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EVALUATION OF THE BENEFITS OF THE BRITISH LUNG FOUNDATION'S INTEGRATED BREATHE EASY VOLUNTARY GROUP NETWORK

Findings from the outcome, impact and economic evaluation

Evaluation team:

Principal Investigator: Dr Rowena Merritt
Statistician: Tracy Pellatt-Higgins
Health economist: Dr Olena Nizalova
Qualitative researcher: Dr Ferhana Hashem
Data support officer: Tony Rees

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“Having that doctor here, he can answer so many questions about our health problems with the lungs whereas your doctor doesn’t have time...”
(Person living with a lung condition attending an integrated Breathe Easy Group)

“It’s a good way of reinforcing the information that I may have given patients in the clinic or their homes. When they come here and they hear it from me again, they hear it from their peers, it really reinforces it, they remember it, and they believe it.”
(Healthcare professional supporting an integrated Breath Easy Group)

“Coming to the group here that gives me the opportunity to mix with people who have the same condition, and it allows us to get together.”
(Person living with a lung condition attending an integrated Breathe Easy Group)

“Normally if you had been with a group of people and you find that you have got to cough and you can’t stop coughing for a while you know, they look at you and as though you’ve got something really horrible that they are likely to catch you know.”
(Person living with a lung condition attending an integrated Breathe Easy Group)

“I think it is very important to have health care professionals present at these meetings…to be there as a support to help dispel myths, to answer questions that people may not feel comfortable asking their GPs.”
(Healthcare professional supporting an integrated Breath Easy Group)

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EXECUTIVE SUMMARY

Introduction

Over the past two decades, the British Lung Foundation (BLF), has made impressive progress setting up a nationwide support network of Breathe Easy (BE) groups for those living with lung conditions, and their family and friends who support them. In 2014, with a grant from the National Endowment for Science, Technology and the Arts (Nesta), the BLF started a nationwide project to integrate more of their BE groups into the existing local healthcare pathway. The two year project has been independently evaluated by the Centre for Health Services Studies, at the University of Kent. This report details the findings from the outcome and economic evaluation work.

Methods

The study was designed to assess the impact of Integrated Breathe Easy (IBE) groups on the mental and physical wellbeing of people living with and affected by a lung condition. We wanted to compare outcomes for: 1) people who did not attend any BE group; 2) Standard Breathe Easy groups (not integrated within local healthcare pathways); 3) Converted Integrated Breathe Easy groups (where existing BE groups were converted into IBE groups); and 4) New Integrated Breathe Easy groups (newly started IBE groups).

Survey instruments were used to collect outcomes data for people living with a lung condition and their carers within the first month of attending an IBE group, and then every 6 months after that date. People attending standard or not attending any BE group were also sent the surveys every 6 months. A number of well-established and validated survey instruments were used in this study, including the COPD Self-Efficacy Scale (CSES), Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS), Morisky 8-Item Medication Adherence Questionnaire, and the European Quality of Life Questionnaire (EQ-5D). Additional impact data was collected by monthly telephone calls with people living with a lung condition to capture unplanned hospital admissions and GP visits.

Three economic calculations were performed for this study, including: Benefit-Cost Analysis; Social Return on Investment Analysis; and Cost-Effectiveness Analysis.

Findings

A number of key findings should be noted:

- For each pound invested in the IBE groups there is a return of a minimum of £5.36, i.e. £4.36 in net gain through better health outcomes of participants.
- For each pound invested in the IBE groups, there is a net gain of £22.70 in social return.This value of social return includes the £4.36 of net gain in quality of life from a conservative estimate based on highest cost and lowest (NICE recommended) cost-effectiveness threshold of £20000, NHS cost savings, and a range of social benefits.
- IBE groups are more cost effective than standard BE groups in improving well-being of participants.
- People living with a lung condition in converted and new IBE groups felt more confident managing their lung condition and felt more in control of their lung condition compared to standard BE groups.
- There was a 42% reduction in unplanned GP visits and a 57% reduction in unplanned hospital admissions in IBE groups compared to the standard BE groups.
- 87% of people in converted and new IBE groups felt less likely to be admitted to hospital because of their lung condition, compared to 67% in standard BE groups. Similar figures were observed for GP and nurse visits.
- There was some evidence of a decrease in carer's burden at 6 months when compared to baseline for new IBE groups that was not seen in the other groups.
- Carers in existing IBE groups felt more confident to support their partner or friend (97%), felt they had a better understanding of lung conditions (98%), and knew more about services available locally for people supporting others with lung conditions (90%).
- People living with a lung condition who attended any type of BE group had significantly greater quality of life at 6 months compared to people who did not attend a BE group. Those attending BE groups maintained quality of life throughout the study whereas quality of life decreased by more than 20% for those who did not attend a group.
- People attending standard BE groups and converted IBE groups had significantly greater levels of self-efficacy (CSES) than people who did not attend a BE group. Those attending standard BE and converted IBE groups maintained self-efficacy throughout the study whereas there was a decrease of 17% for those who did not attend a BE group.
- It was more common for people who were members of a BE group to remember their medication when travelling and take their medication regularly, even when their symptoms feel under control, when compared to people who did not attend a BE group.
- People attending converted and new IBE groups maintained wellbeing throughout the study whereas there was a decrease of 12% for those who did not attend a BE group.

Conclusions and recommendations

Conclusion:
IBE is a cost effective programme which has positive outcomes in terms of self-efficacy, health outcomes and wellbeing for attendees, providing cost savings and wider social benefits to local communities.

> › Recommendation:
> The IBE model is therefore an appropriate model for local commissioning.

Conclusion:
Data shows that benefits over a range of intended IBE outcomes become increasingly marked with time, reflecting a process of acquiring new skills and knowledge which becomes reinforced the longer a person attends the group.

> › Recommendation:
> To maximise benefits and intended outcomes, resources should be applied to sustaining membership and attendance.

Conclusion:
There is a correlation between local healthcare pathway integration and levels of healthcare professional referral.

> › Recommendation:
> Attention should continue to be paid to referral mechanisms with clear and robust referral pathways.

Conclusion:
Some attendees had a varied and mixed understanding of what to expect from an IBE.

> › Recommendation:
> Regardless of referral route, it is imperative that participant's expectations are managed.

Conclusion:
Volunteers involved in the IBE groups had positive experiences of the role and would like more opportunity to feedback.

> › Recommendation:
> Attention should continue to be paid to opportunities for volunteers to feedback on administrative processes associated with their role.

This evaluation demonstrates that the IBE model is an effective and robust delivery model to support people living with lung conditions. The findings from the study demonstrate that IBE group participants have benefitted hugely and this has had positive impacts on the quality of their lives. The model has shown cost savings to the NHS in both primary and secondary care. With relatively modest set up, low running and sustainability costs IBE offers significant return on investment.

1. INTRODUCTION

The BLF is dedicated to improving the lives of people affected by lung conditions. For over 20 years, a cornerstone of this activity has been the development of a network of people-led groups known as 'Breathe Easy' (BE) groups. Groups promote self-care via peer support, education and information giving. Integral to the success of the network are passionate and community-based volunteers, who drive groups forward to increase the health and wellbeing of their attendees. Volunteers are responsible for key roles within groups, with healthcare professionals working in partnership with some groups, providing advice, talks and establishing effective referral pathways.

With an average of 6,000 regular attendees each year and overall membership of 17,000, the popularity of BE groups has remained high. Despite this, groups were often seen as useful ad hoc opportunities to healthcare pathways, but not always integral to them. This sometimes resulted in varying levels of engagement from healthcare professionals, fluctuating referral rates and differing levels of delivery.

To address this, in 2011 an adapted version of the BE model was implemented in Stoke-on-Trent as part of the NHS Lung Improvement Programme. In partnership with Stoke-on-Trent Primary Care Trust and healthcare providers, the project was successfully included in service specifications and the job descriptions of respiratory healthcare professionals. This clearly demonstrated that self-care groups do not need to be delivered in isolation and can be effectively integrated into local respiratory healthcare pathways.

In 2014, the BLF secured two years of funding from Nesta to develop and test the IBE group model on a wider scale in England, particularly the impact of the model on the burden of lung conditions on individuals and the NHS. This project has been evaluated in this report.

1.1 Integrated Breathe Easy groups:

How they work

The Nesta-funded project identified three key criteria of the new integrated model:

1. Recognition by Commissioning Organisations
- Include 'Support to Breathe Easy' in respiratory service specifications
- Include the project as a standing item on respiratory forums
- Contribute to Breathe Easy programme of activity

2. Support and Sign-up from Healthcare Professionals
- Attendance at eight or more Breathe Easy group meetings per year
- Promotion of groups to service users and carers
- Contribute to Breathe Easy programme of activity

3. Participation by Breathe Easy groups
- Work in partnership with the BLF team, CCG and healthcare professionals
- Record and communicate data on attendance and healthcare professionals support at monthly meetings

The development of the IBE model was informed by a Theory of Change which included the intended intermediate outcomes (appendix I).

1.2 The model in action

The BLF implemented the model in 24 existing BE groups and 19 new groups, totalling 43 IBE groups. Between May 2014 and November 2015, 9,149 attendances have been recorded across all group meetings and 1,432 people have attended an IBE group for the first time. Furthermore, community engagement events in targeted high risk locations for Chronic Obstructive Pulmonary Disease (COPD) have attracted 854 people affected by lung conditions.

1.3 Evaluating the impact of the IBE groups: An independent evaluation

In order to ascertain the impact of the IBE groups, the Centre for Health Services Studies at the University of Kent was commissioned to undertake an independent and rigorous evaluation of the integrated model. The evaluation was split into two parts:

1. A process evaluation; and
2. An outcome and economic evaluation.

In spring 2015, at the end of Year One of the project, a report was produced which detailed the findings from the process evaluation. This was done at that early stage to ensure that the recommendations for improvements could be implemented in Year Two of the project.

This report details the findings from the outcome and economic evaluation work. The methodology is detailed in Appendix II.

1.4 Report terminology

In this report we refer to:

- People living with a lung condition (patient);
- Carers: people who support (unpaid) a partner, family member or friend who due to living with a lung condition cannot manage without this support;
- Standard Breathe Easy groups (Standard BE) – existing BE groups that had not been integrated into the local health service pathway;
- Converted Integrated Breathe Easy groups (Converted IBE) – existing BE groups that had been subsequently integrated into the local health service pathway; and
- New Integrated Breathe Easy groups (New IBE) – new groups specifically established to be integrated into the local health service pathway.

2: OUTCOME AND IMPACT EVALUATION FINDINGS

Key points:

- More than 90% of people agreed that they felt more confident and more in control of their lung condition in new and converted IBE groups, this was significantly higher than standard BE groups.
- Unplanned GP visits were lower in IBE groups, 39% of people had unplanned visits, compared to 67% in standard BE groups.
- Unplanned hospital admissions were lower in IBE groups, 13% of people had unplanned admissions, compared to 30% in standard BE groups.
- People who attended a BE group had similar self-efficacy at baseline and 6 months later. People who did not attend a group had lower self-efficacy (mean reduction of 16 points) at 6 months, a statistically significant change compared to standard BE groups and converted IBE groups.
- People who attended a BE group had similar well-being scores at baseline and 6 months later. People who did not attend a group had lower well-being (mean reduction of 5 points) at 6 months, a statistically significant change compared to converted and new IBE groups.
- Quality of life scores were similar at baseline and 6 months for people who attended a BE group. There was a reduction in quality of life at 6 months for people who did not attend any group (mean reduction of 0.1333 in EQ-5D), a statistically significant change compared to the other groups.
- 44% of participants in converted IBE groups strongly agreed that they knew more about local services available for people living with lung conditions, compared to 29% in standard BE groups and 33% in new IBE groups. This may be due to the longer average length of membership for converted IBE group members.
- 24% of Participants in standard BE groups strongly agreed that they felt closer to other people since joining the group, compared to 14% and 9% in converted and new IBE groups respectively. This again may be linked to the average length of membership which was longer for BE group members compared to IBE groups.
- No new IBE group members had stopped adhering to treatment plans without telling their doctor at 6 months.
- It was more common for people who did not attend any BE group to sometimes forget their medication when travelling (32%) or stop taking their medication when their symptoms feel under control (21%) compared to people who attend a BE group.
- 55% of carers in the converted IBE groups were in strong agreement with the statements about feeling more confident to support their partner/friend.

2.1. Recruitment and participant flow

The project started in April 2014, and baseline data from the first participants were collected in June 2015 and continued until September 2015. A total of 46 Breathe Easy (BE) groups provided data on participants' outcomes and were included in this study. Of these, 16 were existing BE groups that were not part of the local health service pathway (**standard** BE groups), 16 were an existing standard group that had been integrated into the local health service pathway (**converted** IBE groups) and the remaining 14 groups were new groups specifically established to be integrated into the local health service pathway (**new** IBE groups). An additional 105 people were recruited who had expressed an interest in joining a BE group but did not have access to one in their local area.

Everyone attending the included BE groups were asked to complete a series of surveys to record demographic and outcomes data. Involvement in the study was completely voluntary and hence not all members of the BE groups elected to participate in the study.

The surveys used to collect outcomes data were completed every 6 months by all participants who were present at the BE group meeting on the given date (the date when the 6 month data collection was taking place). This resulted in some individual missing data at each collection time point due to some group members being on holiday or unwell at the time of the meeting.

People who did not attend any BE group were contacted individually either by mail and/or email and asked to complete the relevant surveys.

All available data were included in the statistical analysis and data summaries. The propensity score analysis is shown in Appendix III.

2.2. Outcomes evaluation

The results from the statistical analysis and summaries of outcomes data are presented under headings reflecting the intended intermediate outcomes of attending integrated Breathe Easy (IBE) groups for people living with a lung condition (See Appendix I).

2.2.1. Better understanding of health services

This question was addressed as part of Survey A (see appendix V). People living with a lung condition were asked, *'Thinking back to before you joined Breathe Easy compared to now…'* if they now knew more about the services available to people with lung conditions in their local area. People living with a lung condition were also asked whether they felt they now knew enough about local lung services to tell a new member of the group who to speak to about pulmonary rehabilitation. Table 1 below shows the responses to these questions. Due to the nature of the question, it was only asked to members of the BE and IBE groups (as opposed to those people living with a lung condition who were not members of any BE group).

Table 1. Number of people by type of BE group (percentages in brackets)

Question	Response	Standard BE groups	Converted IBE groups	New IBE groups
I know more about services available to people with lung disease in my local area	Strongly agree	21 (28.8%)	55 (44.4%)	16 (32.7%)
	Agree	41 (56.2%)	58 (46.8%)	31 (63.3%)
	Disagree	9 (12.3%)	8 (6.5%)	2 (4.1%)
	Strongly disagree	2 (2.7%)	3 (2.4%)	0 (0.0%)
I know enough about local services to tell a new member who to speak to about pulmonary rehabilitation	Strongly agree	21 (29.6%)	41 (35.7%)	10 (25.0%)
	Agree	32 (45.1%)	57 (49.6%)	20 (50.0%)
	Disagree	17 (23.9%)	17 (14.8%)	10 (25.0%)
	Strongly disagree	1 (1.4%)	0 (0.0%)	0 (0.0%)

Forty-four percent of participants ‘strongly agreed’ that they now knew more about services available to people with lung conditions in their local area in the converted IBE groups compared to 29% in the standard BE groups and 33% in new IBE groups. A similar pattern was seen in response to the second question about extent of knowledge of local services, however none of the differences were statistically significant. Survey B (see appendix VI) included a question about length of membership of all BE group participants. The average duration of membership for standard BE groups is 50 months, compared to 37 months for converted IBE groups and 11 months for new IBE groups. It seems reasonable to expect people who have been members of groups for longer to have more knowledge than those who have recently joined.

2.2.2. Better understanding of lung conditions

This question was addressed as part of Survey A. Participants were asked, *‘Thinking back to before you joined Breathe Easy compared to now…’* if they now have a better understanding of their lung condition. Table 2 below shows the responses to these questions.

Table 2. Number of people by type of BE group (percentages in brackets)

Question	Response	Standard BE groups	Converted IBE groups	New IBE groups
I have a better understanding of my lung condition	Strongly agree	30 (41.7%)	58 (47.2%)	21 (44.7%)
	Agree	35 (48.6%)	61 (49.6%)	22 (46.8%)
	Disagree	7 (9.7%)	4 (3.3%)	4 (8.5%)
	Strongly disagree	0 (0.0%)	0 (0.0%)	0 (0.0%)

More than 90% of participants ‘strongly agreed’ or ‘agreed’ that they had a better understanding of their lung condition in the standard, converted and new BE groups. There were no statistically significant differences in responses.

2.2.3. Increased medicine management and adherence

The Morisky 8-item medication adherence questionnaire was used to record information about medicine management and compliance.

Responses to the questionnaire are summarised in Table 3 below.

Table 3. Morisky 8-item medication adherence questionnaire: Number of people (percentages in brackets)

Question	Time	Response	Did not attend any BE group	Standard BE groups	Converted IBE groups	New IBE groups
1) Do you sometimes forget to take your medication?	Baseline	Yes	24 (24.2%)	21 (15.6%)	55 (23.7%)	29 (22.8%)
		No	75 (75.8%)	114 (84.4%)	177 (76.3%)	98 (77.2%)
	6 months	Yes	22 (38.6%)	10 (19.2%)	19 (23.5%)	6 (18.8%)
		No	35 (61.4%)	42 (80.8%)	62 (76.5%)	26 (81.3%)

2) People sometimes miss taking their medication for other reasons than forgetting. Thinking over the past two weeks are there any days when you did not take your medication?	Baseline	Yes	15 (15.2%)	19 (14.4%)	30 (13.0%)	15 (11.8%)
		No	84 (84.8%)	113 (85.6%)	200 (87.0%)	112 (88.2%)
	6 months	Yes	13 (22.8%)	7 (13.5%)	11 (14.1%)	3 (9.4%)
		No	44 (77.2%)	45 (86.5%)	67 (85.9%)	29 (90.6%)
3) Have you ever cut back or stopped taking your medication without telling your doctor as you felt worse when you took it?	Baseline	Yes	19 (19.2%)	16 (11.9%)	25 (11.0%)	13 (10.4%)
		No	80 (80.8%)	118 (88.1%)	203 (89.0%)	112 (89.6%)
	6 months	Yes	13 (23.2%)	5 (9.8%)	8 (9.9%)	0 (0.0%)
		No	43 (76.8%)	46 (90.2%)	73 (90.1%)	32 (100.0%)
4) When you travel or leave home, do you sometimes forget to take along your medication?	Baseline	Yes	15 (15.0%)	10 (7.4%)	36 (15.1%)	20 (15.6%)
		No	85 (85.0%)	125 (92.6%)	203 (84.9%)	108 (84.4%)
	6 months	Yes	18 (31.6%)	4 (8.0%)	10 (12.3%)	6 (18.8%)
		No	39 (68.4%)	46 (92.0%)	71 (87.7%)	26 (81.3%)
5) Did you take all your medicines yesterday?	Baseline	Yes	77 (77%)	93 (68.9%)	160 (67.5%)	91 (71.7%)
		No	23 (23%)	42 (31.1%)	77 (32.5%)	36 (28.3%)
	6 months	Yes	45 (78.9%)	36 (70.6%)	48 (59.3%)	22 (73.3%)
		No	12 (21.1%)	15 (29.4%)	33 (40.7%)	8 (26.7%)

6) When you feel like your symptoms are under control, do you sometimes stop taking your medicine?	Baseline	Yes	11 (11.0%)	5 (3.7%)	11 (4.6%)	7 (5.4%)
		No	89 (89.0%)	130 (96.3%)	227 (95.4%)	122 (94.6%)
	6 months	Yes	12 (21.1%)	3 (5.9%)	2 (2.5%)	2 (6.3%)
		No	45 (78.9%)	48 (94.1%)	78 (97.5%)	30 (93.8%)
7) Taking medication every day is a real inconvenience for some people. Do you ever feel hassled about sticking to your treatment plan?	Baseline	Yes	21 (21.2%)	32 (23.7%)	46 (19.6%)	24 (18.9%)
		No	78 (78.8%)	103 (76.3%)	189 (80.4%)	103 (81.1%)
	6 months	Yes	18 (31.6%)	15 (30.0%)	17 (21.3%)	6 (18.8%)
		No	39 (68.4%)	35 (70.0%)	63 (78.8%)	26 (81.3%)
8) Do you ever have difficulty remembering to take your medicine?	Baseline	Yes	20 (20.0%)	13 (9.6%)	38 (16.0%)	21 (16.4%)
		No	80 (80.0%)	122 (90.4%)	199 (84.0%)	107 (83.6%)
	6 months	Yes	21 (36.8%)	8 (16.0%)	13 (16.5%)	5 (15.6%)
		No	36 (63.2%)	42 (84.0%)	66 (83.5%)	27 (84.4%)

There were statistically significant differences in responses at 6 months for questions 3, 4, 6 and 8. No new IBE group members had cut back or stopped taking medication without telling their doctor at 6 months. It was more common for people who did not attend any BE group to sometimes forget their medication while travelling (32%), stop taking their medication when their symptoms felt under control (21%), and to have difficulty remembering to take their medicine (37%), compared to the people who attend a BE group.

2.2.4. Increased opportunities for social contact/interaction

The Warwick-Edinburgh mental wellbeing scale (WEMWBS) includes several questions related to mental wellbeing and about contact with and feelings about other people. WEMWBS changes from baseline at 6 months were analysed using the BE group analysis model and the whole study analysis model.

> *“[The BE group] changed him around, making him realise you can live with COPD… he’s a completely different person now. Actually his first meeting, he was very reluctant to come along, his wife virtually forced him, you know. And just after yesterday’s meeting as he walked out he said ‘Oh I’ll see you next month then’. That was really good, you’re giving them a way forward because it’s a group of people there together and the fact that people are willing to talk about it.”*
>
> IBE Group Chair and living with a lung condition

The estimates of the differences in adjusted means between type of BE group and 95% confidence intervals are shown in Appendix VII. Summary statistics for WEMWBS at baseline and 6 months can be found in Appendix VIII, alongside summaries for the change from baseline at 6 months.

Statistically significant differences were observed in WEMWBS between people who did not attend a BE group and people who were members of converted IBE groups and new IBE groups. People who did not attend any BE group had lower levels of wellbeing at 6 months compared to baseline (mean change from baseline -5.38) when compared to people who attended converted or new IBE groups, who maintained similar well-being scores throughout the study.

There was a question in Survey B about feeling closer to other people, and a question in Survey A about whether group members felt confident to discuss their condition with other people in the group and share experiences in the hope that it will help others. Table 4 shows the responses to these questions.

Table 4. Number of people by type of BE group (percentages in brackets)

Question	Response	Standard BE groups	Converted IBE groups	New IBE groups
I feel closer to other people	Strongly agree	6 (24.0%)	1 (14.3%)	1 (9.1%)
	Agree	19 (76.0%)	4 (57.1%)	10 (90.9%)
	Disagree	0 (0.0%)	2 (28.6%)	0 (0.0%)
	Strongly disagree	0 (0.0%)	0 (0.0%)	0 (0.0%)
I feel confident to discuss my condition with other people in the group and share my experiences in the hope it will help others	Strongly agree	35 (50.0%)	62 (53.9%)	21 (48.8%)
	Agree	31 (44.3%)	52 (45.2%)	22 (51.2%)
	Disagree	4 (5.7%)	1 (0.9%)	0 (0.0%)
	Strongly disagree	0 (0.0%)	0 (0.0%)	0 (0.0%)

"At the last session, we had a pharmacist in and they were explaining to us the different inhalers. They provided some good information on techniques, which really helped me …I think I was taking it all wrong, but I'm not now."
Person living with a lung condition attending an IBE Group

For the first question, 24% of participants in standard BE groups reported 'strongly agreeing' that they felt closer to other people since joining the group, compared to 14% and 9% in converted and new IBE groups respectively, this difference was statistically significant. It seems reasonable that people in the standard BE groups may feel closer to others because they have, on average, longer group membership compared to the IBE groups. A similar percentage of participants 'strongly agreed' and 'agreed' that they felt more confident to discuss their condition with others and share experiences in the standard and IBE groups.

2.2.5. Increased confidence

There were a number of questions related to increased confidence on the final one-off survey (Survey B, appendix VI) and in the short survey recording changes around knowledge of people living with a lung condition about their condition and health care systems. Table 5 shows the responses to these questions.

Table 5. Number of people by type of BE group (percentages in brackets)

Question	Response	Standard BE groups	Converted IBE groups	New IBE groups
I feel more confident managing my lung condition	Strongly agree	24 (33.3%)	52 (43.0%)	15 (31.1%)
	Agree	39 (54.2%)	68 (56.2%)	30 (62.5%)
	Disagree	9 (12.5%)	1 (0.8%)	3 (6.3%)
	Strongly disagree	0 (0.0%)	0 (0.0%)	0 (0.0%)
I feel more in control of my lung condition	Strongly agree	23 (31.5%)	41 (34.2%)	12 (25.5%)
	Agree	37 (50.7%)	76 (63.3%)	31 (66.0%)
	Disagree	13 (17.8%)	3 (2.5%)	4 (8.5%)
	Strongly disagree	0 (0.0%)	0 (0.0%)	0 (0.0%)
I feel more confident to manage my breathing	Strongly agree	8 (32.0%)	2 (28.6%)	1 (10.0%)
	Agree	14 (56.0%)	3 (42.8%)	9 (90.0%)
	Disagree	2 (8.0%)	2 (28.6%)	0 (0.0%)
	Strongly disagree	1 (4.0%)	0 (0.0%)	0 (0.0%)
I feel more optimistic about the future	Strongly agree	7 (29.2%)	1 (14.3%)	1 (9.1%)
	Agree	17 (70.8%)	4 (57.1%)	9 (81.8%)
	Disagree	0 (0.0%)	2 (28.6%)	1 (9.1%)
	Strongly disagree	0 (0.0%)	0 (0.0%)	0 (0.0%)

There were statistically significant differences in participants' responses to the first two questions about confidence in managing and feeling more in control of their lung condition. More than 90% of people 'strongly agreed' or 'agreed' that they felt more confident and more in control of their lung condition in new and converted IBE groups, this was significantly higher than standard BE groups.

2.2.6. Development of new skills

The COPD Self-Efficacy Scale (CSES) records information about confidence in ability to control, organise and execute a course of action required for performing specific tasks that will lead to certain outcomes. CSES changes from baseline at 6 months, and the five subscales of: 1) Negative affect, 2) Intense emotional arousal, 3) Physical exertion, 4) Weather/environment, and 5) Behavioural risk factors, were analysed using the BE group analysis model and the whole study analysis model. The results from the BE group analysis model showed no evidence of statistically significant differences between type of BE group, however from the second analysis including data from people who did not attend any BE group there were statistically significant differences for CSES and the subscales of Negative affect, Intense emotional arousal and Behavioural risk factors in the changes from baseline at 6 months.

> *"It's having that confidence to actually realise that you can, although you can't cure it [lung condition], you can live with it and you can live quite comfortably with it if you take precautions and recognise the signs… it's [the BE group] given me a lot more confidence definitely."*
> (Person living with a lung condition attending an IBE Group)

The estimates of the differences in adjusted means and 95% confidence intervals are shown in Appendix IX. Summary Statistics for CSES and the five subscales at baseline and 6 months can be found in Appendix X, alongside summaries for the change from baseline at 6 months.

Statistically significant differences were observed in CSES between people who did not attend any BE group and people who were members of standard BE groups and converted IBE groups. People who attended a BE group had similar self-efficacy at baseline and 6 months later, the mean change from baseline for standard BE groups, converted IBE groups and new IBE groups were 1.59, -3.74 and 6.25 respectively. People who did not attend a group had lower self-efficacy at 6 months (mean change from baseline of 15.6 points), a statistically significant change compared to standard BE groups and converted IBE groups.

Statistically significant differences were also observed in the Negative affect subscale between people who did not attend a BE group and those who attended a BE group (Appendix XI). People who attended a BE group of any type had similar self-efficacy with regard to Negative Affect at baseline and 6 months later, the mean change from baseline for standard BE groups, converted IBE groups and new IBE groups are 0.591, -0.433 and -1.64 respectively. People who did not attend a group had lower self-efficacy for this subscale at 6 months (mean change from baseline of 6.19 points), a statistically significant change compared to the other groups.

Statistically significant differences were observed in the subscale of intense emotional arousal between people who did not attend a BE group and those who attended a BE group (Appendix XII). People who attended a BE group of any type had similar self-efficacy with regard to Intense emotional arousal at baseline and 6 months later, the mean change from baseline for standard BE groups, converted IBE groups and new IBE groups are 0.5, -0.714 and -0.520 respectively. People who did not attend a group had lower self-efficacy for this subscale at 6 months (mean change from baseline of 3.48 points), a statistically significant change compared to the other groups.

Statistically significant differences were observed in behavioural risk factors between people who did not attend a BE group and people who were members of converted IBE groups (Appendix XIII). People who attended a BE group of any type had similar self-efficacy with regard to behavioural risk factors at baseline and 6 months later, the mean change from baseline for standard BE groups, converted IBE groups and new IBE groups were 0.637, -0.018 and 0.533 respectively. People who did not attend a group had lower self-efficacy for this subscale at 6 months (mean change from baseline of 1.6 points), a statistically significant change compared to converted IBE groups.

There were a number of questions related to development of new skills on Surveys A and B. Table 6 below shows the responses to these questions.

There were statistically significant differences in responses to the question about feeling less likely to be admitted to hospital and not feeling the need to visit their doctor/nurse as often. 31.5% of people living with a lung condition 'strongly agreed' with the statement about feeling less likely to be admitted to hospital in converted IBE groups compared to 16.4% in standard BE groups and 23.4% in new IBE groups. Similarly, 26% of people in converted IBE groups 'strongly agreed' with the statement about not feeling the need to visit their doctor or nurse as often, compared to 11.3% in standard BE groups and 19.6% in new IBE groups.

Table 6. Number of people by type of BE group (percentages in brackets)

Question	Response	Standard BE groups	Converted IBE groups	New IBE groups
I feel in control of my medical condition	Strongly agree	8 (30.8%)	1 (14.3%)	4 (33.3%)
	Agree	17 (65.4%)	4 (57.1%)	7 (58.3%)
	Disagree	1 (3.8%)	2 (28.6%)	1 (8.3%)
	Strongly disagree	0 (0.0%)	0 (0.0%)	0 (0.0%)
I feel in control of my life	Strongly agree	6 (23.1%)	0 (0.0%)	3 (25.0%)
	Agree	19 (73.1%)	5 (71.4%)	6 (50.0%)
	Disagree	0 (0.0%)	2 (28.6%)	3 (25.0%)
	Strongly disagree	1 (3.8%)	0 (0.0%)	0 (0.0%)
I feel more capable of getting a job/volunteering	Strongly agree	3 (13.6%)	0 (0.0%)	1 (9.1%)
	Agree	13 (59.1%)	2 (28.6%)	5 (45.4%)
	Disagree	4 (18.2%)	3 (42.8%)	4 (36.4%)
	Strongly disagree	2 (9.1%)	2 (28.6%)	1 (9.1%)
I have more knowledge of what to do if I am unwell	Strongly agree	26 (35.6%)	56 (45.4%)	18 (40.0%)
	Agree	39 (53.4%)	62 (50.4%)	25 (55.6%)
	Disagree	8 (11.0%)	5 (4.1%)	2 (4.4%)
	Strongly disagree	0 (0.0%)	0 (0.0%)	0 (0.0%)
I feel I am less likely to be admitted to hospital with my lung condition	Strongly agree	12 (16.4%)	39 (31.5%)	11 (23.4%)
	Agree	37 (50.7%)	69 (55.6%)	30 (63.8%)
	Disagree	20 (27.4%)	13 (10.5%)	6 (12.8%)
	Strongly disagree	4 (5.5%)	3 (2.4%)	0 (0.0%)
I don’t feel I need to visit my doctor/nurse because of my lung condition as often	Strongly agree	8 (11.3%)	32 (26.0%)	9 (19.6%)
	Agree	35 (49.3%)	61 (49.6%)	26 (56.5%)
	Disagree	25 (35.2%)	22 (17.9%)	11 (23.9%)
	Strongly disagree	3 (4.2%)	8 (6.5%)	0 (0.0%)

2.2.7. Increased wellbeing and resilience

The European Quality of Life questionnaire (EQ-5D) includes one question related to each of the following dimensions:

- Mobility
- Self-care
- Usual activities
- Pain/discomfort
- Anxiety/depression

Health states from EQ-5D were converted into utility scores before analysis and changes from baseline at 6 months were analysed using the BE group analysis model and the whole study analysis model.

> *"I was completely shocked [when I was diagnosed with COPD]. I thought it was for older people and I didn't know much about it. The group, it was a blessing for me. It took my fear away seeing what other people can do with their lives despite COPD."*
> (Person living with a lung condition attending an IBE Group)

The differences in adjusted means and 95% confidence intervals are shown in Appendix XIV. Summary Statistics for EQ-5D at baseline and 6 months can be found in Appendix XV, alongside summaries of the change from baseline at 6 months.

Statistically significant differences were observed in EQ-5D utility scores between people who did not attend a BE group and people who did attend a BE group. People who attended a BE group of any type had similar quality of life at baseline and 6 months later, the mean change from baseline for standard BE groups, converted IBE groups and new IBE groups are -0.041, 0.0102 and -0.00704 respectively. People who did not attend a group had lower quality of life at 6 months (mean change from baseline of -0.133), a statistically significant change compared to the other groups.

2.2.8. Reduced call upon GP services

Monthly telephone calls with a subset of participants were used to collect data retrospectively on unplanned GP visits in relation to lung condition. These data were collected for participants in converted and new IBE groups, standard BE groups, and for people who did not attend any BE group. The information recorded is presented in Table 7.

Table 7. Unplanned GP visits in relation to lung condition

Number of people living with a lung condition (%)		**Type of group**		
		Did not attend any BE group	**Standard BE groups**	**Converted and new IBE groups**
Unplanned GP visit(s)?	Yes	17 (50.0%)	22 (66.7%)	12 (38.7%)
	No	17 (50.0%)	11 (33.3%)	19 (61.3%)

38.7% of IBE group members had unplanned GP visits in relation to their lung condition during the study, compared to 66.7% in standard BE groups and 50% of people who did not attend any BE group.

2.2.9. Reduced risk of unnecessary hospital admissions

Impact data was also collected retrospectively by monthly telephone call on unplanned hospital visits and admissions in relation to lung condition.

As with the GP visits, these data were collected for a subset of participants in converted and new IBE groups, standard BE groups, and people who did not attend any BE group. The information recorded is shown in Table 8.

Table 8. Unplanned hospital admissions in relation to lung condition

Number of people living with a lung condition (%)		**Type of group**		
		Did not attend any BE group	**Standard BE groups**	**Converted and new IBE groups**
Unplanned hospital admission(s)?	Yes	8 (23.5%)	10 (30.3%)	4 (12.9%)
	No	26 (76.5%)	23 (69.7%)	27 (87.1%)

12.9% of participants from IBE groups had unplanned hospital admissions compared to 30.3% in standard BE groups and 23.5% of people who did not attend any BE group, suggesting that those attending IBE groups were less likely to have exacerbations leading to unplanned admissions.

2.2.10. Carers supporting those living with a lung condition

Data were available for a small number of carers supporting a person living with a lung condition. The modified carers checklist and WEMWBS outcomes are summarised in Tables 9 and 10.

> *"When I joined this group I found a lot more things to help me relax if I got into a situation where I started really getting short of breath or whatever and things like that. Before that I would just sit and be breathless or call the doctor or an ambulance, and that was it."*
> (Person living with a lung condition attending an IBE Group)

Table 9. Summary Statistics Carers checklist

Time	**Type of Group**	**Summary statistics**				
		Mean	Median	Standard Deviation	Range	N
Baseline	Did not attend any BE group	22.7	21.0	4.7	9.0	5
	Standard BE group	25.4	27.0	6.4	20.0	19
	Converted IBE group	22.5	23.0	7.0	28.0	73
	New IBE group	23.1	24.5	6.5	20.0	29
6 months	Did not attend any BE group	.	.	.	.	0
	Standard BE group	26.0	25.0	1.7	3.0	3
	Converted IBE group	22.3	23.0	7.4	23.0	19
	New IBE group	14.8	14.0	6.1	15.0	5

There was some indication of reduced burden for carers supporting a person living with a lung condition in new IBE groups. The mean score at baseline is 23.1 for new IBE groups (N=29), which is similar to the baseline scores for the other groups. At 6 months the mean score for new IBE groups is 14.8 (N=5) and is lower than seen in the other groups, however this is based on 6 month data for only 5 participants making it difficult to draw firm conclusions.

Table 10. Summary Statistics Carers WEMWBS

Time	Type of Group	Summary statistics				
		Mean	Median	Standard Deviation	Range	N
Baseline	Did not attend any BE group	52.0	50.0	6.9	16.0	5
	Standard BE group	45.5	44.0	8.0	29.0	19
	Converted IBE group	47.2	46.0	11.0	47.0	72
	New IBE group	44.6	46.5	9.8	36.0	29
6 months	Did not attend any BE group	.	.	.	.	0
	Standard BE group	40.7	40.0	2.1	4.0	3
	Converted IBE group	48.2	46.0	10.6	41.0	20
	New IBE group	46.0	45.0	13.5	27.0	5

The wellbeing scores were higher in converted and new IBE groups at 6 months (mean scores 48.2 and 46.0 respectively), suggesting greater wellbeing of family carers in these types of BE groups, but again the numbers are small and we would expect to see variability in the mean response with such small numbers.

The BLF Survey (Survey A, Appendix V) was adapted for carers providing support for people living with a lung condition and responses to key questions related to the intended intermediate outcomes of the IBE are shown in Table 11.

Table 11. Number of carers by type of BE group (percentages in brackets)

Question	Response	Standard BE groups	Converted IBE groups	New IBE groups
I feel more confident in supporting my partner/friend with their lung condition	Strongly agree	2 (16.7%)	21 (55.3%)	4 (57.1%)
	Agree	10 (83.3%)	16 (42.1%)	3 (42.9%)
	Disagree	0 (0.0%)	1 (2.6%)	0 (0.0%)
	Strongly disagree	0 (0.0%)	0 (0.0%)	0 (0.0%)
I have a better understanding of their lung condition	Strongly agree	4 (30.8%)	20 (52.6%)	2 (28.6%)
	Agree	9 (69.2%)	16 (42.1%)	5 (71.4%)
	Disagree	0 (0.0%)	2 (5.3%)	0 (0.0%)
	Strongly disagree	0 (0.0%)	0 (0.0)	0 (0.0%)
I have more knowledge of what to do if my partner/friend becomes unwell	Strongly agree	3 (25%)	18 (47.4%)	2 (28.6%)
	Agree	7 (58.3%)	18 (47.4%)	5 (71.4%)
	Disagree	2 (16.7%)	2 (5.3%)	0 (0.0%)
	Strongly disagree	0 (0.0%)	0 (0.0%)	0 (0.0%)
I feel breathe easy has resulted in less GP and hospital visits	Strongly agree	1 (7.7%)	9 (26.5%)	2 (28.6%)
	Agree	6 (46.2%)	15 (44.1%)	2 (28.6%)
	Disagree	6 (46.2%)	10 (29.4%)	3 (42.9%)
	Strongly disagree	0 (0.0%)	0 (0.0%)	0 (0.0%)

Table 11. (continued)

I feel more in control	Strongly agree	0 (0.0%)	10 (25.6%)	2 (28.6%)
	Agree	9 (69.2%)	25 (64.1%)	5 (71.4%)
	Disagree	3 (23.1%)	4 (10.3%)	0 (0.0%)
	Strongly disagree	1 (7.7%)	0 (0.0%)	0 (0.0%)
I know more about the services available to people supporting others with lung disease in my local area	Strongly agree	0 (0.0%)	23 (57.5%)	3 (42.9%)
	Agree	12 (93.3%)	13 (32.5%)	4 (57.1%)
	Disagree	0 (0.0%)	4 (10.0%)	0 (0.0%)
	Strongly disagree	1 (7.7%)	0 (0.0%)	0 (0.0%)
I feel confident to discuss my situation with other people in the group and share my experiences in the hope that it will help others	Strongly agree	4 (33.3%)	13 (34.2%)	3 (42.9%)
	Agree	5 (41.7%)	24 (63.2%)	3 (42.9%)
	Disagree	2 (16.7%)	1 (2.6%)	1 (14.3%)
	Strongly disagree	1 (8.3%)	0 (0.0%)	0 (0.0%)
I know enough about local lung/carer services to tell a new member who to speak to about pulmonary rehabilitation	Strongly agree	1 (8.3%)	6 (17.1%)	2 (28.6%)
	Agree	6 (50.0%)	23 (65.7%)	3 (42.9%)
	Disagree	3 (25.0%)	6 (17.1%)	2 (28.6%)
	Strongly disagree	2 (16.7%)	0 (0.0%)	0 (0.0%)

The number of carers who responded was low in most of the groups with the exception of converted IBE groups. The majority of carers in the converted IBE groups were in strong agreement with the statements about feeling more confident to support their partner/friend, having a better understanding of their partner/friend's lung condition, and knowing more about the services available to people supporting others with lung conditions in the local area.

SECTION 3: HEALTH ECONOMIC FINDINGS

Key points

IBE groups deliver positive results when compared to standard BE groups in improving wellbeing of people living with lung conditions and are more cost effective than standard BE groups in improving well-being of participants:

- For every pound invested in the IBE groups there is a return of a minimum of £5.36, i.e. £4.36 in net gain through better health outcomes of participants.
- For every pound invested in the IBE groups, there is a net gain of £22.70 made up of the value of better health outcomes, the NHS cost savings and a range of wider social benefits.

Where possible, we have looked into the differences between the new IBE groups and standard BE groups.

3.1. Measurement of resource use

At the time involvement of people living with or affected by a lung condition and volunteers in all types of BE groups was not expected to be different, we have assumed that the opportunity cost for them was the same, and have only measured the difference in organisational resources. Table 12 provides basic information about the groups, which was used for the health economics analysis work. As can be seen, the average number of members per group was higher in both the new IBE groups and in the converted IBE groups compared to the standard BE groups. The same is true about the number of carers supporting the person living with the lung condition attending the groups and volunteers.

Table 12. Basic information about groups

	IBE	New IBE	Converted IBE	BE	diff (all IBE - BE)	diff (new IBE - BE)
Number of member per group per month	22.62	19.90	25.00	8.80	14.18	11.10
Number of family Carers (20-25% of the member, assume 22.5%)	5.09	4.48	5.63	1.98	3.19	2.50
Number of volunteers	5.40	4.00	6.00	2.50	2.90	1.50
Number of groups	30.00	14.00	16.00	16.00		

Table 13 summarises the approach to the estimation of the cost of setting up the IBE groups per member over the 6-month period (evaluation costs not included in the calculation of average cost per group).

Table 13. Project resource use for creating new and converted IBE groups

Total number of integrated groups supported via the project	43
Project operational budget	£306,688
Project duration (months)	24
Average cost per group per 6 months	£1,783.07
Average number of members per group	22.62
Average incremental cost per IBE per member over 6-months period	£78.83

In addition to the cost of setting up new and converted IBE groups, the IBE groups differ from the standard BE groups in operational costs due to the fact that the former involve a nurse specialist for 2 hours per month. This is clearly an opportunity cost to the NHS, since during this time the nurse could have been receiving patients or performing other direct duties. For this study, the NHS costs of running the IBE groups was estimated by combining the information on time involvement of the nurse specialist and the corresponding hourly rate based on the 2013 Unit Costs[1] (p.186) (Table 14).

As the Nesta funds were allocated in the financial year of 2013/14, we carried out the analysis with 2013 prices. As the outcome analysis evaluated impact of 6 months period, the NHS cost measure was also standardised to per participant over 6-month period. The research team only used information from Columns (2) and (4) (detailed in Table 14) due to the fact that all of the IBE groups were located outside London. As the exact grade and qualifications of the nurses attending the groups are not known, the research team used both estimates (with and without qualifications) when calculating the cost effectiveness measures.

Table 14. Estimating the NHS costs of running IBE groups

	Base		**Including qualifications**	
	London	Non-London	London	Non-London
	(1)	(2)	(3)	(4)
NHS COPD nurse (Nurse Specialist from Unit Cost) per 6 months	£528.00	£512.16	£600.00	£582.00
hours per month	2	2	2	2
cost per hour	£42.00	£40.74	£49.00	£47.53
number of months	6	6	6	6
Average number of member per group	22.62	22.62	22.62	22.62
Average incremental cost per IBE per participant per 6 months	£22.28	£21.62	£25.99	£25.21

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[1] Curtis, L, 2013, Unit Costs of Health and Social Care 2015, Personal Social Services Research Unit, University of Kent, Canterbury.

The third resource measure estimate was the NHS cost savings due to changes in unplanned hospital admissions and GP appointments. The research team derived this information from the monthly telephone calls to people living with a lung condition (as detailed in Sections 2.2.8 and 2.2.9) and attached the unit costs based on the 2013 Unit Cost data[2].

Table 15 shows a number of measures on which the research team collected information from people living with a lung condition on a monthly basis, asking them to recall what happened to them in terms of unplanned hospital admissions and GP appointments related to respiratory conditions.

The IBE group participants on average had 0.61 fewer GP episodes and one fewer GP appointment than those in the standard BE groups. The same is true about the hospital admissions (0.32 fewer hospital admission episodes and 1.45 fewer nights spent in the hospital once admitted). However, there were no statistically significant differences in the number of outpatient use and the average number of days on antibiotics or steroids.

Given the availability of the unit cost data, the research team assigned the monetary value to the summary measures, such as number of GP appointments and hospital episodes, with a statistically significant difference between the IBE (both new and converted) and standard BE groups.

For the cost per GP appointment, the appointment lasting for 11.7 minutes was used as the measure, with qualifications including the direct care staff costs from Table 10.8b (Unit Cost 2013: p. 191), in the amount of £45 per consultation. For a cost per hospital episode the research team referred to Table 7.1 from Unit Cost (2013) and used the national average figure for non-elective inpatient short stays (one day or less) of £598 per episode (as most of the hospital stays in the sample are one to two nights).

The research team also estimated the average price per night of a hospital stay from the same table using 5.87[3,4] as an average length of stay and the non-elective inpatient stay of £2,581 (Unit Cost 2013: p. 107). So that £2,581/5.87 ~= £440 per night.

Table 15. NHS Cost Savings per person over a 6 month period

Cost categories/group	BE	IBE	Incremental diff (IBE-BE)	Cost per Unit	Incremental cost diff (IBE-BE)
	(1)	(2)	(3)	(4)	(5)
Number of GP episodes	1.10***	0.48***	-0.61		
	[0.98]	[0.72]			
Average number of GP appointments	2.06**	1.03**	-1.03	£45.00	-£46.45
	[2.03]	[1.76]			
Hospital admission episodes	0.45*	0.13*	-0.32	£598.00	-£192.90
	[0.81]	[0.43]			
Number of hospital outpatient appointments	0.55	0.06	-0.48		
	[2.03]	[0.25]			
Number of hospital nights	1.58**	0.13**	-1.45	£439.69	-£638.26
	[3.51]	[0.72]			
Days used antibiotics/ steroids	5.23	4.39	-0.84		
	[7.50]	[7.42]			

Note: ** -statistically significant difference at 5% level, *** - statistically significant difference at 1% level

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2. Curtis, L, 2013, Unit Costs of Health and Social Care 2015, Personal Social Services Research Unit, University of Kent, Canterbury.
3. Department of Health. Reference costs guidance for 2012-13. [Available online] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/214923/2012-13-reference-costs-guidance.pdf. Accessed 14th March 2016
4. Calculated as an average length of stay weighted by the number of Finished consultant episodes.

3.2. Outcome estimates

Table 16 provides a summary of the estimates which were used in the economic evaluation of the IBE. The research team focused on the Quality Adjusted Life Years (QALY) as the summary outcome measure. This provides a conservative estimate, but it is a well-established and trusted measure for cost-benefit analysis. Although the estimated impact of the project is not statistically significant at 5% level (p-value ~0.20), this is as expected given the size of the sample we explored in the analysis and the ability of the EQ-5D scale to pick up improvements in the outcomes related to lung conditions. This measure comes from a rigorous analysis exploiting the clustered structure of the data and relying on propensity score matching given the baseline characteristics of participants, making the analysis which follows plausible and trustworthy.

In addition, we use the estimated impact of the participation in an IBE group relative to a standard BE group on wellbeing measured in WEMWBS score change from the baseline. Both impact on QALY and WEMWBS shows that the IBE groups deliver positive results when compared to the standard BE groups in improving wellbeing of people living with lung conditions (and this effect is stronger for the new IBE groups for WEMWBS).

Table 16. Summary of Estimated Effects on Outcomes

	Incremental	**Incremental**
	Diff IBE-BE	**Diff new IBE-BE**
Change in QALY compared to baseline	0.049	0.034
	[0.038]	[0.053]
Change in WEMWBS compared to baseline	5.949*	8.387*
	[2.986]	[3.842]

Note: ** -statistically significant difference at 5% level, *** - statistically significant difference at 1% level

3.3. Cost analyses

Before turning to the three types of analyses detailed in appendix II, a simple cost-utility ratio (with the difference in costs in the numerator and the difference in QALYs gained in the denominator) has been estimated to compare this with the NICE recommended threshold of £20,000 per QALY. Table 17 shows the results, which indicate that the cost per QALY of the IBE groups is much smaller than the recommended threshold, which is an indication that the programme is cost effective.

Table 17. Estimating Incremental Cost-Utility Ratio

	Incremental Cost	**Diff IBE-BE**		**Diff new IBE-BE**	
		Incremental benefit	**ICUR**	**Incremental benefit**	**ICUR**
	(1)	(2)	(3)	(4)	(5)
Low estimate	£100.44	0.049	£2,049.79	0.034	£2,954.11
High estimate	£182.87	0.049	£3,732.02	0.034	£5,378.50

The difference in costs between the low estimate and high estimate is due to the differences in the NHS costs when excluding and including qualifications[5]. As can be seen, the estimates of Incremental Cost-Utility ratios in Columns (3) and (5) range from £2,049.79 to £5,378.50, which is below the recommended £20,000 NICE threshold level, which is an indication that the programme is cost-effective.

Table 18 summarises the estimation of the Incremental Cost-Benefit Ratios for both high and low cost estimates as well as for high and low threshold levels when comparing all IBE groups to standard BE groups, and when comparing only the new IBE groups to standard BE groups.

Table 18. Estimating Incremental Cost-Benefit Ratios

Cost bounds	Incremental Cost	Threshold per QALY	Diff IBE-BE		Diff new IBE-BE	
			Incremental benefit	ICBR	Incremental benefit	ICBR
	(1)	(2)	(3)	(4)	(5)	(6)
Low bound (LB)	£100.44	£20,000	0.049	9.76	0.034	6.77
	£100.44	£30,000	0.049	14.64	0.034	10.16
High bound (HB)	£182.87	£20,000	0.049	5.36	0.034	3.72
	£182.87	£30,000	0.049	8.04	0.034	5.58

When comparing, based on the average effect across all of the IBE groups, the estimated Incremental Cost-Benefit Ratios vary from 5.36 for the high cost estimate and low threshold value assigned to the gain in QALYs to 14.64 for the low cost estimate and high threshold value (Column (4) in Table 18).

This means a positive return: for each pound invested in the IBE groups there is a return of a minimum £5.36 and a maximum of £14.64, i.e. £4.36 to £13.64 in net gain through better health outcomes of people living with a lung condition. The estimates are a bit more modest when comparing only the new IBE groups to the standard BE groups, which may be explained by the fact that it takes time to reach the highest level of potential benefit when the group is starting from scratch, compared to an integration based on an existing group. Nevertheless, the Incremental Cost-Benefit Ratios for this case are at least 3.72 implying a net gain of £2.72 per pound invested. One should note, that all the values in Table 18 are based on a conservative estimate, implying that in reality we are likely underestimating the true returns.

The next calculation incorporates the wider effects by taking into account:

- The NHS savings (based on Column (5) in Table 15), PLUS
- Social benefits to the people living with lung condition and those affected by lung condition (including volunteers) (based on Column (3) in Table 19).

The calculation only focuses on the incremental costs and benefits to people living with a lung condition of all IBE groups relative to standard BE groups.

The value of volunteering is derived from the differences in the number of volunteers and the intensity of their involvement in IBE groups vs. standard BE groups following the analysis shown in the Housing Associations' Charitable Trust Social Value Bank[6]. As the data shows, on average the IBE groups are larger, have more carers participating and are attracting more volunteers than the standard BE groups (Table 12). Hence, the corresponding differences in the social value of the IBE groups.

HACT Social Value is based on the analysis of the British Household Survey data to show the correlation between levels of social action such as engagement in volunteering with measures of Life Satisfaction. The value of this increase is assessed in relation to the increase in household income that would be required to produce the same level of increase in Life Satisfaction. This is of course only one way of valuing volunteering but it is the one commonly

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5. Including of staff qualifications is not done in most cost analysis, as it is hard to collect the data on this. We do not have this information either, but we are aware of the fact that the NHS nurses' qualifications could have varied and therefore presenting a possible range of effectiveness accounting for variation in qualifications

6. HACT and Daniel Fujiwara. Community Investment values from the Social Value Bank. [Available online] www.hact.org.uk/ www.simetrica.co.uk). Source: www.socialvaluebank.org. License: Creative Commons Attribution-NonCommercial-NoDerivatives license (http://creativecommons.org/licenses/by-nc-nd/4.0/deed.en_GB). Accessed 3rd March 2016

used in similar Social Return on Investment Analyses, and therefore has been chosen for this study.

For volunteers we derive the value of £2,582 per annum[7]. Extra benefit for both people living with lung conditions and their carers is gained through social engagement (regular participation in their local BE group) and for that the amount of £1,824 per annum is allocated[8]. Column (1) shows the differences between an average IBE group and an average standard BE group in the average numbers of participants, family carers and volunteers. Column (2) cites the social value per person per annum as allocated in the HACT Social Value Bank. Column (3) shows the social value per person per 6 months. The resulting incremental social value for the project over 6 months period is presented in Column (4): with most value accruing through the regular group participation of people living with lung conditions (£378,115.20) plus £85,075.92 for carers and £112,317.00 for volunteers. The social value to the people living with lung conditions alone is much larger than the operational costs of the project of £575,508.12.

Table 19. Estimating Incremental Wider Social Effects

	Diff IBE-BE	**Social Value per person p.a.**	**Incremental social value per participant over 6 months period**	**Incremental social value for the project over 6 months period**
	(1)	(2)	(3)	(4)
Average number of participants per group per month	13.82	£1,824.00	£912.00	£378,115.20
Average number of Carers (20-25% of the participants)	3.11	£1,824.00	£912.00	£85,075.92
Average number of volunteers	2.90	£2,582.00	£1,291.00	£112,317.00
Total social value of the project				£575,508.12

Using the estimates from Column (4) in Table 19, we estimate the social return on investment (SROI), adding one by one NHS cost savings and various wider social benefits. Table 20 summarises this process starting with the most conservative scenario with high costs and low threshold level per QALY of 5.36 (as presented earlier). The estimates of the SROI suggest significant social return, up to £23.70 per pound invested, which is £22.70 of net gain.

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[7] This is based on code EMP1408 from the Social Value Bank for those older than 50 outside of London (since all of the IBE groups are outside London).

[8] This is the value for the code EMP1409 from the Social Value Bank

Table 20. Estimating Social Return on Investment (SROI)

Basis	SROI	Assumptions Considering Health and Social Benefits
A. Basic: high cost, low threshold per QALY	5.36	Health benefit cost per participant of £393.65, low threshold level of £20,000 per QALY, most conservative estimate of the effect on quality of life.
B. Basic + NHS cost savings	6.67	This is as above plus the most conservative estimate of NHS cost savings due to the reduction in GP visits (valued at £44 per visit) and hospital admissions valued at £615 per short-stay admission.
C. Basic + NHS cost savings+ social value of group participation of people living with lung condition	11.66	This is as above plus the estimate of the social benefit accrued to participants via regular participation in the local group valued at £1,824 p.a.
D. Basic + NHS cost savings+ social value of group participation of people living with lung condition + social value of group participation of carers	16.64	This is as above plus the estimate of the social benefit accrued to carers via regular participation in the local group valued at £1,824 p.a.
E. Basic + NHS cost savings+ social value of group participation of people living with lung condition + social value of group participation of carers + social value of volunteering	23.70	This is as above plus the estimate of the social benefit of volunteering valued at £2,582 p.a.

Table 21 presents an alternative way to estimate the SROI, completely omitting the effect on health of people living with a lung condition as measured by the QALY gain, taking into account the fact that the estimates of this gain were not statistically significant. As can be seen, even without taking into account gains to people living with a lung condition in terms of health outcomes, NHS cost savings and wider social outcomes ensure cost effectiveness of the integration.

Table 21. Estimating Social Return on Investment without health gains

Basis	SROI	Assumptions Considering Health and Social Benefits
NHS cost savings	1.31	Most conservative estimate of NHS cost savings due to the reduction in GP visits (valued at £44 per visit) and hospital admissions valued at £615 per short-stay admission.
NHS cost savings+ social value of group participation of people living with lung condition	6.30	This is as above plus the estimate of the social benefit accrued to participants via regular participation in the local group valued at £1,824 p.a.
NHS cost savings+ social value of group participation of people living with lung condition + social value of group participation of family carers	11.28	This is as above plus the estimate of the social benefit accrued to carers via regular participation in the local group valued at £1,824 p.a.
NHS cost savings+ social value of group participation of people living with lung condition + social value of group participation of family carers + social value of volunteering	18.34	This is as above plus the estimate of the social benefit of volunteering valued at £2,582 p.a.

Finally, the cost-effectiveness analysis is conducted to evaluate a slightly different dimension of the IBE effect – the mental wellbeing of participants. We did not incorporate this measure into the main cost-benefit analysis for two reasons.

First of all, there is no established way to attach a monetary value to the WEMWBS score. Secondly, even if we were able to do this, it is not clear to what extent an overlap exists with the quality of life measure we derived from the EQ-5D score and the WEMWBS score. However, the research team wanted to explore this measure as it allows them to combine wellbeing gain to people living with a lung condition to that of carers supporting them.

Unfortunately, the estimation of the incremental impact of the IBE groups relative to standard BE groups turned out to be not feasible due to small sample of carers supporting someone with a lung condition responding to the survey. In spite of this, we performed the cost-effectiveness analysis for participants' mental wellbeing only as the impact on WEMWBS is the strongest among all outcomes suitable for economic analysis, both statistically and economically (as shown in Table 16).

Table 22 presents the cost-effectiveness estimation with resulting incremental cost-effectiveness ratios (ICER) indicating that a 1-point increase in WEMWBS comes at the cost of £16.88 to £30.74 (£11.98 to £21.80 when comparing only new IBE groups to standard BE groups), which seems to be quite an inexpensive way of improving mental wellbeing. To compare, Bryson et al. (2012)[9] found that the WEMWBS score increases by 5.1 points for men and by 5.6 points for women when moving from the lowest household income quintile to the highest. Applying our estimates of a cost per 1-point increase to the mentioned 5.1 points and annual basis results into a cost of £172 to £314 – which is below the difference in annual household income between the lowest and the highest quintiles (£5,500 vs £80,800)[10], pointing towards high cost-effectiveness of the IBE groups relative to standard BE groups. It should be noted that it is likely that this is an underestimation of the effect on mental wellbeing because this analysis does not include the impact on carers supporting a person living with a lung condition for which the qualitative study findings (detailed in Section 5 of this report) also shows positive effect.

Table 22. Estimating Incremental Cost-Effectiveness Ratio for WEMWBS

	Incremental cost	IBE-BE		New IBE-BE	
		Incremental effect	ICER	Incremental effect	ICER
	(1)	(2)	(3)	(4)	(5)
LB cost: WEMWBS	£100.44	5.949	£16.88	8.387	£11.98
HB cost: WEMWBS	£182.87	5.949	£30.74	8.387	£21.80

Although the presented estimates offer a menu of choices depending on the threshold per QALY and the willingness of the reader to take into account wider social benefits, it is advisable to rely on the most conservative estimates of the net gains which are based on the NICE recommended value per QALY of £20,000 and pay attention to the included wider social benefits. Therefore, for the comparison purposes, it is recommended to rely on the most conservative SROI of 5.36 which only includes benefits via gains in quality of life.

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[9] Bryson A., Green F, Bridges S, and Craig R. (2012). Wellbeing, Health, and Work. NIESR Discussion Paper No. 387. Accessed online at http://www.niesr.ac.uk/sites/default/files/publications/dp387.pdf on March 3, 2016.

[10] http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/dcp171778_407906.pdf

SECTION 4: VOLUNTEERING SURVEY FINDINGS

Key points:

- On average there are more volunteers involved with IBE groups (4-6 per group) than standard BE groups (2.5 per group).
- 75% had not received any training for their role but the same percentage were very satisfied or satisfied with the level of help and guidance they received.
- Social links and cultural identity were very important to volunteers in their role.
- 63% would recommend volunteering with BLF to other people.
- The main challenges for volunteers were time to do the role and support a family member living with a lung condition, plus ensure their own health was not impacted by the role commitment.
- Volunteers were open to any type of further support and one suggested that the required paperwork and accessing bank accounts could be improved.

At the start of the study, there were no plans to look at the impact of volunteering. However after the increased acknowledgment of the publication by the Cabinet Office's titled: *Wellbeing and civil society: Estimating the value of volunteering using subjective wellbeing data (2013)*[11], the research team decided to consider the impact of volunteering within its health economic calculations. The findings from the survey (which is explained in Appendix II) are detailed in this section.

The value of volunteering, not solely on the individual volunteering, but also in relation to the sustainability of the IBE groups, was recognised also by the BLF. They then strived to increase the number of volunteers involved with the IBE groups. On average 2.5 volunteers are actively volunteering for each standard BE group; 6 for the converted IBE groups; and 4 for the new IBE groups.

4.1. Demographics

In total, 8 volunteers responded to the survey. They held a variety of volunteer roles within their IBE group. Their roles ranged from "Chair" and "Joint Chair" to "Treasurer" and "Medical Advisor". Most of the volunteers were female (N=6; 75%). Ages of the volunteers ranged from 45 to 81 years of age, with the average age being 62 years and a median age of 63.5 years. The majority considered themselves to be of "White" ethnicity (N=7) and one volunteer said they were of "Asian/Asian British" ethnicity.

Most of the respondents (50%) had been a volunteer for their local BE group for 1 to 2 years, while 25% had been a volunteer for a total of 3-5 years and the final 25% 6-10 years (Table 23).

Table 23. Number of years volunteering for BLF

Total number of years volunteering for BLF	Frequency	Percentage
1-2 years	4	50
3-5 years	2	25
6-10 years	2	25

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[11] Fujiwara D, Oroyemi P, McKinnon E (2013). Wellbeing and civil society: Estimating the value of volunteering using subjective wellbeing data. Department for Work and Pensions and the Cabinet office. Working paper No 112. Accessed 22/02/16 online: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/221227/WP112.pdf

4.2. Survey findings

Most of the respondents (75%) reported that they did not receive any training from the BLF in relation to their volunteer work. Of the two who did receive training, both reported that they were satisfied with the training they received. Seventy-five percent of the respondents said they were very satisfied or satisfied with the level of help or guidance they received as volunteers from the BLF; 25% were neither satisfied nor dissatisfied. When asked about additional support they would like to receive, half of the volunteers wrote in responses. They said they were open to any type of support available, but only one put forth a specific recommendation:

> *"A chance to feedback on quality of forms provided by BLF for BE's use. A more flexible approach to access bank account. It is very limiting and old fashioned."*

Volunteers were asked to discuss how volunteering changed them in certain ways. Respondents overall seemed to feel that money was not relevant in considering their volunteer position – in terms of free training, their earning power, and being reimbursed for volunteer activities most said volunteering was irrelevant (Figure 1). However, social links and cultural identity were not only relevant, but very important in their position as volunteers (Figures 2 and 3).

Figure 1. How Volunteering affected volunteers' personal lives

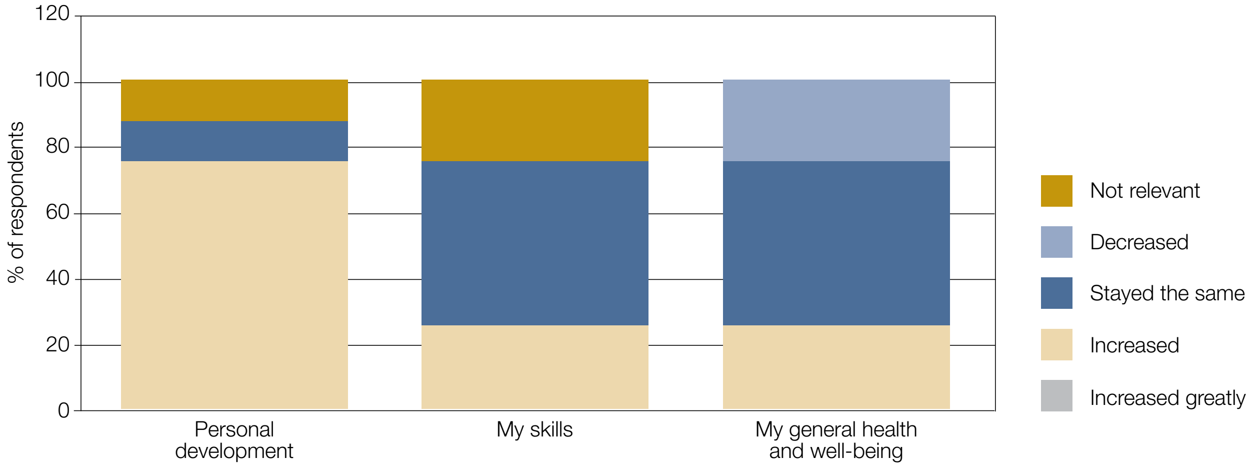


Figure 2. How Volunteering affected volunteers' social lives

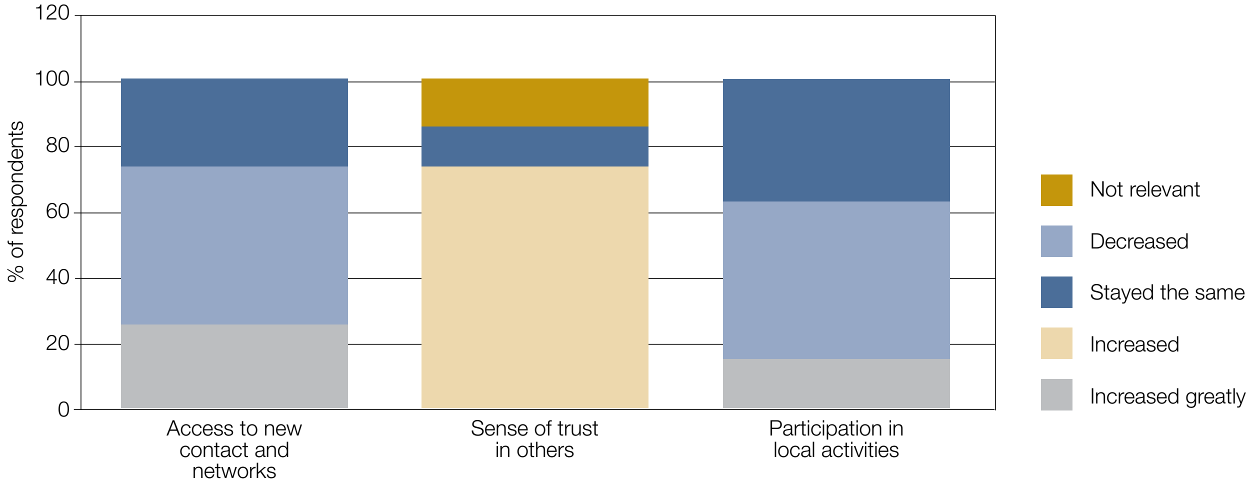
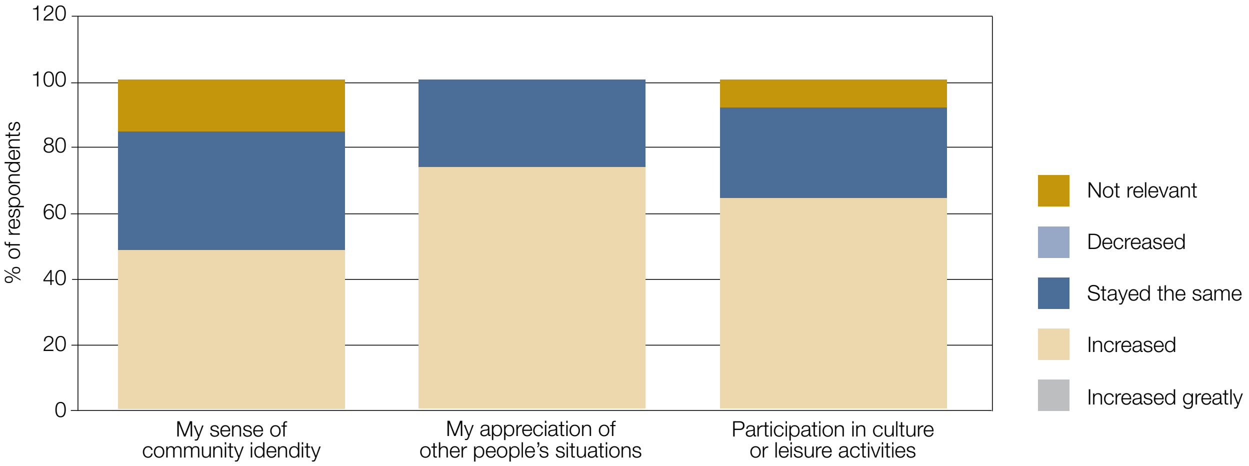


Figure 3. How Volunteering affected volunteers' community lives



Sixty-three percent of volunteers (N=5) said they would recommend volunteering with BLF to other people, while 38% (N=3) responded that they did not know if they would recommend volunteering with BLF to other people.

In terms of the benefits of volunteering, respondents cited feeling good from helping others, not feeling 'on my own', and making new friends.

One volunteer said volunteering helped them to have a sense of routine in their life, another one commented that it make them feel "useful" again.

> *"As someone who has long term multiple health issues it keeps me focused, gives structure and a sense of worth. Also imparting my knowledge and expertise to others for the wider benefit locally and nationally with BLF."*
> (Volunteer)

The main challenges to being a volunteer were said to be having enough time between working and caring for others (e.g. family members in poor health) and making sure being a volunteer does not negatively impact their health. One volunteer said it can be difficult to stop volunteering even if you need to stop to stay well due to feelings of obligation.

SECTION 5: QUALITATIVE INTERVIEW FINDINGS

Key points:

Findings indicate benefits of attending an IBE including:

- Increased knowledge and awareness of their lung condition;
- Increased confidence to self-manage lung condition;
- Social networks/friendships; and
- Building skills to improve self-management.

Healthcare professionals found IBE improved:

- Time efficiencies;
- Relationships between professional and people living with or affected by a lung condition; and
- Greater awareness of lung conditions from the people living with or affected by lung conditions.

Throughout the two years of this project, 46 participants were interviewed in-depth, consisting of 11 healthcare professionals, and 26 people living with or affected by a lung condition attending an IBE group. The remaining participants were steering group members for the project.

Thirty of the 46 participants were interviewed in Year One for the process evaluation, and a further 16 were interviewed during Year Two (2 healthcare professionals, 12 people living with a lung condition, and 2 carers supporting someone living with a lung condition). The findings detailed below are from the Year Two interviews only. The findings from the Year One interviews are detailed in the full Process Evaluation report (submitted by the University of Kent team to BLF in April 2015).

The following sections detail the reported benefits of being involved in the IBE groups, for both people living with or affected by a lung condition, and for local healthcare professionals.

5.1. Benefits for people living with or affected by a lung condition

5.1.1. Increased knowledge and awareness

All those attending an IBE group, saw the IBE group meetings as a place for people to learn more about their lung condition. This learning was acquired from other people attending the meetings and from presentations made by healthcare professionals (as well as informal chats with the professionals during the tea breaks).

"The rest of us in the [group] here, they can only share their experiences with you whereas a health professional has got a great deal more scope of experience haven't they? So that is a lot better, more beneficial for each person in the groups, so your peers can learn as well as trying to teach you what they went through."

(Person living with a lung condition)

The informal chats and question-and-answer sessions with healthcare professionals were often valued higher than the formal presentations as then they could directly ask questions that were personal to their own situation.

Carers attending also found the groups informative and gained knowledge on how they can deal with certain situations.

"I learn a lot also, as at the end of the day, I'm the one who needs to remind him [husband] and I feel when we go to the doctors he just accepts what the doctor says, but I need to fight his [husband's] corner and it helps me coming here as I learn more, so…I can fight the corner better."

(Person supporting someone with a lung condition)

5.1.2. Increased confidence to self-manage lung condition

Many people living with a lung condition talked about the self-management tips they had been taught, again by both the healthcare professionals and from fellow group members. This increased their confidence greatly and they felt more able to manage their condition as a result (and less reliant on input from their GP and hospital Consultant). With the healthcare professionals attending the groups regularly, people living with a lung condition also felt more cared for by the NHS practitioners.

"Well when you're at the doctors, they are very busy and they don't have the amount of time to explain, it's like ten minutes in and then they have to tap on the computer. But here (IBE group), the nurses; they really care about you."
(Person living with a lung condition)

5.1.3. Social networks/friendships

All of the attendees interviewed valued the social side to the IBE groups (and viewed them very much as a social as well as educational forum). They particularly enjoyed the fact that they could socialise with others who understood how they were feeling and that they did not become embarrassed if they could only talk slowly, or constantly needed to catch their breath. For some, it broke the isolation they felt after being told their diagnosis, especially if they did not have a partner or close family relative/friend to share the news with. It also gave them a reason to leave their house and break the isolation that way.

"I felt better in myself once I did start to come because when you are first diagnosed you think you are the only one. I suppose it's different if you've got family around you and a husband, and I hadn't and there is nobody really to talk to about it who understands, so coming to this group you've got somebody to talk to about it which is you know, a big weight off your mind."
(Person living with a lung condition)

Carers supporting a person living with a lung condition also enjoyed the social element of the groups and a couple of the participants interviewed kept coming to the groups and remained heavily involved with them even after their partner (who had been the one living with a lung condition) had passed away.

"I started to come with my husband and then when he passed…I still wanted to come to the group as people had become my friends also."
(Person affected by a lung condition)

5.1.4. Building skills to improve self-management

Some of the people living with a lung condition also talked about the new skills they had learnt whilst attending their local IBE group, which helped them manage their respiratory conditions in a more effective way. These included breathing techniques, understanding how to take their medication in a more effective manner, and exercise techniques.

"Basically as far as I am concerned I need to help myself. I've got the condition we're talking about and I know that it's never going to get better. It's going to be there all the time and only deteriorate over time but my whole objective is to try and retard that deterioration as long as I can, so I can remain active… Through the singing group I have learnt to control my breathing better, learned breathing techniques which really help."
(Person living with a lung condition)

For others, although the IBE groups were more seen as a social event, they found the groups a good source of information on other services that they could access.

5.2. Benefits for healthcare professionals

5.2.1. Time efficiencies

The healthcare professionals felt that, by attending the groups and being able to answer many people's questions at once, it was an efficient use of their time. The meetings also served as an opportunity to exchange health information in a comfortable, low-pressure setting. Healthcare professionals found it useful because they felt like they could provide more individualised support and help for people living with a lung condition by attending the meetings.

"I do think it is a very good way of disseminating information. It's a good way of reinforcing the information that I may have given patients in the clinic or their homes. When they come here and they hear it from me again, they hear it from their peers, it really reinforces it, they remember it, and they believe it."
(Healthcare professional)

The healthcare professionals also recognised that, for many of the attendees, unless they came to a group they would not usually have the opportunity to speak to, or meet more senior consultants who sometimes came to the IBE groups to deliver a lecture.

5.2.2. Improved relationships and greater awareness of lung conditions

The healthcare professionals said they benefitted from participating in the IBE groups in that the groups enabled them to foster a deeper, and therefore a more effective, relationship with people living with a lung condition. The groups were eye-openers for the professionals as they often helped them realise what the day-to-day life was like for people living with or affected by a lung condition, and provide more person-centred care.

"It broadens my mind also. You understand the day-to-day struggles [of people living with a lung condition] in more detail. I think it makes me a better doctor."
(Healthcare professional)

"I think the health care professional is there to facilitate and guide because it helps clarify any misunderstandings because we all come with our own ideas about a disease coloured by our own experience, and that may not be generalizable to everybody else with the same disease. So I think it is beneficial but not a mandatory requirement for a health professional to be there because the groups will learn from each other, but a health care professional may be able to guide them and answer some of the questions that would linger."
(Healthcare professional)

SECTION 6: CUSTOMER JOURNEY MAPPING

'Journey mapping' is a tool adapted from commercial marketing and is frequently used by the NHS and other UK Government departments to understand a user's experience of a service or product. For example, a journey map might be developed to describe all the experiences a user has with a service or a number of services and the emotional responses they provoke – from their first impression of the building, to speaking to staff or receiving information. Customer journey mapping is a way to see a service from the user's perspective in order to make recommendations for improvements that are customer, or person-centred.

At the end of Year One, four customer journey maps were presented in the Process Evaluation report. The maps visualised the experiences of new group members and detailed their journey through the following steps:

1. First exposure: How people living with or affected by a lung condition found out about their local IBE group.
2. Decision to attend: What factors influenced people living with or affected by a lung condition decision to attend.
3. Transportation: How they travelled to the IBE group venue and any difficulties experienced (for example, finding the venue, parking, etc.).
4. First impressions: Of the venue and welcome from existing members.
5. Experience at the meeting: Feedback on the structure of the meeting.
6. Feelings afterwards: If they would attend the group again and perceived and actual benefits gained from the group.

- The findings from the customer journey mapping work conducted in Year One were mixed. They showed that often people living with or affected by a lung condition found out about the groups through word-of-month or adverts in local papers or from posters/flyer distributed locally, as opposed to recommendations from their healthcare professionals.
- Recommendations to attend made by a healthcare professional encouraged people to attend more than an advert.
- Attendees were not always explained the nature of the group beforehand and were unclear what to expect.
- The groups could sometimes feel rather closed to new members (somewhat 'cliquey'), however this was easily overcome if new members were welcomed at the door by a regular attendee, introduced to others, and made to feel part of the group.
- Even though they appreciated support from healthcare professionals attending the group and valued the opportunity to talk to them on a more informal level, it was often the social networking which encouraged them to become regular group members.

Six customer journey maps were also completed in Year Two of the study, 4 of which are presented in Figures 4-7. The remaining 2 journey maps were very similar to those presented in Figures 4-7, and therefore have not been included in this report. The exemplar maps show that many of the issues that had been identified in Year One had been overcome and the findings were overwhelmingly positive.

Due to the greater involvement of healthcare professionals in the groups, the IBE groups appeared (from the attendee's perspective) to be more integrated with the NHS services and more people living with a lung condition discussed hearing about the groups from a healthcare professional.

> *"I received a letter off my GP. He told me about the group and my wife and I decided to go."*
> (Person living with a lung condition)

Encouragement and "in-person" recommendations to attend often reduced initial anxiety as there was more explanation of what attendees could expect from the group. Although attendees did respond to advertisements, Figure 6 illustrates initial anxiety levels because preparatory information was rather limited in the advertisement. The first impressions provided by a group to new attendees was vital in allaying apprehension. Nevertheless, for some there could be feelings of being overwhelmed but this was more often because they generally felt uncomfortable in groups. For these people it was important to be accompanied by a partner or friend for support.

Many of the groups had also worked to increase numbers of new members. This made the groups feel more open, and less of a "clique".

“During the break, some ladies came and asked me if I would like a cup of tea, how I took it…then they bought it to me, with a posh biscuit. It was like being in a restaurant! I don’t have anyone at home to serve me anymore”
(Person living with a lung condition)

The variety of speakers from NHS services was also noted and was helpful for those attending the groups. However, the social aspect was still the main draw, in particular the friendship networks people gained from being a member of a group (figures 4 & 7).

“My wife, she used to have a great social life. But now…I still get out and go places but she doesn’t really. And I then end up feeling guilty leaving her at home, so we both end up sitting at home. It’s good for her to get out….and for me too.”
(Partner)

For sustained attendance, the meeting experience was very important. Figures 4, 6, & 7 illustrate how the social aspects underpin a positive experience. Nevertheless, for some attendees it was the learning acquired from healthcare professionals and peers that was identified as the most valuable feature of attendance (Figure 5).

“I do listen to them [the healthcare professionals attending the group]…. I often wondered about the inhalers I’ve been taking, whether they are the right ones so I’ve been able to question them about that, and then to know that I am using the right ones so they are suited to me … it gives you a peace of mind.”
(Person living with a lung condition)

Figure 4: Customer journey map #1

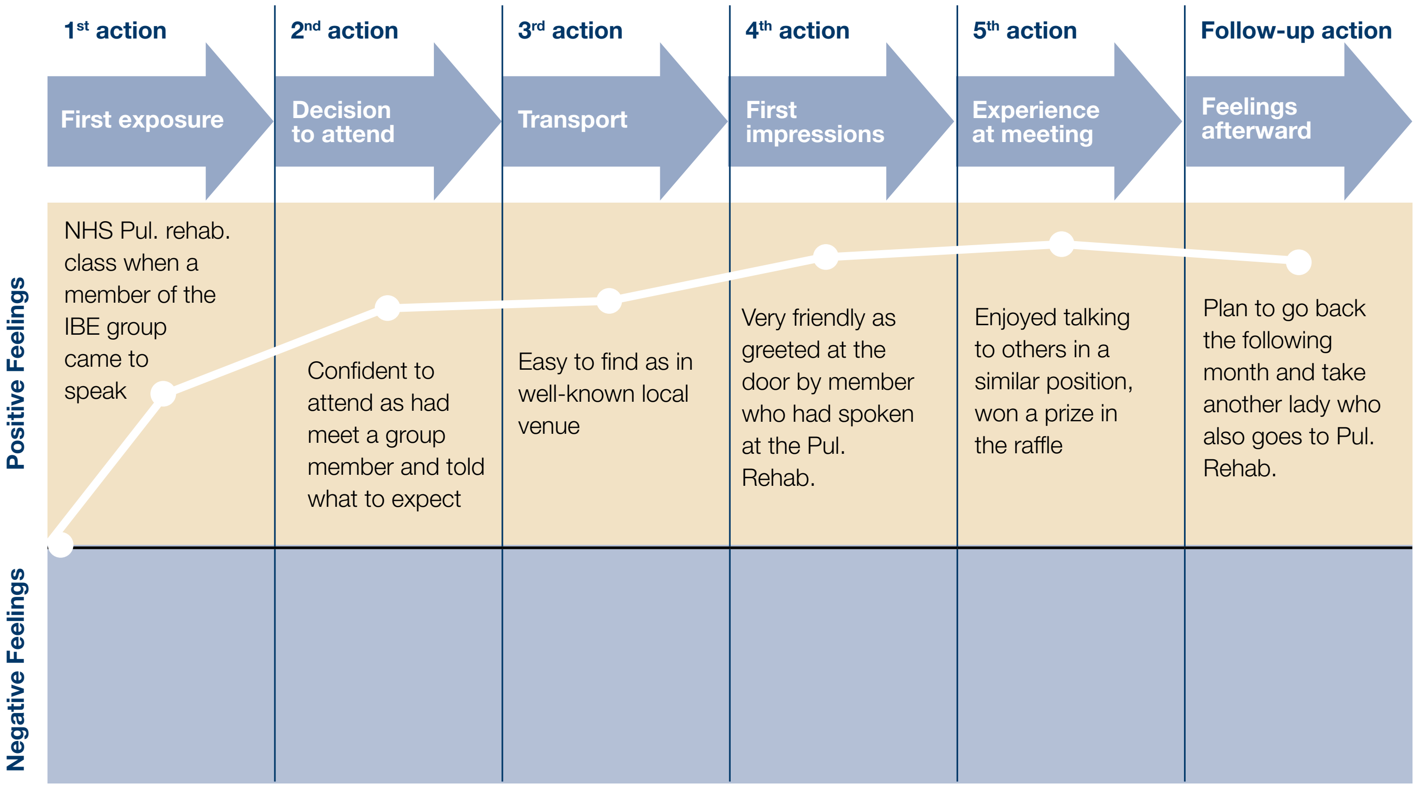


Figure 5: Customer journey map #2

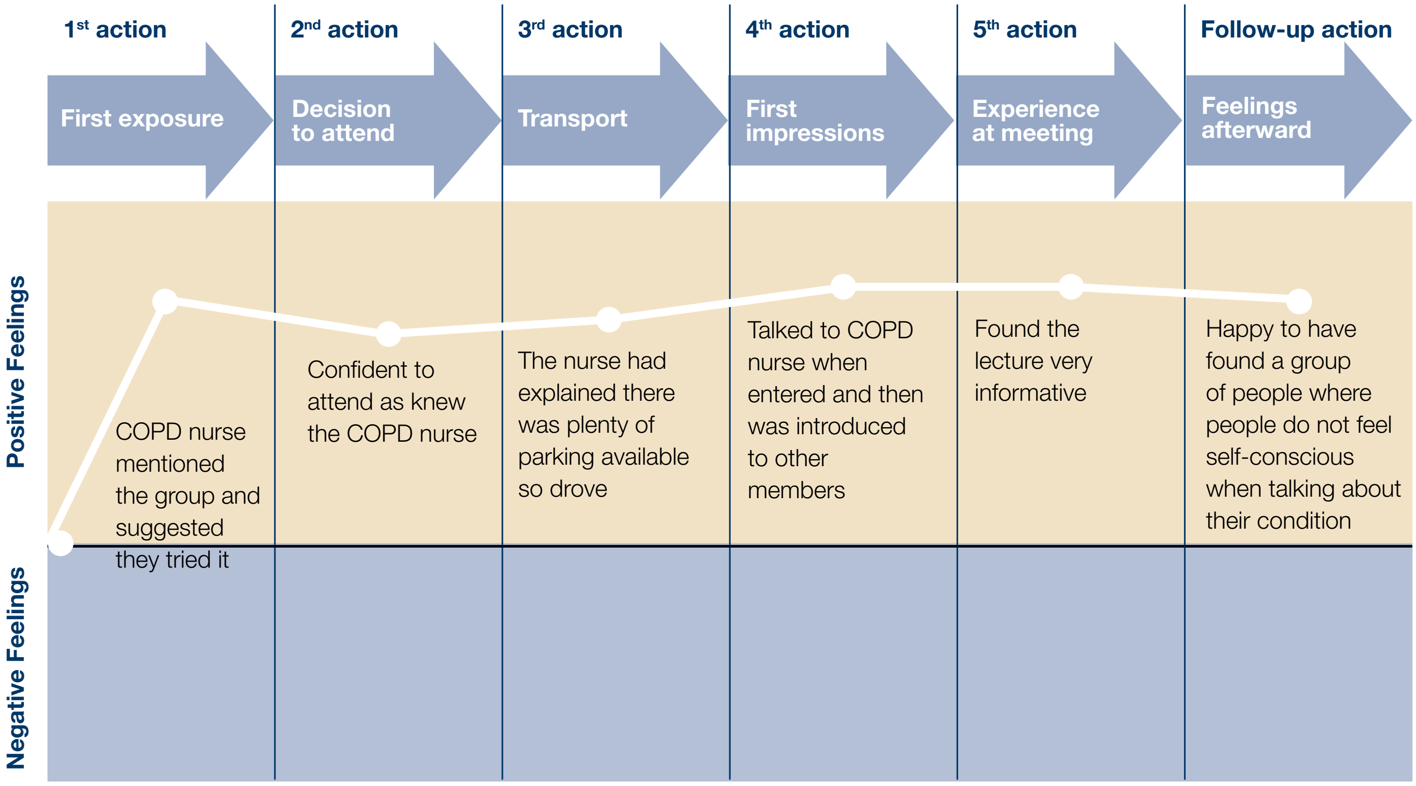
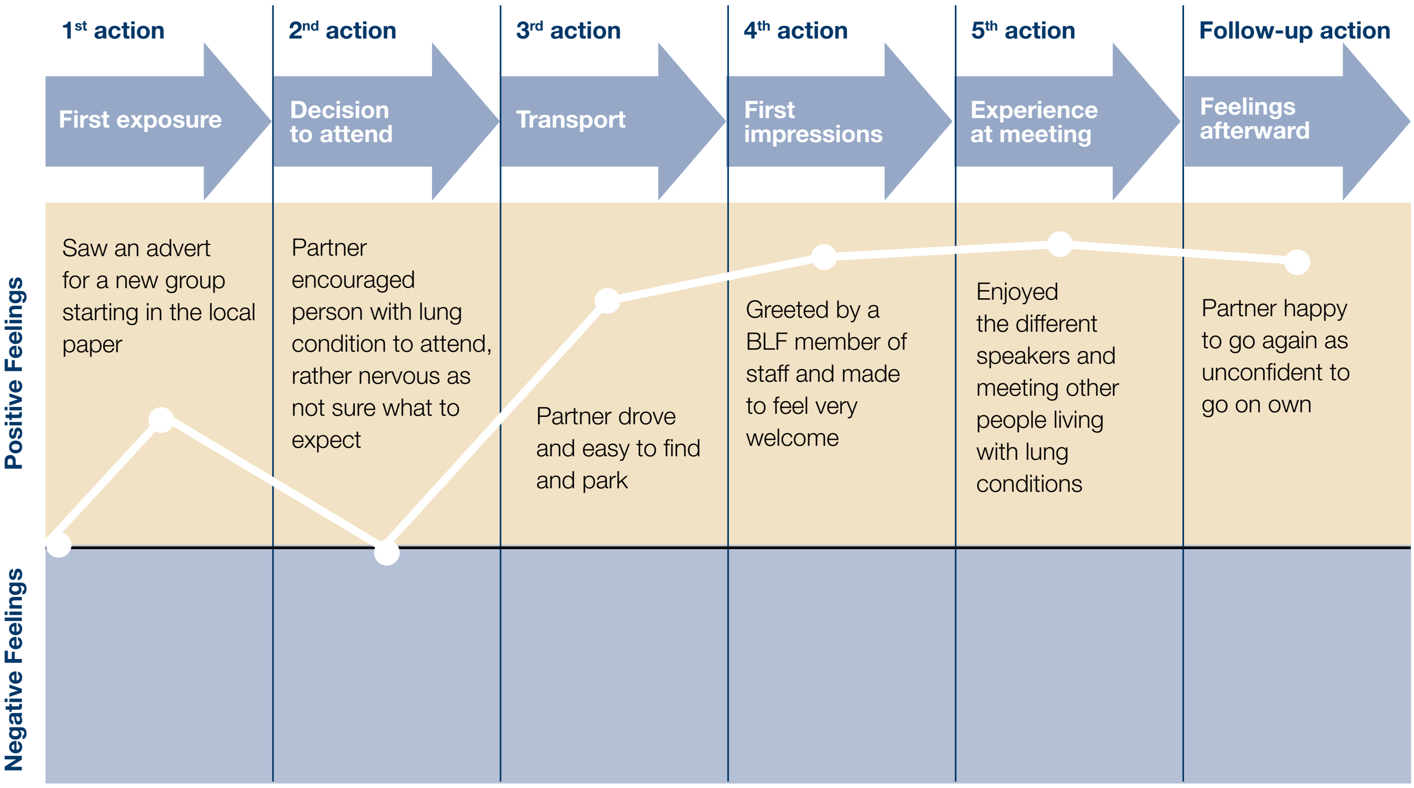


Figure 6: Customer journey map #3



Saw an advert for a new group starting in the local paper

Partner encouraged person with lung condition to attend, rather nervous as not sure what to expect

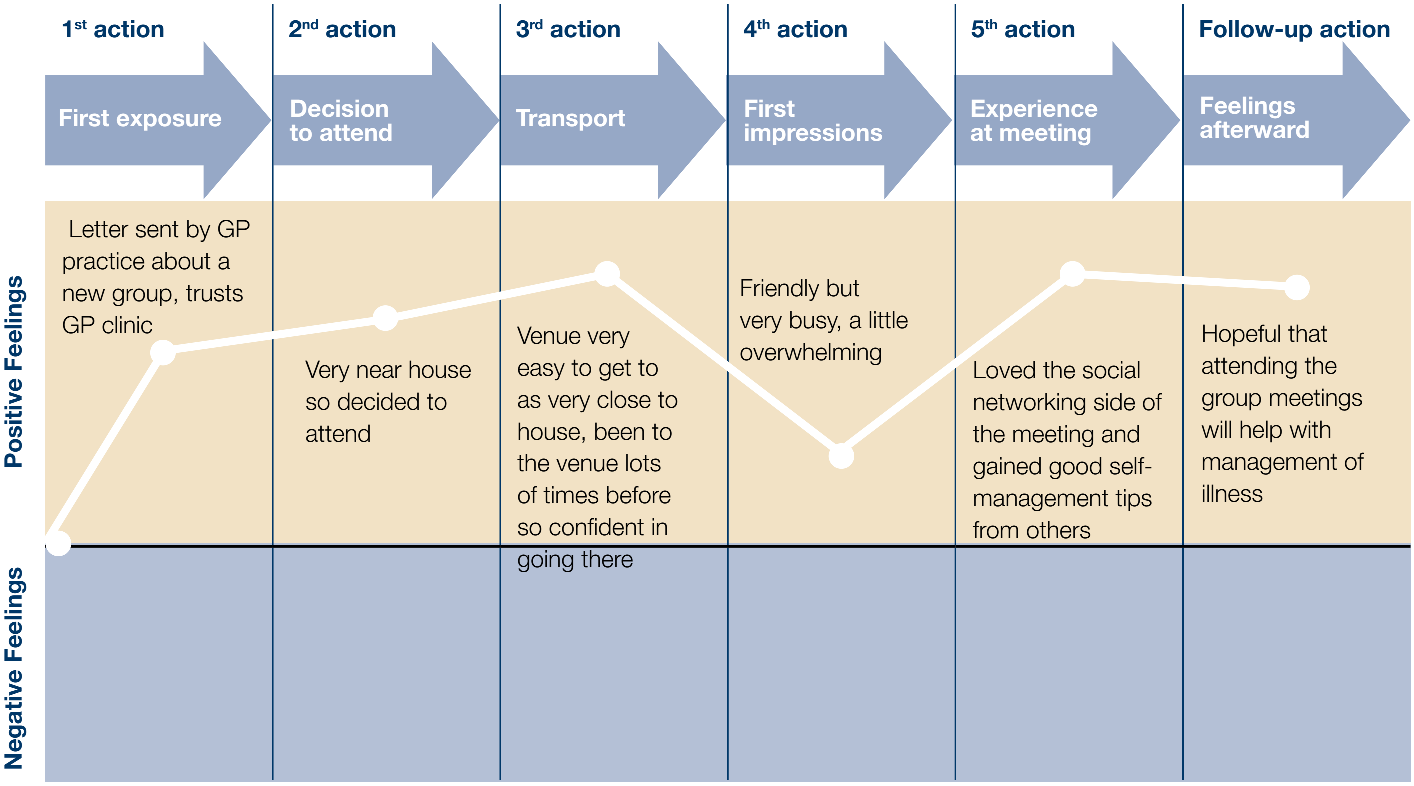
Partner drove and easy to find and park

Greeted by a BLF member of staff and made to feel very welcome

Enjoyed the different speakers and meeting other people living with lung conditions

Partner happy to go again as unconfident to go on own

Figure 7: Customer journey map #4



Letter sent by GP practice about a new group, trusts GP clinic

Very near house so decided to attend

Venue very easy to get to as very close to house, been to the venue lots of times before so confident in going there

Friendly but very busy, a little overwhelming

Loved the social networking side of the meeting and gained good self-management tips from others

Hopeful that attending the group meetings will help with management of illness

SECTION 8: CONCLUSIONS AND RECOMMENDATIONS

This report details the outcome, impact and economic findings in relation to the new IBE group model which the BLF are now implementing. A summary of the key findings is presented in this section; the headline is followed by relevant supporting evidence.

8.1. Summary of the findings

A number of key findings should be highlighted.

- IBE groups are more cost effective than standard BE groups in improving wellbeing of participants;
  - For every pound invested in the IBE groups there is a return of a minimum of £5.36, i.e. £4.36 in net gain through better health outcomes of participants.
  - For every pound invested in the IBE groups, there is a net gain of £22.70 made up of the value of better health outcomes, the NHS cost savings and a range of wider social benefits.

- People living with a lung condition in converted and new IBE groups felt more confident managing their lung condition and felt more in control of their lung condition compared to standard BE groups. These differences were statistically significant. In converted and new IBE groups 99.2% and 93.6% of people agreed or strongly agreed with the statement about feeling more confident, compared to only 87.5% in standard BE groups. 97.5% and 91.5% of people in converted and new IBE groups reported feeling more in control of their lung condition compared to 82.2% in the standard BE groups.

- There is a reduction in unplanned GP visits and hospital admissions in IBE groups compared to the standard BE groups. 38.7% of people in IBE groups had unplanned GP visits and 12.9% had unplanned hospital admissions, compared to 66.7% unplanned GP visits and 30.3% unplanned hospital admissions in standard BE groups.

- People living with a lung condition in converted and new IBE groups felt significantly less likely to be admitted to hospital because of their lung condition and did not feel the need to visit their doctor or nurse as often, compared to standard BE groups. 87.1% of people in converted IBE groups and 87.2% in new IBE groups either agreed or strongly agreed that they felt less likely to be admitted to hospital, compared to 67.1% in standard BE groups. Similar figures were observed for GP and nurse visits.

- There was some evidence of a decrease in carer's burden at 6 months when compared to baseline for new IBE groups that was not seen in the other groups. Wellbeing was also higher for carers in IBE groups (existing and new) compared to the other groups. The number of carer responses was small however making it difficult to draw firm conclusions.

- Carers in existing IBE groups felt more confident to support their partner or friend, felt they had a better understanding of lung conditions, and knew more about services available locally for people supporting others with lung conditions.

- People living with a lung condition who attended any type of BE group had significantly greater quality of life at 6 months compared to people who did not attend a BE group. The difference in quality of life between Standard BE groups, converted IBE groups and new IBE groups and those that did not attend a group are 0.077, 0.143 and 0.138 respectively (95% confidence intervals 0.0055 to 0.15, 0.079 to 0.21 and 0.051 to 0.22). The change in quality of life for converted and new IBE groups is of similar magnitude.

- People attending standard BE groups and converted IBE groups had significantly greater levels of self-efficacy (CSES) than people who did not attend a BE group. The difference in self-efficacy between standard BE groups and those who did not attend a group was -13.9 (95% confidence interval -23.5 to -4.3); the difference in self-efficacy between converted IBE groups and those who did not attend a group was greater at -18.6 (95% confidence interval -27.0 to -10.2). There was not a statistically significant difference between new IBE groups and people who did not attend a BE group, but the majority of people in new groups had been members for less than one year, and it seems reasonable that their self-efficacy may not have improved as much. People who attended any type of BE group had significantly greater levels of self-efficacy with regard to Negative affect and Intense emotional arousal when compared to people who did not attend a BE group. People in converted IBE groups had significantly greater wellbeing with regard to behavioural risk factors compared to those who did not attend a BE group.

- There were statistically significant differences between the type of BE group in some aspects of medical adherence. It was more common for people who were members of a BE group to remember their medication when travelling and take their medication regularly, even when their symptoms feel under control, when compared to people who did not attend a BE group.

- There were statistically significant differences in wellbeing between type of BE group. People who attended converted and new IBE groups reported greater wellbeing at 6 months compared to people who did not attend a BE group. The difference in wellbeing scores between converted IBE groups and those who did not attend a BE group is 5.10 (95% confidence interval 1.4 to 8.8); the difference in wellbeing between new IBE groups and those who did not attend a BE group is slightly greater, 6.73 (95% confidence interval 1.8 to 11.6).

8.2. Conclusions

The IBE is a cost effective programme which has positive outcomes in terms of self-efficacy, health outcomes and wellbeing for attendees, providing cost savings and wider social benefits to local communities. The evaluation showed that benefits over a range of intended IBE outcomes became more marked with time, reflecting a process of acquiring new skills and knowledge which becomes reinforced the longer a person attends the group. The evaluation also suggested a correlation between local healthcare pathway integration and levels of healthcare professional referral. For some attendees there was a varied and mixed understanding of what to expect from an IBE. Volunteers involved in the IBE groups had positive experiences of the role and the evaluation suggested some would welcome more opportunity to feedback on the processes involved in running the IBE programme.

8.3. Recommendations

Based on the findings, five main recommendations are made:

- Given the model provides NHS cost savings and wider social benefits, it is recommended as an appropriate model for local commissioning.

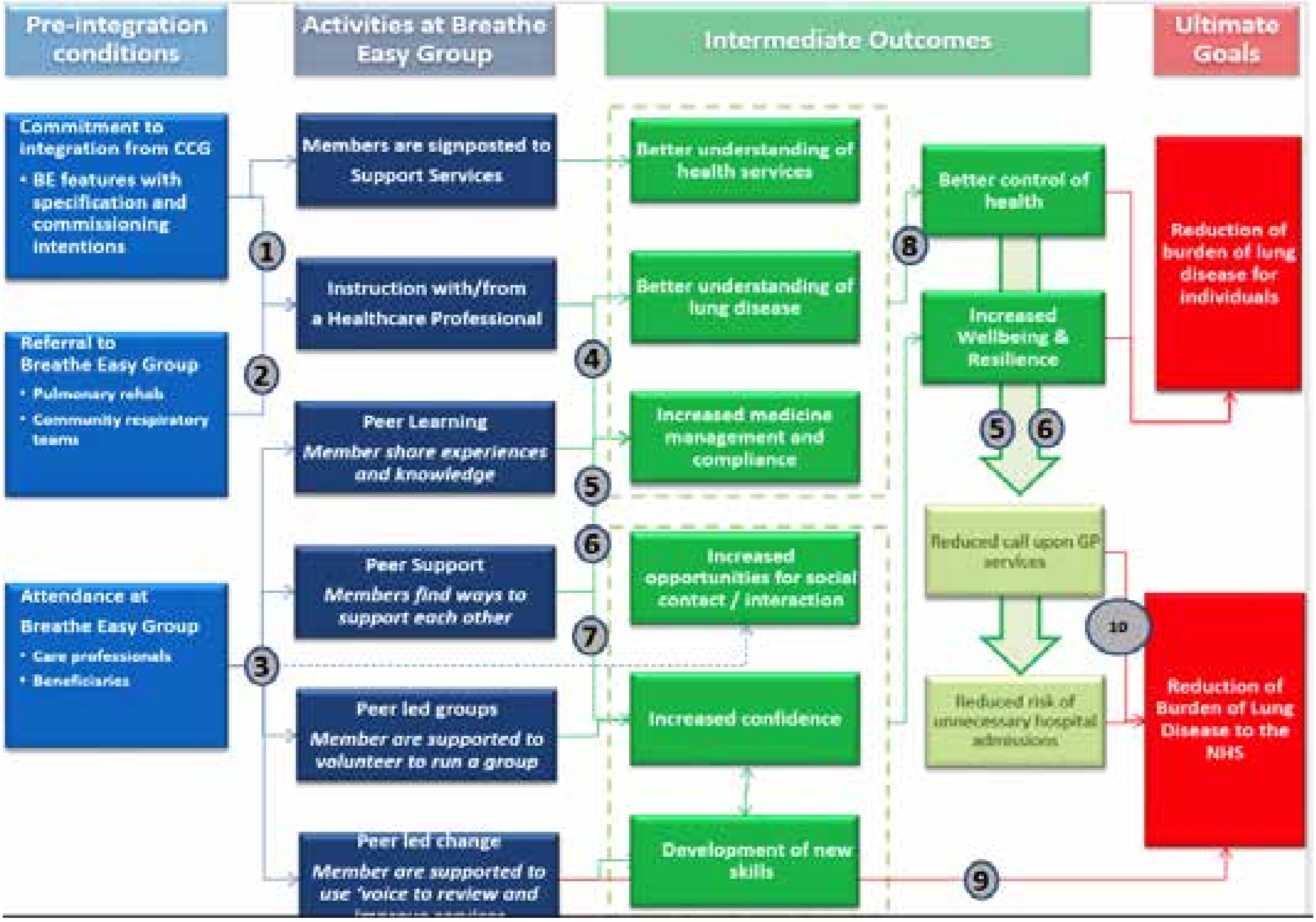
- To maximise benefits and intended outcomes, resources should be applied to sustaining membership and attendance.

- To ensure local healthcare pathway integration, attention should continue to be paid to referral mechanisms with robust and clear referral pathways.

- For all referral routes including self-referral it is important that adequate preparation is provided on what to expect from the programme.

- Attention should continue to be paid to volunteer opportunities to feedback on administrative processes associated with their role.

APPENDIX I: INTEGRATED BREATHE EASY THEORY OF CHANGE



APPENDIX II: METHODOLOGY

Aims of the evaluation

The overall aim of this evaluation study was to use a mix of research methods to understand:

- The impact for people living with or affected by a lung condition of attending the BE groups on their wellbeing (both physical and mental wellbeing); and
- What the benefits are of improving the integration of the BE groups into the existing NHS services and pathways, in terms of benefits for people living with or affected by a lung condition, clinicians and commissioners.

Key research questions

With the overall aims in mind, the key research questions that this project aims to answer include:

- What is the impact of attending BE groups (both integrated and standard groups) on the physical and mental wellbeing of people living with or affected by a lung condition?
- What is the impact of improving integration of BE groups for people living with or affected by a lung condition?
- What is the incremental cost-effectiveness ratio of the IBE groups?

Outcome/impact evaluation methods

Study design

The study was set up as a non-randomised parallel group cluster study, designed to assess the impact of IBE groups on the mental and physical wellbeing of people living with or affected by a lung condition.

The primary analysis for this evaluation study is intention-to-treat. This was chosen as the primary analysis method as the research team focused on comparing outcomes in integrated and standard BE groups, in the knowledge that these groups differ in many aspects of integration compliance.--Intention-to-treat analysis allows an assessment of both efficacy and compliance, and provides a pragmatic assessment of effectiveness.

The study comprises of four treatment arms:

1. People who did not attend any BE group
2. Standard Breathe Easy groups (not integrated within local health service pathways)
3. Converted Integrated Breathe Easy groups (where existing BE groups were converted into IBE groups)
4. New Integrated Breathe Easy groups (newly started IBE groups)

With the support of the BLF, the research team recruited participants who did not attend any BE group through the BLF's national helpline. This enabled them to identify people who had telephoned the BLF to enquire about local groups within their area but where there had not been a local group for them to attend. When the research team contacted the potential participants in relation to this study, they were all asked again if they would attend a BE group, if there was one in their local area. Only the people who answered 'yes' to this question were included in the study.

The standard BE groups were also recruited with the help of the BLF. The BLF identified groups where the Clinical Commissioning Group (CCG) had either not bought into the integrated model or where there was only very sporadic attendance of healthcare professionals (or no attendance) at the group meetings.

The third arm, the converted IBE groups (where existing BE groups had been converted into IBE groups), were those where the BLF had engaged successfully with the CCG and local healthcare professionals as part of this project, and that there was strong local support for the integrated model.

Finally the fourth arm, the newly formed IBE groups, were established by the BLF in areas where the charity had local support from the CCG and healthcare professionals in relation to the integrated model and where there were no existing (or insufficient) local groups.

2.2.1 Study population

The participants in this study were mainly members of BE groups and family carers. The BE groups who participated in the study were geographically throughout England, in rural and urban areas. The maximum number of people who agreed to participate in any BE group was 34, and the average number of people per group is 10. The number of family carers is much lower.

As mentioned previously, the people who did not attend any group were identified as being interested in attending a BE group but they did not currently have access to a group.

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12. COPD stands for Chronic Obstructive Pulmonary Disease. It includes the conditions emphysema and chronic bronchitis, and affects around 3 million people in the UK. BLF, 2016. [Available online] https://www.blf.org.uk/support-for-you/copd. Accessed 3rd March 2016
13. Wigal JK, Creer TL, Kotses H. The COPD Self-Efficacy Scale. Chest. 1991 May;99(5):1193-6.
14. A. Bandura, "Health promotion by social cognitive means," Health Education and Behavior, vol. 31, no. 2, pp. 143–164, 2004.
15. Tennant R, Hiller L, Fishwick R, Platt S, Joseph S, Weich S, JParkinson J, Secker J, and Stewart-Brown J. The Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS): development and UK validation. Health Qual Life Outcomes. 2007; 5: 63.
16. Warwick Medical School. http://www2.warwick.ac.uk/fac/med/research/platform/wemwbs/ (accessed January 2016)

Survey instruments

Survey instruments were used to collect outcomes data for participants and any family carers within the first month of attending a BE group, and then every 6 months after that date. As BLF were required to set up the groups in a staggered manner (as according to their agreement with NESTA), this resulted in some groups having less follow-up data than others (for example, for some groups, the research team only had baseline and 6-month data, as they were not set up until summer 2015). Those who did not attend any BE group were also sent the surveys every 6 months.

A Theory of Change model used to guide the original development of the IBE including the intended intermediate outcomes (see Appendix I). These outcomes were used to identify which surveys should be used/questions asked. In Appendix IV, the surveys and questions used are detailed against each of the Theory of Change intermediate outcomes. A number of well-established and validated survey instruments were used in this study. Where possible, the research team used instruments that were specially designed for and/or tested with people with lung conditions. Table 1 details the survey instruments and provides information about the type of questions they ask and what they are designed to measure.

Table 1. Survey instruments

Name of survey instrument	Theoretical base/ Background	Measures
The COPD[12] Self-Efficacy Scale[13] (CSES)	Self-efficacy refers to one's confidence in their ability to control, organize, and execute a course of action required for performing specific tasks that will lead to certain outcomes. Belief in one's efficacy to exhibit behavioural control is a common pathway through which psychosocial influences affect the adoption and maintenance of health behaviour change[14].	The 34-item COPD Self-Efficacy Scale specifically assesses self-efficacy in individuals with COPD. The instrument has a five-factor structure: Negative affect, Intense emotional arousal, Physical exertion, Weather/environments, and Behavioural risk factors.
WEMWBS scale (The Warwick-Edinburgh Mental Wellbeing Scale)[15]	The scale was used to support the following[16]: Monitoring of wellbeing Evaluating projects and programme which could have an influence on mental wellbeing Investigating the determinants of mental wellbeing	WEMWBS is a 14 item scale with 5 response categories, summed to provide a single score ranging from 14-70. The items are all worded positively and cover both feeling and functioning aspects of mental wellbeing
Morisky 8-Item Medication Adherence Questionnaire[17]	Adherence to medication is a crucial part of patient care and indispensable for reaching clinical goals. The WHO, in its 2003 report on medication adherence, states that "increasing the effectiveness of adherence interventions may have a far greater impact on the health of the population than any improvement in specific medical treatment"[18]. By opposition, nonadherence leads to poor clinical outcomes, increase in morbidity and death rates, and unnecessary healthcare expenditure.	The first seven items are Yes/No responses while the last item is a 5-point Likert response. The additional items focus on medication-taking behaviours, especially related to underuse, such as forgetfulness, so barriers to adherence can be identified more clearly.
European quality of life questionnaire (EuroQoL)[19], EQ-5D	The EuroQoL is EQ-5D™ is a standardised instrument for use as a measure of health outcome. It is primarily designed for self-completion by respondents and is ideally suited for use in postal surveys, in clinics and face-to-face interviews.	The EuroQoL questionnaire includes single item measures of: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each item is coded using 3-levels (1 = no problems; 2 = some problems; 3 = severe problems). The instrument includes a global rating of current health using a visual analog scale (VAS) ranging from 0 (worst imaginable) to 100 (best imaginable). An additional single item measure of health change (better, much the same, worse) was included.

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17. Morisky DE, Ang A, Krousel-Wood M, Ward H. Predictive validity of a medication adherence measure for hypertension control. J Clin Hypertens. 2008;10:348–54.

18. Sabaté E. Adherence to Long-Term Therapies: Evidence for Action, World Health Organization, Geneva, Switzerland, 2003.

19. Brooks R, Rabin R, de Charro F, (eds): The Measurement and Valuation of Health Status Using EQ-5D: A European Perspective: Evidence from the EuroQol BIO MED Research Programme. Rotterdam: Kluwer Academic Publishers; 2003

In addition to the surveys detailed in Table 1, three other surveys were completed, as one off activities. These included:

1. Survey A: A short survey recording changes around knowledge of their conditions and health care systems/ new skills developed was also used. This was a survey developed, and used previously by the BLF. People living with or affected by a lung condition attending the BE groups completed this survey, but not participants who did not attend a BE group (survey presented in Appendix V).
2. Survey B: The final one-off survey was sent out at the end of the two-year programme (survey presented in Appendix VI). This was done based on the observation of Professor Daniel Kahneman, Nobel Prize Lecturer (2002). Professor Kahneman points out that remembered experience differs from immediate reaction; both are valid measures of experience[20]. Therefore the survey asked a series of questions to people living with a lung condition about how they felt prior to attending the BE group around the areas of:
    - Quality of life
    - Self-efficacy (for example, agreeing or disagreeing with the following statements: I feel in control of my life; I feel in control of my medical condition, etc.)
    - Social capital (for example, agreeing or disagreeing with the following statements: I feel more confident; I feel closer to others, etc.)
3. A survey conducted with volunteers who run BE groups: The survey used was developed by the National Council for Voluntary organisations. The tool was part of their Volunteering Impact Assessment Toolkit, and looked at the impact of volunteering in relation to personal gains (for example, confidence and general wellbeing), economic gains from volunteering (for example, access to free training courses), and social benefits (access to social networks, etc.).

Demographic data collected

At baseline participants completed a short form which detailed the following information:

- Age
- Gender
- Current legal marital status
- Employment status
- Support with everyday needs, including household chores, personal care, etc. (and who gives this support if applicable)

At baseline family carers also completed a short form which collected information on the following:

- Age
- Gender
- Current legal marital status
- Employment status

The form then went on to ask the following questions:

Over the past month, on an average week, how many days have you been engaged in providing care to your partner/relative/friend?	Please provide details here
On an average day, how many hours do you spend taking care of your partner/relative/ friend?	
Over the past month, have you or your partner had any help from social services/charities?	Yes No
Over the past month, have you had to change your work status and/or adjust your working hours/ take leave/ arrange for special hours etc. to accommodate your caring responsibilities?	Please provide details here
Do you help your partner/relative/friend with transportation/commuting to/from the Breath Easy group?	Please provide details here
How much time do you usually spend on this (including the duration of the Breath Easy Group meeting, if you are participating in the group or just waiting)?	Please provide details here
How would you rate your health in general? (please circle one)	Excellent Very good Good Fair Poor
Do you have any chronic health condition (heart condition, diabetes, lung condition, arthritis, etc.)?	Please provide details here

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[20] Maps of Bounded Rationality. [Available online] http://www.nobelprize.org/nobel_prizes/economic-sciences/laureates/2002/kahneman-lecture.html. Accessed 3rd March 2016

Monthly phone call data: Unplanned hospital admissions and GP visits

Additional impact data was collected retrospectively by monthly telephone calls with people living with a lung condition to capture unplanned hospital admissions and GP visits (in relation to their lung condition only). Details on the medications prescribed and length of stays in hospital (if applicable) were also recorded during the monthly telephone calls. The calls were carried out for a total of 6 months.

Data from the above instruments were also used to support the economic evaluation work, the methods for which are detailed in Section 2.3.

Key measures

All of the scales detailed in Table 1 were used when determining the outcomes of the intervention, at 6 months after joining a group. Initially 12 months was going to be used as the time period. However, due to the staggered nature of the groups set-up, as well as many of the newly started IBE groups not being established until the final year of the project (leading to only baseline and 6-month data being collected), 6 months was chosen as the time period.

Composite scores of CSES, WEMWBS and the modified carer's checklist were calculated for analysis, as were CSES subscales of negative affect, intense emotional arousal, physical exertion, weather/environment and behavioural risk factors. Health states from EQ-5D were translated into utility scores using the Cross-walk Index Value Calculator.[21]

Data management and analysis

Data management

An SPSS[22] database was created by the Data Manager. This contained a separate sheet for each data type and included participant information (demographic details), primary and secondary outcome measures, treatment and BE group information and visit dates.

Data were directly imported from the SPSS database to SAS (Statistical Analysis Software)[23] datasets prior to Statistical Analysis, using the SAS IMPORT procedure.

CSES consists of a composite overall score and five subscales:

N = Negative Affect (items 6, 11, 12, 16, 20, 21, 23, 24, 27, 31, 32, 33)
I = Intense Emotional arousal (items 1, 4, 8, 10, 15, 125, 18, 30)
P = Physical Exertion (items 5, 9, 13, 29, 34)
W = Weather/Environment (items 2, 3, 7, 17, 22, 25)
B = Behavioural risk factors (items 19, 26, 28)

Composite scores of the individual items of the CSES, EQ-5D and WEMWBS measures were calculated. Changes from baseline (Month One) were calculated from the composite scores at 6 months for statistical analysis. Where individual item scores were missing, the composite score or subscale score was also considered to be missing.

Statistical Analysis

To address potential selection bias due to the non-randomised nature of the study design, propensity scores were derived prior to the statistical analysis of outcome measures. Propensity scores are a suitable methodology for adjusting for baseline differences that may be expected in non-randomised designs, to enable derivation of unbiased estimates of treatment differences.

The goal of the propensity score analysis was to balance observed covariates between BE groups from the treatment arms in order to mimic what happens in a randomised trial. Propensity scores were calculated using multinomial logistic regression (Imbens, 2000;[24] Faries et al. 2010)[25], with treatment group as the dependent variable and BE group level baseline covariates as independent variables. The covariates used in the propensity analysis were selected because they were considered to be potentially related to group allocation and outcomes and were obtained from the English indices of deprivation 2015[26].

Estimates of the index of multiple deprivation, and the seven deprivation domains of income, employment, education skills and training, health deprivation and disability, crime, barriers to housing and services, living environment and the supplementary index IDAOPI (Income deprivation affecting older people Index) were obtained for each area where there was a BE group. The standard BE groups were defined as the reference in the propensity score analysis.

To account for the complexity of the study design, two models were used in the statistical analysis as outlined below:

- BE group analysis model – Individual level mixed effects analysis of covariance (ANCOVA). The model includes a fixed effect for type of BE group, a random effect for BE group (cluster) and is adjusted for propensity scores at BE group level (cluster level).
- Whole study analysis model – ANOVA with fixed effect for treatment arm.

The BE group analysis model was used to analyse data from participants who attended BE groups (converted IBE groups, new IBE groups and standard BE groups, and accounts for the hierarchical nature of the design.

The whole study analysis model was used to analyse data from all four treatment arms and does not account for clustering or adjust for propensity scores.
The outcomes EQ-5D, WEMWBS and CSES at 6 months were analysed using both analysis models. Diagnostic tests and plots to assess the assumptions of normality were performed prior to analysis.

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[21] EQ-5D-5L Value Sets [Available online] http://www.euroqol.org/about-eq-5d/valuation-of-eq-5d/eq-5d-5l-value-sets.html Accessed 3rd March 2016

[22] SPSS Statistics is a software package used for statistical analysis

[23] SAS is a software suite developed by SAS Institute for advanced analytics, multivariate analyses, business intelligence, data management, and predictive analytics.

[24] Imbens, GW, 2000. The role of propensity score in estimating dose-response Functions. Biometrika, vol 87, No. 3, pp706-710

[25] Faries DE et al., 2010. Analysis of observational health care data Using SAS. Chapter 2. SAS Press, North Carolina

[26] Department for Communities and Local Government. English indices of deprivation 2015. [Available online] https://www.gov.uk/government/statistics/english-indices-of-deprivation-2015. Accessed 14th March 2016

In the case of non-normality, equivalent non-parametric approaches were utilised, or where appropriate, the data were transformed prior to analysis. There was some evidence of a bi-modal distribution for the EQ-5D utility scores and these data were rank transformed prior to analysis to facilitate a non-parametric like analysis. The propensity scores were evaluated to assess balance across treatment arms, and a sensitivity analysis of outcomes was performed for BE groups with propensity scores within the same range for each treatment arm. Sensitivity analysis of the BE group analysis model was also performed excluding propensity score adjustment.

Summary statistics of the outcomes were calculated and presented in tables. Summary and individual level data are presented graphically to illustrate the main findings from the statistical analysis. Summaries of data for carers and impact data on unplanned hospital admissions and GP visits (in relation to lung condition) are also presented.

The data were analysed using SAS software (version 9.3).

Ancillary Analysis

Two separate sensitivity analyses were performed for continuous outcome measures. The first was performed using the BE group analysis model but without adjustment for propensity scores to assess the impact of using propensity scores to adjust for baseline imbalance in the analysis. A second sensitivity analysis was performed, again using the BE group analysis model but this time only including BE groups with propensity scores within the same range for each treatment arm. This is similar in approach to matching propensity scores between treatment arms, and is another way of accounting for any baseline imbalance between treatment arms due to the non-randomised nature of the design.

Economic evaluation

Approaches to economic evaluation

Economic analyses

There are several ways to perform economic analyses:

1. Cost analyses; and
2. Analyses that combine costs and outcomes.[27]

1. Cost analyses include the following**:**
Cost of illness: Studies sum the costs incurred for treating or supporting people with similar problems.[28]
Cost-offset: Studies “involve the comparison of costs involved with costs saved” (p. 920).[29]
Cost minimisation: Analysis compares alternatives to find the treatment option with the lowest cost when no significant difference in outcomes has been identified.

2. Analyses that combine costs and outcomes include the following:
Cost-consequences: Studies involve the calculation of the total cost of an intervention in the situation when there is no possibility to combine the effect on outcomes across two or more dimensions. The total costs are presented together with the consequences along various dimensions and the decision maker is facing the task of weighing the outcomes and comparing the total effect to the total costs.

Cost-effectiveness: This analysis combines costs with a single outcome dimension and computes the ratio of the difference in costs to the difference in outcomes between the treatment and control groups.

Cost-utility: The analysis compares the cost of an intervention to a preference-weighted health-related quality of life measure, such as the Quality Adjusted Life Year (QALY).

Cost-benefit: The analysis refers to a situation when both costs and outcomes are valued in monetary terms.
For this study, as there were several outcome measures, it would have been ideal to combine them in one measure converted to QALYs as suggested by National Institute for Health and Care Excellence (NICE). However, since neither CSES nor WEMWBS scores can be converted into utility scores, which could then have been aggregated, it was only possible to use the QALY change derived from the change in the EQ-5D scores using the Cross-walk Index Value Calculator.[30]

However, the research team postulated that solely using the EQ-5D measure would lead to an underestimation of the effect of the IBE groups, as this would fail to take into account any changes in people living with a lung conditions’ wellbeing and the wider social outcomes, as well as the effect on the wellbeing of carers, and the value of volunteering.

Taking into account these considerations, the calculations performed for this study offer a range of economic measures which, as they cannot be combined into one outcome, should be reviewed as a set. As this study evaluates the outcomes at 6 months, in the health economic calculations everything was adjusted to this interval. The research team bring all the measures to the -per patient, per 6-month period base - to directly compare to the estimates of the incremental benefit from the statistical analysis.

Due to the seriousness of the lung conditions the people living with a lung condition involved in this study have (and the progressive/degenerative nature of conditions such as COPD), it was assumed that the BE groups are more likely to improve quality of life, as opposed to extend life-years. Therefore the health economic calculations focus on the benefits received during the 6

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[27] Romeo, R., Byford, S., & Knapp, M. (2005). Annotation: Economic evaluations of child and adolescent mental health interventions: a systematic review. Journal of Child Psychology and Psychiatry, 46(9), 919-930.

[28] Beecham, Jennifer. (2014). Annual Research Review: Child and adolescent mental health interventions: a review of progress in economic studies across different disorders. Journal of Child Psychology and Psychiatry
55:6 (2014), pp 714

[29] Romeo, R., Byford, S., & Knapp, M. (2005). Annotation: Economic evaluations of child and adolescent mental health interventions: a systematic review. *Journal of Child Psychology and Psychiatry*, 46(9), 919-930.

[30] EQ-5D-5L Value Sets [Available online] http://www.euroqol.org/about-eq-5d/valuation-of-eq-5d/eq-5d-5l-value- sets.html. Accessed 3rd March 2016

months of group participation and do not extend the benefits beyond this period. It should be noted that this could be an underestimation of the benefits gained, given the educational and skills building components of the group sessions, which is likely to continue improving quality of life into the future. However, there is no available data on the long-term effects of the groups which could be used.

Analysis methods performed in this study
Three analyses were performed for this study based on the findings of effectiveness from the BE group analysis model and costs estimates:
Benefit-Cost Analysis
Social Return on Investment Analysis (accounting for wider effects)
Cost-Effectiveness Analysis

1. Benefit-Cost Analysis

The incremental benefit-cost ratio is used to compare the IBE Groups to the non-integrated BE groups. The differences in benefits and costs between the two groups were calculated to obtain the ratio of the equivalent worth of incremental benefits to that of incremental costs.

$$IBCR = \frac{\Delta B}{\Delta C} = \frac{B_{IBE} - B_{IBE}}{C_{IBE} - C_{BE}} = \frac{\Delta QALY}{\Delta INT}$$

ΔINT represents the incremental total cost of running the IBE group per participant relative to the non-integrated BE group based on the value of time of a respiratory nurse[31] and the cost of setting up the IBE groups.

Change in QALYs is calculated from the EQ-5D scores for the people living with a lung condition and valued in monetary terms. The threshold value for an incremental cost per QALYis valued at £20,000 as suggested by NICE[32]. However, this is the lower bound of the QALY set in 1999 and it has not been updated since to account for inflation. Thus, for this study, two IBCRs were calculated – one based on a value of £20,000 per QALY and one based on a value of £30,000 per QALY.

2. Social Return on Investment Analysis (accounting for wider effects)

As the process evaluation showed at the end of Year One, and as the qualitative results in this report also demonstrate, the BE groups have social value beyond that of health improvement. The BE groups also provide positive social outcomes for people living with a lung condition (through social interaction with other people living with a lung condition attending the groups) and through benefits gained from volunteering.

To ensure that these benefits are taken into consideration when performing the economic calculations, the research team have used the Social Return on Investment (SROI)[33] tool. This tool was developed based on the users' views of the social benefits they receive which were obtained from focus groups and other consultations. We simply rely on the average values for two categories – volunteering and regular attendance of local BE groups – from the Social Value Bank[34]. The total value of volunteering is derived from the differences in the number of volunteers in IBE vs. non-integrated BE groups and the Social Value Bank[35]. Similarly, the total value from group participation is derived from the differences in the number of people living with a lung condition and carers in the IBE vs. non-integrated BE groups and the corresponding value from the Social Value Bank.

3. Cost-Effectiveness Analysis

Although the measures described in analyses (1) and (2) above allow for the comparisons with other interventions and for a combination of both patient's health outcomes and the wider social outcomes to people living with a lung condition and volunteers, there still could be an underestimation of the effect along other dimensions of wellbeing. However, those dimensions do not allow for a conversion of benefits into a monetary measure to allow for an easy integration into the ICBR introduced above. Therefore, a Cost-Effectiveness Analysis has been used with people living with a lung conditions' wellbeing as primary outcome for this.

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31. The time of a respiratory nurse was used as the cost, although it should be acknowledged that different healthcare professionals attended different groups at various stages of the study. However, the research team went for the most consistent healthcare professional, who attended monthly (as opposed to attending for a one off lecture), This was a respiratory/COPD nurse usually.
32. NICE. How NICE measures value for money in relation to public health interventions. [Available online] http://publications.nice.org.uk/how-nice-measures-value-for-money-in-relation-to-public-health-interventions- lgb10b/nices-approach-to-economic-analysis-for-public-health-interventions Accessed 16th March 2016
33. NEF, Social Return on Investment [Available online] http://www.proveandimprove.org/tools/sroi.php Accessed 3rd March 2016
34. HACT, working with Daniel Fujiwara (from the Cabinet Office), have created the largest bank of methodologically consistent and robust social values ever produced. The values can provide a basic assessment of social impact, provide evidence of value for money, and compare the impact of different programmes. The values can also be used within a full Social Return On Investment or Cost-Benefit Analysis.
35. HACT and Daniel Fujiwara. Community Investment values from the Social Value Bank. [Accessed online] www.hact.org.uk/ www.simetrica.co.uk). Source: www.socialvaluebank.org. License: Creative Commons Attribution-NonCommercial-NoDerivatives license (http://creativecommons.org/licenses/by-nc-nd/4.0/deed.en_GB Accessed 3rd March 2016
36. Glaser, B., Strauss, A. (1967). The discovery of grounded theory. Chicago: Aldine.

The Incremental Cost-Effectiveness Ratio (ICER) is estimated based on the WEMWBS scores, as a summary measure of wellbeing. This allows the research team to combine the changes in the wellbeing of both people living with a lung condition and carers. Both can be served as additional measures which allows for economic evaluation of different dimensions of wellbeing.

$$ICER^{CSES} = \frac{\Delta C}{\Delta E} = \frac{C_{IBE} - C_{BE}}{(\mathrm{CSES}_{IBE} - \mathrm{CSES}_{IBE})^{Patient}} = \frac{\Delta INT + \Delta HCUse}{\Delta CSES^{Patient}}$$

$$ICER^{WEMWBS} = \frac{\Delta C}{\Delta E} =$$

$$\frac{C_{IBE} - C_{BE}}{(WEMWBS_{IBE} - WEMWBS_{IBE})^{Patient} + (WEMWBS_{IBE} - WEMWBS_{IBE})^{Carer}} =$$

$$\frac{\Delta INT + \Delta HCUse}{\Delta WEMWBS^{Patient} + \Delta WEMWBS^{Carer}}$$

There are limitations with the ICER calculation and, therefore, when interpreting the results, caution should be taken, due to:

- The same incremental cost appears in the numerator of all the suggested measures; and
- Some of the dimensions of wellbeing in all measures may overlap. The first works towards overestimation of the Cost per Unit, while the other will tend to underestimates it.

Qualitative methods

In addition to the outcome and economic evaluation work (which is quantitative in nature), a number of in-depth, qualitative interviews were conducted with members of the IBE groups. Although this was not required by the BLF or NESTA as part of the Year Two evaluation, the research team felt that the report would be incomplete without including the views of the group members, described in their own words.

Approach

Principles of Grounded Theory were used throughout the qualitative interviews to guide sampling, data gathering, and data analysis[36]. The phrase ‘grounded theory’ refers to theory that is developed inductively from a body of data, rather than from the preconceptions of the researchers. Therefore, findings from such studies should have high validity. The approach is iterative, in that ongoing sampling, data gathering and data analysis inform each other over time, as tentative theoretical explanations are generated during data analysis, and subsequently tested through further data gathering. In this way, a circular process ensues in which theory is gradually, but robustly, developed.

2.4.2. Sampling

Purposive sampling was used to increase the generalisability of the study’s findings and to ensure a mix of participants took part. The sample included:

Volunteers from the IBE groups;
Healthcare professionals; and
Group members.

2.4.3. Data collection

All participants were interviewed once over the telephone or face-to-face. The individual interviews were conducted between April 2015 and March 2016. When permission was given, the interviews were recorded.

As with all qualitative research studies, the discussion guide was used as an ‘aide-memoire’ and as a general framework for discussion, ensuring that all themes were covered with the necessary prompts but, at the same time, enabling discussions to be spontaneous, flexible and responsive to the thoughts and opinions of those being interviewed.

For this study semi-structured interviews were conducted. The questions focused on the benefits participants and healthcare professionals received from attending the IBE groups.

Data analysis

Audiotapes were transcribed verbatim. The transcripts used accepted procedures for indicating exclamations, pauses and emotion, providing additional information on how the participants expressed themselves (Seale, 1997; Field and Morse, 1985)[37]. Transcriptions were imported into the computer program NVIVO (Qualitative Solutions and Research Pty Ltd, 2011)[38].

In addition to the individual interviews detailed above, 6 customer journey maps were developed, also using qualitative interview techniques. The findings are detailed in Section 7.

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[37] 37. Field, P., Morse, J. (1985). Nursing research: The application of qualitative approaches. Aspen: Rockville. Seale, C., Silverman, D. (1997). Ensuring rigour in qualitative research. Eur J Public Health, 7, 379-84.

[38] 38. Qualitative Solutions and Research Pty Ltd (2011). NVIVO. Victoria, Australia.

APPENDIX III: PROPENSITY SCORE ANALYSIS

The design of the study is not randomised and as such there is the potential for selection bias. It is possible that those groups integrated in the healthcare pathway differ in some way to those that are not integrated or to those that have been newly established. The area where the group is located is a possible contributory factor to selection bias and outcomes. For example there may a tendency for IBE groups to be in less or more deprived areas, and groups in more deprived areas may have different outcomes or levels of severity compared to those in less deprived areas.

In order to account for this potential for selection bias the Index of Multiple Deprivation (IMD) and associated deprivation indices were obtained for each BE group and used to calculate propensity scores for each group so any imbalance can be accounted for in the estimation of differences between types of BE group in the main statistical analysis.

IMD is the official measure of relative deprivation for small areas in England. Every area is ranked from the most deprived to the least deprived, with lower ranks representing more deprived areas. The IMD and domain ranks were compared prior to the propensity score analysis. Table 1 below shows the mean of the ranks for each type of BE group.

Table 1. Summary of Indices of deprivation by type of BE group

Mean of deprivation ranks	Type of BE group		
	Standard BE groups	Converted IBE groups	New IBE groups
Index of Multiple deprivation	11821	11577	8781
Income	12072	12207	9218
Employment	12519	11228	8591
Education Skills and Training	15866	10589	6481
Health Deprivation and disability	12579	11091	8293
Crime	9465	12096	11444
Barriers to housing and services	15946	18812	18506
Living Environment	10687	13587	17257
IDAOPI	12056	14906	12027

For most of the indices, and the overall IMD, mean values in standard BE groups and converted IBE groups are similar, whereas lower values were observed for new IBE groups, suggesting that these groups are in more deprived areas than the other groups. The difference between the standard BE groups and new IBE groups was statistically significant for education, skills and training. Large differences were observed between the type of BE group for living environment, health deprivation and disability and employment, although none of these were statistically significant.

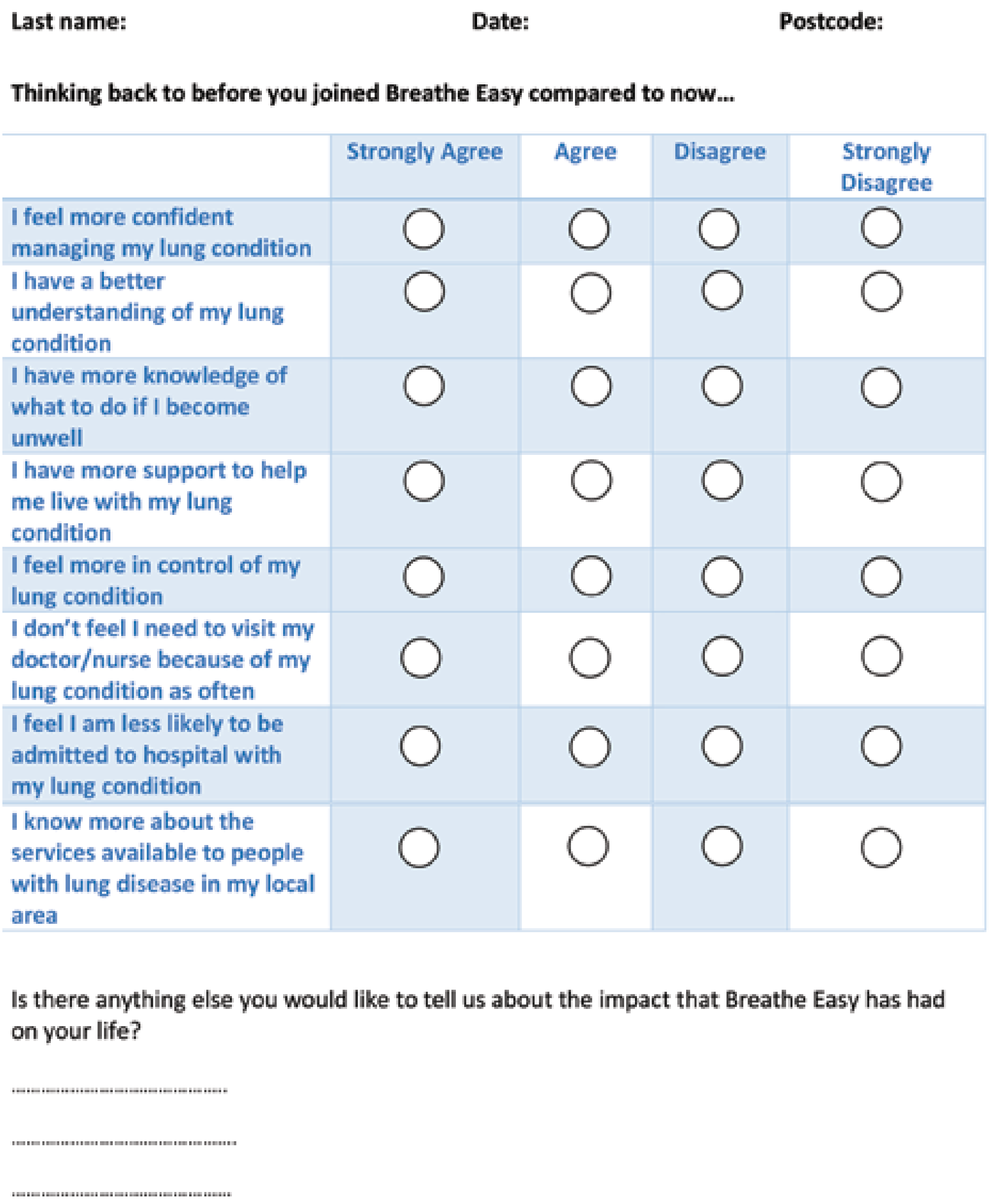
Propensity score analysis was undertaken, including the covariates described above to account for these observed imbalances, and propensity scores calculated for each BE group to be used as covariates in the main statistical analysis.

The balance of propensity scores was compared across groups, and a range of scores that were present for all types of BE group was identified. A sensitivity analysis was performed including BE groups with propensity scores within this range (see Appendix III for more details of this analysis).

APPENDIX IV: SURVEYS USED/ QUESTIONS ASKED AGAINST THE THEORY OF CHANGE MODEL

THEORY OF CHANGE CATEGORY	QUESTIONNAIRE	ACTUAL QUESTION/S
Better understanding of health services	Survey A	I know more about the services available to people with lung disease in my local area
	Survey A	I know enough about local lung services to tell a new member who to speak to about pulmonary rehabilitation
Better understanding of lung disease	Survey A	I have a better understanding of my lung condition
Increased medicine management and compliance	Survey B	I do not forget to take my medicine
	Morisky 8-Item Medication Adherence Questionnaire	All questions included in the analysis
Increased opportunities for social contact/ interaction	WEMWBS	All questions included in the analysis
	Survey B	I feel closer to other people
	Survey A	I feel confident to discuss my condition with other people in the group and share my experiences in the hope that it will help others
Increased confidence	Survey A	I feel more confident managing my lung condition
	Survey A	I feel more in control of my lung condition
	Survey B	I feel more confident to manage my breathing
	Survey B	I feel more optimistic about the future
Development of new skills	CSES	All questions included in the analysis
	Survey B	I feel in control of my medical condition
	Survey B	I feel in control of my life
	Survey B	I feel more capable of getting a job/volunteering
	Survey A	I have more knowledge of what to do if I become unwell
	Survey A	I feel I am less likely to be admitted t to hospital with my lung condition
	Survey A	I don’t feel I need to visit my doctor/nurse because of my lung condition as often
Increased wellbeing and resilience	EuroQoL	All questions included in the analysis
Reduced call upon GP services	Phone data collected monthly	All questions included in the analysis
Reduced risk of unnecessary hospital admissions	Phone data collected monthly	All questions included in the analysis

APPENDIX V: SURVEY A



Last name: **Date:** **Postcode:**

Thinking back to before you joined Breathe Easy compared to now…

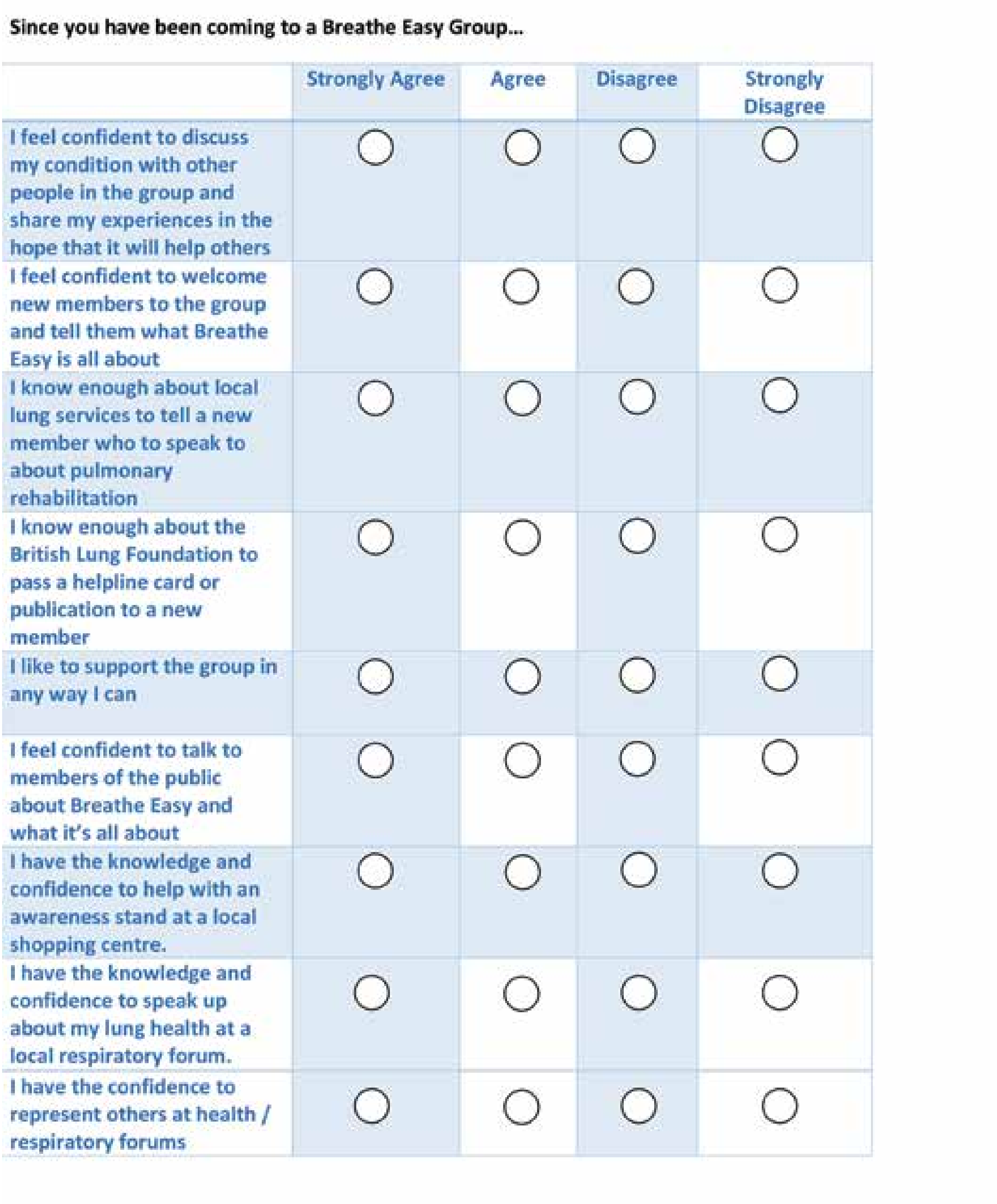
	Strongly Agree	Agree	Disagree	Strongly Disagree
I feel more confident managing my lung condition	○	○	○	○
I have a better understanding of my lung condition	○	○	○	○
I have more knowledge of what to do if I become unwell	○	○	○	○
I have more support to help me live with my lung condition	○	○	○	○
I feel more in control of my lung condition	○	○	○	○
I don't feel I need to visit my doctor/nurse because of my lung condition as often	○	○	○	○
I feel I am less likely to be admitted to hospital with my lung condition	○	○	○	○
I know more about the services available to people with lung disease in my local area	○	○	○	○

Is there anything else you would like to tell us about the impact that Breathe Easy has had on your life?

……………………………………………

……………………………………………

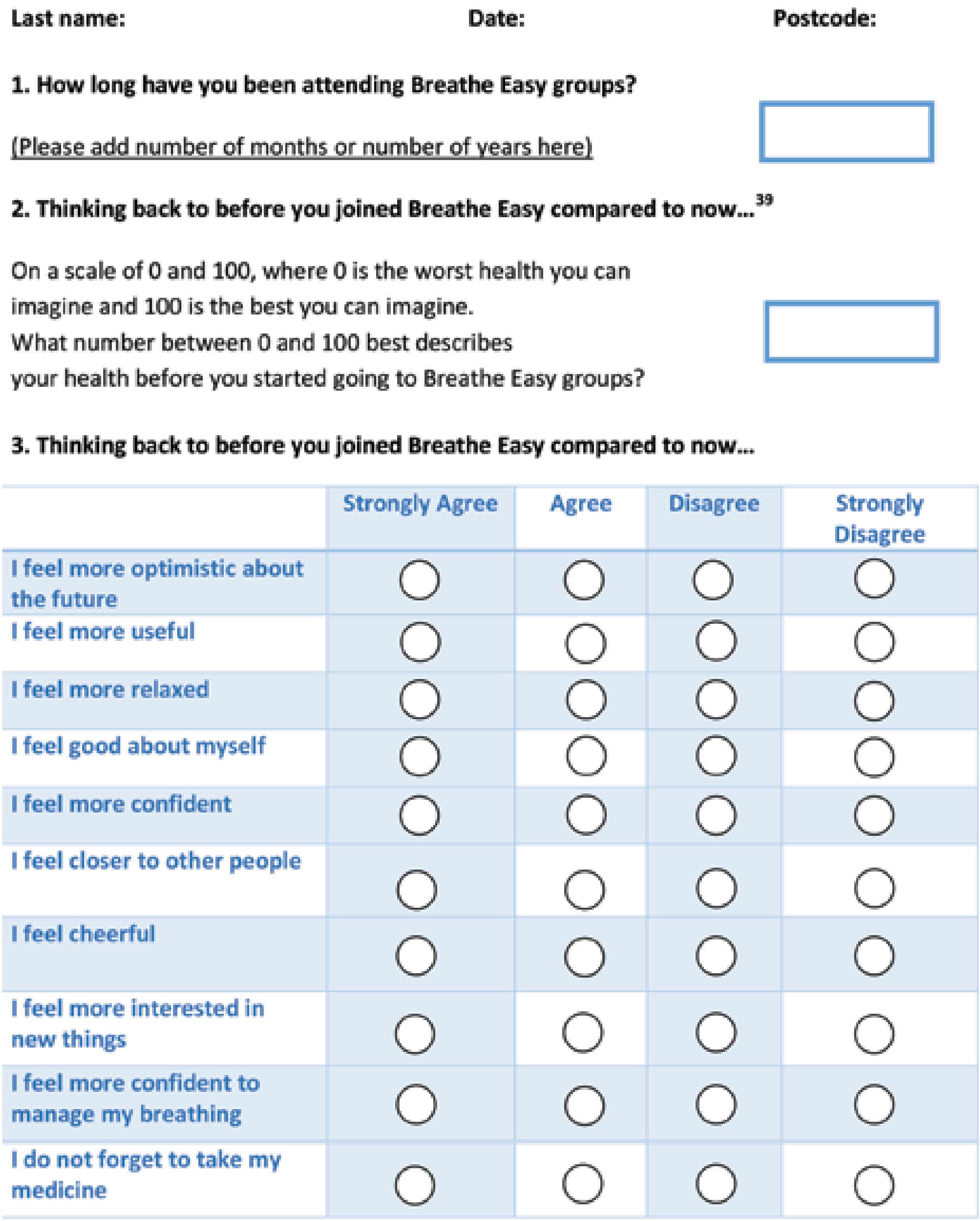
……………………………………………



Since you have been coming to a Breathe Easy Group...

	Strongly Agree	Agree	Disagree	Strongly Disagree
I feel confident to discuss my condition with other people in the group and share my experiences in the hope that it will help others	○	○	○	○
I feel confident to welcome new members to the group and tell them what Breathe Easy is all about	○	○	○	○
I know enough about local lung services to tell a new member who to speak to about pulmonary rehabilitation	○	○	○	○
I know enough about the British Lung Foundation to pass a helpline card or publication to a new member	○	○	○	○
I like to support the group in any way I can	○	○	○	○
I feel confident to talk to members of the public about Breathe Easy and what it's all about	○	○	○	○
I have the knowledge and confidence to help with an awareness stand at a local shopping centre.	○	○	○	○
I have the knowledge and confidence to speak up about my lung health at a local respiratory forum.	○	○	○	○
I have the confidence to represent others at health / respiratory forums	○	○	○	○

APPENDIX VI: SURVEY B



Last name: **Date:** **Postcode:**

1. How long have you been attending Breathe Easy groups?

(Please add number of months or number of years here) ☐

2. Thinking back to before you joined Breathe Easy compared to now…[39]

On a scale of 0 and 100, where 0 is the worst health you can imagine and 100 is the best you can imagine.
What number between 0 and 100 best describes your health before you started going to Breathe Easy groups? ☐

3. Thinking back to before you joined Breathe Easy compared to now…

	Strongly Agree	Agree	Disagree	Strongly Disagree
I feel more optimistic about the future	○	○	○	○
I feel more useful	○	○	○	○
I feel more relaxed	○	○	○	○
I feel good about myself	○	○	○	○
I feel more confident	○	○	○	○
I feel closer to other people	○	○	○	○
I feel cheerful	○	○	○	○
I feel more interested in new things	○	○	○	○
I feel more confident to manage my breathing	○	○	○	○
I do not forget to take my medicine	○	○	○	○

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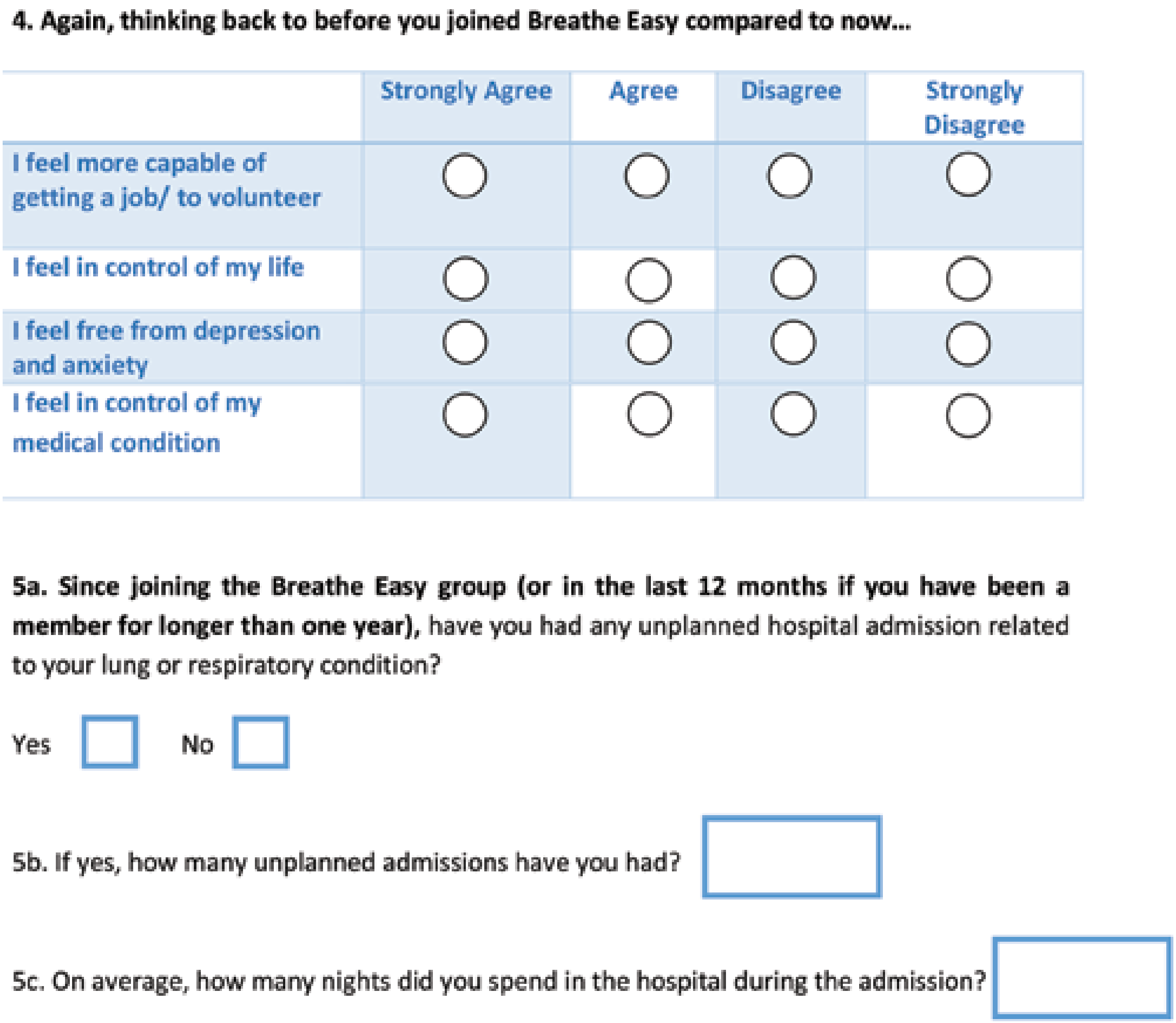
[39] For participants in the control arm, question one was removed and for the other questions, the wording was changed to read: Since your involvement in this study… and a date added for when the participant had joined the study.



4. Again, thinking back to before you joined Breathe Easy compared to now…

	Strongly Agree	Agree	Disagree	Strongly Disagree
I feel more capable of getting a job/ to volunteer	○	○	○	○
I feel in control of my life	○	○	○	○
I feel free from depression and anxiety	○	○	○	○
I feel in control of my medical condition	○	○	○	○

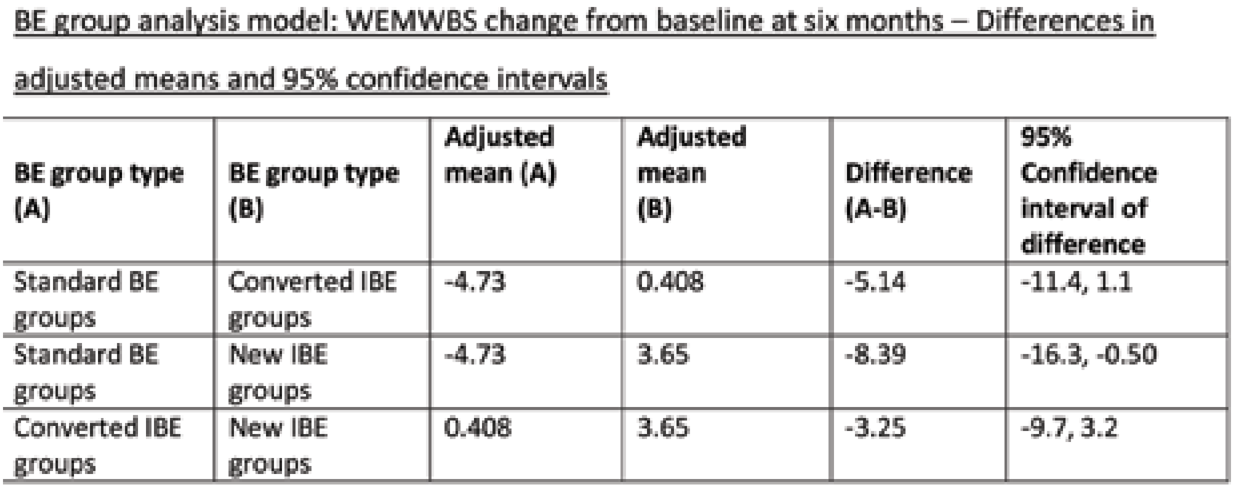
5a. Since joining the Breathe Easy group (or in the last 12 months if you have been a member for longer than one year), have you had any unplanned hospital admission related to your lung or respiratory condition?

Yes ☐ No ☐

5b. If yes, how many unplanned admissions have you had? ☐

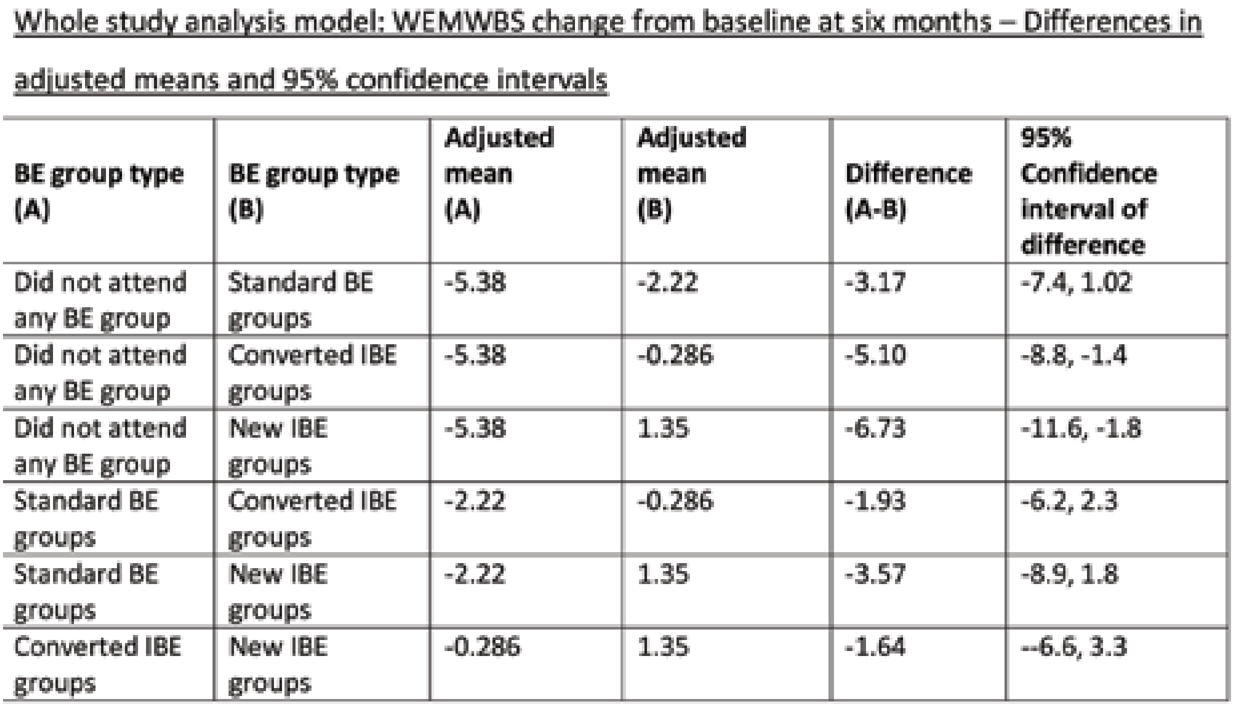
5c. On average, how many nights did you spend in the hospital during the admission? ☐

APPENDIX VII: WEMWBS CHANGE FROM BASELINE AT SIX MONTHS



BE group analysis model: WEMWBS change from baseline at six months – Differences in adjusted means and 95% confidence intervals

BE group type (A)	BE group type (B)	Adjusted mean (A)	Adjusted mean (B)	Difference (A-B)	95% Confidence interval of difference
Standard BE groups	Converted IBE groups	-4.73	0.408	-5.14	-11.4, 1.1
Standard BE groups	New IBE groups	-4.73	3.65	-8.39	-16.3, -0.50
Converted IBE groups	New IBE groups	0.408	3.65	-3.25	-9.7, 3.2



Whole study analysis model: WEMWBS change from baseline at six months – Differences in adjusted means and 95% confidence intervals

BE group type (A)	BE group type (B)	Adjusted mean (A)	Adjusted mean (B)	Difference (A-B)	95% Confidence interval of difference
Did not attend any BE group	Standard BE groups	-5.38	-2.22	-3.17	-7.4, 1.02
Did not attend any BE group	Converted IBE groups	-5.38	-0.286	-5.10	-8.8, -1.4
Did not attend any BE group	New IBE groups	-5.38	1.35	-6.73	-11.6, -1.8
Standard BE groups	Converted IBE groups	-2.22	-0.286	-1.93	-6.2, 2.3
Standard BE groups	New IBE groups	-2.22	1.35	-3.57	-8.9, 1.8
Converted IBE groups	New IBE groups	-0.286	1.35	-1.64	--6.6, 3.3

APPENDIX VIII: SUMMARY STATISTICS FOR WEMWBS AT BASELINE AND SIX MONTHS

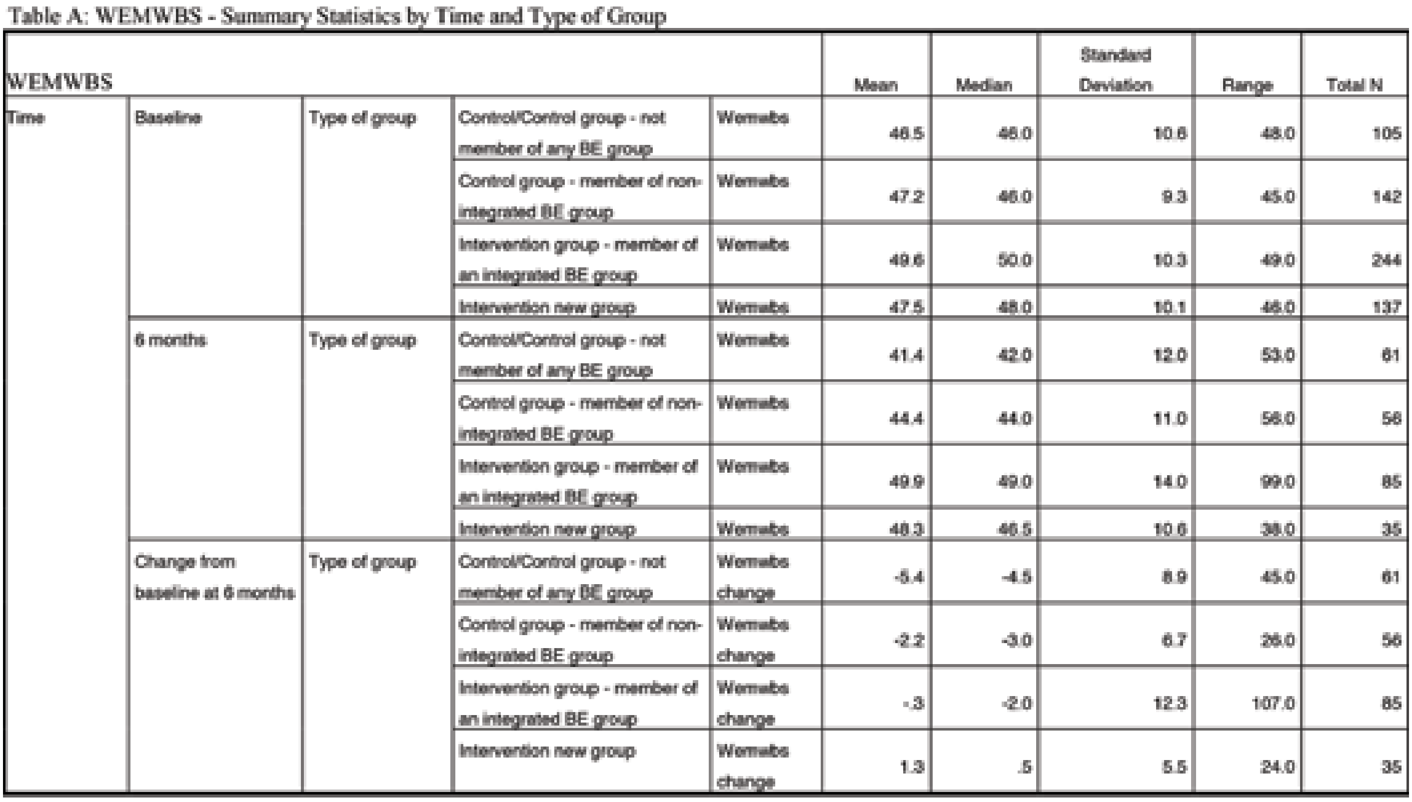
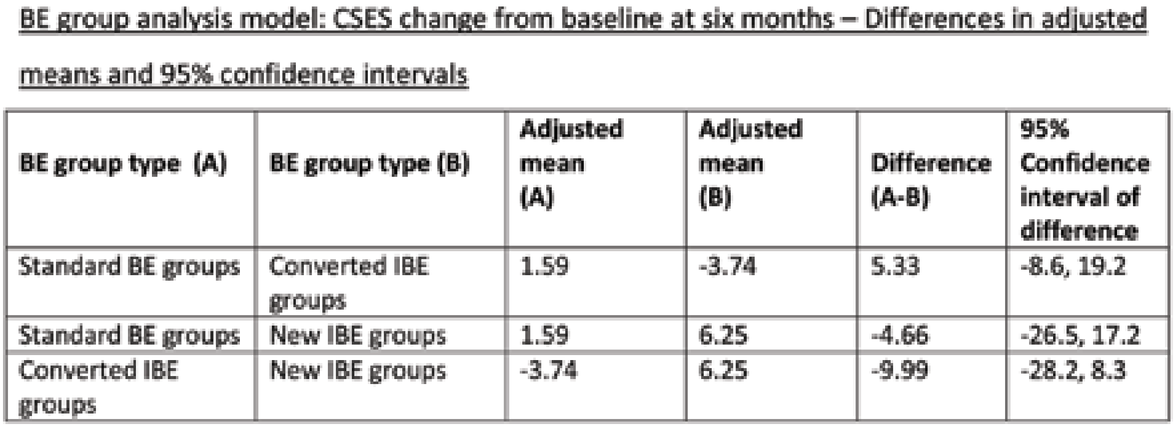


Table A: WEMWBS - Summary Statistics by Time and Type of Group

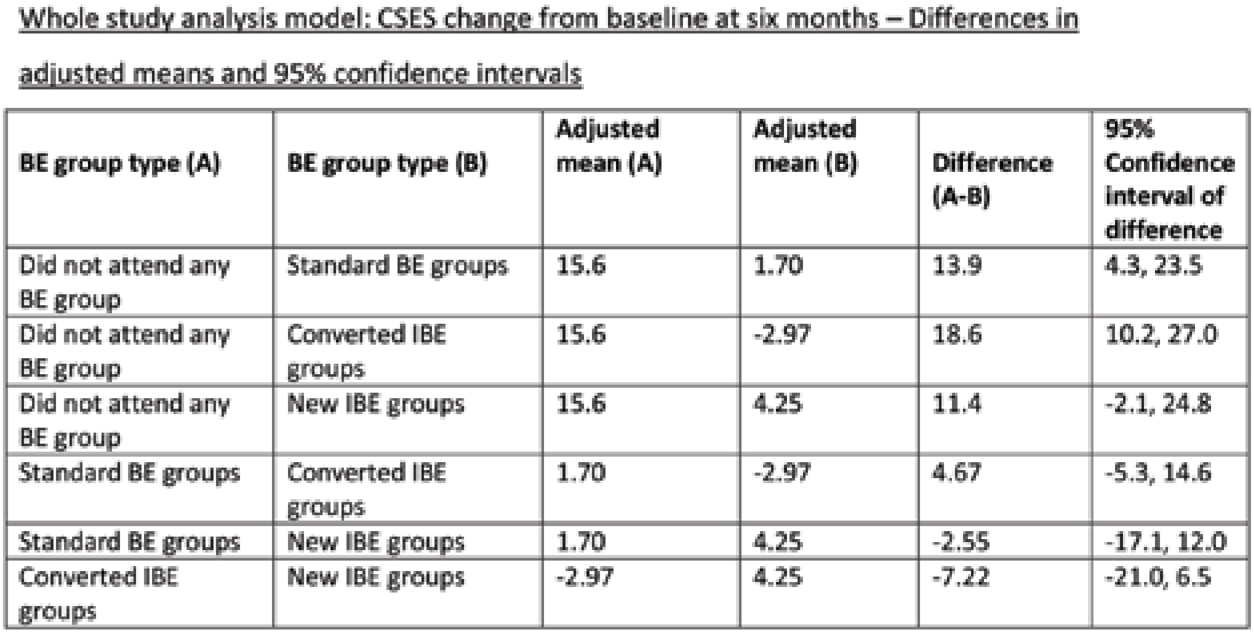
WEMWBS					Mean	Median	Standard Deviation	Range	Total N
Time	Baseline	Type of group	Control/Control group - not member of any BE group	Wemwbs	46.5	46.0	10.6	48.0	105
			Control group - member of non-integrated BE group	Wemwbs	47.2	46.0	9.3	45.0	142
			Intervention group - member of an integrated BE group	Wemwbs	49.6	50.0	10.3	49.0	244
			Intervention new group	Wemwbs	47.5	48.0	10.1	46.0	137
	6 months	Type of group	Control/Control group - not member of any BE group	Wemwbs	41.4	42.0	12.0	53.0	61
			Control group - member of non-integrated BE group	Wemwbs	44.4	44.0	11.0	56.0	56
			Intervention group - member of an integrated BE group	Wemwbs	49.9	49.0	14.0	99.0	85
			Intervention new group	Wemwbs	48.3	46.5	10.6	38.0	35
	Change from baseline at 6 months	Type of group	Control/Control group - not member of any BE group	Wemwbs change	-5.4	-4.5	8.9	45.0	61
			Control group - member of non-integrated BE group	Wemwbs change	-2.2	-3.0	6.7	26.0	56
			Intervention group - member of an integrated BE group	Wemwbs change	-.3	-2.0	12.3	107.0	85
			Intervention new group	Wemwbs change	1.3	.5	5.5	24.0	35

APPENDIX IX: CSES CHANGE FROM BASELINE AT SIX MONTHS



BE group analysis model: CSES change from baseline at six months – Differences in adjusted means and 95% confidence intervals

BE group type (A)	BE group type (B)	Adjusted mean (A)	Adjusted mean (B)	Difference (A-B)	95% Confidence interval of difference
Standard BE groups	Converted IBE groups	1.59	-3.74	5.33	-8.6, 19.2
Standard BE groups	New IBE groups	1.59	6.25	-4.66	-26.5, 17.2
Converted IBE groups	New IBE groups	-3.74	6.25	-9.99	-28.2, 8.3



Whole study analysis model: CSES change from baseline at six months – Differences in adjusted means and 95% confidence intervals

BE group type (A)	BE group type (B)	Adjusted mean (A)	Adjusted mean (B)	Difference (A-B)	95% Confidence interval of difference
Did not attend any BE group	Standard BE groups	15.6	1.70	13.9	4.3, 23.5
Did not attend any BE group	Converted IBE groups	15.6	-2.97	18.6	10.2, 27.0
Did not attend any BE group	New IBE groups	15.6	4.25	11.4	-2.1, 24.8
Standard BE groups	Converted IBE groups	1.70	-2.97	4.67	-5.3, 14.6
Standard BE groups	New IBE groups	1.70	4.25	-2.55	-17.1, 12.0
Converted IBE groups	New IBE groups	-2.97	4.25	-7.22	-21.0, 6.5

APPENDIX X: SUMMARY STATISTICS FOR CSES AND THE FIVE SUBSCALES AT BASELINE AND SIX MONTHS

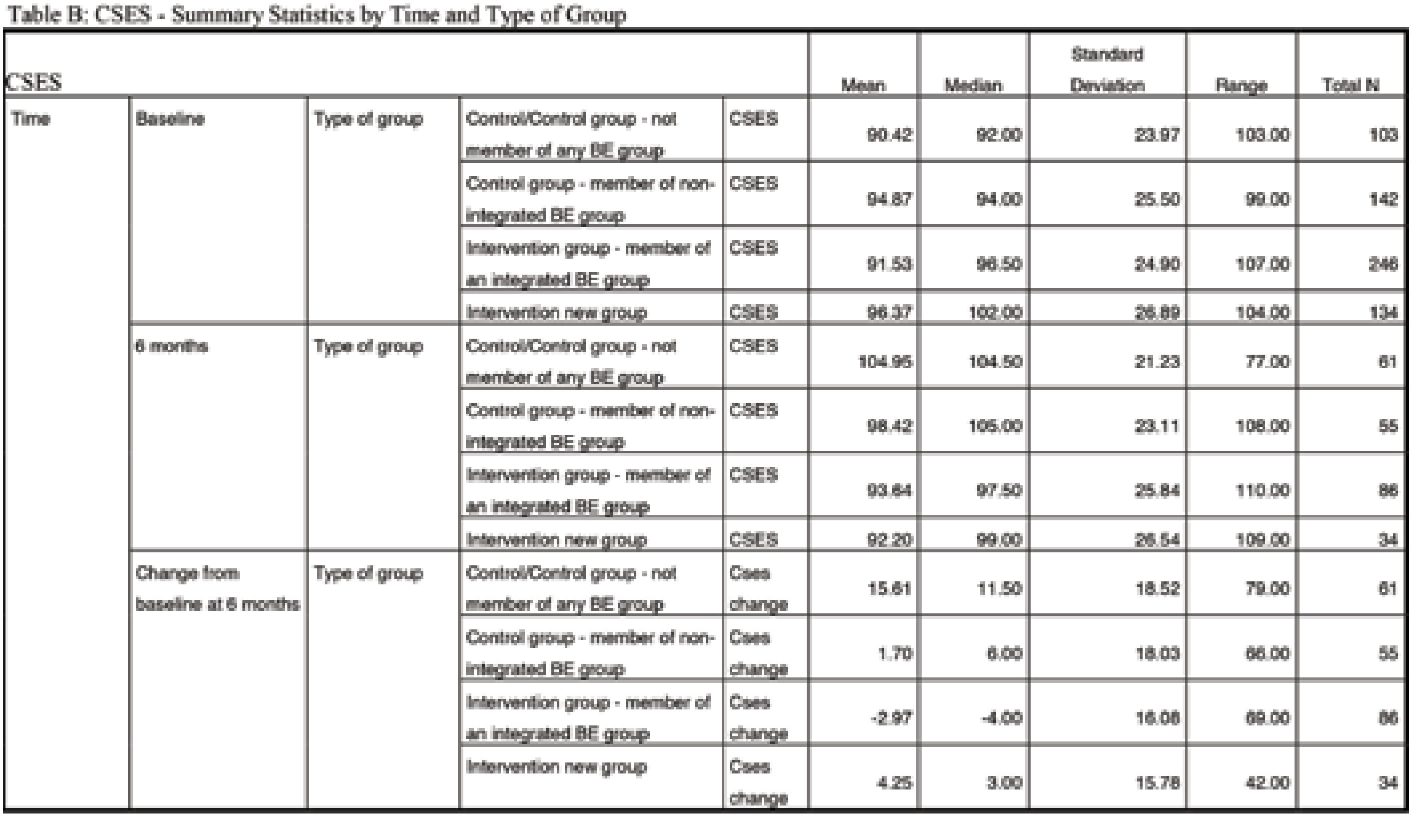
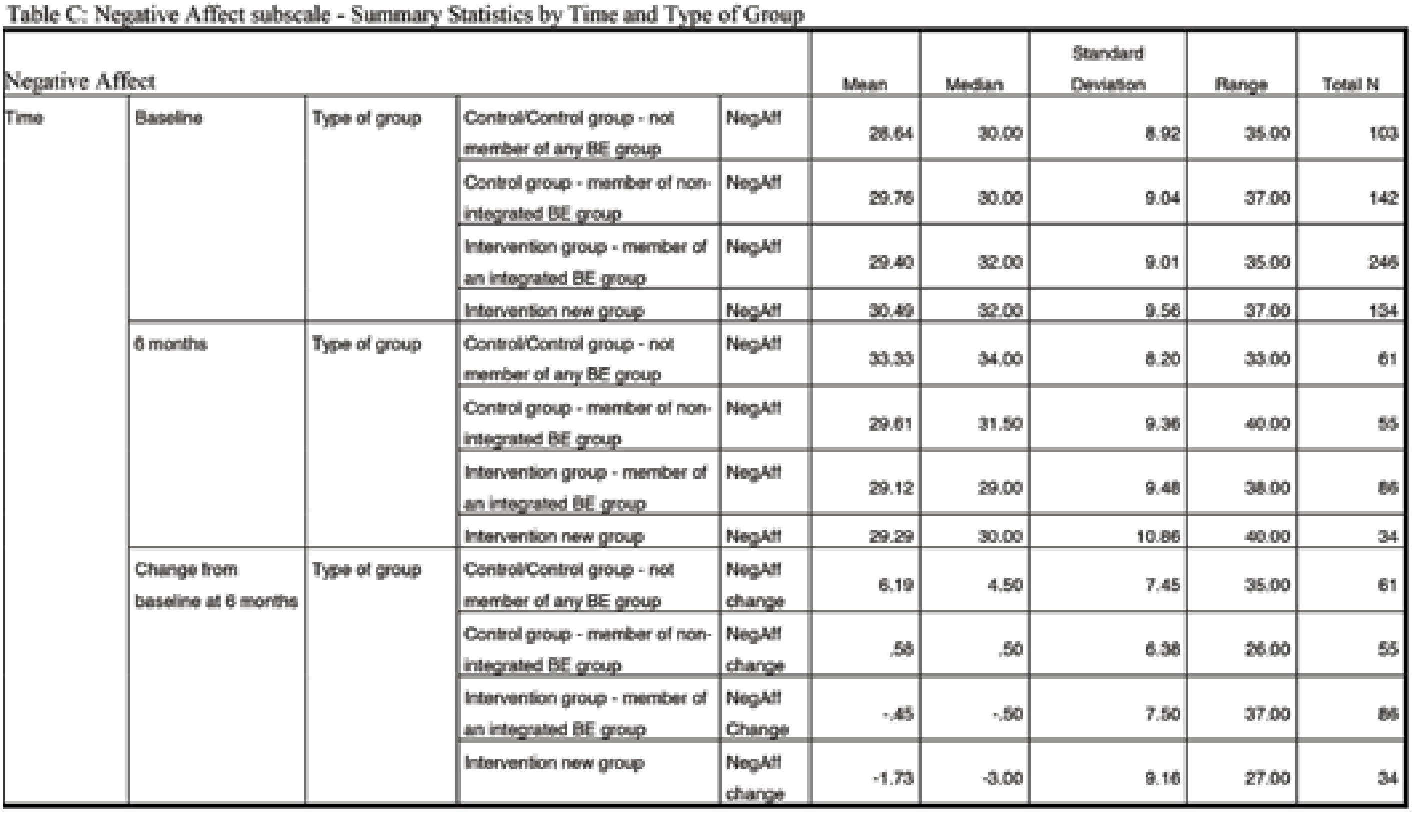


Table B: CSES - Summary Statistics by Time and Type of Group

CSES					Mean	Median	Standard Deviation	Range	Total N
Time	Baseline	Type of group	Control/Control group - not member of any BE group	CSES	90.42	92.00	23.97	103.00	103
			Control group - member of non-integrated BE group	CSES	94.87	94.00	25.50	99.00	142
			Intervention group - member of an integrated BE group	CSES	91.53	96.50	24.90	107.00	246
			Intervention new group	CSES	96.37	102.00	26.89	104.00	134
	6 months	Type of group	Control/Control group - not member of any BE group	CSES	104.95	104.50	21.23	77.00	61
			Control group - member of non-integrated BE group	CSES	98.42	105.00	23.11	108.00	55
			Intervention group - member of an integrated BE group	CSES	93.64	97.50	25.84	110.00	86
			Intervention new group	CSES	92.20	99.00	26.54	109.00	34
	Change from baseline at 6 months	Type of group	Control/Control group - not member of any BE group	Cses change	15.61	11.50	18.52	79.00	61
			Control group - member of non-integrated BE group	Cses change	1.70	6.00	18.03	66.00	55
			Intervention group - member of an integrated BE group	Cses change	-2.97	-4.00	16.08	69.00	86
			Intervention new group	Cses change	4.25	3.00	15.78	42.00	34

Table C: Negative Affect subscale - Summary Statistics by Time and Type of Group



Negative Affect					Mean	Median	Standard Deviation	Range	Total N
Time	Baseline	Type of group	Control/Control group - not member of any BE group	NegAff	28.64	30.00	8.92	35.00	103
			Control group - member of non-integrated BE group	NegAff	29.76	30.00	9.04	37.00	142
			Intervention group - member of an integrated BE group	NegAff	29.40	32.00	9.01	35.00	246
			Intervention new group	NegAff	30.49	32.00	9.56	37.00	134
	6 months	Type of group	Control/Control group - not member of any BE group	NegAff	33.33	34.00	8.20	33.00	61
			Control group - member of non-integrated BE group	NegAff	29.61	31.50	9.36	40.00	55
			Intervention group - member of an integrated BE group	NegAff	29.12	29.00	9.48	38.00	86
			Intervention new group	NegAff	29.29	30.00	10.86	40.00	34
	Change from baseline at 6 months	Type of group	Control/Control group - not member of any BE group	NegAff change	6.19	4.50	7.45	35.00	61
			Control group - member of non-integrated BE group	NegAff change	.58	.50	6.38	26.00	55
			Intervention group - member of an integrated BE group	NegAff Change	-.45	-.50	7.50	37.00	86
			Intervention new group	NegAff change	-1.73	-3.00	9.16	27.00	34

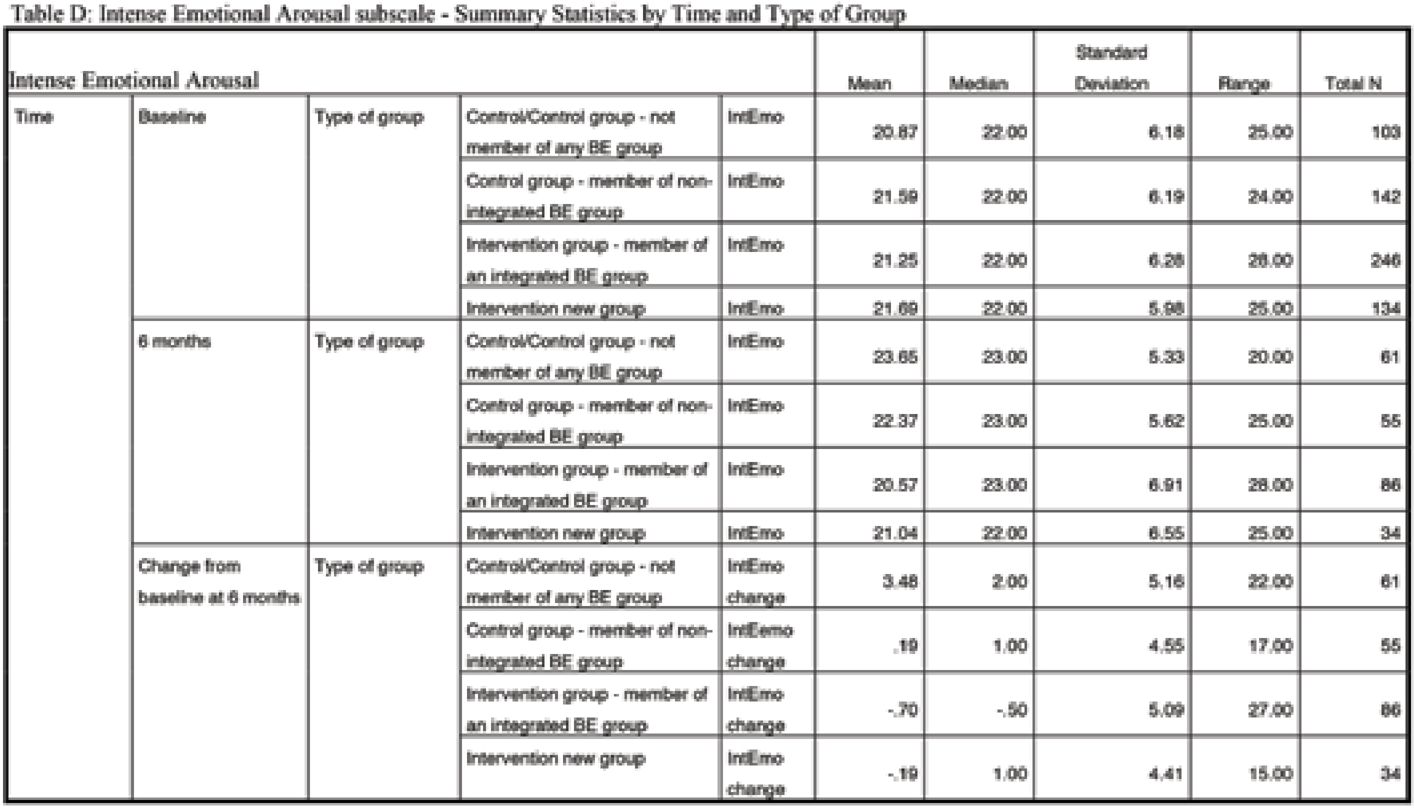


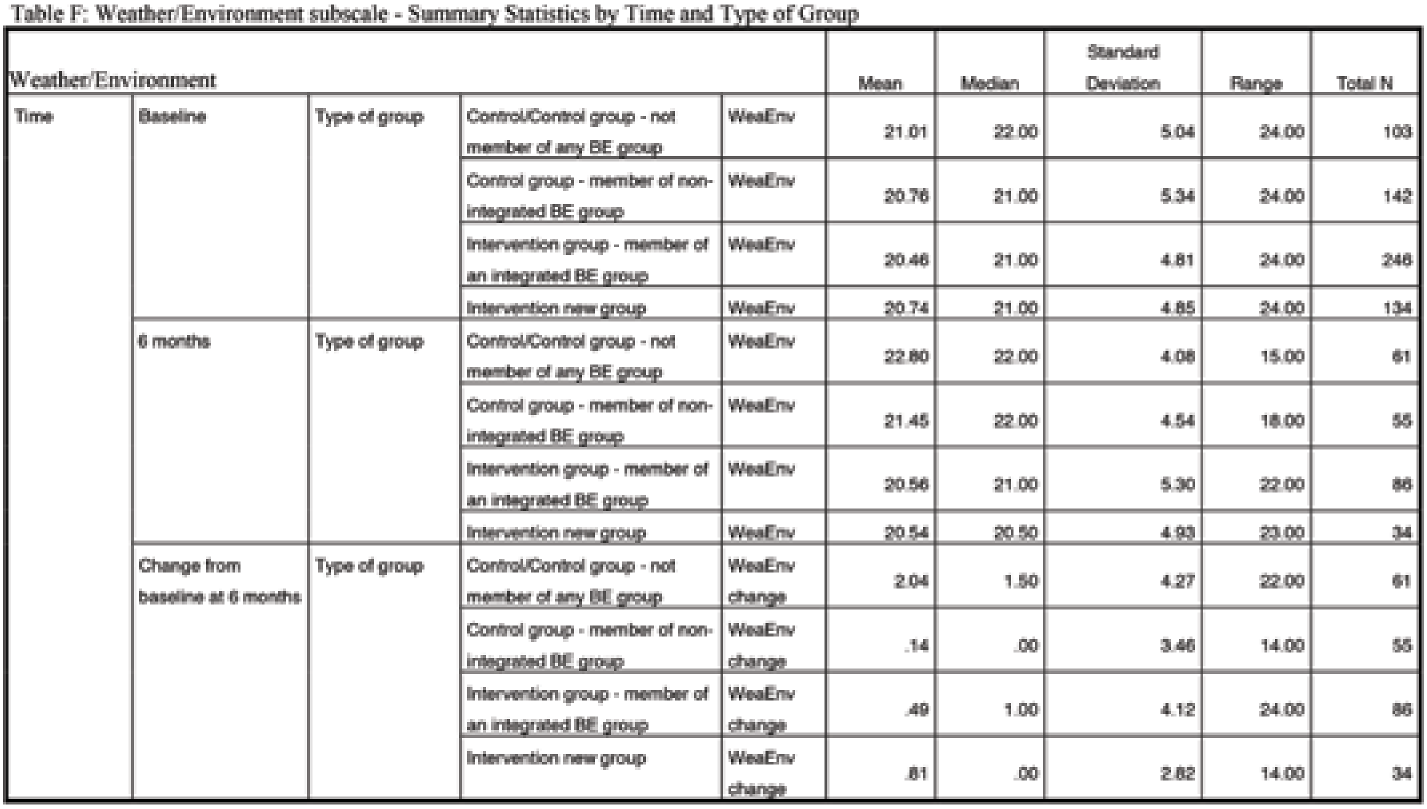
Table D: Intense Emotional Arousal subscale - Summary Statistics by Time and Type of Group

Intense Emotional Arousal					Mean	Median	Standard Deviation	Range	Total N
Time	Baseline	Type of group	Control/Control group - not member of any BE group	IntEmo	20.87	22.00	6.18	25.00	103
			Control group - member of non-integrated BE group	IntEmo	21.59	22.00	6.19	24.00	142
			Intervention group - member of an integrated BE group	IntEmo	21.25	22.00	6.28	28.00	246
			Intervention new group	IntEmo	21.69	22.00	5.98	25.00	134
	6 months	Type of group	Control/Control group - not member of any BE group	IntEmo	23.65	23.00	5.33	20.00	61
			Control group - member of non-integrated BE group	IntEmo	22.37	23.00	5.62	25.00	55
			Intervention group - member of an integrated BE group	IntEmo	20.57	23.00	6.91	28.00	86
			Intervention new group	IntEmo	21.04	22.00	6.55	25.00	34
	Change from baseline at 6 months	Type of group	Control/Control group - not member of any BE group	IntEmo change	3.48	2.00	5.16	22.00	61
			Control group - member of non-integrated BE group	IntEemo change	.19	1.00	4.55	17.00	55
			Intervention group - member of an integrated BE group	IntEmo change	-.70	-.50	5.09	27.00	86
			Intervention new group	IntEmo change	-.19	1.00	4.41	15.00	34

Table E: Physical Exertion subscale - Summary Statistics by Time and Type of Group

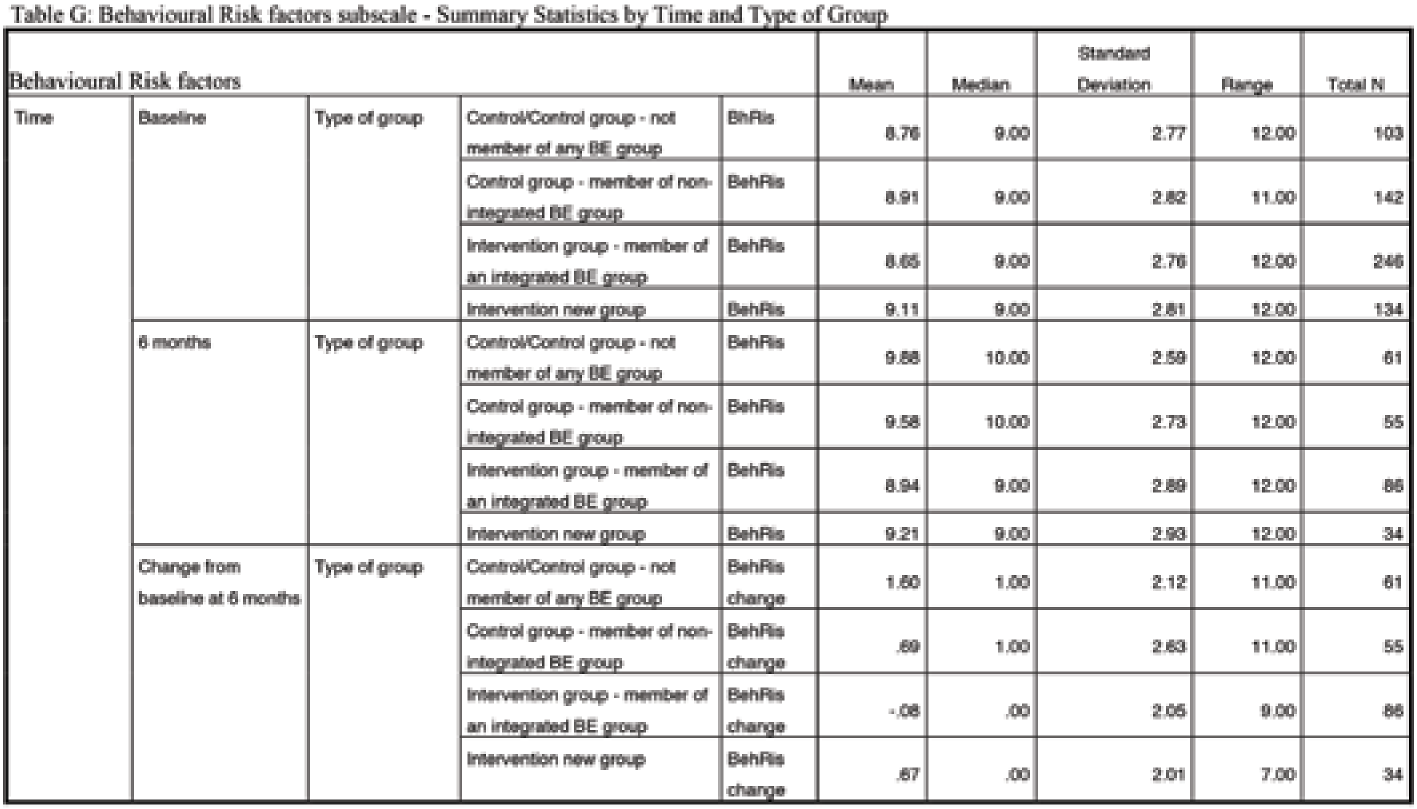
Physical Exertion					Mean	Median	Standard Deviation	Range	Total N
Time	Baseline	Type of group	Control/Control group - not member of any BE group	PhyExe	14.54	15.50	3.63	16.00	103
			Control group - member of non-integrated BE group	PhyExe	14.30	14.50	4.05	15.00	142
			Intervention group - member of an integrated BE group	PhyExe	13.97	15.00	3.70	16.00	246
			Intervention new group	PhyExe	14.51	15.00	3.59	15.00	134
	6 months	Type of group	Control/Control group - not member of any BE group	PhyExe	15.34	15.00	3.11	11.00	61
			Control group - member of non-integrated BE group	PhyExe	14.53	15.00	3.82	15.00	55
			Intervention group - member of an integrated BE group	PhyExe	14.31	15.00	4.30	16.00	86
			Intervention new group	PhyExe	14.32	15.00	3.38	16.00	34
	Changes from baseline at 6 months	Type of group	Control/Control group - not member of any BE group	PhyExe change	1.29	1.00	3.08	18.00	61
			Control group - member of non-integrated BE group	PhyExe change	.51	.00	2.82	14.00	55
			Intervention group - member of an integrated BE group	PhyExe change	.13	.00	2.64	13.00	86
			Intervention new group	PhyExe change	.50	.00	2.69	11.00	34

Table F: Weather/Environment subscale - Summary Statistics by Time and Type of Group



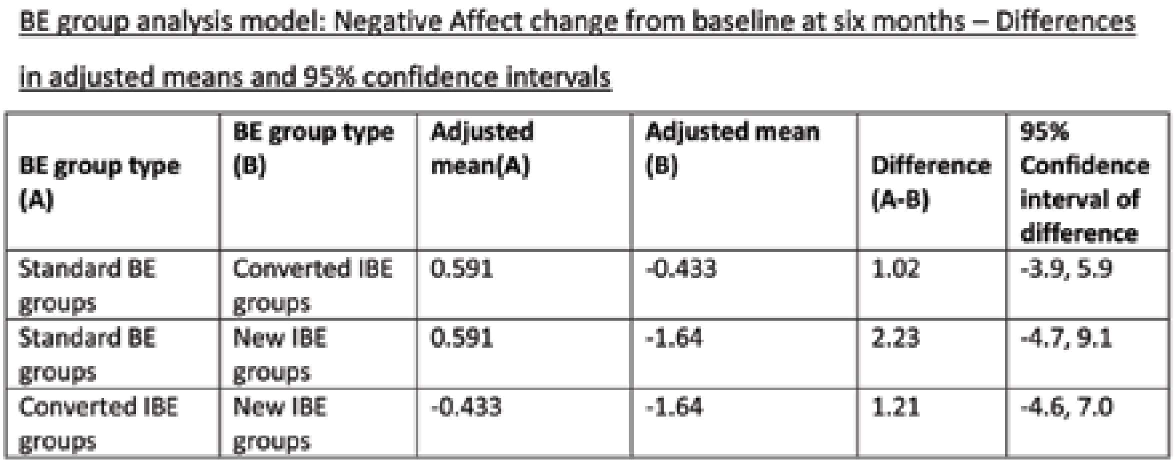
Weather/Environment					Mean	Median	Standard Deviation	Range	Total N
Time	Baseline	Type of group	Control/Control group - not member of any BE group	WeaEnv	21.01	22.00	5.04	24.00	103
			Control group - member of non-integrated BE group	WeaEnv	20.76	21.00	5.34	24.00	142
			Intervention group - member of an integrated BE group	WeaEnv	20.46	21.00	4.81	24.00	246
			Intervention new group	WeaEnv	20.74	21.00	4.85	24.00	134
	6 months	Type of group	Control/Control group - not member of any BE group	WeaEnv	22.80	22.00	4.08	15.00	61
			Control group - member of non-integrated BE group	WeaEnv	21.45	22.00	4.54	18.00	55
			Intervention group - member of an integrated BE group	WeaEnv	20.56	21.00	5.30	22.00	86
			Intervention new group	WeaEnv	20.54	20.50	4.93	23.00	34
	Change from baseline at 6 months	Type of group	Control/Control group - not member of any BE group	WeaEnv change	2.04	1.50	4.27	22.00	61
			Control group - member of non-integrated BE group	WeaEnv change	.14	.00	3.46	14.00	55
			Intervention group - member of an integrated BE group	WeaEnv change	.49	1.00	4.12	24.00	86
			Intervention new group	WeaEnv change	.81	.00	2.82	14.00	34

Table G: Behavioural Risk factors subscale - Summary Statistics by Time and Type of Group



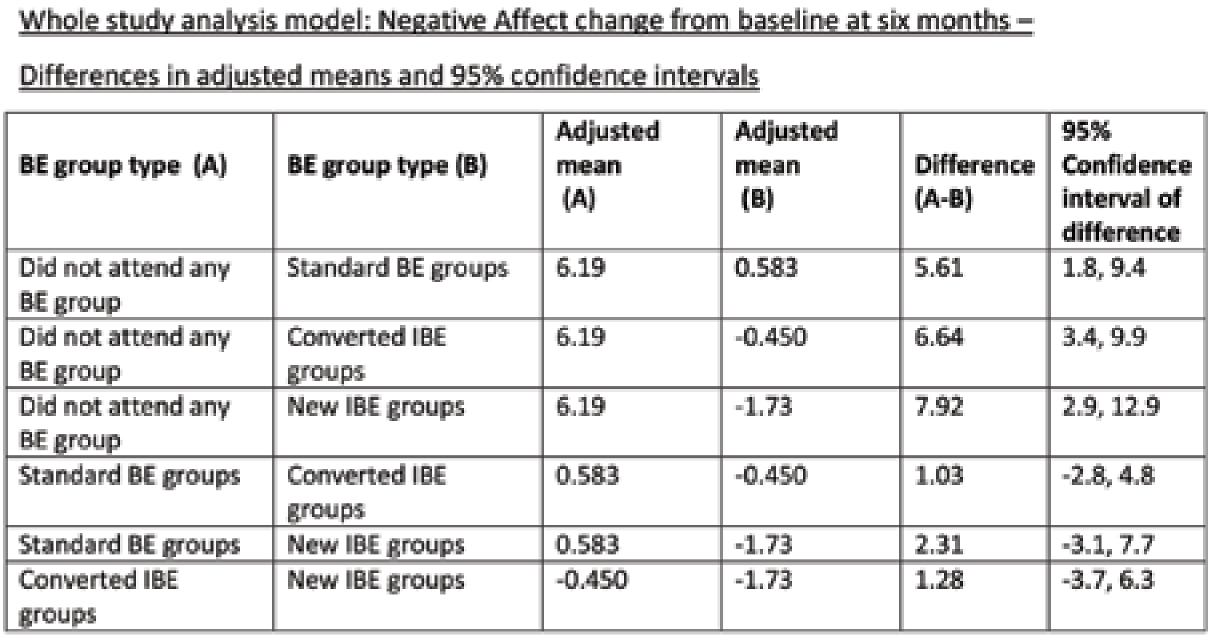
Behavioural Risk factors					Mean	Median	Standard Deviation	Range	Total N
Time	Baseline	Type of group	Control/Control group - not member of any BE group	BhRis	8.76	9.00	2.77	12.00	103
			Control group - member of non-integrated BE group	BehRis	8.91	9.00	2.82	11.00	142
			Intervention group - member of an integrated BE group	BehRis	8.65	9.00	2.76	12.00	246
			Intervention new group	BehRis	9.11	9.00	2.81	12.00	134
	6 months	Type of group	Control/Control group - not member of any BE group	BehRis	9.88	10.00	2.59	12.00	61
			Control group - member of non-integrated BE group	BehRis	9.58	10.00	2.73	12.00	55
			Intervention group - member of an integrated BE group	BehRis	8.94	9.00	2.89	12.00	86
			Intervention new group	BehRis	9.21	9.00	2.93	12.00	34
	Change from baseline at 6 months	Type of group	Control/Control group - not member of any BE group	BehRis change	1.60	1.00	2.12	11.00	61
			Control group - member of non-integrated BE group	BehRis change	.69	1.00	2.63	11.00	55
			Intervention group - member of an integrated BE group	BehRis change	-.08	.00	2.05	9.00	86
			Intervention new group	BehRis change	.67	.00	2.01	7.00	34

APPENDIX XI: NEGATIVE AFFECT CHANGE FROM BASELINE TO SIX MONTHS



BE group analysis model: Negative Affect change from baseline at six months – Differences in adjusted means and 95% confidence intervals

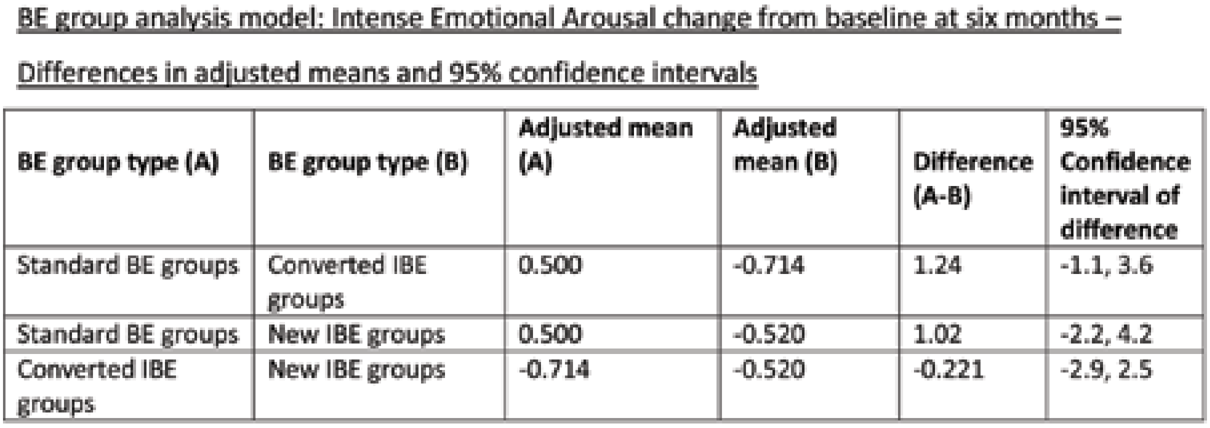
BE group type (A)	BE group type (B)	Adjusted mean(A)	Adjusted mean (B)	Difference (A-B)	95% Confidence interval of difference
Standard BE groups	Converted IBE groups	0.591	-0.433	1.02	-3.9, 5.9
Standard BE groups	New IBE groups	0.591	-1.64	2.23	-4.7, 9.1
Converted IBE groups	New IBE groups	-0.433	-1.64	1.21	-4.6, 7.0



Whole study analysis model: Negative Affect change from baseline at six months – Differences in adjusted means and 95% confidence intervals

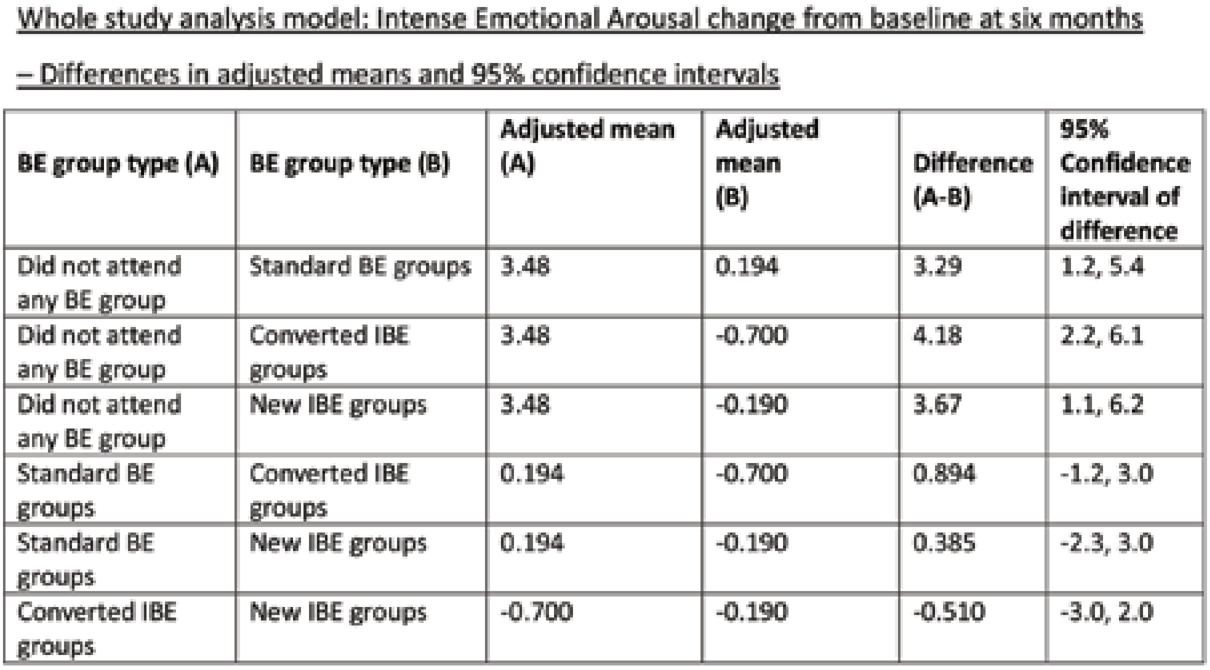
BE group type (A)	BE group type (B)	Adjusted mean (A)	Adjusted mean (B)	Difference (A-B)	95% Confidence interval of difference
Did not attend any BE group	Standard BE groups	6.19	0.583	5.61	1.8, 9.4
Did not attend any BE group	Converted IBE groups	6.19	-0.450	6.64	3.4, 9.9
Did not attend any BE group	New IBE groups	6.19	-1.73	7.92	2.9, 12.9
Standard BE groups	Converted IBE groups	0.583	-0.450	1.03	-2.8, 4.8
Standard BE groups	New IBE groups	0.583	-1.73	2.31	-3.1, 7.7
Converted IBE groups	New IBE groups	-0.450	-1.73	1.28	-3.7, 6.3

APPENDIX XII: INTENSE EMOTIONAL AROUSAL CHANGE FROM BASELINE AT SIX MONTHS



BE group analysis model: Intense Emotional Arousal change from baseline at six months – Differences in adjusted means and 95% confidence intervals

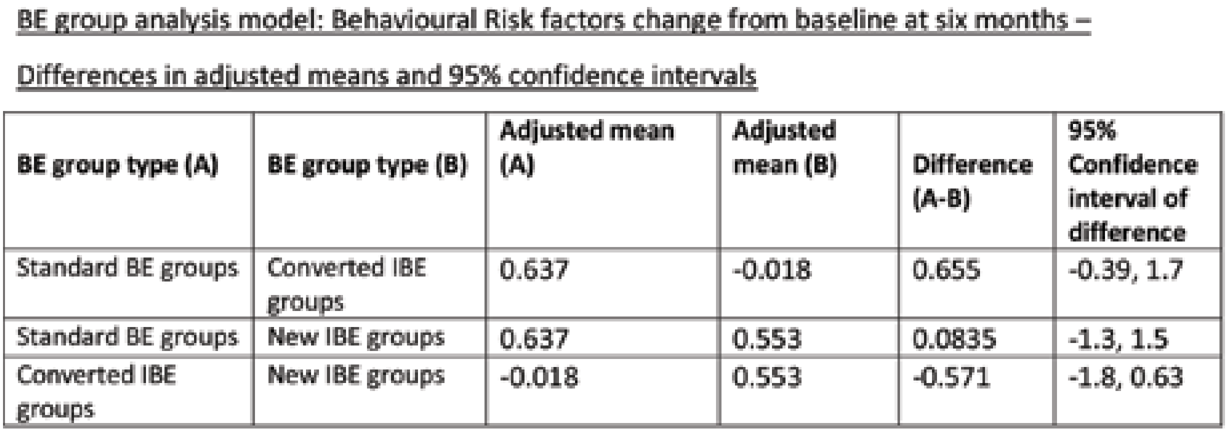
BE group type (A)	BE group type (B)	Adjusted mean (A)	Adjusted mean (B)	Difference (A-B)	95% Confidence interval of difference
Standard BE groups	Converted IBE groups	0.500	-0.714	1.24	-1.1, 3.6
Standard BE groups	New IBE groups	0.500	-0.520	1.02	-2.2, 4.2
Converted IBE groups	New IBE groups	-0.714	-0.520	-0.221	-2.9, 2.5



Whole study analysis model: Intense Emotional Arousal change from baseline at six months – Differences in adjusted means and 95% confidence intervals

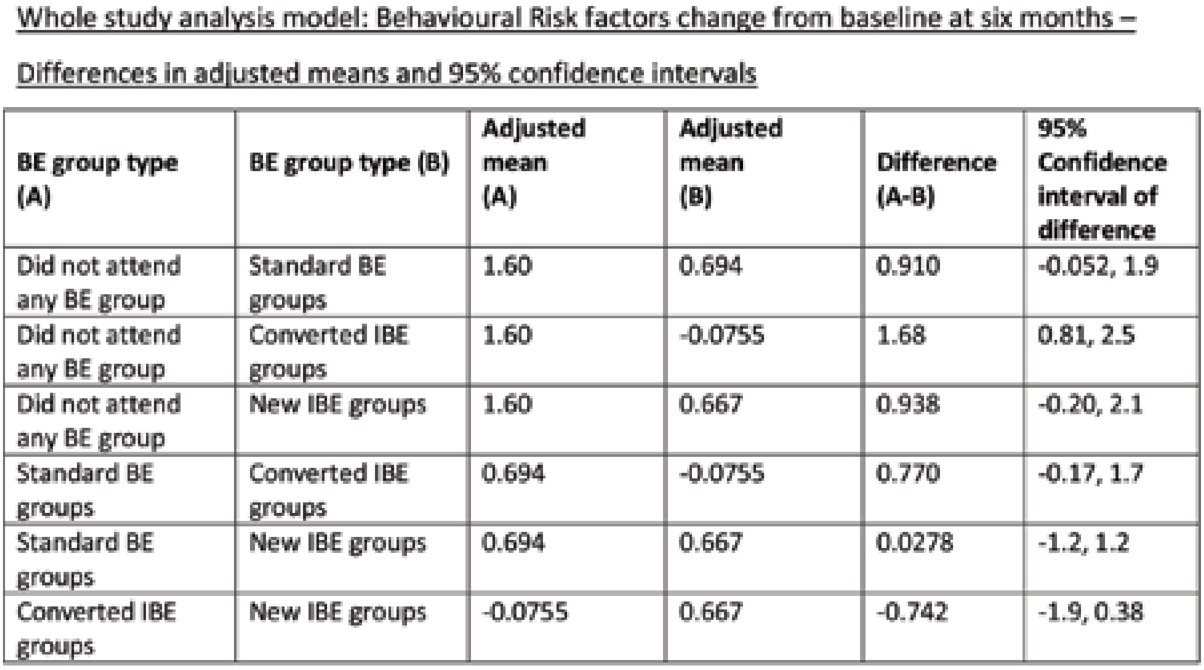
BE group type (A)	BE group type (B)	Adjusted mean (A)	Adjusted mean (B)	Difference (A-B)	95% Confidence interval of difference
Did not attend any BE group	Standard BE groups	3.48	0.194	3.29	1.2, 5.4
Did not attend any BE group	Converted IBE groups	3.48	-0.700	4.18	2.2, 6.1
Did not attend any BE group	New IBE groups	3.48	-0.190	3.67	1.1, 6.2
Standard BE groups	Converted IBE groups	0.194	-0.700	0.894	-1.2, 3.0
Standard BE groups	New IBE groups	0.194	-0.190	0.385	-2.3, 3.0
Converted IBE groups	New IBE groups	-0.700	-0.190	-0.510	-3.0, 2.0

APPENDIX XIII: BEHAVIOURAL RISK FACTORS CHANGE FROM BASELINE AT SIX MONTHS



BE group analysis model: Behavioural Risk factors change from baseline at six months – Differences in adjusted means and 95% confidence intervals

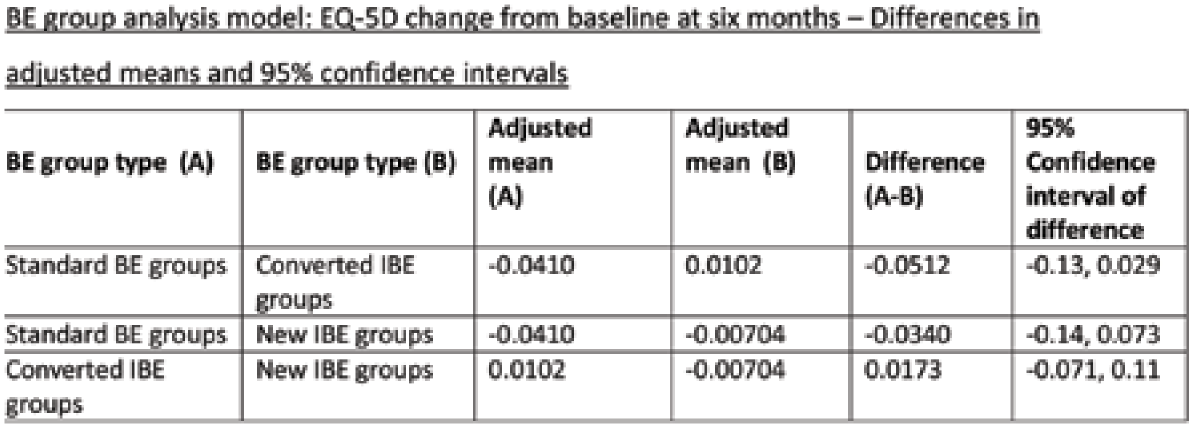
BE group type (A)	BE group type (B)	Adjusted mean (A)	Adjusted mean (B)	Difference (A-B)	95% Confidence interval of difference
Standard BE groups	Converted IBE groups	0.637	-0.018	0.655	-0.39, 1.7
Standard BE groups	New IBE groups	0.637	0.553	0.0835	-1.3, 1.5
Converted IBE groups	New IBE groups	-0.018	0.553	-0.571	-1.8, 0.63



Whole study analysis model: Behavioural Risk factors change from baseline at six months – Differences in adjusted means and 95% confidence intervals

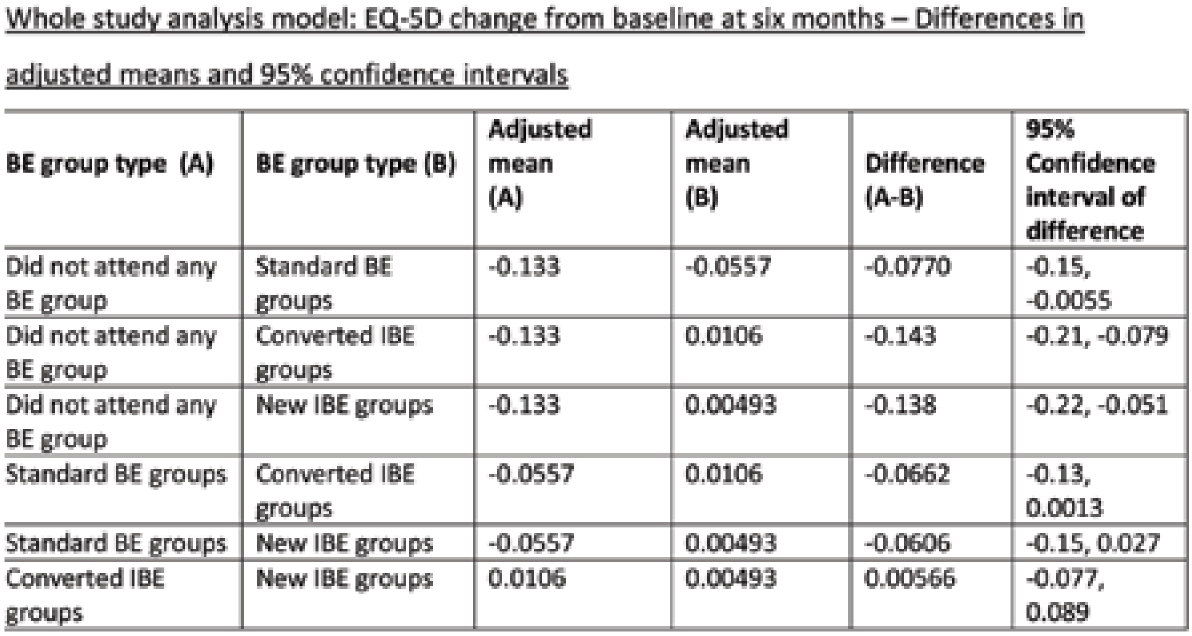
BE group type (A)	BE group type (B)	Adjusted mean (A)	Adjusted mean (B)	Difference (A-B)	95% Confidence interval of difference
Did not attend any BE group	Standard BE groups	1.60	0.694	0.910	-0.052, 1.9
Did not attend any BE group	Converted IBE groups	1.60	-0.0755	1.68	0.81, 2.5
Did not attend any BE group	New IBE groups	1.60	0.667	0.938	-0.20, 2.1
Standard BE groups	Converted IBE groups	0.694	-0.0755	0.770	-0.17, 1.7
Standard BE groups	New IBE groups	0.694	0.667	0.0278	-1.2, 1.2
Converted IBE groups	New IBE groups	-0.0755	0.667	-0.742	-1.9, 0.38

APPENDIX XIV: EQ-5D CHANGE FROM BASELINE TO SIX MONTHS



BE group analysis model: EQ-5D change from baseline at six months – Differences in adjusted means and 95% confidence intervals

BE group type (A)	BE group type (B)	Adjusted mean (A)	Adjusted mean (B)	Difference (A-B)	95% Confidence interval of difference
Standard BE groups	Converted IBE groups	-0.0410	0.0102	-0.0512	-0.13, 0.029
Standard BE groups	New IBE groups	-0.0410	-0.00704	-0.0340	-0.14, 0.073
Converted IBE groups	New IBE groups	0.0102	-0.00704	0.0173	-0.071, 0.11

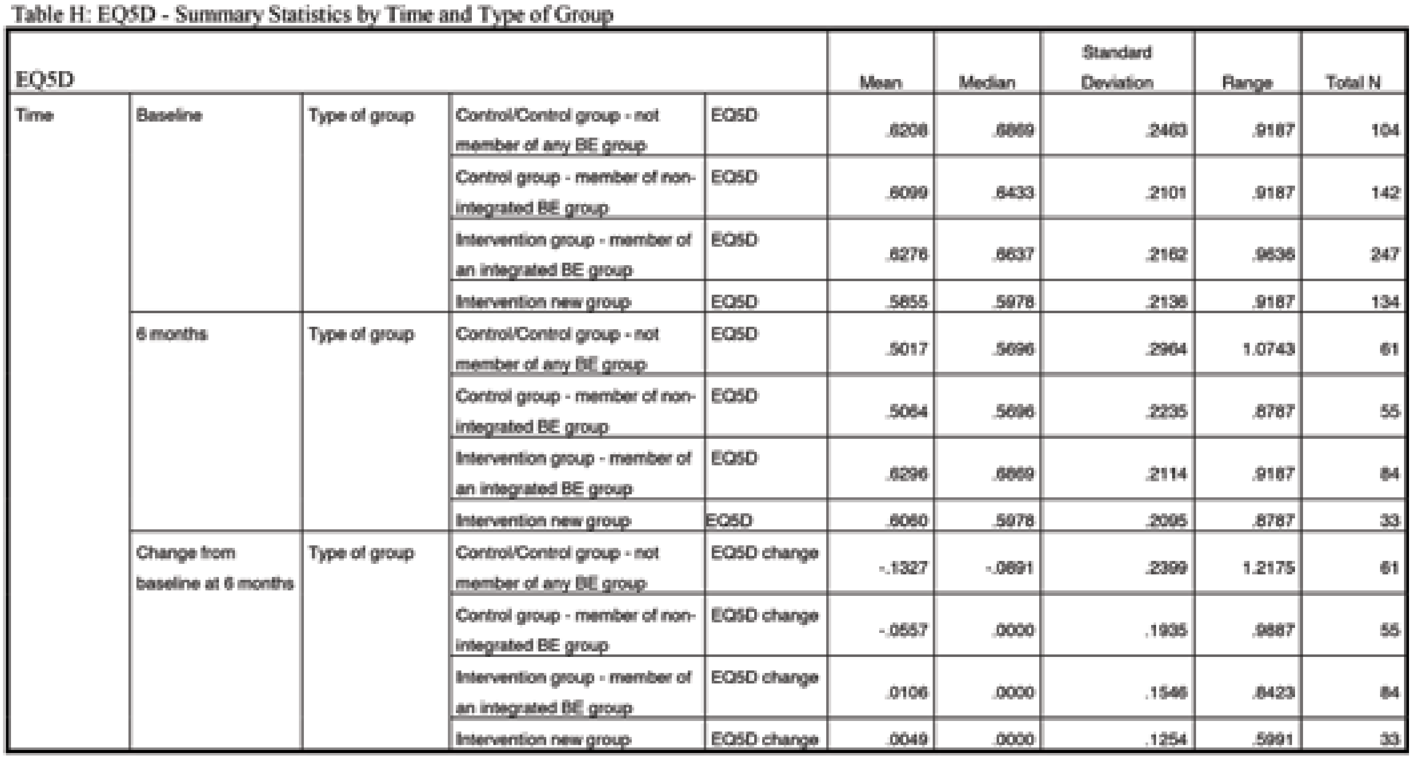


Whole study analysis model: EQ-5D change from baseline at six months – Differences in adjusted means and 95% confidence intervals

BE group type (A)	BE group type (B)	Adjusted mean (A)	Adjusted mean (B)	Difference (A-B)	95% Confidence interval of difference
Did not attend any BE group	Standard BE groups	-0.133	-0.0557	-0.0770	-0.15, -0.0055
Did not attend any BE group	Converted IBE groups	-0.133	0.0106	-0.143	-0.21, -0.079
Did not attend any BE group	New IBE groups	-0.133	0.00493	-0.138	-0.22, -0.051
Standard BE groups	Converted IBE groups	-0.0557	0.0106	-0.0662	-0.13, 0.0013
Standard BE groups	New IBE groups	-0.0557	0.00493	-0.0606	-0.15, 0.027
Converted IBE groups	New IBE groups	0.0106	0.00493	0.00566	-0.077, 0.089

APPENDIX XV: SUMMARY STATISTICS FOR EQ-5D AT BASELINE AND SIX MONTHS

Table H: EQ5D - Summary Statistics by Time and Type of Group



EQ5D					Mean	Median	Standard Deviation	Range	Total N
Time	Baseline	Type of group	Control/Control group - not member of any BE group	EQ5D	.6208	.6869	.2463	.9187	104
			Control group - member of non-integrated BE group	EQ5D	.6099	.6433	.2101	.9187	142
			Intervention group - member of an integrated BE group	EQ5D	.6276	.6637	.2162	.9636	247
			Intervention new group	EQ5D	.5855	.5978	.2136	.9187	134
	6 months	Type of group	Control/Control group - not member of any BE group	EQ5D	.5017	.5696	.2964	1.0743	61
			Control group - member of non-integrated BE group	EQ5D	.5064	.5696	.2235	.8787	55
			Intervention group - member of an integrated BE group	EQ5D	.6296	.6869	.2114	.9187	84
			Intervention new group	EQ5D	.6060	.5978	.2095	.8787	33
	Change from baseline at 6 months	Type of group	Control/Control group - not member of any BE group	EQ5D change	-.1327	-.0891	.2399	1.2175	61
			Control group - member of non-integrated BE group	EQ5D change	-.0557	.0000	.1935	.9887	55
			Intervention group - member of an integrated BE group	EQ5D change	.0106	.0000	.1546	.8423	84
			Intervention new group	EQ5D change	.0049	.0000	.1254	.5991	33

APPENDIX XVI: LIMITATIONS TO STUDY

As with all evaluation studies, there were some limitations which should be noted. Initially the research team had planned to randomise by group, as opposed to individuals attending the groups, as the intervention is by nature a group intervention lending itself to a cluster randomised design. However, this was not done, as it quickly came apparent from the process evaluation interviews with professionals working at a CCG level, that they wanted data from their areas specifically. Therefore if the research team did randomise and their local BE group was not included, then this data would not be available to them.

The standard BE groups were often much smaller in size than the integrated BE groups (i.e. had fewer members) and also were more likely to drop-out of the study, despite members of the research team often visiting the groups to explain about the study. This was partly caused by their small group numbers, but also the fact that they felt less engaged and attached to the BLF as the integrated groups did.

To ensure a robust evaluation of the outcomes, existing survey instruments were used as these had been previously validated. As with all survey instruments there were some limitations with these. For example, in relation to the Warwick-Edinburgh Mental Wellbeing Scale, although widely used in the UK to evaluation services and impact of policies, there are no social values attributed to the scores. Therefore, when doing the cost-effectiveness analysis, we were unable to use this data.

Finally, at baseline participants were asked basic demographic information, including age, gender, marital status, and employment status. However, as participants were joining the groups at different time points, often those attending the group for the first time completed a 6-month survey pack which did not have the demographic questions attached. Therefore, there is missing demographic data, and therefore we could not include individual level baseline covariates in the statistical analysis as originally planned.

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