit parks and such"</i>
<i>"more canulas [sic] provided as they harden so quickly"</i>
<i>"cylinders of o2 are more difficult to move and the small ones are bulky and not portable. I have cluster headaches and could not take a small o2 cylinder outside"</i>
<i>"Think it's important to try to keep same nurses to patients, a trust and repartee build up, and shouldn't be broken"</i>
<i>"Need support to understand and apply to have assistance in having a refund on my electricity bill as my use of oxygen increases by usage"</i>
<i>"It would be nice to meet people with the same problem as me."</i>
<i>"It was suggested during the assessment that my portable device may be taken away as it has not been used much, seeing as I was shielding for a year, I did not use it, but now I am starting to get out and this equipment enables me to do so. The manner that this was suggested was not appropriate."</i>
<i>"Perhaps a more relevant questionnaire for people like me, who use oxygen intermittently after a seizure."</i>

<i>"I would like more help with my IBS as I am sad. I don't go out very much as I am always feeling like not getting up on a morning, as I am going to toilet a lot, sometimes I go on a night too and I get very low and start crying."</i>
<i>"...always on time easy to solve any problems"</i>
<i>"I am disappointed in the new delivery of oxygen bottles ... This company is nowhere near as B.O.C were"</i>
<i>"As I have a concentrator the re-instatement of a cylinder would be helpful and reassuring for me, but this is probably because of the extra cost"</i>
<i>"Don't see oxygen nurse at hospital"</i>
<i>"Quieter machine if possible"</i>
<i>"Make the print larger, I have very poor eye sight"</i>
<i>"Electricity refund re using concentrator could be more as electricity is always going up"</i>
<i>"Just changed suppliers. Look like I'm going to have the same treatment as always very good. More than a job. Go out of their way too - feels you matter"</i>
<i>"Some of the oxygen tanks delivered still show 3/4 to full after they are empty which in turn means have to phone emergency line!"</i>
<i>"Very long winded for some who will be poorly"</i>
<i>"Some of questions very badly phrased"</i>
<i>"Did not see if I could carry oxygen up and downstairs"</i>
<i>"yes"</i>
<i>"Has never applied/in care home 5 years now 97. I was prescribed oxygen after chemo for cancer which left me with mainly 3 faults, I've found the breathing to be my biggest problem I'm not mobile now and extra weight does not help! I cope may days with aid of oxygen in fact everyday! Particularly every morning"</i>
<i>"[Name removed] live in supported living so staff have answered on her behalf as she could not manage the questions"</i>
<i>As I have COPD and sleep apnea [sic] I have the home oxygen attached to c pap machine every night and at the moment I'm waking upon a morning feeling tired.</i>
<i>My daughter is my registered carer and is available to me 24/7</i>
<i>As this was only a risk assessment no health was talked about</i>
<i>I stop using the oxygen occasionally depending upon temperature / humidity</i>
<i>Question 19, home oxygen doesn't make any difference to getting short of breath. I am of the opinion that home oxygen is for your heart, as when you get low on oxygen your heart has to work harder. When using home oxygen you still get short of breath. I wish it did help with shortness of breath. I think it is possible that using oxygen helps to recover quicker</i>

Conclusion

Overall, the Home Oxygen Assessment Service was evaluated highly by survey respondents with 59.86% rating their experience as excellent. Positive comments were made about the information provided, how involved they were in decision making, the training provided to use equipment and the responsiveness of the customer service team.

Furthermore, respondents didn't really have any problems using or storing their oxygen and knew who and how to call the customer service team if they needed help.

However, respondents did express a desire for more information and would have liked a leaflet as many did not have any information to read following their assessment. Although the

time waited for an assessment was deemed reasonable, more frequent reviews was raised as an issue, Respondents said they would like more visits, more regular follow ups or expressed that they hadn't had a visit or a recent visit.

Although the majority of respondents said the weight of their portable equipment was manageable nearly 40% said it wasn't.

When asked about how home oxygen impacts on their quality of life, most participants stressed not having to be admitted to hospital due to breathing problems and not having to call the emergency services due to breathing problems as most important.

The service could be most improved by being able to get advice from the service at any time during the day, being able to be referred to other healthcare professionals/services and by providing more information on the safe use of oxygen

There didn't seem to be any duplication between the Home Oxygen Assessment Service nurses and nurses from the respiratory team at the hospital with most saying they were not in contact with the hospital respiratory team. Overall, the service is rated very highly with most survey respondents having a very positive experience.

Appendix

Demographics of survey respondents.

Table: Service user/carers (n=659)

Response	%
Service user	96.66%
Carer	3.34%

Table: Age (n=684)

Response	%
Under 18	0%
18-24	1%
25-34	3%
35-44	14%
45-54	27%
55-64	92%
65+	526%
Prefer not to say	21%

Table: Gender (n=683)

Response	%
Male	43%
Female	56%
Non-binary	0%
Gender nonconforming	0.15%
Other	0.15%
Prefer not to say	0.15%

Table: Gender identity matching sex registered at birth (n=682)

Response	%
Yes	98%
No	1%
Prefer not to say	0.59%

Table: Pregnant (n=665)

Response	%
Yes	0.60%
No	73.54%
Prefer not to say	0%
Not applicable	26%

Table: Marital status (n=685)

Response	%
Single (never married or in a civil partnership)	8%
Cohabiting	3%
Married	53%
In a civil partnership	0.73%
Separated (but still legally married or in a civil partnership)	1%
Divorced or civil partnership dissolved	9%
Widowed or a surviving partner from a civil partnership	23%
Prefer not to say	1%

Table: Disability (n=680)

Response	%
Yes	97%
No	3%

Table: Caring responsibilities (n=639)

Response	%
None	86%
Primary carer of a child or children (under 2 years)	0.31%
Primary carer of a child or children (between 2 and 18 years)	0.78%
Primary carer of a disabled child or children	0.16%
Primary carer or assistant for a disabled adult (18 years and over)	3%
Primary carer or assistant for an older person or people (65 years and over)	6%

Secondary carer (another person carries out main caring role)	2%
Prefer not to say	3%

Table: Race/ethnicity (n=672)

Response	%
Asian/British Asian: Bangladeshi	0.60%
Asian/British Asian: Chinese	0%
Asian/British Asian: Indian	0%
Asian/British Asian: Pakistani	0.15%
White: British	98%
White: Irish	0.30%
White: European	0.15%
Black/British Black: African	0.15%
Black/British Black: Caribbean	0%
Mixed Race: Black & White	0%
Mixed race: Asian & White	0%
Gypsy or traveller	0%
Rather not say	0.30%

Table: Sexual orientation (n=649)

Response	%
Heterosexual or straight	95%
Gay man	0.15%
Gay woman or lesbian	0.46%
Bisexual	0.15%
Asexual	0.15%
Prefer not say	3%
Other	2%

Table: Religion (n=666)

Response	%
No religion	18%
Christianity	76%
Buddhist	0%
Hindu	0%
Jewish	0%
Muslim	0.15%
Sikh	0%
Prefer not to say	2%
Other religion	4%

