Exercise, COPD & Me

A Social Return On Investment Study For Siel Bleu Ireland

9 January 2020

Siel Bleu IRELAND

WHITEBARN CONSULTING

SOCIAL VALUE INTERNATIONAL

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Awarded 9 January 2020

Ben Carpenter

Chief Executive Officer
Social Value International

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Siel Blue Ireland is a social enterprise with registered charity status. It is part of the international Siel Bleu network that also has operations in France, Belgium and Spain. Two French sport science graduates established Siel Bleu in 1997 with a view to addressing the unmet physical activity needs of older adults. Siel Bleu provides older people with life enhancing adapted exercise programmes irrespective of their background, health status or level of ability. Siel Bleu Ireland came into being in 2010 as part of an Ashoka Changemakers initiative. Starting with only three weekly classes with a handful of participants, today it provides services to almost 6,000 individuals per week. These are delivered in nursing homes and day care centres, in community settings and in private homes. *Exercise, COPD & Me* is only one of a number of programmes run by Siel Bleu Ireland.

www.sielbleu.ie

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Whitebarn Consulting was established by Sandra Velthuis in 2005. Whitebarn Consulting provides a range of supports to community groups, charities, voluntary bodies, non-governmental organisations, social enterprises, and the private and public sector bodies that work with them. More than 100 clients have been served since Whitebarn Consulting was set up. Most Whitebarn Consulting contracts focus on outcomes, impact and social value. Sandra was the first Accredited Practitioner of Social Return On Investment (SROI) in the Republic of Ireland. She is a member of Social Value International and The Wheel.

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Social Value UK for the provision of assurance services on behalf of Social Value International.

If only I'd known

If only I'd known a long time ago the way the things would turn out as I would grow
Taking pills day after day
No difference in dose from December to May
Cough and spluttering it's not very nice
Shortening of breath affecting your life
Social life curtailed when things are bad
All in all you can feel quite sad
Having a belly laugh not any more
Even a good cry is out of the door
It's hard to explain
You can't make it right
Walking the floor through the night
What's happened to my wardrobe
It gave me such a fright
Push and shove
Squeeze and pull
They still won't fit me right
I didn't know the tablets would have these side effects
Someone should have told me just what to expect
There can be a lot of bad days
Good ones can be few
But make the most of everyone enjoying what you can do
Being positive can be hard
But try with all your might
Cos after all you're still alive
So follow your Doctor's advice

Ann Murphy (COPD Support Ireland) [1]

Acronyms used in report

APA	Adapted Physical Activity
CAT	COPD Assessment Test
CEO	Chief Executive Officer
COPD	Chronic Obstructive Pulmonary Disease
GP	General Practitioner
HSE	Health Service Executive
MUST	Malnutrition Universal Screening Tool
OECD	Organisation for Economic Cooperation and Development
PCCC	Primary, Community and Continuing Care
PRP	Pulmonary Rehabilitation Programme
SROI	Social Return On Investment

[Note that numbers used in this report have been rounded up and down to the nearest integer wherever possible]

Contents

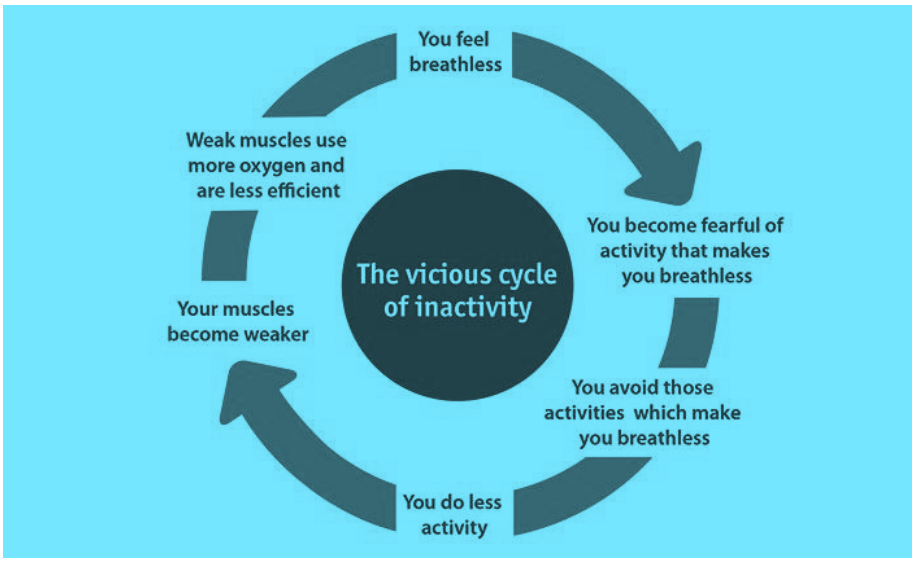
Why this evaluation?

Because COPD is so prevalent

Chronic Obstructive Pulmonary Disease (COPD) is the umbrella term for lung conditions that limit the airways and cause breathing difficulties (notably chronic bronchitis and emphysema). It mostly affects people over the age of 35, with a particular prevalence amongst the over-70s [2] and those from lower socio-economic groups [3]. More than 500,000 people in Ireland are believed to be living with COPD, although less than half of these have been diagnosed [4]. A decrease in COPD rates due to a societal reduction in smoking [5] is likely to be offset by a growing and ageing population, at least in the medium-term. Any initiative that has the potential to benefit such large numbers of people should be properly evaluated.

Because COPD is such a serious condition

COPD is a chronic, lifelong condition, with direct and indirect costs to individuals, their loved ones, the healthcare system, and so on. Whilst the symptoms of COPD can be managed with medication and lifestyle changes, it cannot be cured. COPD is progressive and the more severe it is, the greater the negative impact. A vicious cycle of inactivity [6] has been identified, as illustrated in below. Ireland has the highest hospital admission rate for COPD in the OECD [7] [8]. COPD is the fourth leading cause of death worldwide [9] and Ireland has one of the highest mortality rates from COPD in Europe [10]. It is vital that there is solid evidence about the value of any interventions that might enable the disease to be managed better.



Because there is already evidence that Siel Bleu interventions work

Since its inception, Siel Bleu Ireland has received much positive feedback about its programming from many quarters and has been in receipt numerous awards [11]. Furthermore, its internal monitoring systems suggest that real improvements are indeed being made as a result of its programmes. Such evidence is encouraging, but is not always enough on its own; occasionally, external research is warranted.

An example of such external research was the HAPPIER project undertaken in 2013, which evaluated the Siel Bleu nursing home programme across Europe [12]. This randomised control trial undertaken by the Paris School of Economics and School for Advanced Public Health Studies, found that older persons' stability increased and they had fewer falls, which resulted in substantial savings for the healthcare system. The subjective wellbeing of participants also increased significantly, and there were spin-off benefits for healthcare staff.

It was in this buoyant context that Siel Bleu Ireland commenced its *Exercise, COPD & Me* programme in 2014. The programme was developed collaboratively between Siel Bleu Ireland, COPD Support Ireland, St Michael's Hospital in Dun Laoghaire and Professor Tim McDonnell, who is a consultant respiratory physician and the National Clinical Lead for the Health Service Executive (HSE) COPD Programme. It was funded by pharmaceutical company Boehringer Ingelheim. The programme was not created in isolation and itself used – and continues to use – high quality research that points to the benefits of regular exercise for pulmonary rehabilitation [13] [14] [15] [16] [17] [18] [19] [20] [21]. Initial results [22] and ad hoc feedback certainly suggest that the *Exercise, COPD & Me* programme is very worthwhile to a range of different individuals and organisations. Given the scale of the programme today, Siel Bleu Ireland believes that more in-depth analysis of the programme's social value is necessary.

Because of the remaining needs that Siel Bleu Ireland programmes can meet

Siel Bleu Ireland is convinced that it is doing important work. It would like to expand its reach so that as many people as possible have the opportunity to benefit from its programmes. In order to persuade potential beneficiaries, donors, funders and partners of the benefits of its programmes, the organisation needs further high quality, up-to-date evidence to back up its assertions. Commissioning a fresh and independently verified study of one of its most promising programmes will undoubtedly help in this regard.

Because it will provide important learnings for Siel Bleu Ireland

Any third-party evaluation is likely to bring to the fore information that might not otherwise have been uncovered. Siel Bleu Ireland is very receptive to receiving such insights, whether positive or negative, and has committed to using them to improve the *Exercise, COPD & Me* programme. It may also be able to apply such learnings to its other programmes. Siel Bleu Ireland is particularly interested in finding out if the approach used to in this study to assess social impact/value might be replicable to its other patient group programmes [23].

Because it will provide important learnings for others

Additionally, Siel Bleu Ireland may be able to share its learnings with external bodies. For instance, other members of the Siel Bleu network may wish to take on board the Irish findings. Also, Siel Bleu Ireland may be able to use the report to further raise awareness amongst policy makers of the important role physical activity can play in the lives of older adults and adults living with illness. Finally, Medtronic, which began investing in *Exercise, COPD & Me* in 2015, is also interested in measuring the social value of the programme.

The research process

Adhering to the principles of social value [24]

1: Involve stakeholders
2: Understand what changes
3: Value the things that matter
4: Only include what is material [25]
5: Do not over-claim
6: Be transparent
7: Verify the result

Scoping the evaluation

This is not the report of a medical trial. Whilst medical research is referred to where appropriate and whilst any physio-psycho-social metrics that have been gathered are used to full effect, its primary goal it is to understand the extent to which different people/organisations value all notable changes that have come about as a result of the *Exercise, COPD & Me* programme.

It is second nature for us to think and talk about financial value: the same is not true for social value. We know certain things in life are far more important than money, but we often find it difficult to explain why this is so and we struggle to value these things, which can lead to them being under-appreciated and not properly accounted for. This is where social value studies, such as this one, come in. These studies do not pretend to provide the perfect answers to difficult questions. However, they do go some way to calculating, in a robust and transparent manner, the value of changes that are caused by activities. SROI studies do this by using, wherever possible, the unit with which people are already familiar – money – in a process that is known as 'monetisation'. This does not mean that all of the figures that are shown in this report are actual cash flows that have taken place. It simply means that an attempt has been made to equate the value that people place on certain benefits/disbenefits caused by the programme to other things that they attach importance to in their lives, and at the same time compare these to the value of any financial and non-financial resources they have invested, so that the 'social return' of the programme can be established.

This evaluation does not purport to value the entire Siel Bleu Ireland organisation. The only aspect of its work that is being evaluated is its community-based *Exercise, COPD & Me* programme. This includes all aspects of the programme from design to delivery to evaluation. It also includes the informal (but as will be shown, no less important) socialising that most programme participants engage in before, during or after the formal classes.

The period under evaluation is January to December 2018, which reflects the organisation's financial year. Work that took place prior to 1 January 2018 or since 31 December 2018 is therefore not valued, although it is occasionally mentioned to provide context. It is, however, acknowledged that values generated by the programme during 2018 may be reaped in 2019 and beyond.

Mapping stakeholders

Stakeholders in this context are the individuals and organisations that experienced change as a result of the activities undertaken by Siel Bleu Ireland in the roll-out of its *Exercise, COPD & Me* programme. Stakeholders are best placed to describe the changes they experience as a result of programming and their views should inform the results, alongside other information gathered. It is important to ascertain who the key stakeholders are, that is; those who change most directly and most notably. Those stakeholders judged as not being in receipt of material outcomes were therefore excluded (see table below).

Stakeholder	Include?	Notes
COPD Support Ireland	Yes	Direct beneficiary
People with COPD participating in programme	Yes	Direct beneficiaries
Family members/friends of participants	Yes	Indirect beneficiaries
Siel Bleu Ireland trainers	Yes	Indirect beneficiaries
Community venues	Yes	Indirect beneficiaries
Healthcare professionals	Yes	Indirect beneficiaries
The state (HSE)	Yes	Indirect beneficiary
Local Sports Partnerships	No	Not aligned [26]
Programme creators	No	Too historical
Medtronic	No	Too distant from programme delivery

Engaging stakeholders

Adhering to the *Ethical Guidelines* of the Social Research Association [27], a stakeholder engagement plan was drawn up. This commenced with informal discussions with a handful of current and former representatives from Siel Bleu Ireland and COPD Support Ireland to fully understand the programme and the environment in which it operates.

In order to gain clarity on the different outcomes generated for different stakeholders, research that was primarily qualitative in nature was then undertaken. The classes themselves were of primary interest in this regard. Resource constraints meant it was not possible to engage directly with all 16 local COPD Support Ireland groups that ran classes. The in-depth knowledge of Siel Blue Ireland staff was instead used to select three groups that were as representative of the whole as possible, in terms of their geographical location, socio-economic status of the catchment area, class size and length of operation. The consultant observed one *Exercise, COPD & Me* class at each location and had informal chats with venue staff and trainers. The three classes were preceded or followed by focus groups that addressed the questions listed in appendix 1. Twenty-five people – 23 with a breathing condition and two family members – participated in the focus groups. Taken together, the class observations and the discussions on the day with programme participants, family members, venue staff and trainers, satisfied the consultant that consultees were sufficiently diverse to gain a reasonable first impression of the effects of the programme on its main stakeholders.

Furthermore, all of the trainers who had contributed to the programme during the year under evaluation were invited to participate in a one-to-one telephone interview; seven took up this offer. Finally, Siel Bleu Ireland provided the details of a number of HSE staff who they felt had a fair to good understanding of the programme and these were contacted; four chose to be interviewed. These public servants were also the primary informants about the effects of the programme on the state [28]. The interview skeleton used for these conversations can be found in appendix 2.

Then, to help the process of evidencing and valuing the outcomes, largely quantitative research was undertaken by means of two surveys. Both surveys were anonymous in order to generate honest answers.

Firstly, an incentivised [29] paper-based [30] survey for participants and their relatives/friends was publicised. Copies of the survey were handed out by trainers over a two-week period at the 16 relevant classes. Trainers provided attendees with an explanation of the importance of completing the survey. Those present were asked to bring home at least one further survey for a family member or friend and they were also encouraged to give copies of the survey to anyone with whom they were in contact but who were absent on the day or no longer attending after doing so in 2018. This survey garnered 114 responses (see appendix 3).

Secondly, a short online survey was sent to more than 30 pertinent healthcare professionals whose contact details had been identified through Siel Bleu Ireland files, the initial round of telephone interviews and an online search, with a request that this survey be completed and circulated amongst relevant colleagues. This survey achieved a further 14 responses (see appendix 4).

Describing programme inputs, activities and outputs

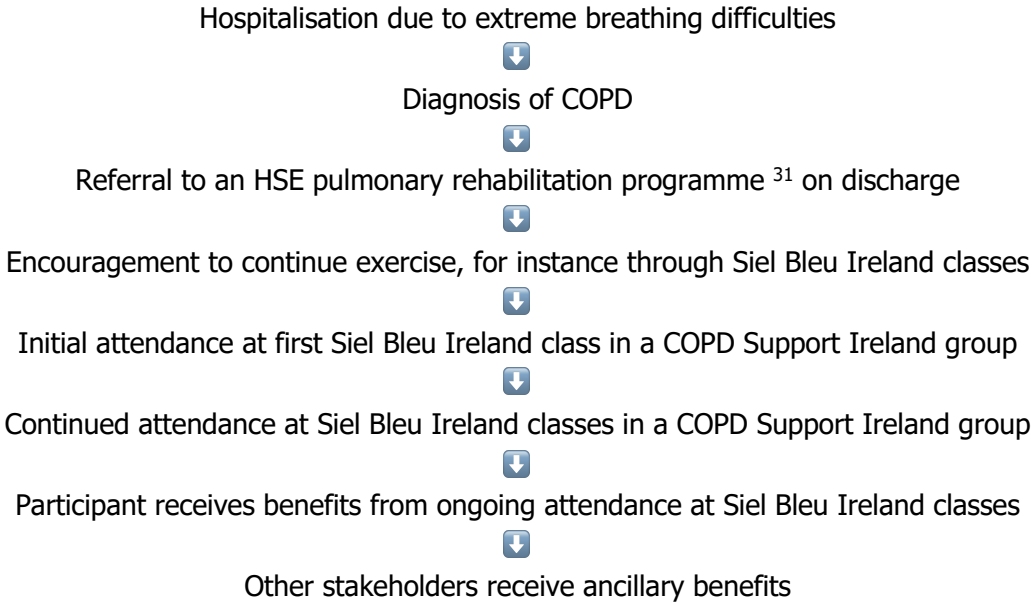
Detailed information on all aspects of the programme was gathered, synthesised and written up.

Mapping and evidencing outcomes

Outcomes are the changes that occur as a result of programme activities. They can be major or minor, positive or negative, anticipated or unexpected. Some outcomes are direct and immediate. At other times, there are one or more intermediate outcomes leading to ultimate outcomes.

People suffering from breathing problems are without doubt the primary beneficiaries of the *Exercise, COPD & Me* programme. However, some outcomes were also generated for their family and friends, for the trainers delivering the sessions, for the community venues where the sessions were held, for healthcare professionals, for the state and for COPD Support Ireland. Each of these is considered in turn in the chapters that follow. Note that whilst Siel Bleu Ireland invested in the programme, no outcomes have been allocated to the organisation itself, nor to its office-based staff.

It became apparent during the course of the research that there was not one single outcomes pathway for a person with COPD, nor for those individuals and agencies around them, although a typical route might look something the below:



During the qualitative phase of the research, the focus group and interview skeletons were used as the starting point for detailed discussions with stakeholders about their experience of, and views on, the programme. Whilst stakeholders were invited to talk freely, they were also gently guided to think about the programme through a social value lens, which was an alien concept to most of them. Probing questions were asked as necessary. The copious notes of these discussions were analysed thematically to identify one or more relevant and discrete outcomes for each stakeholder group, as well as the order in which these changes happened, enabling logical 'chains of events' to be drawn up. The outcomes in the chain tested for materiality (relevance) are underlined. To increase confidence in the chains of events, they were triangulated with external research wherever possible. The descriptions of the outcomes were also tested for sense and clarity with Siel Blue Ireland staff before the start of the quantitative phase.

For each stakeholder group, the question was asked 'should this group be subdivided because they experience different changes?'. In particular, it was expected that there would be material differences between the outcomes experienced by various kinds of programme users, reflecting differences in where they were living, which support group they attended, how much they got out of the classes, and so on. However, despite searching for these, no discernible patterns were in fact evident and it was eventually deduced that it was not the case that there were clearly identifiable subgroups. The only subgroups that could be defined with any certainty were those within the stakeholder group who had experienced the change (and were therefore included) and those who had not (and were thus excluded).

Unanticipated and negative outcomes were specifically sought out. Unintended results were few, but where they occurred, they were incorporated into the chains of events. No negative outcomes were in fact identified by stakeholders. However, it was found that there would be scope to release further social value in the future by making certain changes both to the programme [32] and to the context in which it operates. Suggestions for how various obstacles might be removed are given at the end of each outcomes chapter.

Valuing outcomes

A range of valuation techniques are available to those calculating SROI [33], including revealed preference, stated preference, wellbeing valuation and cost-based methods. The choice of monetisation approach will be informed by many factors, including the nature of the outcome, the audience for the results and the availability of resources. In this study, a mix of techniques was used, as described in each section. Hard data, proxies and reasonable estimates were used to establish equivalent monetary values for each outcome and these were tested for sense and clarity with those verifying the results. In order not to overclaim, any assumptions made were named, a very conservative approach to the calculation of value was adopted, and care was taken not to double-count. This almost certainly means that the total social value generated by the Siel Bleu Ireland *Exercise, COPD & Me* programme has been underestimated, but this is preferable to overclaiming one's social value.

The process of valuing outcomes included consideration of the commencement and duration of outcomes (where proxies were used, care was taken to ensure these relate to the same duration as the outcomes) and the amount of change effected. It also included examination of the following:

- Deadweight: would the outcome have happened anyway, in the absence of Siel Bleu Ireland? [34]
- Displacement: did the outcome lead to another outcome, possibly a negative outcome, happening elsewhere?
- Attribution: was the outcome caused solely by Siel Bleu Ireland or did other organisations or people also play a part?
- Drop-off: does the effect of the outcome last or does it lessen over time?

Consultees were primarily asked questions about these factors during the qualitative phase, with fewer questions of this nature being posed in the quantitative phase, where there was a greater reliance on external research and professional judgement.

By doing the above, a further assessment could be made about the materiality of outcomes; namely, were they still sufficiently significant to be accounted for?

Calculating the social return

To calculate the programme's impact, for each outcome, the number of stakeholders experiencing the change was multiplied by the selected value. If applicable, percentage deductions were then made for deadweight, displacement, attribution and drop-off. Standard calculations were undertaken to discover the programme's SROI, which was then subject to a sensitivity analysis (see appendix 5).

Note that this report is supplemented by a 'value map', which is an Excel spreadsheet containing all the calculations necessary to determine the programme's social return. Due to the nature of the value map, there is a potential to become overly fixated on the final figure indicating the programme's social return in numerical form and to ignore the rich narrative that precedes it. Whilst every effort has been made to manage the research process to the highest professional standards and whilst the rationale for all calculations is reported transparently throughout, it should be remembered that the final figure presented is inherently risky. Reasons for this are many and include:

- Not having been in a position to gauge the views of every single stakeholder and thereby potentially missing out on unheard views
- A potential simplification of chains of events, because people's lives are not linear
- Using average scores from surveys where the range of responses was broad, not narrow
- Having been forced to estimate where hard figures were unavailable
- Having used imperfect proxies, often from a different jurisdiction, where no better alternatives appeared to be available
- Arguably not having sourced sufficiently robust information from stakeholders about the more technical aspects (deadweight, displacement, attribution and drop-off)
- A lack of time and money to verify the report results with all stakeholders
- Research bias [35].

It is nonetheless hoped that the professional judgements made are sufficiently sound for readers to trust the evaluation results and, where appropriate, implement the arising recommendations.

Verifying, assuring and embedding

Final feedback on the emerging narrative and results was sought from five high-level verifiers:

Verifier	Rationale
Board member of Siel Bleu Ireland	Patient advocacy expert involved in setting up the initial *Exercise, COPD & Me* programme and with a particular knowledge of apposite research and the healthcare system
National Manager of Siel Bleu Ireland	Senior staff member, providing oversight of Siel Bleu Ireland, the research project, relations with COPD Support Ireland and other key matters
Brand and Communications Manager of Siel Bleu Ireland	Project manager of the research project with an excellent understanding of both the organisation's internal workings and its external relationships
Development Officer of Siel Bleu Ireland/trainer	Key staff member with an in-depth knowledge of all aspects of the programme, including day-to-day contact with participants, trainers, community venues and healthcare professionals
Chairperson of the board of COPD Support Ireland	Senior healthcare professional specialising in respiratory medicine, with a very good understanding of the main beneficiary group, the HSE and its staff and the patient support group

Verifiers' commentary was limited; it was broadly felt that the draft report represented the programme and the social value it generates for different stakeholders in a fair manner. Reasonable suggestions for making changes to the language used and cross-referencing additional research were actioned.

The report was then submitted to Social Value International for external assurance. Extensive assessor feedback was reflected upon and incorporated.

Finally, the consultant and Siel Bleu Ireland discussed how the results of the study would be communicated, internally and externally, and used into the future to make programme improvements.

Programme inputs

Inputs overview
Inputs are the resources, financial and non-financial, that were invested into the programme. Different stakeholders made different levels of investment, but not all of these were subsequently valued, as shown below.

Siel Bleu Ireland
During 2018, Siel Bleu Ireland made around **€4,000** of its central funds available to the *Exercise, COPD & Me* programme.

Four staff at Siel Bleu Ireland headquarters invested time and energy into overseeing, administering and growing the programme. The amount of time given ranged from the minimal (two days by the Brand and Communications Manager) to the considerable (at least 25 days by the Development Officer, who undertakes this role in addition to occasionally delivering classes on the programme). The associated employment costs during the year were €4,798. However, as these form part of their salary, which is a staff benefit, they are not valued here as an input.

The organisation provides each trainer with an equipment bag to the value of €500, which is also used for their work on other Siel Bleu Ireland programmes (their usage on the *Exercise, COPD & Me* programme accounts for around 10% of their total usage). Additionally, each trainer carries an oximeter worth €25 to test blood oxygen levels during these classes. Equipment has to be replaced approximately every three years. The total value of equipment for the programme for the year under evaluation was therefore c. **€300** and this has been included in the valuation.

People living with COPD attending classes in local COPD Support Ireland groups
The people living with COPD and attending the classes are all members of their local support group. The costs of having the classes delivered were largely covered by the groups themselves, by charging €3 to €5 per head per class attended and by engaging in small scale fundraising activities, such as organising sales of work/seeking donations from local businesses. The groups' costs were as follows:

- A quarterly payment of €600 to Siel Bleu Ireland for the classes, totalling €30,274 for the year
- Venue rental, totalling €9,026 for the year
- Occasional ancillary costs (not valued separately due to their ad hoc nature).

However, the above total of €39,300 has been reduced by grant funding of €6,400 for the classes, because this is already counted under the state (see below). The total investment by people with COPD was therefore **€32,900**.

Most of the groups incorporated a social element (tea/coffee/lunch). Focus group participants were probed about the financial implications of this. They regarded the nominal cost of a drink/snack as an ordinary day-to-day one, not a class-specific one, and were adamant that this should therefore not be included in the calculations, as there is no obligation for individuals to join in or to purchase such refreshments. Nor has allowance been made for any time or travel costs associated with attending classes, again because participants themselves did not consider these to be sufficiently substantive or suitable for inclusion. The view was expressed that if they were not travelling to classes they would likely be travelling elsewhere, with the same time and cost implications (if any).

Their family and friends

Family members and friends of people with COPD invest concern for their loved one, but this is a nebulous concept that has not been valued. As with the participants, the view was expressed by relatives that any time costs, refreshment costs or transport costs were not any sufficiently material to be included, and this was felt to be true even if they accompanied their loved one to classes.

Exercise, COPD & Me **trainers**

The programme is delivered by qualified, experienced and vetted physical trainers who share the Siel Bleu Ireland vision and philosophy. They have degrees in sports science and similar subjects. They receive additional training for working with people who live with COPD as part of their employment package. A total of 12 trainers ran sessions during the year.

On average, a trainer spends two to three hours per session in terms of preparation, travel, set-up/pack-away, delivery and any post-session work. This investment of time and skills is reimbursed through salaries (the associated employment costs during the year were €10,459). As indicated earlier, because these form part of salaries, which are a component of the outcomes allocated to trainers, they are not valued here as an input. Some of the work undertaken by trainers, such as session planning and assisting with this evaluation, is unpaid, but has not been separately valued either due to its ad hoc nature.

Trainers use their own vehicles to travel to and from classes, but they are reimbursed for wear and tear and distance travelled at a rate of 30c/km (the total cost of which during 2018 was €6,734 – again this has not been valued separately).

Community venues hosting *Exercise, COPD & Me classes*

A total of 16 venues was used for the COPD classes. These were a hotel, arts/heritage centres, community/resource centres, church/parish halls, sports/leisure clubs and HSE primary care centres. Most, though not all, levied a venue rental charge for their premises, ranging from €5 to €50 per class. The cost of these has been allocated to the local support groups, not to the venues themselves.

Healthcare professionals

Healthcare professionals did not make a direct investment into the programme during 2018.

The state

COPD Support Ireland secured HSE National Lottery funding of **€6,400** on behalf of one of its support groups [36]. It is noted that the HSE also provides some of its primary care centres as venues, but this has not been valued separately as the state does not ordinarily charge for such venue usage.

COPD Support Ireland

It proved impossible to gain accurate data on the staffing costs incurred by this organisation in terms of supporting the *Exercise, COPD & Me* programme. The time input by the Chief Executive Officer (CEO) and a contractor has been estimated and valued at **€15,000** [37]. Any additional time that may have been spent by members of the organisation's board has not been valued as it is assumed to be very limited.

Total inputs

The total value of these inputs during the year was **€58,600**, broken down as follows:

Programme activities and outputs

Programme overview

Exercise, COPD & Me is a group-based Adapted Physical Activity (APA) programme for people living with COPD, delivered in the community to people from varying backgrounds. Its focus is not on the illness itself, but rather on the promotion of health and fitness.

Location

The programme was piloted in Bray, County Wicklow and rolled out in phases. Since the start, four groups have folded, for a variety of logistical reasons. At the time of writing, there are 23 active groups. The map below shows the 16 groups that were operational during 2018 (Athlone, Ballyfermot, Bray, Carlow, Drogheda, Finglas, Galway, Huntstown, Kilkenny, Longford, Mullingar, Sligo, Tallaght, Thurles, Waterford and Whitehall).

Activities

Classes take place nearly every week of the year: they are one hour in length and are in most cases preceded or followed by a chat over 'a cuppa'. In the classes, trainers use a mix of walking, chair-based exercises, standing exercises, and exercises using equipment such as agility mats, boxing gloves with sparring pads, sponge balls, exercise batons, strength rings, resistance bands and falls prevention equipment. A circuits approach is often employed. The exercises are tailored to the group and are adaptable for each group member, depending on their level of fitness and confidence. The pace and level of activity rises as time progresses and participants gain in confidence and ability.

Assessment
A baseline assessment usually takes place when people start on the programme. The following variables are tested:

- COPD Assessment Test (CAT) [38]
- Muscular strength: bicep curls with a dumbbell [39] over 20 seconds [40]
- Aerobic endurance: 6-minute walk test [41]
- Flexibility: back scratch test [42]
- Agility and dynamic balance: 8-foot-up-and-go test [43]
- Nutritional status: Malnutrition Universal Screening Tool (MUST) [44] [45].

Re-testing is sometimes done at 12- and/or 24-week intervals, although many participants resist retesting because they feel it takes away from exercise time.

Outputs
During 2018, 656 exercise sessions were delivered to 255 regular [46] attendees, although the total group size, including occasional attendees, was undoubtedly larger [47]. No waiting lists were in operation. It should be noted that some participants had respiratory issues other than COPD (such as asthma or pulmonary fibrosis) and some did not have respiratory problems at all, but came to accompany their loved one to class.

Local group	No. of sessions held	No. of regular attendees	Notes
Athlone	42	15	
Ballyfermot	47	20	
Bray	72	25	2 sessions per week
Carlow	40	20	
Drogheda	19	15	
Finglas	29	10	
Galway	24	8	
Huntstown	44	15	
Kilkenny	31	15	
Longford	39	15	
Mullingar	45	15	
Sligo	47	15	
Tallaght	48	20	
Thurles	39	15	
Waterford	42	10	
Whitehall	48	22	
Total = 16	**Total = 656**	**Total = 255**	

Outcomes and impact for people living with COPD

"Everyone has a cup of tea before we start. We have fun during the class but we do get a good workout I might add. Our group has become like a little family. Some of us are now meeting for coffee on a Tuesday morning to catch up on the gossip. The class has enhanced my life so much in every way, not all physically but mentally too. We all have so much in common because we understand the problems we face. Some of the group are on oxygen but it doesn't stop them from taking part, I think that's what I love most all. Everyone tries to do their best even when they are finding it hard."

How the outcomes are brought about

By definition, people with COPD are suffering ill-health (and many have comorbidities, such as high blood pressure or arthritis). Their rationale for attending the classes is to improve their health, but also their wellbeing more generally.

Whilst the benefits of exercise for managing the condition are well-known, there are numerous potential barriers that might prevent a person with COPD from realising these benefits, some of which are explored below.

People may not be aware of the existence of classes. Classes also needs to be available within reasonable travel distance from a person's home. This can be problematic in rural areas where distances are often greater than in cities and where public transport provision tends to be poor. People often have no option but to drive or be driven. Travelling is particularly difficult for those who are dependent on additional oxygen during the day.

Even if a class is available at a place and time that potentially suits, it is common for people to have fears, such as believing that exercise will make their breathlessness worse or that they will embarrass themselves. They can also be ashamed of having smoked in the past, and possibly still smoking today. Their feelings of fatigue, anxiety, depression and stigmatisation are very real. It is vital, therefore, that they are made to feel very welcome, regardless of their circumstances, and that they are properly reassured; both the trainer and the fellow participants have a role to play in this. Having strong local leadership, including ensuring that cliques do not form, appears to be very important in terms of achieving participant buy-in.

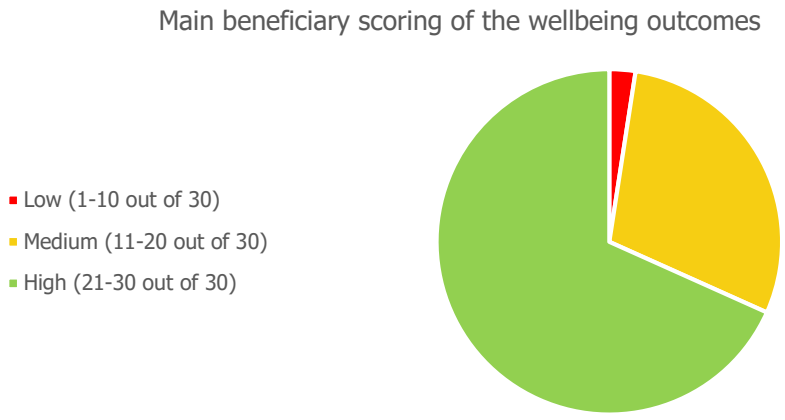
It is also possible that some people are put off by the level at which the class is pitched (finding it either too easy or too advanced) or by the profile of the group (for instance, a person aged in their forties or fifties might not wish to attend if the majority of the other people are in their seventies and eighties), and therefore stop coming. Or, they might attend but not take the class as seriously as they could (this might be expressed, for instance, by not challenging themselves enough in certain exercises, or by wearing clothing/footwear that is inappropriate for the task at hand, or by stretching out the social time at the expense of the exercise time).

Furthermore, people may be very committed to the class, but may, for a variety of reasons, struggle to attend consistently – many reported finding it especially difficult to exercise if the weather is very hot or very cold, for example. A final barrier was the perceived increased risk of infection from other people who are prone to colds and flus.

Despite all of the obstacles noted, those who do attend, and continue to do so on a regular basis, can reap many rewards. Note that many of the participants expressed a desire for more frequent classes, so that they could maximise these rewards.

Programme participants identified that their physical and their mental and their social wellbeing were improved by the programme and this was confirmed by the views of healthcare professionals, trainers and their circle of family and friends. External research would certainly back up these assertions [48]. However, care must be taken not to overclaim these outcomes, which are known to be very closely interconnected. Whilst the evidence from similar interventions for physical wellbeing improvements and social wellbeing improvements is strong, it is somewhat weaker for mental wellbeing [49] [50]. After the initial inclusion and even valuation of mental wellbeing as a separate outcome, the decision was subsequently made to remove it from the social value account. This in no way suggests that participants are not gaining psychological benefits from the *Exercise, COPD & Me* programme, but rather that those benefits are a component of their physical wellbeing and especially their social wellbeing.

The data from the main survey were analysed further to establish if subgroups of participants could be identified on the basis of outcomes achieved. Those with COPD and other breathing problems were ranked according to the scores they gave out of 10 for each of the wellbeing outcomes examined. Variety in the responses was expected and was found. But other than a handful of outliers, with no discernible pattern, respondents tended to score within a relatively narrow range and almost always for all three [51] outcomes (in other words, very few said they had not experienced any of the outcomes at all). The only clusters that could arguably be identified were those who scored very highly across all outcomes categories, those who gave medium scores, and those who scored relatively lowly, as per the chart below. However, closer inspection revealed that the two survey respondents who had given lower scores had only been attending the classes for a short period of time and may therefore not yet have reaped the programme's full benefits, and those scoring at a medium level were in fact far closer to the top end of the category than the bottom one. Armed with this information, it was decided that any further subdivision would have been artificial and was therefore avoided.



Chain of events

Overcome any potential obstacles associated with attending *Exercise, COPD & Me* classes **>** regularly attend *Exercise, COPD & Me* classes, which involves:

- Taking part in an exercise programme that has been specifically adapted for people with COPD **>** improved physical wellbeing
- Socialising with peers before and/or during and/or after classes **>** improved social wellbeing

Valuing improved physical wellbeing

Regular physical activity can slow the progress of COPD and even reverse some of its most disabling effects, even for those with severe COPD [52]. Note that exercise cannot cure COPD, however, and that impaired lung function will persist. Sometimes, improvements resulting from attending classes are highly visible, such no longer needing to use a wheelchair or a nebuliser. At other times, they are more subtle, but nonetheless beneficial in terms of an individual's physical health, fitness and wellbeing [53].

Siel Bleu Ireland pre- and post-testing reports [54] [55] [56] [57] [58] [59] show fitness improvements in the vast majority of participants, and for some participants these improvements were substantial (with social facilitation – the tendency for people to do better on simple tasks when in the presence of other people – undoubtedly playing a role). However, in some cases very little change was shown over time and in other instances, a deterioration was recorded (although more often than not this was felt to be due to having had an 'off' day). MUST screening was not done consistently and where it was undertaken, provided little useful data. It also proved difficult to compare results across different groups. Notwithstanding that the data are not for exactly the same time period as this evaluation and do not cover all of the 16 sites, they nevertheless lend confidence to the assertion that real physical wellbeing improvements are being made by the programme. Secondary data analysis for the six groups for which monitoring reports are available, shows the following mean percentage improvements for those 41-43 [60] participants tested on two separate occasions for four metrics:

Muscular strength	Aerobic endurance	Flexibility	Agility and dynamic balance
34% improvement	26% improvement	15% improvement	11% improvement

The gains in muscular strength and aerobic endurance are particularly impressive, but the increases in flexibility and agility/dynamic balance are also noteworthy.

In addition to these indicators of improved fitness, participants themselves referred to having an improved mood, being able to breathe more easily, experiencing less mucus build-up, having more energy, sleeping better, being less dependent on oxygen therapy, having to visit the doctor less frequently, having fewer crisis events and recovering more quickly when they were ill. Trainers found that participants became increasingly conscious about the need to exercise and the advantages brought about by physical activity and they often sought to challenge themselves more as a result. As their self-confidence increased, some asked for 'homework' so that they could continue to practise at home and/or started doing additional physical activities, such as walking, golf or Pilates. Furthermore, health professionals pointed to reductions in the use of medication, lowered heart rates, improved postural control and the reduced likelihood of hospital readmission. Improved cognitive function due to increased blood flow to the brain was also posited, but it is unclear whether this is a true effect.

Improved physical wellbeing appears to have been attained for everyone who took part, that is, some 255 people. Different individuals made different levels of effort, and some trainers pushed participants more than others, but it did not prove possible to subcategorise people according to the physical gains they had made. Though imperfect, an average score was therefore used. Survey respondents rated their mean physical improvement after attending the classes as eight points on a 10-point scale.

As this outcome is one pertaining to wellbeing, it is appropriate to use the wellbeing valuation approach [61]. The proxy that has been used is the value of frequent mild exercise for the over-50 age group, which matches the stakeholder group and activity. This is around €6,247 per person [62] [63], but this figure has been reduced by 20% to allow for the fact that the improvements identified were on average scored 8 out of 10, not 10 out of 10 (€4,998).

The benefits of regular exercise are felt quickly and research shows that they should last a minimum of one year afterwards [64], although the effect may drop off over time if participation discontinues; 50% drop-off has therefore been allowed. No displacement was identified.

Whilst physical activity plays a crucial role in the management of COPD, it is not the only one: diet, smoking cessation and medication are amongst a number of factors that have also be shown to be important [65]. However, the interplay of these factors is complex and no definitive attribution rates could be established from external research sources. A midway rate of 50% attribution has been used to allow for this uncertainty: factors other than the exercise classes undoubtedly enabled participants to experience relatively good physical wellbeing, but most participants were not currently smokers and most had been using drugs to manage their condition for some time before starting on the programme (little is known about participants' diets), so the programme definitely made a difference to them.

Deadweight also had to be allowed for. Siel Bleu Ireland classes may not have been participants' only option for exercising. In theory, some might have been able to achieve the same outcomes with home-based exercise, some might have felt sufficiently confident to attend a mainstream gym, others might have attempted generic gentle community-based programmes [66], and yet others might have attended specialist pulmonary classes offered by other providers [67] [68] [69]. However, a lack of money, motivation, confidence, knowledge or some other barrier would likely have prevented many from participating in such alternatives. The standard rate of 27% deadweight advised for health outcomes [70] would seem reasonable, therefore.

Total impact (physical wellbeing)
€465,189

Valuing improved social wellbeing
The nature of COPD means it can cause people with the condition to lead increasingly socially isolated and monotonous lives. Making a decision to attend the classes can signal the start of having some control over the condition, rather than being entirely controlled by it.

Many referred to the programme as being a way of 'getting you out of the house' and the classes were described by one participant as 'a weekly injection of positivity'. It is patently clear to anybody observing an *Exercise, COPD & Me* class that the participants enjoy being there immensely. Classes are professionally run to achieve fitness, but they are also fun: full of laughter and gossip. The interaction between trainers and participants is excellent and it is clear that they appreciate each other. Furthermore, the peer support provided was deemed to be very valuable, in terms of authentic encouragement, gaining tips and making new friends. There were numerous references to 'camaraderie', 'a sense of community', 'like a family', and so on. Some local groups are particularly strong in this area, operating text/WhatsApp groups, organising lifts, checking in when someone is absent, making hospital visits if someone is ill, coordinating outings, and so on. Spin-off benefits were also in evidence. Participants explained that as a result of the classes, their zest for life had returned and they felt more motivated to be socially active, both inside and outside of the class setting. Some felt able to begin to make other positive lifestyle choices, like opting for a better diet. Things which had seemed outside of their grasp, such as gardening or playing with grandchildren, once again became a possibility, which reinforced their upward spiral of emotions.

Excluding the 2% of survey respondents who said that the classes had had no positive effect on their social lives and extrapolating this to the full group, it was found that 250 people's social wellbeing had nonetheless improved. Continuing to adopt an average approach, survey respondents reported a mean improvement in their social wellbeing of eight points on a 10-point scale after attending the classes.

Wellbeing valuation would again appear to be a reasonable technique [71]. The proxy used is the value of membership of a social group for the over-50s, which is around €2,235 per person [72] [73], but in line with the previous calculations this has been reduced by 20% to account for the fact that the improvement was on average scored as 8 out of 10 (€1,788).

Although it was apparent from discussions held during the qualitative phase of the research that for a small minority of participants the exercise class was their sole social outlet, especially if they felt deeply stigmatised by their illness, the reality is for that for others they may have relatively readily accessed other ways of improving their social lives, such as in a hobby club, voluntary group or informal network. Deadweight at the standard rate of 19% advised for community and social outcomes [74] would seem reasonable, therefore, and has been allowed.

Attribution is undoubtedly a factor although the degree to which it plays a role is unclear. The focus group discussions and one-to-one interviews suggested that other players do contribute to the change. Healthcare professionals, together with family members/friends, often persuade persons with COPD to try the classes out and then encourage them to keep attending. These, therefore, need to be accounted for. Furthermore, being in a socially appealing environment on a regular basis may begin to increase participants' social networks and open up other social opportunities that contribute to their sense of social wellbeing, but these have little to do with the classes themselves. Unfortunately, no accurate information on attribution could be secured and a midway rate of 50% has been used to allow for this uncertainty.

It is also uncertain how long this outcome lasts. Even if participants do not continue the classes, the experience of 'having flexed their social muscle' and the new contacts made might continue into the year beyond, with some 50% drop-off. No displacement was found.

Total impact (social wellbeing)

€181,035

Adding the gross annual value of the two wellbeing benefits together results in €646,224, or in the region of €2,500 per person. It is worth contextualising this result with the findings of subjective wellbeing research in the UK, which found the monetary equivalent cost of having a chest/breathing problem was approximately -€2,600 and the cost for experiencing anxiety/depression was well in excess of -€56,000 [75] [76].

Maximising the WELLBEING outcomes for people with COPD

- Siel Bleu Ireland, in collaboration with COPD Support Ireland and health care professionals, advertising classes more.
- Siel Bleu Ireland, in its publicity materials for the programme, directly addressing people's potential fears about attending, including showing a wide variety of participants in terms of gender, race, disability etc.
- Siel Bleu Ireland considering whether the direct and indirect costs associated with attending the classes could be off-putting for people with COPD who are economically disadvantaged.
- Siel Bleu Ireland rolling out more *Exercise, COPD & Me* classes, both by increasing the frequency of classes in current locations and by going to new locations.
- Siel Bleu Ireland giving serious consideration to the potential advantages and disadvantages of segmenting its classes according to ability and age.
- Trainers strongly encouraging the wearing of suitable clothing and footwear for classes.
- Siel Bleu Ireland implementing a far more consistent and rigorous testing regime [77] [78].
- Siel Bleu Ireland integrating data collection into activities, rather than doing so as an add-on.
- Health professionals advising whether it would be worthwhile to use the Borg Dyspnoea Scale [79] to ascertain participants' perceived breathlessness.
- COPD Support Ireland nurturing strong leadership amongst its local support groups.

Outcomes and impact for their family and friends

"They're no longer just waiting for them to die."

How the outcomes are brought about

People living with COPD need the care and support of those around them. This can, at times, be challenging for those providing that care and support. They may be very much in the dark about the condition and how it is best managed, both in acute situations and on an ongoing day-to-day basis. They may feel helpless or overburdened by caring responsibilities [80]. For patients with advanced stage COPD, the carer burden can be especially high [81] [82]. Anything that improves the lives of the person with COPD can indirectly alleviate some of the stresses associated with the condition for their relatives and friends. Survey respondents perceived a remarkable average nine-point increase in the physical, mental and social wellbeing of their loved one after attending *Exercise, COPD & Me* classes, highlighting the importance of these classes both to the person with COPD and their relative or friends.

As noted earlier, a family member or friend is often the catalyst for a person living with COPD to attend classes, both emotionally (for instance, by encouraging them) and practically (for example, by giving lifts). As noted previously, some even join in, which means they too receive the physical, psychological and social benefits of the classes, although care should be taken not to overemphasise this, as they are not the primary beneficiary.

When the individual commences classes, their relatives/friends may benefit from some much-needed respite. They are also often pleasantly surprised to see that their loved one is more capable than they had feared and less disabled by her/his condition. They start seeing them in a different light, which improves their relationship and, ultimately, their own quality of life.

Chain of events

Concern for their relative or friend who is living with COPD **>** active or passive encouragement for her/him to attend *Exercise, COPD & Me* classes **>** outcomes experienced by programme participant lead to personal benefits, either direct and/or indirect **>** enhanced quality of life

Valuing an enhanced quality of life

Focus group and survey data show that the majority of family members and friends of people living with COPD achieved the outcome of an enhanced quality of life, although this result should not be overestimated, because the participation of their loved one in the programme is only one of many factors influencing their quality of life. Unfortunately, there are no hard figures for the numbers of people experiencing this change [83]. At the very least, it could be assumed that for every regular programme participant, one person in their close network benefited. However, 10% of survey respondents in this category felt that they had not benefited themselves, so the overall number has been reduced to 229.

Survey respondents reported an average seven-point increase in their quality of life as a direct result of the classes; this is considered sufficiently material (significant) for inclusion. The benefit to family members/friends is only assumed to last during the time that the individual continues to participate actively in the *Exercise, COPD & Me* programme; no drop-off therefore applies. Although relatives/friends did not make direct reference to it, it was clear from observing the classes that some of them gave lifts to classes and a few even stayed to observe or take part, which is time that they might have been able to spend differently. The consultant judged that a nominal 10% of displacement should therefore be included.

The Global Value Exchange contains various valuations pertaining to improvements in the quality of life of carers. The one that resonates most from the descriptions of the experience given by stakeholders themselves is 'carers have improved wellbeing and life satisfaction', which has a willingness to pay value of c. €40 per hour [84] [85]. With a total of 656 classes, the total value therefore comes to €26,240, or an average of €103 per family member/friend. However, this figure has been reduced 30% to €72, to account for the fact that an average outcomes score of 7 out of 10 was given, as opposed to 10 out of 10.

As achieving this improvement in quality of life hinges on their loved one's actual attendance at these classes, it would appear appropriate to use a similar deadweight percentage as that used for participants; 24% is the average in this instance.

Once more, it did not prove possible to source accurate attribution rates. At the very least, healthcare professionals and the persons living with COPD have played a role in affecting this outcome and these other actors thus need to be accounted for. In the absence of any more robust evidence, it would seem fair to use midway rate of 50%. No drop-off applies.

Total impact
€5,639

Maximising the ENHANCED QUALITY OF LIFE outcome for family and friends
• Siel Bleu Ireland and COPD Support Ireland making it clear in publicity materials that a person attending classes is welcome to bring along a relative or friend if this would make them feel more comfortable. • Trainers ensuring that the primary focus remains on the persons with COPD, not their relative or friend.

Outcomes and impact for trainers

"It's a 100% worthwhile job."

How the outcomes are brought about
Although trainers would have been made aware of COPD and similar respiratory conditions as part of their formal education, delivering the programme has definitely increased their understanding of breathing problems. They have not only benefited from additional training organised via Siel Bleu Ireland, they have also seen in practice how COPD negatively affects people and how exercise and social contact can improve lives. More than one trainer said that it had 'opened their eyes' and that their empathy towards people living with COPD had increased.

Trainers clearly conveyed the message that they derived particular pleasure and a strong sense of purpose from delivering this programme, as opposed to other Siel Bleu Ireland programmes, which is why they have been included as a stakeholder group and why outcomes have been allocated to them. Reasons for this include the lack of cognitive problems within the participant group, participants' drive and commitment, the very visible improvements, and the genuine gratitude expressed by group members and their relatives. They also compared it favourably to coaching sports (which can be overly competitive) and to working in a mainstream gym (where the focus is invariably on physique/aesthetics, which can be construed as shallow). They talked instead about recognising the importance of having fun, integrating physical activity into day-to-day life, and promoting health and wellbeing for people who happen to be living with a chronic condition. They expressed the opinion that since starting work on the programme, they were even more appreciative of their own health and had become even more passionate advocates for healthy lifestyle choices (especially taking regular exercise and not smoking).

Of course, success amongst participants is not universal; some do not continue their attendance, relapses do happen from time to time, and some people die. Whilst this can be disappointing for the trainers, the work itself remains very meaningful to them, they experience very high levels of job satisfaction and they benefit from the self-esteem associated with this.

Although the issue of trainer remuneration was only alluded to in vague terms, low salary levels and an expectation to do some unpaid work (for example, for class preparation and for participation in this evaluation) do appear to be a risk area for the staff retention. This may be compounded by the relative isolation of the job, especially for those trainers who are based outside the Dublin region. Internal records show that the average length of employment of trainers within Siel Bleu Ireland is three-and-a-half years, which, if the conditions are right, is a time period that probably has the potential to be extended.

Chain of events
Secure employment with Siel Bleu Ireland **>** deliver the *Exercise, COPD & Me* programme amongst other Siel Bleu Ireland programmes **>** receive direct benefits (salary, training, etc) and indirect benefits (insight, purpose/meaning, etc) **>** job satisfaction **>** remain in post for 3.5 years on average

Valuing job satisfaction

Out of the 12 trainers who delivered classes on the programme, at a minimum, the ten that remain in post can be said to have achieved the positive outcome of job satisfaction as a direct result of delivering the classes (it cannot be assumed that the two trainers who left their posts feel the same way and they have therefore not been included in the calculations). This sense of satisfaction commenced straightaway, but will cease once the employee leaves (though they may of course continue to have fond memories of working at Siel Bleu Ireland).

Whilst the trainers' job satisfaction cannot be wholly attributed to the *Exercise, COPD & Me* programme, because they spend the vast majority (c. 90%) of their time on other Siel Bleu Ireland programmes, it was singled out as being particularly satisfying for them. A more reasonable 80% of attribution has therefore been allowed. No deadweight, displacement or drop-off were identified during the consultation phase, nor in subsequent discussions with Siel Bleu Ireland staff and these have thus been set at 0%.

Research [86] [87] shows that whilst pay is an important consideration in job satisfaction, it is not the only factor, nor necessarily the most consequential one. This would certainly appear to hold true here. Trainers' pay is not as high as they might achieve elsewhere. The differential between what they earn and the average pay in Ireland of someone with a degree in exercise and sport science is €6,233 and it is this proxy that has been judged appropriate for valuing trainers' job satisfaction [88] [89] [90].

Total impact

€12,466

Maximising the JOB SATISFACTION outcome for trainers
• Siel Bleu Ireland ensuring that it recruits trainers with the same levels of enthusiasm for the programme and its potential, and the same skills in delivering it. • Siel Bleu Ireland offering an attractive benefits package. • Siel Bleu Ireland, in partnership with others, providing ongoing professional development opportunities for trainers in the area of respiratory disease. • Siel Bleu Ireland ensuring there are networking, peer learning and support opportunities for trainers throughout Ireland.

Outcomes and impact for community venues

"We're seeing people in here now that would never have come into the community centre before."

How the outcomes are brought about

The availability of an appropriate and affordable venue in the community appears to be a key factor in hosting successful classes to which people will want to keep coming. The best venues are not associated with a hospital, are close to where participants live, and have good public transport links, ample free parking and somewhere to have refreshments (an on-site café is ideal). A large, attractive room without excess furniture and with good ventilation is needed to enable the full range of exercises that are part of the programme to be undertaken. Although it is not essential for the venue to have a fully kitted-out gym – and this may in fact put off reluctant participants – it is nonetheless a bonus if the room being used already has some equipment available, because this maximises class time.

Most of the venues at which the classes are held benefit financially from this, albeit modestly. They generally do not seek to make a major profit from venue hire and often only rent to groups that realise some sort of social benefit, which the classes certainly do and which is backed up by external research [91].

Clearly, groups themselves wish to minimise their overheads. However, the introduction of a small charge for those who pay nothing for venue hire at the moment, or a slightly higher rental rate in locations where the charge is presently very low, might be acceptable to groups if there is sufficient local demand and if the quality of the community venue can be guaranteed.

Chain of events

Provision of premises in the community for the community **>** local COPD Support Ireland groups avail of premises **>** increased revenue **>** able to continue to provide community premises

Valuing increased revenue

A direct cost calculation was considered appropriate here, because the outcome is a financial one. Five venues did not charge the groups for hire during 2018, meaning that only 11 achieved a financial benefit, which, from the total fees paid to community venues in 2018, is readily calculated as an annual average of €821 per venue. This outcome was immediate and does not carry forward into future years (it can of course be repeated if classes continue to take place and rent continues to be charged). No allowances were felt to be necessary for deadweight, displacement, attribution or drop-off.

Total impact

€9,026

Maximising the INCREASED REVENUE outcome for community venues
• Siel Bleu Ireland, in partnership with COPD Support Ireland and others, securing high quality venues for all *Exercise, COPD & Me* classes.

Outcomes and impact for healthcare professionals

"It's fantastic having somewhere to refer patients to after pulmonary rehab."

How the outcomes are brought about

Healthcare professionals work in line with the *National COPD Clinical Care Programme* [92]. A person with COPD is under the care of a multidisciplinary team, with physiotherapists playing a particularly important role in terms of pulmonary rehabilitation and ongoing self-management, of which regular exercise is an especially valuable component. For those who avail of it, the HSE pulmonary rehabilitation programme is excellent. There appear to be problems in some areas, however, with inconsistent inward and outward referral practices, long waiting lists and a lack of follow-up. Ideally, a COPD patient should repeat the pulmonary rehabilitation programme every two years and engage in home-based and/or community-based activities in between, but this rarely happens as a matter of course. It is the experience of healthcare professionals that people often stop home exercise after a few weeks, pointing to a need for more facilitated group-based activity.

Many healthcare professionals in primary and secondary care are not yet aware of the *Exercise, COPD & Me* programme, but those who are undoubtedly value it (in the survey, they gave it an average score of eight out of 10). They have a good relationship with Siel Bleu Ireland staff and very much appreciate that they have somewhere to send patients once they have finished pulmonary rehabilitation. The Siel Bleu Ireland programme is not the only place where they can and do refer patients, but it definitely acts as an additional resource for them that makes their job somewhat easier. It should be noted that gaps in community service provision remain.

Healthcare professionals like that classes use simple equipment, because it reinforces their message that exercise is something that can be done easily by people themselves. They also believe that some people with COPD are far more likely to listen to advice provided by their peers rather than that given by medics.

Anecdotally, healthcare professionals report seeing those people with COPD who they have referred to exercise classes back in hospital less regularly than those who do not attend such classes, but no consistent records are kept of this. The belief that those patients are coping relatively well with their condition is nonetheless satisfying for the healthcare professionals. However, as these ultimate outcomes are harder to grasp hold of, only the more definitive access to an additional resource is valued.

Chain of events

Work hard to meet the diverse needs of a growing population of patients with COPD **>** but have concern about patients exiting pulmonary rehabilitation not continuing home-based exercise **>** become aware of the Siel Bleu Ireland *Exercise, COPD & Me* programme **>** now have access to an additional resource **>** refer patients to programme **>** professional satisfaction is gained from knowing patients stand a better chance of managing their physical and mental health by participation on the programme

Valuing access to an additional resource

It is extremely difficult to ascertain for how many healthcare professionals the programme offered access to an additional resource that they found beneficial in their working lives. Survey responses tell us that, at a bare minimum, 11 healthcare professionals felt that being able refer people to the programme made their job easier, with only two stating it did not (subdivision of this stakeholder group was not felt to be warranted at this time due to the low numbers involved, although this may be necessary in future). However, as the survey did not yield a high response rate, and as the total pool of healthcare professionals who might refer patients is in fact unknown [93], there must be others for whom the existence of the programme eased their professional lives. This includes people working in the seven areas where classes were held, but where survey respondents did not indicate they had referred patients. A total of 18 has therefore been estimated, but this is felt to be a very conservative figure.

The outcome starts from the moment a healthcare professional is able to refer a patient to the programme and will only last as long as the classes occur – the moment a class is no longer available, access to the resource would cease. Allocating an apt value to the outcome was challenging, not least because healthcare professionals were far more likely to mention the benefits of the programme to their patients, rather than to themselves. Nonetheless, the time saved and/or sense of doing one's best for the patient were valued strongly and hence considered material (relevant and significant). This benefit might reasonably be compared to having regular access to the services of a social prescribing coordinator [94], which is a relatively novel post in the Irish healthcare/social services system. Such as coordinator performs community referral as a primary function, whereas that is a secondary function of healthcare professionals. It is this proxy that has therefore been put to use. It has been estimated that a healthcare professional benefits to the equivalent of one hour of a social prescribing coordinator's salary per week [95], which equals €1,189 per year. In some cases, these professionals may not feel quite as strongly as others that the classes are of practical help them. Also, they may have other options where they can, and do, refer patients after pulmonary rehabilitation [96]. The initial telephone interviews and subsequent survey responses would suggest that c. 25% of deadweight needs to be allowed. No displacement, attribution or drop-off were found to apply.

Total impact

€16,052

Maximising the ACCESS TO AN ADDITIONAL RESOURCE outcome for healthcare professionals
• The HSE standardising its community referral pathways. • Siel Bleu Ireland, in partnership with COPD Support Ireland local groups, developing more and stronger links with all those healthcare professionals who might refer people with COPD on to the programme. • Siel Bleu Ireland, in partnership with COPD Support Ireland, inviting healthcare professionals to upskill trainers and do occasional inputs to local groups. • Siel Bleu Ireland increasing the number of locations at which it delivers its *Exercise, COPD & Me* programme, ideally in conjunction with COPD Support Ireland.

Outcomes and impact for the state

> "On completion of program all patients should be provided with information regarding existing voluntary groups/networks to which they can contact for ongoing support and social interaction. Patients also need information on local venues where they can continue to exercise, links with community centers, PCCC and local gyms may be beneficial … Following a PRP patients should be advised of their local support group or to consider establishing a group if there is none in their locality." [97]

How the outcomes are brought about

The state has a duty of care towards its citizens and its commitments in this regard are outlined in public policy. Public policy is supportive of community-based programmes as a part-solution to improving the nation's health. The 2018 *Sláintecare Implementation Strategy* [98] reaffirms Sláintecare's eight guiding principles, two of which resonate especially strongly in the context of the *Exercise, COPD & Me* programme: the fact that patients are paramount and the fact that they should access care at the most appropriate, cost-effective service level, with a strong emphasis on prevention and public health.

There is an increasing focus on integrated care for chronic diseases that affect a large number of health service users, including COPD. The stated goal of the HSE Integrated Care Programmes is to treat patients at the lowest level of complexity that is safe, timely, efficient and as close to home as possible [99].

The 2018 publication *Living Well with a Chronic Condition: Framework for Self-Management Support* [100] explains that if people are more empowered to look after their own long-term condition, there is less pressure on the health system. It states that there is a need for generic interventions, including peer/social support, as well as disease-specific interventions. In terms of COPD specifically, it references the draft 2016 *COPD Model of Care*, which acknowledges patients' need for support with health behaviour change, the requirement to recognise and manage depression and anxiety, and the important role of exercise. It recommends that the standardisation and further roll-out of pulmonary rehabilitation be prioritised.

Inarguably, the Irish health system is under severe stress. Anything that can be done to minimise pressure on the system is likely to be welcomed by government. A social initiative should never be run solely because it makes savings for the public purse. Notwithstanding, statutory resources are finite and ways are usually sought to achieve goals in as cost-effective manner as possible, as evidenced by the Irish Government Economic and Evaluation Service's extensive value for money reviews [101]. Not all interventions save public money but they may nonetheless be judged worthy of public investment if they deliver enough high-quality outcomes [102]. It would appear, however, that the Siel Bleu Ireland *Exercise, COPD & Me* programme does in fact result in cost savings for the state, most directly for the HSE.

Chain of events

The state establishes public policy goals **>** attempts delivery of goals in the context of constrained public resources **>** makes limited investment into community-based programmes to ensure pulmonary health **>** healthcare use by COPD patients decreases **>** public money saved **>** saved monies redirected to address same or other public policy goals

Valuing public money saved

The exact amount of change is, unfortunately, difficult to calculate, not least because of a lack of national data on COPD [103]. Broad estimations of value transfer must therefore be made. Research tells us that health service use is reduced if COPD patients undertake supervised maintenance exercise. As noted earlier, the benefits of regular exercise are felt quickly and they should last a minimum of one year afterwards [104]. This may result in many different savings to the state, such as a reduced need for costly drugs, either for the respiratory condition itself [105] [106] and/or for the associated depression and anxiety [107] [108]. However, arguably the most noteworthy saving is fewer/shorter hospital admissions due to acute exacerbations. In 2016, there were 15,460 discharges of patients who had been admitted to adult acute hospitals with a primary diagnosis of COPD [109]. The average cost of a hospital stay in that same year was €6,841 [110], resulting in a staggering total cost of €105,761,860.

We do not have definitive data on the extent to which people living with COPD were able to reduce their hospital stays following their participation on the programme. However, internal testing records, together with focus group and survey data, found that the physical health of the majority of participants had undoubtedly improved. Adopting the lowest rate of reduced risk for hospitalisations from a meta-analysis (28%) [111] and extrapolating this to the number of regular programme participants, all of whom had indicated that their physical health had improved, this would suggest that 71 of them might have avoided a hospital stay in the year they were exercising, or in the year beyond, reducing the potential cost to the HSE by €485,711. Research also shows that self-management interventions that target both physical and mental health are particularly effective at reducing accident and emergency visits and the health-related quality of life of patients [112].

The deadweight, displacement, attribution and drop-off rates for the physical wellbeing outcome for participants were then mirrored, because using different rates would have provided a distorted impression of the programme's impact.

Total impact

€177,285

Maximising the SAVE PUBLIC MONEY outcome for the state
• Siel Bleu Ireland raising awareness of its existence amongst appropriate policy-makers. • The HSE rolling out a standardised pulmonary rehabilitation programme that names the *Exercise, COPD & Me* programme as a suitable post-rehabilitation community option. • The state investing resources in proven community-based programmes that fit its public policy goals [113].

Outcomes and impact for COPD Support Ireland

"You don't have to suffer alone, we are here to support you."

How the outcomes are brought about

Founded in 2013, COPD Support Ireland [114] is a small charity set up to support and advocate for people living with COPD, and their carers. It is currently without paid employees [115]. Its stated mission is to maximise the quality of life of people living with or at risk of COPD and to support those who care for them. Today, it has a membership of 27 local groups, most of which make use of the Siel Bleu Ireland *Exercise, COPD & Me* programme, although only 16 did so in 2018.

The consultant has extensive experience of the kinds of challenges faced by small charities like COPD Support Ireland, especially in the early years of their lifecycle. The continuation and growth of classes at a time of organisational flux undoubtedly helped a momentum to be maintained that must have been useful to COPD Support Ireland [116] and is therefore considered material (relevant). However, the organisational development outcome derived by COPD Support Ireland from the programme should not be overstated. The fact that the organisation advertises the classes and has invested time in seeking funding for these classes indicates that it considers them worthwhile, but there appears to be little active enthusiasm within the organisation for the further development of the programme at present. Indeed, it could be argued that at the moment the goals of Siel Bleu Ireland, COPD Support Ireland and the local groups are not as aligned as closely as they could be.

Chain of events

Early-stage patient/carer support group **>** partners with Siel Bleu Ireland **>** invests time into rolling out the *Exercise, COPD & Me* classes to its member groups **>** organisational development **>** contributes to its own long-term survival

Valuing organisational development

The momentum referred to above has in fact been stepped up by Siel Bleu Ireland in 2019 and may continue to do so in 2020 and beyond. As such, the organisational development outcome starts in the year under evaluation and can be expected to continue beyond this time. However, it will not continue indefinitely if no further growth takes place within COPD Support Ireland. The consultant has used professional judgement to estimate that a total period of three years should be allowed.

Whilst it would theoretically have been possible for COPD Support Ireland to provide its own classes or to partner with another provider of exercise classes, the fact that no apparent efforts were made to do so would suggest that no deadweight or attribution need to be allowed for. Similarly, no displacement or drop-off was identified. However, it is almost impossible to value the amount of organisational development that took place and a decision has therefore been made not to exceed the value of the time that was invested by COPD Support Ireland in helping the programme to flourish.

Total impact
€15,000

Maximising the ORGANISATIONAL DEVELOPMENT outcome for COPD Support Ireland
• COPD Support Ireland and its local groups discussing and agreeing their respective roles in relation to the *Exercise, COPD & Me* programme and other local group activities. • Siel Bleu Ireland and COPD Support Ireland discussing and agreeing their respective roles in relation to the *Exercise, COPD & Me* programme. • COPD Support Ireland securing paid staff who can undertake further development work, nationally and regionally.

Calculating the social return

Summarising the value of the impact

Stakeholders	Outcomes	Impact values
People living with COPD	Improved physical wellbeing	€465,189
People living with COPD	Improved social wellbeing	€181,035
The state (HSE)	Save public money	€177,285
Healthcare professionals	Access to an additional resource	€16,052
COPD Support Ireland	Organisational development	€15,000
Trainers	Job satisfaction	€12,466
Community venues	Increased revenue	€9,026
Family and friends	Enhanced quality of life	€5,639
		Total = €881,691

It would thus appear that the *Exercise, COPD & Me* programme in 2018 had a major impact on its stakeholders. All outcomes were still found to be materially significant, but the impacts on family and friends of people living with COPD and community venues were found to be more marginal than the other outcomes. However, they are not worthless and, on balance, have been retained as part of the overall calculation.

A very high social return

The SROI could then be calculated. This was done by establishing how much value was generated in the year under evaluation and how much in subsequent years. In order to calculate the present value, the costs paid and benefits received in different time periods were added up and discounted using a standard discount rate of 3.5% [117]. The value of the inputs (€58,600) could then be subtracted from the present value (€1,308,016) in order to derive the net present value of €1,249,416.

The SROI ratio is the present value divided by the value of the inputs, namely 22.32 : 1. Alternatively, the net SROI is the net present value divided by the value of the inputs, which is 21.32 : 1. These figures imply a level of accuracy that is unhelpful. They were derived using a large number of assumptions and approximations and are inherently risky. This risk is heightened by the very high SROI ratio that appears to have been achieved.

In order to increase the level of confidence about the judgements made, sensitivity analysis was then undertaken (see appendix 5). The final ratio was found to be especially sensitive to the wellbeing values calculated for participants and by association, the savings for the state. On the basis of this, a more nuanced and meaningful claim can be made:

For every euro equivalent invested into the *Exercise, COPD & Me* programme in 2018, considerable social value was created. The exact amount is unclear, with the most cautious calculations placing it at more than €10 and the less guarded ones at around €22.

By any standards, this is a very high social return, for which Siel Bleu Ireland and its partners must be congratulated. The organisation is nonetheless urged to continue to find ways to keep increasing this return, so that the growing numbers of people with COPD, and those around them, can reap the very real benefits offered by the programme.

Appendices

Appendix 1: focus group skeleton

[Focus groups were coordinated by Siel Bleu Ireland staff and the consultant and facilitated and recorded by the consultant]

Welcome
Introduction to consultant
Introduction to session, including ground rules
Answering questions/addressing concerns

When did you start coming to the classes?

What effect have the classes had on you? What changes did you experience?
(Follow-up with questions about what happened next)

Was it just you who experienced an effect or did anyone else get impacted too? How?

Were all the changes positive or were there any negative changes too?

Were you surprised by any of these changes? Were they unexpected?

Wouldn't these changes have happened anyway if you hadn't come to the classes?

Didn't anyone else contribute to the changes you described? By how much would you say?

Couldn't you have gained these benefits elsewhere?

How would you value the outcomes? What would they be equivalent to?

Is there anything else you wish to say?

Explain next steps:
- Survey – please complete and ask others too
- Final draft – do you wish to receive a copy?

Thank you

Appendix 2: interview skeleton

[Initial email contact was made by the consultant, followed up by the scheduling of a telephone call with willing stakeholders for a brief structured interview – extensive notes were taken]

Recap on consultant and project
Assurance of confidentiality
Answering questions/addressing concerns

Confirm nature of involvement with/relationship to Siel Bleu Ireland and the *Exercise, COPD & Me* in particular (including inputs and outputs)

What effect has this had on you/your organisation? What changes did you experience? (Follow-up with questions about what happened next)

Was it just you who experienced an effect or did anyone else get impacted too? How?

Were all the changes positive or were there any negative changes too?

Were you surprised by any of these changes? Were they unexpected?

Wouldn't these changes have happened anyway if you hadn't been involved with the *Exercise, COPD & Me* programme?

Didn't anyone else contribute to the changes you described? By how much would you say?

Couldn't you have gained these benefits elsewhere?

How would you value the outcomes? What would they be equivalent to?

Is there anything else you wish to say?

Explain next steps:
- Survey – please complete and ask others too
- Final draft – do you wish to receive a copy?

Thank you

Appendix 3: survey results participants and their families/friends

[The survey was distributed via the trainers (with a request to distribute to relevant family and friends if at all possible). In order to maximise response rates, all those who wanted were entered into a prize draw for a one-to-one exercise session with one of the Siel Bleu Ireland trainers. A total of 114 responses was received. The survey answers are provided below. Where a 10-point Likert scale is provided, 1 = not at all and 10 = greatly.]

I have COPD (n = 100)

74 Yes
26 No

I have another breathing condition (n = 94)

27 Yes
67 No

I am a family member or friend of someone with a breathing condition (n = 89)

49 Yes
40 No

During 2018, I took part in one or more *Exercise, COPD & Me* classes in: (n = 106)

15 Bray
13 Kilkenny
10 Ballyfermot
10 Tallaght
10 None of the above
8 Athlone
8 Carlow
7 Drogheda
7 Whitehall
6 Huntstown
5 Thurles
4 Galway
3 Longford
2 Sligo
2 Waterford
0 Finglas
0 Mullingar

[Note that 4 respondents attended classes in more than one location]

How many classes did you attend that year? (n = 92)

10	1-10 classes
13	11-20 classes
16	21-30 classes
14	31-40 classes
39	40+ classes

To what extent did attending the classes improve your physical health? (n = 98)
Range: 4-10
Average: 8

To what extent did attending the classes improve your mental health? (n = 96)
Range: 1-10
Average: 7

To what extent did attending the classes improve your social life? (n = 97)
Range: 1-10
Average: 8

Is there anything in particular you would like to say about the effect the classes have had on <u>your own wellbeing</u>? (n = 68)

Sample answers:

"I feel like I am doing something to help myself. I look forward to attending class."

"It gives you the incentive to get up, and get out and mix with people, and get to make new friends, as well as feeling a lot fitter."

"Appear to have a general increase in energy levels."

"I had difficulty climbing stairs, now I can climb easily."

"As I walk 8-10km every day (weather permitting), difficult to say."

"I have had only one mild chest infection in over twelve months which is a lot less than I would have had before I started the classes."

"Really helped giving me confidence to keep fighting with the help of friends."

"It's nice to meet people who have the same complaint as you. I have made new friends and look forward to meeting them every Friday. My breathing has improved 100% and have less exacerbations of my COPD."

"Sharing COPD related health problem with other gave me a better understanding of my own. I made friends and we are now there to support each other."

Is there anything in particular you would like to say about the effect you attending the classes has had on the <u>quality of life of your family and friends</u>? (n = 40)

Sample answers:

"Family and friends has remarked on my fitness, breathing and general mood – how improved I've become overall."

"Family are happy to see me socialising and exercising, it has helped alleviate their worries about my ability to cope with COPD."

"It has helped me get some of my strength back since I was in the hospital last year. Which is a good thing my family don't have to worry as much"

"Made life for my carer easier."

"My family are delighted I started two years ago attending the class and have been amazed at my improvement and are very pleased that I am getting to meet people and find out plenty of information on my condition and the exercise programme."

"My humour was better so I was easier to live with."

"My youngest daughter who lives fairly near and who keeps in close contact is very pleased to see the effect, both physically and mentally, which attending the classes has had on my life."

"They all claim I am more alert, more active. I am more tolerant of my very young nieces and nephews and able to play with them more."

"Well I am able to do household chores to an extent and not asking them to do everything."

In your opinion, to what extent did attending the classes improve the physical, mental and social <u>wellbeing of your loved one</u> who has a breathing condition? (n = 32)
Range: 5-10
Average: 9

Is there anything in particular you would like to say about this? (n = 15)

Sample answers:

"Being an independent person this has greatly helped in bringing her back to the outgoing lady we know plus letting her realize there is still a social side to life."

"COPD can be a very debilitating illness. For my family member I witnessed a marked increase in their mental and social wellbeing. I am not entirely sure of the physical improvements."

"It was lovely to see the confidence come back for this person. Getting out and about socializing with other COPD sufferers greatly reduced the social anxiety that can come with it."

"Mam's breathing has improved, she can do normal day to day things that she would have normally found difficult, such as doing the washing. Going to this class gives her confidence."

"The support of the group and attending physio have added to my husband's wellbeing."

"There was a noticeable difference in my dad's physical and mental wellbeing upon completing the classes. All changes were for the better."

To what extent did your loved one attending the classes improve <u>your own quality of life</u>? (n = 29)
Range: 1-10
Average: 7

Is there anything in particular you would like to say about this? (n = 16)

Sample answers:

"We had more to discuss and it made our relationship more positive."

"His improvement in mood made my life easier; less argument during the time after the course."

"Attending classes etc. gave my family member a sense of purpose again + source of conversation and interest, which increased the mood level and decreased some stress and anxiety that some family members can experience."

"I am happy that she enjoys the classes and finds them beneficial. It's almost 2 years since Mam needed an antibiotic."

"I don't have to worry about her as much and there is less pressure on me to help with all the household things."

"The class provides a social experience as well as a physical one, which helps good form for my Mum. This improves life for us both."

"I had house to myself and was glad to see that my husband was being proactive. Yes, I think it has a positive effect."

Is there anything else you would like to say about the programme? (n = 60)

Sample answers:

"I feel very lucky and thankful that the classes are close to me location wise and also extremely affordable."

"It is a great place for people with COPD to gather and talk to each other and have a space for exercise without feeling self-conscious."

"XXX is very clear and encouraging. The activities are varied. It has given me confidence to try a class in my local gym."

"The programme has made a positive impact on our lives and if possible they should be held more often."

"Hopefully the programme will continue and spreading news of it to other sufferers."

"I just hope the classes continue, because I am more likely to take part in exercises when I am meeting up with a group."

"A very positive initiative which should be government supported."

Appendix 4: survey results healthcare professionals

[The SurveyMonkey survey was sent via email link to 32 individually addressed recipients working in areas where the groups were operational during 2018 (with a request to distribute amongst other healthcare professionals if at all possible). A total of 14 responses was received. The answers are provided below.]

Were you aware of the Siel Bleu Ireland *Exercise, COPD & Me* programme prior to receiving this survey? (n = 14)

13 Yes, I already had a good awareness of the programme (93%)
1 Yes, but I did know much about it (7%)
0 No, I had never heard of it (0%)

Have you ever referred any people to the Siel Bleu Ireland *Exercise, COPD & Me* programme? (n = 14)

13 Yes (93%)
1 [118] No (7%)

To which Siel Bleu Ireland *Exercise, COPD & Me* classes did you refer people? (n = 13) [119]

5 Bray
2 Finglas, Galway
1 Ballyfermot, Carlow, Kilkenny, Tallaght, Thurles, Whitehall
0 Athlone, Drogheda, Huntstown, Longford, Mullingar, Sligo, Waterford

Does being able to refer people to the Siel Bleu Ireland *Exercise, COPD & Me* programme make your job easier? (n = 13)

8 Yes, considerably (62%)
3 Yes, slightly (23%)
2 No, not at all (15%)

Please explain why this is so (n = 13)

"It's just another venue/option available to our COPD patients who wish to continue exercising or the location may suit better."

"As the classes provide somewhere for people to exercise with confidence despite suffering from a chronic respiratory disease."

"Patients need to continue exercising post pulmonary rehab."

"It enables me to ensure that the patients are continuing to exercise after discharge from hospital. I find compliance with a home exercise programme is improved with those that attend one outside of the home and this in turn reduces exacerbations and hospital admissions."

"It is very important than people maintain the progress they have made in pulmonary rehabilitation programme, this programme enables that, it is also a very valuable social outlet for people with COPD."

"It provides an option for continued physical activity following on from pulmonary rehab."

"I run the 8-week pulmonary rehab programme for COPD in the hospital in XXX and now with the exercise class in the community with Siel Bleu my patients can continue their group classes safely in the community."

"Nice to have a community based programme that encourages my patients to continue their new exercise regime having completed pulmonary rehab and received all the education regarding exercising safely."

"Provides an option that's closer to home for many persons – that's accessible by public transport and good car parking options – that has high quality staff – that provides a support network for people with COPD – that provides a safe space for people to exercise – the programme is also very functional."

"It's a direct follow on from our pulmonary rehab programme."

"It gives me an option to signpost people to a structured exercise group after pulmonary rehab finishes."

"At the moment I don't require it but it is still a valuable service."

"While the pulmonary rehabilitation programme is great, ideally we need to get people to join a programme that is continuous so that they incorporate exercise as a lifestyle choice. The exercise support groups work well for people who use them as a way to continue exercising after they have completed pulmonary rehabilitation and learnt the basics on how to manage their condition."

How do you rate the Siel Bleu Ireland *Exercise, COPD & Me* programme out of 10? (n = 14)
Range: 6-10
Average: 8

Is there anything you wish to say about the Siel Bleu Ireland *Exercise, COPD & Me* programme, or indeed about any related matter? (n = 9)

"All of my patients who have engaged with Siel Bleu exercises classes have nothing but high praise for the class and the instructor."

"I have heard that some trainers push the participants harder than others, I think it would be better if they were more uniform in their approach. Attend training from rehab physios."

"I think it would be lovely if it could be formalised into a pulmonary rehabilitation continuation programme with increased support from pulmonary rehab trained health professionals."

"Excellent programme and feedback from patients is very positive. We need a lot more of these programmes nationally."

"I think all exercise programmes done for people living with chronic respiratory conditions should incorporate the Borg Dyspnoea Scale so people can exercise according to their perceived level of breathlessness."

"Perhaps have oxygen saturation monitors [120]."

"Great asset in community. Would like to see marketing towards a younger population too."

"Some inconsistencies across the various locations but that is now being addressed."

"Good option for patient post rehabilitation to keep long term exercise programme in place."

Appendix 5: sensitivity analysis

Why a sensitivity analysis?
SROI studies must not overclaim. After establishing the ratio of 22.32 : 1. , it was tested for sensitivity, assessing the extent to which it would change if assumptions made earlier in the process were different.

Inputs
All of the inputs were concrete figures, with exception of the staff time input of COPD Support Ireland, which was roughly calculated as €15,000 for the year. Halving or doubling this input only slightly changes the ratio (between 21.95 : 1 and 23:06 : 1). There is no sense that €30,000 worth of staff time was in fact invested in the programme during 2018, however, and it was not felt necessary to alter the value of the input.

Length of accountability period
A conservative approach to outcome duration was adopted, with the maximum length of the accountability period being three years. If all of the outcomes only occurred in the year that the activity took place, the ratio would only drop to 15.05 : 1. However, that is somewhat unrealistic, not least because research tells us that certain outcomes are known to last for longer than this (the benefits of regular exercise and the associated positive outcomes for the state).

Number of people affected
Some of the beneficiaries were single organisations, in which case the numbers are clear. The number of trainers who stayed in their job and the number of community venues that levied a charge are also concrete figures. However, estimates had to be made for all other stakeholders. We can be relatively confident about the numbers of direct beneficiaries (people living with COPD), but the numbers of indirect beneficiaries (their family members/friends and healthcare professionals) are less known. It should be noted that very conservative figures were adopted in the first instance. However, if these were reduced by one-third each, the ratio would drop to 22.20 : 1. If they were reduced by two-thirds each, it would drop to 22.07 : 1, but this is known to be unreasonable due to the survey results.

Proxy values
Financial proxies had to be found for all but two outcomes (the value of the income stream for community venues and the value of organisational development for COPD Support Ireland, for which it was felt that the value for the outcome should not exceed the value of the investment). Considerable efforts were expended in sourcing reasonable proxies. The greatest values were generated for participants, for whom initially three, but subsequently two, different outcomes were found. There was thus a danger of double-/triple-counting, although every effort was made to avoid this. If only the physical wellbeing outcome is valued, the ratio drops to 17.74 : 1. If only the social wellbeing outcome is valued, the ratio drops considerably to 10.55 : 1.

Significant value was also created for the HSE. The average cost of a hospital stay is known, but the reduction in the number of hospital stays as a result of programme participation is an estimate (though still informed by research). If that number was halved, the ratio would be 20.08 : 1. Even if it was reduced by three-quarters, the ratio would still be 18.96 : 1. The remaining proxies would seem sufficiently grounded in evidence not to require further testing.

Deadweight

No deadweight was found to apply for some of the valuations. For those where deadweight did apply, the rates were initially doubled, reducing the ratios as follows: 17.97 : 1 (improved physical wellbeing); 21.25 : 1 (improved social wellbeing); 22.29 : 1 (enhanced quality of life); 22:23 : 1 (additional resource); 20.66 : 1 (saving public money). If all of these rates were applied together at the same time, the ratio would lower to 15.11 : 1. The exercise was repeated at an – admittedly highly unrealistic – displacement rate of 95%, with these results: 11.35 : 1 (improved physical wellbeing); 18.02 : 1 (improved social wellbeing); 22.23 : 1 (enhanced quality of life); 22:07 : 1 (additional resource); 18.14 : 1 (saving public money). If all of these rates were applied together at the same time, the ratio would lower to a mere 2.53 : 1, although this is not felt to give a fair impression of the effects of the programme.

Displacement

Displacement was only found to apply in the case of relatives and friends. Doubling the percentage makes almost no difference to the ratio. Indeed, even if the highly unrealistic displacement rate of 95% is applied, the ratio only dips slightly to 22.23 : 1.

Attribution

Attribution rates were assigned to five of the outcomes. The difficulty of choosing appropriate attribution rates was noted. Each was therefore tested at a very high rate of 95%. Doing so for physical wellbeing dropped the ratio to 11.73 : 1; for social wellbeing the figure was 18.20 : 1; for enhanced quality of life it was 22.23: 1; for job satisfaction it was 22.16 : 1; and for savings to the state it was 18.28 :1. If all of these high attribution rates were applied together at the same time, the ratio would reduce to 3.32 : 1, although again, this is not felt to give a fair impression of the effects of the programme.

Drop-off

For those three outcomes were drop-off was felt to apply, the same generous rate of 50% had already been applied, because they were closely interrelated. If they were each increased to 95% at the same time, the overall ratio would reduce to 16.21 : 1.

Conclusion

Initial estimates were already conservative. Harshly testing all the figures does reduce the overall SROI ratio, but not by as great a factor as might have been expected for the majority of outcomes; a high level of confidence can therefore be expressed about those valuations. However, the values for the programme's main beneficiaries are more sensitive and this needs to be taken into consideration when making claims about the programme's overall value.

Endnotes

[1] https://www.copdsupport.ie/copd-support-group/109-2
[2] National Medicines Information Centre, 2013, *COPD*, 19 (4), St James' Hospital http://www.stjames.ie/GPsHealthcareProfessionals/Newsletters/NMICBulletins/NMICBulletins2013/NMIC%20Chronic%20Obstructive%20Pulmonary%20Disease.pdf
[3] M O'Connor, 2010, *Respiratory Strategy Executive Summary*, https://www.lenus.ie/bitstream/handle/10147/593535/Executive+Summary.pdf?sequence=1
[4] National Patient Safety Office, 2017, *National Healthcare Quality Reporting System: Third Annual Report*, Department of Health, https://health.gov.ie/wp-content/uploads/2017/07/NHQRS-2017-Annual-Report.pdf
[5] Note that smoking is the primary but not sole risk factor for COPD
[6] British Lung Foundation, 2014, *The Vicious Cycle of Inactivity* https://www.blf.org.uk/file/viciouscycleinactivityexercise2014jpg
[7] The 36-member Organisation for Economic Cooperation and Development https://www.oecd.org/about
[8] National Medicines Information Centre, 2013, *COPD*, 19 (4), St James, Hospital http://www.stjames.ie/GPsHealthcareProfessionals/Newsletters/NMICBulletins/NMICBulletins2013/NMIC%20Chronic%20Obstructive%20Pulmonary%20Disease.pdf
[9] National Medicines Information Centre, 2013, *COPD*, 19 (4), St James' Hospital http://www.stjames.ie/GPsHealthcareProfessionals/Newsletters/NMICBulletins/NMICBulletins2013/NMIC%20Chronic%20Obstructive%20Pulmonary%20Disease.pdf
[10] Irish Thoracic Society, 2013, *Lung Disease in Ireland: Prevalence and Trends* https://irishthoracicsociety.com/wp-content/uploads/2017/05/Lung-Disease-in-Ireland-December-2013.pdf
[11] Siel Bleu Ireland has received awards from Medtronic, the Nutramino Health and Fitness Awards and Social Innovation Fund Ireland and has also been a finalist in a number of other awards programmes
[12] http://www.sielbleu.ie/home/projects/happier
[13] Li Whye Cindy Ng et al, 2011, Does exercise training change physical activity in people with COPD? A systematic review and meta-analysis, *Chronic Respiratory Disease* https://journals.sagepub.com/doi/abs/10.1177/1479972311430335
[14] B McCarthy et al, 2015, Pulmonary rehabilitation for chronic obstructive pulmonary disease, *Cochrane Database of Systematic Reviews* https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD003793.pub3/full
[15] Wen-hua Liao et al, 2015, Impact of Resistance Training in Subjects With COPD: A Systematic Review and Meta-Analysis, *Respiratory Care*, 60 (8), pp. 1130-1145 http://rc.rcjournal.com/content/60/8/1130
[16] Martijn A Spruit et al, 2016, COPD and exercise: does it make a difference?, *Breathe*, 12, e38-e49 https://breathe.ersjournals.com/content/12/2/e38
[17] AR Jenkins et al, 2017, Efficacy of supervised maintenance exercise following pulmonary rehabilitation on health care use: a systematic review and meta-analysis, *International Journal of COPD*, 13, pp. 257-273 https://www.dovepress.com/efficacy-of-supervised-maintenance-exercise-following-pulmonary-rehabi-peer-reviewed-article-COPD
[18] Mara Paneroni et al, 2017, Aerobic Exercise Training in Very Severe Chronic Obstructive Pulmonary Disease: A Systematic Review and Meta-Analysis, *American Journal of Physical Medicine and Rehabilitation*, pp. 541-548 https://moh-it.pure.elsevier.com/en/publications/aerobic-exercise-training-in-very-severe-chronic-obstructive-pulm
[19] M Beaumont et al, 2018, Effects of inspiratory muscle training in COPD patients: a systematic review and meta-analysis, *The Clinical Respiratory Journal*, 12 (7), pp. 2178-2188 https://www.ncbi.nlm.nih.gov/pubmed/29665262
[20] Camilla Koch Ryrsø et al, 2018, Lower mortality after early supervised pulmonary rehabilitation following COPD-exacerbations: a systematic review and meta-analysis, *BMC Pulmonary Medicine*, 18 (154) https://bmcpulmmed.biomedcentral.com/articles/10.1186/s12890-018-0718-1
[21] Lu-Ling Wu et al, 2018, Effectiveness of meditative movement on COPD: a systematic review and meta-analysis, *International Journal of COPD*, 13, pp. 1239-1250 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5909800
[22] Presented at a poster session of the 2015 Irish Thoracic Society Scientific Meeting https://irishthoracicsociety.com/its-scientific-meeting/its-scientific-meeting-2015
[23] http://www.sielbleu.ie/home/programmes/patient-group-programmes
[24] http://www.socialvalueuk.org/what-is-social-value/the-principles-of-social-value
[25] Materiality of outcomes is determined both in terms of relevance (how important it is to the stakeholder) and of significance (quantity, duration, value and causality)
[26] It became apparent during the research that a version of the *Exercise, COPD & Me* programme is also being delivered by Local Sports Partnerships in Wexford (with some support from Siel Bleu Ireland) and Cork (without the support of Siel Bleu Ireland). These appear to be anomalies that do not align with Siel Bleu Ireland's plans for the further roll-out of the programme and it was not considered worthwhile engaging with them.
[27] https://the-sra.org.uk/common/Uploaded%20files/ethical%20guidelines%202003.pdf
[28] Previous experience has shown: that it is very difficult to pinpoint a ready representative of 'the state'; that an individual with sufficient seniority to be able to give the views of 'the state' (or even the HSE in this instance) is unlikely to know about the organisation/programme under evaluation; and that there is a profound reluctance amongst public representatives and civil servants to proffer public views about the impact of individual organisations or their programmes until such time as they have been informed of the results of high-quality research (and even then it is not guaranteed that they will).
[29] Those who wanted to, were asked to provide a telephone number in order that they could be contacted if they won the prize draw for a one-to-one session with a Siel Bleu Ireland trainer
[30] Chosen in preference to an online survey, due to the relative unfamiliarity with technology amongst the group
[31] The nature of the pulmonary rehabilitation programme varies across the country, but usually comprises two sessions per week for a period of 8-10 weeks, delivered either in a hospital or community-based setting, usually by a specialist physiotherapist. It includes oxygen needs assessment, exercise and education on self-management.
[32] Siel Bleu Ireland began making some of these changes during the course of the study, which is very welcome
[33] Social Value International, 2017, *A Discussion Document on the Valuation of Social Outcomes* http://www.socialvalueuk.org/app/uploads/2017/09/Valuation-of-Social-Outcomes-pdf-1.pdf

[34] This is sometimes referred to as the counterfactual
[35] Martin Shuttleworth, 2019, *Research Bias* https://explorable.com/research-bias
[36] The Bray group was successful in securing €6,400 from the HSE National Lottery Grants at the end of 2017 for expenditure in 2018 https://www2.hse.ie/file-library/national-lottery-grants/national-lottery-payments-2017.pdf
[37] The CEO position was advertised at a salary scale of €49,000 - €55,000; a median salary of €52,000 has been assumed http://copd.ie/we-are-recruiting. The CEO was in post until July 2018. Around two days a week in 2018 were spent developing the exercise groups, which are therefore valued at c. €12,000. Although this ignores any additional employment costs, these might be offset by leave taken, etc. Furthermore, the organisation has a contractor who, since the departure of the CEO has taken on additional administrative work in relation to the programme. Contract fees are unknown; a further €3,000 has been allowed for.
[38] https://www.catestonline.org
[39] The standard is a 2kg weight but some commence with a 1kg weight and others start with or progress to a 3kg weight
[40] See Margaret K Covey, 2012, Upper-Body Resistance Training and Self-Efficacy Enhancement in COPD, *Journal of Pulmonary & Respiratory Medicine*, 9 (1) https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3975911
[41] https://pulmonaryrehab.com.au/patient-assessment/assessing-exercise-capacity/six-minute-walk-test
[42] http://fitt50.hu/sites/default/content/content/online-tesztek_en.php?mode=3-4&email=
[43] http://fitt50.hu/sites/default/content/content/online-tesztek_en.php?mode=3-5&email=
[44] MUST https://www.hse.ie/eng/staff/pcrs/online-services/musttool.pdf
[45] Those who are underweight or overweight might be referred to their GP for further advice
[46] 'Regular' in this case was defined by trainers to mean attending almost every week that the classes are being delivered, barring illness, holidays and similar
[47] It is assumed that around a further five individuals per group only attend for a short time, implying a total population of around 345
[48] For instance: Andrew Steptoe et al, 2015, Psychological wellbeing, health and ageing, *The Lancet*, 385 (9968), pp. 640-648 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4339610
[49] Respondents gave a slightly lower average score for this outcome than for the other two outcomes (7 out of 10 contrasted with 8 out of 10)
[50] National Institute for Health and Care Excellence, 2008, *Mental Wellbeing in Over 65s: occupational therapy and physical activity interventions* https://www.nice.org.uk/guidance/ph16
[51] Physical, mental and social wellbeing because this was prior to removing metal wellbeing as a separate outcome
[52] Mara Paneroni et al, 2017, Aerobic Exercise Training in Very Severe Chronic Obstructive Pulmonary Disease: A Systematic Review and Meta-Analysis, *American Journal of Physical Medicine and Rehabilitation*, pp. 541-548 https://moh-it.pure.elsevier.com/en/publications/aerobic-exercise-training-in-very-severe-chronic-obstructive-pulm
[53] Also evidence by meta-analyses, such as: Isabelle Peytremann-Bridevaux et al, 2008, Effectiveness of Chronic Obstructive Pulmonary Disease-Management Programs: Systematic Review and Meta-Analysis, *The American Journal of Medicine*, 121 (5), pp. 433-443 https://www.sciencedirect.com/science/article/abs/pii/S0002934308001770
[54] Siel Bleu Ireland, 2014, *Report on the Provision of APA with COPD Support Group, Bray*
[55] Siel Bleu Ireland, 2015, *Report on the Provision of APA with COPD Support Group, Ballyfermot*
[56] Siel Bleu Ireland, 2015, *Report on the Provision of APA with COPD Support Group, Drogheda*
[57] Siel Bleu Ireland, 2015, *Report on the Provision of APA with COPD Support Group, Waterford*
[58] Siel Bleu Ireland, *Exercise, COPD & Me, Sligo*
[59] Siel Bleu Ireland, *Exercise, COPD & Me, Whitehall*
[60] Not all participants did all tests
[61] Lizzie Trotter et al, 2014, *Measuring the Social Impact of Community Investment: A Guide to using the Wellbeing Valuation Approach*, HACT https://www.hact.org.uk/measuring-social-impact-community-investment-guide-using-wellbeing-valuation-approach
[62] HACT & Daniel Fujiwara, 2018, *Community Investment Values from the Social Value Bank* https://www.hact.org.uk/value-calculator http://creativecommons.org/licenses/by-nc-nd/4.0/deed.en_GB
[63] £5,527 converted using https://www.poundsterlinglive.com/best-exchange-rates/best-british-pound-to-euro-history-2018
[64] Camilla Koch Ryrsø et al, 2018, Lower mortality after early supervised pulmonary rehabilitation following COPD-exacerbations: a systematic review and meta-analysis, *BMC Pulmonary Medicine*, 18 (154) https://bmcpulmmed.biomedcentral.com/articles/10.1186/s12890-018-0718-1
[65] Nicolino Ambrosino & Enrica Bertella, 2018, Lifestyle interventions in prevention and comprehensive management of COPD, *Breathe*, 14 (3) pp. 186-194 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6118879
[66] For example, http://www.thefitnessleague.ie
[67] For example, private classes in the Beacon Hospital and Blackrock Clinic, as listed in https://www.hse.ie/eng/health/hl/selfmanagement/community-healthcare-east-dublin-south-east-dun-laoghaire-wicklow-directory-of-services-and-programmes-for-adults-with-asthma-copd-diabetes-heart-conditions-and-stroke.pdf
[68] For example, Chronic Illness Exercise Rehabilitation at ExWell Medical https://www.exwell.ie
[69] For example, the Pulmonary programme at the National Aquatic Centre https://www.tonezone.ie/gym-classes
[70] Lizzie Trotter et al, 2014, *Measuring the Social Impact of Community Investment: A Guide to using the Wellbeing Valuation Approach*, HACT https://www.hact.org.uk/measuring-social-impact-community-investment-guide-using-wellbeing-valuation-approach
[71] Lizzie Trotter et al, 2014, *Measuring the Social Impact of Community Investment: A Guide to using the Wellbeing Valuation Approach*, HACT https://www.hact.org.uk/measuring-social-impact-community-investment-guide-using-wellbeing-valuation-approach
[72] HACT & Daniel Fujiwara, 2018, *Community Investment Values from the Social Value Bank* https://www.hact.org.uk/value-calculator http://creativecommons.org/licenses/by-nc-nd/4.0/deed.en_GB
[73] £1,977 converted using https://www.poundsterlinglive.com/best-exchange-rates/best-british-pound-to-euro-history-2018
[74] Lizzie Trotter et al, 2014, *Measuring the Social Impact of Community Investment: A Guide to using the Wellbeing Valuation Approach*, HACT https://www.hact.org.uk/measuring-social-impact-community-investment-guide-using-wellbeing-valuation-approach

[75] Daniel Fujiwara & Paul Dolan, 2014, *Valuing Mental Health: How A Subjective Wellbeing Approach Can Show Just How Much It Matters*, UK Council for Psychotherapy https://www.psychotherapy.org.uk/wp-content/uploads/2018/08/UKCP_DocumentsReportsValuingMentalHealth_web.pdf calculated figures of -£2,052 and -£44,237 which were then adjusted for inflation and transferred into euro costs
[76] Using https://www.bankofengland.co.uk/monetary-policy/inflation/inflation-calculator and https://www.poundsterlinglive.com/best-exchange-rates/best-british-pound-to-euro-history-2018
[77] MUST screening can probably be excluded from this as it does not appear to provide meaningful data
[78] The difficulties of doing this, including the resource implications, are acknowledged, but a far more robust system is likely to benefit the organisation in the future
[79] See https://web.archive.org/web/20080131172946/http://www2.psychology.su.se/staff/gbg/index.html - this was advised by one of the survey respondents
[80] For instance, see Family Carers Ireland, College of Psychiatrists Ireland & University College Dublin School of Nursing, Midwifery and Health Systems, 2019, *Paying the Price: The Physical, Mental and Psychological Impact of Caring* https://www.irishpsychiatry.ie/wp-content/uploads/2019/05/Paying-the-Price-The-Physical-Mental-and-Psychological-Impact-of-Caring.pdf
[81] Morag Farquhar, 2017, Assessing carer needs in COPD, *Chronic Respiratory Disease*, 15 (1), pp. 26-35 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5802659
[82] Marc Miravitlles et al, 2015, Caregivers' burden in patients with COPD, *International Journal of COPD*, 10, pp. 347-356 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4334315
[83] Even the total population is unknown; it is assumed that every participant has a further two individuals in their close network who might be affected by their decision to participate in the programme (that is, 690)
[84]A willingness to pay value of £29.47 per hour in England in 2011 which was adjusted for inflation and transferred into euro http://www.globalvaluexchange.org/valuations/8279e41d9e5e0bd8499f2f24
[85] Using https://www.bankofengland.co.uk/monetary-policy/inflation/inflation-calculator and https://www.poundsterlinglive.com/best-exchange-rates/best-british-pound-to-euro-history-2018
[86] For example: John T Brinkman, 2017, *Pay and Job Satisfaction*, The O & P Edge https://www.opedge.com/Articles/ViewArticle/2017-10-01/pay-job-satisfaction
[87] For example: Shawn Achor et al, 2018, *9 Out of 10 People Are Willing to Earn Less Money to Do More Meaningful Work*, Harvard Business Review https://hbr.org/2018/11/9-out-of-10-people-are-willing-to-earn-less-money-to-do-more-meaningful-work (which found that American workers were willing to forego 23% of their entire future lifetime earnings in order to have a job that was always meaningful)
[88] This approach to measuring job satisfaction was also adopted in the SROI study by the University of Bristol of the Off Centre social enterprise in East London http://static1.1.sqspcdn.com/static/f/579533/20632434/1350309467913/Off+Centre+SROI+Report+Final.pdf?token=rlIudcbHhZ5ItjOOUMHxAgekj50%3D
[89] https://www.payscale.com/research/IE/Degree=Bachelor_of_Science_(BS_%2F_BSc)%2C_Exercise_%26_Sports_Science/Salary gave an average expected annual salary of €30,000 whereas as Siel Bleu Ireland trainers earn an average of €23,767
[90] The actual figures for part-time employees are lower but demonstrate a similar differential. Trainers working part-time are paid at a sessional rate of €20. The average number of hours they spend per session is between two and three, equating to an hourly pay rate of around €8, which is about €5 below the median rate of pay of a personal trainer in Ireland https://www.payscale.com/research/IE/Job=Personal_Trainer/Hourly_Rate
[91] For example: Mat Jones et al, 2013, The role of community centre-based arts, leisure and social activities in promoting adult well-being and healthy lifestyles, *International Journal of Environmental Research and Public Health*, 10 (5), pp. 1948-1962 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3709358
[92] HSE, 2010, *Pulmonary Rehabilitation Model of Care*, https://www.hse.ie/eng/services/publications/clinical-strategy-and-programmes/pulmonary-rehabilitation-model-of-care-2010.pdf
[93] An arbitrary number of 100 has been used, but this is known to be very low in terms of the potential number of healthcare professionals that ought to know about the programme. In particular, none of those contacted were GPs (of whom there are some 2,500 in Ireland https://www.hse.ie/eng/services/list/2/gp).
[94] Social prescribing, in which the health and wellbeing of people is supported by using community-based activities, is slowly becoming a feature of Irish health and social care services.
[95] Two salaries for social prescribing coordinators in Ireland were identified in an online search. The hourly rate for such a position in Bray was found to be €22.87 (https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=3&ved=2ahUKEwjMjIKQ9Z3lAhUBilwKHY7tCh4QFjACegQIAxAC&url=http%3A%2F%2Fildn.ie%2Ffiles%2Fpage_files%2FSocial_Prescribing_Coordinator_Ad_June_2018.docx&usg=AOvVaw23ulFpbqwQ9eq-eD3aQaa0). A similar position in Belfast was found to pay £17.37 per hour, equating to c. €20 per hour depending on currency exchange rates (https://www.communityni.org/sites/default/files/2018-10/Social%20Prescribing%20%28Belfast%29%20Job%20Description.pdf). As the *Exercise, COPD & Me* programme runs in the Republic of Ireland, the higher rate has been used. The total per healthcare professional is €22.87 multiplied by 52 weeks in the year which is €1,189.
[96] For instance, patients attending the Mater Misericordiae University Hospital https://www.mater.ie are more likely to be sent to classes in the relatively nearby Inspire Fitness Centre http://ifcc.ie
[97] HSE, 2010, *Pulmonary Rehabilitation Model of Care*, p. 9 & p. 12 https://www.hse.ie/eng/services/publications/clinical-strategy-and-programmes/pulmonary-rehabilitation-model-of-care-2010.pdf
[98] HSE, 2018, *Sláintecare Implementation Strategy* https://www.gov.ie/en/campaigns/slaintecare-implementation-strategy
[99] HSE, Integrated Care Programmes for the Prevention and Management of Chronic Disease https://www.hse.ie/eng/about/who/cspd/icp/chronic-disease
[100] HSE, 2018, *Living Well with a Chronic Condition: Framework for Self-Management Support* https://www.hse.ie/eng/health/hl/selfmanagement/hse-self-management-support-final-document1.pdf
[101] Irish Government Economic and Evaluation Service, 2018, *Value For Money Review Initiative* https://igees.gov.ie/publications/expenditure-reviewandevaluation/vfmr-initiative-fpas/value-for-money-review-initiative

[102] For an example, see Clare Grant et al, 2000, A randomised controlled trial and economic evaluation of a referrals facilitator between primary care and the voluntary sector, *British Medical Journal*, 320: 419 https://www.bmj.com/content/320/7232/419 which found that a specialist liaison organisation delivered greater clinical benefits outcomes for patients with psychosocial problems than routine GP care.
[103] This problem is outlined in some detail in Irish Thoracic Society, 2018, *Respiratory Health of the Nation* https://irishthoracicsociety.com/wp-content/uploads/2018/12/RESP-Health-LATEST19.12.pdf
[104] Camilla Koch Ryrsø et al, 2018, Lower mortality after early supervised pulmonary rehabilitation following COPD-exacerbations: a systematic review and meta-analysis, *BMC Pulmonary Medicine*, 18 (154) https://bmcpulmmed.biomedcentral.com/articles/10.1186/s12890-018-0718-1
[105] The total cost of COPD drugs is high: in 2017, nearly €92 million was spent on inhalers on the General Medical Services and Drugs Payment Scheme alone: Medicines Management Programme, 2018, *Inhaled Medicines for COPD: Prescribing and Cost Guidance*, HSE https://www.hse.ie/eng/about/who/cspd/ncps/medicines-management/guidance/inhaled-medicines-for-copd.pdf
[106] Figures of this magnitude are nonetheless described as *"grossly underestimat[ing] the total expenditure on pharmaceuticals for the management of COPD in Ireland"* Irish Thoracic Society, 2018, *Respiratory Health of the Nation*, p. 44 https://irishthoracicsociety.com/wp-content/uploads/2018/12/RESP-Health-LATEST19.12.pdf
[107] Abebaw M Yohannes & George S Alexopoulos, 2014, Depression and anxiety in patients with COPD, *European Respiratory Review*, 23, pp. 345-349 https://err.ersjournals.com/content/23/133/345
[108] A Tselebis et al, 2015, Strategies to improve anxiety and depression in patients with COPD: a mental health perspective, *Neuropsychiatric Disease and Treatment*, 12, pp. 297-328 https://www.dovepress.com/strategies-to-improve-anxiety-and-depression-in-patients-with-copd-a-m-peer-reviewed-article-NDT
[109] E Hurley, 2018, *Trends in hospitalisations for COPD 2009-2017*, Trinity College Dublin quoted in Irish Thoracic Society, 2018, *Respiratory Health of the Nation* https://irishthoracicsociety.com/wp-content/uploads/2018/12/RESP-Health-LATEST19.12.pdf - the mean length of stay was noted as 7.7 days and the median was 5 days
[110] Niamh Duff, 2017, Acute Hospital Expenditure Review, Irish Government Economic and Evaluation Service, Department of Public Expenditure and Reform https://www.lenus.ie/handle/10147/622565
[111] AR Jenkins et al, 2017, Efficacy of supervised maintenance exercise following pulmonary rehabilitation on health care use: a systematic review and meta-analysis, *International Journal of COPD*, 13, pp. 257-273 https://www.dovepress.com/efficacy-of-supervised-maintenance-exercise-following-pulmonary-rehabi-peer-reviewed-article-COPD found that the risk of respiratory caused hospital admissions was reduced by 28%-38% following supervised exercise programmes
[112] James J Newham et al, 2017, Features of self-management interventions for people with COPD associated with improved health-related quality of life and reduced emergency department visits: a systematic review and meta-analysis, *International Journal of Chronic COPD*, 12, pp. 1705-1720 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5473493
[113] It should be noted that the total amount made available to local COPD support groups for 2019 from the 2018 HSE National Lottery Grants scheme increased considerably to €52,600, which is very much welcomed https://www2.hse.ie/file-library/national-lottery-grants/national-lottery-grants-payments-2018.pdf
[114] http://copd.ie
[115] A contractor is not an employee
[116] See http://copd.ie/links/news and https://www.facebook.com/COPDSupportGroupsIreland for the limited range of activities undertaken by the organisation in 2018 and the relative importance of the Siel Bleu Ireland classes in the organisational profile
[117] Discounting is a problematic area and there is ongoing debate about appropriate rates. The standard public sector rate advised on p. 67 of The SROI Network's 2012, *A Guide to SROI* has been followed http://www.socialvalueuk.org/app/uploads/2016/03/The%20Guide%20to%20Social%20Return%20on%20Investment%202015.pdf
[118] This person stated that it was not applicable. A second person answered 'no' but the answer to the follow up question asking the reason for this indicated that s/he had in fact made referrals but did not realise that the programme was being delivered by Siel Bleu Ireland.
[119] Some also added classes which were only established in 2019, namely Ballybough, Balally, Clonmel and Drimnagh
[120] Note that these are already in use