Is it feasible to design a useful interface for COPD self-management?

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Declaration

I declare that the work described in this dissertation is, except where otherwise stated, entirely my own work, and has not been submitted as an exercise for a degree at this or any other university. I further declare that this research has been carried out in full compliance with the ethical research requirements of the School of Computer Science and Statistics.

Signed: ___________________

Richard Eibrand

9th July 2015

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I agree that the School of Computer Science and Statistics, Trinity College may lend or copy this dissertation upon request.

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Richard Eibrand

9th July 2015

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Finally, this is dedicated to the memory of father and my son Ben, if they had not been in my life, I would not be half the man I am today.

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Chapter 1. Introduction

1.1 Introduction

This research projects aims to design and develop a dashboard prototype to allow for self-management of Chronic Obstructive Pulmonary Disorder (COPD) with activity data recorded from an activity monitor. Maintaining a consistent exercise pattern has been shown to improve the condition and general wellbeing of individuals with COPD (Garcia-Aymerich et al., 2006; Moy et al., 2009; Watz et al., 2009), by improving their overall quality of life, and also potentially reducing the amount of time required in hospital following an exacerbation. Being able to maintain a steady exercise or activity routine has been shown to be difficult, from a self-management and behaviour point of view, and this is where this research works comes in.

By recording daily activity data by using an activity monitor, which is not in the scope of this current project, a person's daily activity patterns can be recorded and the information recorded can be analysed and formatted to show the levels of activity over a period of time. This information is then to be used to present the individual with a periodic report of their activity, in conjunction with how they have felt over this period of time. These reports could be shared with health care professionals with the aim of assisting the patients to find a meaningful and achievable set of activities within the bounds of their current condition, and becoming part of their self-management plan.

Combining the recorded activity data, and some questions relating to an individuals perceived wellbeing, recorded through a Health Related Quality of Life (HRQoL) questionnaire or other set of related wellbeing questions, it is hoped that such an interface would assist the individuals in maintaining a daily activity regime, by engaging the user with meaningful information about their activity levels, which in turn would benefit with the management of their condition.

1.2 Background

Chronic Obstructive Pulmonary Disease (COPD), is a degenerative disease of the lungs that is treatable but not curable ("WHO | Chronic obstructive pulmonary disease (COPD)," 2015). COPD is often used an umbrella term gathering both chronic bronchitis and emphysema (Living with COPD, 2015). COPD is characterized as severe airflow limitations that is no fully reversible. The progression of the disease is associated with an abnormal inflammatory response to airborne pollutants, such as cigarette smoke, fossil and biomass fuels as well other occupational pollutants. The airflow limitation that ensues is typically caused by a mixture of small airway disease (obstructive bronchiolitis) and emphysema (parenchymal destruction) (Alvaro and Eva, 2007).

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Although COPD is not a well-known condition, the WHO estimates that by 2030, it will be the 3rd leading cause of death world-wide (World Health Organization, 2008). Treatment for COPD is typically a combination of pharmacotherapy regimens, including short/long bronchodilator and steroid inhalers, nebulisers, long term oxygen therapy and in more extreme cases surgery which may include lung volume reduction surgery (LVRS) and lung transplants, pulmonary rehabilitation (NICE, 2010). In addition to the above, pulmonary rehabilitation is also used to aid the patients to recondition their muscles and lungs to deal with the condition.

1.3 Research Questions and Study Aims

For this research, the author wishes to identify the components that would allow for the design of useful interface to assist in the self-management of Chronic Obstructive Pulmonary disease (COPD). In so doing establish the feasibility of such an interface for future development and research.

The research question for this study is: *Is it feasible to design a useful interface for COPD self-management?*

This study aims to:

1. Establish if a self-management portal is of interest to both category of stake holders, namely, patients and health care providers
2. What features in such an interface would be considered beneficial
3. Establish the barriers or other factors, if any, which would make such an interface and associated technology not palatable to the core users
4. Combine the results of the steps above to establish the usefulness and feasibility of such an interface.

Identify the core components that would allow this study to be carried forward into future research work and developments.

1.4 Overview of the Research

To arrive at the findings presented in this study, a two phased approach was undertaken. An in-depth literature analysis and review was undertaken, with a view of identifying the core aspects related to components understood to be essential to answering the research question. These key components are listed in section 2.6. Additionally, from the literature review, a questionnaire was devised to allow the participants identify the features and components that they would consider useful in a prototype interface for self-management of COPD. This prototype would then be evaluated by the study participants and the results of this go towards answering the research question.

1.5 Overview of Dissertation

The structure of the dissertation is as follows

Chapter 1 – this chapter

Chapter 2 - Research Methodology: This chapter will outline the process undertaken to arrive at the findings presented.

Chapter 3 – Literature Review: This chapter presents the current state of research in the core areas identified in this study. This will include:

- A background in COPD as a medical condition, including the challenges faced by individuals with the condition.
- Physical activity as a treatment method
- Physical Tracking activity Devices
- Self-management
- Behaviour Change and motivational aspects

Chapter 4 – Design and Implementation: This chapter will discuss the design and implementation process of the interface, from questionnaire development to implementing the prototype interface.

Chapter 5 – Findings and Results: A breakdown of the results obtained through the various data collection methods, and the significance of these results

Chapter 6 – Conclusion and Future Work: This chapter will draw on all previous chapters to form a conclusion on the study, and based on this put forward a suggested course for future work that has the potential of bringing this area of study forward.

1.6 Conclusion

This opening chapter was composed to outline the flow of the document to come, but also to frame the research question and the background behind the study presented.

The following chapter will outline the rationale and process undertaken in the course of the preparation of this dissertation.

Chapter 2. Research and Methodology

2.1 Introduction

This section will describe the method and approach taken in gathering the research material required for this study. The basis of this study is to establish whether or not a user interface, can be considered useful in assisting its users to self-manage their condition. Of note here is the term usefulness versus usable. The distinction is being made at this point to indicate that the research was guided to identify useful components of the system, and not specifically how these items were displayed and interacted with on a screen.

Creswell (Creswell, 2003) succinctly summarises the approach required in establishing a research design strategy. These questions are summarised as follows:

- As a researcher, what knowledge claims are being made?
- What will inform the procedures from a strategy of enquiry point of view?
- In data collection and analysis, what methods will be used?

Each of the three items listed above will be expanded upon in the sections that follow.

2.2 Knowledge claims – Research Paradigm

Knowledge claims are also referred to as research paradigms. Research paradigms can be interpreted as a particular philosophy by which one aims to answer a research question. From the outset, this study was never going to be an entirely quantitative endeavour, as evidenced by the wording of the research question. Thus the paradigm that applied most to the intended course of research is the constructivist paradigm (Mertens, 2014), or also called the interpretive paradigm. The base assumptions in this paradigm are that knowledge is built by an interaction between the parties involved in the research process, namely the researcher and the person or people being researched. Also that the world, full of complexities for both parties needs to be understood from the standpoint of the people living in this world (Schwandt, 2000).

2.3 Strategy of Enquiry

As noted in section 2.1 a strategy of enquiry, or as termed by Mertens (2014) a methodology, aims to provide direction for research procedures. Mertens (2014) states that the “constructive” label of the research paradigm was coined to denote the fact that this paradigm was founded on the notion that knowledge that we acquired from this reality was socially constructed. When examining the purpose behind the research question, it was deemed appropriate to work with this strategy of enquiry as the knowledge sought, would be from an individual, but yet in a social context.

2.4 Data Collection and Analysis

Data collection and analysis is determined by the core research methods available to the researcher. As stated by (Ford-Gilboe et al., 1995), research methods should not be selected solely because of the specific research paradigm chosen, but more on the basis of what is believed to be a fit for the study in question.

In the case of this particular study, the following research method tools were chosen.

- Literature review;
    - To explore and understand the state of the art in research in relation to the core elements that make up the body of the research, as outlined in section 1.5
- Questionnaires;
    - Questionnaires, based on examples found in the literature were devised to elucidate the core components that would contribute towards answering the research question.
    - Additionally the questionnaires were designed to extract the items that were deemed to be most useful to the participants in order to build the user interface prototype.
- Evaluation Questionnaire of prototype interface;
    - Having gathered the required information deemed to be potentially useful, a prototype interface is to be built. From an evaluation questionnaire based on this prototype, response analysis will be made to provide the final set of data for answering the research question.

2.5 Study participants

Participants will be chosen from two identified stake holder categories as listed below in Table 2.1.

Table 2.1 COPD Stakeholders (Jordan, 2013)

Category	Examples
Customers	Advocacy groups, Support groups
Employees	Respiratory Consultants, Clinical nurse Specialists, Physiotherapists

The concept of stakeholders comes from the work of James Caddle (Paul et al., 2014). His definition of a stakeholder is as follows;

"anyone who has an interest in, or may affected by, the issue under consideration"

(Paul et al., 2014, chap. 6)

Within the scope of this definition, Caddle formulates the stakeholder wheel, with a number of categories of specific stakeholders, each of which have their own role in the project or enterprise being worked on. Of the varied list of stakeholders defined therein, only two of them are deemed to be needed for this particular study. These two stakeholder groups are namely the Customer and the Employee.

The members of the Customer stakeholder group are essentially the consumers of the product or service being purveyed, or system being used. Their importance in the process is paramount to the success of the enterprise, as without them the enterprise would not exist. They are defined as stakeholders because anything that is done by way of change to the system or product that they use has the potential to impact them. Change in this instance must be managed appropriately and carefully so as not to lose this particular stakeholder. The second stakeholder group of interest in this study is the termed as the Employee stakeholders. These are defined as the people who work within an organisation, and have a say in the way that an organisation or practice is being run, as this impacts the services that they deliver.

As outlined in Table 2.2, the Customer stakeholder group is being represented by the patients with COPD. These people are clearly the customers here as they are the ones who will be using the proposed interface to manage their chronic disease. The Employee stakeholders here are the health care professionals. They are defined as such because they too have a stake in this organisation that is the provision of care from the healthcare sector to the patients, i.e. the customers and anything that promotes change for them warrants their inclusion.

2.5.1 Participant Recruitment

Recruitment of the customer category was carried out via a visit to a voluntary COPD support group, where an initial discussion of the project description took place, and to establish if the group was willing to participate.

Stakeholders in the Employees category were originally contacted via telephone, to establish interest in taking part in the study. Further to this a meeting was had with the parties to discuss and explain the background behind the study and to enrol them as participants in the study.

2.6 Literature review

As an initial part of the research process, high level research was carried out to identify the main topics of relevance to the current course of study. The core areas of interest are listed in Table 2.2 below. The areas listed form the primary areas of interest deemed necessary to understand and be knowledgeable in the fields pertaining to this study. A literature review is defined as a thorough summary and objective analysis of available, and relevant research on the chosen topic (Cronin et al., 2008). Cronin et al (2008) further add that the goal of a literature review is to bring the reader up to date with the current literature on a topic, but also to provide the potential justification for future research in the chosen area.

Table 2.2 Core Areas of interest in Literature review search

Area of Interest	Learning Objectives
Burden of Care of COPD, Ireland and Worldwide	- To identify the costs, financial and otherwise of the caring and managing the population with COPD
Benefits of physical exercise for COPD patients	- To ascertain the assumptions and benefits and physical activity and exercise for patients with COPD
State of the art of activity trackers	- Establish the lay of the land in terms of types of activity and exercise trackers and their use within the COPD population
Self-management in relation to COPD	- Establish the importance and benefit of having a self-management plan in dealing with the day to day activities of COPD
Behaviour and motivation aspects for physical activity in patients with COPD	- Identify the core components that both hinder and aid motivation in the COPD population. Additionally identify what is being done to engage in behaviour modification to motivate patients to engage in physical activity or exercise

2.6.1 Search Criteria

To guide the data collection aspect of the literature review, a selection of keywords was chosen to filter the search results. For the majority of all the searches, all terms were prepended with either COPD or “Chronic Obstructive Pulmonary disease”. A selection of these search keywords for the sections outlined in Table 2.2 is shown below in Table 2.3

Table 2.3 Summary list of search terms

Area of Interest	Search Keywords/phrases used
Burden of Care of COPD, Ireland and Worldwide	- “Cost of COPD”, “COPD burden of care”, “cost of copd in Ireland”, “cost of COPD worldwide”
Benefits of physical exercise for COPD patients	- “COPD physical exercise”, “COPD walking”, “COPD training”
State of the art of activity trackers	- “Activity trackers”, “COPD activity trackers”, “exercise trackers COPD”
Self-management in relation to COPD	- “COPD Self-management”, “self-management plans COPD”, “patient education”, “COPD Self-care”
Behaviour and motivation aspects for physical activity in patients with COPD	- “COPD motivation”, “COPD behaviour change”, “COPD modifying behaviour”, “COPD motivational factors”

The list of search terms and queries above is not exhaustive, but aims to highlight the process involved in searching for literature.

2.6.2 Sites and research materials used

The terms listed in Table 2.2 were used across a range of different search engines. Initial searches were made using both google and google scholar search engines. From the results generated by these searches, initial papers were located and briefly reviewed for suitability for inclusion. Other search engines used were the IEEEXplore site, Springer Link, ACM Digital Library, PubMed.gov, BMJ, Elsevier, and Science Direct.

Some of the content returned would not be considered “white” research material, but would be classified as “grey” material, most notably reports, technical reports and findings from Government organisations, as well unpublished papers and content from websites or articles on websites. This was mostly the case in relation to material found on the current batch of consumer grade physical activity trackers.

2.6.3 Inclusion and Exclusion criteria

Of primary importance for inclusion of research material was that the articles, papers and books had to be in English, and related to the domain of COPD. In some cases, papers which reported on elements of behaviour change or motivation were not specific to COPD, but related to diabetes, obesity or cardiac rehabilitation programmes, but were included in the body of research as the content was deemed beneficial, and dealt with chronic disease management.

Primary exclusion criteria included material of a pharmacological nature, where drug treatments were of prime stature within the study. These were excluded on the grounds that the assumptions made by the researcher in this study was that such material and research work would be considerably out of the scope of the researcher to understand. Additionally, these research journals and conference papers had very little to no inclusion on aspects of physical exercise that are the core of this study.

Additionally, out of the returned results from direct searches, a large amount of additional research material was identified through reading the references in the papers identified. These proved as beneficial as the direct searches as they were directly relevant to the topics of interest already found. A note must be made at this point that this in itself proved a time consuming endeavour, as the tendency was to follow up on as many of these potentially interesting references as possible. This snowball effect, although beneficial, was also detrimental in terms of time, as a considerable amount of time can and was spent following references, discipline is required to call it a day when sufficient amount of material has been gathered.

2.6.4 Breakdown of search results

A summary table of the number of returned papers and research resources identified using the search strategies outlined above is listed in Table 2.4.

Table 2.4 Count of research material found per main category

Area of Interest	Number and types of results
Burden of Care of COPD, Ireland and Worldwide	- 11 Journal titles - 14 Web Page articles - 1 book - 4 reports (2 from HSE)
Benefits of physical exercise for COPD patients	- 21 Journal titles - 1 Conference paper - 2 web page articles
State of the art of activity trackers	- 8 Journal titles - 14 Web page articles - 3 reports - 4 conference papers
Self-management in relation to COPD	- 10 Journal titles - 1 book section
Behaviour and motivation aspects for physical activity in patients with COPD	- 30 Journal Titles - 16 Conference papers
Totals (for the headings outlined here)	- 70 Journal Titles - 30 Web pages - 21 Conference papers - 7 Reports

In addition to the research material identified in Table 2.4, a considerable additional amount of research material was identified in other areas. Of particular note in this discussion is the amount of research material reviewed in order to establish the questionnaires used during the requirements gathering phase of the project. These are listed in Table 2.5, alongside additional categories reviewed.

Table 2.5 Summary of additional research material

Area of Interest	**Number and types of results**
COPD Questionnaires	- 34 Journal titles - 1 book - 12 Web pages
General research material on COPD	- 34 Journal titles - 12 Web pages - 2 Reports - 4 book sections
Integrated Care within COPD/Patient Centred	- 10 Journal titles - 7 Web pages
COPD research projects – larger scale, telemedicine	- 10 Journal titles - 16 Conference papers
Totals	- 87 Journal titles - 36 Web pages - 17 Conference papers - 9 Reports - 5 Book sections

2.7 Ethical Considerations

As the research project would require the involvement of human participants, ethical approval from the research ethics committee in the School of Computer Science and Statistics, Trinity College Dublin was required. Approval was granted on the 25th of May 2015. A copy of the approval can be found in Appendix I:.

The supporting documentation for the ethical approval can be found in Appendix A: through to Appendix F:.

The study did not include any medical information, or patient identifiable information, and as such did not require further approval from either of the two stakeholder categories. Other than the Data Protection Act, no other relevant legislation applies in relation to this project and all data gathered will be dealt with in the appropriate fashion, namely;

- Demographic details of participants will be appropriately coded. Participant and code details will be kept in a secure encrypted format, ensuring participant identities and data will be anonymized.

- If audio recordings are consented to by participants, these recordings will be transcribed to an electronic format and recordings subsequently deleted within a 5 day period.

- The questionnaire data will be only be kept for the duration of the study, and will be destroyed after thesis submission on the 9th of July 2015

2.8 Conclusion

This chapter provided the background behind the research and methodology that was involved in this study. It described the research paradigm employed and the reasons why, while also stating the range of material and how it was obtained. The time and effort that was involved in establishing the above was considerably greater than anticipated, but also provided a valuable insight into the process that is required to carry research such as the research presented in this document.

Chapter 3. Literature Review

3.1 Introduction

This chapter aims to give an insight into the various aspects that form the core of this study. From the burden of care that COPD creates on the patient, their family and the health networks, to technological components such as activity trackers, and to self-management within COPD which touches on behaviour change and motivational characteristics. When combined, each of these areas will build a picture of what is being aimed at in this study.

3.2 Burden of care of COPD

COPD is a condition that develops slowly over time, and is typically diagnosed in patients over 40 years of age (WHO, 2015a). Under diagnosis of people suffering from COPD is estimated to be quite high, and the prevalence of the disease in Ireland, estimated at 26%, is not truly understood, but can be inferred from the high number of hospital admissions for treatment of COPD and deaths recorded with the underlying cause of death as being COPD (O’Connor, 2014).

Currently the burden of care on the Irish health services is visible from the following numbers that highlight the situation (HSE, 2013);

- 13,098 primary diagnosis discharge per annum
- 122,263 bed days per annum
- Mean Length of Stay of 9.2 days
- 18,500 exacerbations of COPD in Primary Care per annum

Average day rate costs for HSE hospital stays average €494, whereas HSE Regional hospitals typically cost €758 per night, HSE Country hospitals €506, and HSE District hospitals €217 per night) (Bogan et al., 2010). COPD patients over the age 65+ would stay on 9 nights on average, which adds up to approximately €7,000 per stay. This cost would exclude the actual medical and staff costs associated with treating the condition. In the Royal College of Physicians of Ireland (RCPI) positional paper on COPD (O’Connor, 2014), O’Connor lists the following figures as costs to the healthcare system attributable to COPD in 2011.

- 110,242 bed days = €91,186,895
- 3,269 day cases
- For patients with primary and secondary diagnosis of COPD, 29,072 bed days = €248,175,318

- In 2013, costs for patients attending hospital outpatient departments equalled €9,575,670
- Medication in 2012, under the State run drugs scheme, cost €650,00,000

All of the amounts listed aim to highlight the high cost of caring for patients with COPD in Ireland alone. O'Connor (2014) further highlights that in the EU in 2011, the annual economic burden of COPD totalled a staggering €141.4 billion. This amount can be broken down as follows;

- €23.3 billion; direct health care costs
- €25.1 billion; indirect costs
- €93 billion; monetised cost of Disability-Adjusted Life Year (DALY)(WHO, 2015b)

These figures highlight the economic burden of treating COPD, let alone the burden imposed on the patients and their families which is equally difficult to bear.

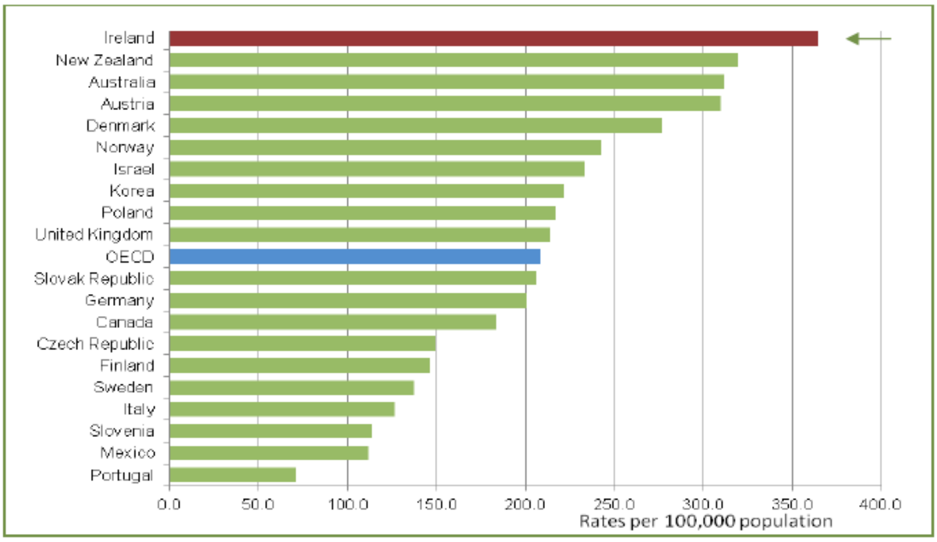
To add to the overall picture of the burden of care for COPD in Ireland, the cost of healthcare in Ireland has steadily risen since 2005, making it one of the highest among the EU15 (Callan et al., 2011). In that period (2005 to 2012), the cost of healthcare has risen by 20%. Furthering the difficulties, the budgets available to healthcare have already been heavily cut in the last couple of years. Table 3.1 shows the savings required in the health care budget from 2012 through to 2014 (Evetovits, 2012).

Table 3.1 Savings required in Irish Healthcare spending

Year	Savings Required (in Millions)
2012	-€735
2013	-€352
2014	-€404
Total	***-€1,491***

The above reductions in the Irish Health Care budget put a greater strain on all services that were being provided, meaning that fewer and fewer services are made available. This is especially true in the case of long term programmes and preventative measures required by certain medical conditions. With the upturn in the economy that has been slowly emerging, the 2015 Health service budget saw the first increase for seven years, albeit modest in terms of the amounts involved. An additional €635 million in spending, with an additional capital budget increase of €382 million

As a result of the lack of investment in the overall health infrastructure over the last decade, development in Primary care initiatives, among others, have suffered a great deal. Many conditions could be treated before the need for hospitalization occurs, furthermore, if adequate facilities were in place, follow up procedures post discharge, would already reduce the burden on the hospital system. Both the "Health system responses to financial pressures in Ireland" report (Evetovits, 2012) commissioned by the Department of Health, and chapter 2 "The performance of the Irish Health System in an International context" in the Budget Perspective 2012 report (Callan et al., 2011) commissioned by the ESRI, refer to the fact that Ireland has particular inefficiencies in the rate of hospital admissions for Ambulatory Care Sensitive Conditions, especially with regard to COPD whose rates currently rate as the highest in the OECD (OECD, 2012) (Figure 3.1)



Note: Rates are age-sex standardised to 2005 OECD population.
Source: OECD Health Data 2011.

Figure 3.1 Graph showing OECD COPD Hospital admission rates with Ireland at the top.

With such high numbers within the existing population, looking ahead towards the future and where the demographic projections are leading, notably that the population of persons aged 35 and over is projected to increase between 51% and 94% by 2036 (ITS/HSE/ICGP, 2008), the burden of illness associated with COPD will likely escalate as a result. Preventative measures need to be put in place in order to minimize the potential economic and social impact of more individuals being diagnosed with COPD.

The National Clinical Care programme for COPD (HSE, 2013) aims to put in place a number of measures in order to reduce COPD admissions by 1,500 people a year. This is to be achieved through a combination of improved COPD guideline and algorithms, decision support tools and self-management tools. The key objectives of this Clinical care programme are to improve the quality of care by decreasing mortality and morbidity of patients with early and correct diagnosis. Included in this is notion of providing the correct treatment based on accepted best guidelines for treatment which spans all care providers, from pharmacies to GPs and includes self-management. Another key objective is to improve access to facilities and treatments such as pulmonary rehabilitation. From an access standpoint, implementing COPD outreach centres and programmes aims to reduce admissions to hospitals, thereby reducing cost but more importantly keeping the patients, when possible out of hospital and within their own home environments. The stated aims and objectives of this programme would help in reducing the overall burden of care on both the health system, but more importantly on the patients themselves.

3.3 Physical Exercise in COPD

Ventilatory requirements for individuals with COPD are increased due to a reduction in the lungs capacity as a result of narrowing of the airways. This narrowing of the airways means that more effort is required to get the required amount of air into the lungs, and in turn can lead to dyspnoea (shortness of breath), fatigue and ultimately exacerbations (worsening of symptoms). These symptoms contribute to a lack of willingness to carry out exercises as the patient ultimately feels uncomfortable or unwell as result (Troosters et al., 2013). This leads to a vicious cycle in which the patient is not willing to exercise, as they are concerned about their condition, but by this lack of activity, end up worsening their condition as they are then less able to carry out simple activities (see Figure 3.2). This cycle ends up in many cases with the level of COPD increasing to a point where exacerbations occur, and the patient is more often than not admitted to hospital to receive treatment to stabilise their condition. Garcia et al. (Garcia-Aymerich et al., 2006) have shown that physical activity levels are mortality predictors and also predictors of hospitalisations, and that poor levels of activity contributes to a progression of the disease.

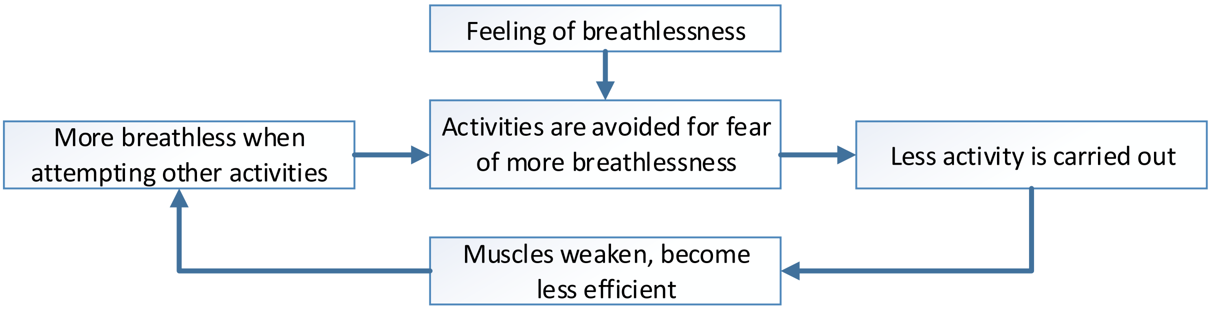


Figure 3.2 Cycle of Inactivity and Breathlessness

Troosters et al. (Troosters et al., 2013) make an important distinction in that physical activity is quite different to exercise tolerance. Physical activity can be defined as the act of exercising, whereas exercise tolerance is an individual’s ability and tolerance to carrying that exercise. This distinction is important to note as it forms a baseline for developing exercise regimens that are specific to patients with specific conditions.

A number of studies have been carried out to assess the level of benefit that physical activity has in managing COPD. Watz et al. (Watz et al., 2009) list a number of such studies in their own research, and although each of those studies came up with up their own results, it is interesting to note the disagreement between them. For example, Watz et al. (2009) mention two studies that found correlations between airway obstruction and physical activity, two who found no such correlation, and a third who only found a loose correlation. This might lead one to wonder what their criteria for establishing their result and conclusions was, but also proves another point. The point being that measuring or establishing markers in the levels of physical activity for a COPD patient is not an easy task, as there are typically many factors involved. In their own study Watz et al. (2009) noted results improved when the duration of the study increased.

Measurement of exercise capacity, in patients with COPD has been found to be a valuable and important clinical outcome (Glaab et al., 2010), whereas physical activity, according to Glaab et al. (2010) is not yet there. This is due to the fact that even with improved mechanical devices to record said activity, the validity of these devices has yet to be clinically proven. Glaab et al. (2010) note that the variability of sensitivity between differences devices has been detected. It is the author’s belief that although this may the case, the very specifics of the data recorded need not be fully accurate in order to give the user a good sense of their activity levels. That being said, in the greater context of providing a platform from which self-management of COPD is to be established, these variabilities in the data need to be normalised so as to present a uniform picture and correct, albeit approximate, representation of a patients activity levels.

3.4 Physical Activity tracking devices

Data collection for use with the proposed design explained in this study, is out of scope due to costs involved, time to create a proper validated study, and also the potential ethical issues that would be involved in generating the exercise programs required to collect the required data, and the clinical involvement and supervision that would be required. This section will deal with describing the technology and modalities of various physical activity tracking devices, and the role they would play in the overall system discussed.

Wearable computing and devices, which can be defined as sensor tools that collect data that can be worn about the body (bracelets, watches, earings, etc) are following an upward trend. The advent and continual development of mobile phones into so called smart phones, has lead the way to a new burgeoning economy of devices that are capable of interfacing with these smart phones, to provide a whole new range of data sets (PWC, 2014). Smaller, cheaper to produce and more accurate sensors are adding to the wealth of data generating options available today. Generating data in and of itself, is not difficult, it is the meaningful interpretation and presentation of this data that is of primary value which provides the utility of these devices.

The last number of years has seen a proliferation of activity trackers and fitness trackers, and according to sites that track the development of such devices, it appears many more are on the way ("Compare Activity Trackers/Fitness Bands," 2014).

Figure 3.3 shows the variety of types that activity trackers come been developed in recent times.

Figure 3.3 Different types and shapes of activity trackers ("Compare Activity Trackers," 2014)

Activity trackers as the ones shown in the figure above, store and record activity data. In some cases, this data is exportable by the device owner, but in some cases, only in limited fashion or by paying for a premium package. One such device brand that typically requires additional payment is the Fitbit brand (FitBit Inc., 2015) but it by no means not the only one. Although one can pay a premium subscription package to access this data, it is believed in some cases that this data should be freely available (Payne, 2014). Additionally the data that one can access in this case is typically daily summary data that is presented in a particular fashion. Although this data can be of considerable use, as it can show trends in activity, the more detailed data is not as easily accessed. In the case of the Fitbit devices, this level of granular data is called intraday data, and measures the activity recorded within short intervals of time, minute by minute. With the Fitbit platform, the intraday data can currently be acquired by getting access to a dedicated developer key on request from the Fitbit API developer team, which makes it ungainly for usage in the wider community (Fitbit, 2014). Other methods of extracting this data do exist, but are more work around solutions rather than an actual direct API link (Ramirez, 2014). With this in mind, it must remembered that the data is what is important from these devices, as this is what forms the basis of actually understanding the activity profile of the patients. Getting access to the data is important, and to the correct data is even more important. In developing future work along these lines with devices as the ones mentioned here, having proper access to the correct data is paramount. Choosing the correct device with the proper access to the right data should be considered a very important point in any further study with such commercial type devices.

Most, if not nearly of the existing devices are designed to be used in conjunction with a smart phone, but they are not limited to smart phones only. As for the Fitbit, other devices provide a means to interface with the tracking device directly from a PC or laptop. This is important to note as although smart phone penetration into the consumer community at large, it is slower in getting into the population above a certain age. Barriers of adoption of smart phones within the elderly population have been found to be multiple and include, financial reasons, poor vision which impairs identifying all elements on the device screens, and just as importantly a lack of knowledge and interest in such devices with these capabilities (Mohadisdudis and Ali, 2014). There is an upward trend in the usage and penetration of smartphones for the over 55's, but as reported by a report from Deloitte (Lee et al., 2014), there are still of number of challenges to address for the penetration of smart phones to increase within this age category.

3.4.1 Data from Activity Tracking devices

Going past the issues of getting access to the data outlined in the previous section. The daily summary activity data can be of benefit from the standpoint of seeing if one has achieved a particular step count or distance within a given period. Table 3.2 and Figure 3.4 show how this data be interpreted and displayed.

Table 3.2 Daily totals of activity levels

Date	Total Steps	Total Distance Covered	Sedentary Minutes	Lightly Active Minutes	Fairly Active Minutes	Very Active Minutes
20/04/2015	15300	11.37	665	292	21	44
21/04/2015	12902	9.61	820	178	16	51
22/04/2015	8285	6.16	1265	122	25	28
23/04/2015	16078	11.95	1117	229	36	58
24/04/2015	14654	10.91	688	280	40	27
25/04/2015	10012	9.4	1411	250	35	30
26/04/2015	13539	10.06	1046	338	31	25
27/04/2015	15445	11.48	1033	353	14	40

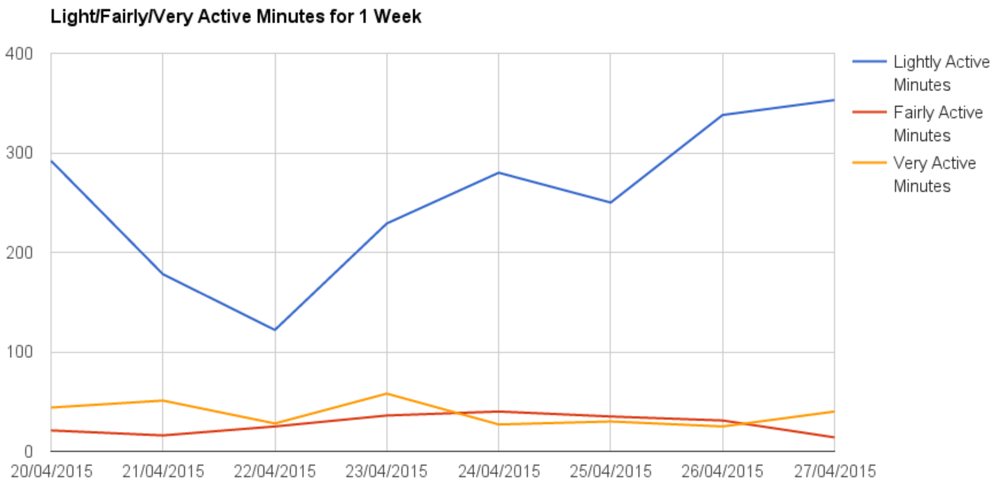


Figure 3.4 Graph showing one week of daily activity, categorised over 3 ranges of activity

From the examples shown above, it is possible to see how the data could be interpreted and viewed, and is one example of the type of data available.

Intraday data on the other hand, shows the activity levels during the course of the day, at 1 minute intervals, as shown in Figure 3.5.

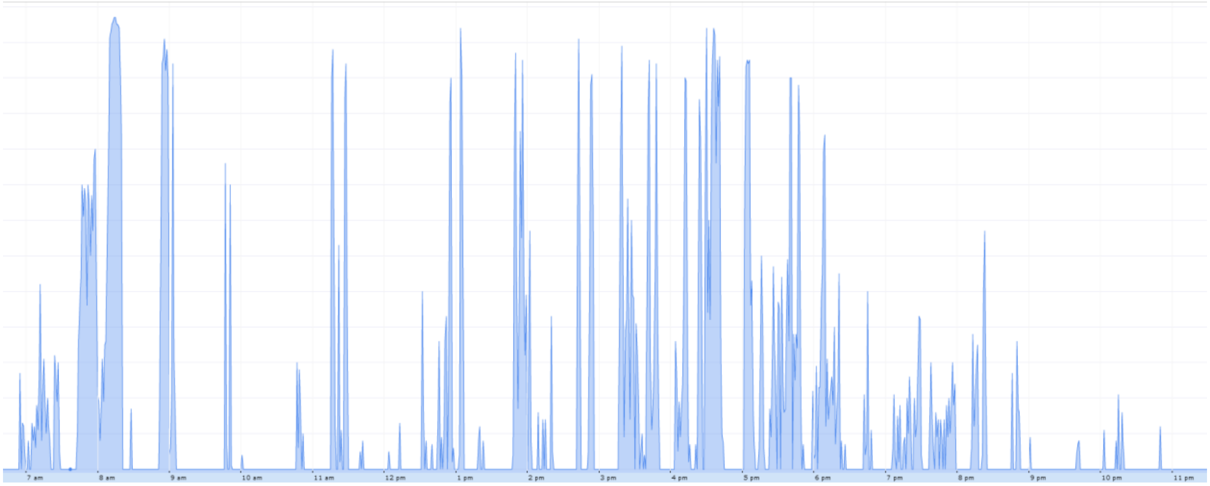


Figure 3.5 Full day of intraday data for 24 April 2015

The chart generated above is from the intraday data for 24th of April 2015 (see Table 3.2 Daily totals of activity levels for counts of that day). The large spikes indicate large amount of activity, and the flat lines indicate what are termed as sedentary periods. In this example, the data is representative of fairly typical week day. Zooming on this graph, to a period between 8:51am and 9:06, one can see an intense activity pattern, followed by a small lull for a couple of minutes, followed by another spike until a flat lined is reached at 9:06am. This particular sequence represents getting off the train, getting a coffee and continuing the walk to work for the author.

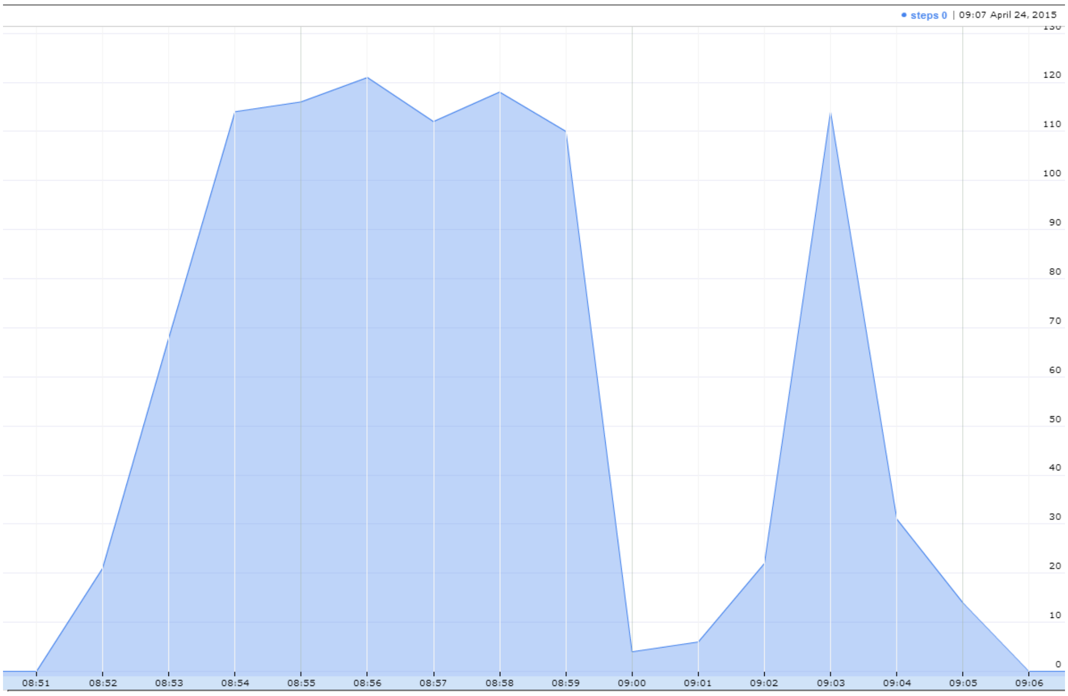


Figure 3.6 Zoom on activity period between 8:51am and 9:06am

Outside of the well-known manufacturers, there are also other companies creating sensor devices suitable for activity tracking. One such device is the MetaWear board from a company called Mbientlabs (Mbientlab, 2015). They develop small sensors boards that contain all the required electronics to create tri-axial pedometers. Additionally, a fully specified API is available for developers to develop their own applications based on these sensors. In terms of the MetaWear board, this is already the case with two pedometer based applications available on the both the Apple App Store, and google play (Gleeson, 2015)

3.5 Technology Acceptance

In a report from Arning et al. (Arning and Ziefle, 2009) they state that there is a good sense of technological acceptance in the elderly population in comparison with a younger population, and that this acceptance is based on a number of key points. These points are namely that the technology to be used ought to be timely with the information it provides, in other words that the information provided is accurate and up to date with their condition. In addition, the sense that the technology used would not restrain the mobility of the individuals, to ultimately avoid institutional care. From a design point of view for an eHealth system aimed at an elderly population, usability and reliable technology that can be trusted with personal data would lead to a greater chance of the technology in question being accepted. Arning and Ziefle (2009) emphasise the point that in order for the system to be ultimately accepted and used by the target audience, usability ought not to hamper successful interaction with the technology, if this were to happen, the users' acceptance would be lost.

In comparison with general ICT technological acceptance, Arning and Ziefle (2009) highlight that their research shows that users of eHealth technologies would be more willing to deal with the complexities of data safety. In conjunction with this, they have also remarked that the users of eHealth technologies are more disposed to sharing of their personal data with appropriate professionals involved in their care, than they would of normal ICT technology generated data.

This highlights the strong connection that any such system ought to have with the end users and the parties with which they are entrusting this sensitive and personal information to. This connection should be brought about by thinking about this interaction during the design and implementation process.

Although technology acceptance is important, a factor that has to borne in mind is that the socio-economic status and in some cases advanced age of individual COPD sufferers means that they may not be in a position to own or be willing to own technology such as the technology proposed in this study. Additionally, if the cost has to be borne personally, some individuals, regardless of how much they may be interested in this technology and its potential benefits, may not be in a financial position to acquire such devices and assorted infrastructure. The PWC report (PWC, 2014) on Wearable technology market acceptance in the U.S. indicates that there is a tendency for potential users to avail of such technologies if the cost of them was either offset by a reduction in health insurance premiums. This could also be further extended to include that if such technology were made available as part of a health treatment from a health organisation standpoint, then the acceptance and use may gain wider acceptance. A similar idea was carried out during the O2 trial in conjunction with the NHS ("O2 | O2 Health | Health at Home," 2013, "O2 Health launches Health at Home," 2013), where The O2 Health at home package provided the patients with the following tools ("O2 Health launches Health at Home telehealth service," 2013);

- Tablet computer, pre-loaded with relevant software
- Pulse oximeters
- Weighing scales
- Blood pressure monitors

The patients having this technology made available to them, were subsequently able to manage their condition thereby reducing their stay in hospital by 59%.

A study carried out Milton Keynes, as part of an EU project, has demonstrated the benefits of telecare for COPD patients. The collaborative project run by CommonWell (Delaney et al., 2012) aimed to overcome a gap in communications that existed between health and Social care provision. The service was rolled out to COPD patients that had been discharged from hospital. A specific discharge pathway specially designed for them was provided which included referrals from community nursing teams. The pilot consisted of 108 patients who were provided with monitoring equipment for vital statistics and a home telecare unit for sending out alerts if necessary. Throughout the course of the study some of the benefits were noted as follows, notably that out of the 108 patients involved in the study 168 hospital admissions over the course of one year were avoided, and additional 85GP visits were avoided also. These results are stated to demonstrate the fact that even with the technology overhead of having to deal with a number of monitoring devices, considerable benefit was achieved by all parties. It is believed that because the benefits were felt and noticed and the design of the system was such to make it useable for the user that such benefits were achieved. The point being made here is that if the correct structure is put in place around technology, there is a greater chance of it being accepted.

3.6 Health Status and Health Related Quality of Life

Health Related Quality of Life (HRQoL) is defined by the Centre for Disease Control as follows

> *"HRQoL is a broad multidimensional concept that usually includes self-reported measures of physical and mental health." (CDC, 2011)*

This definition is quite broad, as is the topic of Health related quality of life. The definition given above aims to highlight that in order to assess the health of individual, more than just physical characteristics need to be taken into consideration. The mental and psychological aspect of an individual has as much to play in their overall wellbeing as just physical characteristics.

This is highlighted in a number of areas of related to research in behaviour change and self-management in COPD, which will be discussed in greater detail in section 3.7.

Assessing an individual's HRQoL is not a straightforward matter, and is at the centre of many research projects involved in COPD, and is typically done by means of questionnaires (Blanco-Aparicio et al., 2013; Engström et al., 1998; Mazur et al., 2011; Puhan et al., 2007; Schünemann et al., 2005; Sintonen, 2001; Ståhl et al., 2003) . There exists many of these questionnaires, and some with more reported successes than others in relation to capturing the required information, namely measuring the patients perceived health related quality of life. Table 3.3 outlines a selection of the questionnaires reviewed.

Table 3.3 Selection of HRQoL Questionnaires reviewed

Name	**Description and usage**
LINQ	Based on interview questions designed and validated by COPD patients. It is interested in determining level of knowledge needs of patients. It is a self-administered questionnaire. LINQ was designed to assist clinicians in establishing what patients would benefit from information, and just as importantly, the type information this patient requires. (Hyland et al., 2006; Jones et al., 2008)
BCQK	It tests knowledge that is appropriate for COPD patients of the condition. In many way is it similar to the LINQ questionnaire, in its aims and objectives. Also of note is that this questionnaire has also been used to test the knowledge of HCPs involved in the care of patients with COPD. (Edwards and Singh, 2012; White et al., 2006)
St. George's Respiratory Questionnaire (SGRQ)	Disease-specific instrument designed to measure impact on overall health, daily life, and perceived well-being in patients with obstructive airways disease. A popular and often used health status questionnaire, which has been validated across generic disease conditions, and COPD/Asthma specifically. (Jones, 2001; Puhan et al., 2007)

AQ20	No questions in the AQ20 are specifically related to physical activity per say, although some questions ask about the patients state during strenuous activity (Aquiles Camelier, 2003, p. 20).
BPQ and BPQ-S	Neither versions have any direct questions that are related to physical activity or exercise. The questions are more related about how the individual feels when taking part in some activities and gauges the level of discomfort during those activities (Hyland et al., 1998).
COPD Activity Rating Scale CARS	Aim is to measure life-related activities in patients with COPD, essentially how much the individual is affected by their condition by rating their ability to carry out certain tasks (Morimoto et al., 2003).
COPD Test Online (CAT)	Simple test which aims to measure the impact of the condition on the individual. Again, no specific question asking the user about activity of exercise levels (Jones et al., 2009).
CCQ	The Clinical COPD Questionnaire (CCQ) measures health status and can be used to assess health-related quality of life (HRQL) (Sundh et al., 2012)
SF-36 (RAND)	A set of generic, coherent, and easily administered quality-of-life measures. These measures rely upon patient self-reporting and are now widely utilized by managed care organizations ("SF-36 Survey from the RAND Medical Outcomes Study," 2009; Mahler and Mackowiak, 1995)
Chronic Respiratory Disease Questionnaire (CRDQ)	Disease specific HRQL that contains four dimensions. Includes the following areas • Dysponea • Fatigue • Emotional function • Feeing of control over disease (Guyatt et al., 1987)

Please note that Appendix G: contains links to the actual questionnaires listed above for further review.

The questionnaires listed in Table 3.3 have been selected primarily because of their inclusion and specificity to COPD research work.

Health Status or Health Related Quality of Life questionnaires are designed to measure the impact of disease on a patient's life in a quantifiable, objective and standardised manner (Jones, 2001). These types of questionnaires address a number of areas, such as i) assessing the psychological and emotional impact of the disease on the patient ii) the physical impact of the disease on the patient and according to Jones (2001) the majority of the items on such questionnaires iii) assessing the disturbance to daily life due to implication of the disease on activities of daily living.

Although there are many Health Status/HRQoL questionnaires available, each with varying levels of success in establishing their stated aims, it is important to note the observations of Jones (2001). Namely that in treating chronic conditions, if a patient is able to identify and point to the fact that the impact on their daily life due to their disease has been reduced and that there has been a reduction in symptoms, then there is clinical significance in that. It must also be noted at this point that such questionnaires are used over a period of time in order to establish the benefits of a particular treatment course and or pulmonary rehabilitation programme. Typically by being administered at the start of a treatment plan, to establish a baseline of where the patient is in relation to their perceived health status, and then at the end to establish if the treatment plan has had an impact on their health status. Such questionnaires are also used to get a point in time view of the patient's health status.

The aim of these questionnaires, is to assess in one form or another, the level of education or knowledge that COPD patients have about their condition. By inference, measuring the level that they have also highlights the lacuna in their knowledge and aims to assists health care professionals (HCPs) in providing the missing links and knowledge required to manage their condition. Only two of the research papers identified the lack of knowledge of same HCPs charged with providing this care (Bertella et al., 2013; Edwards and Singh, 2012). With the care and management of COPD moving even more into the realm of primary care, gauging the level of knowledge that general practitioners, community nurses and ambulatory care service providers about the condition proves equally important in ensuring that the correct care is given in the correct context at the correct time.

In the context of this particular study, the focus was primarily on identifying questionnaires that attempted to measure the impact and benefits of physical activity, and those that did not. The purpose of this was to attempt to establish linkages within these questionnaires as to the benefits of physical activity and how such questions were being asked. This was done to assist in formulating the wording in the data collection questionnaires (see Appendix A: and Appendix B:).

3.7 Self-management and Behaviour change

In order for the proposed system to function as expected and to have the benefits that are claimed that it should bring, an understanding of the core components of self-management and behaviour are required. The reason for this is multi-faceted, and is broken down as follows.

Self-management:

- To allow patients to manage their condition, and understanding of what comprises self-management ought to be understood.

- The benefits of same need to be brought to the fore and incorporated into the proposed system

Behaviour Change:

- Behaviour and habits determine how people interact and deal with certain situations. As mentioned above the vicious cycle of breathlessness that patients with COPD suffer from, needs to be broken down into manageable chunks to help to overcome them. The design of the user interface must make use of behaviour change techniques (motivation/goal setting and rewards) in order to allow for the most benefit to be achieved.

As defined by Effing et al. (Effing et al., 2012), self-management plans ought to aim for structural behavioural change, which would in turn carry on with the beneficial treatment effects after programmes (pulmonary or others) have been completed. Notably, Effing (2012) also states that these programmes of behaviour change should be tailored for the individual receiving it, be mindful and take the participants perspectives into account and be ready to change as the participant's condition changes over time and if other co-morbidities come into play.

By definition self-management plans infer that they are plans that are managed by the individual alone. From researching this in quite some depth, it appears that although that is very true, the involvement of a health care professional (HCP), be it either a GP, respiratory nurse or consultant, certainly provides added benefit and meaning to the self-management plan (Apps et al., 2013; Effing et al., 2012).

Another common theme identified in the literature is that there appears to be little in the way of standards for developing self-management plans (Apps et al., 2013; Effing et al., 2012). In itself this would pose a problem in that if there is no standard mechanism or template for the developing and applying self-management plans, then their efficacy can be questioned. The non-standardised approach in this case poses a difficulty in establishing good baselines and controls against which to form judgements on the benefits and values of various components of the self-management plans. In contrast to this Bourbeau and Palen (Bourbeau and Palen, 2009) state that there is now enough sufficient scientific evidence to support the claim that self-management plans are worthy of recommendation to patients with COPD. This is in contrast to statements by Benzo (Benzo et al., 2013) that a number of studies have shown there to be little to no benefit in self-management plans benefiting patient with COPD (Benzo, 2012; Bucknall et al., 2012; Fan et al., 2012)

3.8 User interface for behaviour change

Title: Is it feasible to design a useful interface for COPD Self-management?

Designing an interface with the aim of motivational and behavioural change is complicated task. Many factors have to be taken into consideration to make it effective, informative and useful. Behavioural tendencies that have proven effective have been said to be based on the same principles of unmediated communication, namely that timely information dissemination has been shown to provide the best response from people, that the information provided has to be tailored to the situation at hand, as well as being subtle and easy to process and digest (Nawyn et al., 2006). Technological advances in the last few years have provided us with relatively cheap devices and sensors that permit the collection of data and subsequent representation of this data along the behavioural science principles which include among others, self-monitoring, suggestion, and conditioning. The above describes the ideas behind the work of Nawyn et al. (2006) who developed phone based app to promote the disruption of particular sedentary behaviour (watching television) based on principles of behaviour change promoted by B.J. Fogg (Fogg, 2002).

Nawyn (2006) summarised some of these concepts and how the relate to proactive interfaces for behaviour modification into a table similar to the one shown in Table 3.4

Table 3.4 Behaviour modification: pro-active interface strategies

Strategy	Definition
Goal Setting	The setting of concrete achievable goals promotes behaviour change by orientating the individual toward a definable outcome
Self-monitoring	The evaluation of progress towards specific outcome goals helps people who are motivated to change their behaviour more effectively
Proximal feedback	Timely feedback occurring at the time, or not long after a specific activity is more effective in behaviour change
Operant conditioning	Combining increases in desirable behaviour actions can be increased by pairing those actions with rewards
Shaping	Pre-existing behaviour can be conditioned into a more suited behaviour by rewarding near misses to the actual end goals
Consistency	The built in desire to be consistent with what we say and do is beneficial in assisting end users to achieve their goals

Interface built using the strategies listed in Table 3.4 are more likely to be effective in getting the wanted end result of a behaviour change application or system.

3.9 Conclusion

This section aimed to highlight the core components that were considered during the research, design and implementation phases of this study. By combining all of the above categories and sections, it is believed that a better and more considered solution can be designed and implemented.

Chapter 4. Design and Implementation

4.1 Introduction

This chapter will present the design and implementation principles used to create the prototype aiming to answer the research question stated in section 1.3. The chapter will also include wireframes and use cases developed.

This will include analysis of the returned questionnaires and how they were combined into the end prototype. The purpose of this section is to highlight the rationale for including and developing certain sections of the interface over others.

4.2 Questionnaire Design

The questionnaires were designed to gather as much relevant and specific information that would allow for the building of a suitable prototype. In order to do this, the questionnaires were made up of sections to establish the more favoured components among the cohort of study participants.

The components or categories used in the design of the questionnaire mentioned above are listed in Table 4.1, along with a brief description of what was sought from those sections.

Table 4.1 Listing categories used in questionnaire, along with description

Questionnaire Section	Brief Description
Section 1: Demographic/Condition details Questions 1 to 6	Section used to map out demographic details of cohort participants. Also aimed at getting information regarding exposure to health professionals.
Section 2: Self-management Questions 7 to 13	Section used to identify why exercise may not be undertaken
Section 3: Reasons for not exercising Question 14	Section used to establish the prevalence and prior knowledge of Self-management within COPD
Section 4: Motivational considerations Questions 15 to 20	Section used to establish what motivational considerations were in play for cohort participants getting involved in exercise

Section 5: Goal Settings and objectives Questions 21 to 24	Section used to establish what the cohort would identify as beneficial in settings goals and objectives
Section 6: Environment Questions 25 to 28	Section used to establish if the local environment of the participant was suitable for exercising
Section 7: Technology Questions 29 to 41	Section used to get establish the technical proficiency of participants
Section 8: User interface (UI) Queries Questions 42 to 46	Section used to establish what visual forms for interpreting the data would be considered most beneficial
Section 9: Activity Based information Questions 47 to 54	Section used to establish baseline points of view into the types and levels of activities the participants were involved in
Section 10: Additional questions Question 55	Section used to identify other components that would not fall directly into any of the categories listed above

4.2.1 Demographics/Condition

Demographic data in a questionnaire is used to determine the characteristics of a population. In order to get a sense of the demographic spread, the basic demographics questions of age, gender, and occupation were asked. Following a number of questions relating to their condition was also asked. The rationale behind this was to ascertain what category of the disease the participants fell in, and also to get a sense of their awareness of their condition.

4.2.2 Self-management

The questions in this section are based on research that shows that having a self-management plan is beneficial to patients with COPD, and that being involved in the formulation of the self-management plan benefits the individuals as it provides them with a greater sense of engagement in the process (Bourbeau et al., 2004; Bourbeau and Saad, 2013; Effing et al., 1996, 2012). This has been discussed in greater depth in section 3.7.

4.2.3 Reasons for not exercising

The reasons why someone may not partake in physical exercise can be varied. Lack of motivation, lack of time can be included among those reasons. For individuals suffering from COPD, the condition can engender real reasons such as fear of shortness of breath. This section of the questionnaire was included to establish which specific reasons might hinder a person with COPD from exercising, and from this to establish what could be included in the prototype to promote physical activity. Danilack et al. (Danilack et al., 2013) carried out such a study and found that although the study participants endorsed many of the reasons cited in this section of the questionnaire as reasons for not exercising more, this was not directly correlated in the actual measurement data recorded during the course of their study.

4.2.4 Motivational Considerations

One of the premises behind behaviour change is that motivation is improved and leads to better adherence to goals and challenges set (Consolvo et al., 2009, 2008, 2006; Hilberink et al., 2006).

4.2.5 Goal Settings and objectives

The importance of setting goals cannot be under estimated. Goals are required in order to set the pace and the direction that the patient both needs and wants to go to (Consolvo et al., 2009, 2006; Prochaska and Velicer, 1997; Shilts et al., 2004; Verplanken and Wood, 2006).

4.2.6 Environment

Environment related questions also came from Danilack et al. (Danilack et al., 2013), and were included to establish if the type of environment the participants lived in was suitable for them to exercise, or go for a walk in. In the event of this not being the case, the interface may potentially propose that alternate locations which might be suitable, such as a nearby park or shopping mall.

4.2.7 Technology

These questions are to gauge the level of technological knowledge of the participants, to establish whether or not the technology would be a barrier for them in making use of such a system (Bickmore et al., 2005). Understanding the level of technological knowledge is of key importance, especially to determine to core technology items that they use. If the participants primarily used PCs for example, a system designed visually for a mobile phone would not have the same visual appeal, and potentially as a result, would not have the same effect.

4.2.8 UI/Interface

These questions are being asked to get an idea of the group's preference to one representation of the activity data over another. In knowing this, the design could be made more appealing, and ideally to be considered more useful for the participants.

4.2.9 Activity Information

This set of questions was included to establish how the activity data and information should best be represented. Including the participants and users preferences is vital in allowing them to engage with the end product that you hope them to use and to gain most benefit from.

4.2.10 Additional Questions

The final section of the questionnaire was aimed to establish if in addition to the representation of their activity data and goal setting achievements, other elements would be considered useful. These additional features relate to information regarding medication, exercise routines, copy of self-management plan. The rationale for including these questions was to see if adding this type of additional information to the interface would add value to it, and hence make it more appealing and useful to the users.

4.3 Design Principle

The design principle used for the development of the interface was based on the User-centred design process (Norman and Draper, 1986). The process aims to involve the user from the earliest stages and throughout the course of the development of the interface. This level of involvement can take different paths. From initial inclusion during the requirement gathering phase, through the iterative development of the system throughout the course of the development of the interface. This level of involvement can take different paths. From initial inclusion during the requirement gathering phase, through the iterative development of the system and onto the final stage of evaluation of the design (Abras et al., 2004).

The user-centred design process can be represented as shown in Figure 4.1 User-Centred Design Process.

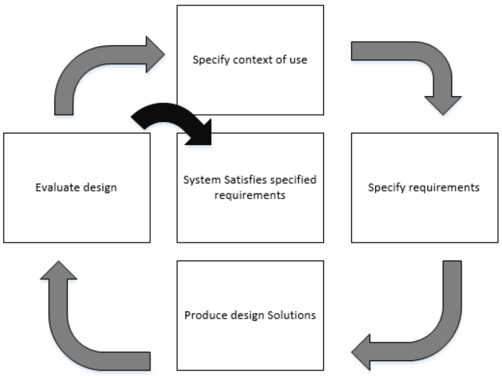


Figure 4.1 User-Centred Design Process

What is meant by figure above, is that the user can and should be involved in as many of these stages as possible and for as many iterations as is required until the system design finally meets the specifications outlined.

The user-centred process also works along the following key principles (Usabiltiy.net, 2015)

- Design for the users and their tasks
- Be consistent
- Use simple and natural dialogue
- Reduce unnecessary mental effort by the user
- Provide adequate feedback
- Provide adequate navigation mechanisms
- Let the user drive
- Present information clearly
- Be helpful
- Reduce errors

The principles above are not hard and fast rules to follow, but rather good indicators of what should be involved in systems that have been designed with this process in mind.

What is worth bearing in mind also, is that the proposed interface design is not meant to be fully fledged functional system, its intention is to be prototype of an interface that could then be further developed at a later stage, following more refined requirements gather and formal design specification.

4.4 User-Interface Prototype

The interface was built following the results gathered from the questionnaire designed and discussed in section 4.2, and the results of phase 1 of the questionnaire gathered in discussed in section 5.2.

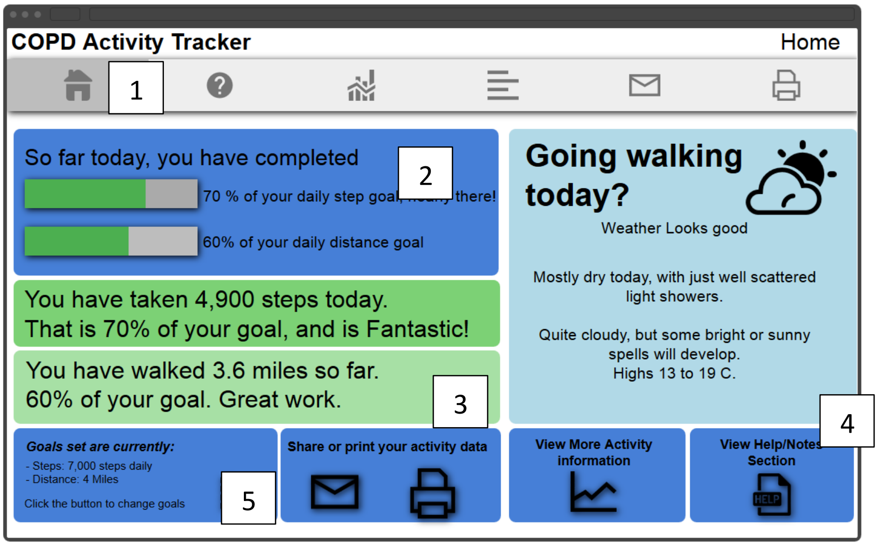
The prototype interface was built using a tool Proto.io (http://proto.io).

Please note that only the top level pages will be described here in the following sections. The remainder of the prototype screenshots are viewable in Appendix H:.

4.4.1 Option 1 – Accessing the Home Page

On accessing the home page of the interface, the user is presented with a dashboard showing them;

1) A menu bar to bring the users to any of the other sections they may wish to choose from
2) Current activity to date, and what percentage of the goals that was set has been met in graphical format, along with message to encourage them along their way.
3) Current activity to date, and what percentage of the goals that was set has been met in text format, along with message to encourage them along their way.
4) Display of current weather conditions to assist them in planning their activities.
5) Small view of the goals that are set, and additional set of navigation links at the bottom of the page



So far today, you have completed

70 % of your daily step goal, there!

60% of your daily distance goal

You have taken 4,900 steps today.
That is 70% of your goal, and is Fantastic!

You have walked 3.6 miles so far.
60% of your goal. Great work.

Weather Looks good

Mostly dry today, with just well scattered light showers.

Quite cloudy, but some bright or sunny spells will develop.
Highs 13 to 19 C.

Goals set are currently:
- Steps: 7,000 steps daily
- Distance: 4 Miles

Click the button to change goals

Figure 4.2 Initial Home Screen

Error! Reference source not found. shows an alternate screen displaying different colours if the activity is not in line with the goals set, and if the weather is inclement.

4.4.2 Option 2 – Help Screens

The Help section is the section that contains the self-management information sections, as well as the help material such as training videos, and a link to the medication notes section.

The user has a number of options here:

1) Click on the Self-management if feeling well button
2) Click on the "What do if feeling unwell button"
3) Click on the "What to do if feeling very unwell" button
4) Click on the "What to do in the case of an emergency"
5) They can choose to watch of the provided training videos, or click a link to bring to page that has more videos.
6) Click on the Medication Notes button to bring them to a page with details on their medication
7) Click on any of the links in the "Useful Resources" to get more information

This section contains information regarding your medication.
Click the button below for more information.

Click on the links below to go these websites with helpful information on COPD

COPD Ireland
Irish COPD facebook page
HSE COPD Resource page

COPD Outreach Centres
St. Michael's COPD Outreach
AMNCH (Tallaght) COPD Outreach
Beaumont COPD Outreach

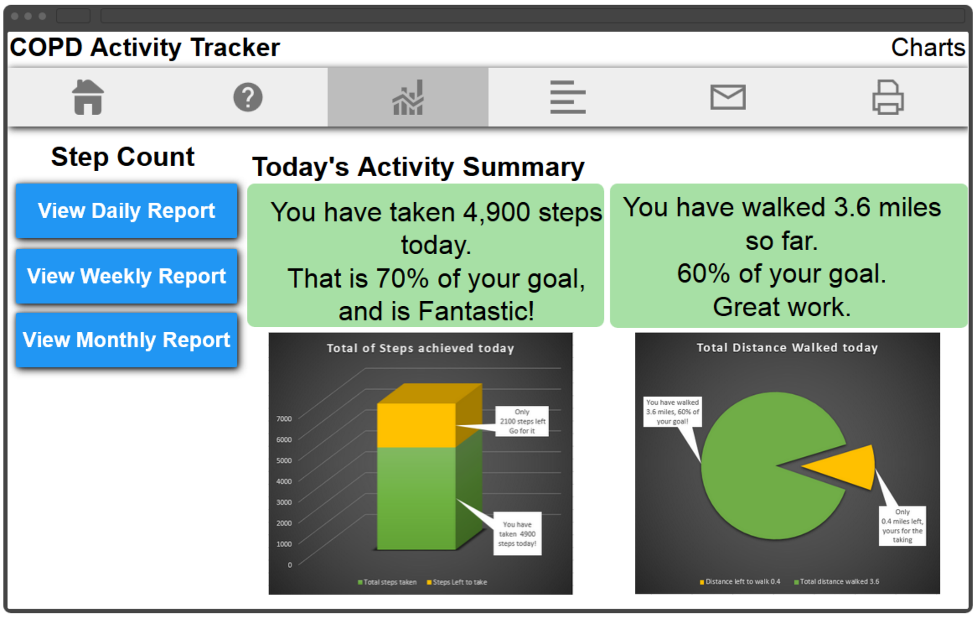
Figure 4.3 Initial Screen of Help Section

Of the options 1 to 5, each of those brings the user to a new page, where they can view helpful information to help them manage their condition depending on they feel at the time, but also record how they are feeling. These records are avaible for them to view within the interface, and also to send them to a either a pre-selected contact, or a free-form entry contact. The medication notes section brings to the user to a page with displays their current COPD related medication.

4.4.3 Option 3 – Charts Screen

This screen gives the user the option of viewing their step count reports over different time ranges. The default page that the interface opens on is on graphs showing their current daily activity, as shown in Figure 4.4. Again the user has a number of options here:

1) Click on Daily Report to see their Daily report.
2) Click on View Weekly report which will show them a weekly summary report of their activity
3) Click on View Monthly report which will show them a Monthly summary report of their activity, and also provide a button to compare activity versus wellness data.



You have taken 4,900 steps today.
That is 70% of your goal, and is Fantastic!

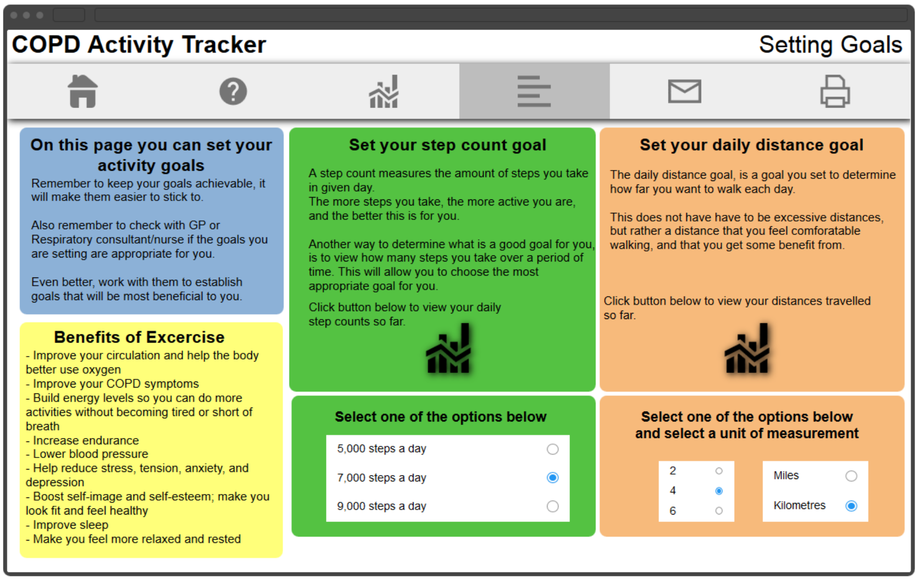
You have walked 3.6 miles so far.
60% of your goal.
Great work.

Figure 4.4 Initial page of the Charts page

4.4.4 Option 4 – Goal setting screen

This screen allows the users to set their own goals and provides information regarding what the goals mean.

1) One option allows the user to set the goal for total amount of steps in one day
2) Other option allows the user to set the goal for total distance walked in one day



On this page you can set your activity goals

Remember to keep your goals achievable, it will make them easier to stick to.

Also remember to check with GP or Respiratory consultant/nurse if the goals you are setting are appropriate for you.

Even better, work with them to establish goals that will be most beneficial to you.

Benefits of Excercise

- Improve your circulation and help the body better use oxygen
- Improve your COPD symptoms
- Build energy levels so you can do more activities without becoming tired or short of breath
- Increase endurance
- Lower blood pressure
- Help reduce stress, tension, anxiety, and depression
- Boost self-image and self-esteem; make you look fit and feel healthy
- Improve sleep
- Make you feel more relaxed and rested

Set your step count goal

A step count measures the amount of steps you take in given day.
The more steps you take, the more active you are, and the better this is for you.

Another way to determine what is a good goal for you, is to view how many steps you take over a period of time. This will allow you to choose the most appropriate goal for you.

Click button below to view your daily step counts so far.

Select one of the options below

5,000 steps a day ○
7,000 steps a day ●
9,000 steps a day ○

Set your daily distance goal

The daily distance goal, is a goal you set to determine how far you want to walk each day.

This does not have have to be excessive distances, but rather a distance that you feel comforatable walking, and that you get some benefit from.

Click button below to view your distances travelled so far.

Select one of the options below and select a unit of measurement

2 ○
4 ●
6 ○

Miles ○
Kilometres ●

Figure 4.5 Initial (and only) Screen of Goal Setting page

4.4.5 Option 5 – Print/Email Screens

These screens both share the same functionality, namely to share the information contained within the system by either email or printing a copy of the report.

1) The screen provides options for selecting which activity data to select from
    a. Today's activity data
    b. This week's activity data
    c. Last month's activity data
2) To select the recipient from a pre-defined list
3) Or to enter a new recipient.

The same options are available for sharing of wellness data. As a reminder, this is the data that is entered on the subsequent self-management screens in the Help section.

4.5 Access to Prototype

The prototype can be viewed at the following URL:

http://projects.eibrand.net/projects/COPDAT

4.6 Conclusion

The preceding chapter discussed the design and implementation of the prototype based on data and information gathered from participants in the study. It also provided a brief overview of the layout and flow of the prototype that was designed and implemented. Please note to view additional screenshots of the interface, please refer to Appendix H:.

Chapter 5. Findings and Results

5.1 Introduction

This chapter is aimed at putting forward the findings and results gathered during all phases of the research project. These finding and results will be based on the collation of the data gathered and discussed in Chapter 2 and Chapter 4 and from analysis of the documentation reviewed in Chapter 3.

Data collection for both stakeholder groups was lower than expected, but all the same, it is believed that enough data was acquired for analysis and to be able to draw a conclusion from it.

5.2 Customer Questionnaire Data Phase 1 results

In Chapter 4, the design of the questionnaires was discussed. To gather the information required, an analysis of existing COPD related exercise and health status questionnaires was carried out and combined into a specific questionnaire for this study. Two categories of participants were identified, namely a Customer category, and an Employee category. The Customer category relates to patients with COPD, who are customers of the health service and services of health care professionals, but also as the category of users that would avail of the proposed interface. This particular category of individuals are at the core of the research project and it was from them that the majority of the data was gathered, and for whom the interface was designed.

The design of the study discussed in Chapter 4 aimed to gather data that would allow for the design and implementation of a self-management interface. In order to do so, the questionnaire was aimed to identify the aspects of such an interface that would be seen as most beneficial and ultimately lead to building the interface based on these aspects. These results are discussed in section **Error! Reference source not found.**.where each the questionnaire categories are listed with their respective results. This data was then used to design the interface, which was then evaluated by the same cohort in order to answer the research question, these results are discussed in section 5.3.

Please refer to Table 4.1 for further details on the sections outlined below.

5.2.1 Section 1: Demographics/Condition Details – Questions 1 to 6

Questions 1& 2, Age and Gender:

For this phase of data collection, the total number of participants was 6. With an age profile of minimum age 72, maximum 78 and a median of 74.4 years of age. The split of male to female was 33% and 66% respectively.

Question 3, Disease severity measured by MRC grade:

Only one participant responded with the classification of their disease. Difficult to tell if this was a case of the individual not knowing this information or simply not wanting to share it, as all questions on the questionnaire are optional.

Question 4, Past/Present Occupation:

As expected, the responses were mixed. House wives, Costume supervisor, bus driver, and an unexpected answer, teacher's pet, and retired. In hindsight this question was misleading and did not allow for proper distinction of background, as the question asked "what is your present or past occupation?" such wording could not allow for determining which was present or past, although this could be inferred from the age range.

Question5, Attendance to pulmonary rehabilitation:

All of the participants had attended some form of pulmonary rehabilitation at some point in the past. In retrospect, asking for a timeline as to when this would have been done might have also provided some useful information. Such as whether or not the material of the program had been relevant and still applicable to them now. It has been found that participants of pulmonary rehabilitation programs do have a tendency of adhering to an exercise regime for a short time after attending such programmes, but that there is a marked decline in their activity levels thereafter (Bourbeau and Bartlett, 2008).

Question 6, Current contact with Health Care providers (HCPs):

The participants were asked to answer yes/no/Comment for this question, in a table which listed a number of different HCPs. The category most represented in this category was Respiratory Specialist/Physiotherapist and consultants with 83% percent of the participants seeing these HCPs. Practice nurse or nurse practitioners were seen by 50% of the group. An omission was made on this table and should have included GPs, as all participants mentioned their interaction with their GPs during the evaluation of the prototype interface. The sense of the groups' interaction with the HCPs and GPs during this discussion was revealing, and lead to a sense of displeasure in the care and understanding given by these care givers.

5.2.2 Section 2: Self-Management – Questions 7 to 13

The questions in this section were asked to get a sense of the level of involvement in the creation and maintenance of their self-management plan.

Of the respondents, 50% had a self-management plan, 17% did not and 33% did not respond. During the initial introduction of the author with the group, when explaining what this study was about, a number of the attendees at the meeting looked a little confused when mentions of self-management plans were made. What followed was a relatively heated discussion among the group about what a self-management plan was, the benefits of having one or not disadvantages of not having one. One person said, “You don’t need a self-management plan, all you need is common sense”. The group members that had originally asked what a self-management plan did not appear to have understood much of the group conversation. Based on the above, it is difficult not to think that had there been a greater group of respondents to the survey, the percentages of those who did not have self-management plan would be greater.

Of those that have a self-management plan, they came from different sources. One was self-made with some information provided by a physiotherapist. Another came from having completed a pulmonary rehab programme, and the other came from the support group from which the study participants came. The respondent who had received the self-management plan from the pulmonary rehab programme commented that the information sheet was very badly printed and hard to read.

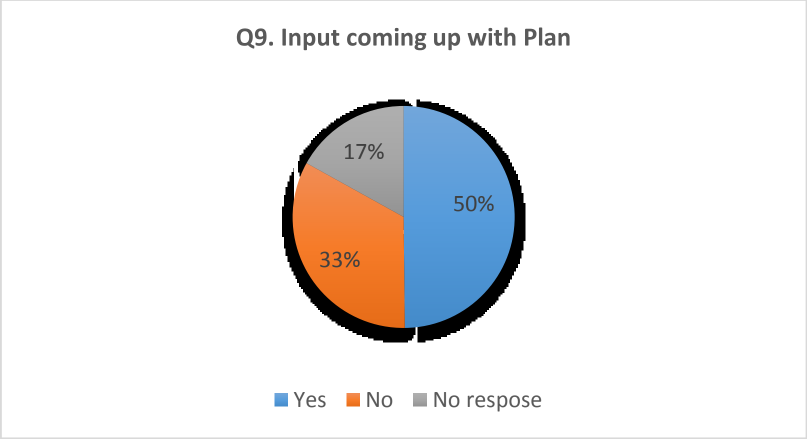


Figure 5.1 Respondents with input on creating self-management plan

The value of the self-management plan to those who had one yielded a split response. 50% of the respondents answered both yes and no to this question. The next question should have been proposed differently. It asked the respondents what they feel should be included within the self-management plan, as opposed to perhaps what the respondents felt that this self-management plan was lacking in, and what it did well in. Having this information would have allowed for inclusion of the missing elements into the prototype interface. Only 33% of respondents answered this question with "nothing else" as an answer to what they felt should be included in a self-management plan and the other being a single word "motivation". One can possibly infer from that this last respondent was looking for more help in motivation to carry out exercise routines or physical activity as this respondent had received their plan from a pulmonary rehab programme, but perhaps this is too far an assumption to make.

Self-management plans in their own right are not all about exercise of physical activity but rather a whole approach to managing COPD, which includes diet, exercise, and medication adherence. The second last question in this section related to establishing if the existing plans had enough information to help manage activity levels. Each of the answer options, namely yes/no and no response received scored 33%.

The final question in this section was aimed at establishing what specific features or aspect of a custom made self-management plan might be beneficial for the users. Only one respondent made a suggestion and this was for some form of progress measurement. This was later confirmed as being goal related, to assist the user to see how they were doing in relation to a goal being set.

5.2.3 Section 3: Reasons for not exercising - Question 14

In section 4.2.3 this section of the questionnaire was discussed. Knowing why somebody may want to exercise is one thing, and is established the results for this question are presented in the following section, but knowing what the reasons for not exercising are equally important. The barriers to exercise used for this were adapted from Danilack et al. (Danilack et al., 2013).

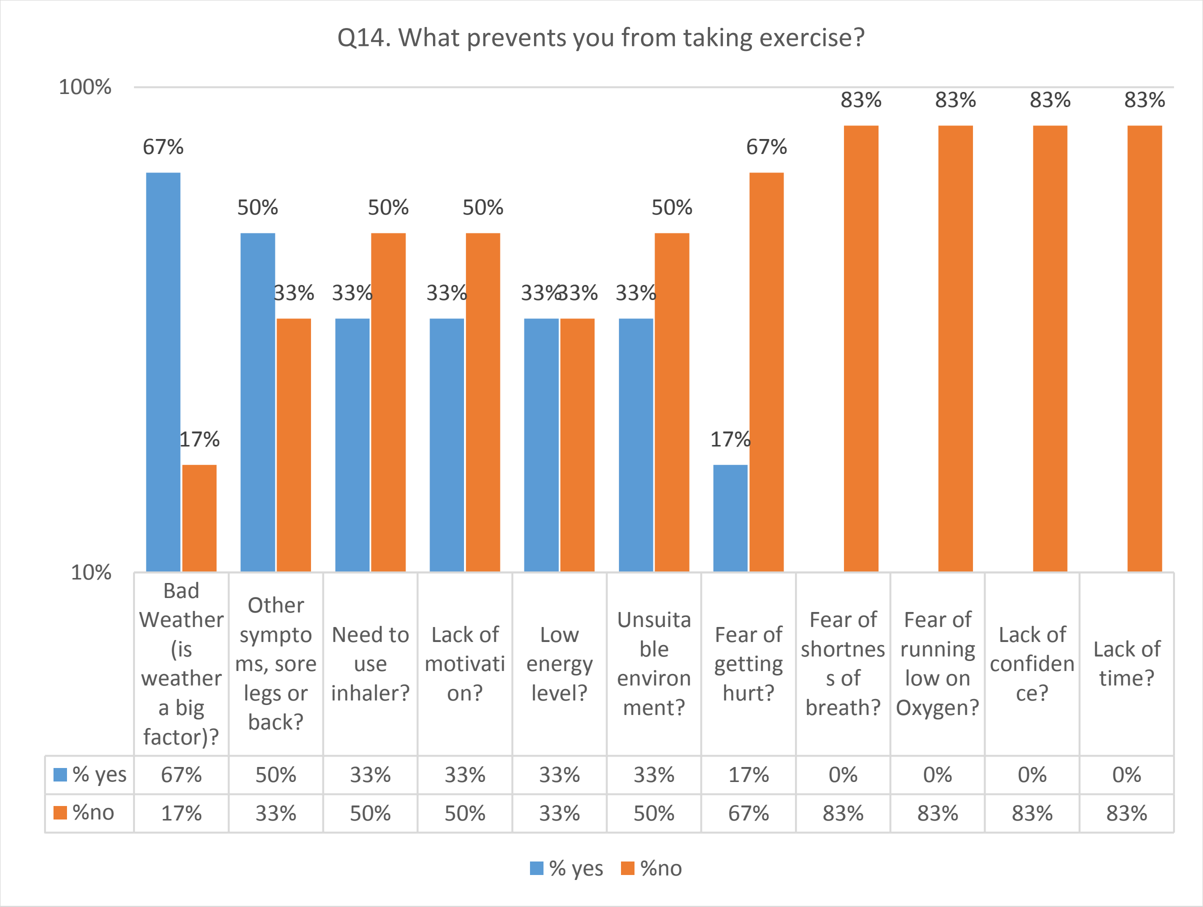


Figure 5.2 Results showing items preventing COPD patients from taking exercise

From the data visible in Figure 5.2 it is clear to see that in the study participants, the biggest contributing factor for not exercising is weather related. Although the reason why the weather affected them was not asked or stated by the participants, it is in line with the findings of Wigal et al. (Wigal et al., 1991). In developing their COPD Self-efficacy scale (CSES) Wigal et al. linked weather as a major factor in patient's ability to manage their condition based on the lowered confidence they feel around bad weather. They further hypothesised that maybe the bad weather may be the cause or onset of health issues, such as colds. It was also found that step counts during cold and wet weather, were considerably reduced (Alahmari et al., 2015). To further extend the link with bad weather and lack of exercise, studies in the seasonality of exacerbations identified that there was an almost double increase in exacerbations during the winter months compared to the summer months (Donaldson, 2012).

Other factors which hindered the participants ability in doing some form of physical activity was aches and pains of legs and backs. When the cycle of inactivity (discussed in section 3.3) is in play, the lack of activity brings about a lack of oxygen to the muscles in the body. This lack of oxygen is what causes the aches and pains felt by these individuals. The aim of pulmonary rehabilitation programmes and physical activity as promoted by all HCPs in managing COPD, is aimed at breaking the cycle of inactivity, to allow the patients to not feel such aches and pains when out carrying out activities of daily living.

Of interest was that a number other factors one might attribute to not wishing to partake in exercise did not score anything at all in this study. Those factors are namely a fear of shortness of breath, running out of oxygen and both lack of time and lack of confidence. For the last two items, it must be noted that of the study participants the average age was 74.4, and the primary stated occupation was that of being retired, so perhaps in this cohort, time was not such a big factor. Additionally, the fact that these participants were already part of COPD support group, meant that a lack of confidence was perhaps not an issue for them, as their participation in such a group would indicate a level of confidence which may not be found in other patients with COPD.

5.2.4 Section 4: Motivational Considerations - Questions 15 to 20

Knowing the factors that might prevent COPD patients from taking exercise is one side of the coin. The other side, and a critical component in trying to incorporate the most useful components in such a prototype as the proposed, is knowing what would motivate people to take exercise. This section of the questionnaire was aimed at this the results shown in Figure 5.3 show the results obtained.

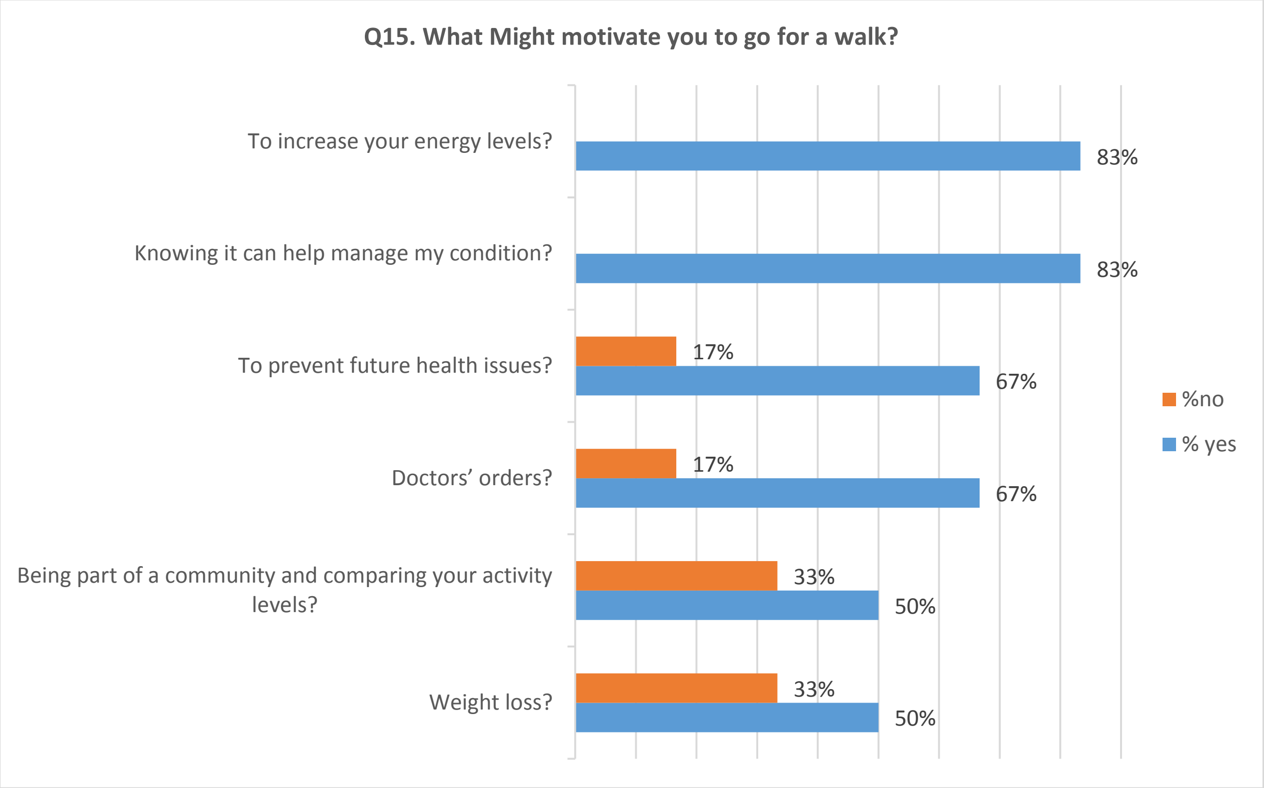


Figure 5.3 Results for potential motivational reasons for exercising

The two strongest reasons stated as being core motivational factors, each scoring equally strongly, was that going for walk would help to increase energy levels and that it would help the individual manage their condition.

Of the next two strongest responses, one was found to be interesting in relation to comments made by the group on the involvement of some of their care teams. The overall sense from the group, was that they found their care lacking, and a lack of interest in the patient's condition and knowledge about COPD was a source of frustration for the participants. With this being said, it appears that they would gladly welcome the motivational impact of having their doctor order them to walk more often. This would lend strength to the thinking that involvement of all HCPs would bring many benefits to the patient, not least in the area of motivation.

All of the participants agreed that being part of a group that could share activities would be a motivating factor. This is very interesting and correlates with the work of Consolvo et al. (Consolvo et al., 2006). In the study by Consolvo et al. they had 3 different versions of an application to record, monitor activity levels in a group of women who wanted to lose weight. What they found was that when comparing the sharing version of their application, versus the personal version, that the participants in the sharing version, were significantly more likely to meet their pre-defined step goals. The sharing in this case is where the users of this particular application could send their step count to some or all of their fitness group, see other people's progress reports and trends over a period of 7 days.

The second part of this question was whether or not the participants would like to a league table of who was most active. The answers were split 40% yes and 60% no in this case, signifying that although there is an interest in sharing information, the manner and format of this sharing must be approached in a considered manner. In conjunction with this, the following question asked that if the participants were part of a setting similar to Operation Transformation, and that their activity and exercise was measured would they feel that this would help them motivate them. For context, Operation Transformation is a television program that has been running since 2008 on RTE television and radio that selects individuals wishing to lose weight and puts them through a series of challenges and weight loss goals over the course of several weeks. The members are assisted by psychologists, health and fitness experts and nutritional experts to assist them in reaching their weight goals. In asking this question, it was believed that if the interest was there, the potential for inclusion of some of the principles of the programme, namely that the objectives and goals are shared among many people, and that there is a group of interested professional parties involved, that this might strengthen the motivational aspect of agreeing and sticking to exercise or physical activity regimes.

The final three questions in this section were of high importance to the core premise of this particular study. At the core of the proposed interface, is the idea that activity/exercise data is to be collected by means of an activity tracker of some form. This data would then be presented to the users by means of the interface, and that other motivational and informational structures would be based around this data. In order for this to be of any benefit, the participants would need to have the understanding that their activity mattered, and this activity is typically measured in step counts or distance travelled. Gauging the interest in knowing this information would indicate the willingness to measure and track their progress.

These last three questions asked the following:

- Question 18: Do you know how far you walk each day?
- Question 19: Would you like to know how far you walk each day?
- Question 20: Would knowing the distance you walk each day be of use to you?

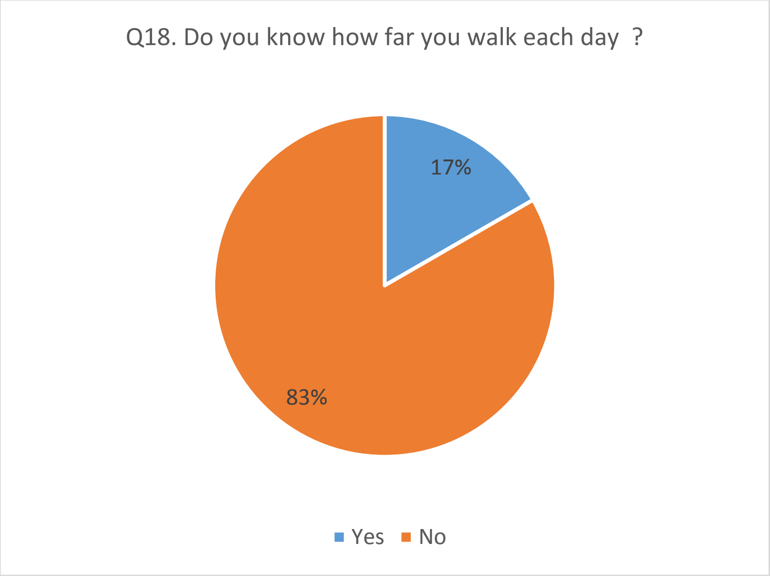


Figure 5.4 How many participants would like to know how far they walk each day

The 83% of the participants did not know how far they walked each day, one suggested that perhaps they walked about 2 miles, but were not sure. The use of an activity tracker as proposed here would remove this doubt and give the user an accurate step measure of the distance they walked for any specific period.

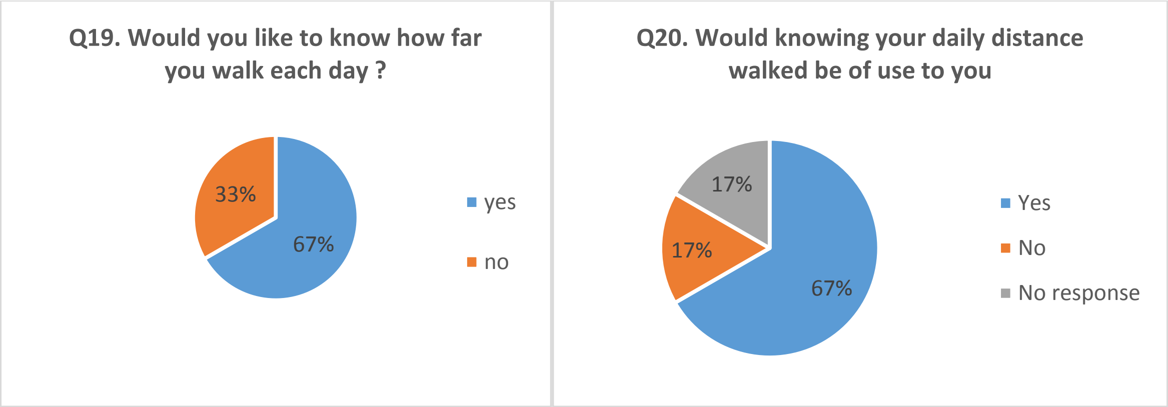


Figure 5.5 Results of questions 19 and 20

These results indicate that there is a willingness and need to know these values, and also indicates the understanding of their importance in relation to knowing what the activity levels are like.

5.2.5 Section 5: Goal Settings and objectives - Questions 21 to 24

Motivation is required and essential for any system that aims to bring about a change in behaviour for any purpose. Goal settings and objectives are equally important, but goals and motivation are symbiotic. In order to achieve any set of goals or objectives, the correct motivation needs to be in place. This section of the questionnaire was aimed at identifying what the participants would consider a good way to measure feedback on their activities and what they would find useful in settings goals and objectives.

The first question in this section dealt with knowing the frequency of when feedback on their activity would be required. Interestingly, the majority of the answers suggested monthly feedback was sufficient for them, only one participant suggested daily feedback.

The participants were then asked to rate how strongly they would rate positive feedback on a scale of 1 to 10. The rationale behind this question was to establish whether positive feedback of the likes of “Great work”, or “Keep going, nearly there” would be accepted and welcomed. One participant did not rate this highly at all, whereas the remainder rated between 8 and 10 out of 10, suggesting that this type of feedback would be welcomed. On this scale, 1 indicates not wanted or liked, and 10 indicates wanted or liked. The following question asked the reverse of the last, namely it asked the participants to rate how strongly they would rate critical feedback of the likes “You can do better” or “Not there yet”. The answers mirrored the previous set only 1 participant rating this type of feedback with a 1, and the remainder between 8 and 10 out of 10. Reviewing the questions and the answers given now, suggests that the questions should have been asked in a different manner, perhaps giving an example of what was meant but positive and critical feedback as outlined above. This would have removed doubt as to what was meant by the questions.

The last question in this section aimed to identify what the users of the interface would consider to be helpful in allowing them to set goals that they felt were achievable. One of the responses indicated that goal setting would be “self-defeating” for them, and that the ability to set a norm or average would be preferred. The perceived impact for this user would be that a goal that was too high would be depressing if they were not met, and that if they are too low would be “boring”. What is to be taken from this suggestion is that arbitrary goal setting is not what is needed within such a system, but rather that by establishing a baseline would benefit the individual in setting achievable goals based on their current abilities. Other suggestions within this question that tie in with the previous section of questions based on the motivation, is to incorporate group meetings with people who are having the same problems with COPD. Such an answer would suggest that the sense of being part of a community is something that is needed and welcomed and should be fostered.

5.2.6 Section 6: Environment - Questions 25 to 28

The first three questions in this section were asked to establish the type of environment available for physical activity to the participants. Also whether or not the environment they had available to them was conducive to walking. In general the participants felt that the environment available to them was safe and suitable for walking. The reasoning behind this set of questions was to see if there was a requirement within the interface to suggest either alternative locations for walking, such as a local shopping centre, or if there was a need to include other means of promoting physical activity from within the interface.

The type of exercise or physical activity was also gathered within this section, and the results are presented in Figure 5.6.

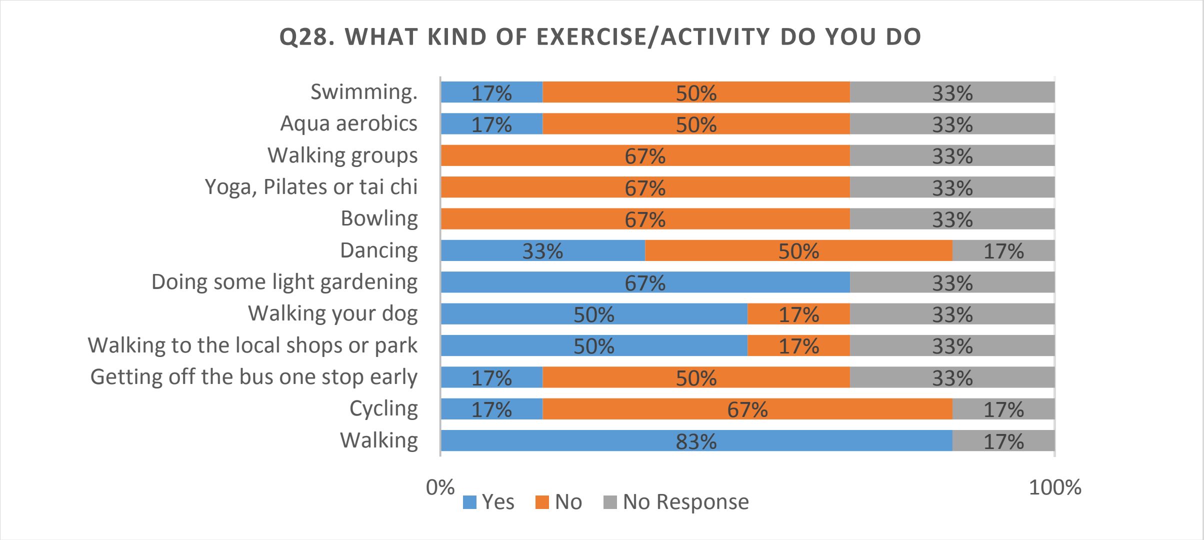


Figure 5.6 Preferred mode of exercise

These results shown in Figure 5.6, show that although there are many forms of exercises available, the preferred mode is walking. This is not unexpected, but what was sought here was to see what other modes of exercise were available to the group on foot of their condition. Beyond simply walking, the other three highest ranking activities were light gardening, followed by dog walking and walking to local shops. The results here highlight the fact that activities, at least within this particular group, are limited to ones that less energetic. Due to the nature of COPD, this is not unexpected, but it does strengthen the hypotheses that walking as a means of physical activity needs to be strengthened and provided with as much support as possible.

5.2.7 Section 7: Technology - Questions 29 to 41

As this interface was to be accessed via a computerised device of some form, the importance of understanding the technological literacy of the cohort was vital. All of the consumer grade physical activity trackers provide an interface on both PC/Laptops and on mobile devices. Mobile phone devices themselves nowadays provide a range activity tracking features due to the built in sensors and apps provided. The major mobile phone vendors such as Samsung, Apple and Sony are big players in this area. At time the time of writing, the accuracy of these devices has not yet been validated within the COPD research community.

The starting questions in this section asked the participants if they knew what an activity tracker was. The response was mixed, with 33% saying yes, 33% no, and the remaining 33% no provided no answer. Asked if anyone owned one, not one person in group did. It became clearer during the one of the meetings with the group that in fact a number of them had already been part of a study from another institution which provided an activity tracker and smartphone as part of their study. With that though the responses in the returned in the questionnaires did not reflect this.

In the previous sections, the notion of being part of a community that would share their activity data were questions that were answered favourably. This was reflected in the strong response of 80% of the participants that were willing to share the data gathered from such an activity tracker.

From a usability and accessibility point of view, the premise would be that having a mobile device, preferably a smart phone, would provide greater access to the data and information contained within the interface. As the results came to show, that not one person in the group owned a smart mobile phone or a tablet. On the other hand, 100% of participants had a laptop or a PC at home with access to the internet. The user’s proficiency at using this equipment was also queried and found to range in the lower end of the proficiency scale, from not very comfortable to moderate. This was to be expected in part due to the age profile of the participants. With that being said, it was surprising to see that at least out of participant group, that all of owned and operated a PC or laptop. The usage was basic, internet use for research, watching DVDs, looking up information and emailing. A high proportion of the users also had a printer, 67% of them.

5.2.8 Section 8: User interface (UI) Queries - Questions 42 to 46

User interfaces mean different things to different people and because of this the correct choices have to be made when designing them. Displaying data as information has to be relevant and meaningful to the users, and not be lost in the complexity of the interface.

The participants were asked if they would consider it useful to see how their respective activity levels compared to their perceived quality of life. With the exception of one no response, all other participants answered yes to this question.

With this information, the next step was to establish which features should be included in the self-management interface. Of interest was to find out how the participants would prefer to see their activity represented. The participants were provided with screenshots of activity data presented in different formats (examples of these can be seen in Appendix A: question43). The responses in this case were scattered and less decisive than hoped. It is felt that this was due to how the question was presented in the questionnaire. The results are presented in Figure 5.7.

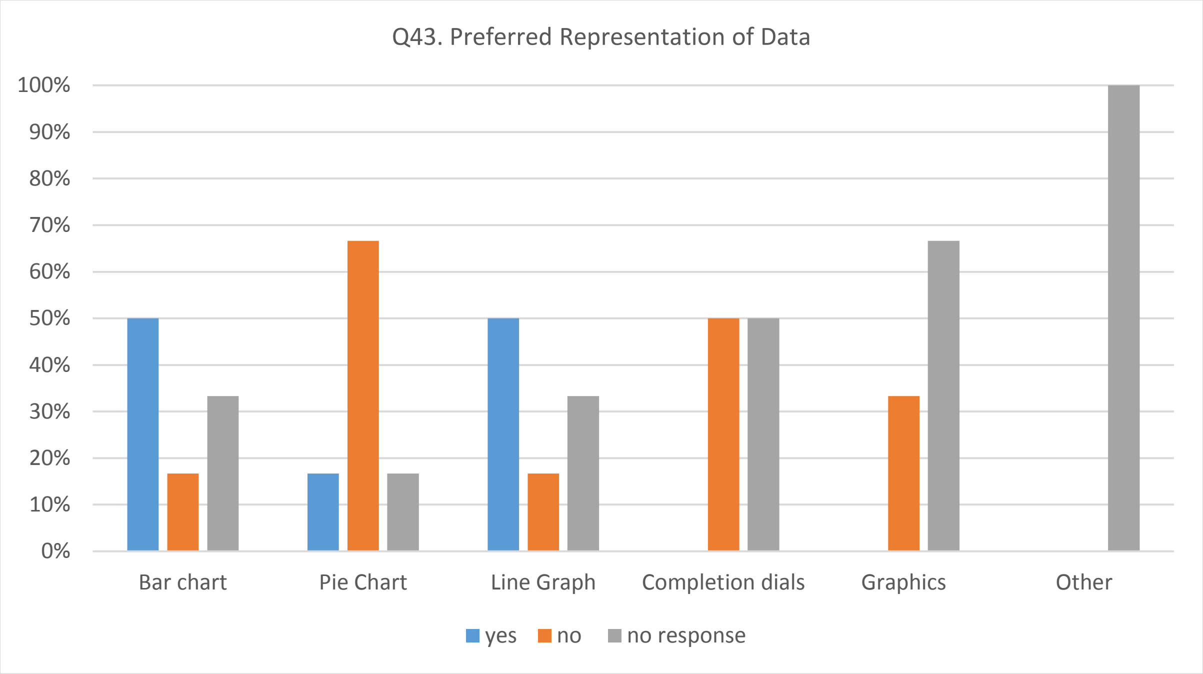


Figure 5.7 Response to preferred representation of data

Comments were entered by the participants in answering these questions, the pie chart and line graph were found to be preferred options. All other options were either too confusing or not clear enough in their representation. A comment was also made that it should borne in mind that the age profile of patients with COPD was typically over 60, and that as a result "the design should be as simple and visible as possible".

Following this the participants were asked what their preference would be in terms of what level of activity they would prefer to be presented with, for example to represent that there has been x amount of activity in a given period, or that there has been y amount of inactivity in a given period. Again the formatting of the question was poor and this led to possibly a misinterpretation of the sense of the question. This being the case, the responses in themselves do show that there is an interest in know both the level of activity and the level of inactivity over a chosen period of time. Additionally, responses included comments that suggested that the users would like to have more information on useful exercises and also to include aspects relating to motivational aspects, specifics of the latter were not given.

The second last question did not receive enough responses to be used conclusively. This most likely as it had already been inadvertently asked and answered in the previous question. The final question was asked to ascertain how the user would prefer to their activity recorded. Activity trackers typically track all activity throughout the course of the day. All of the activity apps reviewed and tested throughout the course of this project offered the user the ability to track a specific exercise course or activity separate to the overall daily achievement. The rationale here was to see which if there was a desire for tracking specific activity data, i.e. going for a walk and measuring the specifics such as distance walked, time taken, average speed and route taken. The responses were primarily yes for the daily activity view as opposed to specific activity, but it difficult to ascertain this for definite based on the wording of the question which gave a choice rather than being clear cut in the question being asked.

5.2.9 Section 9: Activity Based information - Questions 47 to 54

In this section of the questionnaire the participants were asked a number of questions relating to how their activity could be used in a useful manner to them.

The first question related to bringing a printout of their activity to their GP. The rationale here was twofold. The first of these was to see if there was an appetite for having the information in printed format. Although it is understood that one of the aims of health informatics is to remove the need for printed and paper material, in order to appeal to a an older generation, the printout was considered a method of engaging them in sharing the information. It must also be noted that the printout would not negate the fact the information would still be stored electronically. It suggests that this would be a medium by which the participants could share and explain their activity levels with their respective HCPs until such a time as full integration of the activity and exercise data recorded by the participants could be integrated with the health systems at large. To this question, 67% of respondents answered yes.

Along the theme of sharing the data and information from the self-management interface, the types of people they might want to share with was established. As shown in Figure 5.8 Preferences for sharing information, there is a marked preference for sharing the information with health professionals rather than either members of the COPD support group or family members.

When asked if there was preference for either daily or summaries of activity information, the responses seemed to indicate a small preference for weekly, but the response rate was not sufficient enough on this question to establish a strong preference.

Table 5.1 Preferences for daily or weekly summaries of results

Q49. Daily or Weekly summary of activity	**%yes**	**%no**	**%no response**
Daily	33%	50%	17%
Weekly	33%	17%	0%

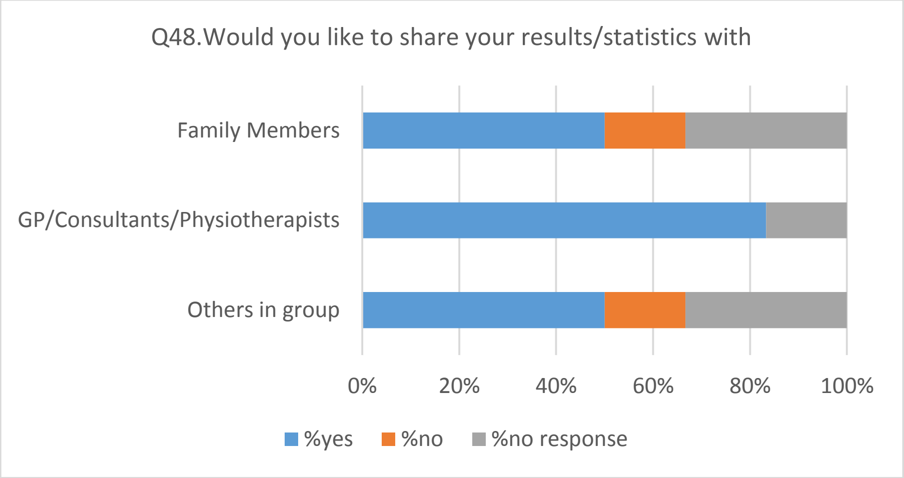


Figure 5.8 Preferences for sharing information

The participants were also asked if they wanted the ability to record exercise based on a specific activity. The responses indicated that 50% of the participants would like this feature, but the other 50% did not respond either positively or negatively. One comment was made that this might be confusing to the users. No other information as to how this might be confusing was made, so it is difficult to ascertain the thinking behind that comment. Such a feature would need to be explained and its use demonstrated to the users, as with all other features contained within the prototype self-management interface.

Whether or not the participants chose to have the option of recording per summary activity, it was felt that an option to record how the user was doing at any particular point the time would be useful. In conjunction with this, the following question asked if the availability of a button to record how they felt after an activity would be useful. The results of both these questions are presented in Figure 5.5.

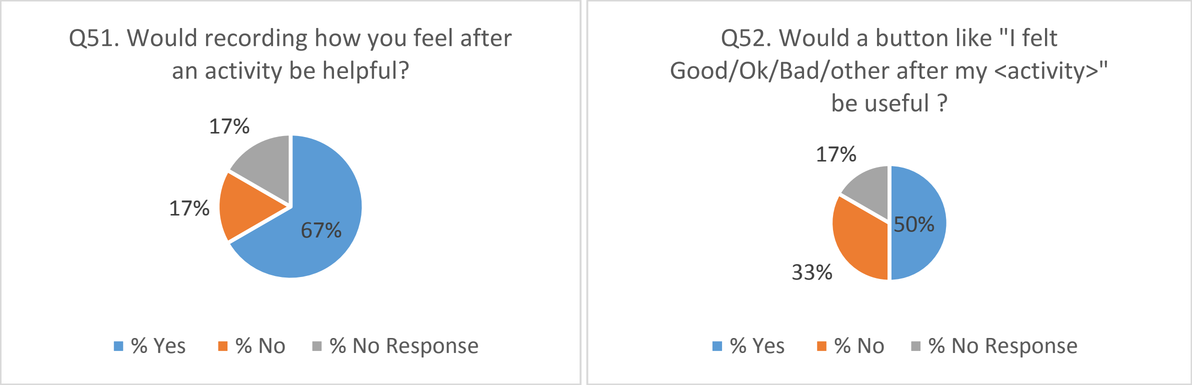


Figure 5.9 Responses to questions 51 and 52

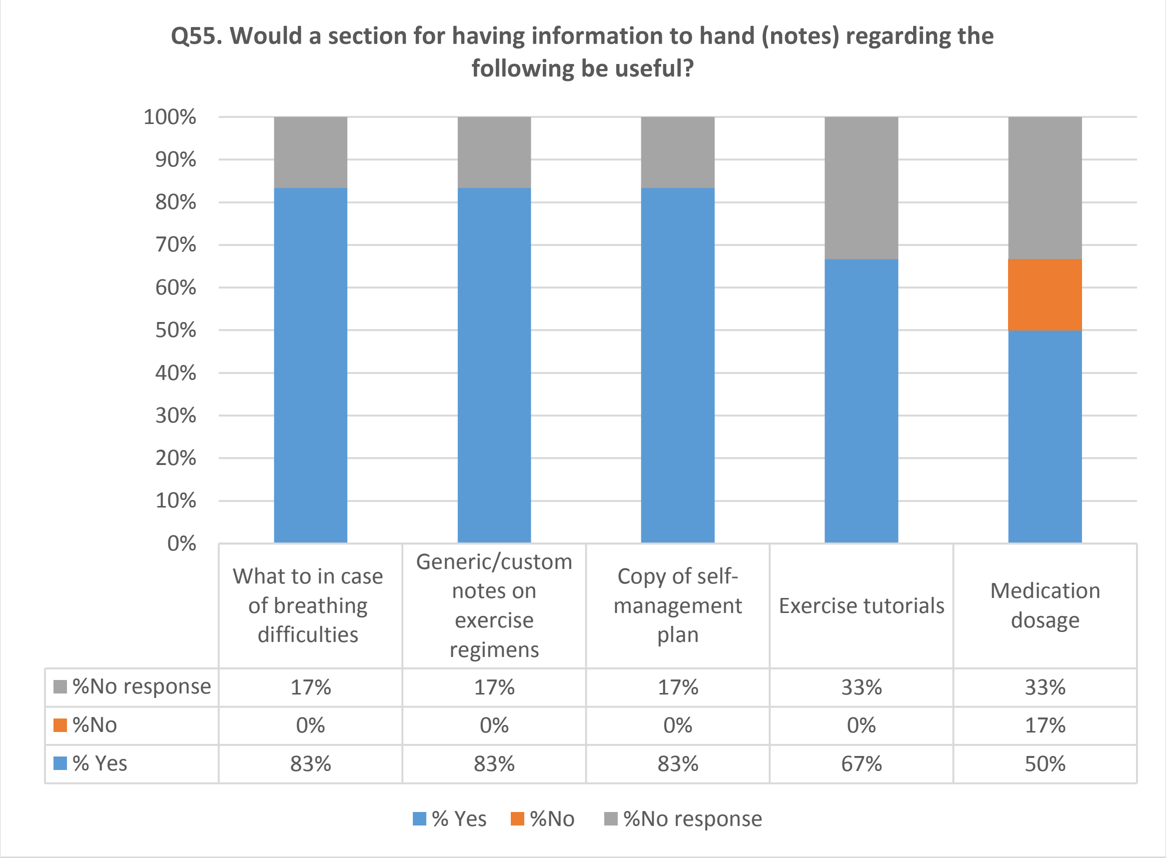
As can be seen from the responses in Figure 5.9 Responses to questions 51 and 52, there appears to be interest in having these features available.

Self-reporting of physical activity levels has to be taken with caution, as it often the case that perceived physical activity or exercise levels do not match the reality of the levels of activity actually undertaken. To this effect, a question was included to ascertain if this was the case with the participants. Outside of the results gathered, it now seems that such a question may not have any benefit, as the participants would not have a way of telling the difference in either case without already monitoring their activity and comparing with what they thought they may have done. The response indicated that 50% of participants did not think this was the case. The author still maintains that without actually quantifying the activity they are engaged in, and comparing it with what they believe they may have achieved, it would be a difficult thing to prove either way.

5.2.10 Section 10: Additional questions - Question 55

The final section of the questionnaire contained one question with a number of options. This section was aimed at identifying what additional aspects would be considered useful in such an interface for self-management as the one proposed. So far the questionnaire had a strong basis on primarily establishing which features would be considered useful in relation to displaying the recorded data from an activity tracker. Self-management however is not simply about displaying activity information, but rather an overall framework aimed at providing the individual with COPD with a range of information to assist them in managing their condition to the best of their ability. Therefore, to supplement the core of the activity information, it was deemed reasonable to ask if there were other features that the participants would consider useful.

The results are quite conclusive in that strongly suggest the interest for such a feature as part of the interface. The results can be seen in Figure 5.10. With only one negative response for the inclusion of medication dosage in the interface, a strong preference all other categories prevailed.



	What to in case of breathing difficulties	Generic/custom notes on exercise regimens	Copy of self-management plan	Exercise tutorials	Medication dosage
%No response	17%	17%	17%	33%	33%
%No	0%	0%	0%	0%	17%
% Yes	83%	83%	83%	67%	50%

Figure 5.10 Additional information items to include in interface

5.3 Employee Questionnaire Data Results

As mentioned in section 2.5, it was felt that having two points of view, from separate but strongly related stakeholder groups in the development of this interface would be beneficial. Gathering only user preferences would provide only one side of the proposed solution, and as such would render the system incomplete. To build a more complete interface, an understanding of both stake holder parties is required. These are namely the customer, i.e. the patient, and the employees, i.e. the health care professionals, charged with the care and support of the customer categories.

The questionnaire for this category was considerably shorter than for the customer section, as what was sought from it did not require as much detail. As such, the questions are not broken down into sections as the customer questionnaire had been. Additionally the questions were more open and had a different range of answers. The summarised responses are presented in Table 5.2.

Table 5.2 Employee category Questionnaire results

Employee Questions	**Summary of Employee responses**
Q1. In relation to physical activity/exercise, what data would you like to see from your patients?	Step counts were stated as information points that would be beneficial to the respondents. One respondent provided a list of items that would be useful to them for review. In addition to the specifics of activity data that could be recorded with an activity tracker, they also suggested that a BORG score for breathlessness and volumetric airflow measure would be good for them. The latter item would require additional equipment for the patient to have, such as a Bluetooth enabled spirometer which exists (Thormed, 2015; Vitalograph, 2015), and could be used but the inclusion of such devices falls outside of the scope of this project.
Q2. Do you consider activity data to be a useful metric to establish current state of your patient's condition?	Yes from all respondents
Q3. In addition to activity data, which of the questionnaires listed in Appendix A would you see as beneficial information (if you use any of them)?	The common questionnaire used by the respondents was used The COPD Assessment Tool (CAT) questionnaire (Jones et al., 2009). One of respondents also provided a brief but interesting breakdown on the questionnaires. Additionally, of the questionnaires, some were new to the this HCP
Q4. If you do use a questionnaire from the list in appendix A (or another), how often would you use it?	Again, the CAT questionnaire seems to be a popular choice here, and is used frequently in the rehabilitation clinic. It is also used pre and post rehabilitation programme, at 8 weeks and one year.
Q5. How useful would this activity information and self-administered questionnaire be to you?	Responses indicate that this information would be very useful the professionals.
Q6. If yes to Q5, what format would be of most use to you?	See below
Q6a. Graphs, numerical data, other?	50% of the respondents answered that both modes would be useful, and the remaining 50% indicated that numerical data would be of more use.
Q7. Would you prefer to have this information emailed to you, or accessed via web browser, or presented in another fashion?	The preference from all respondents here is for web based access to the information. It was felt that such information sent by email would get lost in the clutter.
Q8. Based on the data sheets presented what information jumps out at you that you would feel is valid in relation to	The format that this question was asked in, yielded somewhat unclear answers. One respondent answered as follows "I would prefer a,b ,c and d to be presented in activity information to plan an intervention."

assisting a patient in dealing with their condition?	
Q8a. Data sets of level of activity/inactivity i.e. active minutes	No specific response
Q8b. Number of steps taken daily	50% of respondents answered yes
Q8c. Number of steps over the course of a week – what would you consider to be an achievable/realistic/beneficial amount? I.e. what step goal would you consider for your patients?	A comment was made here that the number of steps shown in the image was too high (7,000) and that a baseline for each individual should be established prior to setting of goals.
Q8d. Distance travelled	Not a popular option, steps count was suggested as a preferred metric.
Q9. From a motivational standpoint, what in your experience have you found to be beneficial in enticing patients to carry their exercises, or to be more active?	One respondent answered with “Activity Prescription Log” with no further information. It is being assumed that this means that if the patient has such an “activity prescription log” that motivation is improved with the recipient.
Q10. Bearing in mind the GOLD COPD Assessment table (see below), what level of difference in exercise tolerance between the various categories (A, B, C, D) would you expect?	This question did not get any responses. On review, the wording is not clear, and as such it can be understood that the respondents were not clear on what was being asked.
Q11. In relation to question 10, would the proposed interface for self-management be more beneficial to one category of patient than another, which one, and why?	The respondents answered this question quite differently. 50% felt that there should be no distinction between any of the patients, regardless of the severity of the disease. While the remaining 50% suggested that patients in the C and D categories would require one to one self-management for at least an 8 to 10 week period to see behaviour change.
Q12. Would you have your own categorisation of patients to rate their condition level? If so, could you tell me?	The respondents did not have their own categorisations, and both used the COPD GOLD assessment table.

Q13. Feedback: what type of feedback do you feel would be beneficial both to the user, and to yourself? In the case of the user, the feedback would benefit them in relation to understanding how their improvement in taking part in physical activity aids in managing their condition. In your case what feedback from patients would be beneficial in assisting them to manage their condition?	From the HCP point of view, they felt that feedback ought to come be meaningful to them, and that a view on their activity data and information would be a good feedback mechanism.
Q14. Would it be possible for me to follow up with more questions at a later stage in relation to this research?	All respondents agreed to this.
Q15. What features would you believe could make such a system useful?	50% of the respondents suggested that the proposed interface ought to be simple and that it should work. Extrapolating from this, one can take that to mean that having an overly complex system would not be of benefit, as interest in using it would be lost. The remaining 50% was more prescriptive in terms of features. They suggested that activity information be included or spirometry information, as well as record of perceived breathlessness, although not stated implicitly this implies using the mMRC dyspnoea scale. Additionally they suggested that reminders be included to complete their activity prescription.
Q16. Do you think that such a system could be useful/beneficial for the patients you deal with?	All respondents agreed that having information from a system such as the one prescribed would be beneficial to them. It was encouraging to see this, as being both professionals involved in treating these patients, having this additional information to hand would allow them to provide a greater level of care to them.
Q17. Would reporting sedentary time (time spent being inactive) be useful?	Respondents were split on this question, with a 50% split on yes and no. An additional question here to ask why they would have found this information useful should have been included.
Q18. What do you believe is the biggest motivational block to individuals carrying out exercise, or physical activities?	In order to provide suitable motivational parameters, one has to understand what might be acting to negatively impact motivation. The responses here varied somewhat. One suggestion was that there a lack of emphasis on the benefits of physical activity and exercise and what it could do for the patient in terms of allowing them to lead better lives with the condition. Additionally, the lack of activity prescription and professional supervision was stated, as well as a reward system. The notion of a reward system was not investigated to within the scope of this study.

Q19. Based on question 18, what would be your suggestion for the optimal approach in dealing with this block in a system like this?	The types of approaches provided to this question were quite different. Of the approaches mentioned, one stated that short education segments and to provide a feedback loop between health care worker and patient would be beneficial. Other options suggested was to provide handheld device with tele monitoring. Both of these answers very much echo the toughts and ideals of the proposed interface.
Q20. Any other thoughts or suggestions you'd like to share as part of your contribution to this study?	Other than keeping it simple, nothing was provided.

5.4 Customer questionnaire – Evaluation results

With the data gathered from the first round of questionnaire responses, the prototype interface discussed in Chapter 4 was designed. Once the self-management interface had been completed, the prototype was demonstrated to a group of participants. This was followed by a questions and answer session on the interface, where the participants were given the opportunity to ask questions about the interface, how it functioned and why some features had been designed as they were. Following this, completion of a questionnaire was requested from the attendees. Unfortunately the turnout was lower than expected for this phase, and only 4 participants completed the questionnaires and provided feedback.

The results of this ten item questionnaire are presented in Table 5.3.

Table 5.3 Customer Evaluation of interface response

Question/Respondents	**A**	**B**	**C**	**D**
1. What is your impression of the proposed interface?	Very good	Confusing	Good	Good
2. What part of the interface did you find most useful and why?	Step information	The icons	Exercise charts	Sharing data page
3. What part of the interface did you find least useful and why?	None	Block Graph	blank	Icons on charts.
4. Which part of the interface would you believe could be expanded on and how?	blank	blank	blank	don't know
5. Are there any parts of the interface you feel could be left out, if so why?	No	blank	no	no

6. What was your impression of the representation of physical activity?	Very good	Good	good	ok
7. Having seen the proposed interface, do you feel that it would help you manage your condition better than you currently do? If so, how? (Yes/No/Comment)	yes	No	yes	yes
8. Would you rate such a system/interface as useful? (Yes/No/Comment)	yes	yes	yes	yes
9. On a scale of 1 to 10, where 1 is the least useful, and 10 is the most useful, what score would you give the proposed solution? (tick the appropriate box)	10	6	8	8
10. Other thoughts, comments or suggestions	Blank	Too complicated for present mostly elderly people with COPD.	blank	no

Reviewing these responses provides valuable feedback on the potential usefulness of an interface for self-management of COPD. The overall sense of the feedback received from this evaluation was positive and would certainly provide input into further iterations to refine the interface into something that a greater number of potential users would find not only beneficial, but something that they would want to use.

5.5 Analysis of the evaluation results

66% percent of respondents found that the interface made a good impression on them. This was encouraging, as designing an interface for an elderly population, who by their own admission, were not as versed in technology, presented a challenge in terms designing something that would make a positive impression.

Of all the responses, no one seemed to agree on what feature they found the most useful from the interface. This does pose a challenge in interpreting the responses, but perhaps the benefit of these varied responses is that it means the each different response indicates that there were more than one useful feature. The responses in the questionnaire alone for the items least useful were equally difficult to interpret at face value. During the Q&A session after the demonstration of the interface, suggestions were made as to how the diary charts Appendix H: could be improved to be more easily read and interpreted rather than the implemented designs.

When asked about which feature they felt could be expanded upon and improved, the questionnaire responses were inconclusive. As mentioned above, the Q&A session did indicate that the diary charts (Appendix H:) could benefit from reviewing the icons used. With the exception of one blank response, it was felt that all features contained within the interface had a value and benefit, and that none of them needed to be removed.

In terms of how the physical activity and exercise was presented, all responses were positive. This is considered important, as it from the display of this information that it was felt that a great deal of the benefit could be acquired.

The answers to the following three questions would in essence provide an answer to the core of the research question as stated in section 1.3, namely "*Is it feasible to design a useful interface for COPD self-management?*" it must be stated here that it was not sought to prove that this was the case, but rather to see what the answer would be.

Question 7, asked if such an interface as the one presented could be seen as helping the user to manage their COPD better than they currently were, 66% of the respondents answered yes, with only one negative response.

Question 8, asked if such an interface for COPD self-management could be considered useful, in this case, 100% of the respondents answered yes.

Question 9, asked the participants to rate the usefulness of the proposed interface on scale of 1 to 10, with 1 being the least useful, and 10 being the most useful. The average response to this was 8, over the median of 5, indicating that overall the system could be considered useful.

The final question aimed to establish if the participants had other thoughts and comments to make on the interface. Only one actual response was provided, being that this respondent believed that the proposed interface was considered too complicated for at present for elderly people with COPD. This could be taken to mean that this respondent considered the current cohort of patients with COPD of an age where they would find it difficult to use due a lack of digital literacy.

A comment that was made a number of times during the Q&A session was that although they felt that the proposed interface would be useful and could help them with their condition, they felt that it would benefit the younger and future patients with COPD who would be more exposed to technology and computer interfaces in general. It was also mentioned that they could see a benefit of such an interface being put on a mobile device, but that would simply be too much for them to be able to handle.

5.6 System Usability Scale – SUS

In addition to the ten item questionnaire discussed above, the participants were also asked to complete a system usability questionnaire, known as SUS (Affairs, 2013) from the Digital Equipment Corporation. The System Usability Scale (SUS) was designed as a quick measure to record the perceived usability of a computer system.

The results of this scale are shown in Table 5.4

Table 5.4 System Usability Scale Scores

Question	A SUS Score	B SUS Score	C SUS Score	D SUS Score
1. I think that I would like to use this system frequently	2	1	0	1
2. I found the system unnecessarily complex	1	3	4	1
3. I thought the system was easy to use	2	0	4	2
4. I think that I would need the support of a technical person to be able to use this system	2	0	4	4
5. I found the various functions in this system were well integrated	2	1	2	2
6. I thought there was too much inconsistency in this system	3	3	4	2
7. I would imagine that most people would learn to use this system very quickly	3	1	4	3
8. I found the system very cumbersome to use	3	2	4	3
9. I felt very confident using the system	2	2	2	3
10. I needed to learn a lot of things before I could get going with this system	0	0	0	2
Results	50	32.5	70	57.5

It must be noted that the scale results do not indicated percentages, even though the answers range from 0 to 100, where scores nearer to 0 are considered negative, and scores nearer 100 are considered positive scores. In effort to provide a correlating metric by which to assess the scores gathered from a SUS questionnaire, and to provide an absolute judgement of usability Bangor et al. (Bangor et al.,

2009) carried out a study where they added a 7 point adjective-anchored Likert scale to the SUS surveys. The 7 point Likert scale results correlated extremely well with the SUS surveys results (r=8.22). Based on this information, it was decided to use the chart shown in Figure 5.11 Mean SUS Scores corresponding to 7 adjective ratings so as to give and adjective meaning to scores collected as part of this study's' SUS survey.

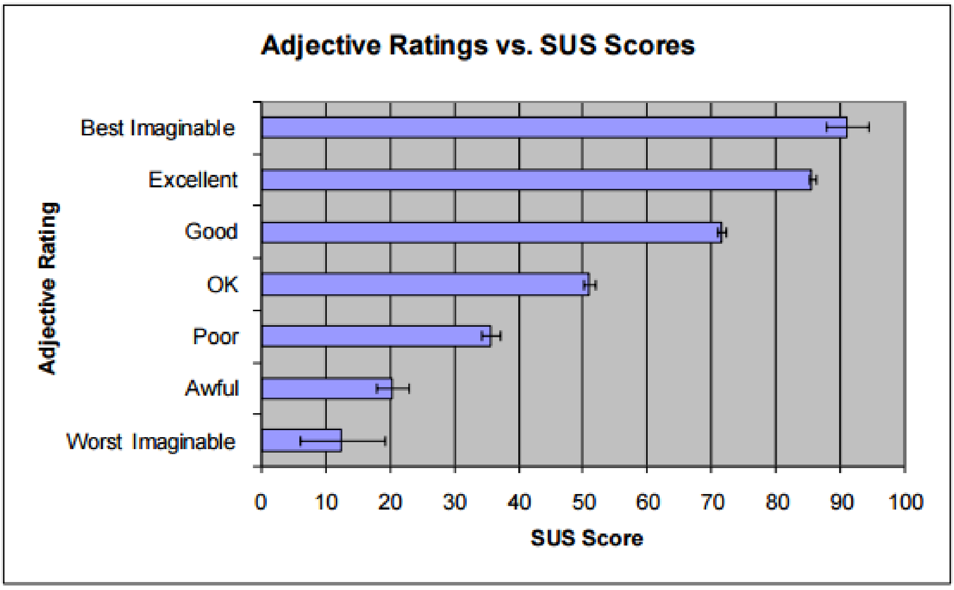


Figure 5.11 Mean SUS Scores corresponding to 7 adjective ratings (Bangor et al., 2009)

Using the chart in Figure 5.11, Table 5.5 shows how the scores for this interface fared

Table 5.5 SUS Scores and Adjective Scale Equivalent

	A SUS Score	B SUS Score	C SUS Score	D SUS Score	Average SUS Score
SUS Scores	50	32.5	70	57.5	**52.5**
Adjective Equivalent	OK	Poor	Good	Good	**Good**

5.7 Conclusion

The preceding sections of this chapter were written with the aim of giving the reader a view on the data collected and the interpretation of same. It is hoped that a suitable rationale for why each question was asked was provided and in doing so, would help shape the building of the interface as it was. Omissions or unsuitable questions were highlighted with the purpose of pointing out that errors were made and that these errors perhaps impeded the data collection process. It is felt that there was only a small number of those and that the study and data collection did not suffer as a result.

From the results outlined above, it is evident that there is a desire and a need for an interface such as the one proposed within both communities of stakeholders. The individuals with COPD who very generously contributed their time to this study allowed for a framework to be developed that has the potential to be expanded in the future. The HCPs contributions reflected the understood needs of such a system to the author, while at the same time provided additional insight and suggestions as to what could be improved and also expanded upon in the feature.

The primary finding from an analysis of all of the returned questionnaire data, is that it is felt that the research question has been answered, and that it is feasible to develop a prototype interface for COPD self-management.

Chapter 6. Conclusion and Future Work

6.1 Introduction

The following sections aim to summarise the preceding chapters, but also to provide additional information which would not have been covered previously. Strengths and limitations of the study, recommendations for future work, and a reflection piece.

6.2 Strengths and Limitations of the Study

From the outset, this study did not aim to build a fully working interface, or fully fledged system to provide a loopback mechanism between the patients and the healthcare providers, rather it aimed at a different approach. This approach was to get as familiar with the existing state of the art in the field of self-management of COPD, the strengths and weaknesses of same, and to pinpoint the benefits of physical activity and exercise for these individuals with COPD.

Having the understanding of the aspects mentioned above, and what it meant to the patients, and understanding how the questionnaires worked in relation to what was beneficial and significant in providing a self-management interface allowed the author to get the relevant information from the study participants in relation to building a prototype interface. The strength of the study was that this knowledge enabled an interface to be built and for it to be deemed useful by the participants.

Limitations within the study was that the number of participants, in both the customer and employee categories was lower than expected. As such, the spread and significance of the results were not as statistically meaningful as they may have been otherwise. In addition to that, more insight from the HCPs could have provided additional features within the interface, which would have added value to it for both the patients and the HCPs.

6.3 Dissemination of Findings

The results and findings of the study will be shared back with all of the stakeholders involved in its creation. This will be provided in two formats, one an executive overview of the findings, and the other in a soft copy (electronic file) of the dissertation.

6.4 Recommendations for Future Research

A particular track that could warrant more work is to have a greater engagement with the participants in the customer category. These are the users of the end system, and the system has to work for them along all of the themes identified in this study. To expand on this, a greater use of user-centred design ought to be used in order to establish the context of what would be more useful to the users.

It can be argued that including information needs questionnaires such as LINQ (Hyland et al., 2006; Jones et al., 2008) or the BCKQ (White et al., 2006) into an interface for self-management would allow to track the knowledge requirements of the patients over time. In so doing, and by enabling the feedback loop between the patient and their respective HCPs, knowledge about the condition can be strengthened between both parties. In so doing, a greater level of awareness on behalf of both parties would provide a sense of understanding of the condition and what it means to the patient.

During the evaluation of the prototype with the COPD Support group, it was mentioned a number of times that the understanding the GPs had of the condition and how to manage it was poor and lacking compassion. By including the HCPs within this knowledge sharing loop, and primarily within the primary care aspect, it would be hoped that these poor encounters experienced from the patients would be a thing of the past.

It is felt that there is a great of deal of scope to work on a larger scale study of this nature. It would be multi-phased longitudinal study whereby it would include establishing the level of knowledge that the spectrum of HCPs dealing with COPD patients across the continuum of care have on the condition. Another phase would be to get a similar questionnaire to the one devised in this study to a greater population of patients, to truly get a sense of the user's needs, both perceived and unmet. Along a parallel track to this phase, establishing which of the activity trackers on the market provide the most suited modality and ease of use from a user point of view, but also in terms of integration with the proposed interface. The final phase would be running of pilot, where a sample of the COPD population would be provided with activity trackers and access to the interface and seeing whether such a framework provided the benefits one feels that it should.

A further stream of potential future research, which would tie in with the previous suggestion, would be in the area of behaviour change and motivational aspects. It is believed that there is a great deal of scope there for the development of frameworks that could not only benefit COPD, but other chronic conditions as well.

6.5 Reflections on the Study

The process of carrying out the research for this study has been an eye opener. Not only from the point of the workload requirements, but also in terms of the breadth and scope of research, projects and studies that one comes across during the process.

Many new interesting fields have been opened up throughout the course of this study, which is exciting and challenging at the same time. The process from start to finish is a huge undertaking, and it must be said that one also got to learn a lot about one's self in the process.

Although so much material was covered during the course of the research phase, it is felt that only a small part of it made it into the final product, which feels wasteful somehow. In saying that, of the knowledge and domains discovered it is strongly believed and hoped that it will be of use in the future.

6.6 Conclusion

To conclude the research question will be stated here again, as well the study's aim and objectives.

The research question for this study was: *Is it feasible to design a useful interface for COPD self-management?* And the study aimed to:

1. Establish if a self-management portal is of interest to both category of stake holders, namely, patients and health care providers
2. What features in such an interface would be considered beneficial
3. Establish the barriers or other factors, if any, which would make such an interface and associated technology not palatable to the core users
4. Combine the results of the steps above to establish the usefulness and feasibility of such an interface.

From the above, it can be said that all of the study aims were met, and that the research question was answered positively, with 100% of the study participants agreeing that they found the demonstrated prototype interface for COPD self-management to be useful.

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Glossary

Abbreviation	Meaning
ACS	Ambulatory Care Services
ADL	Activities of Daily Living
COPD	Chronic Obstructive Disease
GP	General Practitioner
HCP	Health Care Professional
HRQoL	Health Related Quality of Life
HSE	Health Service Executive
ICT	Information Communications Technology
mMRC	Modified Medical Research Council

Appendix A: Questionnaire for Customer stakeholders

Customer Questionnaire

Each question is optional. Feel free to omit a response to any question; however the researcher would be grateful if all questions are responded to.

Introduction

Thank you for taking the time to fill in this questionnaire, your time and contribution is greatly appreciated.

Before proceeding, please take note of the following points.

1. Please do not name third parties in any open text field of the questionnaire. Any such replies will be anonymised
2. In the extremely unlikely event that illicit activity is reported I will be obliged to report it to appropriate authorities.

If you feel you do not have space to write in your answers in the boxes provided, please write the question number and your answer on a separate sheet and return with this questionnaire.

Questionnaire

1. What is your age?
2. What is your gender?
3. Severity of disease as measured by MRC grade - if you know it?
4. What is your present or previous occupation?
5. Have you attended any formal pulmonary rehabilitation/education programmes?
6. Do you have a contact with any of the following Health professionals in dealing with your condition?

Contact with the following	Yes	No	Comment
a. Practice nurse/nurse practitioners			
b. Respiratory specialist physiotherapist			
c. Outpatient clinic/hospital consultant			
d. Other			

7. Do you have a self-management plan (yes or no)?
8. If yes, who provided it?
9. Did you have input in coming up with the plan?
10. How do you find the plan? (Good/bad/lacking/Comments?)
11. What would you like to have included in the plan?
12. Do you think that the self-management plan you have has enough information about helping you manage your exercise/activity levels?
13. What other type of information (specific to activity or exercise) would you like to see in your self-management plan?
14. What prevents you from taking exercise?

Question	**Yes**	**No**	**Comment**
a. Fear of shortness of breath?			
b. Need to use inhaler?			
c. Fear of running low on Oxygen?			
d. Other symptoms, sore legs or back?			
e. Lack of motivation?			
f. Lack of confidence?			
g. Bad Weather (is weather a big factor)?			
h. Low energy level?			
i. Lack of time?			
j. Fear of getting hurt?			
k. Unsuitable environment?			
l. Others - explain?			

15. What might motivate you to go for a walk?

Item	Yes	No	Comment
a. Doctors' orders?			
b. Weight loss?			
c. Knowing it can help manage my condition?			
d. To increase your energy levels?			
e. To prevent future health issues?			
f. Being part of a community and comparing your activity levels?			
g. Other factors that might motivate you, please list in the comment box			

16. Would being part of a group who could share activities motivate you?
    a. To compare results (Yes/No/Comment)?
    b. Have a league table of who is most active (Yes/No/Comment)?
    c. Comments:

17. If you were part of a setting similar to Operation Transformation (if you are familiar with it), and activity is tracked and recorded, do you feel this would help with motivating you (Yes/No/Comment)?
18. Do you know how far you walk each day (Yes/No/Comment)?
19. Would you like to know how far you walk each day (Yes/No/Comment)?
20. Would knowing your daily distance walked be of use to you (Yes/No/Comment)?
21. How often would you like to get feedback (Daily/Weekly/Monthly/Other)?
22. How strongly would you rate positive feedback (1 not liked, 10 wanted)?

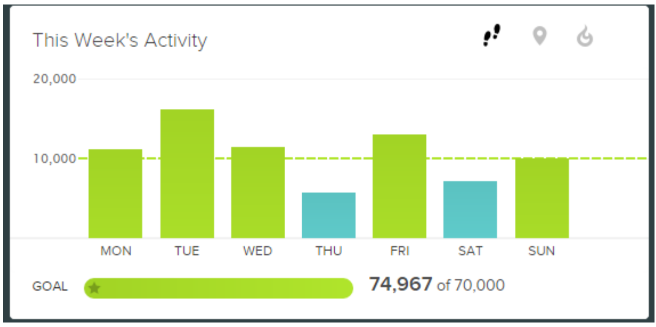
23. How strongly would you rate critical feedback (1 not liked, 10 wanted)?
24. **24.** What would help you most in setting goals that you feel are achievable (write in box below)?

25. Do you feel unsafe going for walk where you live (Yes/No/Comment)?
26. Are the footpaths'/sidewalks in a condition for walking (Yes/No/Comment)?
27. Are there shops/facilities/services nearby (Yes/No/Comment)?
28. What kind of exercise/Activity do you do – answer in box below

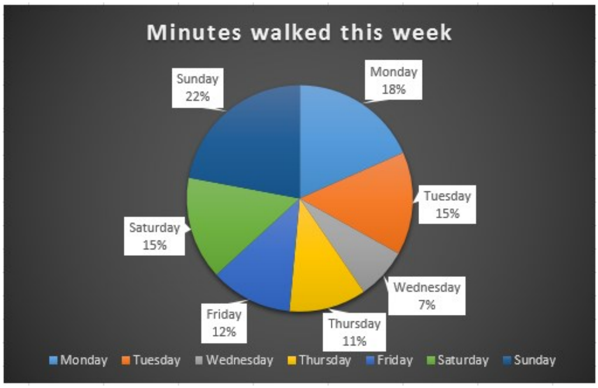
Activity	**Yes**	**No**	**Sometimes**
a. Walking			
b. Cycling			
c. Getting off the bus one stop early			
d. Walking to the local shops or park			
e. Walking your dog			
f. Doing some light gardening			
g. Dancing			
h. Bowling			
i. Yoga, Pilates or tai chi			
j. Walking groups			
k. Aqua aerobics			
l. Swimming.			

m. Other:			

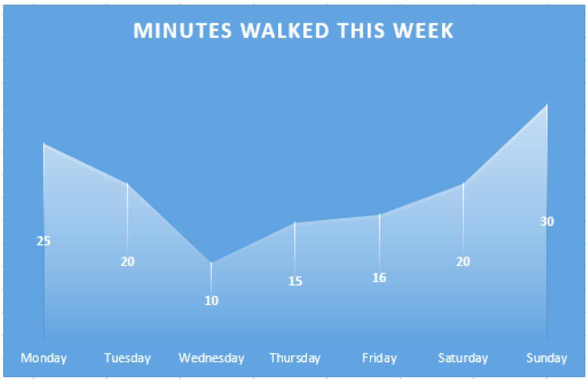
29. Do you know what an activity/fitness tracker is (Yes/No/Comment)?
30. Do you own an activity tracker of any form (Yes/No/Comment)?
31. If so, what model/type? (FitBit/Jawbone/Pedometer (step counter) Other?)
32. Would you mind sharing the data recorded from it (Yes/No/Comment)?
33. Do you have a smartphone or tablet (Yes/No/Comment)?
34. Do you have a computer or laptop (Yes/No/Comment)?
35. Do you have the internet at home (Yes/No/Comment)?
36. How comfortable are you in using it (Yes/No/Comment)?
37. Do you use apps on it (Yes/No/Comment)?
38. What do you do with it (Yes/No/Comment)?
39. Do you have a printer (Yes/No/Comment)?
40. Do you have the internet at home (Yes/No/Comment)?
41. Do you use Wi-Fi (wireless internet) at home (Yes/No/Comment)?
42. If you saw how your activity level compared with your quality of life, would you walk more (Yes/No/Comment)?
43. What way would you prefer this to be shown to you?
    a. Graph?



(Yes/No/Comment)?

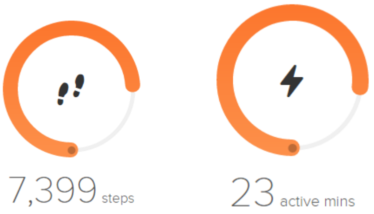
b. 

(Yes/No/Comment)?

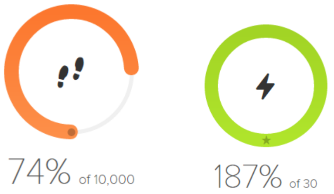
c. 

(Yes/No/Comment)?

d. By numbers? (Where the coloured part of the circle represents the total amount achieved of a set goal?)

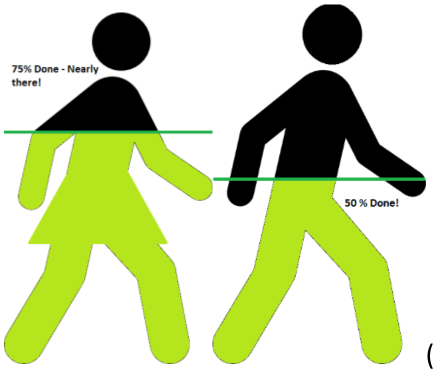


(Yes/No/Comment)?



(Yes/No/Comment)?

e. Pictures?



(Yes/No/Comment)?

f. Other methods – what would you like to see?

44. From the data that is being gathered about your activity, which would you value more?
    a. Activity, e.g. that there has been X amount of activity today/weekly/monthly?
    b. This activity can be categorised into active, moderately active (Yes/No/Comment)?
    c. Inactivity, e.g. that there has been X amount of inactivity in one day (Yes/No/Comment)?
45. From your level of activity/inactivity
    a. How long I was inactive or active today (Yes/No/Comment)?
46. Would you prefer to have the overall daily activity recorded, or just when going for a walk (Yes/No/Comment)?
47. Would you like to bring a print out of your results/statistics to your GP/Consultant (Yes/No/Comment)?
48. Would you like to share your results/statistics with:
    a. Others in group (Yes/No/Comment)?
    b. GP/Consultant/Nurse/Physiotherapist (Yes/No/Comment)?
    c. Family members (Yes/No/Comment)?
49. Would you prefer a:
    a. Daily summary of activity level? (Yes/No/Comment)?
    b. Weekly summary of activity level (Yes/No/Comment)?
50. Per activity summary? E.g. walking, around the house, gardening?
51. Would recording how you feel after an activity be helpful?
    Dyspnoea scale (shortness of breath) Scale 1 to 5?
    a. Where 1 = Tired, out of breath

   b. Where 2 = Tired but feeling ok
   c. Where 3 = Just a little out of breath
   d. Where 4 = Fine, no or very little side effects
   e. Where 5 = Good

52. Would a button like "I felt Good/Ok/Bad/other after my <activity>" be useful (Yes/No/Comment)?
53. Do you think you remember the level of activity differently to what actually happens? I.e. do you think you are more active than you actually are (Yes/No/Comment)?
54. If so, by how much?
55. Would a section for having information to hand (notes) regarding the following be useful
    a. Medication dosage (Yes/No/Comment)?
    b. Exercise tutorials (Yes/No/Comment)?
    c. What to do in case of breathing difficulties (Yes/No/Comment)?
    d. Generic/custom exercise regimen notes (Yes/No/Comment)?
    e. Copy of self-management plan (Yes/No/Comment)?

End of Questionnaire

Many thanks for your time in completing this questionnaire, your time and input is very much appreciated.

Please return the completed questionnaire in the self-addressed stamped address envelope provided, or to the following address:

Richard Eibrand

29 Verbena Avenue,

Bayside,

Dublin 13

Appendix B: Questionnaire for Employee stakeholders

Employee Questionnaire

Each question is optional. Feel free to omit a response to any question; however the researcher would be grateful if all questions are responded to.

Introduction

Thank you for taking the time to fill in this questionnaire, your time and contribution is greatly appreciated.

Before proceeding, please take note of the following points.

3. Please do not name third parties in any open text field of the questionnaire. Any such replies will be anonymised
4. In the extremely unlikely event that illicit activity is reported I will be obliged to report it to appropriate authorities.

If you feel you do not have space to write in your answers in the boxes provided, please write the question number and your answer on a separate sheet and return with this questionnaire.

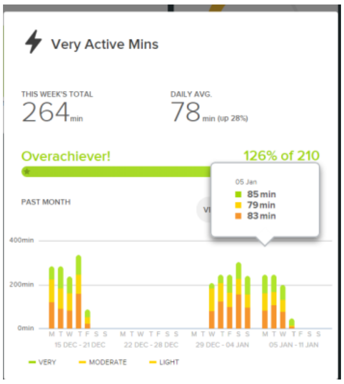
Questionnaire

1. In relation to physical activity/exercise, what data would you like to see from your patients?
2. Do you consider activity data to be a useful metric to establish current state of your patient's condition?
3. In addition to activity data, which of the questionnaires listed in Appendix A would you see as beneficial information (if you use any of them)?
4. If you do use a questionnaire from the list in appendix A (or another), how often would you use it?
5. How useful would this activity information and self-administered questionnaire be to you?
6. If yes to Q5, what format would be of most use to you?

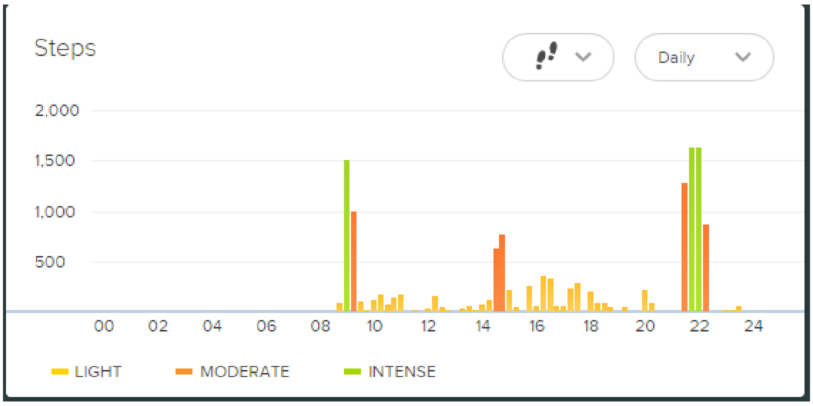
   a. Graphs, numerical data, other?

7. Would you prefer to have this information emailed to you, or accessed via web browser, or presented in another fashion?
8. Based on the data sheets presented what information jumps out at you that you would feel is valid in relation to assisting a patient in dealing with their condition

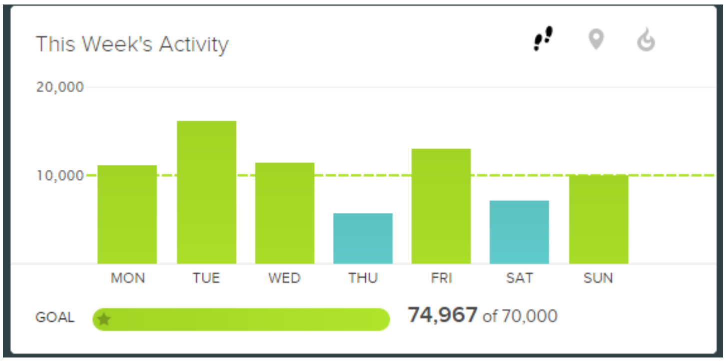
   a. Data sets of level of activity/inactivity i.e. active minutes



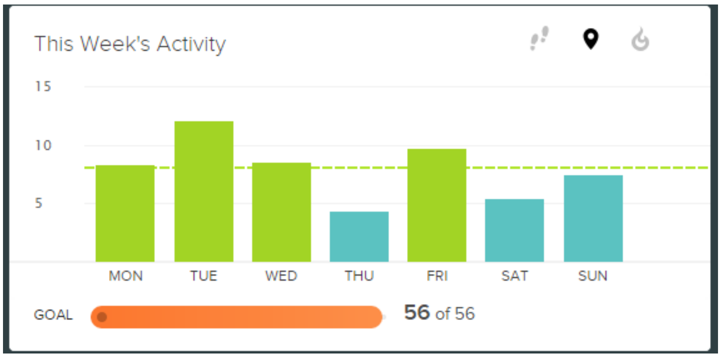
   b. Number of steps taken daily



   c. Number of steps over the course of a week – what would you consider to be an achievable/realistic/beneficial amount? I.e. what step goal would you consider for your patients?



d. Distance travelled



9. From a motivational standpoint, what in your experience have you found to be beneficial in enticing patients to carry their exercises, or to be more active?
10. Bearing in mind the GOLD COPD Assessment table (see below), what level of difference in exercise tolerance between the various categories (A, B, C, D) would you expect?

Patient	Characteristic	Spirometric	Exacerbations per year	CAT	mMRC
A	Low Risk Less Symptoms	GOLD 1-2	<= 1	< 10	0-1
B	Low Risk More Symptoms	GOLD 1-2	<=1	>=10	>= 2

C	High Risk Less Symptoms	GOLD 3-4	>=2	<10	0-1
D	High Risk More Symptoms	GOLD 3-4	>=2	>=10	>=2

11. In relation to question 10, would the proposed interface for self-management be more beneficial to one category of patient than another, which one, and why?
12. Would you have your own categorisation of patients to rate their condition level? If so, could you tell me?
13. Feedback: what type of feedback do you feel would be beneficial both to the user, and to yourself? In the case of the user, the feedback would benefit them in relation to understanding how their improvement in taking part in physical activity aids in managing their condition. In your case what feedback from patients would be beneficial in assisting them to manage their condition?
14. Would it be possible for me to follow up with more questions at a later stage in relation to this research?
15. What features would you believe could make such a system useful?
16. Do you think that such a system could be useful/beneficial for the patients you deal with?
17. Would reporting sedentary time (time spent being inactive) be useful?
18. What do you believe is the biggest motivational block to individuals carrying out exercise, or physical activities?
19. Based on question 18, what would be your suggestion for the optimal approach in dealing with this block in a system like this?
20. Any other thoughts or suggestions you'd like to share as part of your contribution to this study?

Participant Information letter – Customer Category

Participant Information letter- Customer

PROJECT TITLE: Is it feasible to design a useful interface for COPD self-management?

LEAD RESEARCHER: Richard Eibrand

RESEARCHERS CONTACT DETAILS:

Email: eibrandr@tcd.ie **Phone:** 087 6181793

BACKGROUND OF RESEARCH:

The aim of this research is to establish if it feasible to design a useful interface (digital based, i.e. phone/tablet/computer screen) for COPD self-management. Many devices exist to measure physical activity, notably by measuring walking activity, such as amount of steps walked, distance travelled and intensity of activity. In itself, this data is of limited use. This project aims to evaluate how to present the information gathered in such a way as to help individuals with COPD to better manage their condition by engaging in meaningful exercise.

PARTICIPANT SELECTION:

You have been invited to participate in this study as you are part of a voluntary group suggested to me by Prof. Tim O'Donnell.

PROCEDURES OF THIS STUDY:

There are two parts to your involvement in this study, which include the filling in of a questionnaire, evaluating the outcome of the first questionnaire, and the filling in of a second questionnaire. The process and reasoning is outlined below.

Part 1:

In order to understand the elements that makes this information useful, a series of questions in the form of a questionnaire, will be asked in order to build a picture of what is meaningful to the individual looking at this data. This information will then be used to build a useful interface (for a mobile phone for example, or a web page), that will demonstrate how the data collected by these activity monitors can be used display the exercise activity levels.

Part 2:

The information that was provided in part 1 was collated and assembled into the prototype interface that will be presented before filling in part 2, which is the evaluation questionnaire. This questionnaire is devised to learn what aspects of this interface are considered beneficial and whether or not you found the interface to be useful.

The process described above is summarised below in terms of input required:

1. Completion of a questionnaire to build the basis of the prototype mentioned in step 2
2. Reviewing a prototype interface based on questions answered in first questionnaire
3. Completion of a second questionnaire designed to establish the useful of the prototype interface designed in step 2

Title: Is it feasible to design a useful interface for COPD Self-management?

Consent may be sought for making an audio recording of the evaluation and completion of the second questionnaire of the study. This recording will be deleted no longer than 5 days after the initial recording, once it has been transcribed.

Declarations of conflicts of interest:

The researcher has no conflicts of interests in carrying out this research work.

Debriefing Arrangements

At any stage, any queries or questions from participants will be dealt with at time of query, and if required, followed up by post or email, and no later than 2 weeks after initial request.

Voluntary Participation:

Your participation in this study is entirely voluntary, and you maintain the right to withdraw and to omit any individual responses without penalty.

Duration of participation:

It is expected that your time contribution as a participant in this study will be approximately 30 to 40 minutes

Anticipated Risks and Benefits of participation:

There are no risks associated with this study. In terms of benefits, the results of the study will be made available to you.

Data confidentiality

All information provided during the course of this study will be anonymised, and will be dealt with highest confidentiality. The data gathered will be used to a) create a visual interface which has no bearing or linking to individuals b) to form a viewpoint of the suitability of the interface and as such will be based on anonymised aggregated data.

All data, including personal data contained in the consent form, will be treated within the full rigours of the Data protection (and Amendment) Act of 2003, notably section 3.

Of note is that the data gathered during the course of this study, will only be used for the purposes of this study, and any potential subsequent related publications.

Cautions about inadvertent discovery of illicit activities

In the extremely unlikely event that illicit activity is reported during the course of the interviews or filled in somewhere on the questionnaires, the researcher is duty bound to report such activities to the appropriate and relevant authorities.

Provision for verifying direct quotations and their contextual appropriateness

In some cases it may be necessary to verify direct quotations provided during the course of the interviews and to verify their contextual appropriateness, the researcher retains the rights to do when and if needed.

Audio Recordings

If audio recording of the interviews is permitted by the participant to enable the researcher to capture all of the interview, none of these recordings will be made available to anybody but the researcher. Nor will they be replayed in any public forum or subsequent presentations of the research. The recordings will be transcribed after having been made, and digital audio files destroyed within 5 days of the recording having been made.

Appendix C: Participant Information Letter – Employee Category

Participant Information letter- Employee

PROJECT TITLE: Is it feasible to design a useful interface for COPD self-management?

LEAD RESEARCHER: Richard Eibrand

RESEARCHERS CONTACT DETAILS:

Email: eibrandr@tcd.ie **Phone:** 087 6181793

BACKGROUND OF RESEARCH:

The aim of this research is to establish if it feasible to design a useful interface (digital based, i.e. phone/tablet/computer screen) for COPD self-management. Many devices exist to measure physical activity, notably by measuring walking activity, such as amount of steps walked, distance travelled and intensity of activity. In itself, this data is of limited use. This project aims to evaluate how to present the information gathered in such a way as to help individuals with COPD to better manage their condition by engaging in meaningful exercise.

PARTICIPANT SELECTION:

You have been invited to participate in this study as you are part of a voluntary group suggested to me by Prof. Tim O'Donnell.

PROCEDURES OF THIS STUDY:

There are two parts to your involvement in this study, which include the filling in of a questionnaire, evaluating the outcome of the first questionnaire, and the filling in of a second questionnaire. The process and reasoning is outlined below.

Part 1:

In order to understand the elements that makes this information useful, a series of questions in the form of a questionnaire, will be asked in order to build a picture of what is meaningful to the individual looking at this data and potentially using it in a clinical setting. This information will then be used to build a useful interface (for a mobile phone for example, or a web page), that will demonstrate how the data collected by these activity monitors can be used display the exercise activity levels.

Part 2:

Title: Is it feasible to design a useful interface for COPD Self-management?

The information that was provided in part 1 was collated and assembled into the prototype interface that will be presented before filling in part 2, which is the evaluation questionnaire. This questionnaire is devised to learn what aspects of this interface are considered beneficial and whether or not you found the interface to be useful.

The process described above is summarised below in terms of input required:

1. Completion of a questionnaire to build the basis of the prototype mentioned in step 2
2. Reviewing a prototype interface based on questions answered in first questionnaire
3. Completion of a second questionnaire designed to establish the useful of the prototype interface designed in step 2

Consent may be sought for making an audio recording of the evaluation and completion of the second questionnaire of the study. This recording will be deleted no longer than 5 days after the initial recording, once it has been transcribed.

Declarations of conflicts of interest:

The researcher has no conflicts of interests in carrying out this research work.

Debriefing Arrangements

At any stage, any queries or questions from participants will be dealt with at time of query, and if required, followed up by post or email, and no later than 2 weeks after initial request.

Voluntary Participation:

Your participation in this study is entirely voluntary, and you maintain the right to withdraw and to omit any individual responses without penalty.

Duration of participation:

It is expected that your time contribution as a participant in this study will be approximately 30 to 40 minutes

Anticipated Risks and Benefits of participation:

There are no risks associated with this study. In terms of benefits, the results of the study will be made available to you.

Title: Is it feasible to design a useful interface for COPD Self-management?

Data confidentiality

All information provided during the course of this study will be anonymised, and will be dealt with highest confidentiality. The data gathered will be used to a) create a visual interface which has no bearing or linking to individuals b) to form a viewpoint of the suitability of the interface and as such will be based on anonymised aggregated data.

All data, including personal data contained in the consent form, will be treated within the full rigours of the Data protection (and Amendment) Act of 2003, notably section 3.

Of note is that the data gathered during the course of this study, will only be used for the purposes of this study, and any potential subsequent related publications.

Cautions about inadvertent discovery of illicit activities

In the extremely unlikely event that illicit activity is reported during the course of the interviews or filled in somewhere on the questionnaires, the researcher is duty bound to report such activities to the appropriate and relevant authorities.

Provision for verifying direct quotations and their contextual appropriateness

In some cases it may be necessary to verify direct quotations provided during the course of the interviews and to verify their contextual appropriateness, the researcher retains the rights to do when and if needed.

Audio Recordings

If audio recording of the interviews is permitted by the participant to enable the researcher to capture all of the interview, none of these recordings will be made available to anybody but the researcher. Nor will they be replayed in any public forum or subsequent presentations of the research. The recordings will be transcribed after having been made, and digital audio files destroyed within 5 days of the recording having been made.

Appendix D:Informed Consent form for participants – Customer Category

TRINITY COLLEGE DUBLIN - INFORMED CONSENT FORM Customer Category

BACKGROUND OF RESEARCH:

The aim of this research is to establish if it feasible to design a useful interface for COPD self-management. Many devices exist to measure physical activity, notably by measuring walking activity, such as amount of steps walked, distance travelled and intensity of activity. In itself, this data is of limited use. This project aims to evaluate how to present the information gathered in such a way as to help individuals with COPD to better manage their condition by engaging in meaningful exercise.

PROCEDURES OF THIS STUDY:

In order to understand the elements that makes this information useful, a series of questions will be asked in order to build a picture of what is meaningful to the individual looking at this data. This information will then be used to build a useful interface (for a mobile phone for example, or a web page), that will demonstrate how the data collected by these activity monitors can be used display the exercise activity levels. Subsequently, the interface designed will be shown to the participant, and a series of evaluation questions will be asked regarding the prototype. The opinions and answered questions will then be analysed and aggregated to establish whether or not there is benefit in such an interface.

The process requires the following input:

4. Completion of a questionnaire to build the basis of the prototype mentioned in step 2
5. Reviewing a prototype interface based on questions answered in first questionnaire
6. Completion of a second questionnaire designed to establish the useful of the prototype interface designed in step 2

Consent may be sought for making an audio recording of the evaluation and completion of the second questionnaire of the study. This recording will be deleted no longer than 5 days after the initial recording, once it has been transcribed.

There is no risk involved in participation in this study.

PUBLICATION:

Title: Is it feasible to design a useful interface for COPD Self-management?

The data and information collected in this study is primarily for part completion of a Master's of Science in Health Informatics in Trinity College Dublin. Additionally, it may be used to provide source information for papers to be published in conference papers or journals relevant to the fields of research this project addresses.

Individual results will be aggregated anonymously and research reported on aggregated results.

PARTICIPANT DECLARATION:

- I am 18 years or older and am competent to provide consent.
- I have read, or had read to me, a document providing information about this research and this consent form. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction and understand the description of the research that is being provided to me.
- I agree that my data is used for scientific purposes and I have no objection that my data is published in scientific publications in a way that does not reveal my identity.
- I understand that if I make illicit activities known, these will be reported to appropriate authorities.
- I understand that I may stop electronic recordings at any time, and that I may at any time, even subsequent to my participation have such recordings destroyed (except in situations such as above).
- I understand that, subject to the constraints above, no recordings will be replayed in any public forum or made available to any audience other than the current researchers/research team.
- I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights.
- I understand that I may refuse to answer any question and that I may withdraw at any time without penalty.
- I understand that my participation is fully anonymous and that no personal details about me will be recorded.
- I understand that if I or anyone in my family has a history of epilepsy then I am proceeding at my own risk.
- I have received a copy of this agreement.

PARTICIPANT'S NAME:

Title: Is it feasible to design a useful interface for COPD Self-management?

PARTICIPANT'S SIGNATURE:

Date:

Statement of investigator's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

RESEARCHERS CONTACT DETAILS:

Name: Richard Eibrand
Email: eibrandr@tcd.ie
Phone: 087 6181793

INVESTIGATOR'S SIGNATURE:

Date:

Appendix E: Informed Consent Form for participants – Employee

TRINITY COLLEGE DUBLIN - INFORMED CONSENT FORM Employee Category

BACKGROUND OF RESEARCH:

The aim of this research is to establish if it feasible to design a useful interface for COPD self-management. Many devices exist to measure physical activity, notably by measuring walking activity, such as amount of steps walked, distance travelled and intensity of activity. In itself, this data is of limited use. This project aims to evaluate how to present the information gathered in such a way as to help individuals with COPD to better manage their condition by engaging in meaningful exercise.

PROCEDURES OF THIS STUDY:

In order to understand the elements that makes this information useful, a series of questions will be asked in order to build a picture of what is meaningful to the individual looking at this data. This information will then be used to build a useful interface (for a mobile phone for example, or a web page), that will demonstrate how the data collected by these activity monitors can be used display the exercise activity levels. Subsequently, the interface designed will be shown to the participant, and a series of evaluation questions will be asked regarding the prototype. The opinions and answered questions will then be analysed and aggregated to establish whether or not there is benefit in such an interface.

The process requires the following input:

1. Completion of a questionnaire to build the basis of the prototype mentioned in step 2
2. Reviewing a prototype interface based on questions answered in first questionnaire
3. Completion of a second questionnaire designed to establish the useful of the prototype interface designed in step 2

Consent may be sought for making an audio recording of the evaluation and completion of the second questionnaire of the study. This recording will be deleted no longer than 5 days after the initial recording, once it has been transcribed.

There is no risk involved in participation in this study.

PUBLICATION:

Title: Is it feasible to design a useful interface for COPD Self-management?

The data and information collected in this study is primarily for part completion of a Master's of Science in Health Informatics in Trinity College Dublin. Additionally, it may be used to provide source information for papers to be published in conference papers or journals relevant to the fields of research this project addresses.

Individual results will be aggregated anonymously and research reported on aggregated results.

PARTICIPANT DECLARATION:

- I am 18 years or older and am competent to provide consent.
- I have read, or had read to me, a document providing information about this research and this consent form. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction and understand the description of the research that is being provided to me.
- I agree that my data is used for scientific purposes and I have no objection that my data is published in scientific publications in a way that does not reveal my identity.
- I understand that if I make illicit activities known, these will be reported to appropriate authorities.
- I understand that I may stop electronic recordings at any time, and that I may at any time, even subsequent to my participation have such recordings destroyed (except in situations such as above).
- I understand that, subject to the constraints above, no recordings will be replayed in any public forum or made available to any audience other than the current researchers/research team.
- I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights.
- I understand that I may refuse to answer any question and that I may withdraw at any time without penalty.
- I understand that my participation is fully anonymous and that no personal details about me will be recorded.
- I understand that if I or anyone in my family has a history of epilepsy then I am proceeding at my own risk.
- I have received a copy of this agreement.

PARTICIPANT'S NAME:
PARTICIPANT'S SIGNATURE:
Date:

Statement of investigator's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

Title: Is it feasible to design a useful interface for COPD Self-management?

RESEARCHERS CONTACT DETAILS:

Name: Richard Eibrand

Email: eibrandr@tcd.ie

Phone: 087 6181793

INVESTIGATOR’S SIGNATURE:

Date:

Appendix F: Invitation to participate in study – Customer stakeholders

Dear <insert name>,

My name is Richard Eibrand and I am an MSc Student currently studying Health Informatics at Trinity College Dublin.

As part of the course study, I have to complete a research project that will form part of our Thesis in partial fulfilment of the MSc.

My research project is based on the idea that the use of activity or exercise information gathered from an activity tracking device such as a Fitbit or similar activity tracker, can be of benefit to individuals that suffer from COPD. These devices are small, relatively cheap and can collect data about the amount of steps taken in a day (or time periods within that day), distance travelled, and the intensity of the activity.

The premise of the study is that the activity data collected, such as amount of steps walked daily and the intensity of the activity can be presented to the user in such a way as to help them better manage an exercise regime which in turn can help bring about improvements in their health status and their associated health related quality of life (HRQoL). The aim of the study is not to show such improvements, but primarily to gather the information that would develop and design a prototype interface for either a smart device (phone or tablet) or a web page that would facilitate self-management of the condition.

Would you be in a position to participate in a semi-structured interview on this topic? I estimate that the time required would be approximately 30 to 40 minutes. If not, would you be willing to fill in an online questionnaire which contains the same material as the semi-structured interview?

Kind regards,

Richard Eibrand

Appendix G: List of available questionnaires

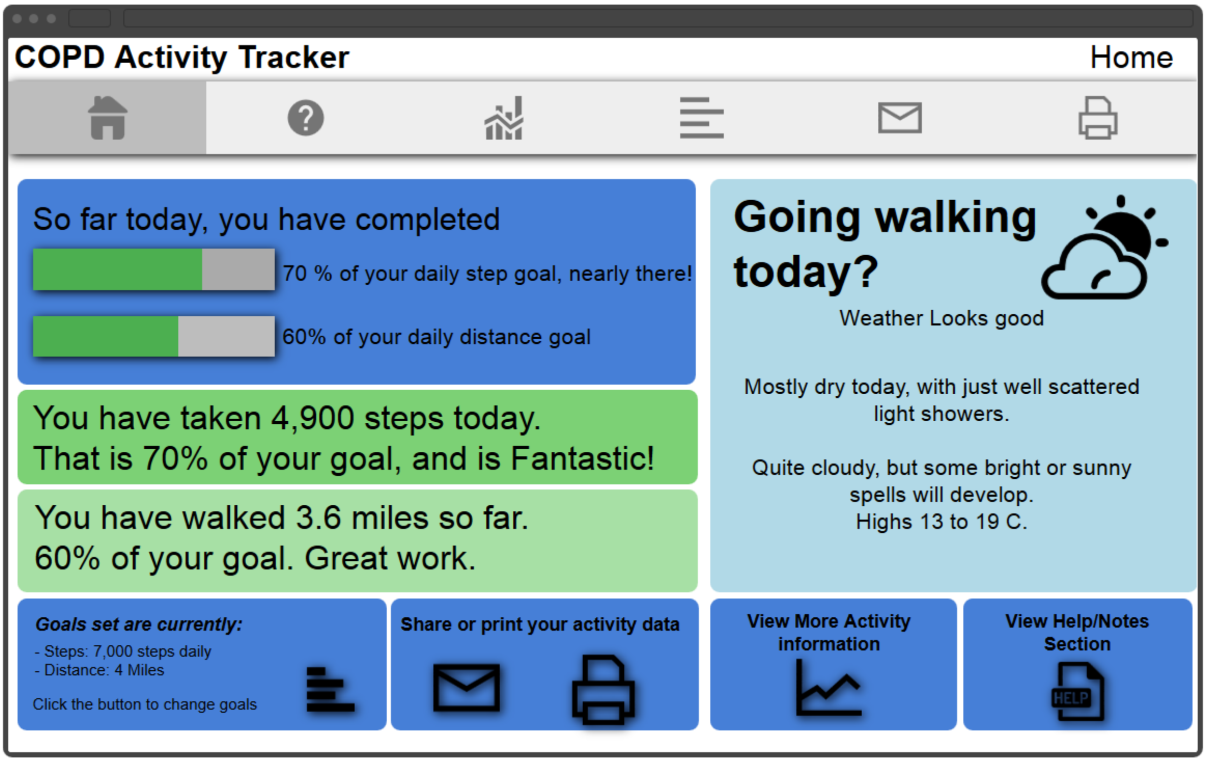
Name	Notes	Link
LINQ	Based on interview questions designed and validated by COPD patients. Interested in determining level of knowledge of patient	http://www.linq.org.uk/PDFquestionnaires/LINQenglish.pdf
BCQK	It tests knowledge that is appropriate for COPD patients of the condition	http://crd.sagepub.com/content/3/3/123.full.pdf
St. George's Respiratory Questionnaire (SGRQ)	Disease-specific instrument designed to measure impact on overall health, daily life, and perceived well-being in patients with obstructive airways disease.	http://www.healthstatus.sgul.ac.uk/sgrq/sgrq-downloads short version http://www.healthstatus.sgul.ac.uk/sgrq-c
AQ20	No questions in the AQ20 are specifically related to physical activity per say, although some questions ask about the patients state during strenuous activity.	http://link.springer.com/article/10.1186/1477-7525-9-4
BPQ and BPQ-S	Neither versions have any direct questions that are related to physical activity or exercise. The questions are more related about how the individual feels when taking part in some activities and gauges the level of discomfort during those activities.	http://www.psy.plymouth.ac.uk/research/mhyland/bquest.pdf and http://www.psy.plymouth.ac.uk/research/mhyland/bpq.pdf
Name	**Notes**	**Link**

COPD Activity Rating Scale CARS	Aim is to measure life-related activities in patients with COPD, essentially how much the individual is affected by their condition by rating their ability to carry out certain tasks.	http://onlinelibrary.wiley.com/doi/10.1046/j.1442-2018.2003.00131.x/abstract
COPD Test Online	Simple test which aims to measure the impact of the condition on the individual. Again, no specific question asking the user about activity of exercise levels.	http://www.catestonline.org/
CCQ	The Clinical COPD Questionnaire (CCQ) measures health status and can be used to assess health-related quality of life (HRQL) From <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3532021/>	http://ccq.nl/?page_id=4
SF-36 (RAND)	A set of generic, coherent, and easily administered quality-of-life measures. These measures rely upon patient self-reporting and are now widely utilized by managed care organizations From http://www.rand.org/health/surveys_tools/mos/mos_core_36item.html>	http://www.rand.org/health/surveys_tools/mos/mos_core_36item.html
Name	**Notes**	**Link**

Chronic Respiratory Disease Questionnaire (CRDQ)	Disease specific HRQL that contains four dimensions. Includes the following areas • Dysponea • Fatigue • Emotional function • Feeing of control over disease	http://thorax.bmj.com/content/42/10/773.full.pdf+html

Appendix H: Screenshots of COPD Self-management interface

Home Screen 1: Goals on track with goals, weather good



So far today, you have completed

70 % of your daily step goal, nearly there!

60% of your daily distance goal

You have taken 4,900 steps today.
That is 70% of your goal, and is Fantastic!

You have walked 3.6 miles so far.
60% of your goal. Great work.

Weather Looks good

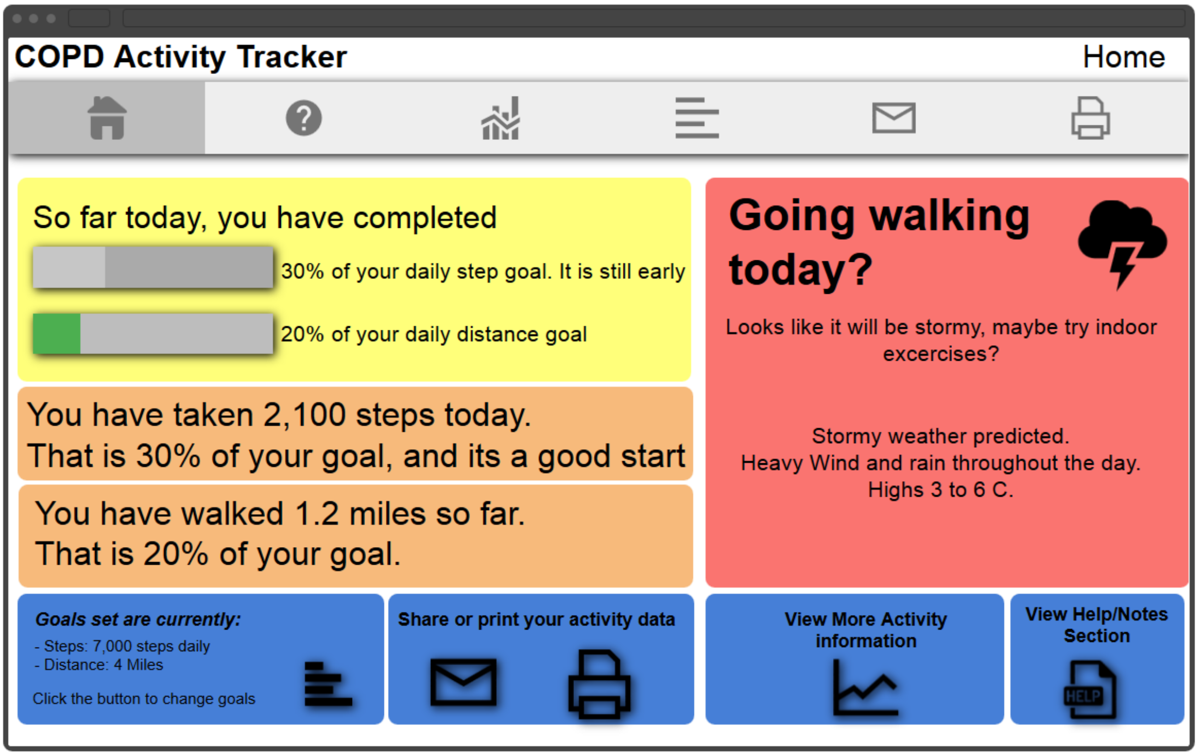
Mostly dry today, with just well scattered light showers.

Quite cloudy, but some bright or sunny spells will develop.
Highs 13 to 19 C.

- Steps: 7,000 steps daily
- Distance: 4 Miles

Click the button to change goals

Home Screen 2: Goals not on track with goals, weather bad



So far today, you have completed

30% of your daily step goal. It is still early

20% of your daily distance goal

You have taken 2,100 steps today.
That is 30% of your goal, and its a good start

You have walked 1.2 miles so far.
That is 20% of your goal.

Looks like it will be stormy, maybe try indoor excercises?

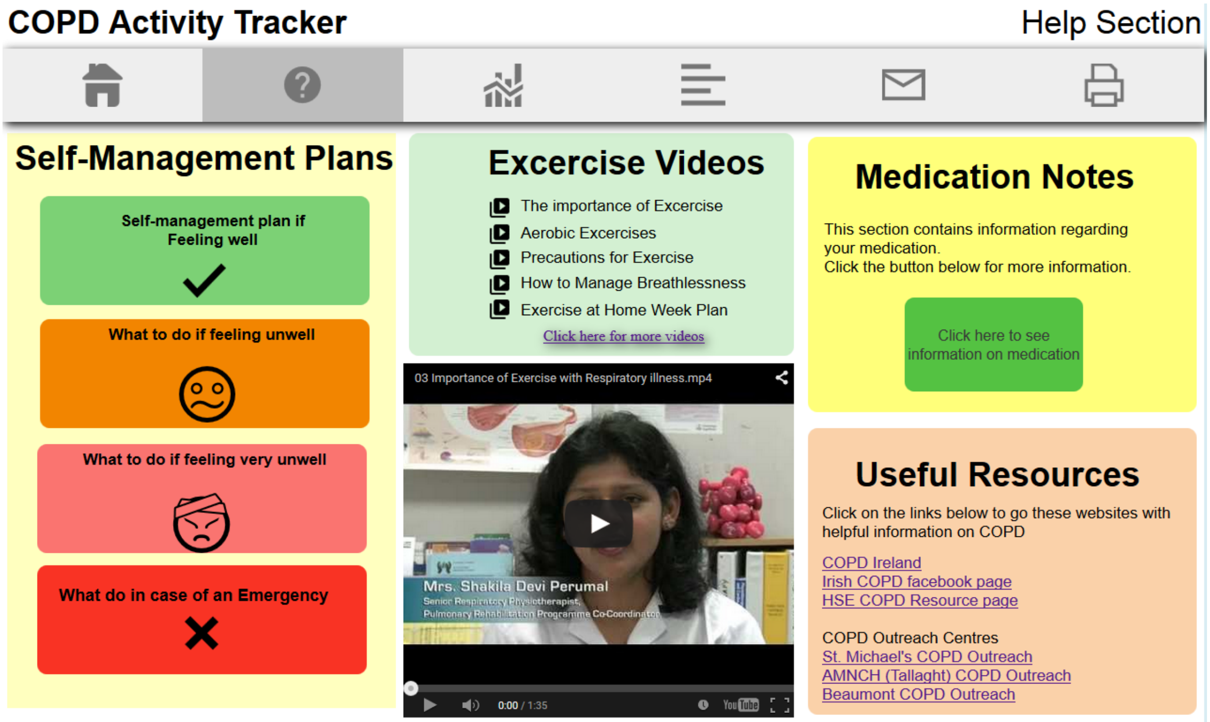
Stormy weather predicted.
Heavy Wind and rain throughout the day.
Highs 3 to 6 C.

- Steps: 7,000 steps daily
- Distance: 4 Miles

Click the button to change goals

Title: Is it feasible to design a useful interface for COPD Self-management?

Help Screen 1



COPD Activity Tracker

Help Section

Self-Management Plans

Self-management plan if Feeling well ✓

What to do if feeling unwell

What to do if feeling very unwell

What do in case of an Emergency ✗

Excercise Videos

- The importance of Excercise
- Aerobic Excercises
- Precautions for Exercise
- How to Manage Breathlessness
- Exercise at Home Week Plan

Click here for more videos

Medication Notes

This section contains information regarding your medication.
Click the button below for more information.

Click here to see information on medication

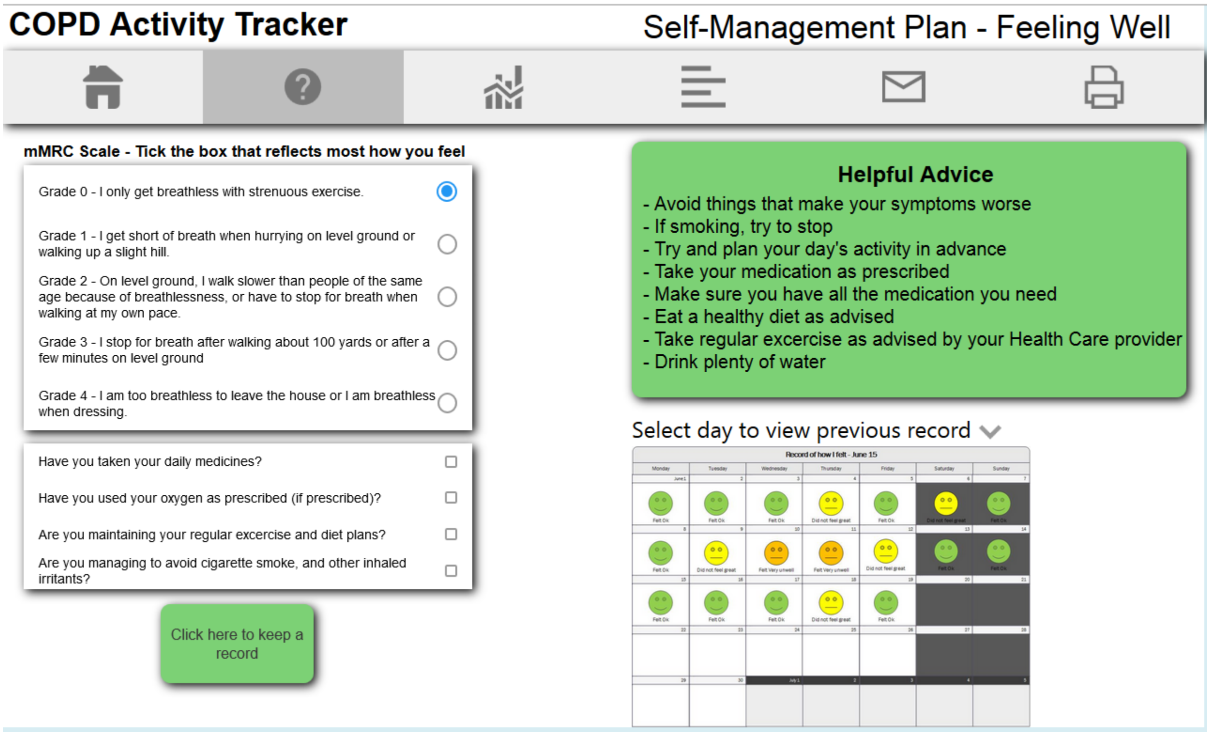
Useful Resources

Click on the links below to go these websites with helpful information on COPD

COPD Ireland
Irish COPD facebook page
HSE COPD Resource page

COPD Outreach Centres
St. Michael's COPD Outreach
AMNCH (Tallaght) COPD Outreach
Beaumont COPD Outreach

Help Screen -> Feeling Well. mMRC dypnea scale, checklist, calendar view of how user felt, info box



COPD Activity Tracker

Self-Management Plan - Feeling Well

mMRC Scale - Tick the box that reflects most how you feel

- Grade 0 - I only get breathless with strenuous exercise. ●
- Grade 1 - I get short of breath when hurrying on level ground or walking up a slight hill. ○
- Grade 2 - On level ground, I walk slower than people of the same age because of breathlessness, or have to stop for breath when walking at my own pace. ○
- Grade 3 - I stop for breath after walking about 100 yards or after a few minutes on level ground ○
- Grade 4 - I am too breathless to leave the house or I am breathless when dressing. ○

- Have you taken your daily medicines? ☐
- Have you used your oxygen as prescribed (if prescribed)? ☐
- Are you maintaining your regular excercise and diet plans? ☐
- Are you managing to avoid cigarette smoke, and other inhaled irritants? ☐

Click here to keep a record

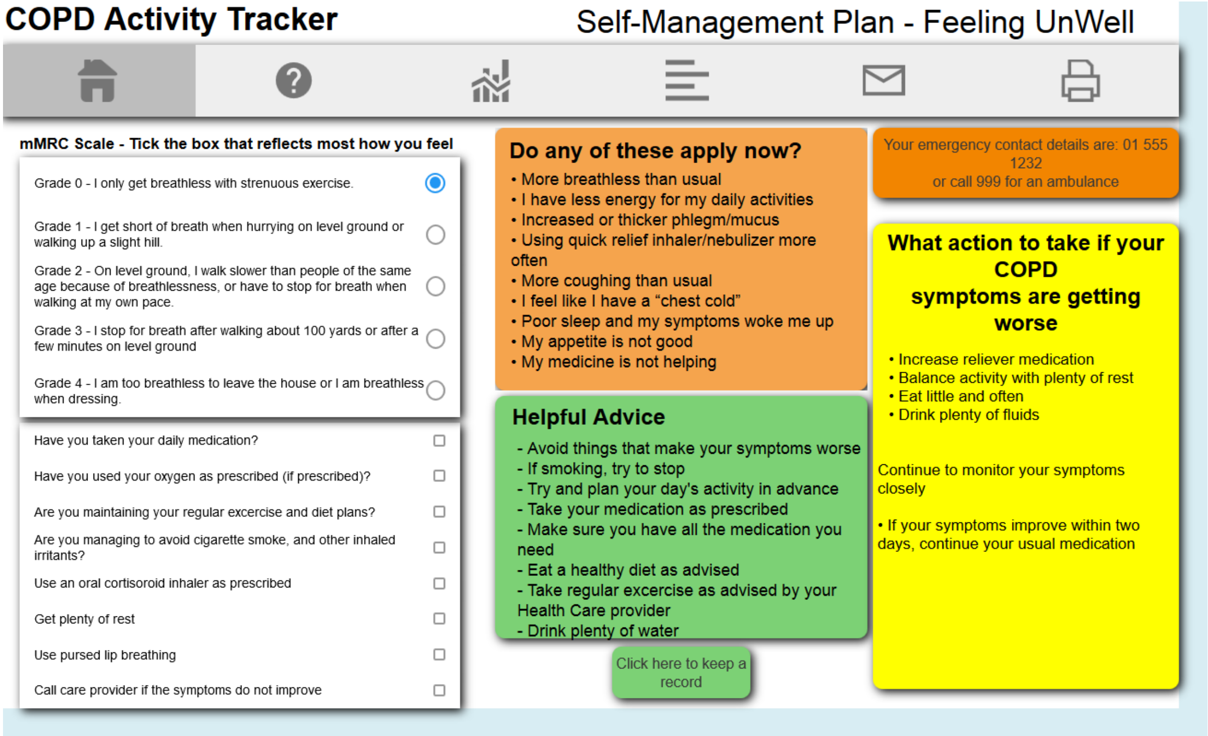
Helpful Advice

- Avoid things that make your symptoms worse
- If smoking, try to stop
- Try and plan your day's activity in advance
- Take your medication as prescribed
- Make sure you have all the medication you need
- Eat a healthy diet as advised
- Take regular excercise as advised by your Health Care provider
- Drink plenty of water

Select day to view previous record

Help Screen -> Feeling Unwell with additional information on what to do to manage the situation

Title: Is it feasible to design a useful interface for COPD Self-management?



COPD Activity Tracker

Self-Management Plan - Feeling UnWell

mMRC Scale - Tick the box that reflects most how you feel

Grade 0 - I only get breathless with strenuous exercise. ●

Grade 1 - I get short of breath when hurrying on level ground or walking up a slight hill. ○

Grade 2 - On level ground, I walk slower than people of the same age because of breathlessness, or have to stop for breath when walking at my own pace. ○

Grade 3 - I stop for breath after walking about 100 yards or after a few minutes on level ground ○

Grade 4 - I am too breathless to leave the house or I am breathless when dressing. ○

Have you taken your daily medication? ☐

Have you used your oxygen as prescribed (if prescribed)? ☐

Are you maintaining your regular excercise and diet plans? ☐

Are you managing to avoid cigarette smoke, and other inhaled irritants? ☐

Use an oral cortisoroid inhaler as prescribed ☐

Get plenty of rest ☐

Use pursed lip breathing ☐

Call care provider if the symptoms do not improve ☐

Do any of these apply now?

- More breathless than usual
- I have less energy for my daily activities
- Increased or thicker phlegm/mucus
- Using quick relief inhaler/nebulizer more often
- More coughing than usual
- I feel like I have a "chest cold"
- Poor sleep and my symptoms woke me up
- My appetite is not good
- My medicine is not helping

Helpful Advice

- Avoid things that make your symptoms worse
- If smoking, try to stop
- Try and plan your day's activity in advance
- Take your medication as prescribed
- Make sure you have all the medication you need
- Eat a healthy diet as advised
- Take regular excercise as advised by your Health Care provider
- Drink plenty of water

Click here to keep a record

Your emergency contact details are: 01 555 1232
or call 999 for an ambulance

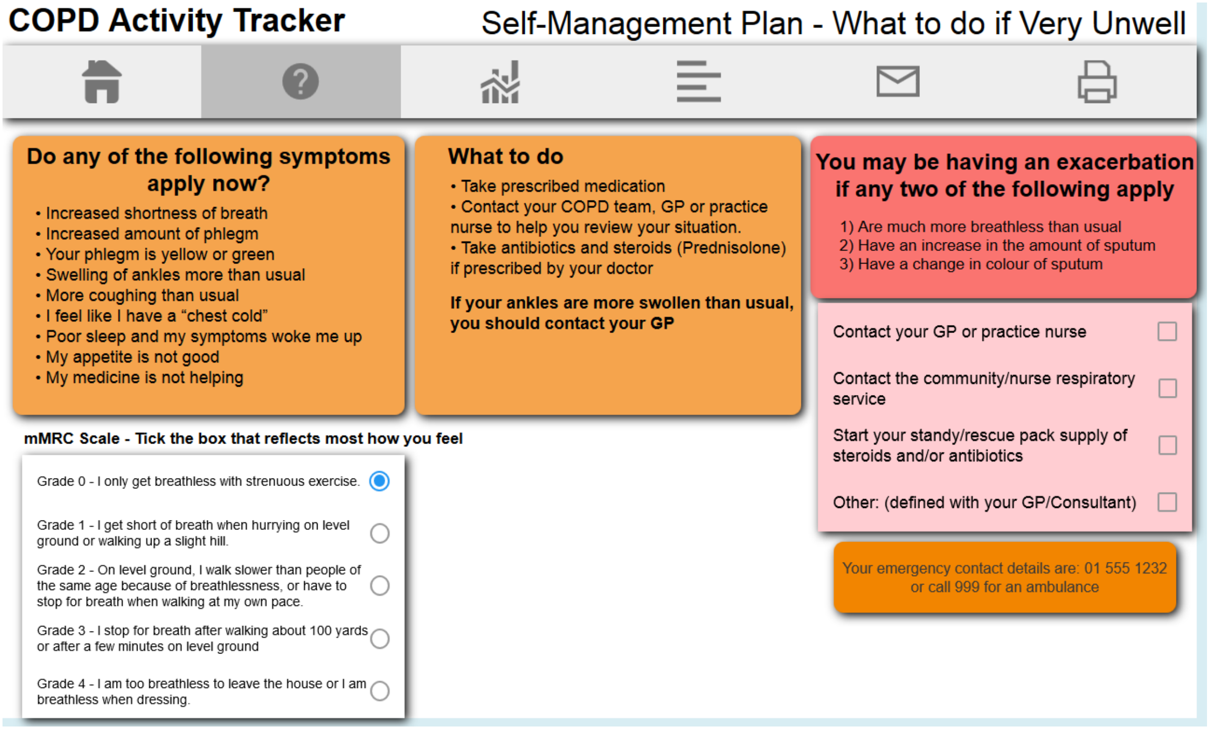
What action to take if your COPD symptoms are getting worse

- Increase reliever medication
- Balance activity with plenty of rest
- Eat little and often
- Drink plenty of fluids

Continue to monitor your symptoms closely

- If your symptoms improve within two days, continue your usual medication

Help Screen -> Feeling very unwell, more pointed information on what to do to manage the situation



COPD Activity Tracker

Self-Management Plan - What to do if Very Unwell

Do any of the following symptoms apply now?

- Increased shortness of breath
- Increased amount of phlegm
- Your phlegm is yellow or green
- Swelling of ankles more than usual
- More coughing than usual
- I feel like I have a "chest cold"
- Poor sleep and my symptoms woke me up
- My appetite is not good
- My medicine is not helping

What to do

- Take prescribed medication
- Contact your COPD team, GP or practice nurse to help you review your situation.
- Take antibiotics and steroids (Prednisolone) if prescribed by your doctor

If your ankles are more swollen than usual, you should contact your GP

You may be having an exacerbation if any two of the following apply

1) Are much more breathless than usual
2) Have an increase in the amount of sputum
3) Have a change in colour of sputum

Contact your GP or practice nurse ☐

Contact the community/nurse respiratory service ☐

Start your standy/rescue pack supply of steroids and/or antibiotics ☐

Other: (defined with your GP/Consultant) ☐

Your emergency contact details are: 01 555 1232
or call 999 for an ambulance

mMRC Scale - Tick the box that reflects most how you feel

Grade 0 - I only get breathless with strenuous exercise. ●

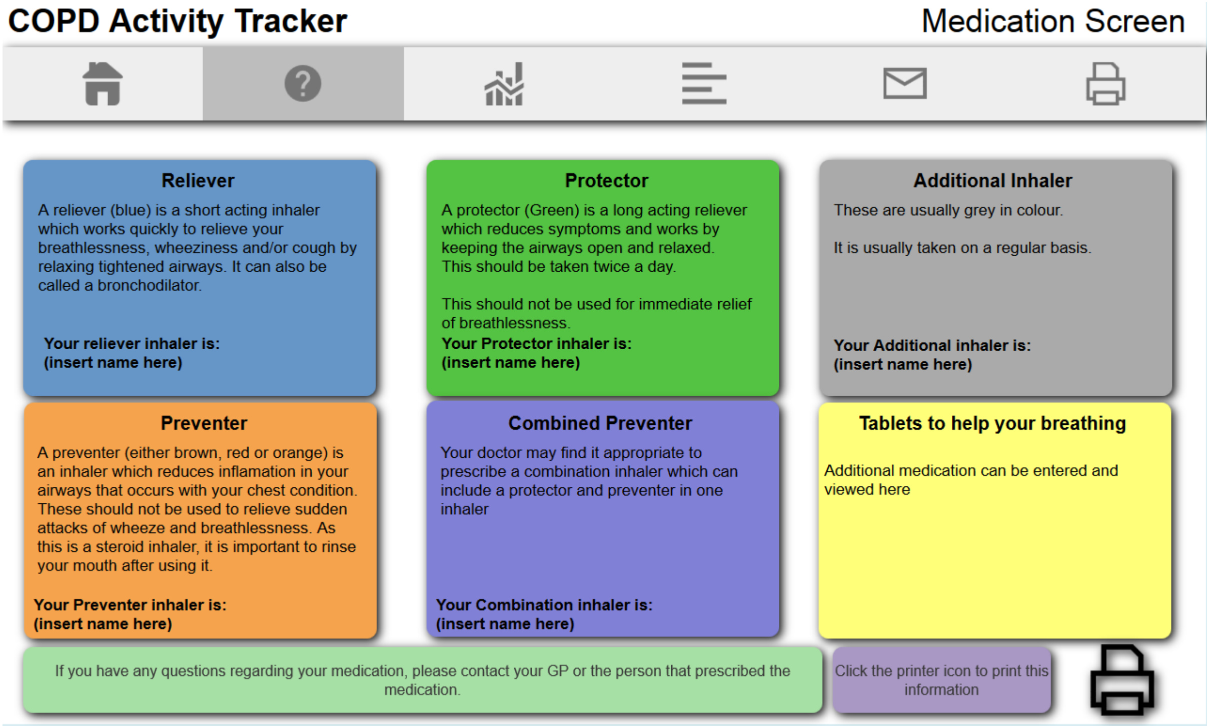
Grade 1 - I get short of breath when hurrying on level ground or walking up a slight hill. ○

Grade 2 - On level ground, I walk slower than people of the same age because of breathlessness, or have to stop for breath when walking at my own pace. ○

Grade 3 - I stop for breath after walking about 100 yards or after a few minutes on level ground ○

Grade 4 - I am too breathless to leave the house or I am breathless when dressing. ○

Help Screen -> Medication notes. A listing of where the users medications and dosages would be entered, with the option to print the screen for reference to be kept with the individual



COPD Activity Tracker

Medication Screen

Reliever

A reliever (blue) is a short acting inhaler which works quickly to relieve your breathlessness, wheeziness and/or cough by relaxing tightened airways. It can also be called a bronchodilator.

Your reliever inhaler is:
(insert name here)

Protector

A protector (Green) is a long acting reliever which reduces symptoms and works by keeping the airways open and relaxed.
This should be taken twice a day.

This should not be used for immediate relief of breathlessness.
Your Protector inhaler is:
(insert name here)

Additional Inhaler

These are usually grey in colour.

It is usually taken on a regular basis.

Your Additional inhaler is:
(insert name here)

Preventer

A preventer (either brown, red or orange) is an inhaler which reduces inflamation in your airways that occurs with your chest condition. These should not be used to relieve sudden attacks of wheeze and breathlessness. As this is a steroid inhaler, it is important to rinse your mouth after using it.

Your Preventer inhaler is:
(insert name here)

Combined Preventer

Your doctor may find it appropriate to prescribe a combination inhaler which can include a protector and preventer in one inhaler

Your Combination inhaler is:
(insert name here)

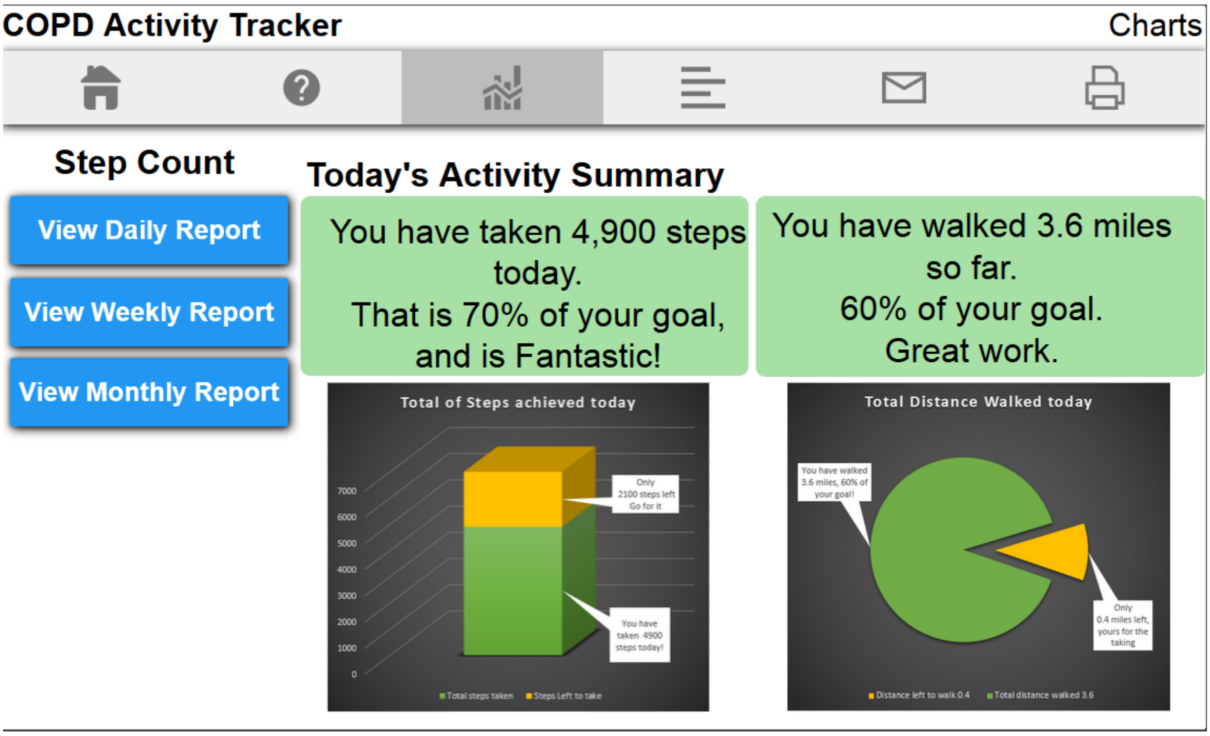
Tablets to help your breathing

Additional medication can be entered and viewed here

If you have any questions regarding your medication, please contact your GP or the person that prescribed the medication.

Click the printer icon to print this information

Charts Screen -> Start page showing the daily activity totals so far, with links to weekly and monthly charts



COPD Activity Tracker

Charts

Step Count

View Daily Report

View Weekly Report

View Monthly Report

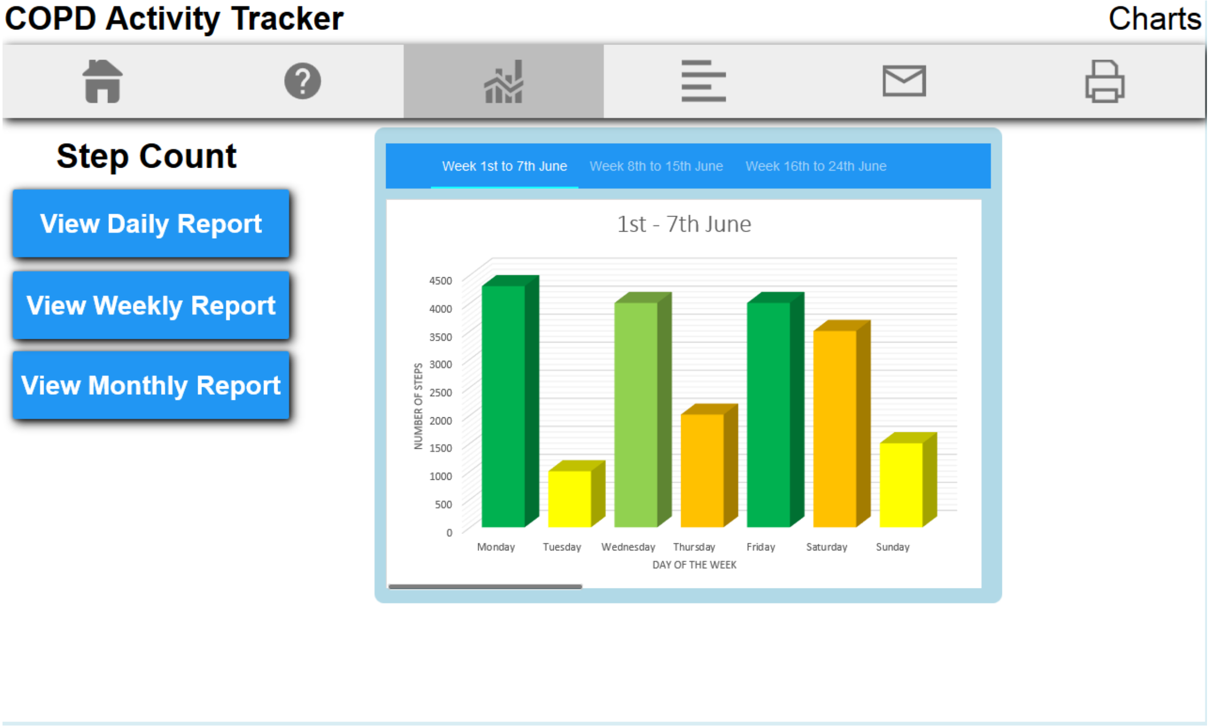
Today's Activity Summary

You have taken 4,900 steps today.
That is 70% of your goal, and is Fantastic!

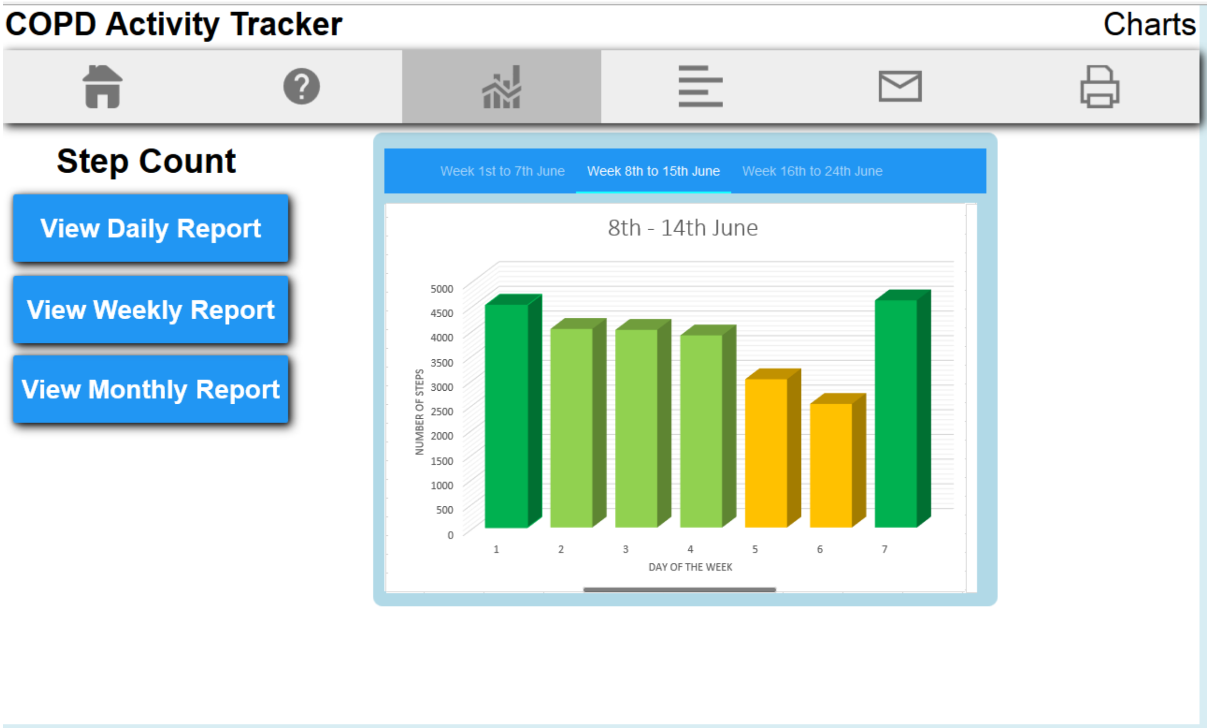
You have walked 3.6 miles so far.
60% of your goal.
Great work.

Title: Is it feasible to design a useful interface for COPD Self-management?

Charts screen -> Weekly view of activity data versus goals. (one of two)



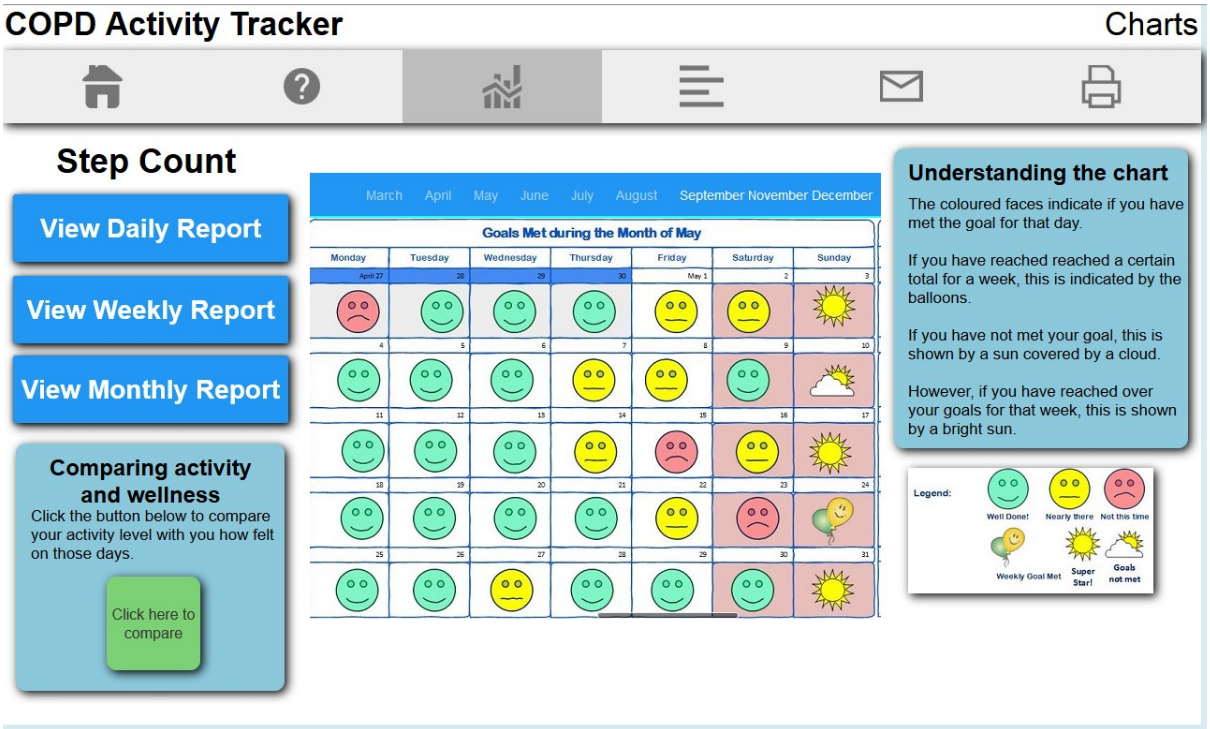
Two of two



Title: Is it feasible to design a useful interface for COPD Self-management?

Charts Screen -> Monthly view of activity

With legends to help visualise when goals were met or not met. Also with a link to comparison chart where user could compare how they felt in relation to the exercise activity they carried out for the same week



Understanding the chart

The coloured faces indicate if you have met the goal for that day.

If you have reached reached a certain total for a week, this is indicated by the balloons.

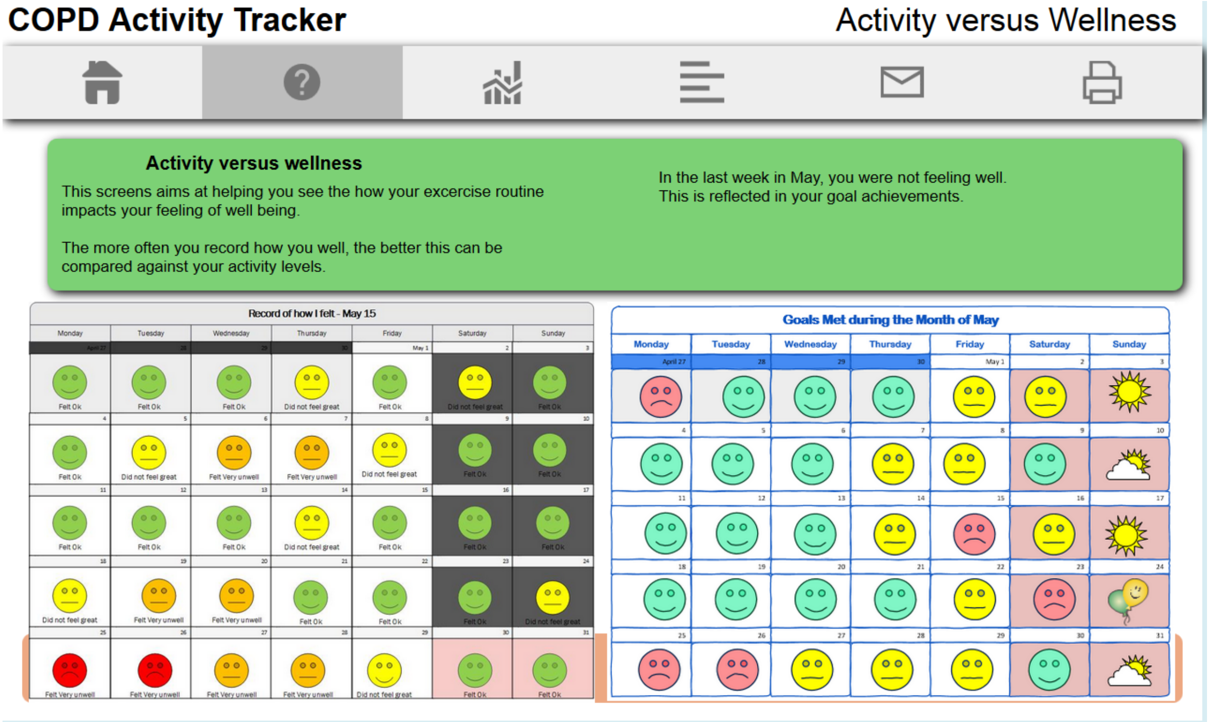
If you have not met your goal, this is shown by a sun covered by a cloud.

However, if you have reached over your goals for that week, this is shown by a bright sun.

Comparing activity and wellness

Click the button below to compare your activity level with you how felt on those days.

Charts screen: Activity Data versus Wellness data



Activity versus wellness

This screens aims at helping you see the how your excercise routine impacts your feeling of well being.

The more often you record how you well, the better this can be compared against your activity levels.

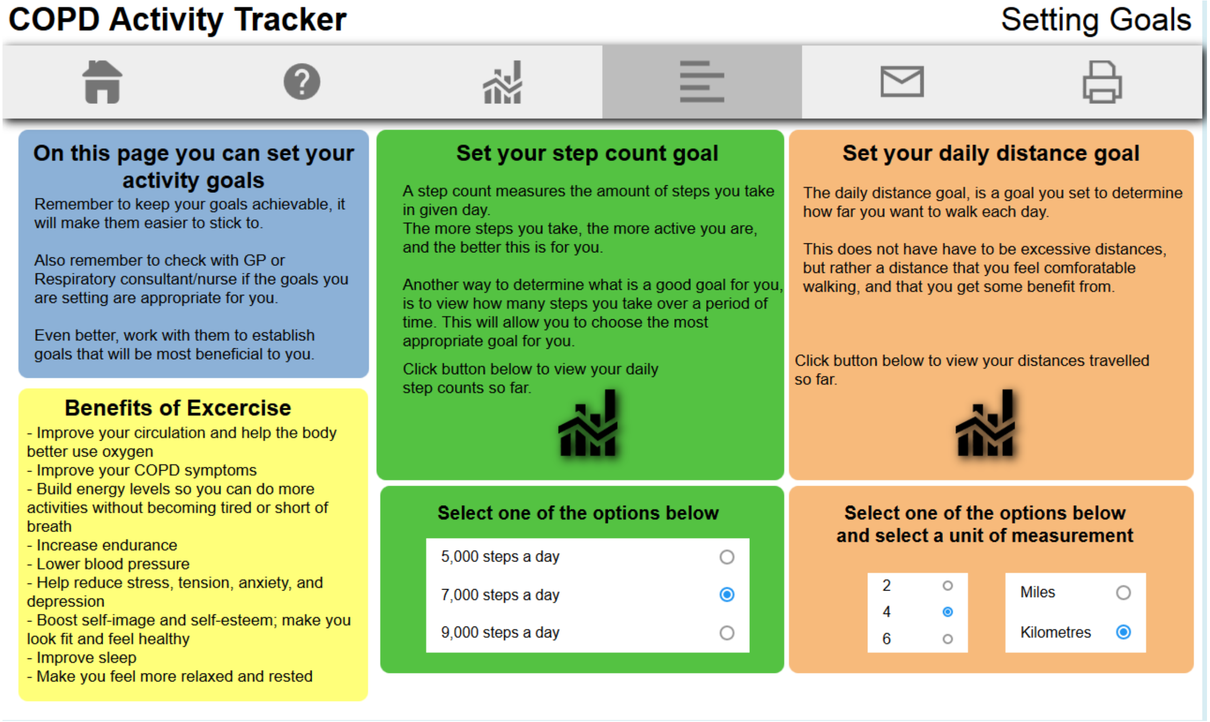
In the last week in May, you were not feeling well.
This is reflected in your goal achievements.

Record of how I felt - May 15

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
April 27	28	29	30	May 1	2	3
Felt Ok	Felt Ok	Felt Ok	Did not feel great	Felt Ok	Did not feel great	Felt Ok
4	5	6	7	8	9	10
Felt Ok	Did not feel great	Felt Very unwell	Felt Very unwell	Did not feel great	Felt Ok	Felt Ok
11	12	13	14	15	16	17
Felt Ok	Felt Ok	Felt Ok	Did not feel great	Felt Ok	Felt Ok	Felt Ok
18	19	20	21	22	23	24
Did not feel great	Felt Very unwell	Felt Very unwell	Felt Ok	Felt Ok	Felt Ok	Did not feel great
25	26	27	28	29	30	31
Felt Very unwell	Felt Very unwell	Felt Very unwell	Felt Very unwell	Did not feel great	Felt Ok	Felt Ok

Title: Is it feasible to design a useful interface for COPD Self-management?

Setting Goals Screen: Explanation on goals and where to set step and distance goals.



COPD Activity Tracker Setting Goals

On this page you can set your activity goals

Remember to keep your goals achievable, it will make them easier to stick to.

Also remember to check with GP or Respiratory consultant/nurse if the goals you are setting are appropriate for you.

Even better, work with them to establish goals that will be most beneficial to you.

Benefits of Excercise

- Improve your circulation and help the body better use oxygen
- Improve your COPD symptoms
- Build energy levels so you can do more activities without becoming tired or short of breath
- Increase endurance
- Lower blood pressure
- Help reduce stress, tension, anxiety, and depression
- Boost self-image and self-esteem; make you look fit and feel healthy
- Improve sleep
- Make you feel more relaxed and rested

Set your step count goal

A step count measures the amount of steps you take in given day.
The more steps you take, the more active you are, and the better this is for you.

Another way to determine what is a good goal for you, is to view how many steps you take over a period of time. This will allow you to choose the most appropriate goal for you.

Click button below to view your daily step counts so far.

Select one of the options below

5,000 steps a day ○
7,000 steps a day ●
9,000 steps a day ○

Set your daily distance goal

The daily distance goal, is a goal you set to determine how far you want to walk each day.

This does not have have to be excessive distances, but rather a distance that you feel comforatable walking, and that you get some benefit from.

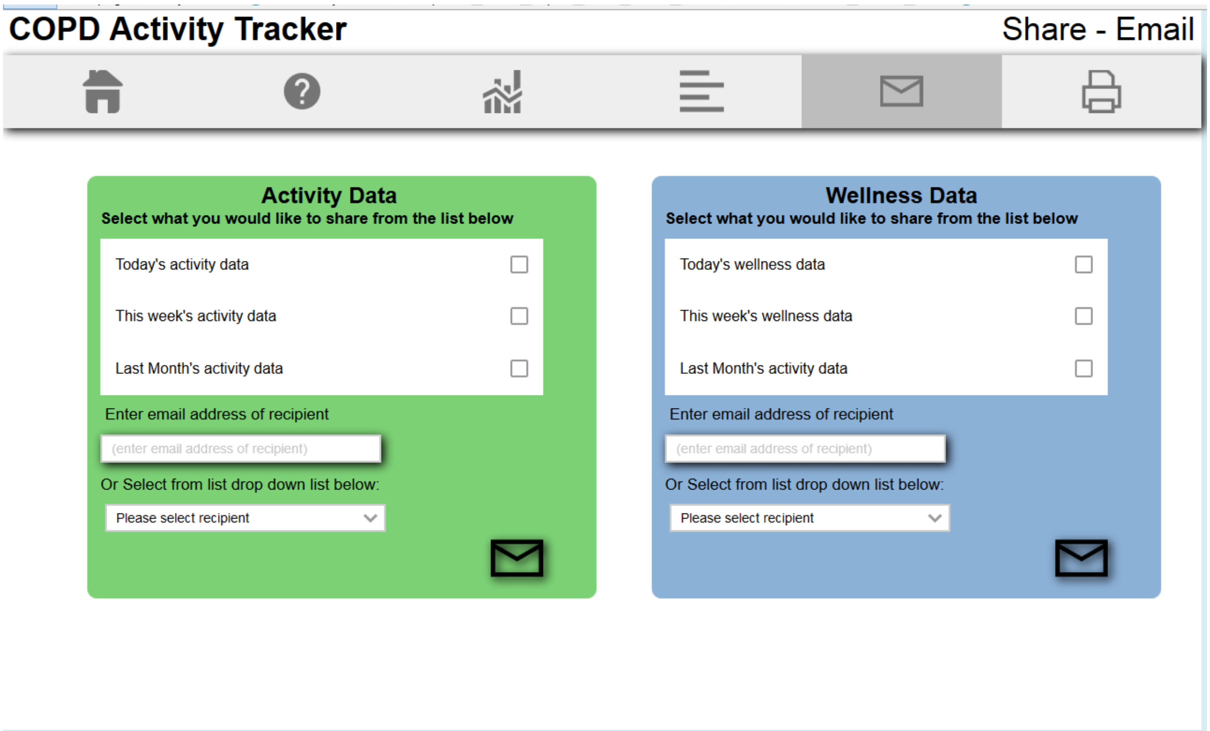
Click button below to view your distances travelled so far.

Select one of the options below and select a unit of measurement

2 ○
4 ●
6 ○

Miles ○
Kilometres ●

Email/Print Screen: Where the user can select what report they want to send/print and to whom



COPD Activity Tracker Share - Email

Activity Data

Select what you would like to share from the list below

Today's activity data ☐
This week's activity data ☐
Last Month's activity data ☐

Enter email address of recipient

(enter email address of recipient)

Or Select from list drop down list below:

Please select recipient

Wellness Data

Select what you would like to share from the list below

Today's wellness data ☐
This week's wellness data ☐
Last Month's activity data ☐

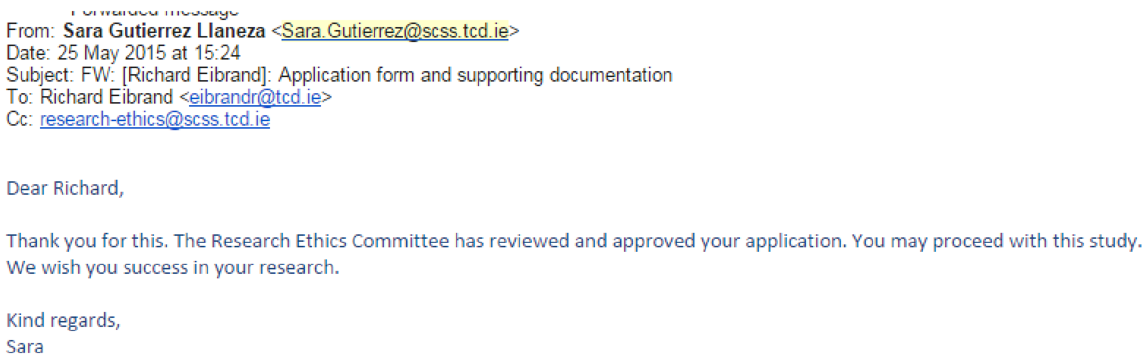
Enter email address of recipient

(enter email address of recipient)

Or Select from list drop down list below:

Please select recipient

Appendix I: Approval from Research Ethics committee from SCSS



Forwarded message
From: **Sara Gutierrez Llaneza** <Sara.Gutierrez@scss.tcd.ie>
Date: 25 May 2015 at 15:24
Subject: FW: [Richard Eibrand]: Application form and supporting documentation
To: Richard Eibrand <eibrandr@tcd.ie>
Cc: research-ethics@scss.tcd.ie

Dear Richard,

Thank you for this. The Research Ethics Committee has reviewed and approved your application. You may proceed with this study. We wish you success in your research.

Kind regards,
Sara