



Market Research Report

The experience of COPD

May 2006

Prepared for:

Australian Lung Foundation

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Executive Summary

- In early 2006, more than 1,686 individuals responded to a self-completion survey sent by the Australian Lung Foundation to its members who have Chronic Obstructive Pulmonary Disease (COPD). Due to the contact that research participants have with the ALF, the survey cannot be considered as a random sample and this may limit its ability to project to the general population. However it is an excellent measure of the effect of COPD on the lives of those with this condition.
- Almost equal numbers of men and women responded to the survey, showing that COPD is not gender-specific. Most research participants are in the 65-79 year age group.
- Those with COPD are more likely to come from rural areas, which suggests that lifestyle factors have far more impact on COPD than environmental factors. To put it simply: the fresh air of the country does not make up for smoking cigarettes.
- While most of those with COPD live with others, just under one-third live alone. Living alone has a strong impact on feelings of loneliness, depression and 'no one to turn to' for those with COPD.
 - Those who live alone have a higher level of feeling that they 'have no one to turn to' and 'feeling alone' since their diagnosis.
 - Analysis shows that special care needs to be taken with those that live alone and are more vulnerable to the effects of isolation.
- Just over one in ten has been hospitalised in the last 12 months. 38% have been hospitalised prior to the past 12 months. Just under two-thirds of those with COPD have never been hospitalised.
 - Where hospitalisations have decreased the biggest impact on reduction comes from medication.
- Just over one-quarter of those with COPD had respiratory problems as children or teenagers. While this is a large number of people, the largest group of those with COPD had no juvenile respiratory problems.
- Three quarters of those with COPD have smoked for more than five years. The impact of smoking on the development of COPD is very clear.

- The social effect of COPD is to confine people to their home. This limits involvement with the wider community, and as a result they have less participation in activities and groups. There is an apparent tendency for those with COPD to become more 'house-bound'.
- Just under one-third of those with COPD use home oxygen. This is more prevalent for those that smoke or have smoked cigarettes in the past.
 - Where home oxygen is used, this limits social interaction.
- There is a double outcome from the initial diagnosis of COPD. The greatest feeling is of 'relief' that an ongoing chronic condition has been identified and for four in ten there is little impact on their emotional wellbeing. But for just over half of those surveyed the outcome includes depression and being 'afraid for the future'.
- Since diagnosis just over half surveyed feel their emotional wellbeing is 'better', with over a quarter feeling there is 'no change'. For just over two in ten their life since diagnosis has become worse.
 - A range of factors has had an impact which improved the lives of those since diagnosis. Improvements come from a multifaceted approach to improve wellbeing. All listed aspects had an impact on wellbeing. These are:
 - pulmonary rehabilitation
 - medication
 - the support of doctors
 - the support of family and friends
 - the support of other health professionals
 - joining a COPD group
 - Where emotional wellbeing has declined, feelings of depression and being 'afraid for the future' played the strongest role in this decline.
 - Those who live alone are more likely for their emotional wellbeing to have become 'worse' since diagnosis. They are more likely to agree that 'feeling alone' and 'no one to turn to' has made their situation worse.
- Just under three-quarters of those surveyed believe there is a seasonal impact in their COPD. The seasons that most physically affect COPD are not the spring and autumn, but summer and winter.
 - Winter and summer are also more likely to have an impact on the emotions of individuals, though for over one-third the emotional effects are felt all year round.

- Just under half of those surveyed are members of Lungnet. Most have been Lungnet members for less than five years.
 - Attendance of Lungnet meetings is mostly monthly, though just over one-third do not attend any Lungnet meetings.
 - The newsletter and face to face meetings are the initiatives that are most used by Lungnet members.

REPORT

The Experience of COPD

Prepared for:

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1. Introduction

In early 2006 the Australian Lung Foundation (ALF) sent self-completion questionnaires to members with COPD. The questionnaire was developed by the ALF in conjunction with leading public relations specialist Burson- Marsteller. Stollznow Research received the questionnaires and completed editing and data processing to data table format.

This is the report on the findings from this survey.

2. Approach

Self-completion surveys were used for this project. As with any self-completion questionnaire, many respondents miss questions. For each question the chart shows the 'base'; the number of people who answered the question. This number varies significantly from question to question and is the result of a self-completion questionnaire being completed by a largely elderly group of individuals. The differences in 'base size' for questions do not have an impact on the reliability of the survey.

The questionnaire was sent to members of the ALF who currently have COPD. This is not a random sample of the population, and therefore caution needs to be used when applying results to the general population. However the findings can be relied upon to give a clear picture of the *experience* of COPD for individuals.

3. Analysis

Cross-tabulation analysis is used in this report. All questions are analysed by demographic groups consisting of:

- gender
- age
- smoker or ex-smoker / never smoked
- living alone / living with others
- diagnosed with COPD for less than 10 years / for more than 10 years

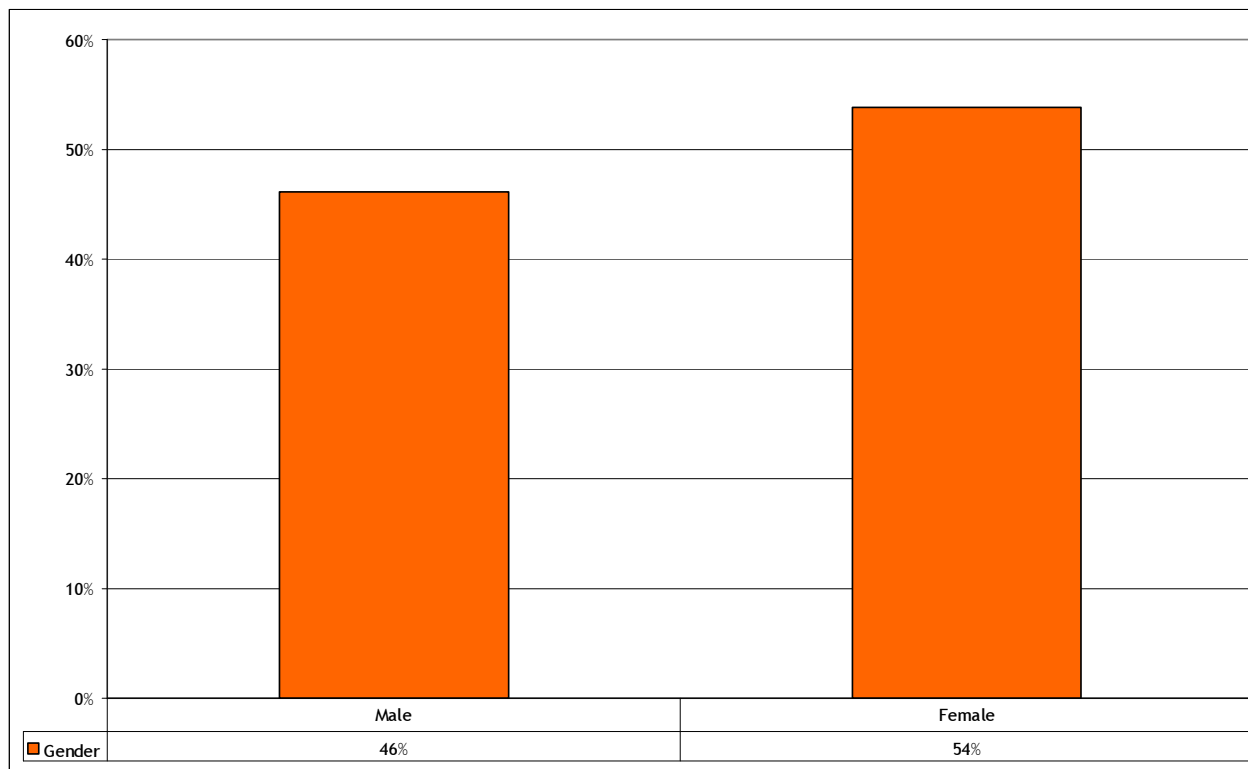
In the report, findings are mostly shown as charts for the 'total', with references to any differences in the text. In some cases where the differences between groups are large, additional charts are used.

If there is no mention of demographic differences this means that there are no statistically significant and meaningful differences.

4. Report

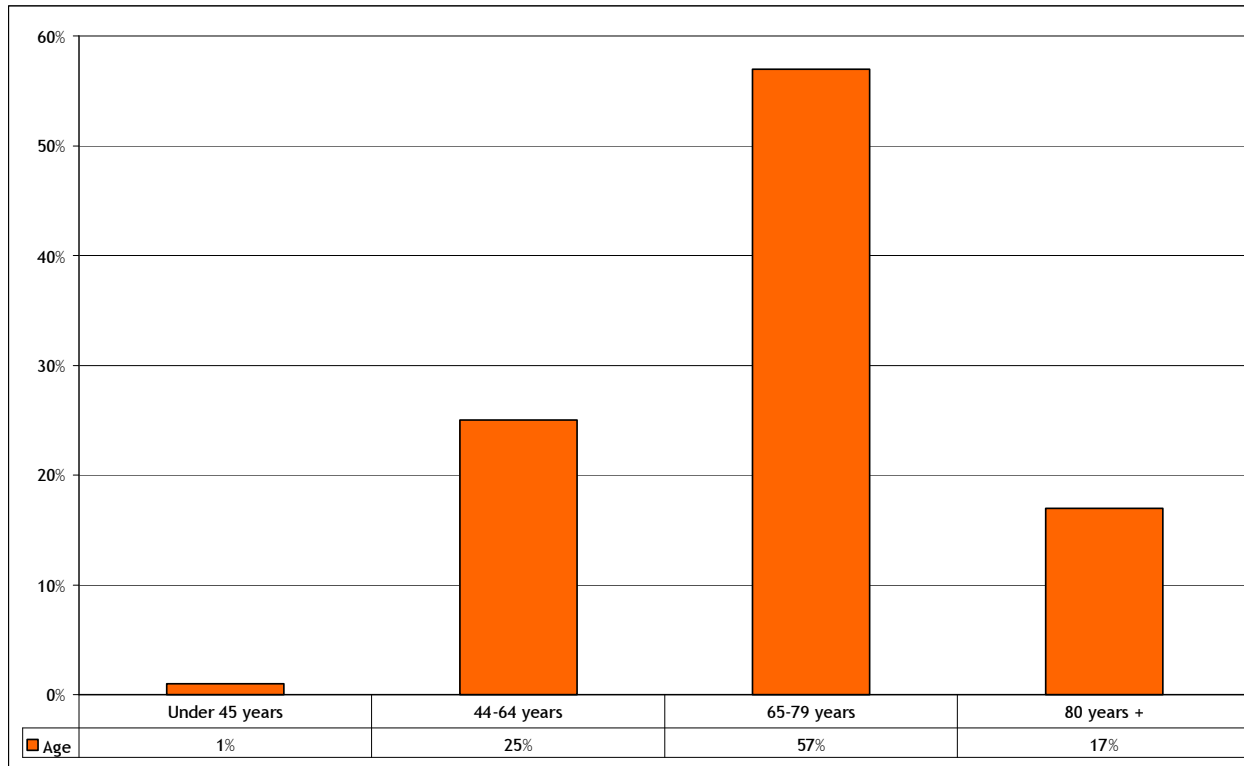
4.1 Demographics

Chart 1: Gender
Base: 1,547



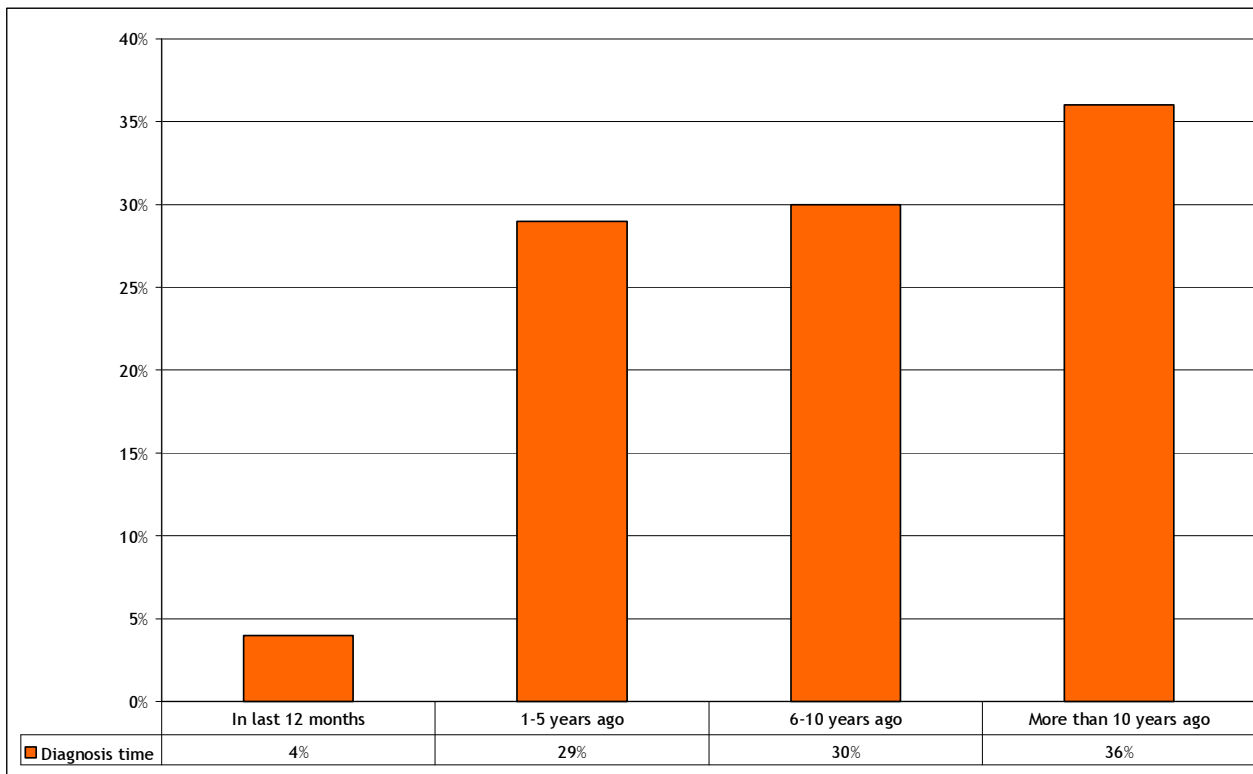
- The split between men and women is very similar to the general population. COPD appears to affect both genders equally.

Chart 2: Age
Base: 1,683



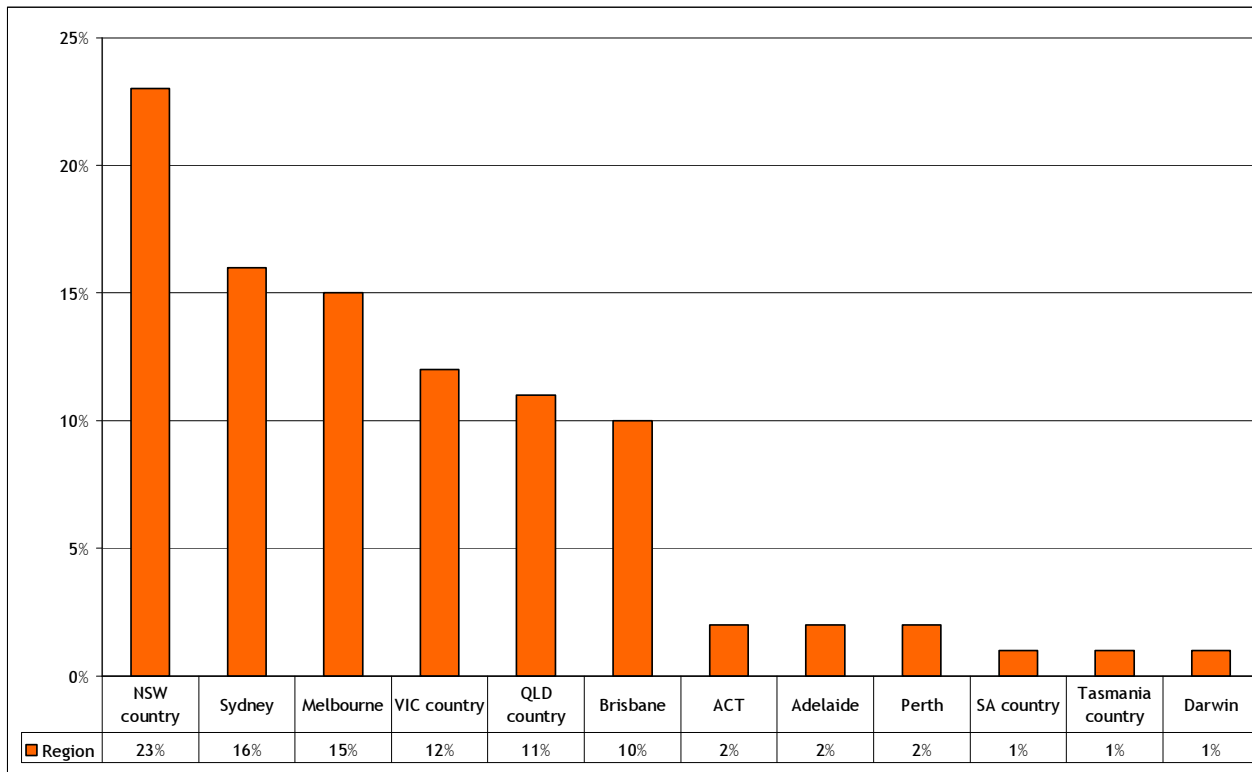
- The *mode* or largest age group is those between 65 and 79 years of age.

Chart 3: Time since diagnosis
Base: 1,661



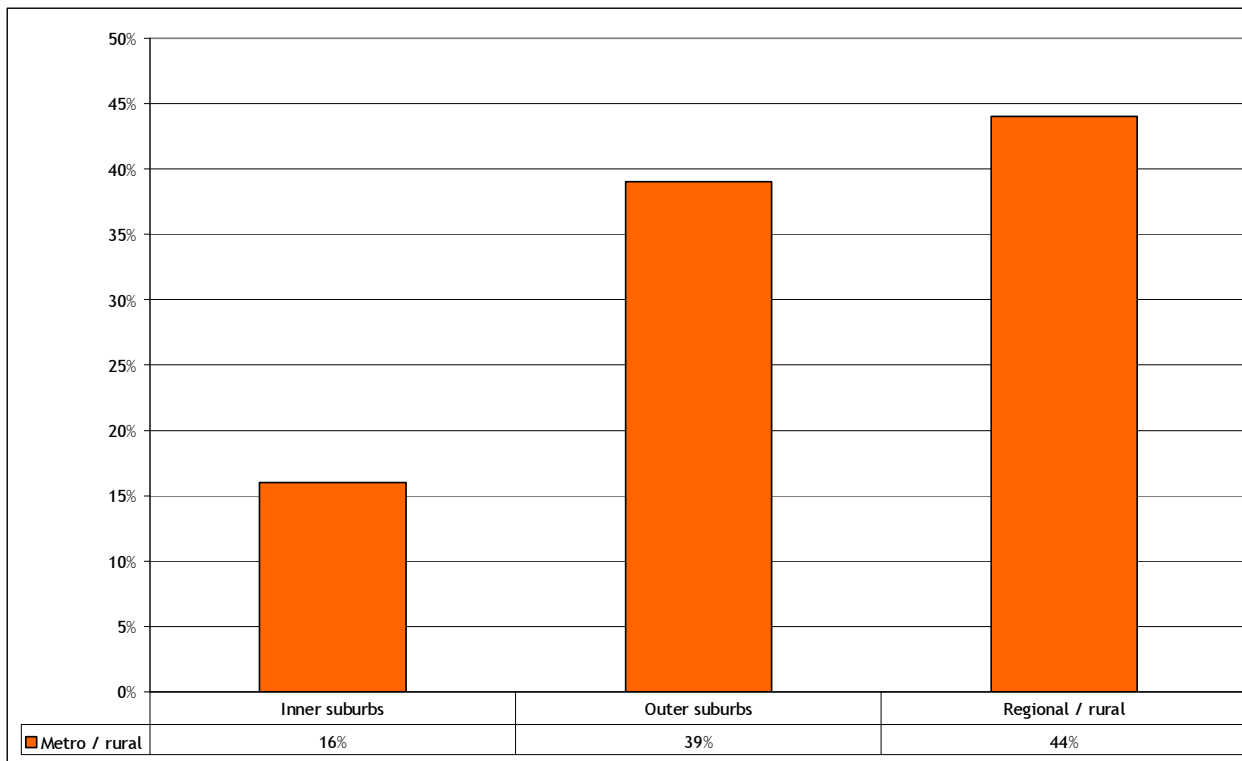
- The time since diagnosis is split evenly between the three time periods.
- Those over 65 years of age are far more likely to have been diagnosed over ten years ago.

Chart 4: Residential region
Base: 1,612



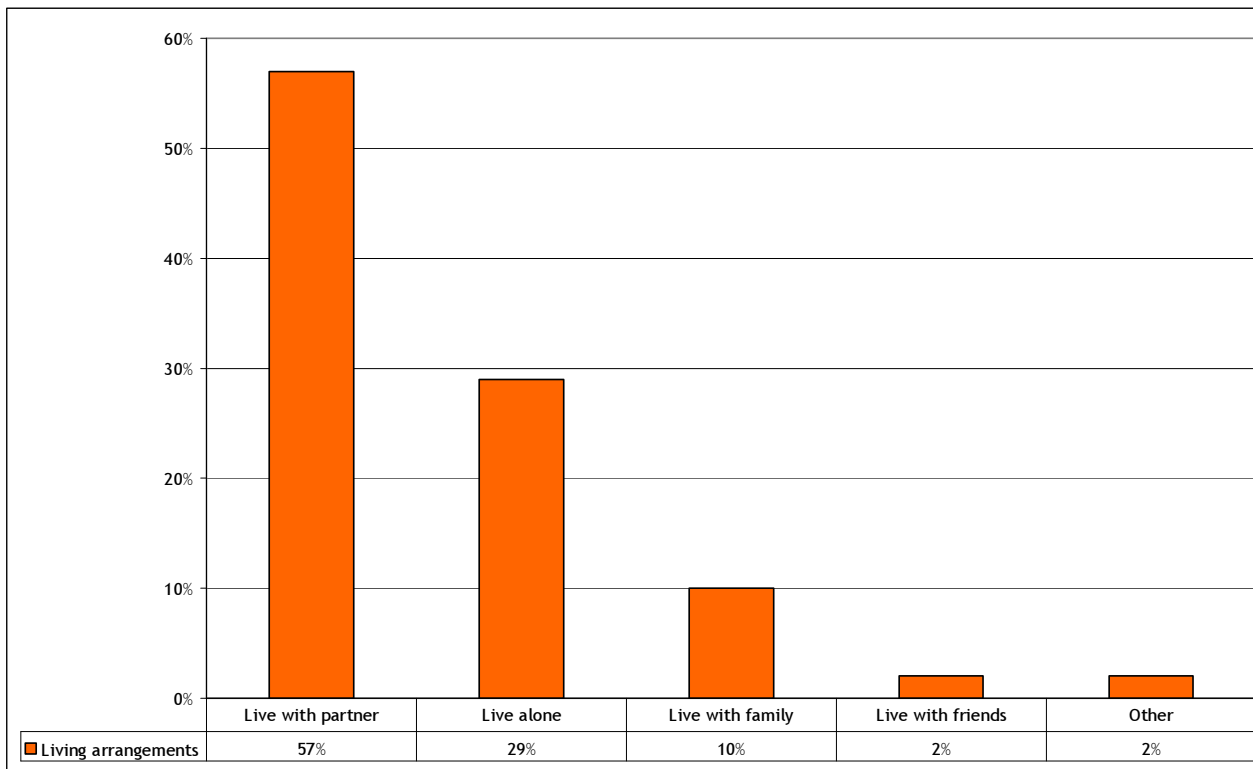
- NSW country areas are the largest group that responded to the survey.
 - This suggests that ‘fresh country air’ does not necessarily improve lung health.
- Sydney and Melbourne have similar levels of contribution.

Chart 5: Metro / regional-rural
Base: 1,646



- While the inner-city areas of Australia undoubtedly have poorer air quality than country areas it is regional and rural areas that have the highest incidence of COPD in this survey.
- Relatively few live in inner-city areas.
 - This suggests that individual lifestyle attributes such as cigarette smoking have the strongest impact on COPD.

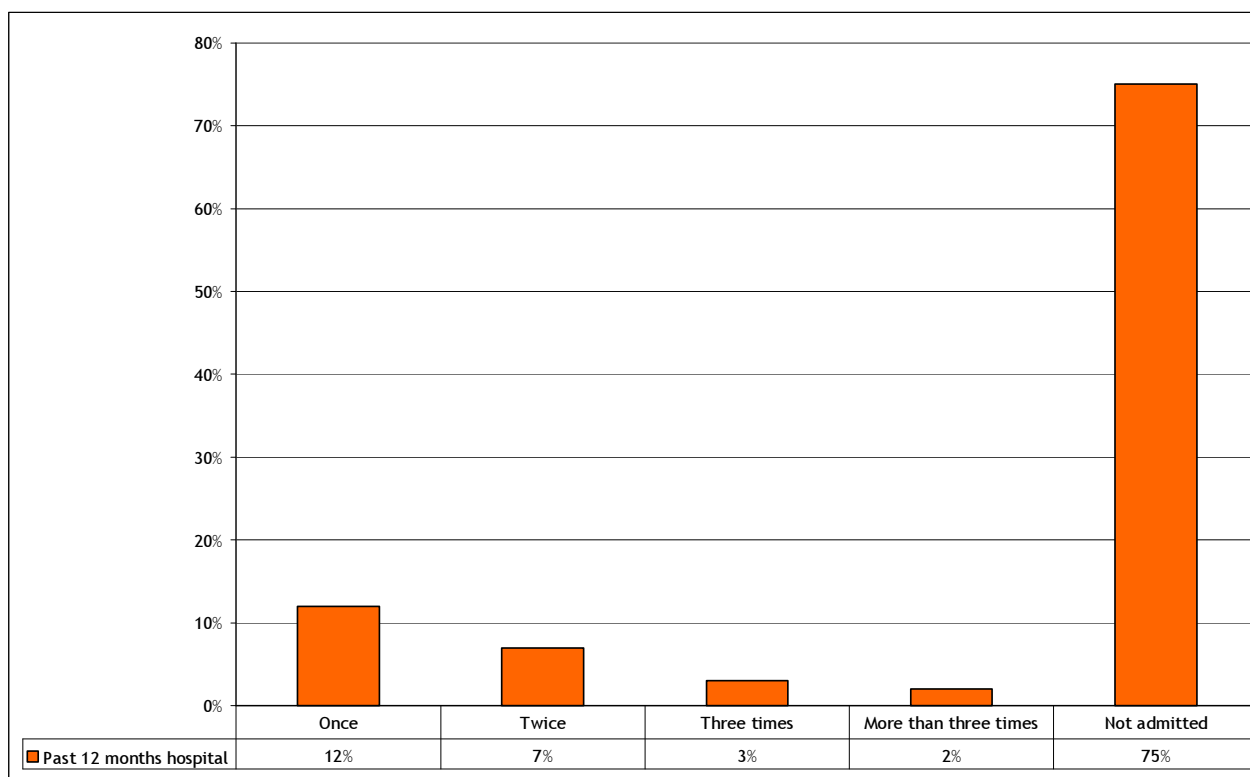
Chart 6: Living arrangements
Base: 1,670s



- While around two-thirds of those with COPD live with others, a third live alone.
- Those over 80 years are far more likely (37%) than younger respondents to live alone.
- Living alone is far more prevalent for women than men. This has an impact on findings later in the report.
 - Men 19%
 - Women 40%

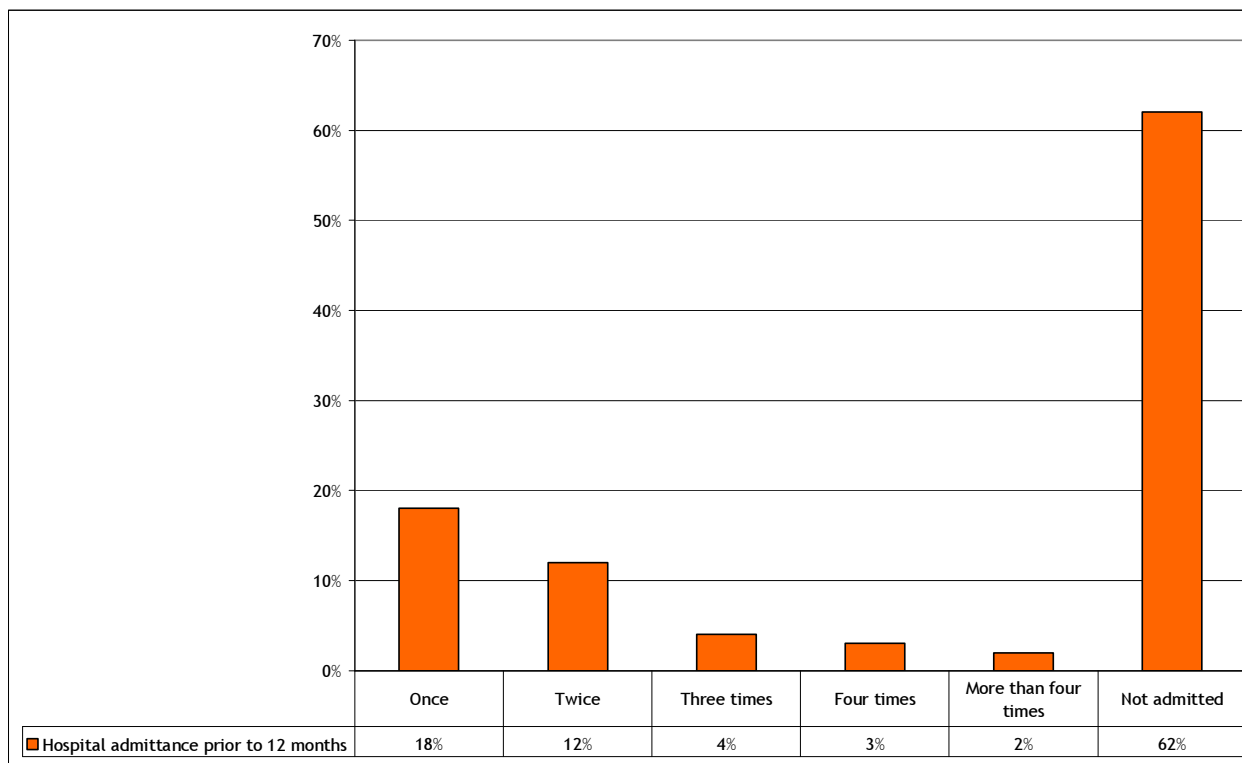
4.2 Hospitalisation

Chart 7: Times admitted to hospital in last 12 months
Base: 1,503



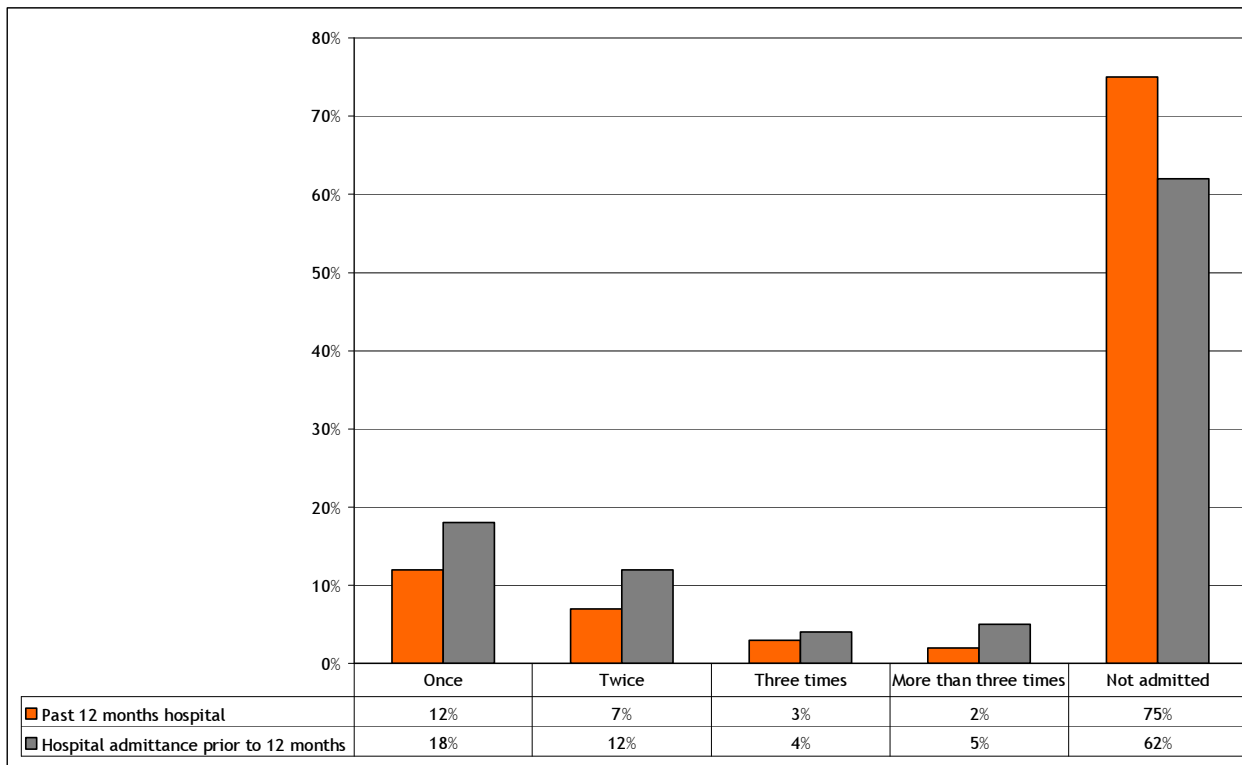
- Just under a quarter (24%) of those with COPD had been hospitalised in the past 12 months.
- 12% - or just over one in ten - had been hospitalised on more than one occasion.

Chart 8: Times admitted to hospital prior to last 12 months
Base: 1,377



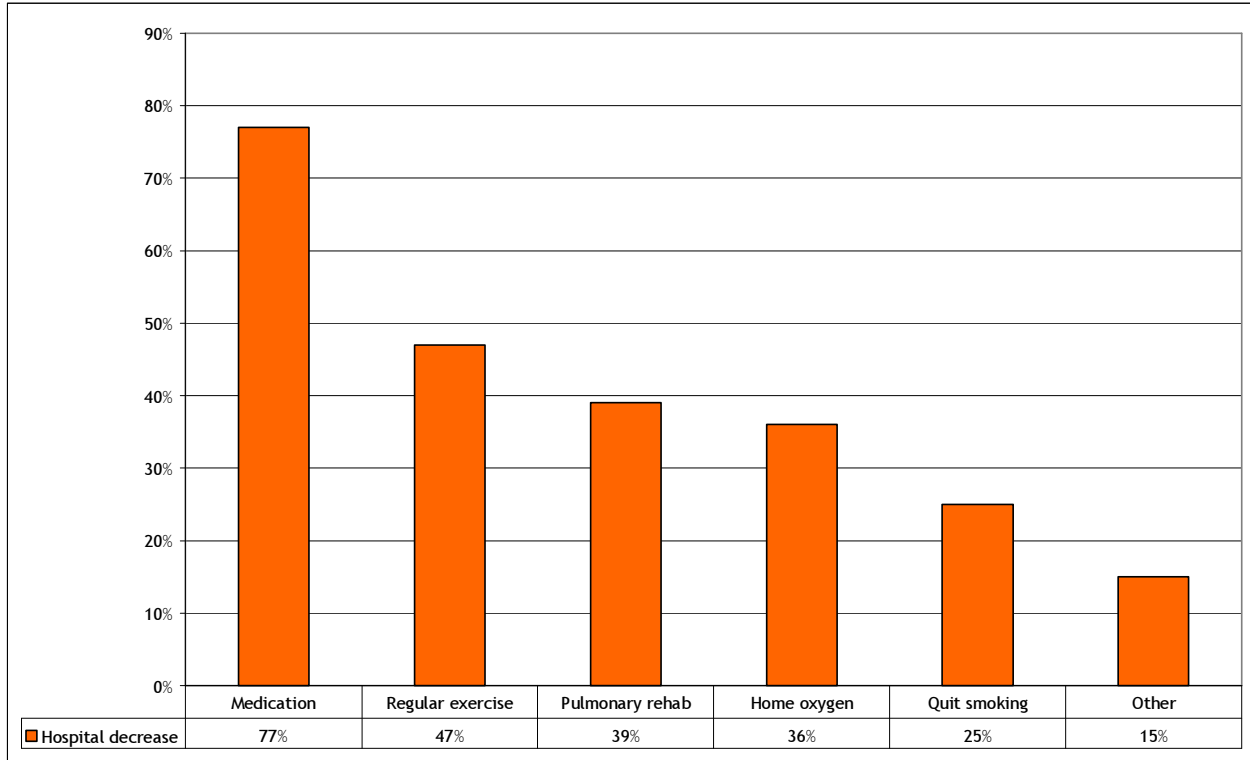
- 38% of those with COPD have been admitted to hospital prior to the past 12 months.
 - Of these just over one in five (21%) have been admitted on more than one occasion.

Chart 9: Past 12 months vs. prior hospital admissions
 Base: 1,503 / 1,377



- This chart compares admissions from the past 12 months to the period prior to this.
- Not surprisingly hospital admissions are less in the last 12 months than the cumulative period prior to this.
- Multiple admissions are far more prevalent in the period prior to the past 12 months.

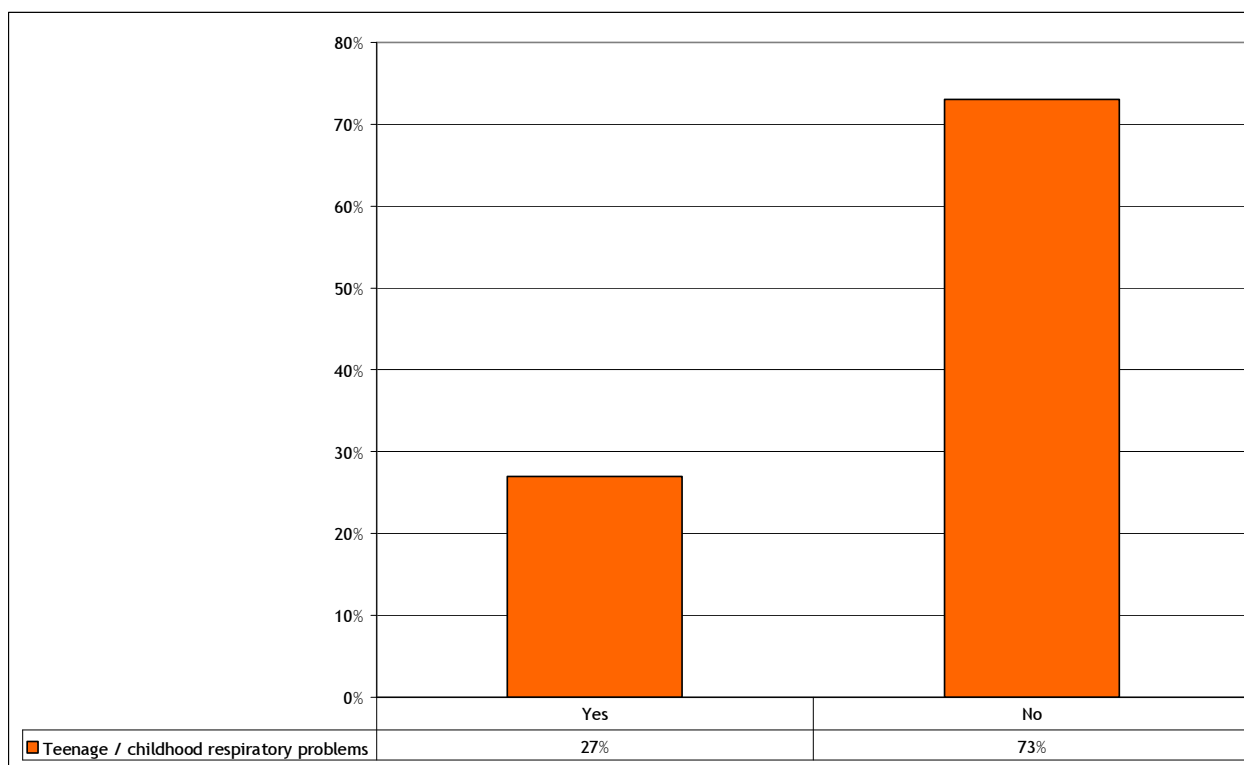
Chart 10: Reasons for decrease in admissions
Base: 378



- For those whose hospital admissions have decreased, medication is the most powerful factor in this reduction.
 - Exercise, pulmonary rehabilitation and home oxygen are about half as effective as medication.
 - Surprisingly ‘quitting smoking’ is only nominated by a quarter of those who have lower hospital admissions. However, many respondents may have quit smoking prior to the past 12 months.

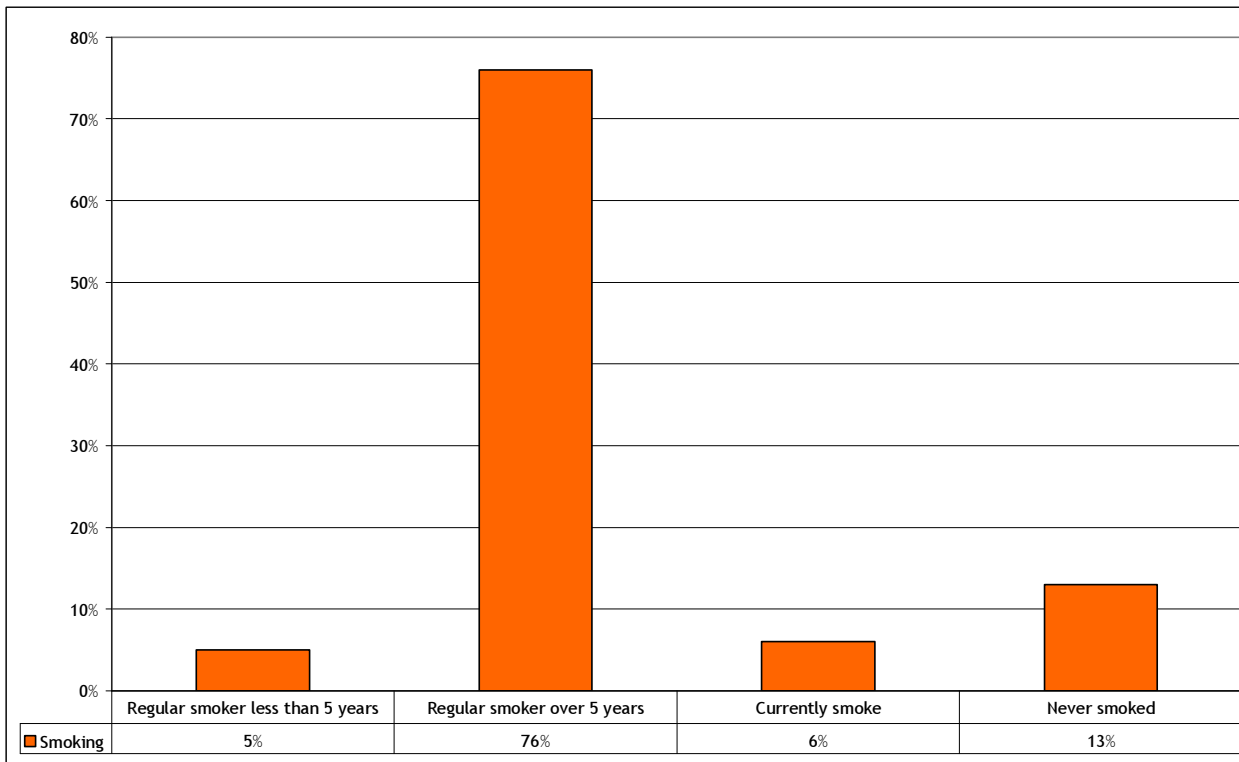
4.3 Past lung health

Chart 11: Teenage / child respiratory problems
Base: 1,662



- Just over one-quarter of those with COPD had respiratory problems as children or teenagers.
- This shows that for three-quarters of respondents these problems occurred in their adult years.

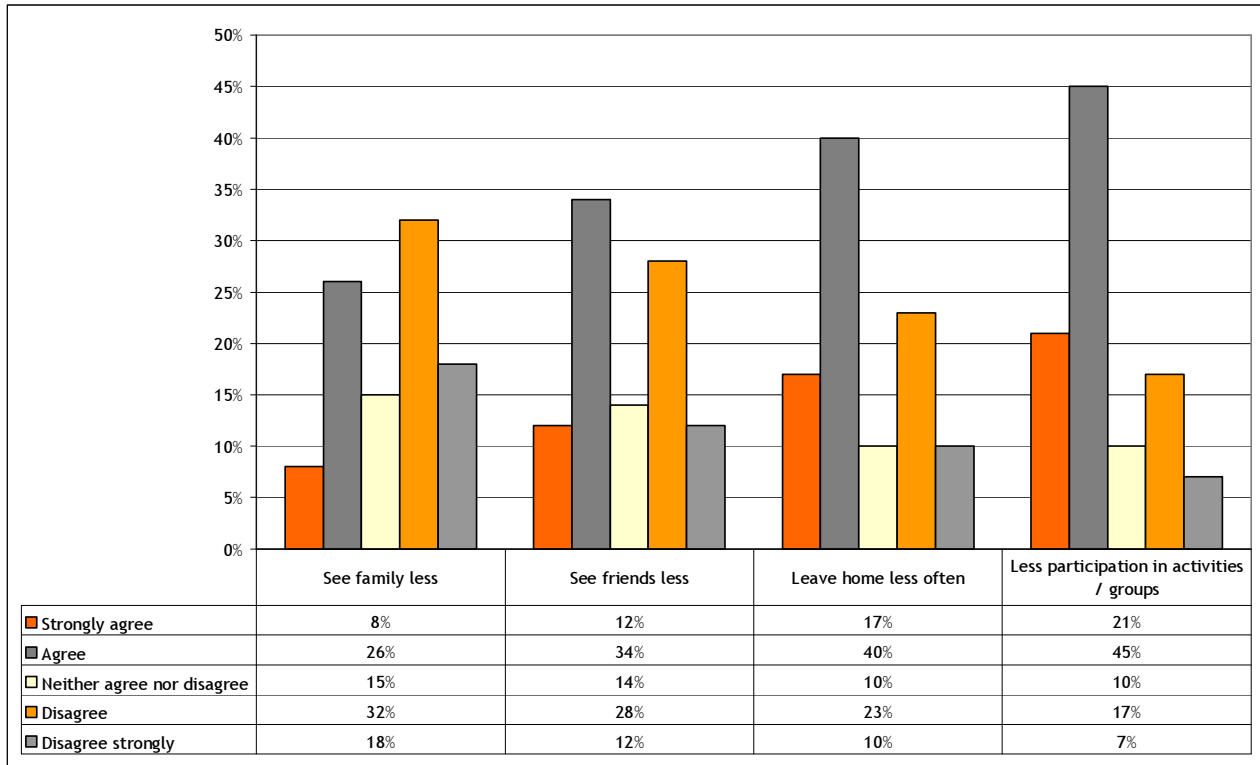
Chart 12: Smoking behaviour
Base: 1,474



- The role of smoking in COPD is shown clearly by the responses shown in the Chart 12.
- Only 13% of those with COPD have never smoked.
- The largest number of individuals is those who have smoked for over five years. The impact of sustained smoking over a long period of time in developing COPD is clear.

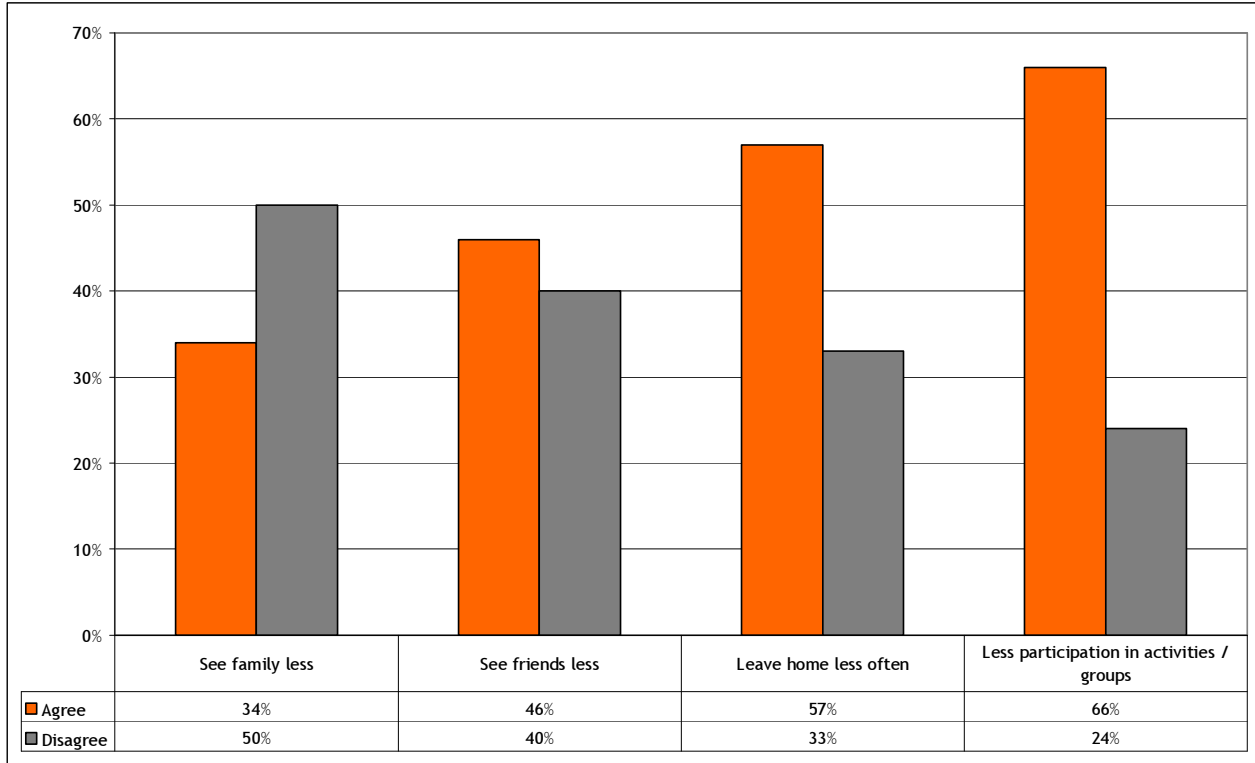
4.4 Community relationships

Chart 13: Effect of COPD on community relationships
Base: 1,544



- Those with COPD were asked to rate the effect of the condition on their relationships with the community.
- The greatest effect is through lower participation in activities and groups.
- This is probably a result of the second greatest problem: those with COPD tend to leave home less often.
- As friends can come to visit a household, seeing less of friends is a less important issue, but 12% still strongly agree with this statement.
- Family are those most likely to visit and so there is the lowest level of agreement with ‘seeing family less’.

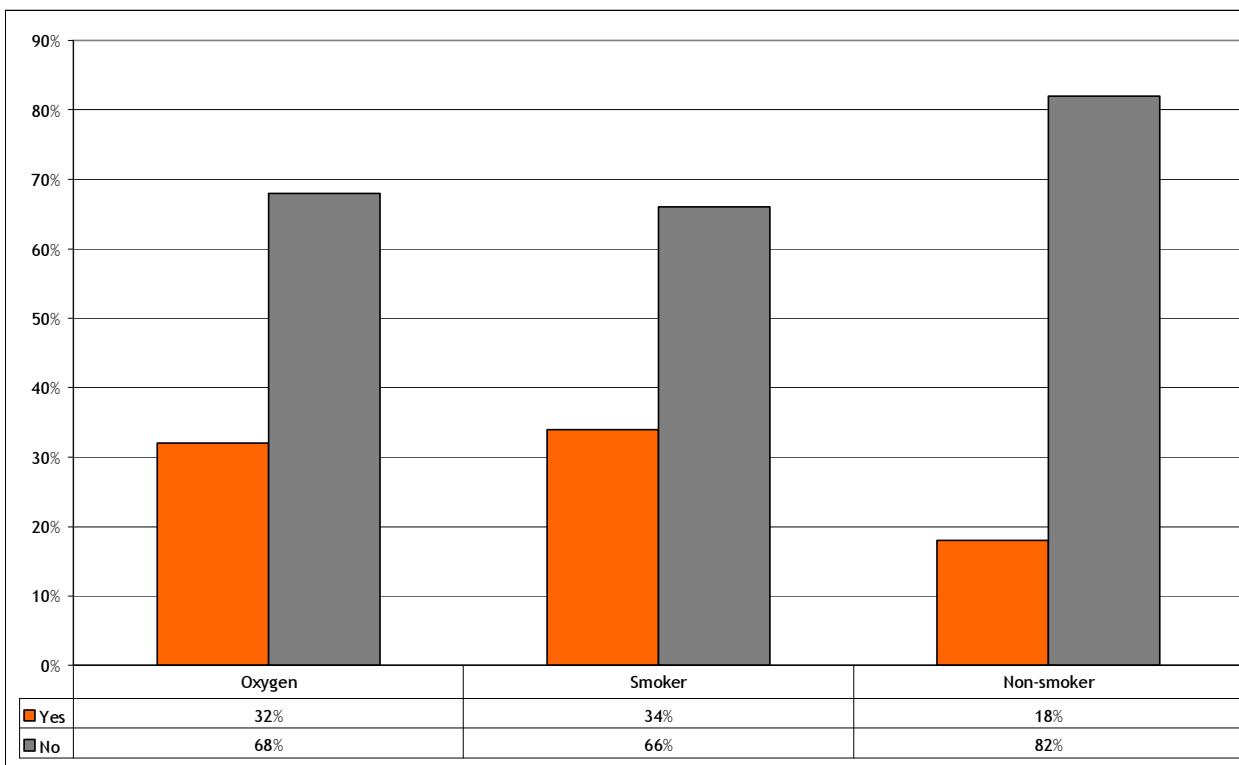
Chart 14: Effects of COPD on community relationships by agree / disagree
 Base: 1,544



- Chart 14 combines ‘agree’ and ‘strongly agree’ and then combines the disagreement statements in the same way. This shows the issues with more clarity.
- The order of issues in the lives of those with COPD is clear. Two-thirds agree that they have less participation in the community, while over half leave the house less.
- This suggests that being housebound is a key impact of COPD. This flows on to a range of limits on behaviour for those with COPD.
- There are no significant differences in these findings in all the demographic groups analysed in this report. The experience of COPD is universal for individuals.

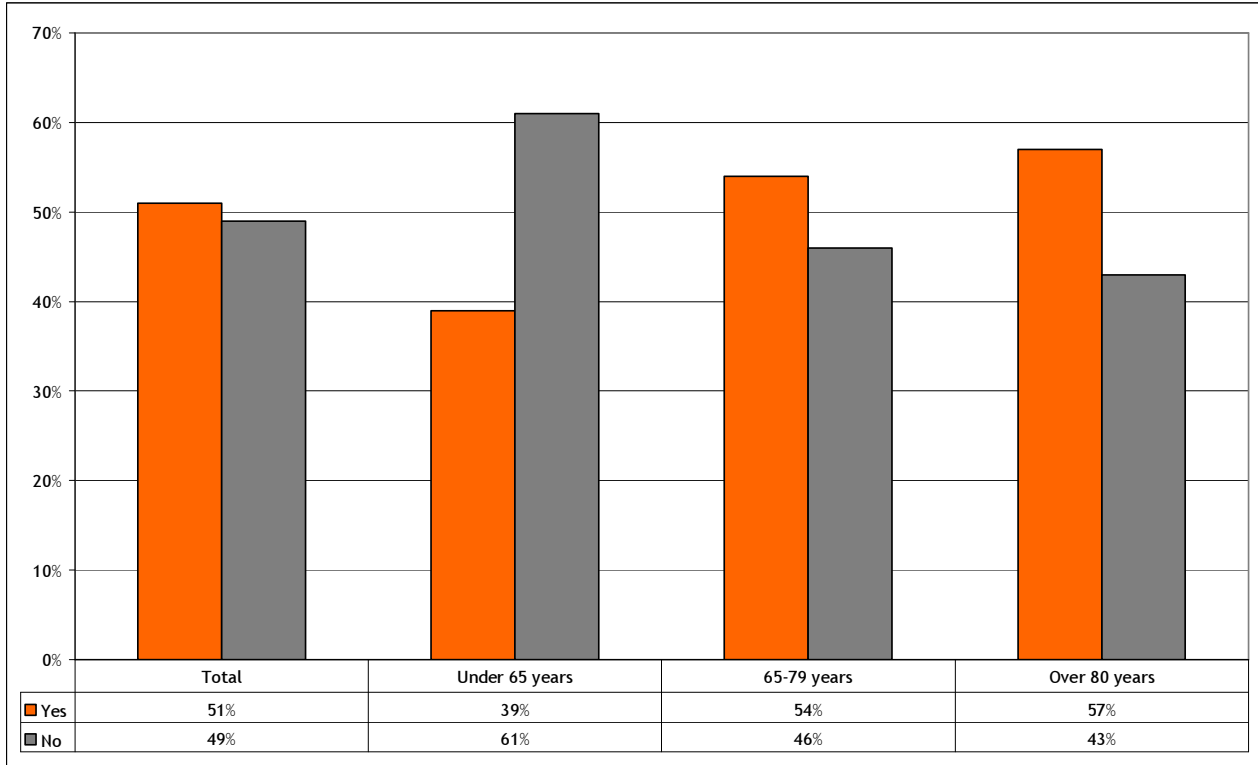
4.5 Home oxygen

Chart 15: Use of home oxygen
Base: 1,650



- Just under a third of those with COPD currently use home oxygen.
- Those who have previously been smokers are far more likely than those who have never smoked to require home oxygen.
- Use of home oxygen is also higher for those who live with others (24%) than those who live alone (35%).

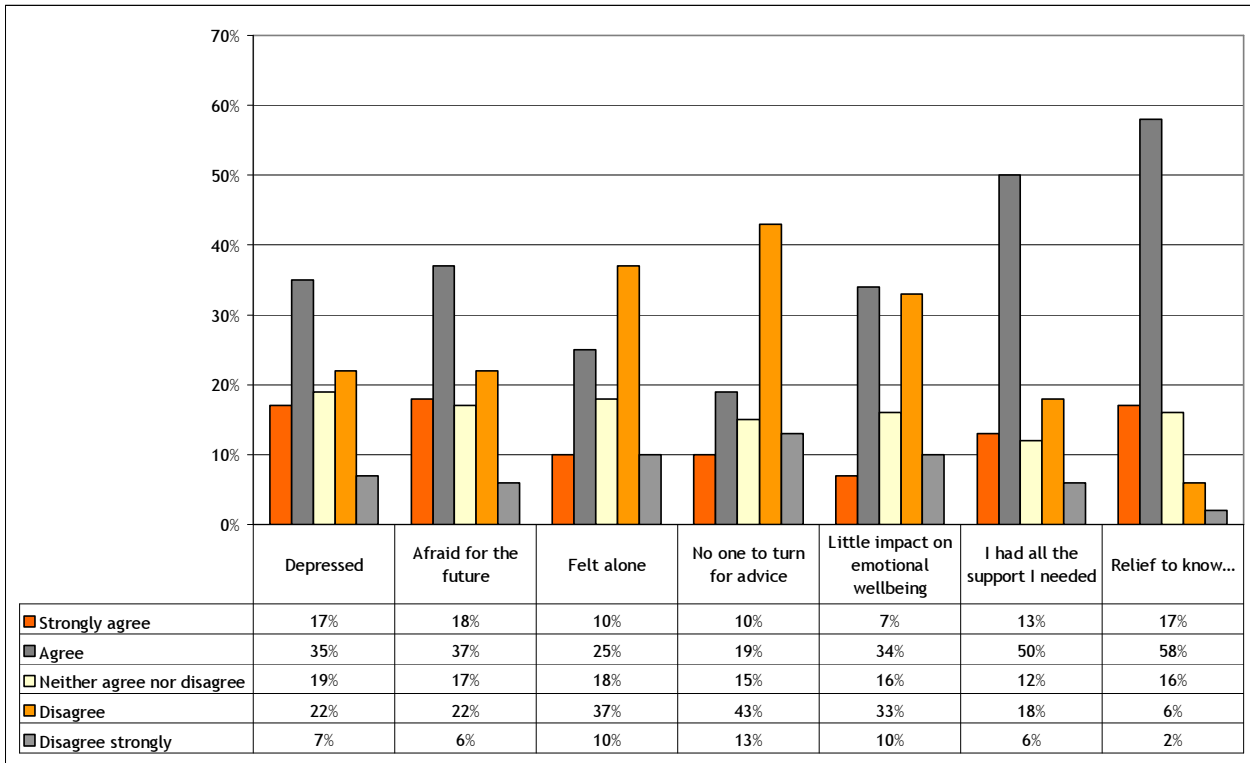
Chart 16: Effect of home oxygen on socialising
 Base: 507 who use home oxygen



- Just over half of those who use home oxygen feel that this means they socialise less.
- The impact of less socialising increase with age. Those under 65 years are least likely, and those over 80 years most likely to be affected by less socialising.

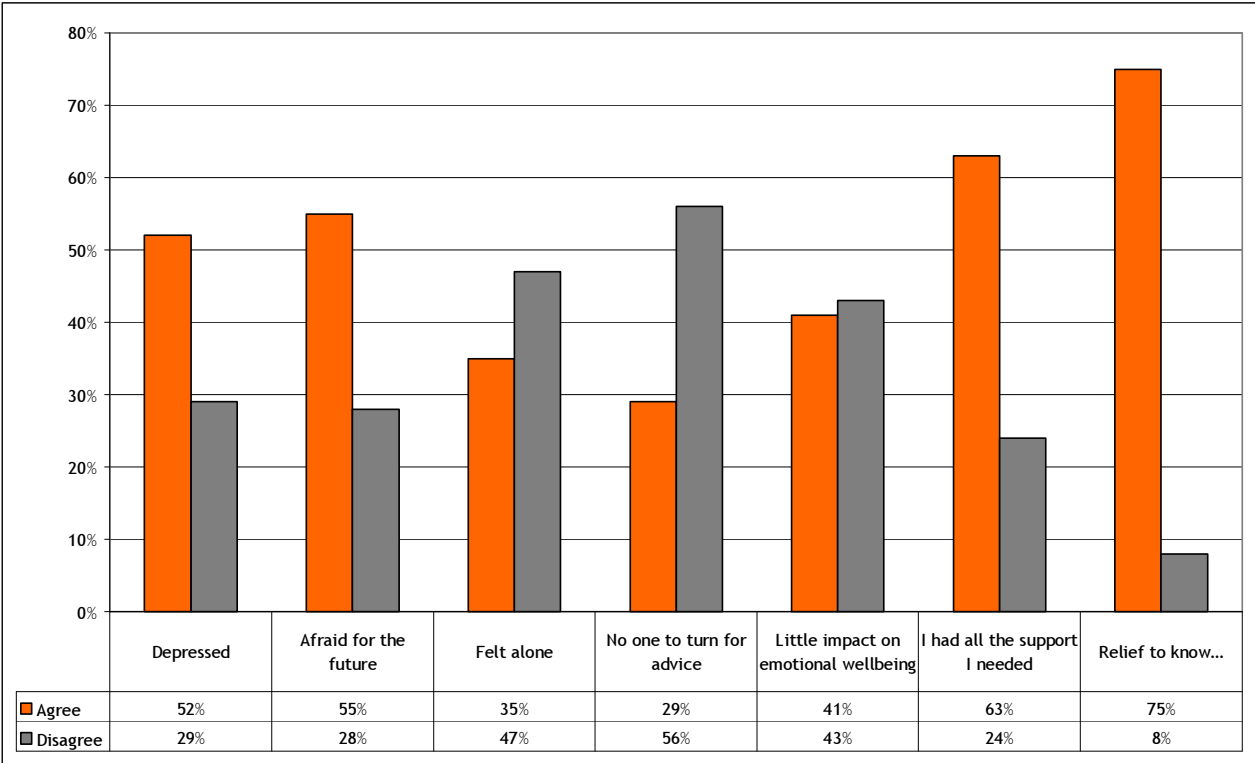
4.6 The impact of diagnosis

Chart 17: Experience of first 6 months since diagnosis
Base: 1,563



- Being depressed and afraid for the future are the strongest negative emotional impacts from diagnosis.
- However there is also a strong feeling of relief that the condition has been identified.
- There is also a positive note with the strong agreement that those with COPD had ‘all the support’ they needed at their time of diagnosis.
- Surprisingly for over one-third feel that there was ‘little impact on emotional wellbeing’ from diagnosis.

Chart 18: Experience of first 6 months since diagnosis by agree / disagree
 Base: 1,563



- Combining the 'agree' and 'disagree' statements gives a clearer picture of the experience of diagnosis.
- The greatest feeling is the relief of diagnosis.
- This is followed by the feeling of 'being supported' at this difficult time.
- Just over two in five felt there was little emotional impact from diagnosis.
- However there are strong negative feelings with over half feeling depressed and afraid for the future.
- Over a third 'felt alone' and over a quarter felt there was 'no one to turn to'.

There are significant differences by analysed demographic groups regarding the effect of diagnosis. Agreement is a combination of 'agree' and 'strongly agree'. Statements where there was little or no difference between groups are not shown.

Feeling afraid for the future

- 55% overall agreement.
- This affected those under 65 years more strongly than older individuals.
 - 72% agreement for those under 65 years
- It was also more likely to affect women than men.
 - 63% agreement for women
 - 45% agreement for men

Feeling alone

- 35% overall agreement.
- This affected those who live alone more than others, but perhaps less than one might expect. While living alone has an impact on 'feeling alone', it is only a 10% increase in agreement.
 - 45% agreement for those living alone
- Feeling alone affected women more than men. Their level of agreement is only slightly less than those who live alone, however women are twice as likely to live alone as men.
 - 26% agreement for men
 - 43% agreement for women

I felt I had no one to turn to for advice

- 29% overall agreement.
- 41% of those under 65 years of age agreed with this statement. Older individuals apparently have more access to advice. This may be from more regular contact with medical professionals.

The diagnosis had little impact upon my emotional wellbeing

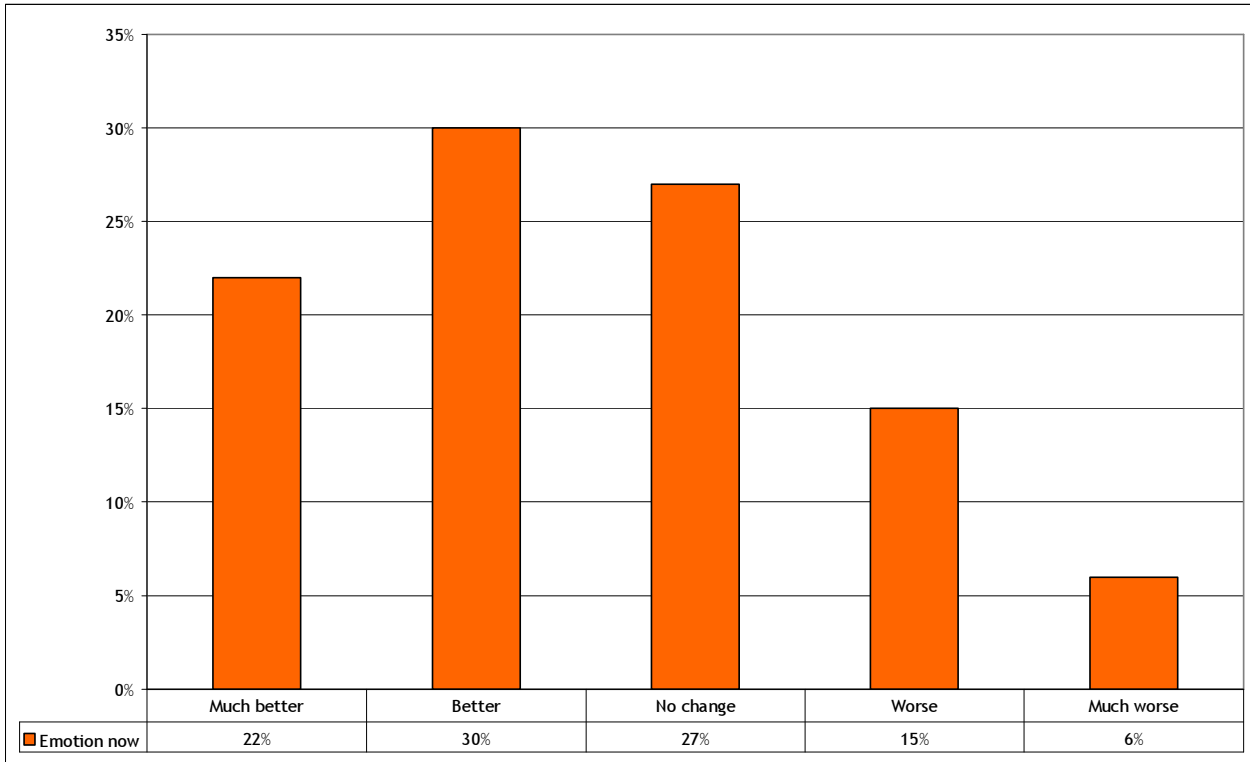
- 41% overall agreement.
- Men show themselves to be less affected emotionally by diagnosis than women.
 - 46% agreement for men
 - 35% agreement for women

I had all the support I needed to deal with the diagnosis

- 63% overall agreement.
- Men also felt they had support more than women.
 - 71% agreement for men
 - 55% agreement for women

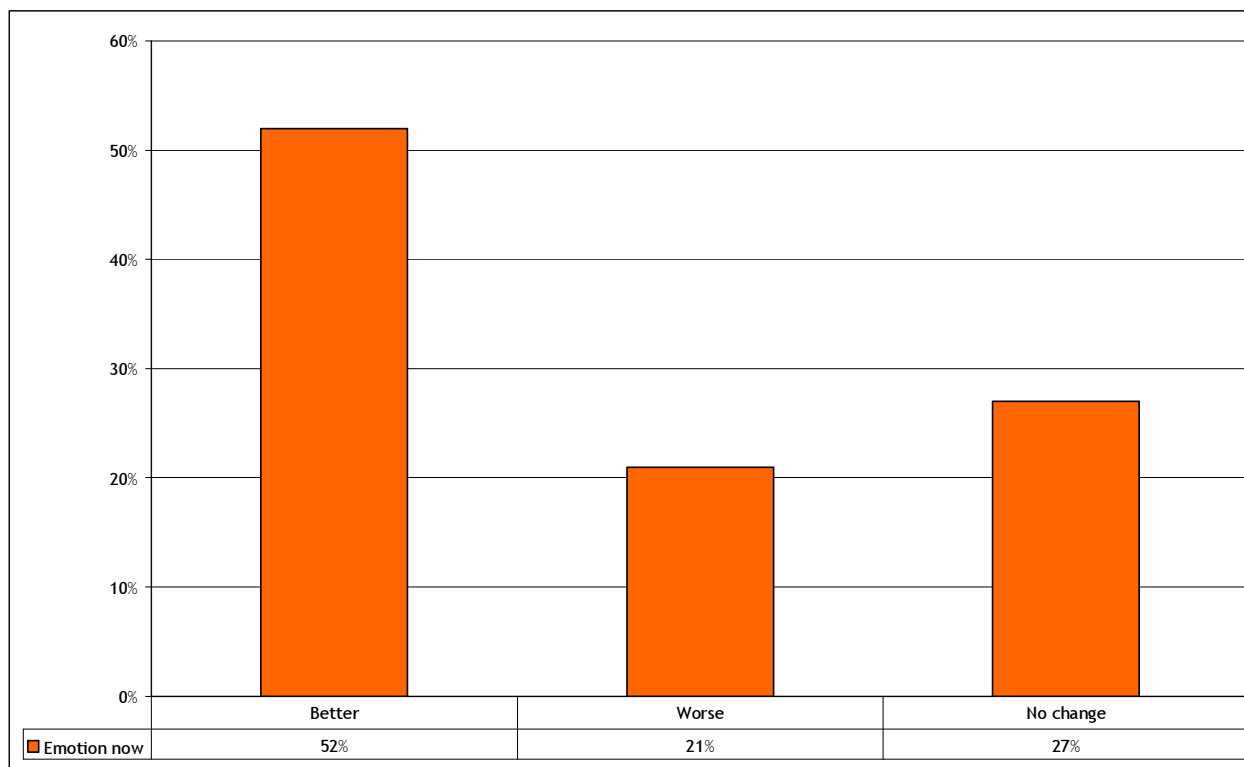
4.7 Emotional wellbeing

Chart 19: Rating of emotional wellbeing now
Base: 1,622



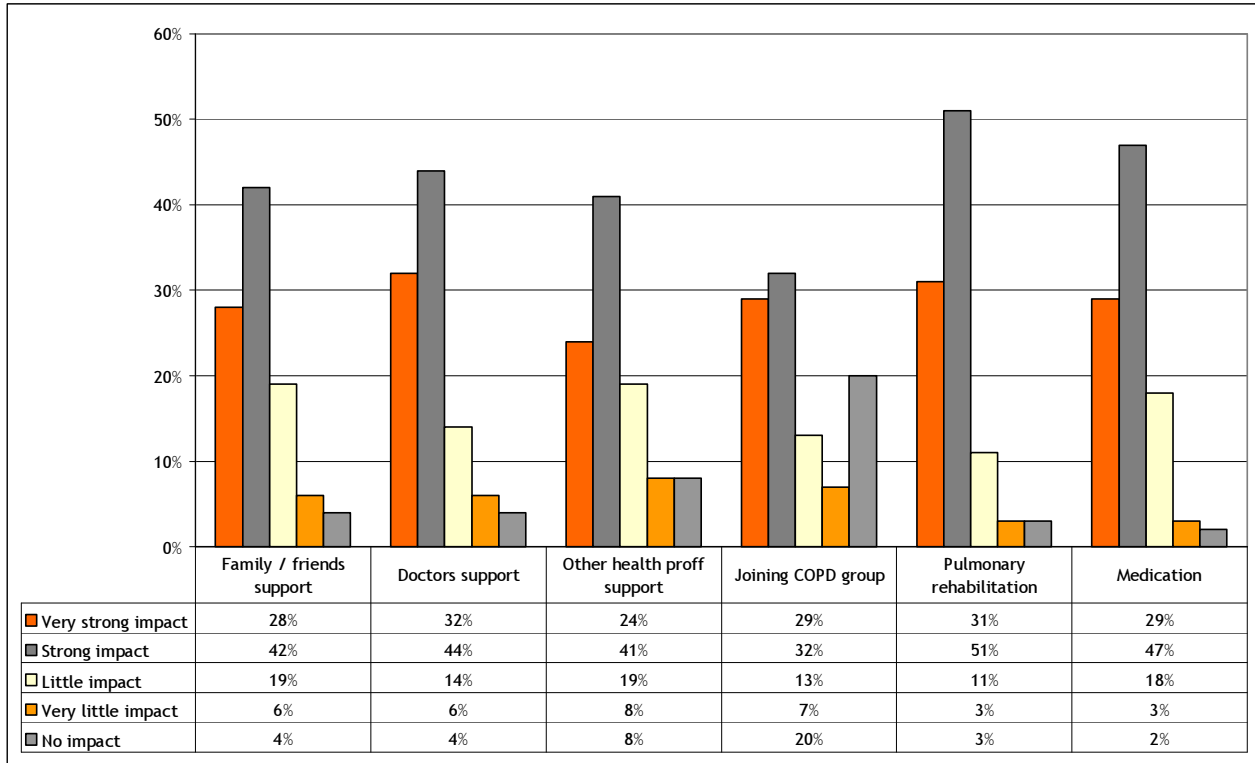
- The experience since diagnosis is positive for over half of those with COPD.
 - One-in-five are feeling ‘much better’ while just under a third are feeling ‘better’.
 - A further quarter has experienced little or no change.
- However 21% or one in five have experienced a decline since diagnosis.

Chart 20: Rating of emotional wellbeing now by better / worse / no change
 Base: 1,622



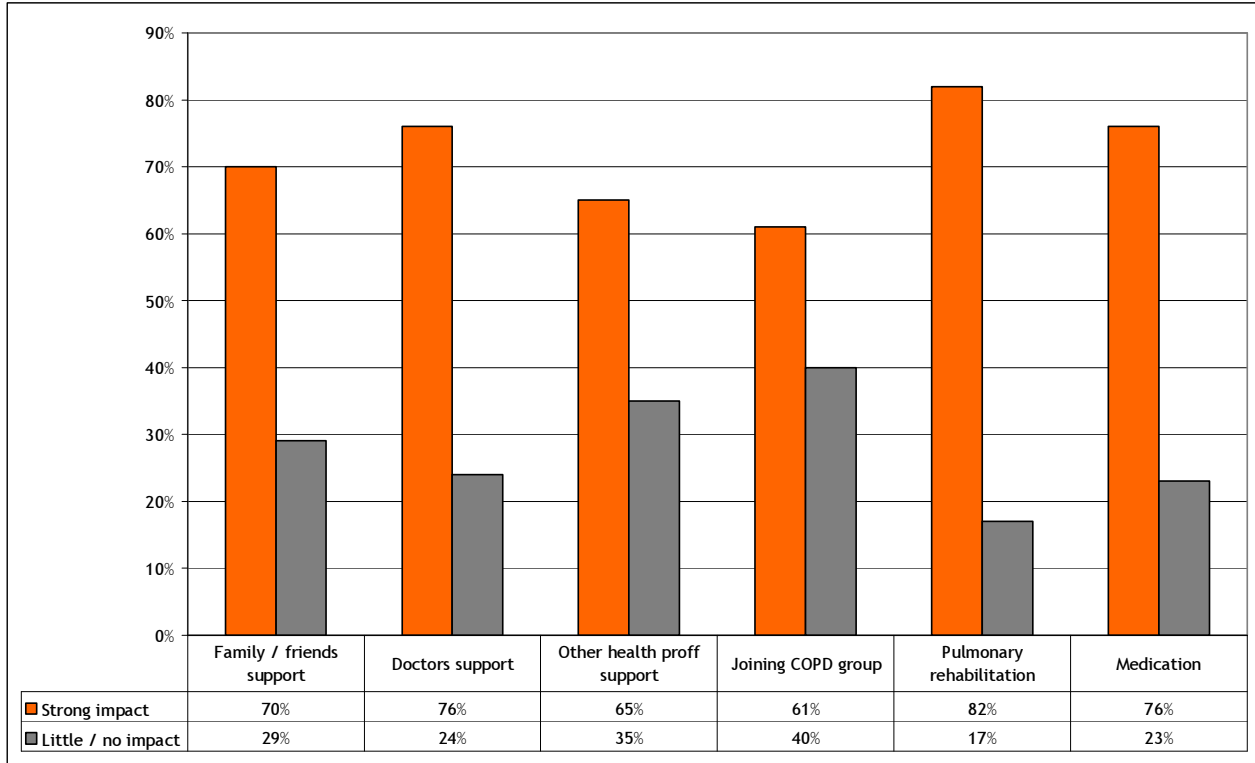
- Chart 19 combines those that have increased and decreased.
- The most common experience is for improvement or ‘no change’.
- The least likely outcome is to feel worse emotionally.
 - This should not hide the fact that feeling worse is still a common experience. Over a quarter of those with COPD feel worse since diagnosis.

Chart 21: Why has emotional wellbeing improved
 Base: 773 who have improved since diagnosis



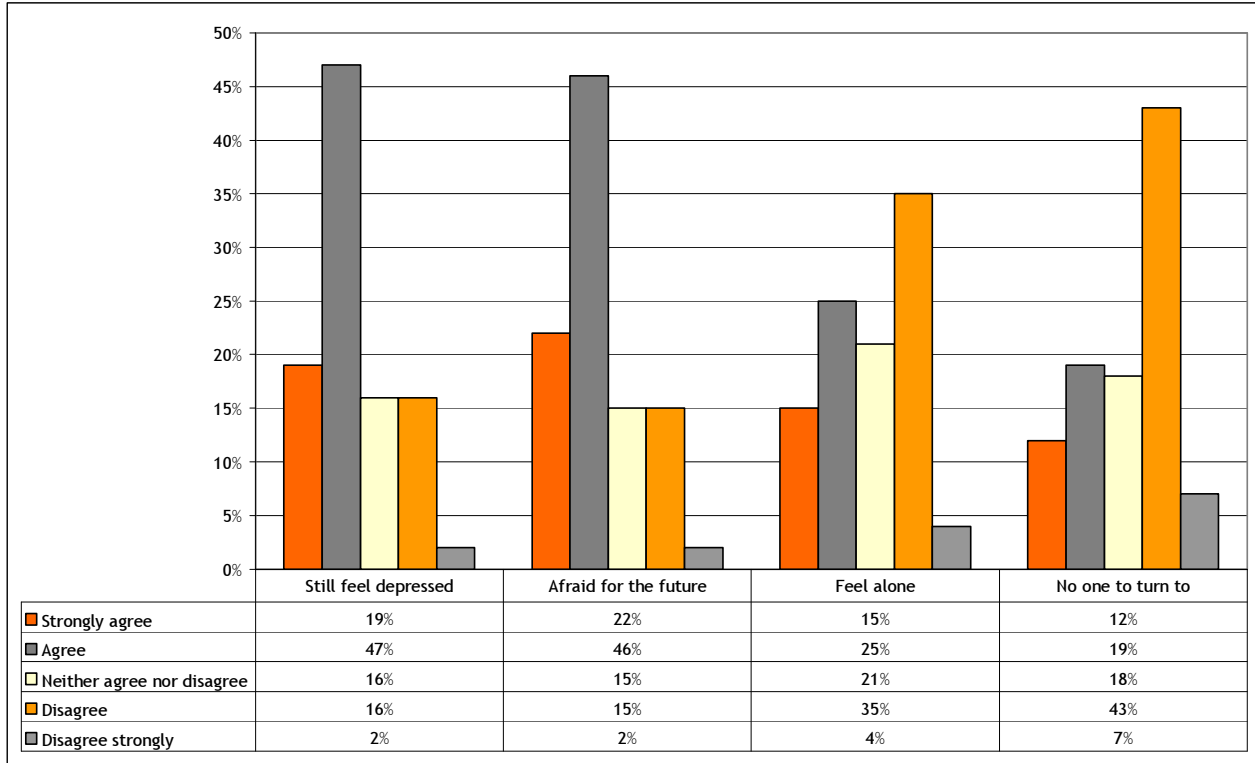
- For those whose emotional wellbeing has improved since diagnosis a number of elements has had a ‘very strong impact’. They are:
 - pulmonary rehabilitation
 - the support of doctors
 - medication
 - joining a COPD group
 - the support of family and friends
- Each of these is similar in their impact on the improvement in emotional wellbeing. This suggests that improvements come from a range of interventions rather than a single source.
- There are no differences by analysed demographic groups. This suggests that the experience is universal for those who have improved.

Chart 22: Why has wellbeing improved by agree / disagree
 Base: 773 who have improved since diagnosis



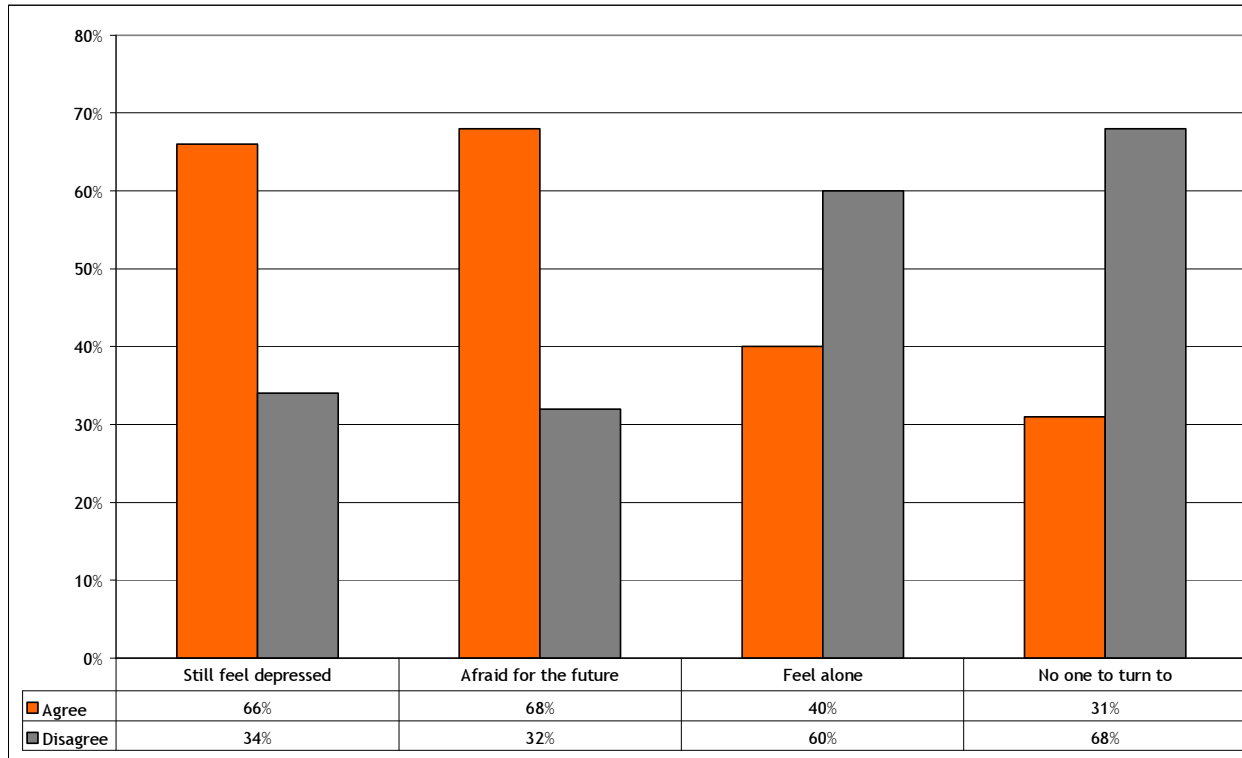
- Chart 20 combines the two top categories of ‘impact’ and the three levels of ‘little impact’.
- This analysis shows that there is little difference between the impact of most interventions.
 - The least impact is from
 - support from other health professionals
 - joining a COPD group

Chart 23: Why has wellbeing declined
 Base: 320 who have declined since diagnosis



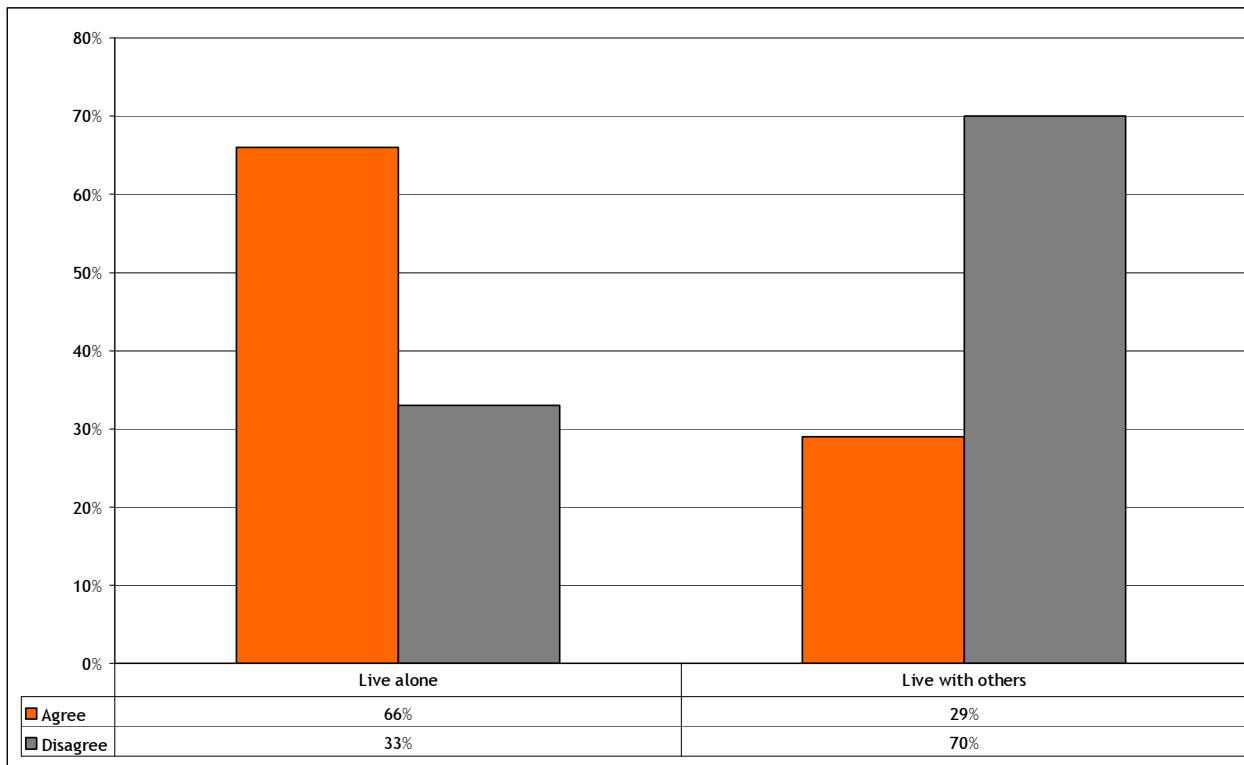
- Those who felt their emotional wellbeing had become worse were given a number of explanations for this decline. They agreed or disagreed with each statement.
- The elements with the greatest impact are
 - 'still feel depressed'
 - 'afraid for the future'
- While 'feeling alone' and having 'no one to turn to' are problems for significant numbers of people, the feelings of depression and fear are the most profound in affecting emotional wellbeing.

Chart 24: Why has wellbeing declined by agree / disagree
 Base: 320 who have declined since diagnosis



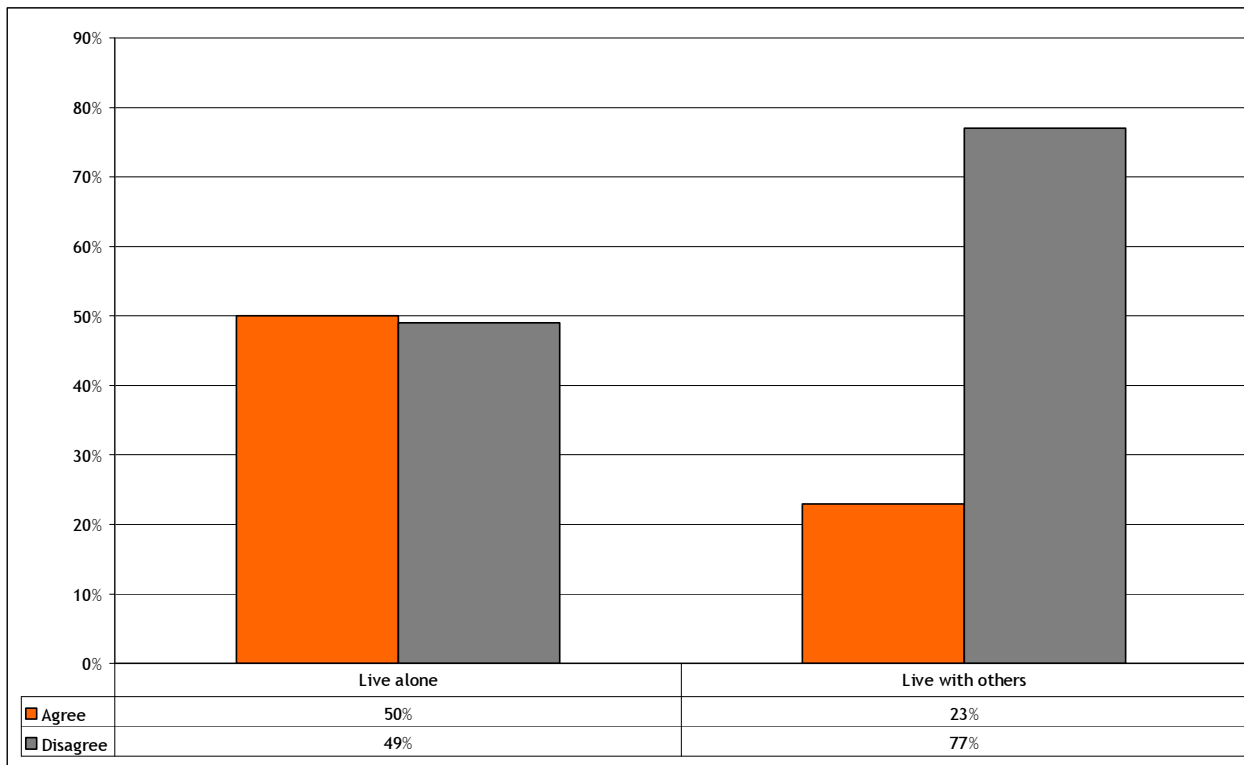
- Combining the ‘agree’ and ‘disagree’ statements shows the effects of depression and fear with greater clarity.
- Over two-thirds of those whose emotional wellbeing has declined agree that depression and fear have the greatest impact on their condition.

Chart 25: “I continue to feel alone”
 Base: 320 who have declined since diagnosis



- Living alone emerges as a significant factor for those who have declined emotionally.
- Over two-thirds of those who live alone feel alone, compared to only 29% of those who live with others.

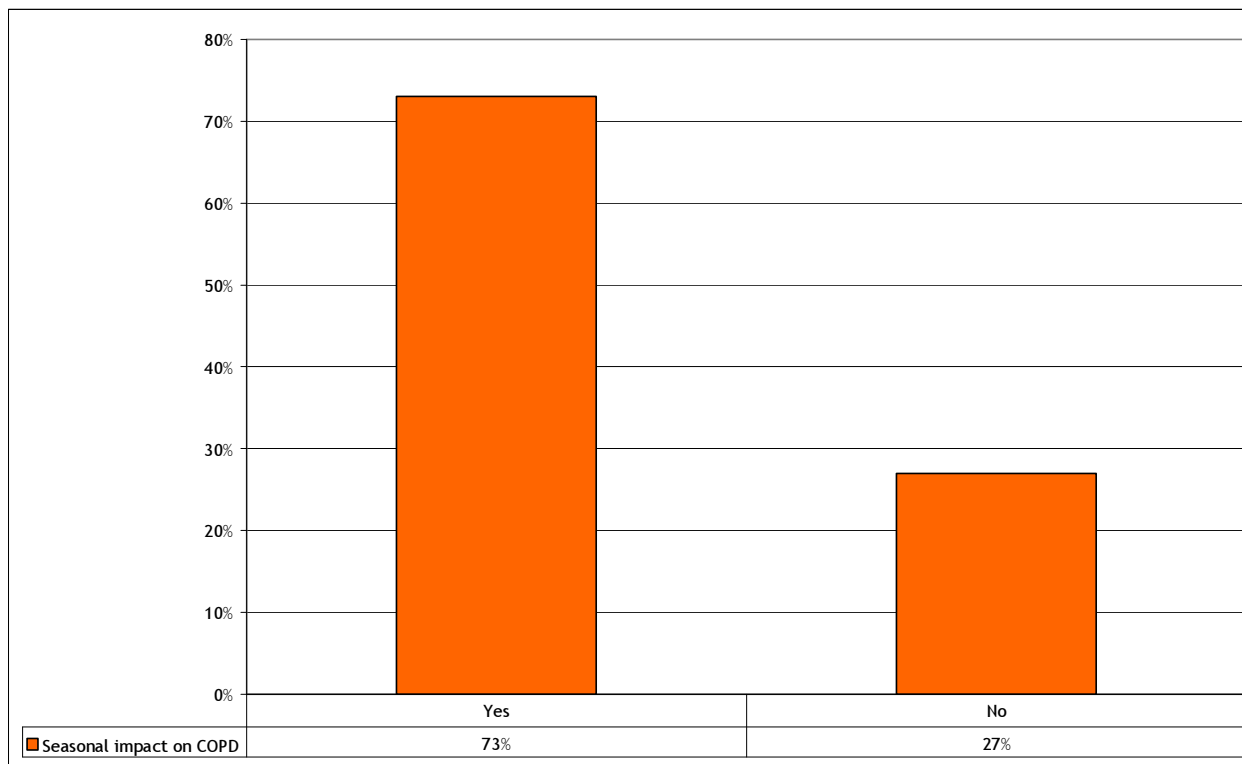
Chart 26: “I continue to feel like I have no one to turn to”
 Base: 320 who have declined since diagnosis



- The same pattern is shown in the findings in Chart 26.
- Half of those who live alone feel they have ‘no one to turn to’ compared to just over one-in-five of those who live with others.

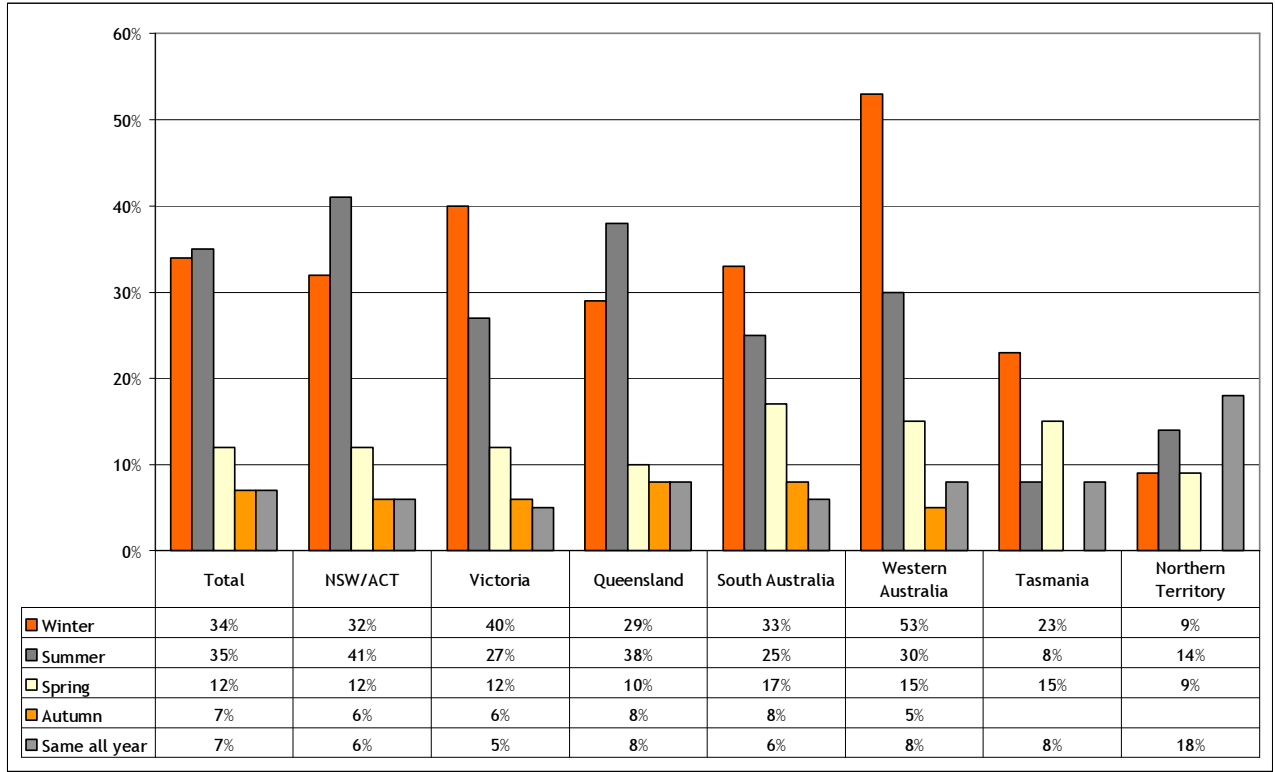
4.8 Seasonal impact

Chart 27: Is there a seasonal impact from COPD
Base: 1,663



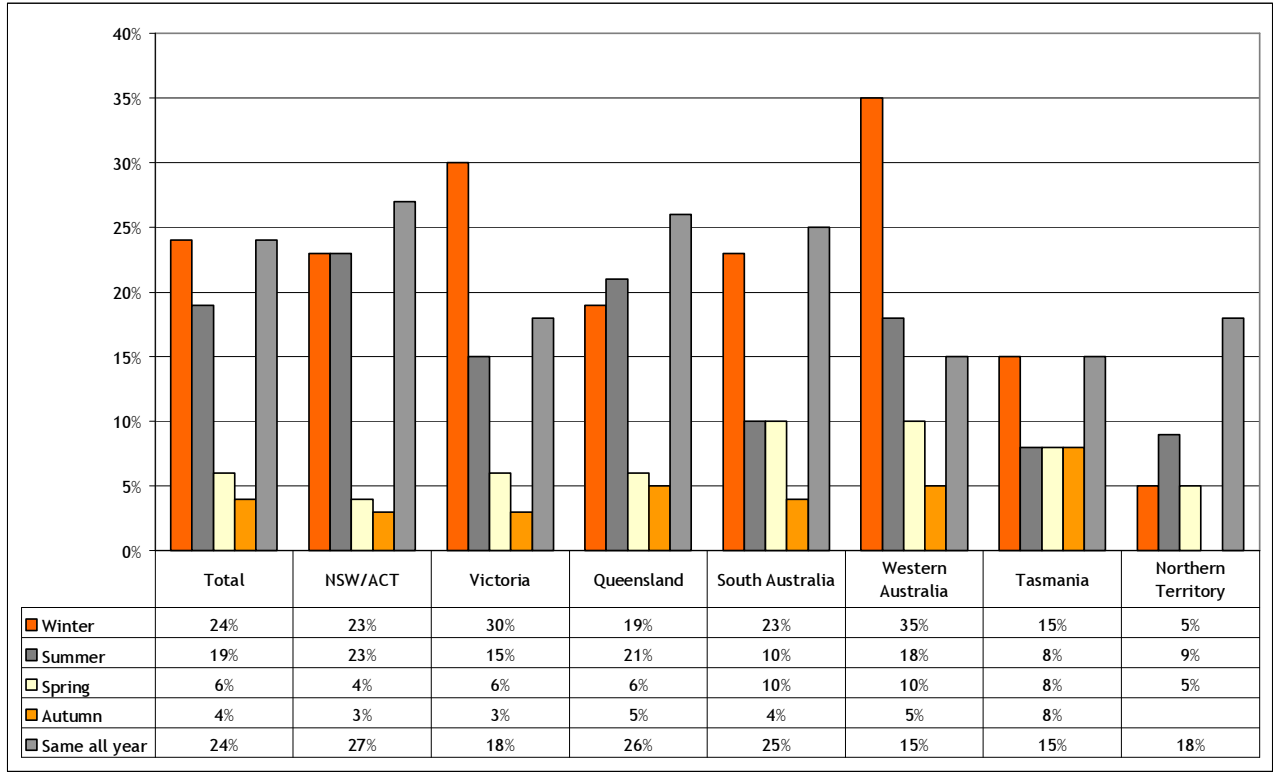
- Just under two-thirds of those with COPD feel there is a seasonal impact on the condition.

Chart 28: Physical impact by state
 Base: 1,194 for 'seasonal impact' / 1,111 for 'emotional impact'



- There are significant variations by state for physical impact.
 - Victorian residents are far more likely to be affected by winter.
 - WA residents while showing a much higher level of being 'affected by winter' is not a statistically significant difference.
 - Those from NSW and Queensland are more likely to be affected by the summer season.

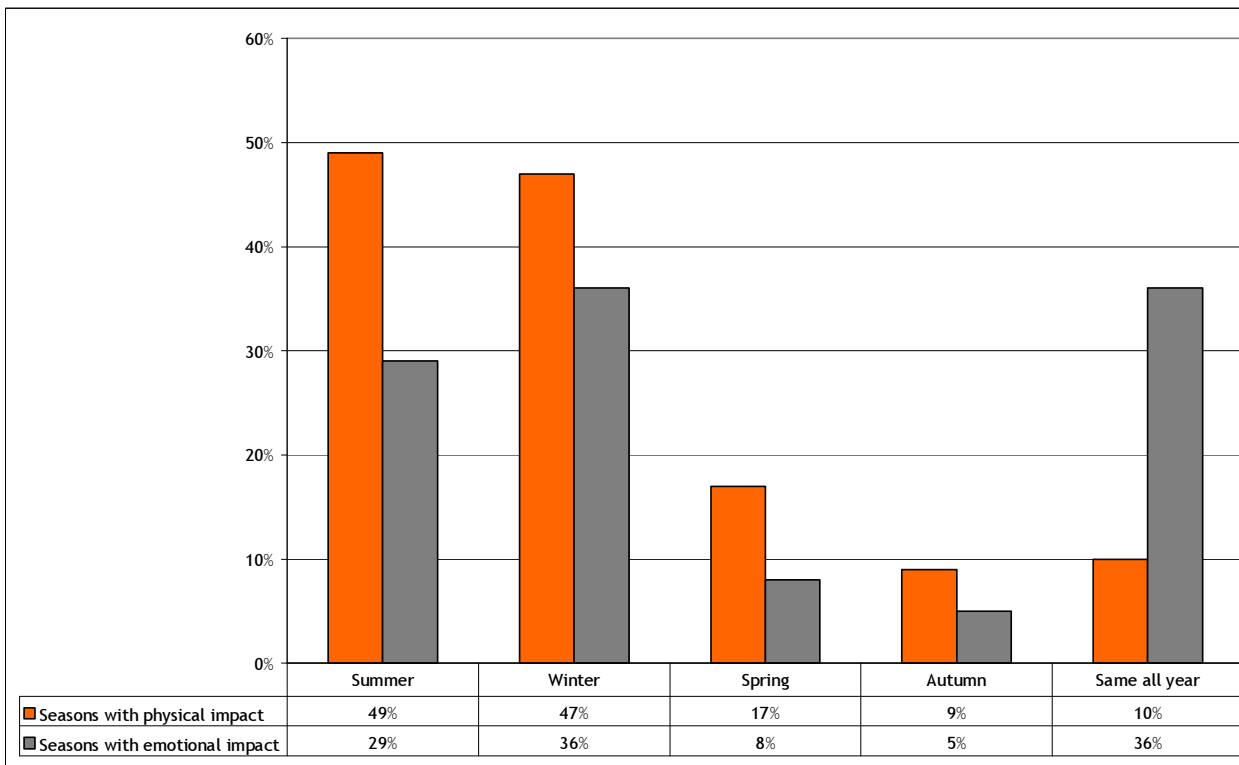
Chart 29: Emotional impact by state
 Base: 1,194 for 'seasonal impact' / 1,111 for 'emotional impact'



- The same effect is seen in the level of being affected emotionally by seasons.

- Winter affects those from Victoria while summer affects those from NSW.
- Residents of Queensland are less likely to be affected by the winter season emotionally, but there is no identifiable affect for summer.

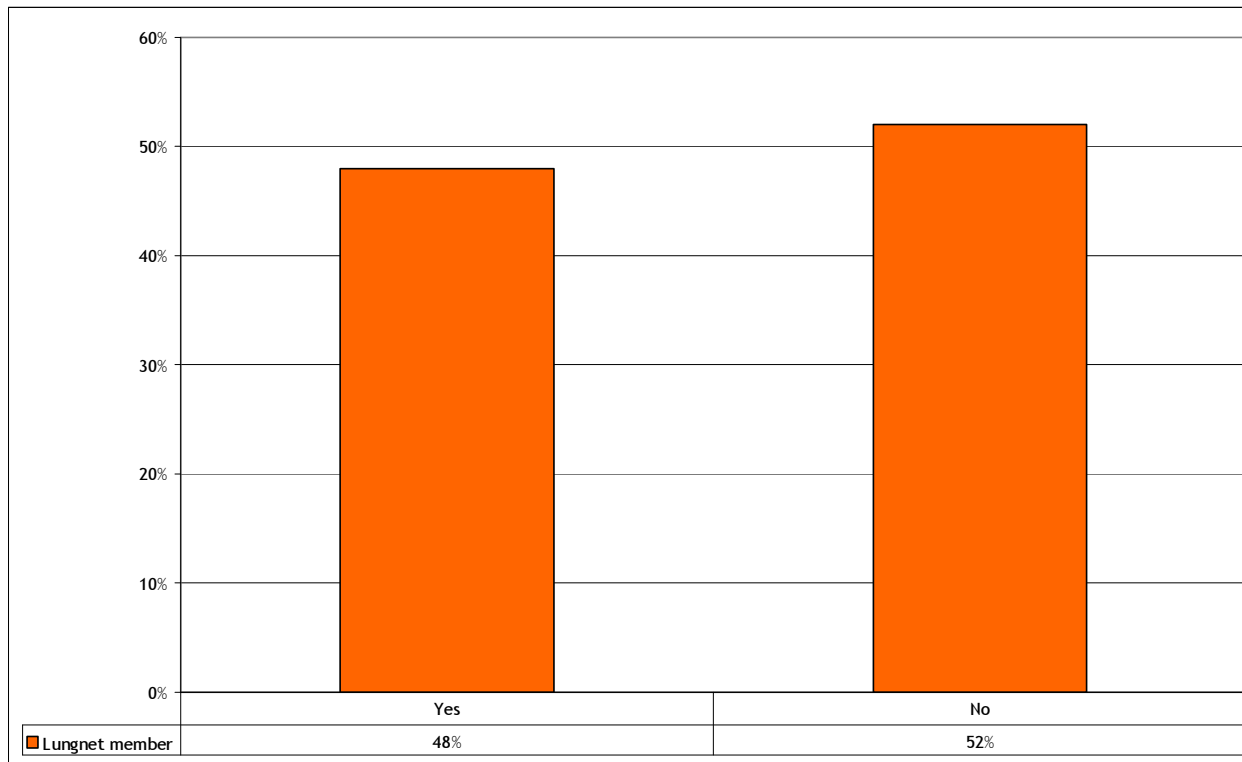
Chart 30: Physical vs. emotional impact
 Base: 1,194 for 'seasonal impact' / 1,111 for 'emotional impact'



- Research participants were asked to compare the seasons where there was a physical impact with those where there is an emotional impact.
- Physical impact is strongest in summer and winter with much lower levels reported for spring and autumn.
- Emotional impact is also strongest for summer and winter, but many feel the emotional impact all year.

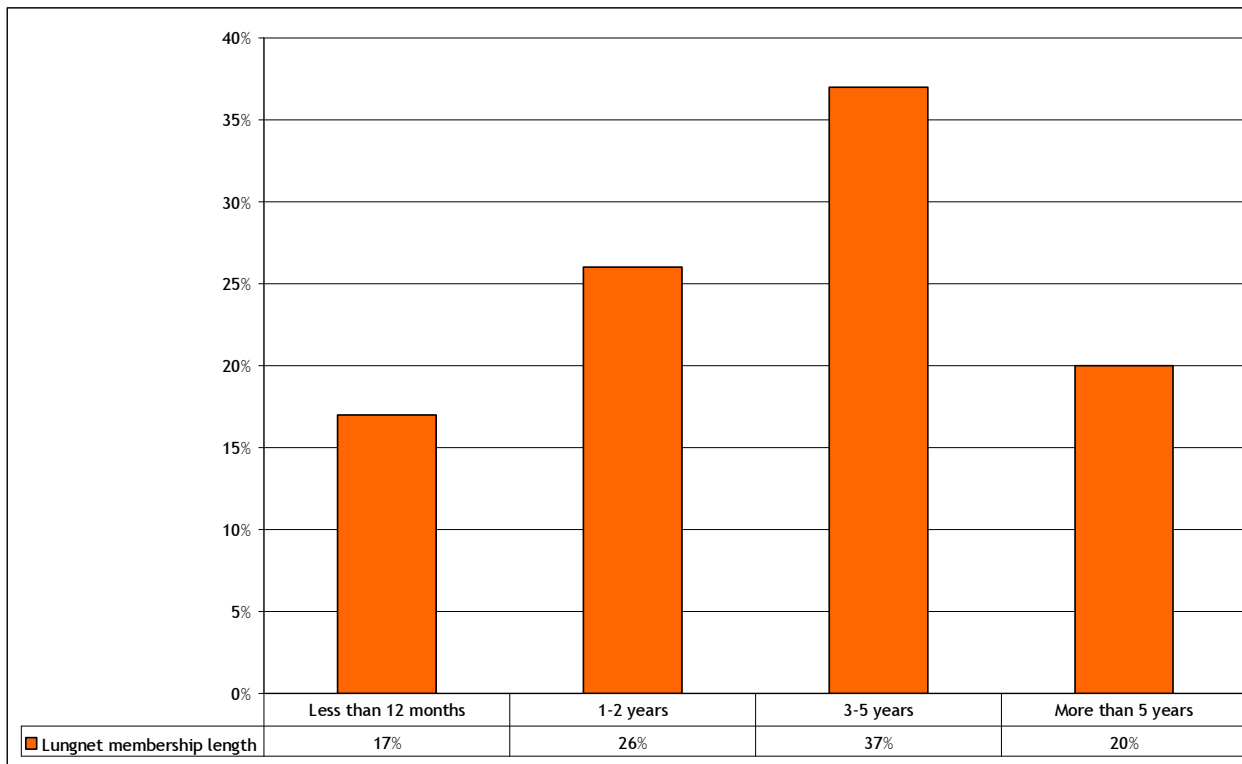
4.9 Lungnet

Chart 31: Member of Lungnet
Base: 1,694



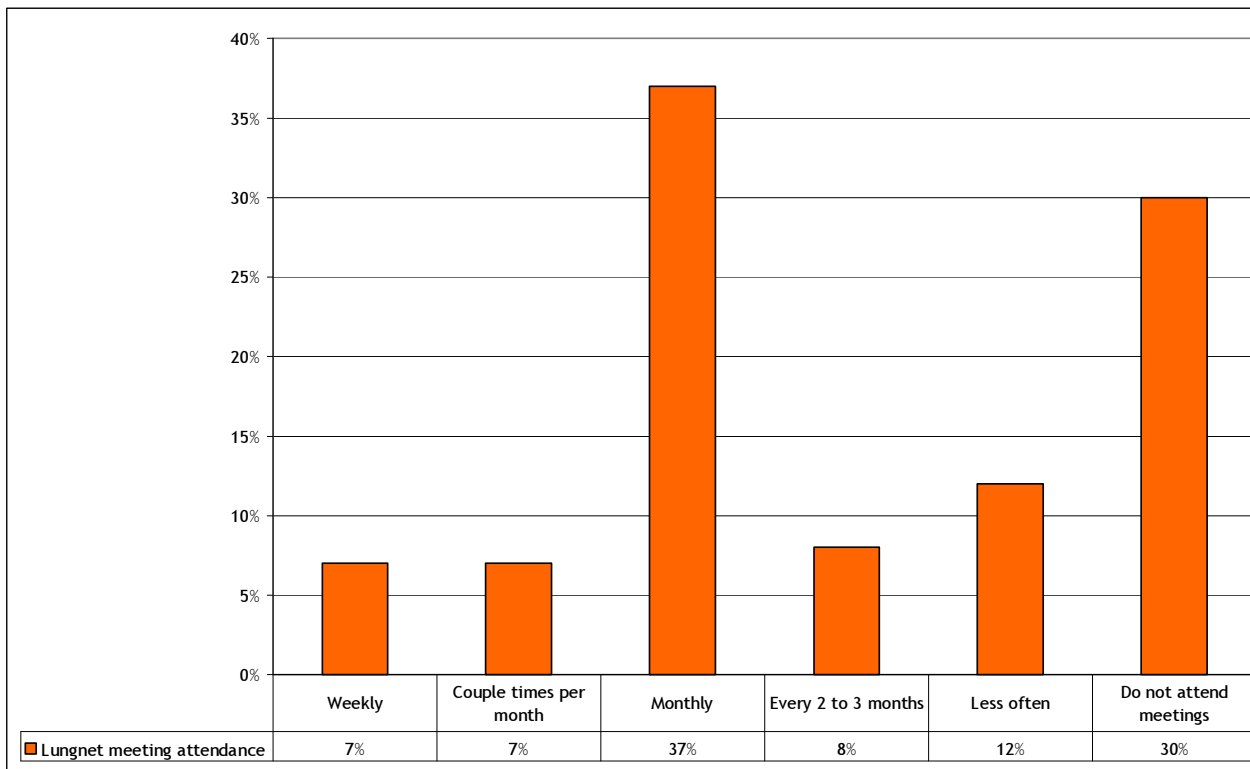
- Just under half of all research participants are members of Lungnet.

Chart 32: Length of Lungnet membership
 Base: 170 members of Lungnet



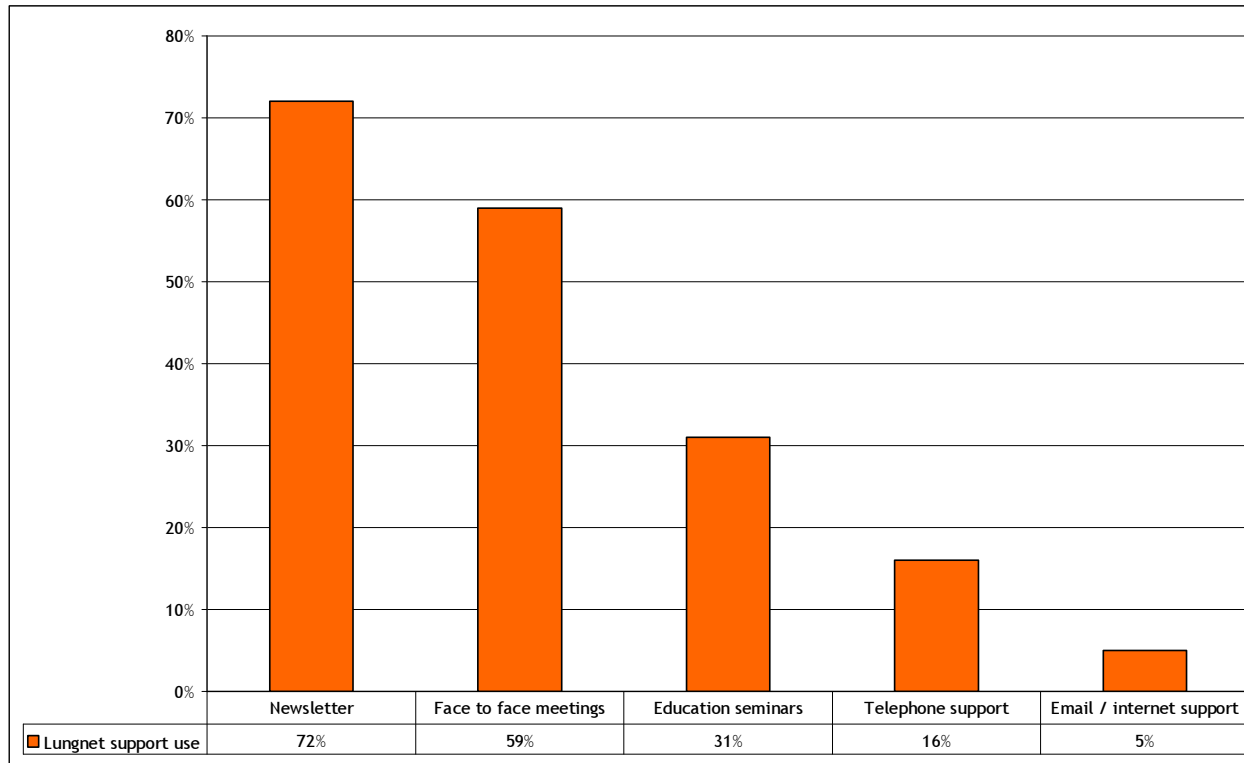
- Lungnet membership is relatively recent with the *mode* (largest number) of research participants being members for three to five years.
 - 20% have been members of more than five years, while just under 20% have been members for less than one year.

Chart 33: Frequency of attending Lungnet meetings
 Base: 769 members of Lungnet



- The most common frequency of attending meetings is monthly.
 - However just under one-third do not attend any meetings.

Chart 34: Use of Lungnet support initiatives
 Base: 770 members of Lungnet



- Newsletters followed by face-to-face meetings are the two most used initiatives of Lungnet.
- Just under one-third of those in Lungnet also use education seminars.
- The least used initiative is email and internet support. Given the age group of those with COPD this is expected as they are less likely than the general population you use internet.